**Validating the Altered Self:**

**A qualitative study of the total laryngectomy experience**

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# Summary

A total laryngectomy (TL) is a lifesaving and life-changing treatment for laryngeal cancer. The required treatments and rehabilitation are specialised and resource intensive because they result in physical and functional changes that primarily affect respiration, swallowing, communication and appearance. Some studies have highlighted significant adjustments required by individuals with laryngectomy (IWL) and their significant others in dealing with the functional changes in the first year after surgery. Several studies have indicated that issues of stress and burden related to levels of disablement may persist in subsequent years for some individuals and their supporters. Symptoms of depression and anxiety, poor coping skills and increased suicide risk have been associated with TL. Our current understanding of the TL experience and adjustment has been determined primarily from self-report surveys, expert opinion, practice guidelines and first-hand accounts. This collective knowledge has represented some socio-cultural populations more than others.

A broad aim for this study was to critically examine the need for, and dimensions of, psychosocial support in TL in order to develop deeper theoretical understanding to inform recommendations to improve services to IWL. The research objectives related to exploring how a group of IWL constructed meaning in relation to their TL experience, examining the influence of biopsychosocial, cultural and linguistic factors on their psychosocial adjustment; the extent to which health professionals addressed IWL psychosocial issues; and more generally, the professional practices that would provide better psychosocial support for IWL. A qualitative research design using constructivist-interpretive methodology was implemented. It included a constructivist grounded theory approach and the theoretical perspective of symbolic interactionism to guide data collection and analysis.

The study was conducted in three stages to ensure depth and breadth of perspectives. The primary source of data was intensive interviewing. Stage 1 involved IWL at least one year post-surgery. Stage 2 involved primary supporters of IWL (e.g. partners). Stage 3 involved health professionals experienced with TL. A range of reflexive methods was used to ensure rigour.

The primary analysis resulted in six categories and associated subthemes

describing the embodied experience of TL. These analyses provided the foundation for the substantive theory *Validating the altered self after total laryngectomy (TL)*. The theory and subsequent *Model of validation* explicate issues such as altered identity and the reframing of the self. They highlight the relationship between how IWL navigate and negotiate interactions and situations as a result of disruption of their self-expression, related competencies and roles. They describe the influence of the processes of developing competence and building resilience combined with contextual factors (e.g. timing and turning points), being supported and personal factors. Together, they provide a theoretical foundation for evaluating and supporting communicative participation, and optimising person-centred practices for this group.

The findings extend our current understanding of the TL experience and self-identity reframing as a consequence of physical, functional and psychosocial changes. They highlight the importance of increased sensitivity to IWL needs during interaction and well-timed competency training for all involved in the care triad—IWL, primary supporters and clinicians—and also identify timely psychosocial supports for IWL and primary supporters.

Limitations of the study and recommendations for future research are also discussed in this thesis.

# Declaration of original authorship

I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Name of candidate: Jane Margaret Bickford

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Date: 15<sup>th</sup> March, 2016

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# Glossary

*Aerodigestive tract* – the area in the oral cavity, pharynx, larynx and upper oesophagus through which air and food pass.

*Alaryngeal communication method (ACM)* – A range of communication methods either audible (e.g. tracheosophageal speech, electrolaryngeal speech and oesophageal speech) or non-audible (e.g. gesture, writing).

*Dysphagia* – impaired swallowing.

*Electrolarynges* – mechanical devices that provide a vibratory sound source that can be shaped by the articulators of the oral cavity when speaking. They are usually hand held against the neck or cheek. They produce a low-pitched artificial sound quality.

*Electrolaryngeal (EL) speech* – An audible alaryngeal communication method using electrolarynges.

*Head and Neck Cancer (HNC)* – malignant or benign tumour located in the head or neck region.

*Health-related quality of life (HRQoL)* – an extensive multifaceted construct that usually encompasses self-reported measures of physical, functional and psychological wellbeing.

*Individual/s with laryngectomy (IWL)* – A person who has undergone total laryngectomy.

*Multidisciplinary team (MDT)* – A range of professionals from different disciplines who work together to manage a health problem.

*Oesophageal (OS) speech* – An audible alaryngeal communication method using air injection to create an egressive airstream to vibrate the PE segment and create sound.

*Oesophagus* – The part of the aerodigestive tract that connects the throat to the stomach.

*Phonation* – The process of the vocal folds closing and vibrating to produce sound.

*Primary supporter* – A person who has provided intensive support during the TL journey.

*Squamous Cell Carcinoma (SCC)* – A form of malignant cancer affecting the mucosa of the aerodigestive tract.

*Surgical Voice Restoration (SVR)* – A surgical fistula is created between the trachea and oesophageal walls where a small silicon voice prosthesis can be inserted. There are different types of prostheses but the functional outcomes are similar between them. All voice prostheses are one-way valves allowing for a small amount of air to be redirected through the prosthesis from the trachea to the oesophagus when the tracheostoma is temporarily occluded. Secretions and swallowed material are

prevented from leaving the oesophagus and entering the trachea.

*TNM Classification* – The staging system used to classify cancers.

*Total laryngectomy (TL)* –Surgical removal of the hyoid bone, larynx and the first two rings of the trachea.

*Trachea* – The cartilaginous structure from the larynx to the bronchi enabling air to pass or be expelled into the lungs, also known as 'the windpipe'.

*Tracheosophageal (TE) speech* - An audible alaryngeal communication method using a prosthesis to enable an egressive airstream from the trachea to the oesophagus resulting in vibration of the PE segment for sound creation.

*Tracheosophgeal fistula (TOF)* – A surgical opening between the trachea and oesophagous enabling placement of a voice prosthesis for TE speech.

*Tracheostoma* – A surgically created permanent opening to the airway in the neck as the result of total laryngectomy. Breathing and coughing occurs via this opening, and it is no longer possible for air to pass up through the oral and nasal cavities.

# 1  Introduction

> I realised what was happening one day. …I meant to respond 'Absolutely!'
> But the word that came out was 'Yes'…. The John Diamond who says 'yes' is
> a different person to the one who says 'absolutely'. (Diamond, 1998, p. 169)
>
> *John Diamond, former journalist for The Times newspaper, London, head and
> neck cancer sufferer.*

A total laryngectomy (TL) is a life-changing and often curative treatment for
advanced laryngeal cancer. Whilst this is not a commonly occurring head and neck
cancer (HNC), the required treatments and rehabilitation are specialised and resource
intensive because a TL results in significant physical and functional changes primarily
affecting respiration and airway management, swallowing, verbal communication and
appearance. Intensive multidisciplinary healthcare and social supports are needed to
assist people and their altered or loss of function can have a considerable psychosocial
impact on them.

## 1.1  Significance

Our current understanding of the TL experience and adjustment has primarily been
determined from self-report, health-related quality of life (HRQoL) research, expert
opinion, practice guidelines and some first-hand accounts. This collective knowledge
has also largely represented specific socio-cultural populations. I provide a brief
overview of the issues here before highlighting this study's contribution to knowledge
in this field and giving an outline of the subsequent chapters of this thesis, including
Chapter 2, which contains a much more extensive critique of the literature.

The obvious impairment after TL is that laryngeal voice production is no longer
possible. Additionally, a significant proportion of individuals with laryngectomy
(IWL)[1] may experience swallowing difficulties in relation to this altered anatomy.
Other more subtle impairments include the inability to inspire or expire air through
the nasal and oral cavities, resulting in impaired sense of smell or taste, and inability
to convey emotion, such as to laugh or cry. Shoulder problems due to damaged nerves
have also been reported to be associated with the surgery. Changes to body image as

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[1] The term 'individual/s with laryngectomy (IWL)' is the preferred term used throughout this thesis to describe the
participants and others who have undergone total laryngectomy. This is a term also used by Blood, Blood,
Kauffman, Raimondi, and Dineen (1995). Other terms such as 'laryngectomee' or 'the patient' are frequently used
to describe this specific population.

result of the tracheostoma can also impact individuals (Doyle, 1994, 2009; Kerawala, 2010; Maclean, Cotton, & Perry, 2009b; Terrell, Fisher, & Wolf, 1998).

This altered, or loss of, function can impact an individual's HRQoL (Armstrong et al., 2001; Krishnan & Maclean, 2013; Noonan & Hegarty, 2010; Verdonck-de Leeuw, Rinkel, & René Leemans, 2014). Some studies have highlighted major adjustments required by individuals and their significant others in dealing with problems related to communication, swallowing and breathing, as well as changed body image in the first year after surgery (Armstrong et al., 2001; Blood, Simpson, Dineen, Kauffman, & Raimondi, 1994; Keszte et al., 2013; Singer et al., 2014).

Several studies have indicated that issues of stress and burden related to levels of disablement may persist in subsequent years for some individuals and their supporters (Ackerstaff, Hilgers, Aaronson, & Balm, 1994; Herranz & Gavilán, 1999; Lee, Gibson, & Hilari, 2010; Maclean, Cotton, & Perry, 2009a; Noonan & Hegarty, 2010). Psychological comorbidity, poor coping skills and increased suicide risk have been reported to be associated with TL and HNC populations (Duffy, Ronis, et al., 2007; Eadie & Bowker, 2013; Gibson & McCombe, 1999; Perry, Casey, & Cotton, 2015; Singer, Herrmann, Welzel, Klemm, & Heim, 2005; Terrell et al., 1998).

In Australia, TL is not a common procedure. Declining incidence relates to a shift away from surgery toward organ preserving treatment and early intervention strategies. However, there remains a small group of people who undergo TL each year. Australia is similar to other high income countries in that it manages TL with specialised healthcare, usually located in a major city or centre. The majority of individuals have their treatment covered by Australia's universal healthcare system. However, a small number of people with private health insurance choose to have their surgery and care in the private hospital system.

There are some unique challenges in Australia related to TL care. These include:

1) Large geographical distances between specialist healthcare and some remote/rural locations.
2) Poor health and social outcomes experienced by Indigenous Australians compared to non-Indigenous Australians.
3) Culturally and linguistically diverse groups that make up Australia's multicultural society.

## 1.2   Major aim and objectives of this study

This study considered these challenges in its aim to critically examine the need for, and dimensions of, psychosocial support in TL from multiple perspectives (e.g. IWL, primary supporters and health professionals) to achieve the objective of developing deeper theoretical understanding to inform recommendations to improve services to IWL. The aim and objectives were informed by unanswered questions in a literature review (see Chapter 2), which became the four research questions:

1) How do people construct meaning in relation to the experience of having and living with a total laryngectomy?
2) How do biopsychosocial factors (e.g. gender, age, family structure/constellation, support networks, SES, level of education, employment situation and geographical location) and/or cultural and linguistic factors (e.g. ethnicity, attitudes, beliefs, practices and linguistic diversity) influence the psychosocial adjustment of IWL?
3) How do health professionals routinely address psychosocial issues with their clients who have total laryngectomy?
4) What kinds of professional practices would provide better psychosocial support for IWL?

The following smaller objectives also arose from the above unanswered questions:

1) To further understand how IWL adjust to TL by exploring the ways in which they construct meaning through having to live with a total laryngectomy.
2) To examine and interpret how biopsychosocial (including support networks), cultural and linguistic factors influence the construction of meaning and psychosocial adjustment of IWL.
3) To crititcally examine how health professionals routinely address psychosocial issues with their clients who have total laryngectomy.
4) To make recommendations for improving services by exploring the kinds of professional practices that would provide better psychosocial support for IWL.

## 1.3   Methodology

A qualitative approach was used to examine the subjective experiences and construction of meaning for a range of IWL in Australia. This involved using constructivist grounded theory and symbolic interactionist methodology to guide data

collection and analysis. The views of significant others such as partners and health professionals were also evaluated. Adjustment to TL was explored using biopsychosocial, cultural and linguistic factors such as gender, age, ethnic and linguistic diversity, socio-econominc status (SES), social supports, geographical location, and socio-cultural beliefs and practices. How individuals attributed meaning to these factors through their social and cultural experiences was also examined. A substantive theory of the TL experience was developed from the data and is presented. Further critique of the data enabled examination of the current provision of psychosocial support for IWL in South Australia. Findings led to recommendations for enhancing practice and ideas for future research, which are also discussed.

## 1.4 Contribution to knowledge

This study's major contribution to knowledge from exploring the need for, and dimensions of, psychosocial support for individuals who have experienced a TL is twofold. The substantive theory of the TL experience grounded in the data— *Validating the altered self after total larynegectomy (TL)*—provides a close representation of the embodied experience of having, and living with, a TL. It highlights the little explored issues of altered identity and the reframing of the self for IWL, and yields language and terminology that exemplifies the experience from the perspective of those affected. The substantive theory suggests original insights into the TL experience and the role others play in supporting individuals to adjust.

The *Model of validation* developed from the data highlights the relationship between how individuals navigated and negotiated interactions and situations as a result of the disruption of their self-expression, related competencies and roles. This dynamic model demonstrates how the processes of developing competence and building resilience, combined with contextual factors, such as timing and turning points, being supported and personal factors influence acceptance of the altered self-identity. The model provides a theoretical foundation for evaluating and supporting adjustment and communicative participation. It also emphasises the important validating roles of significant others, for example primary supporters and health professionals, and the broader socio-cultural context.

Other significant contributions to knowledge include important evidence for competency training for all involved with IWL in order to optimise person-centred practices. While highlighting the many barriers to achieving this, the study provides

significant conceptual understanding of the subjective experiences from which current healthcare practices and advocacy efforts can be appraised and improved. In addition, the study contributes a comprehensive critique of the role of communicative competence and identity reframing after TL. A range of alaryngeal communication methods (ACMs) were explored and are discussed in relation to social acceptability, functionality and the contributions communication partners make during interactions. It also highlights the need for others' increased sensitivity, awareness and accommodation for the communication limitations experienced with all ACMs, and advances understanding of acquired communication impairment and the importance of a social constructivist view when evaluating communicative behaviour.

Finally, extensive exploration of the important role of the primary supporter and the impact of the TL experience on their lives provides strong evidence that this group is emotionally vulnerable. Primary supporters are in need of increased psychosocial support and guidance to manage the care burden and strain associated with their TL experience.

## 1.5   Thesis overview

This thesis contains eight chapters. Following this chapter, Chapter 2, Literature review, provides a critique of the current literature related to TL. Particular emphasis is placed on the literature examining the psychosocial needs identified for the TL population, the relevance of social and healthcare supports addressing these needs, and the influence of the socio-cultural context for individuals undergoing laryngectomy. The literature review enabled me to identify some knowledge gaps, and the four research questions and aims that formed the basis of the current study.

Chapter 3, Methodology and methods, presents the case for a qualitative research design to answer the research questions. Constructivist grounded theory and symbolic interactionism—the chosen methodology for the study—is discussed. Details of the study design and participant sample are provided.

Chapter 4, Data collection and analysis process, discusses the methods used to collect and analyse the data. It also provides details regarding promoting participation of alaryngeal communicators and primary supporters in the research process. I examine how I situated myself within the research process by implementing a range of reflexive methods to ensure the study's rigour.

Chapter 5, Findings: The total laryngectomy experience from multiple

perspectives, presents the primary analysis of the data. It discusses the six categories and associated subthemes describing the TL experience from multiple perspectives that emerged from the analysis. These categories provided the foundational data for the substantive theory presented in Chapter 6.

Chapter 6, A substantive theory: *Validating the altered self after TL*, presents the substantive theory to emerge from the primary analysis. The important phenomena embodying the TL experience are described.

Chapter 7, Discussion and recommendations, discusses the results and emergent substantive theory in relation to the broader literature and other theoretical frameworks. This is a critical facet of a grounded theory study and this section of the thesis explains the presence of theoretical constructs related to biographical disruption, communicative competence and communicative participation. I also discuss how the theory extends our current understanding and assists in answering the research questions. This includes how healthcare practices and psychosocial supports might be improved to assist IWL and their primary support networks.

Chapter 8, Conclusion, provides an overview of the findings and discussion of the strengths and limitations of the current study. I also make some recommendations for future research.

The Appendices offer a range of examples of the supportive materials used during the study's implementation. For example, I have included database search results, , advertising materials, the  introductory letter the participant information form, the consent form, counselling information sheet, an interview guide, the socio-demographic form and a sample of open-to-focused coding. Some participant stories have also been provided along with the abstract from the publication generated from this study's first stage.

# 2  Literature Review

## 2.1  Introduction

In this chapter, the current literature related to TL is critiqued and discussed. Particular emphasis is placed on the literature about the psychosocial needs identified for the TL population, the relevance of social and healthcare supports addressing these needs, and the influence of the socio-cultural context for individuals undergoing laryngectomy in a high-income nation such as Australia. I argue that much of this knowledge has been developed from a narrow research tradition, predominantly positivist, and from expert opinion and clinical guidelines. I then identify where there appear to be gaps in understanding the TL experience, particularly from the perspective of those who have the surgery and the individuals who provide both social and clinical support. I discuss the research questions and aims of the current study from these identified areas.

## 2.2  Defining laryngeal cancer and total laryngectomy

### 2.2.1  Laryngeal cancer

Laryngeal cancer is typically a malignant disease of the larynx (Doyle, 1994). In Australia in 2011, laryngeal cancer formed 18.9% of Head and Neck Cancer (HNC) diagnoses. This was equivalent to 590 cases; 526 males and 64 females (Australian Institute of Health and Welfare (AIHW), 2015a, 2015b;). In other words, 8.7 more men than women are likely to be diagnosed with laryngeal cancer (AIHW), 2015b). This trend is marginally higher than in other high income countries such as the United Kingdom (UK), where the ratio is approximately 4.7:1 (Saunders, Coman, & Guminski, 2014). In 2007 in South Australia, there was a 5.2% increase in the incidence of laryngeal cancer from previous reports with 106 males and 53 females (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries, 2010; South Australia Department of Health, 2013).

Australia experiences an incidence rate for males (3.1 per 100000) similar to other high-income countries such as the UK and Canada. However, the incidence rate for females is one of the lowest recorded for similar countries at 0.3 per 100000 ( (AIHW, 2015a; Saunders et al., 2014). In many high income countries, laryngeal cancer incidence rates have been declining in response to a reduction in tobacco

smoking prevalence rates (Sturgis & Ciniciripini, 2007). The relative five year survival rate of laryngeal cancer after treatment varies between 66-79% in Europe and North America but is lower for low and middle-income countries (Ramroth et al., 2011; Stam, Koopmans, & Mathieson, 1991). An Australian study found a five year survival rate of 67% in individuals treated with TL (Hall et al., 2003).

The risk factors for laryngeal cancer primarily relate to lifestyle factors such as tobacco and alcohol consumption. The amount and duration of tobacco smoking affects risk. Heavy smoking has been described as 35 or more cigarettes per day and heavy alcohol consumption as 100 g per day (La Vecchia, Zhang, & Altieri, 2008; Stewart & Kleihues, 2003; Wynder, Covey, Marbuchi, Johnson, & Muschinsky, 1976). There is a synergistic effect when smoking and alcohol are combined. Heavy consumption of both increases the risk of laryngeal cancer 22 times compared with non-smokers and non-drinkers (British Association Otorhinolaryngologists Head and Neck Surgeons (BAOHNS), 1998). An association between passive smoking and laryngeal cancer has also been reported (Saunders et al., 2014).

Tobacco and alcohol consumption have been associated with other significant socio-cultural determiners of health, including low socio-economic status (SES) in conjunction with low levels of educational achievement, occupation, aging and gender (Doyle, 1994; Thorne, Etherington, & Birchall, 1997). Other risk factors such as genetics and environmental exposures have also been discussed in the general literature (Ramroth et al., 2011; Saunders et al., 2014). How these risk factors are linked to the personal and environmental contextual factors unique to the TL experience is discussed in more depth in section 2.4.3.

Survival rates from laryngeal cancer have gradually improved over the last 30 years for non-Indigenous Australians due to a reduction in smoking, but morbidity and mortality rates from HNC remain higher for Indigenous Australians than the non-Indigenous population (AIHW, 2015a; South Australia Department of Health, 2013). Between 1980 and 2011, non-Indigenous Australian men experienced the greatest improvement in the incidence and mortality rates for laryngeal cancer compared to non-Indigenous women, where the rates have been relatively stable with modest yearly fluctuations (AIHW, 2015b).

Some researchers have reported that incidence rates in other developed countries are also stable rather than reducing for women (Saunders et al., 2014).

Others have forecast that the incidence of laryngeal cancer in women will increase across western countries as a result of aging populations (Saunders et al., 2014; Stewart & Kleihues, 2003; Sturgis & Ciniciripini, 2007). There are currently no projections available for the likely future incidence of laryngeal cancer in Australia. However, the incidence of lung cancer (another tobacco-related cancer) among women matched forecasts of an increase of 2% between 2002 and 2011. This trend was consistent with the increased prevalence of tobacco smoking among women until the mid-1970s, when one third of women smoked (AIHW, 2005; Australian Institute of Health and Welfare & Australasian Association of Cancer Registries, 2010).

### 2.2.2 *Total laryngectomy*

The universal surgical treatment for advanced laryngeal squamous cell carcinoma is TL. This radical surgery can be a curative or palliative treatment and may also be performed to manage other non-malignant laryngeal aetiologies or airway incompetence (Krishnan & Maclean, 2013; Mathieson, 2001). A TL involves surgical removal of the cartilages of the larynx, the vocal folds, hyoid bone and upper two rings of the trachea (Doyle, 1994). The upper trachea and oesophagus are separated and the trachea is surgically joined to the lower neck, creating a permanent tracheostoma. Reconstruction of the pharynx is also required. In Australia, a range of surgical techniques are used to achieve this (Maclean, Cotton, & Perry, 2008). Redirection of the trachea to the neck results in a continuous passage between the upper and lower aerodigestive tract. The functional and psychosocial consequences of these changes are significant and are discussed at length in section 2.4.

Historically, advanced laryngeal cancers have been managed with surgical resection followed by radiotherapy and/or chemoradiotherapy. However, there has been a trend favouring the organ-preserving treatments of adjuvant radiotherapy and chemotherapy (Cohen et al., 2006), despite evidence that individuals with advanced laryngeal cancer experience better survival rates when surgery is combined with chemo-radiation (Dziegielewski et al., 2012; Hall et al., 2003; Maddox & Davies, 2012; Saunders et al., 2014). There have also been some instances where a salvage TL has been required due to failed adjuvant therapies and disease recurrence (Agrawal & Goldenberg, 2008). Individuals with a history of adjuvant therapies have an increased risk of post-operative complications such as poor surgical wound healing (Graboyes, Yang, Kallogjeri, Diaz, & Nussenbaum, 2014; Timmermans et al., 2014).

Public data regarding the local incidence of TL procedures completed in South Australia or Australia-wide is unavailable. In recent times, there has been a decline in TL procedures in favour of organ preserving treatments but a small number of surgeries are completed annually. Two tertiary hospitals provide specialist HNC services to the South Australian community.

## 2.3  Overview of the evidence of adjustment to total laryngectomy

A preliminary review of black and grey literature was undertaken during the planning phase of each stage of this study. These reviews focused on the impact of TL and issues concerning health-related quality of life (HRQoL) and psychosocial adjustment. After the data collection and analysis phases of the project, a more comprehensive review of the literature occurred. This approach to the literature review was consistent with the qualitative methodology chosen for this study. Further detail regarding this is provided in Chapter 3, section 3.8.2.

A sample of the search terms and results is provided in Appendix 1. Due to small clinical populations, an understanding of the effects of TL has come from small to moderately sized research studies, clinical reports and clinical practice guidelines. Many studies have had heterogeneous samples where the TL cohort is part of a larger sample of individuals with a range of different HNC diagnoses or who were managed with other surgical treatments for laryngeal cancer, for example supraglottic laryngectomy. In addition, the TL populations may have experienced organ-preserving treatments and required a salvage procedure, or had pre-operative or post-operative radiotherapy.

There is a range of prevalence data concerning HRQoL, functional and psychosocial outcomes experienced specifically by the HNC and TL populations. The TL experience has been reported to be similar to, but also distinctive from, the experience of having a partial laryngectomy or removal of other head and neck structures such as the nasopharynx or tongue (Boscolo-Rizzo, Maronato, Marchiori, Gava, & Da Mosto, 2008; Herranz & Gavilán, 1999; Ramírez et al., 2003; Sewnaik, Van den Brink, Wieringa, Meeuwis, & Kerrebijn, 2005). Different treatments can result in a range of alterations to function and appearance, and may lead to different recovery trajectories. IWL have been reported to experience poorer adjustment outcomes than individuals who have undergone organ-preserving treatments (Terrell et al., 1998).

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To date, much of the research regarding adjustment to TL has been cross-sectional and retrospective. It is difficult to construct a clear picture because many studies have used small to medium sample sizes, and there is little consistency across study designs or data capture points. Population bias has been frequently described as a methodological flaw in many published studies (Haisfield-Wolfe, McGuire, Soeken, Geiger-Brown, & De Forge, 2009; Murphy, Ridner, Wells, & Dietrich, 2007; Rogers, Ahad, & Murphy, 2007). Many evaluations have privileged self-selected individuals from specific cultural groups who were well enough to participate or who had the literacy skills to answer self-report quality of life questionnaires. Participant recruitment has usually occurred through approaching members of local or online laryngectomy support groups (Blood et al., 1995; Eadie & Bowker, 2013; Evans, Carding, & Drinnan, 2009; Ward, Hobson, & Conroy, 2003). Eadie and Doyle (2005) suggest that many members of laryngectomy groups have higher levels of education and economic stability.

Another criticism of self-selection is that many studies have favoured individuals who choose to take part, and have under-represented those who may be experiencing significant mental health or other health difficulties (Murphy et al., 2007). Screening tools rather than psychiatric evaluation have been used to measure psychological status, which may have resulted in an overestimation of psychological comorbidity (Murphy et al., 2007). Some researchers have argued that the prevalence of mental health problems associated with HNC, and specifically TL, could be underestimated (Haisfield-Wolfe et al., 2009). This is a particular concern because smoking rates are more prevalent within the HNC population compared to the general population and have been associated with increased depressive symptoms (Duffy, Ronis, et al., 2007). Encouragingly, there have been a few more recent multi-centre, prospective, longitudinal studies with increased representation and sample sizes (Armstrong et al., 2001; Keszte et al., 2013; Singer et al., 2014; Singer, Wollbrück, et al., 2013).

## 2.4    Contextualising the life-changing consequences of total laryngectomy

The International Classification for Functioning, Disability and Health (ICF) provided a useful conceptual framework in which to examine the physical and functional changes that primarily affect respiration and airway management, swallowing and verbal communication after TL, and their influence on psychosocial wellbeing (Eadie,

2007; World Health Organisation, 2001). The 'body function and structures', and 'activities and participation' domains of ICF are used here to evaluate the TL experience. The relevance of personal and environmental contextual factors is also discussed (World Health Organisation, 2001). Additionally, I use some of the complimentary dimensions for oncology patients proposed for the ICF framework by Bornbaum, Doyle, Skarakis-Doyle, and Theurer (2013). Using their suggestions, I have described a TL as a health state rather than a health condition, updated personal factors to include comorbidities and dependencies, and endeavoured to capture more comprehensively the subjective elements of the TL experience by accounting for research that has examined health and function using HRQoL measures. Figure 1 provides an overview of the ICF framework in relation to TL.
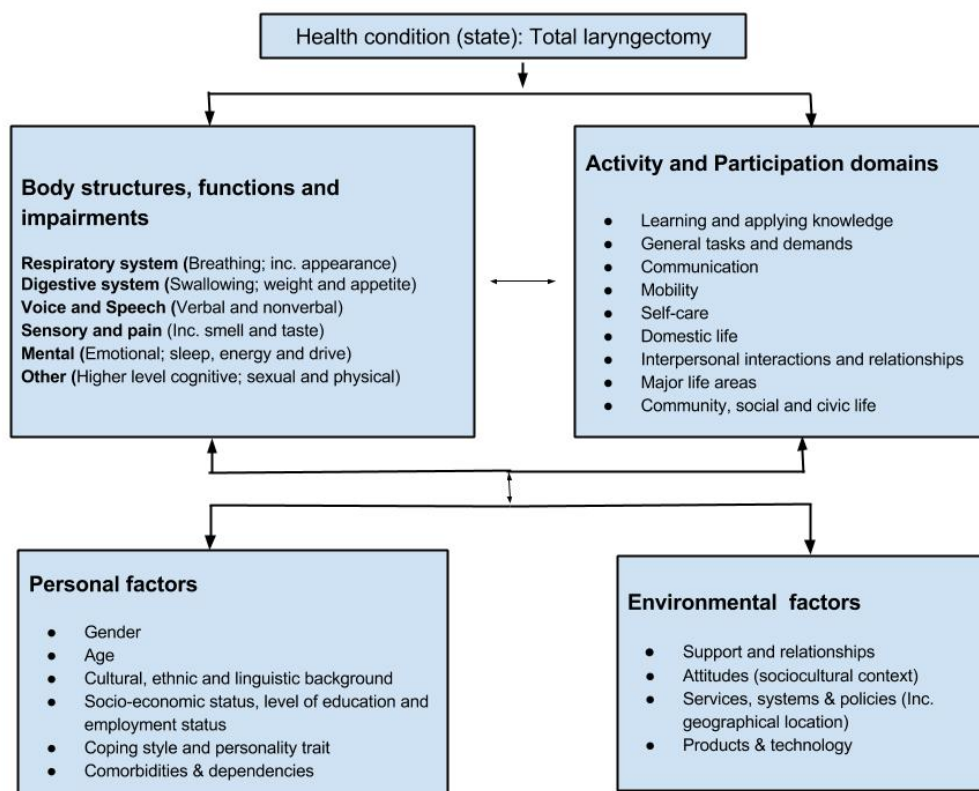


**Figure 1:** **International Classification of Functioning (ICF) framework and the total laryngectomy experience**

### 2.4.1 *Changes to body functions and structures: Related impairments*

The larynx is made up of several cartilages and a sophisticated network of internal and external muscles. It is positioned at the top of the trachea and primarily functions to keep the trachea and respiratory system free of foreign material during respiration

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and degustation. It protects the trachea during swallowing and facilitates the opening of the upper oesophagus for food and fluid to transit to the stomach. Thus, the larynx is an integral mechanism in the digestive system. It also has a crucial role in the phonatory system, enabling voice production for speech (Doyle, 1994; Mathieson, 2001). Surgical removal of the larynx and redirection of the trachea to a stoma in the neck impacts all the systems noted above. Figure 2 represents the pre- and post-operative anatomy. A TL and associated treatments can also affect other functions and structures, including the senses of smell and taste, general mental functions, intimacy and sexuality, sphincteric functions and general physical wellbeing. Weakness and pain often associated with shoulder problems can also occur. Some of these issues are transient, whilst others persist and become chronic.
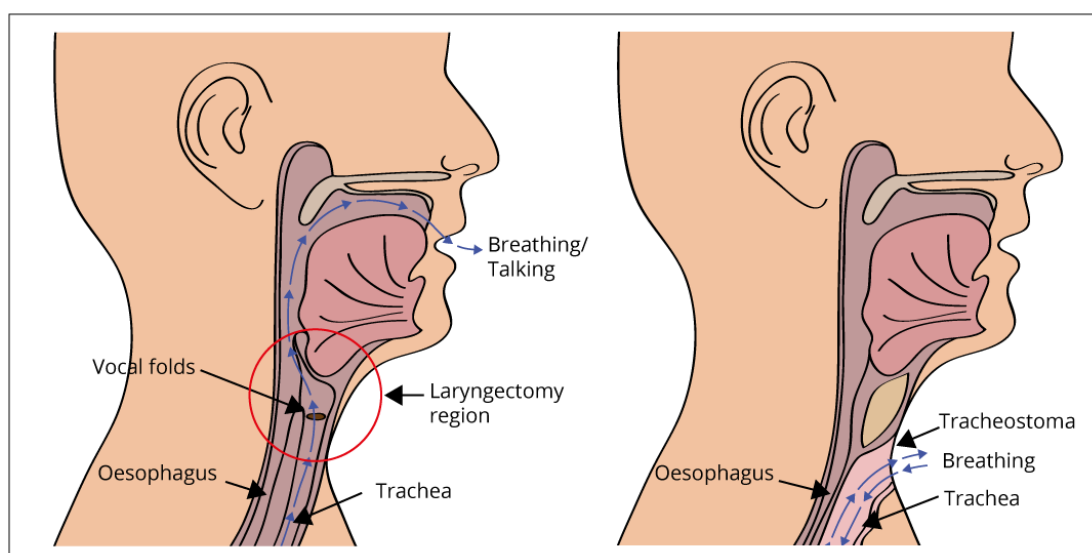


**Figure 2:    Pre- and post-operative anatomy**

*Illustration by Indigo Projects, used with permission*

### 2.4.1.1    *Respiratory system*

*Breathing and airway management*

The upper body structures for respiration are completely altered after TL. The respiratory system no longer terminates through the nasal and oral cavities but through the neck. An individual has to master breathing through a permanent tracheostoma. Airway management can be problematic. Loss of the heat-moisture and filtering properties of the upper aerodigestive tract cause increased mucous production and expectoration. Shortness of breath has also been reported as a persistent problem for IWL. Maintenance of tracheostomal health is imperative for airway integrity. Some individuals successfully use foam bibs or the more sophisticated heat moisture

exchange (HME) outer-housing to cover the tracheostoma. These systems can optimise breathing and significantly improve pulmonary function and comfort. However, irregular neck anatomy and/or reduced manual dexterity are factors that may limit a person's suitability to utilise HME outer-housing (Boscolo-Rizzo et al., 2008; Hilgers & Ackerstaff, 2000; Hilgers, Ackerstaff, Aaronson, Schouwenburg, & Van Zandwijk, 1990; Hilgers, van den Boer, & van den Brekel, 2014; Nordgren et al., 2003; Op de Coul et al., 2005; Singer et al., 2014).

Issues relating to resuscitation may also arise. Education about the altered airway is required because individuals no longer breathe through their upper airway and will not respond to upper airway revival approaches. All attempts to resuscitate must be done via the tracheostoma in the neck (Mathieson, 2001).

*Appearance (tracheostoma and neck anatomy disfigurement)*

Altered appearance also results from the visible disfigurement of a tracheostoma and irregular contouring of the neck after surgery (Mathieson, 2001). Data regarding the psychosocial impact of altered body image after TL is mixed. Up to 25% of IWL report being bothered by their appearance and one third feel it affects their sexual relationship (Op de Coul et al., 2005; Singer et al., 2008). A study by Terrell et al. (1998) suggests that these issues persist longer-term, with IWL reporting they were more affected by their appearance than by alterations in their speech. However, several studies indicate that appearance does not affect overall global QoL scores (Ramírez et al., 2003; Vilaseca, Chen, & Backscheider, 2006; Woodard, Oplatek, & Petruzzelli, 2007). The timing of evaluation could be a factor. Anxiety levels related to facial disfigurement after HNC surgery have been reported to be highest in the early stages of recovery and disruptive to self-care (Dropkin, 2001). The impact of altered appearance is also discussed later in relation to sexual function, gender and age differences, and psychosocial adjustment.

### 2.4.1.2 Digestive system

*Swallowing, weight and appetite*

The return of swallowing function can vary amongst individuals and can depend on surgical technique, history of radiotherapy and/or chemotherapy, age and the presence of co-morbidities such as depression (Maclean et al., 2008, 2009a; Ward, Bishop, Frisby, & Stevens, 2002). Problems may relate to anatomical changes such as reduced pharyngeal propulsive forces or side effects from radiotherapy (e.g. xerostomia,

mucositis, fibrosis, and stricture of oropharyngeal and oesophageal musculature). An individual's ability to return to a textured diet will also depend on oral health, including adequate dentition, minimal oropharyngeal scarring and regular anatomy (Krishnan & Maclean, 2013; Maclean, Szczesniak, Cotton, Cook, & Perry, 2011).

Weight loss is a concern for this population. Many HNC patients present as being malnourished or are at risk of unintentional weight loss over the course of the treatment program. Supplemental and alternative feeding may be required, particularly if patients undergo additional post-operative treatment such as radiotherapy. Poorer HRQoL outcomes have been noted for individuals with feeding tubes (Kiss & Isenring, 2014; Metreau, Louvel, Godey, LeClech, & Jegoux, 2014; Murphy et al., 2007). Post-operative complications and swallowing difficulties can also compound weight loss and affect recovery rate. Low albumin levels suggestive of malnourishment can contribute to poor surgical wound healing and the development of fistulae (Timmermans et al., 2014). Fistulae formation has been recorded as the primary reason for unplanned readmission within 30 days of discharge (Graboyes et al., 2014). Singer et al. (2014) found that appetite loss remained a significant issue at one year after surgery.

### 2.4.1.3 *Voice and speech functions*

Voice and speech functions are crucial aspects of verbal communication and are dramatically altered in TL due to the removal of the larynx. The function of producing sound is no longer possible because the vocal folds of the larynx provide the vibratory source for phonation or voicing (Doyle, 2009). Permanent loss of the voice can significantly impact an individual's ability to communicate verbally and interact in the same way he or she did before the loss. However, there is variation in how individuals respond to these changes in their lives (Ackerstaff et al., 1994; Eadie, 2007).

*Verbal communication*

Voicing in speech conveys paralinguistic and acoustic information. For example, changes in pitch, loudness, vocal quality and intonation can indicate the emotional wellbeing and health status of a person (Aronson & Bless, 2011). A person's voice can also indicate physical, gender and age characteristics (Crystal, 1987; Pasricha, Dacakis, & Oates, 2008). Another important contribution of the voice is the acoustic role it has in differentiating speech sounds. For example, voicing is the distinctive

feature for voiced and voiceless phonemes such as /f/ and /v/, and is an important feature in the production of vowels (Ladefoged, 2001). In fact, vowel differentiation and vocalisation are the means by which verbal emotions and emotive states such as laughing and crying can be conveyed acoustically (Doyle, 2009).

Alaryngeal communication rehabilitation can take time and individuals progress at different rates. Some people may be using audible ACM within two weeks of surgery and others may take much longer. Most IWL will attempt mastery of an audible ACM such as electrolaryngeal (EL) speech, oesophageal (OE) speech or tracheoesophageal (TE) speech within the first year after surgery. Surgical voice restoration (SVR) and the use of a voice prosthesis for TE speech has transformed communication rehabilitation for IWL (Bień et al., 2008; Yoshida, Singer, Blom, & Charles, 1989). Despite the cost and need for regular specialist consultations, TE speech is currently the most popular rehabilitation approach in the western world (Bień et al., 2008; Farrand & Duncan, 2007). Recent studies confirm this trend with significantly higher percentages of participants who have undergone SVR compared to non-SVR (Robertson, Yeo, Dunnet, Young, & Mackenzie, 2012; van der Molen, Kornman, Latenstein, van den Brekel, & Hilgers, 2013; Ward, Koh, Frisby, & Hodge, 2003). Against this trend is a study where a larger number of participants used OE speech and EL speech compared to TE speech (Singer, Wollbrück, et al., 2013). There is also evidence to suggest that TE speakers experience higher success rates over the other methods (Bień et al., 2008; van As, 2001). However, a wide range of TE speech attrition rates (12-74%) has been reported one year post-surgery and longer term (Frowen & Perry, 2001; Singer, Wollbrück, et al., 2013; Ward, Koh, et al., 2003).

Another advantage of TE speech is that it is more naturalistic in the paralinguistic parameters of fluency, pitch, vocal quality, speech rate, prosody, and general social acceptability in comparison to the other techniques (Hilgers & Ackerstaff, 2000; Kazi et al., 2005; Mathieson, 2001; van As, 2001). However, not all individuals are suited to SVR. Some may require the temporary use of an alternative method such as EL or OE speech. All methods require rehabilitation and ongoing maintenance support from skilled health professionals working in an effective multidisciplinary team (Frowen & Perry, 2001; Lawson & Ward, 2014). In Australia, it is the speech pathologist who takes the primary role for communication rehabilitation (Krishnan & Maclean, 2013; Lawson & Ward, 2014).

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*Non-verbal communication*

The impact of TL on non-verbal communication has not been widely evaluated. Non-verbal communication such as writing or gesturing can be interrupted by audible ACMs. For example, to use an electrolarynx or voice prosthesis one usually needs the dexterity of one hand for device placement or digital occlusion of the tracheostoma. Some TE speakers use a hands-free valve to enable communication without using their hands but their success, like that of HME outer-housing, depends on regular neck anatomy, dexterity, regular maintenance and affordability (Hilgers & Ackerstaff, 2000; van As-Brooks & Fuller, 2014; Ward, Acton, & Spurgin, 2014).

### 2.4.1.4    *Sensory functions and pain*

*Smell, taste and pain*

Nasal breathing after TL is no longer possible and this affects olfaction (smell), sniffing and sneezing. Lack of olfaction has a deleterious effect on taste and may impact the appeal of eating and drinking for some individuals (Hilgers & Ackerstaff, 2000). However, in one study, a loss of smell after TL did not significantly influence the enjoyment of eating for the cohort (Op de Coul et al., 2005). Modified sniffing techniques have been developed to facilitate olfaction and enhance taste (van As-Brooks, Finizia, Kerle, & Ward, 2014).

In many TL cases, the accessory nerve in the shoulder is sacrificed during surgery. This can result in long-term muscular weakness of the shoulder and associated bodily pain (Boscolo-Rizzo et al., 2008; Kerawala, 2010; Terrell et al., 1998). There are also reports of pain associated with chemoradiation (Metreau et al., 2014), which may persist for people who need salvage surgery. Finally, a TL is often followed by radiotherapy. Like those who have chemoradiation, those undergoing radiotherapy will experience short-term oropharyngeal mucositis and xerostomia, which may result in transient odynophagia (Givner, Stierwalt, LaPointe, & Spicer, 2014).

### 2.4.1.5    *Global mental functions*

This is a large category with considerable overlap with other areas in the framework. A person's health, psychosocial wellbeing and adjustment after TL are strongly influenced by emotional function, patterns of sleep, energy and drive levels, higher-level cognitive function, perceptual factors, activities and participation domains, and contextual factors including support, coping skills and personality traits.

*Emotional function, sleep, energy and drive*

In the ICF, emotional functions pertain to the appropriateness, regulation and range of emotions a person experiences (World Health Organisation, 2001). The experience of being diagnosed with a life-endangering illness such as laryngeal cancer and subsequent intervention impacts an individual's emotional functioning. Generally, there is evidence of a deterioration of HRQoL, including emotional status at diagnosis, during the early recovery phase and for up to six months. Gradual improvement of symptoms and functions such as breathing, verbal communication and swallowing has been reported over the first year and results in improved emotional status. There is, however, evidence of persisting, longer-term emotional difficulties for some individuals (Boscolo-Rizzo et al., 2008; Eadie & Bowker, 2013; Eadie & Doyle, 2005; Evans et al., 2009; Haisfield-Wolfe et al., 2009; Kazi et al., 2007; Murphy et al., 2007; Rogers et al., 2007; Singer et al., 2014; Terrell et al., 1998).

Retrospective studies have measured depressive symptom rates for the TL group as being between 12% and 36%. These studies used validated tools to screen for depressive symptoms. In the HNC literature, very few studies report psychiatrically-assessed levels of depression or anxiety (Haisfield-Wolfe et al., 2009; Keszte et al., 2013; Singer et al., 2005; Terrell et al., 1998). A prospective cohort study by Keszte et al. (2013) examined psychological comorbidity (e.g. alcohol dependence, affective disorders, depressive symptoms). The rate at three months post-surgery was 25% (*n*= 42/171), which dropped marginally to 22% at 12 months post-surgery. The rates were similar for men and women but the mental health issue varied. The men presented with higher levels of adjustment disorder and alcohol dependence, while the women presented with anxiety-related problems. They also reported that 6% of participants developed mental health problems after surgery and 80% of individuals with alcohol dependency had not developed an alaryngeal voice at 12 months.

A prospective study by Armstrong et al. (2001) highlighted that participants in the first six months after TL had persisting psychological comorbidity indicative of depression and stress. Only a slight improvement was noted at six-months. Overall, the results were poorer compared to groups with no medical condition, a serious medical condition and patients identified with a depressive illness at the same institution. Finally, the authors concluded that the pre-operative measures for

emotional problems, mental health and wellbeing correlated with the six-month post-operative scores and were a reasonable predictor of outcome.

Persisting mental health issues have also been identified in the literature. Terrell et al. (1998) conducted a longitudinal randomised control trial (RCT) of different treatments for advanced laryngeal cancer, in which they examined the HRQoL outcomes of USA veterans 10 years after a TL. They found that 28% ($n$=9/32) of subjects had persisting depressive symptoms; almost double the 15% incidence rate for subjects who underwent organ-preserving treatment. Depressive symptoms in TL and HNC populations can result in sleeping difficulties, which have a subsequent deleterious effect on health domains such as physical functioning, general health, vitality, sexual behaviour and social functioning (Boscolo-Rizzo et al., 2008; Duffy, Ronis, et al., 2007; Singer et al., 2008). Hilgers et al. (1990) found that 24% of 59 male IWL had sleep problems related to disruptive breathing.

Depressive symptom rates in patients being treated for HNC have been recorded between 21% and 46% (Duffy, Ronis, et al., 2007; Lazure, Lydiatt, Denman, & Burke, 2009). In a RCT with HNC patients, individuals with depressive symptoms experienced higher rates of disease recurrence and mortality than those who were not depressed. Although this was a relatively small heterogeneous study, the results were reported to be similar to those for other cancers such as breast, pancreatic and colon (Lazure et al., 2009). In a larger study of 965 HNC patients (TL sample $n$ =14%), 46% were screened with significant depressive symptoms, which had a strong negative association with the HRQoL outcomes (Duffy, Ronis, et al., 2007).

Problems with anxiety and stress-related disorders have also been reported in the TL clinical population. Singer et al. (2008) noted in one study that the incidence of increased to severely increased anxiety levels post-laryngectomy was 17% and 7% respectively. However, a skewed sample should be noted because 93.2% were men, including individuals who had had a partial laryngectomy. Nevertheless, no significant difference was noted between the cohorts on the increased and severely increased anxiety level measures. A recent study examining mental health outcomes reported higher and persisting anxiety-related comorbidity in the female cohort compared to the male cohort (Keszte et al., 2013).

Anxiety levels may also be related to the timing of care. In a case controlled

study of HNC patients (TL sample *n*=66) by Ramírez et al. (2003), 45% reported anxiety and 35.5% were worried about their cancer recurring. Gibson and McCombe (1999) reported that IWL and their spouses experienced increased anxiety near to, and at the time of, discharge. Many of the study participants expressed concern about how they would manage post-discharge. In addition, there are also reports that IWL can experience issues related to survivorship and can have persistent worry regarding their health (Brook, 2011; Eadie & Bowker, 2013; Howren, Christensen, Hynds Karnell, Van Liew, & Funk, 2013; Ramírez et al., 2003; Semple, Dunwoody, Kernohan, McCaughan, & Sullivan, 2008).

Haisfield-Wolfe et al. (2009) conducted a systematic review of the prevalence and correlates of depression in HNC populations. They reported that depressive symptoms at diagnosis was predictive of later depression in the patient journey and that certain factors were highly interrelated. They described how co-occurrence of the following factors affected the overall outcome for a person:

1) socio-demographics such as marital status, gender, age, social support, social disruption, employment status and education level
2) health status, for example multiple comorbidities, smoking, cancer site and advanced tumour stage
3) clusters of symptoms such as pain, insomnia, anorexia, fatigue, wound healing issues, speech and swallowing difficulties
4) specific time points in the illness trajectory.

There appears to be contradictory evidence regarding depressive symptoms being a predictor of HRQoL, particularly in the longer-term. Many studies have associated higher depressive symptom rates with lower HRQoL but a study by Nordgren et al. (2003) suggests that depressive symptoms at one year were not predictive of HRQoL outcomes at five years. de Leeuw et al. (2001) discussed eight prognostic "pre-treatment variables" for HNC patients in predicting the likelihood of psychological comorbidity across the treatment trajectory. They included "tumour stage, gender, depressive symptoms, openness to discuss cancer in the family, available support, received emotional support, tumour-related symptoms and size of informal social network" (p. 892). They found a higher negative predictive value of 83% compared to a positive predictive value of 58%.

Increased psychological comorbidity after laryngectomy has also been

postulated as a precursor for suicidal ideation. Very few studies have specifically examined the prevalence of suicide or suicidal ideation in this population. However, the typical socio-demographic for a HNC patient is similar to the increased risk factors for suicide (male, older age, social isolation, chronic illness, and history of alcohol or drug abuse) (Purcell & Turner, 2014). In a small study by Gibson and McCombe (1999), findings showed persisting high levels of psychological comorbidity six months after surgery. For example, seven out of ten participants displayed reduced self-esteem, tearfulness, depressive symptoms, suicidal ideation, sleeplessness, poor concentration and increased reliance on a spouse for care. Unfortunately, many HNC studies have specifically excluded individuals presenting with suicidal ideation from the study design (Duffy, Khan, et al., 2007; Duffy, Ronis, et al., 2007).

Energy and drive, or motivation levels have also been evaluated in relation to IWL. Ackerstaff et al. (1994) reported that higher fatigue levels were correlated with poorer voice quality outcomes. In another study, Singer et al. (2014) found that fatigue persisted for all of the first year after TL. The same group of researchers also found "that motivation was not a good predictor for the development of speech intelligibility" at one year post-surgery (Singer, Meyer, et al., 2013, p. 843). Self-efficacy is another psychological construct that has been associated with motivation (Maddux & Lewis, 1995). Interestingly, a recent study examining the effects of self-efficacy and QoL outcomes concluded that psychological status rather than self-efficacy was the main predictor of adjustment. It also reported that the sample group demonstrated higher than normative values for self-efficacy but that there was a possible population bias because all participants were members of a laryngectomy support group and demonstrated high levels of engagement and participation (Perry et al., 2015).

### 2.4.1.6 Other functions
A TL affects other body functions but there is considerable overlap with other discrete categories of the ICF framework. Relevant functions not covered earlier are collated here.

### Higher-level cognitive functions
Very little has been documented regarding the impact of higher cognitive functioning on TL outcomes. These functions include information about capacity for abstraction,

organisation and timing, time management, cognitive flexibility, insight, judgement and problem solving. This is an obvious gap in data collection given the prevalence in this clinical population of individuals with a history of alcohol misuse who may experience cognitive side effects from their alcoholism. These issues are further discussed in 2.4.2.4.

*Sexual function and intimacy*

A TL does not alter sexual ability, however more than half of the participants in a large multi-centre study by Singer et al. (2008) experienced a reduction in libido and sexual enjoyment after treatment for laryngeal cancer. It was also reported that these difficulties were not related to level of education, gender, or alcohol and/or tobacco consumption but rather to post-treatment depression, high levels of distress and advanced tumour stage. One third of participants reported a negative impact to their sexual relationship and indicated they were affected more by physical weakness, respiratory noises and excess sputum than by tracheostoma disfigurement, despite 25% reporting they were bothered by their appearance (Singer et al., 2008). Poorer QoL outcomes for sexuality were also reported for both TL and partial laryngectomy participants in a study completed by Bindewald et al. (2007). Fewer sexual problems were reported for a TL group compared with an organ preservation group (Metreau et al., 2014). Poorer sexual functioning in individuals with extensive disfigurement from HNC and participants less than 65 years old has also been reported (Monga, Tan, Ostermann, & Monga, 1997).

*Physical function (including strength, range and sequencing movement)*

General physical weakness and physical functioning can affect IWL for up to 12 months after surgery and longer-term (Boscolo-Rizzo et al., 2008; Singer et al., 2014; Vilaseca et al., 2006). In addition, people may experience a limited range of movement in their arms if the surgery has affected the innervation to the accessory nerve in the shoulder (Kerawala, 2010). Fine motor control, manual dexterity and motor sequencing ability are required for several ACMs and independent manipulation, and caring for the voice prosthesis or the tracheostoma. In addition, a TL can affect some sphincteric functions. Removal of the larynx means that adduction of the vocal folds and fixation of the thorax during exertion activities such as heavy lifting or defecation is no longer possible. This may alter the experience for individuals (Mathieson, 2001).

### 2.4.2 *Effects on activities and participation*

The consequences of TL in relation to activity and participation levels, and capacity to perform daily living tasks must be viewed in a multidimensional way. The ICF framework describes **activity limitations** as pertaining to "difficulties an individual may have in executing activities" and **participation restrictions** as "problems an individual may experience in involvement in life situations" (World Health Organisation, 2001, pp. 212-213). In reviewing the relevant evidence, I discuss how disruptive breathing, disfigured appearance, altered swallowing, changes to communication and, to a lesser extent, physical and higher level cognitive limitations and psychological comorbidity collectively impact the following activity and participation domains outlined by the ICF framework. These are: learning and applying knowledge; communication; mobility; self-care; domestic life; interpersonal interactions and relationships; major life areas such as employment and economic life; and community, social and civic life. Later, I discuss how contextual factors (personal and environmental) relate to psychosocial adjustment (section 2.4.3).

#### 2.4.2.1 *Breathing and tracheostoma issues impact all domains*

The nature of a tracheostoma and the need for airway protection can result in restriction of activities involving water, dust and fumes. Frequent disruptive coughing episodes, excessive sputum production or eructation, breathlessness and respiratory noises can also affect a person's sexuality, social participation, communication ability, fatigue levels and HRQoL (Ackerstaff et al., 1994; Boscolo-Rizzo et al., 2008; Hilgers & Ackerstaff, 2000; Hilgers et al., 1990; Nordgren et al., 2003; Op de Coul et al., 2005; Singer et al., 2008; Singer et al., 2014).

#### 2.4.2.2 *Swallowing difficulties impact social functioning, participation and self-care*

A swallowing disability has been observed to affect HRQoL after TL. Early stage recovery from surgery may require an individual to have food textures (e.g. moist and soft) that are easier to swallow (Ward, Kerle, Hancock, & Perkins, 2014). Problems with swallowing and social eating up to a year post-surgery have also been reported (Armstrong et al., 2001; Singer et al., 2014). The rate of persisting swallowing difficulties, necessitating a modified diet, dependency on a feeding tube or oral nutritional supplements after one year has been reported to be between 26.9% and 71.8% (Maclean et al., 2009b; Metreau et al., 2014; Ward et al., 2002). Long-term severe swallowing problems have also been related to increased psychological

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distress, social avoidance and poorer QoL outcomes (dos Santos Queija, Godoy
Portas, Aparecido Dedivitts, Neutzling Lehn, & Brandão Barros, 2009; Maclean et al.,
2009b).

These findings contrast with those of Woodard et al. (2007), who found in
their retrospective study that longer-term self-reported swallowing deficits did not
greatly impact overall function or HRQoL in TE speakers who were over 65 years old
at diagnosis, had fewer comorbidities and no history of organ preserving treatment.
Similarly, Robertson et al. (2012) reported a large Scottish audit of IWL who
experienced superior swallowing status to people who were also treated post-
operatively with radiotherapy, or who had organ preserving treatment or salvage
surgery. Metreau et al. (2014) reported similar swallowing outcomes between these
different clinical groups.

### 2.4.2.3 Communication changes impact all domains

Little has been documented about the experience of verbal communication loss
immediately after surgery and during the early part of recovery and rehabilitation.
Immediately after the surgery is a time of intensive medical need and dramatic
transition for people. Rodriguez, Thomas, Rowe, and Koeppel (2012) described it as a
period of "sudden speechlessness" (p. 44), where a person was very vulnerable, and
required an empathetic approach and the implementation of a simple communication
system so that his/her basic needs could be met. After the early recovery period most
people will be able to write messages, gesture or mouth their intentions. However,
communication success can be affected by a person's literacy level and the time and
patience of communication partners.

Swore Fletcher, Cohen, Schumacher, and Lydiatt (2012) examined the broader
implications of communication changes from HNC. The functional difficulties
experienced by participants were combined with existential experiences of feeling
grateful for survival and the support received, whilst also finding deeper meaning in
life. Communicative participation and targeted rehabilitation were highlighted as
important. Baylor, Burns, Eadie, Britton, and Yorkston (2011) examined the
perceived "interference" to participation experienced by individuals with
communication impairment; three participants had a TL (p. 269). The results suggest
that emotional, functional, health and environmental factors may interfere with
communicative participation. Some of these factors were deemed to be outside an

individual's control, whilst others were within their control. For example, environmental context and health status were identified as external influences, whereas an internal influence could be when individuals made decisions about participating in communicative events based on what they had learnt from past situations. The authors viewed these decisions as adaptive or maladaptive. The findings also suggest that the participants rated interference higher if a communicative event was important to them.

The accumulative effect of both verbal and non-verbal communication limitations restricting social participation have been measured with voice-related quality of life (VRQoL) tools and other self-report HRQoL measures. Interestingly, there are contradictory reports regarding SVR and VRQoL. While superior outcomes for TE speakers have been reported (Robertson et al., 2012; Ward, Koh, et al., 2003; Woodard et al., 2007), other studies have found that SVR does not result in superior outcomes over other audible ACM and that approximately two thirds of alaryngeal speakers, regardless of their method, experience a moderate-severe voice handicap and a reduction in disease-specific QoL outcomes compared to healthy controls (Evans, Carding, & Drinnan, 2009; Farrand & Duncan, 2007; Kazi et al., 2007).

There is evidence from retrospective, cross-sectional studies that communication changes and subsequent difficulties after TL alone are not determiners of social functioning and global HRQoL beyond the first year (Perry et al., 2015; Ramírez et al., 2003; Robertson et al., 2012; Terrell et al., 1998; Vilaseca et al., 2006; Woodard et al., 2007). Some studies have found that IWL did reasonably well in terms of social functioning and reported better mental health than other people with serious illnesses (Farrand & Duncan, 2007; Schuster et al., 2003). For example, Woodard et al. (2007) found a cohort of IWL rated the domains relating to "speech, eating, social disruption, aesthetics, and overall QoL" as intermediate or high (p. 526). Several researchers have postulated that the positive HRQoL outcomes experienced by the participants in their studies may have been skewed by some of the cohort's successful use of hands-free valves. They remarked that hands-free valves improved the voice signal, reduced disruptive pulmonary issues and minimised frustration with communication (Eadie & Doyle, 2005; Op de Coul et al., 2005). There is also evidence the TL population is not homogenous regarding how alaryngeal communication impacts social outcomes. Individuals who experienced superior health

status at diagnosis, a less complicated treatment pathway and SVR were more likely to experience better outcomes (Robertson et al., 2012; Woodard et al., 2007). For example, Giordano et al. (2011) found that whilst TE speakers experienced more physical limitations and emotional problems affecting role and social functioning compared to healthy controls, they had better social functioning compared to the OE speakers in the same study.

Other reported consequences of TL that affect all alaryngeal speakers in social situations regardless of the ACM being used include reduced ability to alter the loudness of the alaryngeal voice, for example difficulty projecting or whispering, which is problematic in noisy environments (Giordano et al., 2011; Op de Coul et al., 2005; van As, 2001). The issues of noisy or disruptive breathing were discussed earlier and can be particularly problematic during speech events (Ackerstaff, Zuur, & Hilgers, 2007). In addition, the prosodic features of speech, which convey emotion through intonation, have been described as difficult to achieve for all alaryngeal speakers, including TE speech, which is the most naturalistic of the audible ACMs (van As, 2001). Non-speech expressions of emotion, including laughter and crying, also have a different quality to the pre-surgical state (Doyle, 2009).

Moukarbel et al. (2011) found that TE speech had similar acceptability ratings to OE speech, and both were preferred to EL speech. However, TE and OE speakers have reported difficulties having their voice accepted by others when using the telephone (Giordano et al., 2011). A study of the auditory-perceptual ratings by listeners of alaryngeal speech highlighted that even though TE speech and OE speech are more acceptable than EL speech, alaryngeal speaker acceptability was poorer when compared to laryngeal speakers (Eadie, Day, Sawin, Lamvik, & Doyle, 2013a) despite high rates of speaker intelligibility. Eadie et al. also found a moderate correlation between speech intelligibility and speech acceptability. In another study, listeners rated a TE speaker as being less employable due to their TE speech compared to an aged-matched laryngeal speaker (Hughes & Gabel, 2008).

A further consideration regarding the social impact of TE speech is that the fundamental frequency (Fo) – the acoustic correlate of pitch – has been found to be similar amongst speakers regardless of gender. This signifies a marked lowering in speaking Fo for women and not men. One study found the median Fo for the female TE speakers was 111.8 Hz, slightly lower than the men at 115.8 Hz (Kazi, Kiverniti,

et al., 2006). This represents a possible decrease of 80-90 Hz for a female speaker because the mean Fo for women in Australia is 205 Hz (Oates & Phyland, 2000). Good adjustment and acceptance of TE speech amongst male TE speakers has been reported, whereas other researchers have documented that female TE speakers are less satisfied with their lower pitched voice and experience increased voice handicap (Ackerstaff et al., 1994; Eadie & Doyle, 2005; Kazi, Kiverniti, et al., 2006). It has also been reported that listeners judge the social acceptability of male alaryngeal speakers more favourably than female alaryngeal speakers (Eadie, 2007).

### 2.4.2.4 *Physical limitations, higher-level cognitive functioning and psychological comorbidity can impact several domains*

In section 2.4.1 related to body structure, function and impairments, I outlined how shoulder function can be affected by radical neck dissection surgery and result in reduced mobility. Subsequently, it can affect a person's ability to self-care, particularly for their tracheostoma and voice prosthesis. This has received little attention in the published literature. Gibson and McCombe (1999) reported that IWL who were self-managing at discharge (*n*=2/10) had lower psychological comorbidity than the individuals who relied on their spouses for care of their tracheostoma. Gibson and McCombe theorised that this increased spousal responsibility affected a couple's relationship, increased the care burden and may have been indicative of maladaptive dependence.

Higher-level cognitive functions are also important because of the requirements for new learning and applying knowledge in self-managing a tracheostoma and audible ACM. Singer, Meyer, et al. (2013) screened the psychomotor ability of a cohort of IWL and found 33% presented with low perceptual speed ability. However, it is difficult to gauge the meaningfulness of this result because they did not provide any comparative data with an age-matched control group.

The issues of psychological comorbidity over time, and how depressive and anxiety symptoms are strong predictors of global HRQoL and adjustment (Haisfield-Wolfe et al., 2009; Murphy et al., 2007), were discussed in section 2.4.1.6. They provide evidence that psychological comorbidity associated with diagnosis and TL can have an important and pervasive impact on an individual's activity and participation levels.

### 2.4.3  *Influence of contextual factors*

Many personal and environmental factors such as gender, age, level of education, SES and degrees of social support have been identified as possible contributors to HRQoL outcomes and psychosocial wellbeing after TL. Eadie (2007) suggests that personal factors such as gender and coping strategies can interact with environmental factors such as attitudes and social support to produce differential effects on levels of function. Examining these biopsychosocial, cultural and linguistic variables and their inter-relationships further will contribute to the clinical understanding of TL and may lead to improved HRQoL outcomes (Blood, Simpson, Dineen, et al., 1994; Eadie & Doyle, 2005; Terrell et al., 1998).

### 2.4.3.1  *Personal factors*

Personal factors such as gender, age, cultural, ethnic and linguistic background, socio-economic status, level of education, employment status, coping style and personality trait as well as comorbidities and dependencies are considered further here.

*Gender*

Despite fewer women undergoing TL, it has been reported that they experience poorer adjustment and global QoL outcomes compared to men (Eadie, 2007; Gardner, 1966; Lee et al., 2010). A recent cross-sectional study of HRQoL at least one year after TL found that women experienced poorer socio-emotional functioning, and were more likely to live alone and have changed their employment status since surgery (Lee et al., 2010). As mentioned previously, women with laryngectomy experience poorer VRQoL outcomes but have also demonstrated more concern about their appearance and reported more swallowing problems than their male counterparts (Ackerstaff et al., 1994; Kazi, Kiverniti, et al., 2006; Vilaseca et al., 2006).

Higher incidence of disfigurement-associated depressive symptoms in women has also been reported for HNC patients. However, these effects appear to be shielded by levels of social support (Katz, Irish, Devins, Rodin, & Gullane, 2003; Semple et al., 2008). This may explain the results of the study conducted by Moukarbel et al. (2011), which found no significant difference for VRQoL between men and women regardless of ACM. However, two thirds of the sample were men.

*Age*

Diagnosis usually occurs in or near the fifth decade of life. However, it can affect much younger or older people, with the youngest reported in the literature being an

infant at the time of a TL (Mathieson, 2001). Aging populations are prevalent in western communities and researchers predict that despite the fall in HNC incidence rates, the absolute number of annual cases is projected to rise due to aging (Saunders et al., 2014; South Australia Department of Health, 2013).

Age at diagnosis has been reported to predict long-term survival. In a large, multi-centre German study, individuals diagnosed between 50 and 60 years of age had better five year survival rates that those <50 years or > 60 years (Ramroth et al., 2011). However, there are mixed reports as to whether age is a predictor of successful rehabilitation and adjustment to TL. Some authors have reported little difference in QoL outcomes between younger (<65 years, mean=52) and older (> 65 years, mean=73) individuals (Blood et al., 1995; Terrell et al., 1998). Other studies have found that individuals 65 years or older had better self-reported functional and HRQoL outcomes than younger individuals (Woodard et al., 2007).

A meta-analysis of the psychosocial determinants of successful voice rehabilitation revealed conflicting evidence of age as a variable of successful SVR and subsequent TE speech (Singer, Merbach, Dietz, & Schwarz, 2007). Evans et al. (2009) found that surgical and non-surgical speakers' age was not significant, whereas Moukarbel et al. (2011) found age was a significant predictor of success for EL speech, with older participants reporting better VRQoL than younger EL speakers.

*Cultural, ethnic and linguistic background*

Australia's culturally diverse citizenry necessitates healthcare practitioners' provision of culturally sensitive services. It is difficult to obtain information about culturally and linguistically diverse populations' TL experiences due to under-reporting and language as a possible barrier to providing care. In a systematic review examining depression in HNC populations, Haisfield-Wolfe et al. (2009) found as few as 16% of studies reported racial origin. The few studies reporting this variable were from multicultural countries such as the USA. However, many of these study populations were skewed, predominantly representing Caucasian individuals. Currently, no literature describes different cultural perspectives of the TL experience in the Australian context. There is also no public data in Australia related to treatment pathways specifically for advanced laryngeal cancers, however, in line with the poorer social health gradient for Indigenous Australians, the HNC comorbidity and mortality rates for this population are higher than for non-Indigenous Australians (South

Australia Department of Health, 2013). Determiners include lower SES, higher prevalence of smoking and alcohol consumption, and poor access to specialist care because many Indigenous Australians live remotely from major cities where specialist HNC services are located (Krishnan & Maclean, 2013; South Australia Department of Health, 2013)

In the USA, race and SES have been linked to treatment pathway and HRQoL outcomes. For example, there appears to be racial disparity for organ preserving treatments in the USA. These are much more common for White-Americans than other racial groups including African-Americans, Hispanic-Americans and Asian-Americans (Hou et al., 2012).

*Socio-economic status, level of education and employment*
Socio-demographic information related to SES and level of education are reported inconsistently in laryngectomy studies. Some studies provide monthly income or education level of attainment as indicators of SES (Eadie & Bowker, 2013; Singer et al., 2014). It is also important to note that many studies frequently under-represent individuals from low SES backgrounds (Eadie & Bowker, 2013), despite the increased risk of developing laryngeal cancer associated with social disadvantage (Thorne et al., 1997). Low SES is often associated with higher rates of smoking and alcohol consumption, social deprivation, occupational exposure to hazardous materials and delay in seeking specialist medical attention (Gourin & Podolsky, 2006; Saunders et al., 2014; Stewart & Kleihues, 2003). SES is also an important consideration regarding likely treatment pathways and the trajectory of adjustment.

In one of the few population studies available, Reeve et al. (2013) found African-Americans reported higher physical wellbeing than Non-Hispanic Whites. Examination of the interaction of race and SES revealed that low-income African-Americans reported higher emotional wellbeing and fewer symptoms than Non-Hispanic Whites. The low-income Non-Hispanic Whites reported the poorest emotional wellbeing, whilst the African-Americans in the higher wage bracket reported more symptoms.

An Australian study reporting education levels of a cohort of IWL found that the majority of the 83 participants had a secondary level education (67.5%) and 12% reported a tertiary level education (Perry et al., 2015). Other studies from high-income countries where the disease rate is similar to Australia have reported higher levels of

participants with tertiary level education (Eadie & Bowker, 2013; Singer et al., 2014). The Singer et al. (2014) study was prospective and captured a representative sample for the German TL population, whereas Eadie and Bowker (2013) recruited their participants via USA-based laryngectomy support groups, professional lists and contacts. Perry et al. (2015) used a similar recruitment approach. Both groups of researchers have described how this resulted in biased sampling but it is the approach reported widely in other TL literature.

There is limited research available regarding health literacy levels in IWL. An individual's ability to obtain information about TL and make informed decisions about their ongoing health needs may be compromised if they do not have adequate health literacy skills. Beitler et al. (2010) reported a small study sample of IWL ($n$=4/12) with severely inadequate health literacy skills. They found it was more likely for these IWL to get "lost in the system" and have reduced access to healthcare due to inadequate health literacy (p. 29).

Employment status is considered an environmental factor in the ICF (World Health Organisation, 2001), however, it can also be related to SES and level of education. There is evidence that having a TL can have a detrimental effect on an individual's employability. Many people have the surgery when they are well into their career, transitioning to retirement or retired. In Australia, the retirement age is 65 years. There appears to be a trend of significant reduction of employment after TL compared with other HNC treatment, with only 15-30% returning to work. Loss of employment can result in financial hardship and increased social isolation. Individuals with advanced disease and high levels of psychological distress at the time of surgery are reported to have the poorest employment outcomes. One study also documented that some TE speakers experienced changes to their duties due to their communication limitations (Finizia & Bergman, 2001; Nordgren et al., 2003; Ramírez et al., 2003; Relic, Mazemda, Arens, Koller, & Glanz, 2001; Singer et al., 2014).

*Coping style and personality traits*
Psychosocial adjustment is affected partly by coping style and needs to be viewed in relation to general mental functions, social context, relationships, support and personality traits. The influence of a person's coping style is gaining prominence in laryngectomy research. A study by Blood, Simpson, Raimondi, et al. (1994) linked education level with coping ability. It identified that well-adjusted participants used

adaptive coping strategies and had approximately five years more education compared with participants with poorer coping skills (e.g. median =12.3 years versus 7.1 years). The study also confirmed that successful outcomes after TL were associated with adaptive coping and adjustment skills. A similar result was found with a cohort of male TE speakers with a high level of education (Eadie & Doyle, 2005). Contrary to these findings was the study conducted with veterans in the USA, in which many participants were tertiary-level educated and there was a 28% incidence of depressive symptoms one-year post-TL (Terrell et al., 1998).

A more recent study by Eadie and Bowker (2013) evaluated the link between HRQoL outcomes and coping strategies. IWL using avoidant coping strategies experienced poorer outcomes. However, this was the least common coping style for the cohort. The most common strategy (31% of the total coping effort) was "distancing", where individuals refused to think about the stressful event (p. 960).

A few studies have examined factors related to personality traits such as extraversion, agreeableness, psychological stability, openness to experience, optimism, confidence and trustworthiness. Issues related to personality are included here because there are care, intervention and therapeutic implementation issues associated with managing a TL. Frequently, clinical decisions regarding treatment and ACM rehabilitation are made based on a person's cognitive capacity. Personality traits and temperament may also impact adjustment and the need for additional support. In a study of 162 HNC patients by Aarstad, Beisland, Osthus, and Aarstad (2011), low HRQoL and significant distress were associated with high levels of neuroticism, use of avoidance coping and suppression of competing activities. Their definition of neuroticism included the propensity "to worry regardless of the presence or absence of threats, and to report more subjective health complaints than do stable individuals" (p. 391). Another European study with 141 IWL examined their motivation levels and frustration tolerance whilst learning an audible ACM. Fourteen percent (*n*=20) of participants described how they gave up easily and 34% (*n*=48) reported that they were partly discouraged by difficult experiences (Singer, Meyer, et al., 2013).

*Comorbidities and dependencies*
Premorbid physical and mental health issues in conjunction with medical status, treatment pathway and coping styles influence functional and adjustment outcomes.

Collectively, they are also linked with the successful acquisition of alaryngeal communication and adjustment (Eadie, 2007; Perry et al., 2015; Singer et al., 2007). Two or more pre-operative comorbidities, for example hypertension, coronary artery disease or diabetes mellitus, can lead to poorer long-term outcomes but do not increase the risk of post-operative complications, whereas previous radiotherapy to the head and neck increases the risk (Woodard et al., 2007). Ramroth et al. (2011) found that age at diagnosis, tumour stage and development of recurrence or a second primary carcinoma were predictive of long-term survival from laryngeal cancer regardless of treatment.

A reported incidence for alcohol dependence or problem drinking is between 7-16% for TL and HNC populations, which is higher than for the general population (Danker et al., 2011; Duffy, Ronis, et al., 2007; Keszte et al., 2013). Practice guidelines and outcome studies suggest that dependencies related to tobacco, alcohol and substance abuse adversely affect treatment outcomes, HRQoL and survival in this group of patients (Aarstad, Aarstad, & Olofsson, 2007; Danker et al., 2011; Roland & Paleri, 2011). In one study, the IWL were more likely to drink to cope than other HNC participants (Aarstad, Lode, Larsen, Bru, & Aarstad, 2011). There is also an increased risk of developing other cancers (e.g. lung cancer), and a person may be underweight and undernourished if they have sustained a high alcohol consumption for a long period. Both these issues can lead to longer post-surgical recovery periods and post-operative complications (Danker et al., 2011; Roland & Paleri, 2011).

### 2.4.3.2 Environmental factors

Environmental factors such as support and relationships; attitudes linked to socio-cultural context; services, systems and policies related to geographical location; and products and technology are considered further here.

*Support and relationships*

The concept of social connectedness supporting general health and wellbeing is well documented in the broader health literature (Marmot & Wilkinson, 2006; Ward et al., 2011). It has also been recognised that social supports are particularly important in helping an individual to adjust psychosocially to a TL (Doyle, 1994; Ramírez et al., 2003; Relic et al., 2001; Singer et al., 2007). Subjective reports from male IWL reveal that perceived voice quality, adjustment and social support are interconnected (Blood, Simpson, Raimondi, et al., 1994). Perceived social support has been shown to

enhance adjustment, buffer against depression and anxiety, and can assist ACM acquisition and maintenance (Avramika et al., 2011; Eadie, 2007; Howren et al., 2013; Keszte et al., 2013; Ramírez et al., 2003).

An accurate understanding of how limited social supports can affect adjustment is not well established in the literature because individuals with reduced social support have been under-represented compared with individuals who perceive reasonable levels of social support. The available evidence suggests that having the support of at least one close person has health-protecting benefits. For example, Lee et al. (2010) noted in their study that the male subjects were more likely to be partnered compared with the females, and that the females had poorer socio-emotional scores. Relic et al. (2001) found a similar result; regardless of gender, the lower the support, the lower the HRQoL outcomes. Stam et al. (1991) found that the extent of support predicted use of OE speech and dissatisfaction with supports predicted adjustment. A longitudinal, prospective study of HNC patients found that perceived social support at diagnosis was associated with both global and disease-specific QoL outcomes; the greater the support, the more favourable the outcomes (Howren et al., 2013). Another study of successful male TE speakers showed that participants were well supported (Eadie & Doyle, 2005). Avramika et al. (2011) found that subjects, including IWL with higher levels of interpersonal support, appeared to have lower rates of anxiety and depressive symptoms.

A few studies have examined the significance of social supports from the perspectives of primary supporters in the TL and HNC populations (Birchall, Richardson, & Lee, 2002; Blood, Simpson, Dineen, et al., 1994; Gibson & McCombe, 1999; Herranz & Gavilán, 1999; Penner, 2009). Some studies examining psychosocial care for individuals undergoing HNC treatment have reported that the psychological distress and the social functioning of primary supporters may in some cases be equal to, or more than, the effects on the patient due to increased responsibility, disruption to routine and lack of control (Herranz & Gavilán, 1999; Penner, 2009). Primary supporters can experience anxiety at greater levels than the general population, with up to 20% found to have clinically significant psychological comorbidity. Patterns of passive coping style, feeling overwhelmed, turning inward, worry, poor sleep patterns and depressive symptoms have also been documented (Verdonck-de Leeuw et al., 2007; Vickery, Latchford, Hewison, Bellew, & Feber, 2003).

Specific time points in the treatment and recovery pathway are also important to

consider. Blood, Simpson, Dineen, et al. (1994) reported that the strain and burden of caregiving could reduce with time after the original diagnosis, and was also independent of other current life stressors. They found a gender difference in that male carers reported less strain and burden than female carers. However, these results must be treated cautiously because only 20% of the study sample were men.

*Attitudes (socio-cultural context)*

Evaluating the influence of cultural context and socio-cultural attitudes to TL is complex. It is difficult to separate the individual from the influence of community values and the issues raised earlier related to personal contextual factors, activity and participation domains, and cultural, ethnic and linguistic background. Social functioning can be influenced by how accepting people are of the TL. Cultural attitudes to health and wellbeing can influence how individuals respond to their laryngeal cancer diagnosis and treatment pathway. However, it remains poorly understood how a radical surgery such as a TL is interpreted in different cultures or different social groupings. Just as there is a bias of contemporary literature favouring a few ethnic groups (e.g. Caucasian populations) (Eadie & Doyle, 2005; Haisfield-Wolfe et al., 2009), there are also fewer papers reporting the socio-cultural experiences of women compared with men after TL. This is partly justified by the increased prevalence of TL in men but it is evident that there are differences in how men and women experience TL, and how society may respond to their needs (Brown & Doyle, 1999; Eadie, 2007).

Doyle (1994), using Goffman's groundbreaking work on stigma and illness (Goffman, 1963), wrote that there was a real risk of the individual being socially penalised due to the diagnosis of laryngeal cancer and resultant effects of treatment where voicing, speaking and appearance no longer match society's standards of normality. Only a few authors have examined issues of stigma, stereotyping and victim blaming experienced after TL. Very little has been written about the stigma, politicisation or victim blaming effects of laryngeal cancer arising from tobacco smoking. In the general health and cancer literature, there is some discussion of these phenomena (Chapple, Ziebland, & McPherson, 2004; Crawford, 1977; Lebel & Devins, 2008). A small TL study found that when listeners were presented with information about the smoking history of two speakers and then presented with samples of a male TE speaker who had smoked and a typical male speaker who had

not smoked, there was little evidence of stereotyping and victim blaming of the TE speaker. However, the TE speaker was judged as being less employable than the typical speaker (Hughes & Gabel, 2008). This finding may be indicative of choice of ACM influencing general social acceptance. Earlier, I mentioned that female laryngeal speakers are perceived as being less socially acceptable than male alaryngeal speakers (Eadie, 2007). Issues of changed social role have also been highlighted as an important part of self-identity and meaning for IWL (Bickford, Coveney, Baker, & Hersh, 2013).

Very few studies have explored these issues rigorously. However, the intrusiveness of illness and psychosocial impacts have been connected with the perceived levels of stigmatisation an individual experiences in their cultural context (Devins, Stam, & Koopmans, 1994). A French study (Buiret et al., 2007) provides some useful insights into the influence of culture and attitudes to health and wellbeing for this specific population. It highlights the lengths to which some individuals are prepared to go to reverse their TL by considering laryngeal transplantation. Despite the risks, 30.7% of those surveyed said they would opt for the surgery. It was also found that younger individuals (< 59 years old) more than older individuals favoured the procedure (Buiret et al., 2007).

Historically, laryngectomy support groups have been used as a way of providing IWL with peer support (Lawson & Ward, 2014). There have been mixed reports regarding these groups' success and little critique of their participation rates. Interestingly, in South Australia, the laryngectomy support group discontinued several years ago due to falling membership. More generic support is available from a head and neck support group run by the Cancer Council. It is thought that the reduction in the number of TL procedures and easier acquisition of TE speech led to the demise of the laryngectomy-specific support group.

*Services, systems and policies (geographical location)*
Location and service provision are two important interconnected contextual factors relevant to the Australian TL population. Firstly, due to highly urbanised population distribution, HNC services are concentrated in major cities. This enables specialisation but is frequently cited as disadvantaging individuals who live remotely from a city or large urban centre (Burns, Hill, & Ward, 2014; Krishnan & Maclean, 2013). Very little has been written regarding the influence of location on the QoL

outcomes for TL. Thus, there is little understanding of the experiences of individuals who live proximally or remotely from their healthcare provider. These issues are particularly relevant to Australian residents who may have to travel great distances and incur visiting expenses if they live in a rural or remote location (Burns et al., 2012).

Secondly, Australia has a policy of providing universal healthcare where specialist care for a TL can be accessed without cost. However, there is variation from state-to-state regarding the provision and costs of ongoing supports and services (Ward, Burnett, et al., 2014). Individuals with medical insurance also have the opportunity to access hospital and medical services in a private hospital setting in some jurisdictions. Again, little has been documented regarding IWL experiences of these systems.

*Products and technology*

Recent advances and developments in TL treatment and care constitute a final but important contextual factor. The innovation and impact of SVR and TE speech were examined in sections 2.4.1.3 and 2.4.2.3. Other important trends include the increased use of trans-robotic surgery techniques (Smith, Schiff, Sarta, Hans, & Brasnu, 2013), developments with laryngeal transplantation (Luu & Farwell, 2014), and the availability of electronic and screening devices, such as electronic messaging and use of telehealth, to augment and facilitate communication (Burns et al., 2014).

## 2.5  The role of the health professional in providing psychosocial support

Doyle (1994) strongly emphasised the need for sensitive, individual-based approaches to rehabilitation to ensure optimal outcomes. The provision of psychosocial support for IWL by health professionals is described as an important aspect of clinical practice but it is not well evaluated. Issues related to clinical population diversity and the multidisciplinary approach all impact a person's psychosocial experience. The importance of the timing of support, adequate informational counselling, education and targeted psychosocial support has been highlighted and is appraised here.

### 2.5.1.1  *Clinical population diversity*

Despite the typical clinical picture of malignant laryngeal cancer predominantly affecting men near retirement age, the procedure has been used with younger or older people, and with women. A range of other aetiologies may also be treated with a TL,

such as trauma, benign pathology and airway disease (Mathieson, 2001). This, combined with diverse socio-demographics (e.g. younger people, women, non-smokers and people with higher SES), means that healthcare provision must be flexible and sensitive to the needs of all individuals (Hughes, Bamford, & May, 2008). Understanding the psychosocial effects of a TL can assist with the provision of such healthcare.

### 2.5.1.2 *Multidisciplinary approach*

The complexity of the issues faced by individuals who undergo a TL necessitate extensive specialist pre-operative support and post-operative rehabilitation (Lawson & Ward, 2014). Standardised care and multidisciplinary team (MDT) management is a widely accepted and optimal approach to HNC care (Lewis & Weber, 2013; Murphy et al., 2007; National Institute for Clinical Excellence (NICE), 2004b; Roland & Paleri, 2011; South Australia Department of Health, 2013). The MDT usually consists of a head and neck surgeon, oncologist, oncology nurse and several allied health professionals, including a speech pathologist. The nature of the changes and risk of reoccurrence means that IWL have an ongoing need for specialist care that may last for the rest of their lives.

Some authors have postulated that the successful acquisition of TE speech is related to a consistent multidisciplinary approach. Frowen and Perry (2001) found high attrition rates for TE speech after the first year due to attitudes toward the behaviour that were influenced by expectations shaped by education and pre-operative counselling provided by the speech pathologist and surgeon. They recommended a genuine multidisciplinary approach where a patient's motivation, dexterity, visual acuity and respiratory status are thoroughly evaluated.

It is not within the scope of this review to critique all the different roles in the MDT. Here, I focus on speech pathologists because they play an important role in assisting IWL to obtain optimal functional outcomes related to alaryngeal communication, management of the tracheostoma, and rehabilitation of swallowing ability and olfaction. Speech pathologists are also instrumental in educating and supporting individuals with the significant psychosocial adjustments they face (de Maddalena & Pfrang, 1993; Doyle, 1994; Eadie, 2007; Lawson & Ward, 2014; Lee, 2011), and tend to provide the longest ongoing support to a person due to the complexity of the communication and swallowing issues associated with TL. They

typically provide communication equipment such as voice prostheses or electrolarynges. Equipment needs can extend beyond the five-year survival stage and continue to such a time when equipment is no longer required because of illness or death (Krishnan & Maclean, 2013; Lawson & Ward, 2014; Verdonck-de Leeuw et al., 2014). A recent study suggested that IWL who received speech therapy in the first year post-surgery experience superior objective speech intelligibility outcomes to IWL who did not (Singer, Wollbrück, et al., 2013).

### 2.5.1.3 Timing of support

The trajectory of the experience is also examined further here because the immediate post-operative experiences are reported to be very different from those experienced after one year from surgery (Doyle, 1994; Lawson & Ward, 2014). However, it has been identified that IWL appreciate persisting specialist care and nursing care beyond the first year (Noonan & Hegarty, 2010). Many authors agree that the timing of supports is critical in alleviating psychological distress (Ramírez et al., 2003; Semple et al., 2008; Ziegler, Newell, Stafford, & Lewin, 2004). This is also supported by comprehensive clinical guidelines (Lewis & Weber, 2013; National Institute for Clinical Excellence (NICE), 2004a; Roland & Paleri, 2011; South Australia Department of Health, 2013).

### 2.5.1.4 Education (e.g. informational counselling, laryngectomy support visitor)

There is wide consensus that IWL and their primary supporters need well-timed and tailored informational counselling, self-help groups, and training to support an understanding of the surgery and its functional and disfiguring consequences, to aid the fulfilment of care responsibilities and to alleviate stressors for primary supporters (Lawson & Ward, 2014; Penner, 2009; Ziegler et al., 2004). It has been identified that a skilled and empathetic approach can scaffold and support patients and primary supporters throughout the experience, particularly in the early stages after recovery when anxiety levels are usually high (Penner, 2009; Semple et al., 2008). Some authors advocate the use of a laryngectomy support visitor to assist the education process and facilitate acceptance. However, there is a widely held view that this must be arranged sensitively and that the support visitor receive some training (Lawson & Ward, 2014; National Institute for Clinical Excellence (NICE), 2004a; South Australia Department of Health, 2013).

### 2.5.1.5  *Targeted psychosocial counselling*

The availability of professional psychosocial counselling and support has been described as inconsistent despite some studies having shown the benefits of this for both TL and general HNC populations (Keszte et al., 2013; Penner, 2009; Semple et al., 2013). It is surprising how few studies report outcomes following psychotherapeutic interventions over time, given that psychological distress has been identified consistently in a subset of IWL. Keszte et al. (2013) identified that 43% (*n*=18/42) of individuals with psychological comorbidity received counselling but only 7% received psychiatric support. They reported that individuals with poor verbal communication outcomes were the most underserved. They called for specialised services to support individuals because poor mental health appeared to be affecting acquisition of an audible ACM. A recent systematic review also indicated that there remains scant evidence regarding the effectiveness of psychosocial interventions to support adjustment in HNC populations. This is primarily due to the limited number of available studies and methodological issues (Semple et al., 2013). The broader psychiatry literature recommends cognitive behaviour therapy to treat mild to moderate depression (Purcell & Turner, 2014).

A recent RCT with HNC patients reported the benefit of bimonthly counselling from a trained nurse in the first year after treatment. The intervention group experienced significantly lower depressive symptoms than the control group. The subgroup with higher depressive symptoms at the start of the trial also experienced a reduction in symptoms (van der Meulen et al., 2013). Due to the fact that most of the published literature regarding psychosocial adjustment after TL reports outcomes measured by HRQoL and psychometric instruments, it is important to critique the advantages and disadvantages of this methodological approach.

## 2.6  Critique of health-related quality of life (HRQoL) instruments

It has long been documented that health professionals must consider the construct of HRQoL when supporting IWL (Doyle, 1994; Gardner, 1966). However, this has only become a central focus of clinical research in the last 20 years. There has been intense development and application of HRQoL instruments to evaluate HRQoL outcomes after TL (Verdonck-de Leeuw et al., 2014). There has also been a small but noticeable increase in the use of rigorous interpretative methodologies to evaluate the *lived experience* of TL and HNC patients (Noonan & Hegarty, 2010; Swore Fletcher et al.,

2012).

The majority of studies evaluating psychosocial adjustment of the TL population have used HRQoL self-report surveys (Rogers et al., 2007), many of which were not specifically designed for IWL. They are typically multidimensional tools that examine a range of health domains, including physical, emotional and social wellbeing at a specific time point. Some tools evaluate functional skills such as voicing and swallowing, and symptoms such as pain, constipation and dry mouth. There is consensus that multiple instruments examining generic and specific health domains are needed to capture a broad understanding of HRQoL after HNC and a TL (Farrand & Duncan, 2007; Finizia & Bergman, 2001; Murphy et al., 2007; Nordgren et al., 2003). Only with this fuller picture can person-centred interventions be developed (Eadie, 2007).

The efficacy of these instruments to provide a comprehensive impression of a person's HRQoL after head and neck surgery continues to be researched. Some instruments have been further refined. Given the substantial use of HRQoL instruments in TL and HNC research and that current understanding of the TL experience is largely based on HRQoL data, I now outline the instruments in common use. I then discuss the advantages and disadvantages of the utilisation of these tools in understanding IWL perspectives regarding their health and wellbeing.

### 2.6.1.1 Common HRQoL instruments

HRQoL instruments aimed to evaluate different aspects of a person's subjective experience. They can be divided into the following categories: generic; disease specific; site specific; and symptom specific. More comprehensive overviews of other HRQoL tools have been described by Rogers et al. (2007) and Verdonck-de Leeuw et al. (2014).

Generic health instruments are widely used and provide information relating to general physical and psychosocial wellbeing. Table 1 provides an overview of frequently cited instruments.

**Table 1:    Health-Related Quality of Life (HRQoL) Instruments**

| Type | Name |
|---|---|
| Generic health | Medical Outcomes Study Item 36 (SF-36) (Ware & Sherbourne, 1992) <br> The EuroQoL (EQ-5D)™ (The EuroQol Group, 1990) <br> Schedule for the Evaluation of Individual Quality of Life (SEIQoL) (O' Boyle, 1994) |
| Disease-specific | European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30 (EORTC QLQ-C30) (Aaronson et al., 1993) <br> Functional Assessment of Cancer Therapy (FACT-G) (Cella et al., 1993) |
| Site-specific | European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire for Head and Neck Cancer-35 (EORTC QLQ-H&N-35 Version 1.0) (Bjordal et al., 1999) <br> Functional Assessment of Cancer Therapy-Head and Neck (FACT H&N) or FHNSI-10 (Shorthand Version) (List et al., 1996) <br> University of Washington- Quality of Life Scale (UW- QOL-R version 4) (S. N. Rogers & Lowe, 2010) <br> Head and Neck Cancer Inventory (HNCI) (Funk, Karnell, Christensen, Moran, & Ricks, 2003) <br> M. D. Anderson Symptom Inventory-Head and Neck (MDASI-HN) (Rosenthal et al., 2007) <br> University of Michigan Head and Neck Quality of Life (HNQOL) (Terrell et al., 1997) <br> Therapy Outcome Measures (TOM) (Enderby & John, 1997) <br> Therapy Outcome Measures - Australian version (AusTOM) (Perry et al., 2004) <br> Head and Neck Performance Status Scale (HNPSS) (List, Ritter-Sterr, & Lansky, 1990) |
| Symptom-specific | *Voice* <br> Voice Handicap Index (VHI) and the short version VHI-10 (Jacobson et al., 1997; C. A. Rosen, Lee, Osborne, Zullo, & Murry, 2004) <br> Voice Activity and Participation Profile (VAPP) (Ma & Yiu, 2001) <br> Voice-related Quality of Life (V-RQOL) (Hogikyan & Sethuraman, 1999) <br> Voice Symptom Scale (VoiSS) (Deary, Wilson, Carding, & MacKenzie, 2003) <br> Self Evaluation of Communication Experiences after Laryngectomy (SECEL)* (Blood, Simpson, Raimondi, et al., 1994) <br> Voice Prosthesis Questionnaire (VPQ)* (Kazi, Singh, et al., 2006) <br> *Speech* <br> Speech Handicap Index (SHI) (Rinkel, Verdonck-de Leeuw, van Reij, Aaronson, & Leemans, 2008) <br> *Swallowing* <br> Swallowing Quality of Life (SWAL-QOL) (McHorney et al., 2002) <br> Swallowing Care (SWAL-CARE) (ibid) <br> *Psychological morbidity* <br> Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) <br> Beck Depression Inventory (BDI) (Beck, Steer, & Carbin, 1988) <br> Psychosocial Adjustment to Illness Scale (PAIS) (Derogatis, 1986) |

* indicates TL-specific instruments

Disease-specific instruments are also available and are used with individuals diagnosed with cancer. Some of these tools have items relating to symptoms that are often experienced during cancer treatment such as nausea, vomiting or constipation. In addition, they are often used in conjunction with site-specific questionnaires, which provide specific health information relating to HNC (Bjordal et al., 1999; Verdonck-

de Leeuw et al., 2014; Weymuller, Alsarraf, Yueh, Deleyiannis, & Colterra, 2001). A range of validated symptom-specific instruments is also used to measure communication ability and voice-related outcomes. A few instruments have been designed specifically for the TL population. Finally, there are several symptom-specific tools utilised for other domains or functions such as speech skills, swallowing skills, and depression and anxiety (Haisfield-Wolfe et al., 2009; Rogers et al., 2007; Verdonck-de Leeuw et al., 2014).

### 2.6.1.2 Advantages of HRQoL measurement

An important advantage of validated HRQoL instruments is inter-subject and inter-rater use (Pusic et al., 2007). Earlier in this chapter, I provided examples of how the use of validated self-report questionnaires had provided some useful information regarding socio-cultural determinants of wellbeing for TL populations, such as gender, age, coping style and social supports. They can also provide health professionals with a set of measures relating to specific domains such as swallowing and voice abilities, as well as a multidimensional global QoL score. Another advantage is that some instruments such as the EORTC-QLQ H&N 35 and UW-QoL have been altered and improved over time to ensure their validity. For example, the UW-QoL was revised to include the emotional domains *mood* and *anxiety* (Rogers et al., 2002). They can be used both retrospectively and prospectively. Prospective use can indicate improvement or deterioration at critical time points (Singer et al., 2014). They have also been widely used in large clinical trials, and have enabled systematic comparison between heterogeneous groups, and formulation of consistent terminology (Murphy et al., 2007; Rogers et al., 2007).

### 2.6.1.3 Disadvantages of HRQoL measurements

Recent critique of HRQoL measurements in HNC and TL populations indicates that there are some inherent problems in basing information about an individual's health and wellbeing purely on the findings from self-report QoL instruments (Murphy et al., 2007). Firstly, it has been reported that very few instruments used in clinical trials of HNC patients were carefully and rigorously constructed using guideline frameworks recommended by North American agencies such as the Medical Outcomes Trust (MOT). These guidelines describe three stages of questionnaire development. Stage 1 involves reviewing the literature, conducting qualitative patient interviews, and collecting expert opinion to formally define a conceptual model to be measured before

questionnaire items are determined and then pilot tested. Stage 2 involves field-testing on a larger sample. Stage 3 involves psychometric evaluation of the questionnaire. The application of psychometric criteria can result in item reduction (Pusic et al., 2007).

In their systematic review of instruments used to measure QoL status in HNC populations, Pusic et al. (2007) found 12 patient-reported outcome questionnaires that met their inclusion criteria of being written in English, and developed and validated to examine QoL and satisfaction after head and neck surgery. However, only three fulfilled the MOT guidelines. They were the EORTC–QLQ-35, University of Michigan's HNQOL and the HNCI. Four others were developed from expert opinion alone and another seven lacked formal item reduction.

Secondly, the development of HRQoL self-report tools has been largely driven by the need to evaluate QoL outcomes in large population groups participating in clinical trials rather than to specifically measure changes in individuals (Murphy et al., 2007). This reduces their applicability in clinical settings where outcome measurement is becoming increasingly important. A logico-deductive approach to questionnaire development has resulted in specific items that are examined and interpreted as subscale and global scores. Pusic et al. (2007) have argued that development and evaluation of questionnaires should involve qualitative methodolgy and other psychometric approaches such as Rasch Analysis to assist with measuring an individual's health outcomes in clinical practice:

> Rigorous instrument development is important for creating valid, reliable, and responsive disease-specific questionnaires. As a direction for future instrument development, an increased focus on qualitative research to ensure patient input may help to better conceptualize and operationalize the variables most relevant to head and neck cancer surgery. (Pusic et al., 2007, p. 525)

A few authors have speculated that the tools available are not sensitive enough to provide the full picture of the impact of functional impairments on QoL after TL (Baylor et al., 2011; Eadie, 2007). For example, Op de Coul et al. (2005) found that breathing issues can often disrupt speaking after TL but were not accounted for in any available tool. Eadie (2007) discussed the limitations of current HRQoL tools used to evaluate the impact of communication issues after TL, and to facilitate the planning of more meaningful interventions for the client. She examined commonly used symptom-specific and HNC-specific QoL measures in relation to the ICF framework

(World Health Organisation, 2001). She determined that most of these measures evaluate communication ability at the level of impaired body functions, body structures and activity levels, but do not provide information relating to issues of participation or the influence of contextual factors relating to environmental and personal factors. She identified that comprehensive measures of communicative participation were not available to speech-language pathologists. This limited the study of the relationship between *participation restrictions* and QoL because one level of functioning is only moderately related to the next. For example, it has been found that speech impairments are only related weakly to how much someone participates in everyday communication situations. Eadie and her colleagues have developed a Communication Participation Item Bank[2] to remedy this situation (Baylor et al., 2013).

Thirdly, there have been mixed HRQoL outcomes in HNC and TL populations; reflecting differences in study design related to sample size, measurement points and tools used. For example, long-term overall QoL was found to be similar between the TL cohort and the normal population cohort in the UW-QOL ver. 4 and SF-12 ver. 2. However, domain analysis revealed that the TL cohort experienced poorer physical scale subscores in the disease-specific UW-QOL tool. The authors postulated that specific impairments did not predict overall QoL (Vilaseca et al., 2006). A later study contradicted these findings and found that generic HRQoL was worse for the TE speaker cohort than the normal speaker cohort. Similar QoL outcomes were found across alaryngeal speaker groups who used other audible ACMs to communicate (Farrand & Duncan, 2007; Herranz & Gavilán, 1999).

Fourthly, methodological issues are frequently reported and include population bias and measures that are only snapshots in time. The bias issues relate to favouring literate individuals. Popular tools often have limited capacity for free-text response for additional qualitative information not captured by the pre-defined items. A skewed representation of the trajectory of the experience has been reported because many studies report measures completed retrospectively rather than prospectively. Collectively, these factors make it very difficult to compare data sets and reach a consensus regarding the likely HRQoL for individuals where the cancer treatments may be similar (Murphy et al., 2007).

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[2] Communication Participation Item Bank is a unidimensional, multiple item self-report outcomes tool, which measures the construct of communicative participation.

Finally, some authors, including Murphy et al. (2007) and Singer et al. (2014), have raised the issue of positive self-report HRQoL outcomes possibly masking potential late physiologic effects that impact longer-term health and wellbeing outcomes for HNC patients. They have described the issue of a "response shift", whereby Breetvelt and van Dam (1991, p. 981) have theorised that despite the deficits and impairments experienced by cancer patients, individuals learn to adjust to their new life and accept that there are things that cannot be changed. This response is reflected in how individuals perceived and reported their situation in self-report instruments. Murphy et al. (2007) reported that it is important for the results on HRQoL subscales to be interpreted individually rather than as an overall score, and to examine the range of scores. Murphy expressed concern that many scales are not sensitive to small but important health changes, and described the importance of prospective assessment where individuals are assessed at multiple time points and in the long-term.

To summarise, the dominant evaluation tools used in TL and HNC care have been developed using positivist methodologies and emphasise logico-deductive approaches to assessment (Crotty, 1998; Grbich, 2007). This may explain why systematic in-depth assessment of the views of patients with HNC or TL, have been overlooked. Clinicians have assumed they have had reasonably accurate views of their patients' HRQoL. Research examining individuals' perspectives has challenged this, showing that clinicians and other observers (e.g. primary supporters) often only have a view that weakly correlates with that of a patient about their QoL (Allison, Locker, & Feine, 1997; Skevington, 2007). However, there is an increasing trend in health research to use rigorous interpretative methodologies to evaluate the perception of individuals and their supporters about the illness and recovery experience.

## 2.7 The perspectives of individuals with laryngectomy (IWL) and their supporters

The TL and HNC literature contains only a limited number of studies examining first-hand perspective and subjective experience. The few studies available have evaluated the specific phenomena of early recovery from a TL, treatment effects for HNC and issues related to communicative participation. In a descriptive study of 10 TE speakers (*n*= 2/10 women), themes related to "functional difficulties" such as physical

symptoms and speech difficulties emerged. Another major theme included "psychological concerns" and associated depression, regrets and personal resolve (Noonan & Hegarty, 2010, p. 293).

Other studies have examined the lived experience of patients with HNC. Swore Fletcher et al. (2012) conducted a phenomenological study with 39 participants specified as having HNC treatment. They described the main themes as related to communicative participation difficulties and the existential experiences resulting from the post-surgery changes. Semple et al. (2008) examined the perspectives of 10 individuals 6-12 months after their HNC treatment. Five main themes highlighted the changes and challenges experienced, and the personal influences impacting the experiences. They included "physical changes, concerns about cancer, work and day-to-day tasks, interpersonal relationships and social functioning". Two further themes were also identified related to "personal attributes", and included coping skills and "specific informational needs" after treatment (p. 85). These themes illustrate the complex relationship between changes in physical function and the contextual factors in an individual's life, and how they can influence activities and participation such as employment, social engagement and intimate relationships.

The role of identity or self-concept in psychosocial adjustment after TL is also a little explored area. Bickford et al. (2013) reported that the multi-level changes experienced could impact a person's selfhood and may persist for a long time after the surgery. The issues of personal resilience and self-efficacy have been discussed earlier in relation to coping skills.

Also mentioned earlier, recent attention has focused on participation restrictions experienced by IWL. Baylor et al. (2011) have developed a participation self-evaluation tool using a combination of inductive and deductive research methods. The tool has generic application for individuals with communication impairment because Baylor et al.'s research has indicated commonalities related to participation interference experienced across several disorder groups, including laryngectomy. These interference factors relate to the interaction of personal, social and environmental variables.

In addition to these studies, understanding of the patient's perspective has developed through the first-hand experiences described by Brook (2009, 2011) and others. Dr Brook, who is also a physician, has used his experience of being a patient

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to discuss issues related to health professional and patient interaction, the challenges faced with the disabilities he experiences with communication and swallowing, and how these issues have affected him psychologically.

It is surprising there is such little qualitative research or theoretical understanding of the TL experience given the large body of qualitative research examining patient perspectives, lived experience and the psychosocial impact for other major illness resulting in disfigurement, disability and/or life changes, such as breast cancer (Oxlad, Wade, Hallsworth, & Koczwara, 2008), mesothelioma (Clayson, Seymour, & Noble, 2005) diabetes (Paterson, Thorne, Crawford, & Tarko, 1999) and stroke-induced communication impairment (Davidson, Howe, Worrall, Hickson, & Togher, 2008; Parr, 2001). Clearly, given the complexity of the physical, functional and psychosocial issues faced by this clinical population and their supporters, there is scope for further critical analysis of the TL experience.

## 2.8    The knowledge gap related to the total laryngectomy experience and psychosocial needs

The phenomenon of living with TL remains only partly understood despite many studies using validated HRQoL measures. It appears that the collective knowledge we have originates from a predominantly positivist research tradition, yet many of the issues faced, particularly in relation to risk factors for disease development and the challenges of acceptance and adjustment, are firmly rooted in a social context. In other words, in many cases social factors underpin the disease process and the resulting disability can have significant social consequences. Furthermore, there is currently little critique of rehabilitation practices or the relationships between IWL, their supporters and health professionals. Many studies examining the development of alaryngeal communication have taken a narrow medicalised view rather than a social participatory one. This is starting to change with other factors being considered besides the traditional variables of age, gender, time post-surgery and stage of disease. Some researchers are using the WHO-ICF framework to guide their research questions and study design. We are now seeing studies with strong methodological foundations examining the role of social support, coping abilities, motivation and self-efficacy in TL adjustment.

Despite these developments, there remains a noticeable gap in the peer-

reviewed literature regarding an individual's perspective of living with TL and how individuals feel their self-identity has been affected by the procedure. Examination of the impact of biopsychosocial, cultural and linguistic factors on psychosocial adjustment to TL will be possible if the subjective experience is more thoroughly perceived and understood. The primary reason for this limited understanding to date is because there has been little in the way of rigorous interpretative research or theoretical analysis to enhance the understanding of the contributions individuals make in their own acceptance of, and adjustment to, TL. A number of questions remain unanswered by the literature, as already stated in the previous chapter:

1) How do people construct meaning in relation to the experience of having and living with a total laryngectomy?

2) How do biopsychosocial factors (e.g. gender, age, family structure/constellation, support networks, SES, level of education, employment situation and geographical location) and/or cultural and linguistic factors (e.g. ethnicity, attitudes, beliefs, practices and linguistic diversity) influence the psychosocial adjustment of IWL?

3) How do health professionals routinely address psychosocial issues with their clients who have total laryngectomy?

4) What kinds of professional practices would provide better psychosocial support for IWL?

Seeking to answer these questions was the catalyst for the study reported in this thesis.

## 2.9    Conclusion

This chapter has included a review of a wide literature about the prevalence of TL and IWL psychosocial needs. The WHO-ICF framework has been used to consider the structural, functional, activity, participation and contextual factors relevant to IWL, and to touch on what is already known about social and professional supports for IWL. The review has revealed that further examination of the subjective view and meaning of TL for those who experience it, as well as the perspectives of those who provide support, is worthy. Therefore, this study aims to explore the phenomenon of TL as defined by those who experience it, and the defining properties or characteristics people attribute to a TL. The study also aims to generate a more

comprehensive understanding about the psychosocial support needs of this group of people. In the following two chapters, I outline and discuss the research methodology and design used in this study to rigorously evaluate IWL perspectives to provide a solid foundation from which to make recommendations regarding improving psychosocial supports and healthcare practices for this unique population of individuals.

# 3 Methodology and Methods

## 3.1 A qualitative study to examine the subjective experience and psychosocial needs after total laryngectomy

In order gain deeper theoretical understanding of the TL experience to inform recommendations for improving psychosocial supports for IWL, I designed this research study with a number of objectives in mind, as described in Chapter 1. These included exploring co-constructed meanings of having and living with a TL, the social and psychological processes related to experiences of having and living with a TL, and the psychosocial supports defined as being useful and important. A range of perspectives were collected from IWL and providers of support – significant others, including primary supporters –and health professionals to gain these insights. An important aim of this study was to consider the experiences of individuals from diverse backgrounds and demographics. In addition, I wanted to explore how biopsychosocial, cultural and linguistic factors influenced psychosocial adjustment. I predicted that these explorations would enable me to analyse the perceived experiences of psychosocial support before and after TL from different health professionals (e.g. doctors, nurses and allied health practitioners such as speech pathologists). A qualitative research methodology utilising inductive and interpretative methods was deemed appropriate to enable extensive examination of these phenomena.

## 3.2 A constructivist-interpretative orientation

Prior knowledge of the TL experience and HRQoL outcomes has been developed primarily from expert opinion and a logico-deductive research tradition. In Chapter 2, I discussed how many HRQoL instruments have been designed and studies conducted using positivist approaches such as quantitative methods and statistical analyses. Crotty (1998) reported that these studies stemmed from an epistemology called *objectivism*. He stated that this is characterised by a "view that things exist as meaningful entities independently of consciousness and experience, that they have truth and meaning residing in them as objects" (p. 5). This position assumes that objective truth and meaning is obtainable using deductive research methodologies.

The literature review identified that people who have TL are a vulnerable group with complex and sustained care and social support needs as well as greater

risks to mental health. However, the objectivist approach to understanding has negated and failed to account for the subjective TL experience, and has presented only part of the picture to researchers, clinicians and other providers of support. Thus, I sought a different approach and epistemology to inquiry to further explore and understand the experiences of IWL, including their significant others and their healthcare providers. In this study, a constructivist-interpretative orientation was selected because it provided a naturalistic inquiry framework and methods to explore the meanings and understandings people have ascribed to their experiences of having, and living with, a TL. Figure 3 provides an overview of the interactive elements used to guide the development of the framework for the study. This orientation enabled the in-depth exploration, examination and critique of the actions and processes related to these constructed and co-constructed meanings from multiple viewpoints. The phenomena of the TL experience that emerged were then used to examine the research enquiries related to biopsychosocial, cultural and support factors influencing psychosocial adjustment, and what other psychosocial supports may be considered useful and important to improve adjustment outcomes.
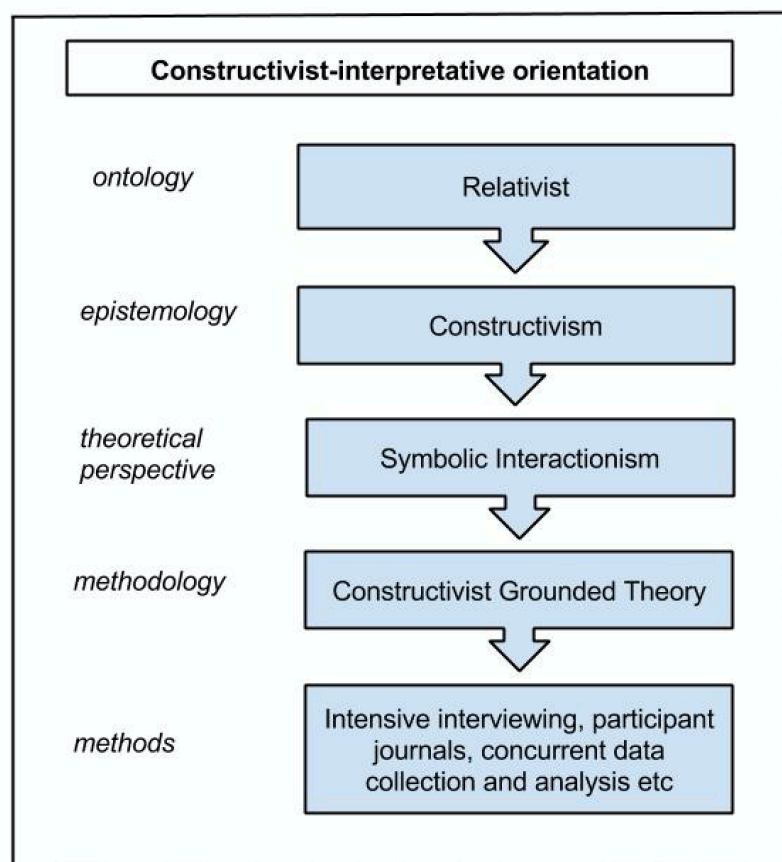


**Figure 3:   Study framework**

Throughout this study, I acknowledged that the social world is produced and reproduced by humans, and that there are multiple realities. I viewed reality as defined by de Laine (1997); an "intersubjective world of cultural objects, meanings and social institutions, derived as a consequence of social interaction" (p. 35). This position also acknowledged the importance of context to constructed meaning and subsequent actions. Thus, this study's ontological position can be described as relativist. Guba and Lincoln (1994) reported that a relativist view assumes reality takes multiple forms, is constructed through social and experiential means, and is specific and situated in nature.

The epistemology of *constructivism* presupposes "the relativism of multiple social realities, recognises mutual creation of knowledge by the viewer and the viewed, and aims toward interpretive understanding of subjects' meanings" (Charmaz, 2003, p. 250). This reiterates the assumption that meaning can only occur because humans have the capacity to use their mind to think about things and that meaning making is constructed rather than discovered (Crotty, 1998). Thus, these assumptions reject an objectivism where there is an objective and universal truth and reality waiting to be identified by a detached observer. The constructivist approach assumes that what we take as real, and as objective knowledge and truth, is based on our perspective (Schwandt, 1994). Thus, during the study, I asked participants to define what they perceived as real and I evaluated where their interpretations of reality led them (Charmaz, 2003, 2014; Guba & Lincoln, 1994).

## 3.3   An inquiry using constructivist grounded theory

I used a constructivist grounded theory (CGT) methodology to obtain multiple perspectives, and to collect data sources for thematic analysis and theory development (Charmaz, 2003, 2006, 2014). Like traditional grounded theory methodology, CGT provides methods for examining and understanding the empirical world. These methods are more flexible and open-ended than the traditional approach. They emphasise the study of people in natural settings while focusing on meaning. CGT strategies are not rigid or prescriptive, which furthers rather than limits interpretative understanding (Charmaz, 2006; Mills, Bonner, & Francis, 2006). I used inductive inquiry methods such as in-depth, intensive interviews and focus groups.

A CGT methodology has clearly defined processes, which assisted me to develop detailed thematic analyses of individuals' perspectives and of theoretical

ideas from raw data. It enables the "rendering"[3] and conceptualisation of defined realities, and "produces limited tentative generalizations, not universal statements" (Charmaz, 2014, p. 51). In other words, as the researcher, I interpreted the scenes and narratives of participant stories rather than taking an authoritative position in defining them. I implemented a range of reflexive methods to ensure that emergent theory was grounded in the data (Charmaz, 2014; Crotty, 1998). Throughout the data collection, analysis and theoretical development phases, I acknowledged that my previous professional background, my own experiences and the relationships I had with the participants shaped this natural inquiry. This methodology aligned with my world-view that meaning is constructed, and that the research act and my position as a former practitioner were worthy of critique in the design, data collection and analytic stages of the study.

This approach departs from the objectivist assumptions and positivist methods of the original grounded theory approach described by Glaser and Strauss, and the later post-positivist versions described by Strauss and Corbin (Charmaz, 2014; Corbin & Strauss, 2008; Glaser & Strauss, 1967; Strauss & Corbin, 1994). According to Charmaz (2000), CGT "celebrates firsthand knowledge of empirical worlds, takes a middle ground between postmodernism and positivism, and offers accessible methods" (p. 510). This manifests with constructivists aiming to include "multiple voices, views and visions in their rendering of lived experience" (ibid, p. 525). In other words, CGT differs from positivist and post-positivist GT positions in that data related to experience is viewed as a representation and not a replication of it (Mills et al., 2006).

Using this methodology, I maintained a relativist stance when examining the subjective experiences and real world existences of participants who had undergone TL or who had provided support. I did not assume that these people's realities or real worlds were unidimensional; rather, I viewed their actions, feelings and thoughts about these experiences and worlds as interactive, meaningful and contextualised (Charmaz, 2003). I also adopted a reflexive position regarding what I attributed to the participants' accounts. I viewed my representation of experiences and meanings as a single interpretation among numerous interpretations and a construction of a shared,

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[3] Charmaz's use of the term "rendering" is not to be confused with the participants' use of "rendering" as expressed in their interviews. I have used Charmaz's rendering in relation to the definitions "an act or instance of interpretation, rendition, or depiction…" or a "translation" (http://dictionary.reference.com/browse/rendering), and used terms such as representation and construction as appropriate.

or individual, phenomenon. In other words, when interpreting and conceptualising the data, I sought to understand both participant meanings and my own interpretations of these meanings.

Throughout this study, strategies used included concurrent data collection and analysis, a two-stage coding process, a range of comparative methods, memo writing to facilitate conceptual development, and a number of sampling techniques to clarify emerging theoretical ideas and facilitate the development of an integrated conceptual framework. During the data collection and analysis phases, I recognised that I was co-creating the data through interaction with the participants. I was aware that reality was a two-way process situated in time and a specific cultural and structural context. I framed the interaction and conferred meaning upon it jointly with the participants. This meant that as the "viewer", I became "part of what is viewed rather than separate from it" (Charmaz, 2000, p. 524). I was not the distant neutral observer described in positivist GT approaches. Rather, my own representation of what I interpreted shaped what I defined, measured and analysed. I sought to determine how participants constructed their understanding of their experiences of TL. I explored tacit meanings in the data and at the same time examined my own assumptions throughout the process:

> To seek respondents' meanings, we must go further than surface meanings or presumed meanings. We must look for views and values as well as acts and facts. We need to look for beliefs and ideologies as well as situations and structures. By studying tacit meanings, we clarify, rather than challenge respondents' views about reality. (Charmaz, 2000, p. 525)

An important goal was to collect data with depth and breadth, and facilitate triangulation by using several sources, for example observations, intensive interviews, participant journals and field notes (Charmaz, 2006; Liamputtong & Ezzy, 2005). In the study's initial stages, I used the open and axial coding continuum described by Corbin and Strauss (2008). Later, I used several coding and theory development strategies described by Charmaz (2003, 2014), including initial and focused coding, cluster diagramming and extensive memo writing. Throughout, I also wrote field notes to develop ideas and move towards theory development.

During analysis, I viewed, coded and recoded the data many times as themes and concepts developed. I also used "theoretical sampling" to facilitate analytical decision making about the data and the sampling frame (Draucker, Martsolf, Ross, &

Rusk, 2007, p. 1137). Charmaz (2003) emphasised the importance of the compare and contrast nature of theoretical sampling, which I adopted by comparing certain findings with other data from the same interview or across interviews to determine if some meanings were implicit. I also gathered data from subsequent interviews and by returning to raw data sets and memos with specific questions about emergent categories.

The CGT approach allowed me to evaluate the data in conjunction with the symbolic interactionist theoretical perspective (Blumer, 1969; Mead, 1934). Symbolic interactionism (SI) provided a range of concepts to facilitate data analysis, conceptual and theory development related to social interaction, and adjustment to changes experienced after TL. It also assisted with revision of the original research design and interview questions as themes emerged. The scope of this study did not permit the building of a formal or grand theory.

## 3.4   The theoretical perspective: Symbolic interactionism

Charmaz (1990, 2014) discusses the value of using a theoretical perspective such as SI when interpreting the data collected using grounded theory methodology. SI examines "how people make sense of their experiences through a common set of symbols" and has "a strong empirical focus" (Liamputtong & Ezzy, 2005, p. 20). A further cornerstone of SI is that "people are able to modify or alter the meanings and symbols they use in action and interaction on the basis of their interpretation of the situation" (Ritzer, 2007, p. 324). In this study, I used an interactionist lens to examine and interpret how the participating IWL appeared to construct and reframe their self-identity as well as their relationship with others and their situated context after TL. Probing questions and specific concepts pertaining to these socio-cultural phenomena were used during the in-depth interviews and when interpreting the data.

Rooted in the interpretivist tradition, SI developed from pragmatic philosophy and social psychology. Crotty (1998) wrote that pragmatic philosophers were interested in "the world of inter-subjectivity and interaction, community and communication, in and out of which we come to be a person and live as persons" (p. 63). Pragmatists examine actions and the consequences of actions. One area of study for pragmatists is to ascertain whether there is any difference between an actor acting one way compared with another way. The genesis of SI is attributed to the work of George Herbert Mead at the University of Chicago in the early 20th century. Mead

provided alternative explanations of social phenomena to the dominant and popular paradigm of reductionist behaviorism (Ritzer, 2007). His teachings have been collated in his book titled *Mind, Self and Society* (Mead, 1934). Later, Herbert Blumer, a former student of Mead's, furthered the theoretical concepts and described them as symbolic interactionism (Blumer, 1969). Together, Mead and Blumer promoted the need for interactionists to be sensitive to context and have a primary focus on the social construction of reality (de Laine, 1997).

An important assumption of SI is that "human agents interpret and define their own action, as well as the action of others, instead of merely reacting to human behaviour in a mechanical fashion" (Elliott, 2008, p. 34). It follows that human interaction involves the use of symbols in conjunction with a process of ongoing interpretation of the meaning of each other's actions (Blumer, 1962). Individual action is viewed as a construction that develops continually through "constant monitoring and interpretation of self-indications, of what others are intending and doing, of the roles they are taking on, and the like" (Elliott, 2008. p. 35). SI has provided an empirical framework and "sensitizing concepts" for studying humans' social worlds (Charmaz, 2014, p. 30). For the purposes of this study, the concepts related to "the act", "the mind" and "the self" were used during the data collection, analysis and theory development stages (Blumer, 1969; Mead, 1934).

### 3.4.1 The act

Melzer (1994) reported that Mead described "the act" as comprising "both overt and covert aspects of human action. Within the act, all that separated categories of the traditional, orthodox psychologies find a place" (p. 49). Mead argued that part of the act involved the abilities to attend, perceive, imagine and reason. It also encompassed "the total process involved in human activity" (ibid). In the current study, I used this definition to examine the issues, actions and underlying processes described as problematic for the participants in relation to the TL experience.

### 3.4.2 The mind and meaning making

Mead (1934) viewed "the mind" as a social process. He theorised that humans have the capacity to think, and have internal conversations with themselves using language and significant symbols. An important part of these internal conversations is the ability to take on the role of the other in an interaction or imagined interaction. The

ability of putting oneself in the place of another enables an individual to better understand the meaning of what the other person says or does. These interpretations can then serve to alter an individual's behaviour.

Mead (1934) posited that humans tend to share "significant symbols" (language) but can act with flexibility when shared meaning is not established. He said that humans have the mental capacity to constantly adapt to one another and the wider context, which assists with the evaluation of the meaning of specific symbols. Mead described "verbal gestures" as being important significant symbols; very important because we hear ourselves. This is qualitatively different from physical gesture because we do not always see ourselves. This audible feedback means that what we say affects us as well as those with whom we are communicating. This ability can have a powerful moderating effect. Mead theorised that when we communicate and before the other person reacts, we can decide mentally whether what we are saying is likely to elicit the desired reaction. If we decide it is not going to elicit the response we want, we can quickly clarify our meaning to elicit what we desire (Mead, 1934, p. 303). Thus, the joint sharing and communicating of meaning occurs through the use of significant symbols such as language and other symbolic tools. Crotty (1998) elaborated the benefits of interaction when he said, "Only through dialogue can one become aware of the perceptions, feelings and attitudes of others and interpret their meanings and intent" (p. 75). It is important to highlight the difference between non-symbolic and symbolic interaction. Blumer (1969) stated that "non-symbolic interaction takes place when one responds directly to the action of another without interpreting that action; symbolic interaction involves interpretation of the action" (p. 8).

It became clear early in the data collection that IWL experience a change to their ability to use and vary the significant symbols in conversation they had been accustomed to using prior to their surgery. Language modifiers, including intonation, loudness and pitch, were no longer accessible and appeared to affect them and others in conversation. Other limitations to communication, such as reduced ability to sustain utterances, speak without disruptive and stigmatising coughing episodes, and the subsequent need to use hand movements for most audible ACMs were also described as impacting the ability to communicate meaning.

Using an interactionist perspective, I perceived "meaning" as a concept and

that "conduct" is meaningful. Thus, individuals put subjective meaning to objects and these meanings affect our actions. They can use their minds to put themselves in the place of others in order to interpret their thoughts and actions. Therefore, "meaning" originally comes from the social situation and not the mind. Individuals can organise and control the way they act and interact. Thus, "the mind" can be seen as a relationship between actor and situation mediated by a set of symbols (Blumer, 1969; Mead, 1934).

These theoretical assumptions prompted me to be cognisant of the other person's viewpoint during the research process and to conscientiously take on the role, or viewpoint, of the other. Thus, I engaged in a symbolic interaction with the studied situation. This was an important part of the process and one promoted by Denzin (1978).

The concepts described above are provided schematically in Figure 4. For example, the able-bodied individual is capable of thought and, when interacting, is capable of mediating his or her overt action or behaviour on the basis of the covert processes of meaning making, interpreting and role-taking.
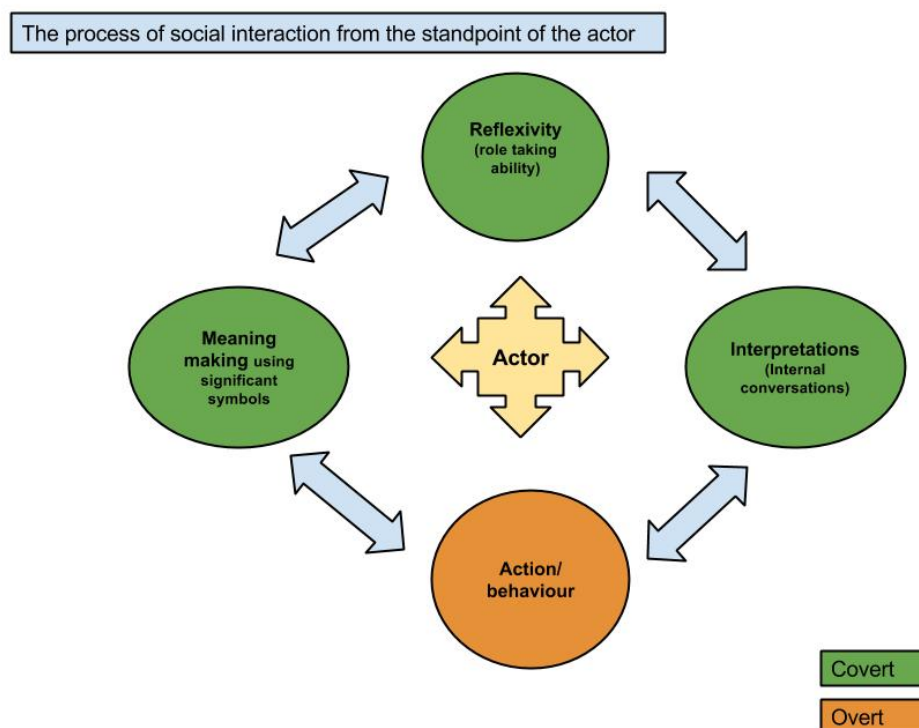


**Figure 4:   Social interaction from the actor's standpoint**

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### 3.4.3 The self

Another important theoretical assumption of SI is that the human capacity for self-awareness contributes to identity formation and maintenance of "the self". When analysing the data, I used de Laine's (1997, p. 73) interpretative model of "Mead's social construction of the self". I have provided an interpretation of her model in Figure 5, which highlights the relationship between "the self", "significant other" and "generalised other" in the formation of "the self". Significant others are the close social actors in an individual's life, whilst the generalised other is perceived as cultural or structural influences such as religious, political or legal systems and ideologies. The significant others in this study were the individuals who played important social roles, and were perceived to have a validating and confirming influence, for example parent, partner or primary supporter, close friend and/or confidante, and health professionals. I considered the larger cultural and structural influences and attitudes impacting a person's life as the generalised other, including attitudes to laryngeal cancer and TL, healthcare resourcing for IWL, and broader community supports such as welfare, suitable public spaces and universal healthcare (de Laine, 1997).
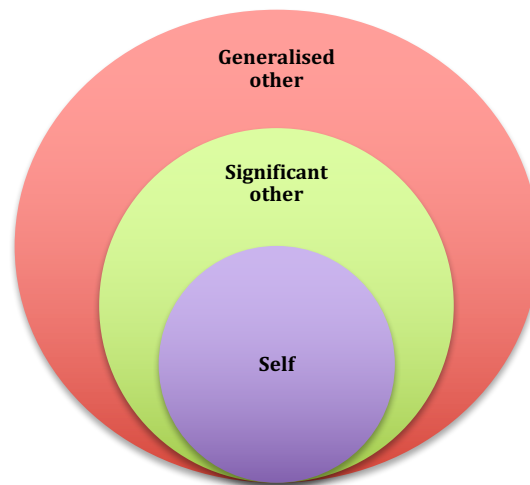


**Figure 5:   Interpretation of Mead's social construction of the self**

Mead posits that "self-awareness" occurs when the self can separate "the 'me' from the 'I', and hence attain a level of reflective distance from the demands of society and culture" (Elliott, 2008, p. 33). This reflexivity represents the ability to:

1) respond to one's self as others respond to it
2) respond to one's self as the collectivity, the generalized other, responds to it

3) take part in one's own conversation with others

4) be aware of what one is saying and to use that awareness to determine what one is going to do next. (Ritzer, 2007, p. 305)

Mead believed that the self is an entity constituting two interacting objects called the 'I' and the 'me'. Elliott (2008) described how "The 'me' is the socialized self, made of internalized attitudes of others as experienced in the early years of life. The 'I' …is the unsocialized self, an assortment of personal desires, needs and dispositions" (p. 33). Mead described the phases of the self with 'me' as being in a continual state of modification, which is changed by the 'I' acting upon it. Both these aspects of the self are also perpetually interacting with the "other"; the "significant other" and "generalised other" (de Laine, 1997, pp. 71-73), as represented in Figure 6.

Themes to emerge from the current study that underpin the substantive theory highlight that reframing of the self was an important part of the subjective experience for the IWL. It was also evident that both the role of the individual and others during the process influenced different reframing patterns and levels of acceptance.
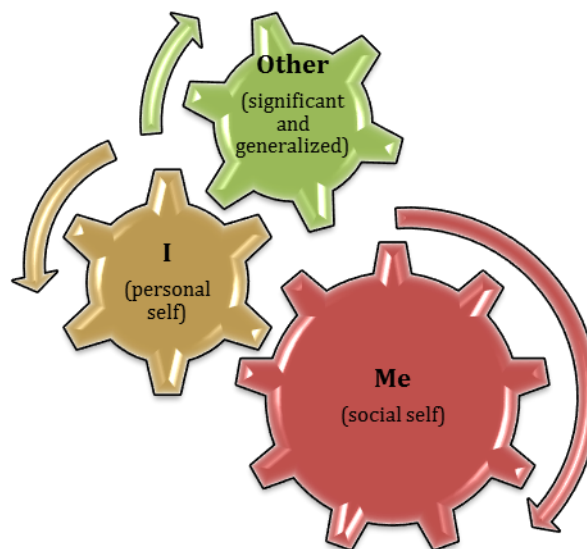
**Figure 6:   Mead's model of self**

Finally, it is important to highlight that SI is not deterministic. It views every person as acting and responding in their own way when interacting. Humans will gather attitudes from the wider group but it is the individual who decides whether to express those attitudes or not (Ritzer, 2007). Elliott (2008) argued that:

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> Mead's distinction between 'me' and 'I' introduces a level of contingency and ambivalence to each social encounter: The 'I' reacts to the 'me' in a social context but we cannot be sure exactly how that 'I' will react. Accordingly, the 'I' in interaction with the 'me' plays a role in the transformation of social structure. (p. 34)

The current study highlights that each individual reconstructed their self-identity differently and that contextual factors such as time, support and personal factors affected the reconstructions. A summary of the strengths and limitations of both CGT and SI in relation to the study design, process and results are provided in the final chapter.

## 3.5   Study design and methods

An overview of the study design and methods is provided in Table 2.

**Table 2:     Summary of study design**

| Aims/Objectives | Methods | Data collection | Data analysis |
|---|---|---|---|
| **Aims:**<br>To examine the need for, and dimensions of psychosocial support in TL to make recommendations to improve services to IWL.<br><br>**Objectives:**<br>1. Explore the constructed meaning and associated actions and processes related to the experience of having and living with a total laryngectomy.<br><br>2. Examine how the biopsychosocial, cultural and linguistic factors influence psychosocial adjustment and meaning construction of IWL.<br><br>3. Examine how health professionals routinely address psychosocial issues with their clients who have total laryngectomy.<br><br>4. Explore the kinds of professional practices that would provide better psychosocial support for IWL. | 1. Undertake a review of the relevant literature to provide an overview of the collective knowledge and conditions that appear to be shaping understanding and practice in the field of total laryngectomy care<br>2. Adopt a constructivist grounded theory (CGT) approach which captures a heterogeneous range of participants who have undergone TL or provided support, e.g. significant others and health professionals (doctors, nurses and allied health), to gather rich data and thick description<br>3. Construct and pilot interview guides with key informants<br>4. Use sampling techniques to guide data collection and analysis<br>5. Use semi-structured, in-depth interviews with participants and group interviewing with some significant others<br>6. Concurrent data collection and analysis, e.g. constant comparative analysis<br>7. Revision of interview guide to reflect new themes and saturation<br>8. Describe themes and relationships emerging from the interview data using a coding structure and memo writing<br>9. Use member checking techniques<br>10. Identify emergent core categories relating to psychosocial adjustment (social, physical and emotional wellbeing) and support<br>11. Apply interpretative theoretical lens symbolic interactionism (SI) to critically examine the data related to social construction of self and psychosocial needs<br>12. Check for theoretical sensitivity, plausibility, directions/centralities and adequacy | 1. In-depth interviews<br>2. Participant journals (people with TL only)<br>3. Researcher field notes<br>4. Socio-demographic information | 1. Use a constructivist-interpretive orientation, e.g. CGT and SI theoretical framework: Initial and focused thematic coding analysis (emphasising action and process) and memo writing leading to category and theory development<br>2. View data in terms of participant assumptions, implicit meanings and tacit rules<br>3. Analyse data in terms of co-construction of meaning between participants, each other and researcher<br>4. Apply SI sensitising concepts<br>5. Look for negative cases<br>6. Tabulate and analyse socio-demographic data |

### 3.6 Research context and participant sampling

#### 3.6.1 *Research context relevance*

This study was undertaken primarily in the urban setting of Adelaide, South Australia; a moderately sized Australian capital city with a population of 1.3 million. The population is skewed to living in the capital, with a statewide population of 1.68 million people. The study was designed with particular attention to recruiting and interviewing participants living in both metropolitan and remote/rural geographical locations. Interviews occurred face-to-face, over the phone, in small groups, one-to-one, in participants' homes, hospital and university offices, and on one occasion a hotel room. Phone and face-to-face interviews in the capital were also conducted with participants from remote/rural locations to widen the sample. The strategies used to attract participants from remote locations and those who could not travel are discussed in the next chapter.

#### 3.6.2 *Sampling techniques*

It was important to try and obtain a wide range of views and experiences. Therefore, purposive sampling techniques, characterised by a combination of criterion, maximum variation and theoretical sampling, were used to capture diverse perspectives and multiple realities of the TL experience (Charmaz, 2014; Liamputtong & Ezzy, 2005) with the objective of understanding the meaning of the experience of having and living with a TL. A total of 10-15 participants were sought for each stage. However, issues related to population size, geographical distance and theoretical saturation affected the rate of participation as well as the need to capture these initial participant estimates.

A second objective was to examine how biopsychsocial, cultural and linguistic factors influence psychosocial adjustment to TL. Therefore, the sampling frame for Stage 1 encapsulated biopsychosocial factors pertaining to gender (men and women), age (young and old), support networks (marital status, family structure, role in the family, carer support, intimate confidante), SES (education level, employment and financial situation) and geographical location (urban, remote/rural). The sampling frame also attempted to incorporate cultural and linguistic factors pertaining to ethnicity (e.g. non-Indigenous Australian, Indigenous Australian), religious diversity (beliefs and practices) and linguistic diversity (English as the first language, English as a second language, very little English).

### 3.6.2.1   Stage 1: Perspectives of individuals with laryngectomy

In Stage 1, participants were people who had undergone TL at least one year prior to the interview. They were residents of South Australia and lived in urban or rural/remote locations. There was a contingency that if recruitment proved difficult, residents of neighbouring states and territories receiving ongoing healthcare from either of the tertiary hospitals would also be invited to participate. However, this did not happen. All individuals invited to be part of the study were able to communicate verbally with TE speech, OE speech or EL speech. Individuals who did not use an audible ACM but could communicate effectively by writing down or mouthing responses were also interviewed.

A diverse range of participants – women, younger or older people, people of different ethnicity, people who were employed and people living in remote/rural settings – were prioritised for interview. Sampling occurred over a 12-18 month period and criteria for interviews were determined by themes that emerged from the data. Predefined criteria for inclusion or exclusion for Stage 1 of this study are shown below.

**Inclusion**

- One year post-TL
- Proficient communicator (alaryngeal, e.g. electrolarynx, voice prosthesis, oesophageal speech or writing)
- Resident of [state's name] (metropolitan and rural)
- Non-resident of [state's name] if receiving ongoing healthcare for TL from [hospital names]
- >18 years old
- Men and women
- English speaking background
- Non-English speaking background with sufficient English

**Exclusion**

- < than one year post-TL
- Diagnosed and treated for other head and neck cancer/s
- <18 years old
- Diagnosed neurological impairment
- Diagnosed cognitive impairment

Twelve participants were recruited (*n=5* females, *n=7* males). These participants' socio-demographic details are presented in Table 3. The cohort used a range of ACMs, including TE speech and EL speech. There was also variation in the time since surgery, marital status, SES, level of education and geographical location. However, there appeared to be little diversity in ethnicity, linguistic background or employment status.

**Table 3: Stage 1 participant details**

| Pseudonym and age | Gender | Communication method | Smoking history | Years since surgery | Relationship status | Ethnicity | Religion | Location | Education level | Income support | Journal completed |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Jack 69 | M | TES | Y | 11 | M | AAb | NR | M | T | pens - C | Y |
| Lyn 63 | F | TES | N | 10 | S | AAb | Chr | M | HS | IP - E | N |
| Len 75 | M | TES | N | 5 | M | AAi | NR | M | T | pens - C | Y |
| Hugh 57 | M | TES | Y | 4 | S | AAi | NK | M | HS | pens - C | N |
| Kath 72 | F | EL, O | Y | 2 | S | AAi | Chr | M | PS | pens - C | Y |
| Valerie 74 | F | TES | Y | 9 | M | AAi | Chr | R | HS | pens - C | Y |
| Mary 75 | F | EL, O | Y | 2 | W | AAi | Chr | M | T | pens - C | Y |
| Christopher 61 | M | EL | N | 10 | S | EAie | O | M | HS | pens - C | N |
| Bill 70 | M | TES | Y | 11 | S | AAi | NK | R | HS | pens- C | Y |
| Annie 65 | F | TES | Y | 9 | W | AAi | NK | R | T | pens - C | N |
| Pieter 61 | M | TES | Y | 4 | M | EAie | NK | M | T | IP - G | N |
| Brian 59 | M | TES | Y | 3 | M | AAi | NK | R | HS | pens- C | N |
| **Totals** | M $n$=7, F $n$=5 age range =57-75 years, mean=66 years, median=67 years | TES $n$=9, EL $n$=3, O $n$=2 | Yes $n$=9, No $n$=3 | range of time 2-11 years, mean=6.5 years, median=7 years | M $n$=7, S/W $n$=5 | AAb $n$=3, AAi $n$=7, Eaie $n$=2, | Chr $n$=4, NR $n$=2, NK $n$=5, O $n$=1 | R $n$=4, M $n$=8 | PS $n$=1, HS $n$=7, T $n$=4 | pens $n$=10, IP $n$=2 C $n$=10, E $n$=1, G $n$=1 | Y $n$=6, N $n$=6 |

*Gender* : Male (M) and Female (F); *Communication method* : Electrolarynx (EL), Tracheoesophageal speech (TES), Other (O); *Smoking history and Journal completed* : Yes (Y), No (N); *Relationship status* : Married (M), Single (S), Widowed (W); *Ethnicity* : Anglo-Australian born (AAb), Anglo-Irish Australian immigrated (AAi), Euro-Australian immigrated with English as second language (EAie); *Location* : Metropolitan (M), Rural (R); *Education level* : Primary school (PS), High school (HS) and Tertiary (T); *Religion* : Christian (Chr), No religion (NR), Not known (NK), Other (O); *Income support* : Pension (pens), Income protection (IP), C=$20001-35000 per annum; E=$50001-60000 per annum, G=$80001-100000 per annum

### 3.6.2.2 Stage 2: Primary supporter perspectives

In Stage 2, group interviews and in-depth, semi-structured interviews were conducted with primary supporters (e.g. partners, spouses, confidantes, carers or adult children) of a person with TL to ascertain what they had to say about their experiences. The exploration of location-related experiences occurred through conducting groups in the metropolitan area of the capital and in a regional location at least 100 kilometres from the specialist laryngectomy services provided by the two tertiary hospitals. Initially, a focus group methodology was planned (Kitzinger, 1995; Morgan, 1996). I designed a stratified sampling frame to facilitate the collection of data related to the experiences of primary supporters, and to compare and contrast their experiences related to geographical location and the gender of their loved one. Again, I did not want to restrict participation and there were limited predefined criteria for inclusion or exclusion, as below.

| Inclusion | Exclusion |
|---|---|
| • Supporter/carer for more than one year for somebody who has had a TL | • Diagnosed and treated for other head and neck |
| • Resident of [state's name] (metropolitan and rural) | • Cancer/s |
| • >18 years old | • <18 years old |
| • Men and women | • Diagnosed neurological impairment |
| • English speaking background | • Diagnosed cognitive impairment |
| • Non-English speaking background with sufficient English | |

I planned four group interviews with three to six participants each to reflect the small numbers of possible participants. This was also appropriate because the topics discussed generated a high degree of participant involvement and may have been emotionally charged for participants (Morgan, 1996). The low response rate for group interviews prevented me from running single gender support groups, although I did run groups in different geographical locations. The first group, which was held in a metropolitan location had three participants ($n=2$ females, $n=1$ male). The second group, held in a regional location, had two women participate. One-to-one interviews were also offered if a participant was unable to attend a group interview and to broaden the recruitment for this stage. Five one-to-one interviews were held. In total, nine primary supporters ($n=7$ female and $n=2$ male) participated in this stage. Table 4 provides socio-demographic details of the Stage 2 participants.

**Table 4:  Stage 2 Participant details**

| Pseudonym and age | Gender | Partner interviewed | Partner's age | Communication method partner | Smoking history | Years since surgery | Relationship status | Ethnicity | Religion | Location | Education level | Income support Income bracket | Family history cancer | Previous healthcare experience | Interview type |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Julie 62 | F | Y | 62 | TES | N | 6 | M | Aai | Chr | M | HS | empl - G | N | N | FG (ftof) |
| Cilla 68 | F | Y | 77 | TES | N | 7.5 | M | EAi | Chr | M | T | pens - C | Y | Y | FG (ftof) |
| Colin 77 | M | Y | 77 | TES | N | 12 | M | AAi | NK | R | HS | pens - C | N | Y | FG (ftof) |
| Fay 77 | F | N | 78 | TES | N | 5 | M | EAi | Chr | R | HS | pens - C | Y | Y | FG (ftof) |
| Rachael 53 | F | N | 64 | TES | N | 3 | M | AAb | NK | R | HS | empl - C | Y | N | FG (ftof) |
| Sonia 49 | F | N | NK | TES | Y | 2 | D | Aai | NK | M (partner R) | NK | pens - C | Y | Y | 1to1 (tel) |
| Helena NK | F | N | NK | TES | NK | NK | NK | NK | NK | R | NK | NK | NK | NK | 1to1 (tel) |
| Tom 36 | M | N | 33 | O | N | 7 | M | AAb | NK | M | T | IP - D | Y | N | 1to1 (tel) |
| Rose 65 | F | N | 77 | TES | N | 5 | M | AAi | Chr | R | HS | pens - C | Y | N | 1to1 (tel) |
| **Totals** | age range =36-77 years, mean=61 years, median=63.5 years | Yes n=3, No n=6 | age range =33-78 years | TES n=8, O n=1 | No n=7, NK n=1 | range of time =2-12 years, mean=5.9 years, median=5 | M n=6, D n=2 | AAb n=3, AAi n=4, Eai n=2 | Chr n=4, NK n=5 | R n=5, M n=4 | HS n=5, T n=2, NK n=2 | pens n=4, IP n=1, empl n=2, NK n=1; C n=6, D n=1, G n=1 | Y n=6, N n=2, NK n=1 | N n=4, NK n=1 | FG (ftof) n=5, 1:1 (tel) n=4 |

*Gender : Male (M) and Female (F),  **Communication method** : Tracheoesophageal speech (TES), Other (O),
**Partner interviewed,  Smoking history, Cancer history and Healthcare experiences** : Yes (Y), No (N),
**Relationship status** : Married (M), Defacto (D),  **Ethnicity** : Anglo-Australian born (AAb), Anglo-Australian
immigrated (AAi), Euro-Australian immigrated (EAi),  **Location** : Metropolitan (M), Rural (R),  **Education level** :
Primary school (PS), High school (HS) and Tertiary (T),  **Religion** : Christian (Chr),  **Income support** : Employed
(empl), Pension (pens), Income protection (IP), C=$20001-35000 per annum; D=$35001-50000 per annum,
G=$80001-100000 per annum  **Interview type:** Focus group (FG), one-to-one (1:1), face to face (ftof), telephone
(tel); Not known (NK)*

### 3.6.2.3  Stage 3: Health professional perspectives

In Stage 3, exploration of experiences occurred through conducting in-depth, semi-structured interviews with health professionals who provide clinical support (primary, secondary and tertiary healthcare settings) to people who undergo TL. These professionals worked in the metropolitan area of the capital and in regional locations at least 75 kilometres from the specialist laryngectomy services provided by the two tertiary hospitals.

This design aimed to collect data about the experiences of health professionals

from different disciplines, with different levels of experience and from different locations. It enabled comparing and contrasting of experiences related to discipline, expertise and geographical location. The sampling also reflected that allied health professionals provide pre-operative and longer-term post-operative supports in acute and community settings. The head and neck surgeons typically provide acute care, with longer-term care provided on an outpatient basis. Thus, individuals who live regionally have to travel to the tertiary treating hospital for review. Head and neck nurses are responsible for the acute care needs of people who undergo TL and community-based nurses are usually involved during the transition back to the community after surgery. The predefined criteria for inclusion or exclusion in Stage 3 is provided below.

**Inclusion**

- Healthcare provider for at least one person who has had a TL
- Employed by a Health Service to provide clinical supports for people who have a TL (both presently and or in the past)
- >18 years old
- Men and women
- Proficient English speaking skills

**Exclusion**

- Has not provided healthcare to at least one person who has had a TL
- <18 years old

Table 5 provides information about the seven health professionals who participated in Stage 3. Six worked in the tertiary hospital system and were members of a multidisciplinary head and neck team. The other participant was a community-based speech pathologist working for a regional health service.

**Table 5:    Stage 3 Participant details**

| Pseudonym and age | Gender | Age range | Profession | Years of practice | Years of practice w TL | Number of TLs supported/year | Ethnicity | Other language spoken | Location | Education level | Employment fraction | Religion | Interview method |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Matilda | F | 30-39 | SD (IP) | 7.5 | 3.5 | 25 | AAb | N | TH1 | M | F/T | NR | ftof |
| Tessa | F | 20-29 | SSP (IP) | 4.5 | 3 | 15 | AAb | N | TH2 | M | F/T | NK | ftof |
| Helen | F | 50-59 | SSW (IP) | 10 | 9 | 5 | Aab | N | TH2 | B | P/T | NK | ftof |
| Maria | F | 50-59 | SRN (IP) | 30 | 20 | 50 | EAb | Y | TH1 | B | P/T | Chr | ftof |
| Joseph-ine | F | 40-49 | SSP (OP) | 25 | 20 | 10 | Aab | N | TH2 | M | P/T | Chr | ftof |
| Saman-tha | F | 30-39 | SP (IP/OP) | 5 | 5 | 3 | Aab | N | CH | B | F/T | NK | tel |
| Edward | M | 40-49 | Sgn (IP/OP) | 20 | 10 | 20 | AsAi | Y | TH2 | M | F/T | NK | ftof |
| **Totals** | **M n=1, F n=6** | **range =20-59 years** | **IP n=6, OP n=3** | **range=4.5-30 years, mean=14.6 years, meadian=15 years, collective years=102** | **range= 3-20 years, mean=10 years, median=9.5 years, collective years= 70.5** | **range=3-50 years, mean=18 years, median=12.5 years** | **AAb n=5, Eab n=1, AsAi n=1** | **Y n=2,N n=5** | **TH2 n=4, TH1 n=2, CH n=1** | **M n=4, B n=3** | **FT n=4, PT n=3** | **Chr n=2, NR n=1, NK n=4** | **ftof n=5, tel n=1** |

*Gender : Male (M) and Female (F); **Other language spoken** : Yes (Y), No (N); **Occupation type** : Senior Dietitan (SD), Senior Speech Pathologist (SSP), Senior Social Worker (SSW), Senior Registered Nurse (SRN), Speech Pathologist (SP), Surgeon (Sgn), Inpatient (IP), Outpatient (OP); **Ethnicity** : Anglo-Irish Australian born (AAb), Euro-Australian born (EAb), Asian-Australian immigrated (AsAi); **Location** : Tertiary Hospital 1 (TH1), Tertiary Hospital 2 (TH2), Community Health (CH); **Highest level education level** : Masters degree (M), Bachelor degree (B); **Religion** : Christian (Chr), No religion (NR), Not known (NK); **Employment** : Full time (F/T), Part time (P/T); **Interview type:** face to face (ftof), telephone (tel)*

## 3.7 Ethical considerations

This study was completed in three stages with three different participant groups. Each stage had a similar research design. Where appropriate, specific considerations were implemented to ensure ethical research conduct for each stage. Participants' interests were respected and efforts were made to ensure their needs were met and risks minimised.

### 3.7.1 Ethics approval

The key phases of research design, data collection and analysis were all guided by an ethical approach outlined in the National Statement on Ethical Conduct in Human Research (The National Health and Medical Research Council, The Australian Research Council, & The Australian Vice-Chancellors' Committee, 2007) and the Code of Ethics (Speech Pathology Association Australia, 2010). The research was conducted with the following guiding principles: respect for persons; equity; non-discrimination; beneficence and non-maleficence. Each stage had its own ethics approval process. Multiple approvals were gained from clinical research ethics committees and governance bodies for conducting each stage of the study with a range of participant groups and in a range of locations. Table 6 provides details of the approvals granted.

**Table 6: Ethics and governance approvals for each stage**

| Stage 1 | Stage 2 | Stage 3 |
|---|---|---|
| Flinders Clinical Research Ethics Committee: Application Number 333/09 approved 17/11/2009<br><br>Royal Adelaide Hospital Ethics Committee: Protocol Number 091205 approved 08/12/2009 | Southern Adelaide Clinical Human Research Ethics<br><br>Committee (SAC HREC EC00188): application number 225:13 HREC<br><br>Approved 03/07/13, amendment approved 07/03/14, a further amendment approved 11/07/14<br><br>Flinders Medical Centre Site Specific Assessment (SSA) approved 15/07/13 SSA number SSA/12/SAC/215<br><br>Royal Adelaide Hospital Site Specific Assessment (SSA) approved 08/07/2013 SSA number SSA/13/RAH/219 | Southern Adelaide Clinical Human Research Ethics<br><br>Committee (SAC HREC EC00188): application number 197:14 HREC/13/SAC/195 approved 17/06/14<br><br>Flinders Medical Centre Site Specific Assessment (SSA) approved 26/08/14 SSA number SSA/14/SAC/358<br><br>Royal Adelaide Hospital Site Specific Assessment (SSA) approved 08/08/14 SSA number SSA/14/RAH/321<br><br>Country Health South Australia Local Health Network Site Specific Assessment (SSA) approved 12/09/14 SSA number SSA/14/SAH/126 |

### 3.7.2   Consent and anonymity

I liaised with two specialist speech pathologists, both members of the multidisciplinary head and neck team at their hospital, to facilitate recruitment for Stages 1 and 2. They were located at each of the tertiary hospitals in Adelaide where head and neck surgery takes place. Both clinicians were supporting people undergoing TL as inpatients and longer-term as outpatients. Each clinician assisted the recruitment of participants for both stages. They sent information about each study to people who were on their caseloads. There was nearly a four-year gap between stages due to the study's sequential nature. Stage 1 recruitment targeted people who had undergone TL at least one year prior. The clinicians sent an information pack, including an introductory letter, participant information form, reply-slip and a reply-paid envelope, to people on their caseloads whom they thought would meet the inclusion criteria. People who returned the reply-slip were contacted by telephone. All enquirers met the inclusion criteria and agreed to participate in the study. Interviews were arranged at mutually convenient times and locations.

Recruitment for Stage 2 involved targeting people who had supported or cared for someone who had undergone TL. The clinicians also agreed to advertise this study and sent an advertisement flyer to people on their caseload. The flyer had some brief information about the study and requested that the study details be passed onto significant others (e.g. a partner or a person who supported them since their TL) who may be interested in participating. The initial flyer mentioned that focus group interviews would be held. This was subsequently changed to offer one-to-one interviews. The study was also advertised on public noticeboards in hospital outpatient clinic waiting areas, shopping centres and public libraries. Potential participants for Stage 2 contacted me by telephone or email and I discussed the inclusion criteria with them. I then sent the Stage 2 introductory letter and participant information form via email or post. Participants who had chosen to be interviewed by telephone were forwarded the consent and socio-demographic information forms as well as the counselling services information sheet. The planning and timing of group interviews was dependent on the availability of all parties (all participants and me).

I liaised with the lead professionals for allied health, head and neck nursing, high dependency nursing and otorhinolaryngology, and head and neck surgery at the

tertiary hospitals in Adelaide where head and neck surgery takes place to assist with the recruitment of health professionals for Stage 3. I also liaised with the provider of community-based allied health services for rural/remote regions in South Australia. Each of these lead professionals endorsed the study. They supported the distribution of the study promotion materials via an email to members of their staff who met the inclusion criteria. Potential participants contacted me by email or telephone and were provided with the Stage 3 participant information and consent forms either electronically or by post. The participants who met the inclusion criteria were offered an interview at a mutually convenient time and location. Interviews occurred face-to-face or by telephone.

Participants were asked to read and sign the relevant Consent to Participation in Research Form for all the study stages and at the commencement of each interview. A verbal description of the form was also given so individuals could decide whether or not to participate at this time. Participants were reminded that they had the right to check, withdraw at any time, and disclose as much or as little as they wished in the interview process, including refusal to answer particular questions. They were also reminded that the results would be reported in a de-identified manner. All of these conditions had previously been provided in the relevant participant information forms.

The procedure for consent in Stage 2 was modified for participants who participated in a group interview. These participants were informed that their confidentiality would be affected due to the focus group methodology, because they were identifiable to other members of their group. However, these participants were reassured they would be given a pseudonym in the transcripts to facilitate anonymity. A similar consent process was followed for the telephone interviews. After verbally reading through the relevant Consent to Participation in Research Form, I asked each participant to give verbal consent. This permission was audio-recorded. I also requested participants to sign and return the form to me.

Reimbursement of reasonable travel costs was offered to each participant in Stages 1 and 2 to compensate them for their time and costs incurred in participating. Stage 3 participants supported the study in-kind and were only offered remuneration for travel costs. All forms, information sheets and advertisements were written to accommodate a range of reading levels. Jargon-free language was adopted and lay terms were used where possible. I have provided examples of the advertising material,

forms and information sheets used to support recruitment, gain consent, support participants and assist with data collection during the study as Appendices 2-6.

### 3.7.3 *Withdrawal from study*

Participants were informed in the relevant participant information and consent forms that their participation in the study was entirely voluntary and they had the right to withdraw from the study at any time without giving a reason. It was clearly stated that if they decided not to participate in this study, or if they withdrew, they could do so freely without affecting the standard of care or treatment for themselves or their partner, relative or friend. Health professionals were informed that their employment would not be compromised.

### 3.7.4 *Cultural inclusiveness*

Participants were treated in a culturally sensitive way. An important aim of the study was to recruit participants from diverse cultural and linguistic backgrounds. One constraining factor, however, was that participants from a non-English speaking background required sufficient English to participate in the interview process.

### 3.7.5 *Confidentiality of research data*

Upholding participant confidentiality was an important aspect of this study. I maintained participant privacy during the study by storing all raw data (audio and video recordings, transcriptions, journals and field diaries) with both identifying and non-identifying information on either DVD, compact disc or as a paper document in a lockable filing cabinet housed in my university-based office. Data confidentiality will be further preserved for a minimum of 5 years after the publication of results. During this period, the discs and paper documents will be kept in a locked storage room at the university that is only accessed by department staff. A similar process was followed for each stage. The exception was in Stage 2, where I made the group interview transcripts available to the whole group for verification. I removed identifying information (names of people, places and locations) from all transcripts and gave participants pseudonyms in all subsequent reporting.

### 3.7.6 *Beneficence and non-maleficence*

It was considered that this study would benefit participants by providing an opportunity to discuss their experiences and challenges related to a TL with a neutral

person who did not judge them for their point of view and was intent on learning about their experiences. There is also literature to suggest that participants in the group interviews were more likely to find it a valuable experience because it put people with similar experiences in touch with one another in a well-supported environment (Hersh & Armstrong, 2014; Kitzinger, 1995). Despite these potential positives, I was aware that qualitative research could cause emotional distress or psychological harm. I did not anticipate that this study would cause problems or adverse risk to participants. I informed every participant in writing (participant information form), and verbally at the time of the interview, that they may experience anxiety or grief as a result of the discussion generated in the interview. In the event a participant became visibly distressed in an interview, I stopped and asked them if they wanted the interview to continue. I also verbally reiterated to each participant that they could withdraw their consent to participate at any time during the data collection phase of the study. All participants were provided a written comprehensive list of free and fee-for-service counselling services. I also informed them that it would be possible to arrange counselling from one of the members of the supervisory team who is a qualified Family Therapist.

### 3.7.7   *Administrative aspects*

This study was designed to minimise the administrative impacts for all stages. I held a 15-30 minute individual meeting with all health professionals who agreed to support and advertise the study. For Stages 1 and 2, I forwarded them pre-packaged information in envelopes for distribution. They were then required to address and send them. For Stage 3, I emailed the electronic advertisement to each lead professional and they forwarded it to health professionals in their service divisions. It was estimated that this process took 5-10 minutes of their time.

## 3.8   Rigour and reflexivity

Validity and reliability in qualitative research are achieved with the principles of rigour. Rigour in this qualitative study was achieved using procedural rigour, triangulation methods and reflexivity as outlined below.

### 3.8.1 Procedural rigour

#### 3.8.1.1 Triangulation

All methodological and analytical decisions throughout the study were documented for auditing purposes and to allow others to assess the significance of the research. I used a range of triangulation methods, as described by Liamputtong and Ezzy (2005), to maximise rigour.

*Methods triangulation* was achieved by comparing and contrasting the data from all stages – interviews with individuals in Stages 1-3 and the group interviews in Stage 2 (audio-recorded and transcribed verbatim), the participant journals in Stage 1, the maintenance of comprehensive field notes by the researcher and extensive memo-writing throughout the study.

*Researcher triangulation* was achieved using a number of verification methods aimed at checking meaning and interpretative rigour. These methods included member checking, in-situ checking and analysis by other researchers. The approach to all these methods will be discussed further in the next chapter under section 4.3.4 'Verification methods'.

### 3.8.2 Reflexivity and the researcher's position

An important tenet of CGT methodology is to acknowledge and critically appraise the role, influence and responsibility of the researcher in the research process. In assuming the theoretical position that all meaning is co-constructed, it was crucial during the study that I used reflexive tools to evaluate myself and my interpretations. I achieved reflexivity in a number of ways. Firstly, I informed the participants that I was a speech pathologist with over 20 years' professional experience. I told them I had worked previously in a number of clinical settings both in Australia and the United Kingdom, where I had been a member of a head and neck surgery multidisciplinary team and had supported patients who had undergone TL across the care continuum. My current role as an educator in two university speech pathology programs was also described. Throughout the study conception and implementation, I have been aware that my interest in this area developed after treating a number of patients who did not typify the common demographic of gentlemen who were in their fifth or sixth decade of life, had significant histories of alcohol consumption and smoking, and were often socially isolated. It had been my experience that I was also

supporting women, older or younger adults, and patients who did not have a history of smoking or drinking.

Another important reflexive issue I managed in this study related to the literature review. The demands of a traditional grounded theory approach conflicted with the need to design the study prior to seeking ethics approval. I decided to complete a preliminary literature review at the beginning of the study and this approach was consistent with CGT (Giles, King, & deLacey, 2013). This enabled me to determine a suitable methodology for this inquiry and I subsequently gained ethics approval to conduct each stage. However, I deliberately set the literature review to one side and did not revisit it until I was required to complete ethics applications for Stages 2 and 3. Again, these subsequent reviews were preliminary rather than comprehensive. After completing the data collection and analysis, and during the preparation of this thesis, I returned to the literature to complete a comprehensive review.

An additional reflexive design element of this study was that I completed all the in-depth interviews and analysis for each stage. I transcribed verbatim 10 of the 12 Stage 1 interviews, audited a postgraduate Qualitative Research Methodology Topic at the beginning of candidature and have had regular supervision from my co-researchers throughout the study. I maintained a field diary and recorded reflections of the personal experiences and insights through each stage of the study to assist my reflexivity and analytic decision making. The field diary complemented the extensive use of memo writing, another tool used to develop codes, categories and theoretical concepts. An example of reflexive decision making was when I moved from the coding approach described by Corbin and Strauss (2008) to the coding approach described by Charmaz (2006, 2014). I found this useful because I began to code using gerunds rather than topic units. This strengthened my ability to describe the psychological and social processes evident in the data.

Throughout the data collection and analysis phases, I endeavoured to acknowledge how my professional perspective as a trained speech pathologist affected my understanding and interpretations of the phenomena of the TL experience in this study (Liamputtong & Ezzy, 2005). I was aware that I used terminology and language in my interviews that could have impacted joint meaning and understanding. I also consciously critiqued the language I have used to describe the data and results

to ensure it is firmly grounded in the narratives. In the next chapter, I provide examples from my field diary, memo writing and coding to represent how I maintained reflexivity throughout the research process.

## 3.9   Conclusion

The research aims, design and methods are aligned with the ontological and epistemological underpinnings of a constructivist-interpretative orientation. A CGT methodology and SI theoretical framework underpinned the study design and procedures. A constructivist-interpretative orientation promotes awareness about how we characterise participants and prompts reflexive examination of the researcher's interpretations. The researcher's attention is sensitised to a range of realities and viewpoints. Thus, a picture of reality is constructed from the collective experience and connection with the participants.

The importance of meaning, actions, processes and context related to the TL experience were the central focus in this study. All participants were perceived as social actors with worthy stories to tell and these stories were at the centre of analysis. The use of semi-structured interview techniques, saturation and triangulation methods assisted with exploring participants' tacit understandings and the meaning they attached to experiences. The following chapter provides further explanation of the research methods used in the study.

# 4  Data collection and analysis process

## 4.1  Introduction

This chapter accounts for the strategies used to optimise recruitment and participation in the study and the grounded theory methods utilised for data collection and analyses. The aim of these strategies and methods was to collect rich data to enable thick description of the experience of having a TL and to explore the supports, including psychosocial, that are important for adjustment and recovery. Multiple perspectives were collected, primarily using intensive interviewing. A few other data collection strategies were also implemented, such as Stage 1 participant journals, a researcher field diary and the gathering of socio-demographic information. Consideration was given to ways in which the research process could be more accessible for participants who were alaryngeal communicators, living in remote locations or who could not travel.

## 4.2  Person-centred research techniques

During the data collecting stages, I used a range of person-centred techniques to build rapport with participants. These included an open and positive attitude, empathy, active listening, open-ended questioning, following a participant's lead, checking participant comfort during the interview, paraphrasing content as a form of in-situ checking of meaning, and reiterating to participants their right to withdraw or change their verbal or written accounts (Liamputtong & Ezzy, 2005; Rogers, 1951). I focused on getting participants to describe their experiences in their own words whilst trying to explore their beliefs, implied significance and underlying influences (Charmaz, 2006, 2014). Implementing this style of inquiry drew on the skills I had developed as a practitioner, and which had been further refined through psychotherapy and qualitative research training. The interview process also sharpened my ability to ask probing questions and promote a comfortable interview environment for participants.

I piloted the interview guides with key informants to further promote a person-centred approach. This enabled me to refine the question schedule to suit future participants. I raised reflexive questions throughout the investigations and analysis, and examined shared meanings and my interpretation of those meanings. I also used the saturation technique to update the interview guides and maintain a close connection between raw data and subsequent data collected (Charmaz, 2014).

It was important in this study to recruit a wide sample of participants. Provisions were made to interview IWL who used a range of ACMs and from a variety of geographical locations. The recruitment in Stage 2 was modified to attract participants who did not want to take part in a group or face-to-face interview. Some difficulties with the dependability and versatility of ACM are discussed in the following section.

### 4.2.1 *The participant-researcher relationship*

I facilitated all recruitment, consent, data collection and analysis for the study. My biographical details have been provided in the previous chapter. I knew a few participants due to previous employment as a speech pathologist working with IWL. However, this did not seem to affect the researcher-participant relationship or the recruitment process. It may have facilitated an additional closeness to these participants, which was reflected in some statements made in the interviews and letters sent by participants to qualify circumstances or give an explanation about why they were unable to participate in some parts of the study.

The participant-researcher relationship was an important part of this study because some of the material covered in the interviews was upsetting for the participants, particularly in Stages 1 and 2. It appeared that in some situations, it was useful to participants to discuss their experiences with a neutral person. For example, the following extracts highlight the closeness developed in the interview and research process. When I interviewed Lyn, 63, she described in detail her difficult personal experience of having a TL and became emotional. The bold text represents my statements, the plain italics represent Lyn's words:

> **Lyn, you are being so honest … I feel that.** *Well, I haven't spoken to anybody about it so you are probably getting the full brunt.* **Well, yeah you know that is ok.**

Cilla, 68, wrote me a letter after I interviewed her partner Len, 75. She apologised for not being present at the interview and started the letter with, *I don't know where to begin with Len, perhaps the beginning of his problems….* She then described the health and adjustment difficulties he had experienced, including several near death experiences. She said that they were very grateful for the care he had received and for the time they had left together. She post-scripted the letter with, *But oh boy, what a journey!*

The interviews were conducted in a range of circumstances and places, but I

believe that I developed rapport and comfort with all participants, even during the telephone interviews.

### 4.2.2  Interviewing alaryngeal communicators

#### 4.2.2.1  Practical issues

Very little is written about the process of researching and interviewing people who use alaryngeal communication. During recruitment, participants using an ACM were invited to participate if it was determined prior to the interview that they would be able to maintain communication for a sustained period. However, prior knowledge of proficiency was not always reliable. The intelligibility of the interview was affected for two participants due to their reduced capacity to use their electrolarynx. I encouraged these participants to write or mouth messages, although it was more difficult to establish everything that was said if mouthing was the predominant technique used.

#### 4.2.2.2  Sustained communication

Most participants had a reasonable command of their TE speech or EL speech. However, the length of the interview highlighted that this was an effortful experience for some and that there would be a cost for participating. Pieter, 61, described how he would not have any alaryngeal voice for days after his interview. Lyn reported in her interview that she found it really difficult to talk when she was emotional. These issues highlighted that the alaryngeal voice appeared to be affected by increased generalised muscle tension and hyperfunction, as described in populations with a larynx (Roy, 2008). Another example where alaryngeal communication disrupted the interview process occurred when interviewing Hugh, 57. Hugh had to take frequent breaks to enable him to cough and clear his airway during our conversation. He also chose to stand throughout, which added an unusual dynamic in the interview, with me sitting on a sofa trying to keep the recorder in range as he walked around his small flat. He reported that airway issues related to mucous build-up frequently interrupted his speech. This was a common experience for other participants, some of whom said that it had improved over time whilst others reported persisting or intermittent problems. Having water available to drink and giving people time to respond were important parts of the interview process. In my interview with Christopher, 61, he stated part way through that he needed a break and wanted a drink. He said that he

often experienced throat dryness and irritation after talking for extended periods.

I also observed during the interviews how an alaryngeal device affected conversational quality. I was able to detect accents, but variations in vocal tone and loudness as well as conversational versatility (e.g. ability to respond quickly, interject or sustain conversation) were all impacted negatively. These observations focused my attention on the importance of accent and vocal tone as significant aspects of a person's identity. This approach to data collection indicated to me early on that a person's communication impairment compromised their ability to be themselves in the interview.

### 4.2.2.3 *Acquisition and maintenance of audible alaryngeal communication methods*

All participants had been using an audible ACM for at least one-year. Several participants reported that post-operative complications or delayed surgical voice restoration had either prevented them from immediately acquiring an audible ACM or had led them to attempt to master several during the first year. This potential difficulty was foreseen when designing the study. Participants had to be at least one-year post-surgery to be eligible. The range of time since surgery was 2-11 years (mean=6.5 years and median=5 years). Another issue for participants using an audible ACM was frequent periods without a prosthesis or device resulting from malfunction or waiting for a replacement. These periods could take a few days or even longer. Rural dwellers often experienced longer timeframes, during which they were dependent on writing or mouthing. This could impact them both personally and socially. Fortunately, these issues did not affect the data collection in this study.

### 4.2.3 *Overcoming barriers to participation*

In Stages 1 and 2 of the study, two visits were made to regional towns – one 166 kilometres north-west and one 182 kilometres north-east of the capital. This ensured adequate sampling and opportunity for participation for people living in remote/rural locations. Nine participants in these two stages lived in regional locations. Additional contingencies were made during Stage 2 because the original design of group interviews only attracted five participants. Provision for one-to-one interviews with primary supporters, which could be held over the telephone, resulted in the recruitment of a further four participants. Their feedback included that they could not travel to a face-to-face interview and they were not keen to take part in a group

interview. In Stage 3, the flexibility of telephone interviews enabled participation of one clinician from a rural centre. Thus, being flexible with the data collection process enabled me to increase the participant pool and gain a wider range of perspectives. As shown in Table 7, flexibility enabled 10 people from remote/rural areas to participate in the study.

**Table 7:    Participant numbers**

| Stage | Number of participants in stage | Number of remote/rural participants |
|-------|--------------------------------|-------------------------------------|
| 1 | 12 | 4 |
| 2 | 9 | 5 |
| 3 | 7 | 1 |
| **Total** | 28 | 10 |

## 4.3  Sources of data

I used a number of data sources to achieve the principles of "theoretical plausibility, direction, centrality and adequacy" (Charmaz, 2014, p. 87). The primary source of data was intensive interviewing. I used criterion and maximum variation sampling techniques to aid this process (Liamputtong & Ezzy, 2005). Additional data was captured from journals written by participants in Stage 1, socio-demographic details and my field diary. Coding, verification methods, memo writing and the updating of interview guides assisted with maintaining theoretical direction and centrality throughout the data collection and analysis phase.

### 4.3.1   Intensive interviews

Intensive interviewing was an important part of the data capturing process. I followed a semi-structured format when interviewing to maximise data collection and obtain thick description and rich data. The data collection occurred over three stages and the interview process of each stage is described below. I used a similar recording procedure for each interview. However, in the group interviews I also used a note taker. The interview guides were an integral part of the interviewing process and I refined them for each stage using key informants and concurrent data analysis.

#### 4.3.1.1  Interview format

I followed a similar format for all the interviews and attended to participants' accounts, silences and the participant-researcher-relationship during each interview

(Charmaz, 2014). Open-ended questioning and clarification of meaning was used throughout. Participants were given opportunities to stop the interview if they appeared to need a break. The following excerpt from an interview with Pieter, 61, demonstrates how I asked very few questions and emphasised some of his terminology to clarify meaning. My questions and statements are indicated by the bold text and Pieter's responses are indicated by the other text. My questioning style also gave Pieter permission not to answer a question if he did not want to.

---

*Interview extract*

**So what do you think about that?**
You know, everything has its benefits and its drawbacks so, … sometimes I think it's really funny that people expect you to do certain things that are plainly physically impossible. Other times – like …I was in Bunnings buying some material and the girl took one look at me and underpriced everything that was on my trolley.
**Underpriced?**
Underpriced. "That's that, that's that, that's that; thank you, sir", you know, kind of feeling sorry for you. And you've got little kids coming up to you saying "what's that on your neck?" and, you know, I love that sort of thing, I don't mind at all.
**Yes, kids are very curious.**
Yeah, but it's good because they open up, they ask the question and adults – you know when I start speaking like this – I have to kind of let you into what I was doing. In the United Kingdom I worked on multi-billion pound projects with a CEO, so my level of skill is very, very high. My ability to communicate, I think, is more than adequate but sometimes I'll go into a shop and the minute I start talking like that people go "now do you understand what I'm saying, sir?" and I'm kind of like, "oh man, this is funny".
**So what do you do, having had that?**
No, I play the game.
**Oh, do you?**
Yes, I play the games. I go, "I think so, yes". So, you know, because I don't have context for their motivation, so it may be out of compassion that they're doing it rather than out of judgement, so because I don't want to pre-empt that, I kind of play along and say – you know, if you feel that you're doing a good thing for me then I'm not going to [break] your bubble.
**They soon learn.**
And I think it's funny; I really do think it's funny. People all of a sudden think, when you speak like this, your IQ has kind of dropped from wherever it was to...
**That's interesting. So you don't clam up, you're quite happy in communication?**
You know to be honest, I'm probably more open and more able to cope with the normal cycle of life now than I was before the...
**Tell me a bit about that Pieter, if you would like.**
You know that's difficult because it goes down to a really deep personal level….
So, what I guess I've done is that I've taken all the positive slants on everything that's happened to me and I've kind of built those on top of each other so that the negatives no longer affect me and the positives add to my quality of life...
**Hmmm.**

---

In the Stage 2 group interviews, the format was similar but less structured, and I

allowed participants more opportunities to interact with one another and discuss things amongst themselves as topics arose.

### *4.3.1.2 The interview process*

In Stage 1 of the study, 12 in-depth, semi-structured interviews were conducted with IWL. Interviews were completed face-to-face in the participant's home or at the university campus. Two interviews were held in a rural location 182 kilometres north-east of the capital. Provision for telephone interviews was made but none occurred. Participants were also given the opportunity to keep a journal to write down any other thoughts they may have after the interview. Eight participants agreed to do this and six were returned. Data collection occurred over a 22-month period and data analysis influenced the recruitment of the final two participants. Further recruitment was not possible due to the small population. This prompted me to consider expanding the study to significant others to triangulate their perspectives with people who had had a TL.

In Stage 2, primary supporter participants were invited to partake in a group or one-to-one interview. Two group interviews took place with three and two participants respectively, one at the university campus and one in a rural location 166 kilometres north-west of the capital. The interviews were semi-structured, enabling an emergent approach, and provided an opportunity to analyse the group dynamic, participant interaction and the material being discussed. A note taker was present for both. After the group interviews, a further four one-to-one interviews were conducted. This facilitated theoretical sampling and testing of theoretical plausibility generated from the group interviews. The Stage 2 interviews occurred over a 13-month period, with recruitment affected by population size. A few additional people enquired about the study but I was not successful in getting them to participate. Sampling stopped at nine participants for this stage.

The significant care role reported by the primary supporter participants and the experiences described by Stage 1 participants prompted the development of the third and final stage of data collection. Stage 3 involved the recruitment of health professionals. Seven one-to-one interviews were conducted either face-to-face or by telephone. Each interview followed a semi-structured format to enable exploration of the issues specific to that individual health professional. Data collection occurred over a 7-month period. The concurrent data analysis influenced criterion sampling and affected participant inclusion criteria.

There were some common elements in the interview process between the stages. Each stage was epistemologically similar for data collection, thus providing the opportunity to analyse participant interaction with the interviewer and the material being discussed across each stage. The interview guide was adapted after each key informant and subsequent interviews to incorporate new themes generated from the data. Each interview ranged from 40-144 minutes and concluded when no new material appeared to be emerging. All participants were asked to complete a socio-demographic information form at the end of their interview. This is discussed in more detail in section 4.3.5.

In addition to the interviews, I kept a comprehensive field diary, noting details and impressions after each interview and documenting the research process more generally. Initially, a single interview with each participant was deemed adequate. However, a subsequent interview was sought with one participant in Stage 3 to clarify data or themes developed in the later stages of the study. Verification of themes also occurred with systematic analysis of the data and continuous updating of the interview guide to ensure it reflected the emerged themes. This approach is discussed further in section 4.3.1.4.

### 4.3.1.3 Recording the interviews

Each interview was audio-recorded using a high quality digital recorder (Roland Edirol-9™) and a Sony™ Dictaphone recorder for back up. This was considered the most reliable and minimally intrusive method of capturing the conversation. The interview data was then transcribed verbatim using the guidelines for transcription specified by Dresing, Pehl, and Schmieder (2012). I transcribed the first 10 interviews. This was a worthy exercise to familiarise myself intimately with the data. However, it significantly slowed down data collection as each interview had to be transcribed before the next one. A professional transcriber took over this task for subsequent interviews. After transcription, I coded and analysed the data.

### 4.3.1.4 Interview guide development

The interview guide was an important feature of the interview process. The first guide contained a series of key questions and some probing questions developed from the literature and my professional experience. Using key questions enabled comparison between interviewees. However, it was also important that the questions were open-ended to maintain a semi-structured format. This facilitated the emergence of new

ideas and allowed each participant's voice to be heard. The guide was trialled with a key informant in Stages 1 and 3 prior to commencement of interviewing for each stage. Piloting of the guide enabled refinement of the questions' relevance and suitability.

I was able to practise conducting a qualitative interview in the first key informant interview. In this instance, the key informant was Jack, 69, who had a TL and regularly volunteered to meet with individuals before they had a TL. The second key informant interview occurred in Stage 3, with Josephine, a senior speech pathologist with 20 years' experience working with IWL. Piloting the interview guide with a group of key informants in Stage 2 did not occur due to the limited available participant pool for group interviews. However, the questions used were developed from Stage 1 data and refined over the course of Stage 2. This was in line with the grounded theory tradition of theoretical direction and theoretical centrality, where the themes were used to shape the questions in the interview guide and subsequently impact the direction of the inquiry. Certain ideas and areas of inquiry became central and were pursued further (Charmaz, 2014). A sample of an interview guide is provided as Appendix 7.

Open-ended questions or conversation starters were designed so that participants had the freedom to describe their experiences in their own way. Some of the open-ended questions used were: "tell me about your experience of total laryngectomy", or "describe a patient you have worked with who has had a TL", or "tell me about how you felt at the time of getting the diagnosis". This style of questioning related to my prior professional knowledge of this area of healthcare and enabled comparison between different accounts. Later in the study, sensitising concepts generated from the SI literature were used as a lens to view and analyse the data generated from the interviews, for example the formation and maintenance of the self and the role of significant symbols during different interactions.

Toward the end of the data collection, questions in interviews were constructed to help test the theoretical adequacy of categories (Charmaz, 2014). This approach also formed part of a theoretical sampling strategy where relevant data was sought to develop the emerging theory.

### 4.3.1.5 *The presence of others in an interview*

During Stage 2, a note taker (co-researcher) attended each group interview and used a

method that involved recording the participant's name at the beginning of each utterance they made. These notations were used to facilitate the verbatim transcription of the entire interview. Efforts were made to try and conduct each interview with participants alone but in one interview in each of Stages 1 and 2, a partner was present for most of the interview, and a family member and a friend were present for a short time in two Stage 1 interviews. During the interviews with the partners present, when each person contributed to the discussion I made a concerted effort to also obtain the participant's point of view.

### 4.3.2   Stage 1 participant journals

In addition to the interviews, I asked Stage 1 participants if they would like to keep a journal for one month after the interview. The journal was ostensibly another ethnographic data collection tool to get participants to record any thoughts they had about the interview and any experiences related to their TL over the following month. The journal's purpose was to give participants who may have found the interview challenging due to their communication difficulties or for emotional reasons another opportunity to share their experience. I deliberately kept the instructions to a minimum to again allow for an open-ended rather than structured process. If a participant agreed, they were given a blank 128 page A5 lined exercise book and a prepaid envelope to return the journal to me one month after the interview. Eight of the 12 participants agreed to take a journal. Six journals were returned. Each had been completed in a different way. Some participants offered an account of a few experiences and others provided daily entries. I coded the journals using grounded theory methodology and added the analysis to the pool of data accumulating with each interview. The journals provided me with another set of data from which to triangulate ideas and introduce questions to the interviews for further examination.

Bill, 70, returned his journal without an accompanying letter. In the extract from Bill's journal, I have kept the many grammatical errors and some misspelt words to remain faithful to the original document. Kath, 72, also returned her journal without an accompanying letter. She described how her outlook had changed and that she also felt thankful for having had the surgery because it had extended her life.

> *Extract from Bill's journal*
>
> 22/02/2011
> Talking about my throught (throat) cancer done me the world of good, I really thought about it. How did people go on in the 1800, 1900, when there was no surgery about. What happened to them did they die or servive them years, evan in the Roman years. We did not have if any throut cancer. There was no technogy like we,v got theses day it's something I think about. Sergerns have saved a lot of lives don't you think so miss Bickford. The talk done me the world of good. My writing not so good Im afraid. Thank you.
>
> 03/03/2011
> If they can transplant Hearts kidneys why can't they transplant VOUCE BOXES. As I said I spoke to people in my town about cancer of the throat what they???? (feel sorry) me with a hole in the neck as they say it happens to people it could to them too. Why be ashamed of a little thing like that if it saves lives OK
>
> 03/03/2011
> Problems with throught cancer is when you had it removed it leaves plenty (?) of work to do to cope with it afterwards but we seem to get over all that why we after we are home to clean it every day because we can't blow our noses or bring it up from the mouth so everythink comes from the hole in the throat first thing in the mornings are difficult because we have to poke and prod to clean whats ever there but its a way of life I think we all cope pretty well at the end of all [sic]

### 4.3.3   Researcher's field diary

I maintained a field diary throughout the duration of the study. I recorded my reflections and interpretations about what I observed in the field and during data analysis (Hennink, Hutter, & Bailey, 2011). I wrote an entry after each interview, which was a useful reference during in-depth analysis of earlier transcripts and my observations at the time of the interview. Entries usually contained information about the interview's timing and setting, and observations about the participant and the interview process. I made notes to myself to follow up on particular ideas in future interviews and the analysis, and wrote a few entries related to general discussions I had with colleagues and my supervisors about the study. I used the diary as a reflexive tool to strengthen my interpretations and approach to data collection and analysis, and to guide my reflections. The following extract was a field diary entry I made after interviewing Len, 75. This was an early interview where themes related to communication and self-identity re-emerged.

Another reflexive observation I made when interviewing Len was that his TE speech ability was not as proficient as the first two participants. I compensated for his delayed or unintelligible responses by trying to anticipate what he was trying to communicate. In subsequent interviews with IWL, I tried to provide more time for responses. This was an important observation because it related to two important emergent categories: Category 1, 'Having self-expression, related competencies and roles change'; and Category 2, 'Navigating and negotiating interactions and situations'.

### *4.3.4 Verification methods*

Member checking is a method of researcher triangulation (Liamputtong & Ezzy, 2005). I used it in different ways throughout the study. The primary purpose of using member checking was to verify and check participants' and my understanding of certain themes and concepts emerging from the data. In Stage 1, I gave participants the verbatim transcripts of their interviews to verify that what was recorded and transcribed was an accurate representation of the interview. In Stages 2 and 3, I sent participants comprehensive thematic interpretations to verify that what was recorded and transcribed was an accurate representation of the interview. I also gave participants the choice of reviewing their verbatim transcripts. This variation in approach reflected four things:

1) no queries were received from Stage 1 participants with regard to the interview process or the transcript

2) sensitive material had been disclosed in interviews and to provide a transcript in paper or electronic form without confirmation from a participant had the potential to breach a participant's right to confidentiality

3) the thematic interpretations enabled participants to see how the data were being interpreted across the study, rather than a single individual's contribution

4) the theoretical sensitivity of themes could be assessed by broadening the exposure of the thematic development for Stages 1 and 2.

Each participant was given one month after receiving the transcript or summary interpretations to return any changes or suggestions. No queries or requests were received.

I used the in-situ checking technique in all interviews to ensure that I had interpreted comments accurately. In the later stages of analysis, I went back to a participant to discuss the plausibility of certain categories and themes to further evaluate constructed meanings and clarify my interpretations. Extraneous to the interviews, other researchers were invited to interpret and thematically code several of the in-depth interviews and Stage 1 participant journals. Finally, during Stages 2 and 3, I met regularly with another research higher degree student using similar methodology. We coded together and ended each session with a discussion about our analysis and the plausibility of our interpretations.

### 4.3.5   Socio-demographic information

At the end of each interview, I invited participants to complete a socio-demographic form. Although the form was tailored for each stage, there were similarities. Appendix 8 has an example of the form used in Stage 2. The form asked for information about date of surgery, age, country of birth, marital status, number of children, country of origin, languages spoken/ ACMs used, SES, level of education, employment status and familial history of cancer. The socio-demographic data collected has been presented earlier in Chapter 3 under subsection 3.6.2 related to sampling techniques.

### 4.3.6   Data management

A number of data-capturing approaches were used during analysis. Coding was completed manually on paper and also using Nvivo qualitative data analysis Software versions 8, 9 and 10 (QSR International Pty Ltd. 2008, 2010, 2014). Both systems have been useful in assisting with management and interpretation of the large volume of data generated. Hard and electronic copies of the coding trees have been maintained for audit purposes and ongoing data analysis.

## 4.4  Data analysis

In the study's early stages, responses were coded using the open coding, axial coding and core category analysis continuum in the grounded theory approach outlined by (Corbin & Strauss, 2008). However, during the study's later stages, this approach changed to follow the constructivist grounded theory coding and analysis method described by Charmaz (2003, 2014). This approach was iterative and accounted for the investigator's role. It was similar to the former approach in that it began with initial coding and advanced to focused coding and category development. Constant comparative analysis was used throughout this data analysis method (Charmaz, 2014).

### 4.4.1   Initial coding

The first stage of data analysis involved line-by-line provisional coding of each verbatim transcript and journal, and was always completed prior to the next interview. Codes were kept brief and specific (Charmaz, 2014). In the early stages, closeness and openness to the data were achieved initially by identifying and naming themes or topics and using invivo coding (Corbin & Strauss, 2008). This approach was later modified in the study to use invivo coding and gerunds for themes (verbs functioning

as nouns with the suffix -ing) to preserve participant voice, actions, and social or psychological processes (Charmaz, 2014). Appendix 9 is a sample of line-by-line coding using gerunds. Straussian questions related to what is going on and why it is occurring were also used to elicit new ways of viewing the data (Grbich, 2007). These questions helped me to seek out unexpressed assumptions, describe underlying processes for actions and constructions, identify the significance of specific ideas, compare data sets and note data omissions (Charmaz, 2014). The iterative nature of this approach also enabled flexibility to revisit and refine initial codes. Coding in these ways enabled strong representation of participants' meanings and experiences as they related to the phenomena at hand.

Finally, I held a reflexive stance whilst coding, acknowledging that my past experience may influence my interpretation of the data, as explained in the previous chapter. This awareness enabled me to view all data as if unfamiliar and new. I also avoided introducing professional terms into the coding at this early stage of analysis, choosing instead to represent a participant's account as authentically as possible. For example, many IWL described their quest to find out what was wrong with them. They reported that it often took a long time, which was contrasted by the sudden actions that took place once they received a diagnosis. The medical literature often describes this as the pre-diagnosis or pre-operative stage. Being guided by the data, I initially labelled this stage 'Getting the diagnosis'. It became apparent that this was an important feature of the experience and that this code related to others.

### 4.4.2   *Focused coding*

The next phase of analysis involved focused coding. The emergent initial codes were synthesised to form larger conceptual groupings, thus elucidating theoretical directions in the data (Charmaz, 2014). Again my involvement in the analysis was considered, and I questioned the properties and conditions for emergence of each code. In some instances, initial codes were found to have theoretical sensitivity and were elevated to focused code status. For example, in Table 8, the initial code 'Getting the diagnosis' was grouped with a number of codes and elevated in part to the focused code level. I later came to describe it as subtheme 5.2, 'Questing and diagnosis stage'. This subtheme formed part of Category 5, 'Timing and stages of the TL journey'. By using the descriptor 'questing', I was able to explicitly represent the embodied experience of the IWL and primary supporter participants.

**Table 8: Theme development**

| Initial code | Focused code | Category |
|---|---|---|
| • Getting a diagnosis<br><br>• Waiting<br><br>• Having treatment<br><br>• Experiencing persisting symptoms<br><br>• Feeling concerned (scared)<br><br>• Being tested<br><br>• Getting the news | • Questing and diagnosis stage | • Timing and stages of TL journey |

In my endeavour to ensure constant comparative analysis, I examined interview accounts, participant journals, field diary entries and initial codes. I compared data sets and looked for explanations and concepts in large segments of data. In the study's early stages, I used axial coding to relate categories (concepts) to lower level codes or categories, and represent how they were related using a coding tree diagram. Later coding involved a more iterative and emergent approach to analysis.

### 4.4.3 Category development

Categories began to emerge as the analysis advanced. The data moved from a descriptive to an abstract level. Charmaz (2014) describes this as "the analytic step of selecting certain codes as having overriding significance or abstracting common themes and patterns in several codes into an analytic concept" (p. 341). Each of the categories has subthemes, which define their category and relate to one another to provide a comprehensive picture of the TL experience from multiple perspectives. An explanation of how this occurs is given in the next chapter). By maintaining codes and categories as processes and actions, I attempted to capture the participants' embodied experiences. This in turn prompted me to ask probing and critical questions about the data.

Refining categories involved changing the properties and names of some to better reflect the empirical data. For example, early in the analysis one category was called 'Operationalising supports in response to need'. However, this category excluded the role of a primary supporter and other supports, and centralised the role of health professional support. The data indicated that health professional support was

just one aspect of support required by people recovering from a TL. I then determined two possible category names; 'Having complex care needs' and 'Receiving external support'. I opted to merge these as 'Being supported' because again it was more inclusive of the role of a primary supporter and other supports. It also maintained the focus on the individual at the centre of the experience.

### 4.4.4  Concurrent methods of analysis

Theoretical sampling was a strategy used to achieve theoretical saturation or theoretical sufficiency. I sought "people, events, or information to illuminate and define the properties, boundaries, and relevance of the categories" (Charmaz, 2014, p. 345) to achieve theoretical sampling with the categorised data. I also evaluated and re-evaluated the emergent themes in later data collection phases to achieve saturation of some themes. I used theoretical sampling of relevant data throughout all stages of category development to develop the substantive theory. This enabled me to elaborate and refine the categories until no new properties emerged, and facilitated the discovery of variation within a category or process as well as promoting more explicit and concise theory development (Charmaz, 2014)

In conjunction with theoretical sampling, I made comparisons within and across analytic stages (raw data, coding, categorisation and conceptual development), thus moving from description to abstract theory development. In addition, I treated recurring interview statements as theoretically plausible (Charmaz, 2014). These statements were visited many times and guided both theoretical sampling and category development. For example, several of the primary supporter participants described how they were very concerned in the early stages of their loved one's recovery and the level of care they received. They described how they stayed at the hospital for long periods and frequently completed care duties. I initially coded this as 'supervigilance', but noted that the ongoing dependence and need for support meant the primary supporters' care role continued after discharge and for many years after the surgery. The process of 'Being there' represented the whole experience and became an important subtheme of Category 6, 'Being supported'.

### 4.4.5  Memo writing

A significant part of the analysis and interpretative process involved memo writing, which I facilitated using cluster diagrams to make connections, see relationships, and

generate ideas and insights (Charmaz, 2014) from categories or themes. Memo writing helped me explore the properties of each category or theme, deepen my analytic decisions and check the empirical data supporting each category or theme's theoretical sensitivity. Opportunities for reflexivity and evaluation of preconceptions also occurred through memo writing. For example, Figure 7 represents the cluster diagram I did prior to writing the memo called 'Confidence', which appears on the next page. The memo contains the elements generated in the cluster diagram.
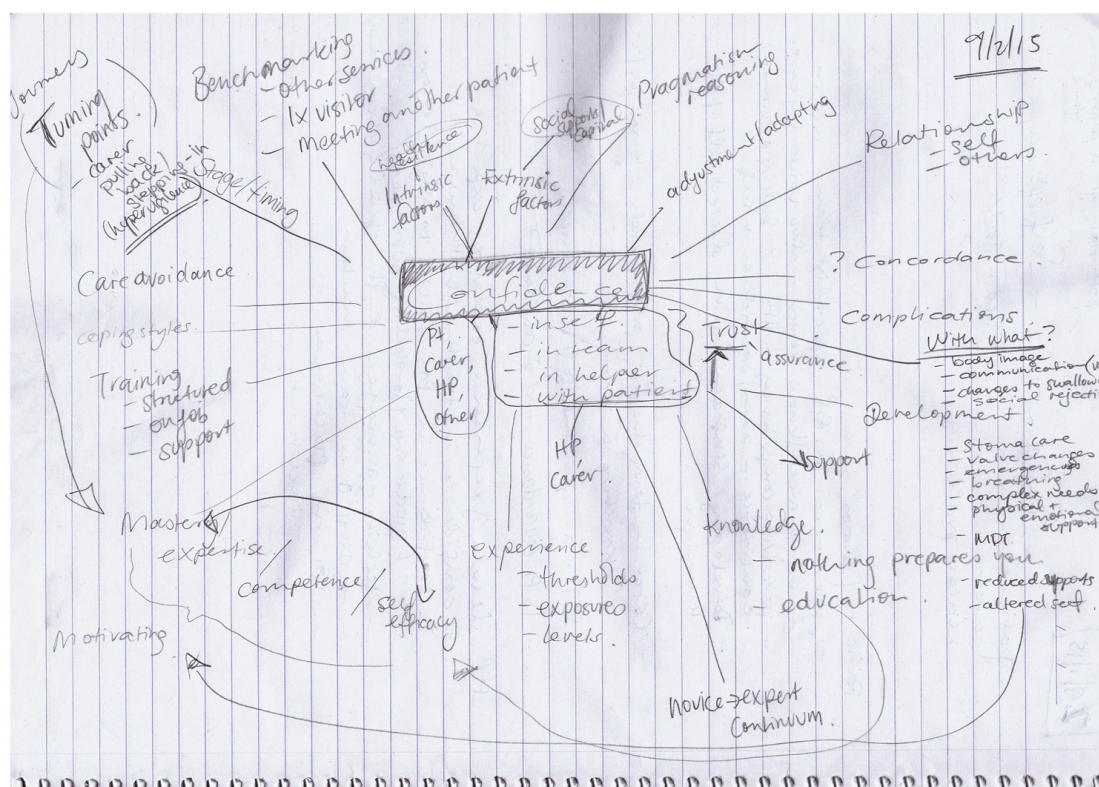


**Figure 7:    Cluster diagram**

The memo was written during the analysis. It was important because it supported both my reflexivity and theory development. I later developed the theme of 'confidence' much further and it became an important part of the multidimensional aspects of 'competence' reflected in the six categories to emerge from the data. These categories are further described in the next chapter.

*Memo:* **Confidence,** *mapped and memo 9ᵗʰ February, 2015*

Key words/phrases: Experience, Knowledge, Guidance, Expertise, Exposure, Competency, Development, Trust, Relevant to all; patient, carer, HP, Threshold of experience/exposure, Benchmarking e.g. lx visitor, meeting another patient, with other services, Care avoidance, "Nothing" prepares you, Pragmatism/reasoning

Confidence is a theme or concept cutting across the patient, significant other (SO) and health professional (HP) experience. It relates to having confidence in oneself, in the team, in the helper, in the loved one and in the patient. It can be viewed from multiple standpoints and is an important part of the total laryngectomy (TL) experience. It also signals the need for support or for development of skills. All report that education is important but that nothing prepares them for the first experience. Trust and assurance assists with developing confidence. To be able to build trust and to provide assurance/guidance a health professional needs to be able to display competence and expertise. There is a novice-expert continuum reported by HPs where in-depth knowledge, exposure and thresholds of experience with laryngectomy care assists development. Structured, on the job training/support is the preferred way to acquire the relevant skills. Experienced HPs are able to adjust and adapt their care to a range of situations and patients and can provide support to patients with both physical and emotional care needs. They can also mentor and train inexperienced HPs; who can avoid caring for a laryngectomy patient if they feel out of depth. Professional confidence is observed by patients and their SOs, as is lack of confidence and this often equated with competence. Confidence instils confidence in them and this is important during an uncertain and emotionally provocative time. Patients and their partners trust the MDT to suggest the right treatments to assist them with managing their health crisis. Very often, there is little time to make decision with rapid response intervention the lifesaving choice. Understandably, shock and grief are experienced but people often have very little time to fully comprehend the veracity of the situation or the changes that are about to occur. HPs must be pragmatic and reasonable in their practice to allow for the emotional experiences of the patient. The relationship between the patient, SO and HPs are really important foundation for the experience. HPs can predict and plan their care by using clinical reasoning and their experiences of other patients.

During the patient treatment journey there are common experiences e.g. waking from anaesthetic with tubes and not being able to talk, breathing and coughing through the neck, communicating the first time via gesture or writing, acquiring alaryngeal communication, learning to care for the stoma, being heard/verbal again but with a different voice, eating again, going home. Developing confidence with the physical changes and needs e.g. appearance/body image (stoma, neck and teeth), alaryngeal communication, neck-breathing, eating, stoma care takes emotional effort and adjustment to the altered self. It can take time to build confidence and there is an increased demand on SOs to bear the burden of the adjustment in the early post-operative recovery phase. SOs are often proactive and hyper-vigilant in the early stages even when they are experiencing their own uncertainties and emotions. The gathering of knowledge about the TL is often haphazard rather than by design. This may reflect the readiness of SOs to absorb the information. Initially the anatomical changes and needs are daunting for SOs but education and support does assist with the development of confidence. As SOs see their partners develop confidence they pull back and allow the reestablishment of independence.

There are some reports that there are turning points in patient journeys and these may relate to the progress of recovery, complications, extrinsic factors such a patient's social supports/capital and intrinsic factors such as the a patient's health and resilience. Confidence is strengthened with mastery and self-efficacy. It is also motivating to a patient. It can be a bit shaky/uncertain without benchmarking e.g. meeting a laryngectomy visitor, or another person who has had the procedure or for HPs comparing the service with another service or work shadowing a more experienced clinician. Confidence building is part of a deliberate strategy to facilitate discharge. Self-care and stoma management is an important skill for individuals who may be faced with an emergency or reduced supports. There is a trend for female partners to maintain an active role in assisting patients with these things; however, mental wellbeing seems to be facilitated when independence is optimised. Independence comes with confidence.

### 4.4.6 *Conceptualising the substantive theory*

The development of the substantive theory *Validating the altered self after TL*

involved conceptualising the six theoretical categories that emerged from empirical

data. These categories became the underlying concepts of the substantive theory. I used extensive integration techniques such as "theoretical sorting" to achieve this level of conceptual understanding (Charmaz, 2014, p. 217). I also organised the focused codes and theoretical memos into a visual representation by placing them on a large wall. This enabled me to develop and change ideas, and led to further revision, the forming of theoretical links and memo writing (Charmaz, 2014). This resulted in making some implicit links explicit. It also highlighted the properties of categories, and their relationships to each other and the core concept. For example, in my initial configuration of major categories and concepts I positioned the categories 'Timing and stages of the journey' and 'Being supported' as the first two categories in the coding tree. However, subsequent analysis and visual representation made it clear that these categories related to context, and that central to these phenomena were 'Having self-expression, related competencies and roles change' and 'Navigating and negotiating interactions and situations'. I moved these categories to the beginning of the sequence.

This approach facilitated the consolidation of my ideas and guided me to go back to the raw data to find evidence to support my tentative conceptual understanding. I refined these categories further and two other categories emerged; 'Developing competence' and 'Building resilience'. The overarching social phenomenon *Validating the altered self after TL* emerged from subsequent analysis as the core concept and central to the TL experience. This is discussed further in the following chapters.

## 4.5 Conclusion

In this study, the approach to data collection and analyses secured a broad range of perspectives, and ensured that participants' voices were respected and dominant in all aspects of the data. The range of grounded theory methods and techniques used for simultaneous data collection and analysis assisted with developing the data from a descriptive to theoretical level in relation to furthering our understanding of the TL phenomenon from multiple perspectives. The following chapter provides the categories and their properties that emerged from the data. This is further expanded as a substantive theory of *Validating the altered self after TL* in Chapter 6.

# 5 Findings: The total laryngectomy experience from multiple perspectives

## 5.1 Introduction

This chapter, presented in three parts, presents the findings related to the data collected about the TL experience from multiple perspectives. The findings are represented as six categories and their subthemes. An overview of these categories and subthemes is provided as a coding framework in Figure 8 (see next page). Each category and its subthemes have emerged from the data as discrete codes. There is, however, considerable overlap between them. Each category has distinct properties, which are discussed along with their relationship with the other categories. All categories have been clustered into specific domains to represent three main areas – the phenomena, the processes and the context – as highlighted in Figure 8.

Each domain is reflected in one part of this chapter. Part 1 represents the phenomena and contains Categories 1-2. Part 2 represents the processes and describes Categories 3-4. Part 3 represents the context and contains Categories 5-6. Further interpretation, conceptualisation and presentation of a substantive grounded theory related to the psychosocial needs of a person who undergoes TL is provided in Chapter 6.

## 5.2 Coding

The narratives in this study reflect a range of perspectives about the TL experience and the psychosocial needs of IWL. The categories emphasise the significance of physical, practical and emotional loss of self-expression, and the subsequent reframing of the self after TL for the IWL. The active role the IWL demonstrated in trying to make meaning of their changed circumstances was strongly evident in the data. It appeared that knowledge and skills, but also time factors, were crucial in assisting the IWL to accept their situation, and feel valued and understood in social interactions. The categories also highlight the important roles of competent and holistic care, positive interactions, social support and adequate resourcing for the IWL and primary supporter participants. In the following section, I discuss each of the major categories and their related subthemes. Quotes from the data are provided to maintain the participants' voices. A summary table with additional data representative of each subtheme is provided at the end of each category section.

**Coding tree with categories and subthemes**

| | |
|---|---|
| 1.1 Difficulty expressing self | |
| 1.2 Losing the pre-laryngectomy self-identity | 1. Having self-expression, related competencies and roles change |
| 1.3 Remaining dependent | |

| | |
|---|---|
| 2.1 Evaluating personal competence (communicative and other) | |
| 2.2 Responding to reactions of others | 2. Navigating and negotiating interactions and situations |
| 2.3 Exerting control | |

| | |
|---|---|
| 3.1 Becoming aware | |
| 3.2 Learning skills and troubleshooting | 3. Developing competence |
| 3.3 Teaching others | |

| | |
|---|---|
| 4.1 Coping with losses and challenges | |
| 4.2 Having mixed feelings (grateful, responsible, overwhelmed, resigned) | 4. Building resilience |
| 4.3 Resuming meaningful activities | |
| 4.4 Finding purpose | |

| | |
|---|---|
| 5.1 Timing in life | |
| 5.2 Questing and diagnosis stage | 5. Timing and turning points in the journey |
| 5.3 Transitioning stage (early and late) | |
| 5.4 Persisting need stage | |

| | |
|---|---|
| 6.1 Getting competent care | |
| 6.2 Perceiving holistic care | |
| 6.3 Having social capital | 6. Being supported |
| 6.4 Being there | |
| 6.5 Resourcing and awareness | |

Phenomena

Processes

Context

**Figure 8:   Category coding framework**

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### 5.3    Part 1: The phenomena

### 5.3.1    *Category 1: Having self-expression, related competencies and roles change*

This category appeared to be central to the phenomena of the TL experience. The narratives from all participants supported the notion that a TL interrupts and destabilises identity, competencies, roles, plans and routines formed by the pre-laryngectomy self. There was strong evidence that all IWL found the surgery sudden, disorientating, distressing, shocking, disaffecting and alienating. Due to the timing of data collection, it was difficult to ascertain the length of time people experienced these feelings. It appeared that they were heightened in the early transition stage and remained difficult in the late transition stage (refer to Category 5). However, for a small number of participants, feeling distressed, disaffected and alienated was still part of their lives many years after their surgery.

The data suggest that changed self-expression and related competencies resulted in IWL suddenly becoming dependent on others. This reliance persisted in many cases. The difficulties with communication also resulted in difficulties expressing their feelings at a time of immense change and turmoil. IWL had to navigate their post-laryngectomy lives differently. They often felt vulnerable and guarded about their altered self-identities in the face of poor understanding or empathy by others. These important themes are explored further in Category 6. It appeared that other people often questioned the identity of these IWL. This was particularly evident when communication and physical changes resulted in gender confusion or stigma. The data suggest that acceptance and capacity to re-engage after TL is related to the extent of disruption to social roles and the individual's capacity to build resilience, develop competencies and feel supported.

#### 5.3.1.1 *Subtheme 1.1: Difficulty expressing self*

Many participants across the different data collection stages identified this subtheme. The IWL stated that they were not able to interact with their loved ones in their customary and familiar way. This subtheme is closely linked with subtheme 1.2 (losing pre-laryngectomy self-identity). There is overlap between loss of self-expression and experiencing an altered self-identity. However, it was important to maintain this specific subtheme to represent the extent to which difficulties with self-expression impacted this group of IWL over time. For example, they described the

difficulty and vulnerability they experienced in the initial stages of recovery when they could not speak:

> *I remember being in intensive care. I couldn't talk, I couldn't communicate, I couldn't write, I couldn't do anything, and laying there, tubes coming out here and I think my bladder, everywhere and nobody spoke to me and said "Well blink your eyes once for 'yes' two for 'no'", "Do you feel this?" "Do you feel that?" No one! They talk over you and I was lying there paralysed ... and... because I had been bleeding... it had obviously run down the back and my hair was full of blood and it was sticking to the pillow. You know those horrible plastic pillows ... it was warm, my hair was stuck to it. ... Not that they would have known that but if they would have said, "Are you comfortable? Blink once for 'yes', and one blink to get help". Lyn, 63*

The narratives highlight the lack of understanding from health professionals about the loss of verbal expression experienced by IWL. Importantly, the stories represented experiences of poor extrinsic validation from others immediately after the surgery. These issues are further highlighted in Category 6.

The primary supporter and the health professional participants appeared to have some awareness of the vulnerabilities experienced by IWL. There was evidence that the primary supporter was a key ally and advocate in the early stages, particularly when the IWL was non-verbal. However, this role may have continued, particularly in relation to using the telephone:

> *Well, to give them support because, you know, they're scared. One minute they've got their voice, the next minute they haven't and it's very scary. Rachael, 53 partner*

Valerie, 74, described how her husband was very supportive during her time in hospital and that he was always there to help and communicate on her behalf:

> *All I did was write on a thing. Colin never left my side ... so he did all the communicating. I didn't do any. I communicated to him and he would communicate to the nurse so really I never had any length of time alone.*

In the early stages after surgery, most of the IWL reported that they used pen and paper to communicate. However, many issues were identified with this. Further discussion regarding the burden this placed on primary supporters and others is provided under Category 6, subtheme 6.4.

The health professional participants highlighted the difficulties with communication. Edward, the surgeon, explained how interactions with patients after the surgery were challenging:

> *Well for us, it's frustrating for us too because we've got to wait for them to write and, you know, surgeons are busy. We don't have time – you know, we don't have enough time to wait half an hour for them to write up all the things they want to tell us.*

This important issue is further explored in relation to competent and holistic care in subthemes 6.1 and 6.2. It again highlights the extrinsic validation a health professional can bring to interactions with IWL.

Many of the IWL described ongoing difficulties with their audible ACM and how this affected their communicative competence. For example, when I interviewed Hugh, he frequently needed to cough and this was very tiring for him. He said that even four years after his surgery he had to *speak in short segments because it just becomes really tiring.*

Brian, 59, also reported he experienced disrupted ability to communicate, particularly in the first six months but his breathing issues have improved. The unreliability of their audible ACM meant that this group of IWL could no longer express their ideas and themselves as they were used to. Pieter, 61, articulated this well:

> *I can't stand in front of people and lecture. Tomorrow, I wouldn't be able to hold this conversation, so that affects my ability to get the message out. From an intellectual perspective, [I'd] probably handle the job quite well. I'm not sure that it's practical….*

The IWL reported that problems with their audible ACM could occur daily, at a specific time of day or intermittently every few months. TE speakers described prosthetic valve maintenance as a significant and debilitating issue, with the valve regularly getting blocked. They reported that this made conversing very challenging. Coupled with a different sounding voice quality, this meant they avoided talking on the phone, in noisy environments, at shops, to strangers or even in familiar company. On several occasions, this was described as a frustrating experience and difficult to accept.

In addition to poor reliability, a few of the IWL reported they also had breathing difficulties that were hard to conceal. Some of these participants described how they experienced disruptive coughing episodes when socialising or in public places. For example, Len, 75, said that even though he coughed less he still experienced airway irritation. He said he managed this by removing himself from social situations and carrying a *hip flask of sherry*.

The data suggest that another impact of altered verbal expression is the ability to express feelings to others. For example, Jack said that after his surgery he could not communicate verbally for over 10 months. He commented upon how difficult it must have been for his partner because he could not express his feelings. However, he

mentioned that he had not really thought about it until the interview. In a similar situation, Valerie said she had not told her husband that it was difficult for her to say goodnight to him when she was lying down. She described how her communication limitations affected her intimacy with him:

> When you go to bed you'd lie there, and ... you might just say, "Goodnight darling I love you", but I can't ... Even to put your thumb up to talk, when you are lying down, it is very difficult to try and talk. You can't communicate ... because of [the] airway.

The primary supporter and health professional participants appeared to be concerned about the emotional toll for IWL due to not communicating one's feelings, particularly in the early stages of recovery when coping with their communication difficulties. For example, senior social worker Helen said:

> With the writing they probably don't talk as much as they normally would if ... they had a larynx, because it's too hard ... [and] it's too embarrassing. That would tend to make people a little bit withdrawn because they're not expressing themselves to the same extent.

Fay, 77 (partner), was one of several female primary supporter participants who expressed her concern that her loved one did not express his feelings well after the event of having the surgery:

> I since have learnt to be more patient because even though he can speak now he is not that vocal and he doesn't express his feelings, and therefore I know... it's eating him up inside at times.

Even though Lyn reported she was often upset, she said that she chose not to show her feelings to her brothers and sisters because she had always been seen as the one in control. It appeared that Lyn experienced conflict over this because she indicated she wanted more empathy and expressed her need to be appreciated, but said she did not want to show her emotions to her family.

Another important aspect to this theme was that the IWL reported that heightened emotions could often disrupt their communication. The female participants reported this difficulty more commonly. Valerie, Lyn and Kath, 72, described the difficulties they had talking when they were emotional. Both Valerie and Lyn appeared to be competent TE speakers, but described difficulties with the reliability of their TE speech when they became emotional:

> It is impossible... when you cry. You will see I have got all these tissues here because you end up with ... phlegm and your ... nose runs. It is just too hard. So it is easier not to cry. That is unusual for me. I'm very good at turning on the tears. Well, I used to be. Valerie, 74

Lyn said that on a number of occasions she'd had panic attacks, rendering her TE speech ineffective. She described how this happened from time to time, and recalled the time she was in another city trying to catch a train and panicked because it was unfamiliar:

> *... I froze and I was scared because I couldn't talk to anybody or ask anybody and that was a panic attack that was real. ... It is a Catch-22 because you can't talk, you freeze and you freeze because you can't talk.*

Kath, who used EL speech, had reduced proficiency using her electrolarynx. She also described the experience of not being able to express part of herself when she was angry or excited whilst barracking for her football team, and this upset her.

Another form of self-expression perceived by the IWL and the primary supporter participants was swallowing competence. Swallowing difficulties appeared to affect perceived quality of life and provided another source of social difficulty or tension with health professionals. All participants expressed some concern when an IWL's swallowing abilities did not their match expectations. For example, Rachael (partner) reported that her husband was not content until he had tried to eat steak, even though health professionals had told him he would not be able to manage. She also reported she changed her own eating patterns and pureed her food because she didn't want him to see her have an ordinary diet. Stories such as these were not isolated. Several participants reported that they could not eat and drink whilst trying to communicate. This impacted them negatively in social situations because they liked to go out to cafes, restaurants and *pubs* to socialise. Annie, 65, said her voice prosthesis often leaked and made her cough so she avoided eating out. Rose, 65 (partner), described her husband's frustration regarding continual enteral feeding.

Similarly, Mary, 75, said she would not go to the dining hall in her care facility because she said *with my PEG that would be embarrassing.* Pieter reported that he was tired of receiving advice that he needed liquid supplements and the dietitian reported that she felt there were *compliance issues* when IWL did not always follow her recommendations.

The data support altered swallowing ability as a loss of personal self-expression that was keenly felt by many of the IWL. Issues arising from this are also explored in subtheme 2.3 and Categories 3 and 4.

Many of the IWL reported that their changed appearance had impacted them socially, and affected how they felt about themselves and their self-identity. They

described being shocked by their post-operative appearance, avoided looking at themselves in the mirror or avoided some interactions. They described the lengths they took to reshape their personal style, which appeared to be another form of validation where intrinsic and extrinsic factors were interconnected. The loss of appearance was symbolic of a loss of pre-laryngectomy self-expression. For example, Annie said she had *horrible marking* from the radiation to her neck. She said she had her teeth removed at the time of the surgery and recalled her reaction:

> *When I come around to my senses ... I couldn't talk and they gave me a pad and I said, "Bloody lovely. Wake up with no teeth and a bloody big hole in your neck".*

When I interviewed Lyn, she was nicely presented and had her hair tied back. She described how she avoided looking at herself in the mirror and how she had to change her clothes because of weight gain. She explained that she needed to have clothes to cover her neck and that this changed her appearance. Valerie also mentioned she made clothes with a high neckline. Lyn later said that she had lost interest in her appearance. Both women described how their altered appearance had limited their personal self-expression. Kath, too, described an alteration in her personal taste and expression, but appeared to be less affected by it:

> *My taste in colours has changed as well. My favourite colours were green and purple, have gone to yellow, orange and pinks ... My taste in foods has changed, I have [also] got rid of a lot of clothes and found what I am buying are totally different to what I would have once ware. Journal entry*

Christopher explained that his stoma made him feel vulnerable. He showed me the silver plate stoma cover he had made. It was engraved and highly personalised. He said he tried to make light of his appearance but had deliberately grown his hair to cover his neck scarring and disfigurement:

> *Firstly, I'm so ashamed. Then I trick myself with this wise sentence, "Holey Man, Holey man. Holey and Holy", and I said ... "I have additional hole in me, I'm a very original". But I still don't want to show this because a lot of muscles were cut in ... of my neck.*

Valerie's appearance continued to trouble her. She made decisions about whether to interact based on how she felt about her appearance. When asked about her neck she said:

> *I hate it. ... I don't think ... I'll ever, ever actually get used to it ... maybe I'm just a bit too proud because my sister will often send me a message on my mobile phone or on Skype and I will go and look in the mirror and see what I look and I think, "Yerk". So I won't bother. I would just ignore it.*

There was strong evidence from the accounts that significant psychosocial and

relational issues were connected to not being able to express oneself in the same way after a TL. The persisting issues with communicative and swallowing competence as well as appearance seemed to relate strongly with levels of social participation and acceptance of the altered self-identity. This subtheme highlights the constraining factors a TL has on developing competence and building resilience, particularly when comparing oneself with one's pre-laryngectomy abilities. The following subtheme further highlights the link between self-expression and loss of self-identity.

### 5.3.1.2 Subtheme 1.2: Losing the pre-laryngectomy self-identity

There appeared to be multiple issues related to this subtheme. As discussed in the previous subtheme, issues related to communicative and swallowing competence, and appearance seemed to collectively impact a person's sense of identity over the trajectory of the TL journey. Other forms of self-expression, such as social roles and occupation or work, are discussed here.

Many of the IWL described how their changed voices and communication abilities had impacted them socially and in their pre-laryngectomy roles. For example, Hugh said he used to enjoy going to the pub but did not do this now due to his communication difficulties. In other narratives, the role of being a grandparent was affected for a number of participants. Valerie said she stopped baby-sitting because she could no longer read to her grandchildren. She appeared to turn her criticism on herself, stating that her pride was the problem:

> *I used to do lots of babysitting, housesitting ... I dropped off from that because it upset me. I couldn't read bedtime stories like I used to. Pride is a terrible thing.*

This was similar for Mary, 75, who reported that her relationship with her grandchildren had changed. She said she didn't like to speak on the telephone to her grandchildren who lived inter-state and that her other granddaughter *is frightened* of her. She then qualified:

> *She is very shy. ... we used to have a lovely relationship, her and I. We used to dance and sing, but not anymore. She is really shy about it all. (She doesn't understand.)*

Several of the primary supporter participants described how their partners had lost friends or acquaintances, and felt excluded or rejected. Tom, 36 (partner), reported that his wife had *lost a lot of friends* after her TL. He mentioned the isolation his partner experienced in social gatherings *because she can't speak and people can't hear her, she tends to be left in the corner.* Similarly, Rose (partner), who lived in a

country town, found that since her husband could no longer drink like he used to, he also became more isolated. She said *he might have one beer and it takes him forever.* She then described how this change resulted in social rejection:

> *If you don't drink you're sort of on the other side of the social thing. You're like an outcast if you don't go to the pub and drink. Some of the people he used to socialise with at the pub don't talk any more, … they isolate themselves from you because he's not one of the boys any more. It's a bit sad really but you find out who your friends are.*

Rose later remarked that her husband had experienced acceptance and understanding from others, and that this was validating for him. I interpreted that it was also validating for her. She said that he liked to go to the bowling club because *he'll chat with the guys* there and *he enjoys their company and they understand.* She reported that she and others *have no problem understanding him, he talks quite clearly.*

Cilla, 68 (partner), also described a dramatic change to her social life. Whilst she tried to continue socialising, she had noticed a big change in her partner Len. She thought that friends had stopped coming to see Len because they couldn't *handle the whole picture.* However, she found that other people, such as her friends, had accepted him.

There were, however, examples where other people had become more friendly and accepting. Contrasting with the above experiences, Brian described the acceptance and familiarity he had in his local country town. He described how he was determined to resume his pre-laryngectomy lifestyle and friendships. However, he voiced that there was a continuum of normality. Similarly, Christopher distinguished between what he described as *normal* and *not normal.* This perception was articulated by most of the participants. It highlighted the issue of personal acceptance or intrinsic validation, and that of the acceptance by others or extrinsic validation.

Another experience reported by both male and female IWL was having their identity questioned due to gender confusion. It occurred frequently for women due to the low pitch of the prosthetic voice and because a TL is typically associated with men:

> *Oh, I rang up for some cosmetic [sic]… and she said, "Get a life you stupid man". And I felt like saying … but she hang up. Annie, 65*

However, Christopher and Pieter, 61, reported that they had lost weight and their *slim* neck shape had also created gender confusion and associated embarrassment. These participants appeared to be bemused that their masculinity was being questioned.

Pieter said he had also been mistaken for being female on the telephone. He said *I get called Miss or Missus or Madam on the phone.* Public perception and general awareness of TL and its causes were important extrinsic validating factors described by this group of IWL. I explore these further in subtheme 6.5.

The IWL also described how the timing of the surgery in their life was important. It affected some participants' capacity to continue working; in fact, very few returned to their old jobs due to the demands on verbal competency. Pieter had been a busy executive working for an international company. His TL had resulted in his semi-retirement. It was unlikely he would return to his job because he was required *to communicate with high-powered people, executives, lots of meetings, lots of briefings.* Now he was unable to rely on his verbal communication due to phlegm build up.

Helen, senior social worker, discussed the issue that many individuals have poor social connections and find meaning through their work. However, returning to work after the surgery was often difficult due to their communication impairment. She described the lengths she went to assist one of her patients who was *frustrated that he couldn't get back to work.* This is further explored in subtheme 5.1, 'Timing in life' (see section 5.5.1.1). It seemed that the importance of this subtheme to this group of IWL related to role disruption, changes to self-expression and to what extent they perceived there was a detrimental difference between their pre- and post-laryngectomy self-identity. This subtheme is also closely tied with subtheme 1.1 and all the other categories. It also appeared to be central to the phenomena of reframing the self after a TL.

### *5.3.1.3 Subtheme 1.3: Remaining dependent*

This subtheme highlighted the persisting loss of independence the IWL experienced due to their communication, breathing, and possible swallowing or physical difficulties. The issue of remaining dependent appeared to impact mood and the relationship between IWL and their primary supporters. A number of the IWL reported that breathing problems caused them concern and sometimes were a safety issue. For example, Len had experienced a lot of airway management problems and said he feared that plugs of mucous would suffocate him. However, the situation had improved and he was proactive about using the ventilator.

Lyn experienced a time when she was not able to explain her situation to

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security guards at a Paris airport. Her sister and niece left her with their bags and went to the toilet. Lyn could not answer the guard's questions. This experience also highlights Lyn's realisation that other people don't perceive her difficulties or empathise with her situation. It was the experience of travelling with her sister and niece that made her more aware that her post-laryngectomy abilities were significantly different to her pre-laryngectomy abilities, and she was much more dependent on others:

> I was sitting looking at all the suitcases, because this was just after 9/11, the guards over there in the airport wear full guns, they were the real deal and he came over and he wanted to know why I had all the suitcases and where were the [others]... I couldn't talk to him or anything else, and then the other two guards came, so there was three of them there and I was feeling bloody scared and then they came back like nothing has happened, and I blew up then and that's when I told them and they did not know what I'm talking about. [They had] no idea what I was talking about ... So other people don't see it.

Jack described how he had also experienced a scary situation where he had little control. Soon after he was discharged from hospital, he experienced an airway blockage and needed emergency help. The only way he could get help was to write the emergency number on his hand and show his wife. Fortunately for Jack, a district nurse was tending to one of his neighbours and she removed the crusted mucous plugging his airway.

There were other reports of persisting difficulties. Many of the IWL and primary supporter participants described how they had plans in place or avoided being alone for long periods in case of an emergency. However, sometimes things didn't go to plan. For example, Fay (partner) mentioned how she usually cared for her husband's stoma but one day she was out and her neighbour helped. She said, *this was the first time in three years that someone actually had to help him and I wasn't there.* Her husband was only able to communicate through gesture and writing. She said he couldn't clean his stoma and valve because *the trachea has shrunk completely and it is difficult to see the speech valve with a mirror.* She described how her neighbour rang but her husband couldn't talk:

> He tapped on the phone and she came over and she said, "Can I help you with anything?" and he just wrote on this little blackboard that he needs his speech valve cleaning, and she'd never done it before but he sort of painted it on the blackboard for her and she realised what she had to do and I was most grateful.

All participants discussed the importance of the return of the functional activities of talking, breathing and swallowing, as well as the adjustment to disfigurement.

Physical and psychosocial factors impacted the rehabilitation and development of competence in these areas. Acceptance of the altered abilities varied amongst participants. Post-operative complications delayed some individuals' communication rehabilitation and acquisition of an audible ACM. Complications also affected their ability to develop competency and build resilience. Remaining dependent influenced the primary supporter participants and health professionals. This is explored more extensively in Categories 3, 4 and 6.

### 5.3.1.4 Category 1 summary

The following table summarises the issues in Category 1 and its three subthemes. Additional participant statements representative of the subthemes are included.

| *Category 1– Having self-expression, related competencies and roles change* | |
|---|---|
| **Subtheme 1.1 Difficulty expressing self**<br>Loss of self-expression (speech, eating, appearance personal tastes). Unreliable audible communication and experiencing difficult situations | *Sometimes it blocks up, the valve, and I can't say a word, I can't even say, 'I'll ring you back' or anything, I've just got to hang up. Brian, 59* |
| **Subtheme 1.2 Losing the pre-laryngectomy self-identity**<br>Loss of social roles and friends, new roles, ways of expressing and friends | *Her friends just don't bother trying to catch up with her anymore. If her girlfriends… go out to a park she might go but because she can't speak and people can't hear her she tends to be left in the corner. She doesn't tend to go out much unless it's with family. Tom 36 partner* |
| **Subtheme 1.3 Remaining dependent**<br>Despite the development of skills in some areas, IWL continue to experience disability and this can have emotional, social and safety implications | *I had a nasty experience soon after the operation one morning. I got up around about 8 o'clock and my wife was still in bed and I realised I couldn't clear my throat. I couldn't breathe properly so I just wrote 000 on my hand and woke her and drew attention to my hand and she jumped out of bed and rang 000. By this stage I was really worried because I couldn't breathe. Jack, 69* |

### 5.3.2 Category 2: Navigating and negotiating interaction and situations

In this category, the daily impacts of the changed roles and competencies experienced by the IWL are considered. Subthemes 2.1 and 2.2 are interconnected and closely linked with Category 1. They were critical areas identified in the data and provide some explanation of how these participants reported they behaved in post-laryngectomy interactions. These subthemes highlight the decisions IWL described making about speaking and interacting, and how they responded when they could not speak. This category gives insight into the difficulties IWL experience when others

lack empathy for their situation.

The data indicate that identity reframing influenced how individuals interacted post-laryngectomy. It appeared that many factors affected an individual's ability to navigate and negotiate interactions. These included their grief and loss experience, others' reactions, levels of support, the social situation (time, place, environment), their care needs, physical changes, their geographical location and socio-cultural norms. The IWL described how they tried to exert some control and manage adversity when engaging and participating in communication and social events. This strategy was used primarily to compensate for their limitations. They also described how they used a number of strategies, including technology, to opt in or out of interaction.

### 5.3.2.1 Subtheme 2.1: Evaluating personal competence (communicative and other)

This subtheme related to a number of areas of self-expression, including the experiences described in Category 1; communication loss and breakdown, the mode of alaryngeal communication, the learning and acquisition of alternative communication, the versatility of the alaryngeal methods, loss of swallowing ability, disfigurement, the loss of role and the impact of these changes on interaction. The IWL described how they felt in the early transition stage when they had swallowing difficulties and no verbal communication. They reported they were scared, embarrassed and frustrated. They said it was a difficult time, affecting their participation and reciprocity.

The data suggest the IWL found it difficult to ameliorate or conceal their communication changes compared to their other disabilities. It appeared that for some of the participants, the grief and loss caused by fundamental changes were greater because their symbolic communication (style, tone, capacity), swallowing ability and appearance were intimately tied with their self-identity. These participants described how they were frequently reminded of their altered self-identity in a range of situations and social interactions. Thus, social interactions tended to be the strongest marker of change.

The IWL described in detail how their changed self-expression affected them personally in their day-to-day interactions with others. It appeared that these participants spent a lot of time evaluating their own performance limitations. They described how they were influenced by situations or others' behaviours, and moderated their own communicative behaviour accordingly. They were also

frequently subjected to unwanted attention from others because they communicated differently. For example, Pieter reported that he could not rely on his TE speech because his voice prosthesis frequently blocked with mucous. Due to this unreliability, he had taught his dog *hand signals to get his attention and get him to sit* so he could control him in traffic.

The following examples demonstrate the extent to which these IWL consistently evaluated their own communicative competence during interaction. Hugh said he used to love conversing and socializing, but since his TL he would rather spend time by himself because talking was really difficult. He said he often had *to stop talking and sit down for a while.* He also reported that he could not make himself heard if there were two other people speaking *because what will inevitably happen, voices rise and then I can't compete.* Hugh explained that his overall expression, including facial expression and spontaneity, had been affected:

> *There is very much coordination between your voice and your face, and things aren't spontaneous anymore. ... You can't have the quick sort of stab (gestures a stab and laughs). Particularly, if you are looking for a laugh and if you miss that split second it is gone, and which of course with this (gestures to stoma and voice prosthesis), there is every likelihood that you are not going to be heard.*

Valerie said she had also lost an important part of her expressive self. She described how she felt about her situation could vary; sometimes she was more affected than other times. She used to *like to sing and dance* and use her *dry wit.* She said *somebody would say something and I would make a catty comment(s).* Now she finds that if she is in a group of more than four of five, *it is almost impossible* to talk. When I asked her about her TL and TE speech, she became upset when she recalled her frustration at trying to communicate the previous night:

> *I tried two or three times to join in the conversation but it (was) too hard. Then somebody else starts talking and they hadn't heard that you had started talking.*

These limitations and difficulties with verbal expression highlight the link between verbal expression and identity. The experiences described by Hugh, Pieter and Valerie also highlight the situated nature of communicative competence. The validating influence of being able to communicate freely was a strong theme in the data. Lyn also spoke candidly about her loss of expression, and how it affected her communicative competence and her sense of self. Like Valerie, Lyn felt she was no longer able to participate socially or be like she was before:

> *I am an outsider looking into the rest of the world ... because ... you take too long to*

*respond to a conversation, it is not instant and the eating, if you are out well forget it. So therefore you are always out listening and you want to say something because I have always been a gabber and had a sense of humour. I could always get a laugh out of the group. I can't do that anymore, (so that bothers me).*

The IWL and primary supporter participants reported that daily experiences of coughing, sounding hoarse, being blocked or even sounding *robotic* when using EL speech all drew unwanted attention to them in both public and private places. Fay (partner) described her experience of shopping with her husband. She said he can't *shout* to get her attention so *he claps his hands and everyone thinks I must be his slave, but they all smile.* Coughing episodes, the tone of voice and appearance were also described as stigmatising, embarrassing and sources of unwanted attention:

*It is a terrible cough. Everyone turns around because they think that they are going to catch it. You can't blame them for it. Kath, 72*

Several IWL talked about experiences where their intentions were misinterpreted. Pieter reported he experienced communication breakdown more frequently in the early stages of recovery when he was reliant on gesture and writing. He said he also used a tablet, but it wasn't always readily available so he gestured instead. In some instances, this was interpreted as being aggressive when really what he needed was some understanding and time:

*You have to have access to the tablet, which isn't always on the bed. It's usually by the side, and the nurse is sitting beside you doing this. You can't, you know, like 'stop' (gestures 'stop' with hand)… And they then see that maybe as a slightly aggressive gesture so, "No, I'm not being aggressive, I'm just asking you to give me a breather".*

Valerie also described how her TE speech was unreliable sometimes and when she tried to convey her intentions she was misinterpreted. She said that even her husband, who had been a wonderful support to her, sometimes perceived that she was shouting at him even though her TE speech lacked significant loudness.

Brian said that he depended on writing in the early stages of his recovery but this was difficult for him and sometimes there were miscommunications:

*I was never a very good speller, so trying to write things was a bit awkward at times, "Oh what's the easiest way to write this?"*

The communication difficulties described by the IWL appeared to be amplified in relation to communication norms and rules, as a well as their knowledge of how they used to perform and react in situations before their laryngectomy. For these individuals, the use of alternative communication took time and was challenging. The unreliability of their communication aids and their breathing issues were problematic,

and resulted in fluctuating communicative effectiveness. The IWL described the mental effort they used during interactions to interpret the likely outcomes. This appeared to highlight the situated nature of the TL experience, and also impacted some individuals' self-worth. This subtheme was closely linked with Category 1 and the other subthemes in Category 2.

### 5.3.2.2 Subtheme 2.2: Responding to the reactions of others

This subtheme was an important one for the IWL and primary supporter participants. It was related to the social consequences of TL and feeling stigmatised, and was also felt by some of the IWL before their surgery. This theme can be considered in different contexts and through the prism of the timing and stages of care.

The IWL and primary supporter participants described how it was *surprised* reactions and *ignorant* behaviour that had the most effect on them. The data suggest that symbolically, reactions from others influenced how participants chose to respond and thus impacted their interactions. Some examples of surprised reactions included gender confusion based on voice and appearance; staring; speaking loudly and/or slowly at the person, assuming they were deaf or cognitively impaired; ridicule; curiosity; humour; pity; horror; sympathy; and cessation of interaction. Lyn described the surprised expression of her surgeon when she presented with a large benign laryngeal tumour requiring a TL:

> *The surgeon [Dr's name] was quite surprised to see me downstairs and they told him that he was doing a laryngectomy. Well, he was very surprised, put it that way.*

One might postulate that it was unusual for someone of Lyn's gender, age and sophistication to be having the surgery, and this is why he looked surprised. Lyn also described how she had experienced stigma for having a smoking-related illness. This was important because she, like two other participants, did not present with a smoking history or a typical laryngeal carcinoma. In her case, she had a chondrosarcoma.

Christopher reported he often had to forewarn people about his electrolarynx because it had been mistaken for a weapon. He also said that it was people's reactions that indicated to him how to behave. This was an excellent description of how the IWL in this study used their lifelong understanding of interactions and attempted to shape situations to optimise the outcomes. Lyn was typical of other participants when she said she felt embarrassed by her low-pitched voice and using digital occlusion when speaking. She said strangers were also embarrassed and *treat you differently*

*straightaway*. The experience of other people's reactions also influenced Annie. She said she chose not to use an electrolarynx despite poor success with her voice prosthesis *because you sound like a robot*. In fact, most of the participants viewed the electrolarynx negatively. Kath said she hated her electrolarynx because it attracted attention.

Brian, a TE speaker, commented about his experience going to the ENT clinic where there were other IWL *with an electric thing and you're like a dalek, like a robot or a machine.* Here, Brian seemed to imply that an electrolarynx is a depersonalising device that becomes a part of the person. Other participants also described these sentiments and said that these devices resulted in a loss of personality, which reduced people to being the object.

This group of IWL gave accounts where they felt frustrated, and withdrew or limited their contributions to an interaction due another person's ignorant behaviour. They described experiences of being overlooked, not being heard or receiving little concession for their disability, usually when another person had little understanding or motivation to accommodate their difficulties. The IWL described how these people could be members of the general public, friends, acquaintances, children, some family members, police and some health professionals, including inexperienced nurses and general practitioners (GPs).

Participants reported the issue of unwanted staring. Rachael (partner) explained that she lived in a country town where there was a general level of understanding and acceptance, *but when you do get some strangers, especially kids, they look.* She described her boss's 5 year-old staring at her partner when she talked to him. *You could actually read what the kid was thinking, "he sounds different".*

It appeared that if a friend or family member behaved insensitively, this was less tolerable and even hurtful because they should have been more knowledgeable and understanding. It could also result in a loss of trust. For example, Valerie reported that when she first had the surgery, most of her family were understanding of her situation but that her grandchildren:

> ... were a bit hesitant. ... the first time I spoke to them ... I wrote on the thing "Don't laugh" and said hello and they both burst out laughing and that kind of upset me. I mean that was my first experience of somebody laughing at my voice.

She was also hurt by her friend's comment that she sounded like *Donald Duck*. She said that the comment discouraged her from communicating:

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*Now that has never left me. I often think about it when I'm talking and it puts me off.*

This comment again reinforces the link between this subtheme and subtheme 2.1.

Jack described experiences where in an initial encounter some *acquaintances intentionally dodge* him. He said that it used to affect him but that he did not have a good grasp of their intentions. Pieter echoed this sentiment. Annie on the other hand was less worried by her voice but had experienced negative responses to it being called names when she used the telephone. She reasoned that there was not much she could do about her voice. She also said that other people had complimented her on her voice and this had been a validating experience. Thus, the data indicate varied responses to adverse social situations.

The IWL reported they experienced pity, threats, rudeness, curiosity, scepticism, intolerance and victim-blaming from strangers, for example children, people on the phone, the general public and shop assistants. They also said they changed how they responded in relation to others' judgements. For example, Lyn said that when interacting, she responded sensitively to *the way that people look at you, the way they talk to you*. She recalled an experience with a shop assistant when she was shopping for some new kitchen appliances:

> *I was in the showroom ... He was talking to me but he wasn't looking at me all the time ... I think he thought I was stupid. I was disgusted and I walked out.*
> .

Rachael (partner) said her husband:

> *... gets annoyed ... when people go "What would you like?" (speaks slowly) as if he's deaf ... or they go "What do you" (speaks loudly) ... and you think "Do they think I'm deaf or something?"*

However, Len reported a different experience:

> *Oh really everybody wherever I go, strangers the whole lot yep just take it as normal.*

The IWL and primary supporter participants gave many examples of experiencing health professionals or other professionals in a public role with a poor understanding of the issues. Some of these problems appeared to further highlight some safety concerns described in subtheme 1.3 and expanded further in Category 6. There were stories of GPs, nurses, emergency physicians and even police officers who incorrectly identified the airway as continuing to the mouth and tried to give oxygen via a facial mask, or worse still, thought it was OK to obstruct the tracheostoma. Brian described several experiences with the police where he was stopped for a random breath test for drink driving. On occasion he was asked by a police officer to blow into the bag from

his mouth and when he told them he *couldn't the officer said*:

> *"Well, what if we block it up?" ... and I said "Well, if I block it I can't breathe at all"... Then they just look at your license ... and away you go.*

Some of the IWL and primary supporter participants described how they had learnt to tolerate ignorance and responded to it by using humour or trying to educate others. A few participants viewed education as futile due to the frequency and randomness of experiences. It appeared that both strategies required mental and social effort, and were fatiguing.

Sonia, 59 (partner), described how her partner had *found the ignorance of people* really frustrating and she thought this was synonymous *with small town syndrome.* However, she said he had become more resilient and grown to accept it. She also remarked that he found it easier in some situations, for example, when he visited her in the city where she lived*:*

> *... when he's here it's water off a duck's back for him now.*

Sonia also reported the importance of maintaining *a sense of humour* between them*,* even when *it was a lot harder.* This couple had experienced a very difficult time. The TL had been an emergency procedure and the recovery was long and complicated. Sonia also reported that her own mental health suffered during the experience. The important role of the primary supporter such as Sonia is discussed in subtheme 6.4.

Jack said he also tried to see the humorous side of life. He described his slow eating as a source of amusement:

> *My mates say ... I am the only person they know that can start off with a hot roast and have the same meal as a cold salad, but as you can see I am not fading away to a shadow.*

It was clear in this study that it took the participants time to build their resilience (Category 4) and learn to tolerate ignorance about their condition. This may have been because it was difficult for them to predict when these situations could occur. The participants reported that the hurtful and offensive verbal and non-verbal reactions from others included abrupt body language, staring, loud speaking, being excluded or not heard, and losing friends or acquaintances.

The primary supporter participants also seemed to be affected by others' responses. They appeared to play an important role in supporting IWL and were able to provide extrinsic validation in the face of uncertainty. As already stated, this subtheme can be linked to all the other subthemes in this category, thus highlighting

the category's interactive nature. The other categories were also highly relevant to this subtheme.

### 5.3.2.3 Subtheme 2.3: Exerting control

The data suggest that the IWL tried to exert some control over their participation, and how they presented themselves to others. They made choices that appeared to relate to the socio-cultural context. Despite broad inclusion criteria, all participants were Anglo or Euro-Australians of mixed genders and ages. The study was not able to attract a wider range of views from ethnically and linguistically diverse groups. These factors were also significant in relation to the reframing of the post-laryngectomy self-identity and subsequently affected their concordance with treatment and recommendations. For example, the issues related to what were considered socially acceptable behaviours and the broader cultural context. The data reflects the participants' socio-cultural demographics.

The IWL reported they would modify or mitigate unwanted attention or judgement by covering the stoma and avoiding eating in public spaces. Participants reported different approaches to their tracheostoma. Some said they fully embraced it and did not conceal it. Others tried to express their personal flair with specially designed stoma covers or clothing. In some cases, the cosmetic seemed to precede the practicalities of humidification. Bill, 70, described how he was very clear about why he chose not to cover his stoma because he felt it attracted undue attention:

> *You are supposed to cover it but I don't for the simple reason you cover it and people notice it. When you don't cover it the only way they know you've got it is when you put your finger there. And you can go in a supermarket and no one looks at you as if you are a freak. Let's put it that way.*

Pieter explained that he had also consciously stopped taking advice and worked out his own path of recovery, a theme that can be tied to Category 4 and subthemes 2.2, 6.1 and 6.2:

> *I think that, that my experience was so misaligned from the information that I'd received that I was no longer willing to participate in the misinformation campaign … I don't want any voice training, I don't want any rehabilitation, I don't want you to put my speech prosthesis in; I will learn how to do all this myself. I will get myself better.*

The participants appeared to use technologies to opt in or out of situations and interactions. Phone and mobile technologies were used more than the Internet. This may reflect the participants' generation, where the age range was 57-75 years. It was

reported that in the early stages of recovery, some of the IWL used tablet technology but sometimes it was easier to write. They also reported they used screening systems so they could decide whether to answer calls:

> *...we now have ... the number displayed ... so I won't answer the phone if he is not here, unless I recognise the number because I've had so many people hang up on me or else call me an idiot. Valerie, 74*

They said they used technology to manage communication. The most popular method appeared to be text messaging to communicate so they were not reliant on using the telephone. For example, Mary reported she has a family living interstate, so she used her *computer to email and with the mobile phone I text*. She agreed that she used these methods to avoid talking. However, it was reported that there were still occasions when the phone could not be avoided and this increased dependency on others.

There appeared to be variable usage of the Internet amongst the IWL and primary supporter participants. Some confirmed they did not use it. Some also identified that they tried to exert control over the information they sourced. Very few had gathered information from the Internet and some described how they had not done so because they did not want to be influenced by other people's views. This was surprising given the absence of a local support group. It appeared that the digital literacy and usage for the IWL and primary supporter participants was low. For example, Brian said of the Internet, *I never used it.*

Another area where it appeared IWL tried to exert control was when eating. In subtheme 1.1, I discussed how swallowing difficulties could lead to a loss of self-expression and self-identity. A strong feature of the narrative was the participants' desire to return to their pre-laryngectomy diet, but they often required calorific and softened foods or their eating rate was affected. This impacted their quality of life and socialising. Their food was a form of personal expression, and had implications for how they wanted to engage socially or accept health professionals' recommendations about what they should eat. For example, Annie found socialising and eating difficult because her voice prosthesis leaked and she coughed. She did not like the way people responded with alarm and tried to help her, so she chose not to go out:

> *I don't go out. Like at Christmas time Joan brought me back before dinner because if I get something stuck in here, I go blue around the gills and everybody will rush up and hit me on the back and all that sort of stuff, so I don't go out for dinner. I don't go out for coffee because that leaks and I've got to put a tissue in.*

Another deterrent to going out and eating is that many IWL may no longer be able to

have the food they like. Matilda, senior dietitian, said swallowing problems from surgery and radiotherapy mean IWL may need softer food, and this can be difficult for them to accept:

> *The main cultural issue I come across in this group is the Australian male culture of steak and chips, and "If I can't eat steak and chips then what am I eating?" They can't go to the pub and eat that meal, that's what really gets them down.*

Fay (partner) reported that her husband had a modified consistency diet in hospital and *loathed it*. She said he asked when he would be given solid food again and it took a lot of negotiating with health professionals to get it provided. It appeared that these IWL used a number of strategies to exert control over their participation and situation.

Earlier in this chapter, examples of how altered self-expression appeared to impact participation were provided in the subthemes 1.1, 1.2, 2.1 and 2.2. There was a clear indication in the data that the participants tried to exert control when socialising but that their functional limitations affected their success. Here, the focus has related to how individuals managed their changed appearance and abilities. This subtheme highlights how participants made choices about their participation, and used avoidance as well as negotiation to exert some control over their circumstances.

### 5.3.2.4 *Category 2 summary*

| *Category 2 – Navigating and negotiating interactions and situations* | |
|---|---|
| **Subtheme 2.1 Evaluating personal competence (communicative and other)** <br> Judging ability and acceptability in interactions and social situations | *I can't really carry on a conversation over the phone with any confidence. I've been very lucky today, I haven't blocked up; usually I block up… and I have to go and clean it out and then it blocks up again so it's not reliable. Pieter, 61* <br><br> *I don't go out anywhere, anywhere! Even if I try and go out to lunch with my sisters,… well I can't because you can't talk,… you can listen and you sit there like a … block of wood. So I don't go anywhere, I don't go to dinners, I don't go to birthdays. … If I do I go … like my children's birthdays, I work … in the kitchen, I do the cooking. You don't have to talk to anyone if you are in the kitchen, if you are doing the cooking and cleaning and everything else, you are just part of the furniture and then meld into the background. Lyn, 63* |

| | |
|---|---|
| **Subtheme 2.2 Responding to the reactions of others** <br> Trying to manage the reactions of others, hardening stance, using humour, getting mixed reactions | *My reaction was I couldn't be bothered with them but once it did, you know. I am mystified as to why. Do they think it's infectious or what? I don't know, I can't answer it … I think another reason, I am just plucking straws because I don't know that may be, they were a bit hard of hearing or just couldn't be bothered to try to listen as you've got to understand someone with this problem. Jack, 69* <br><br> *I felt, I was making a joke of it and sound like Donald Duck. Well what else can you do? Nothing! Annie, 65* |
| **Subtheme 2.3 Exerting control** <br> Challenging situations and the status quo. Sometimes related to issues of concordance and desire for support | *He was told he'd most probably never eat steak. [He] had his operation in June, Christmas we were over in Perth and he had a bit of steak, but the steak just melted in your mouth anyway. But we had some chops and the last mouthful got stuck in there for a day and a half and he ended up getting a straw and sticking it down the valve to try and – I mean down his throat, not down the valve, down his throat – and scratched all the inside and it bled, you know, because it's so tender there, I suppose. Rachel, 53 (partner)* |

## 5.4 Part 2: The processes

### 5.4.1 Category 3: Developing competence

An important category to emerge from the data was how the development of a range of competencies after a TL occurred over time and impacted adjustment and acceptance of the altered self-identity. There appeared to be a pattern whereby the process of developing competence was related to the processes of becoming aware, learning skills, troubleshooting and teaching others. This category was closely linked with Categories 4, 5 and 6. The competencies the participants described included self-care, breathing, communication and swallowing, and also related to the competence of others, including the primary supporter. Later in Category 6, I discuss how health professionals' competency was an important factor for supporting this group of IWL to develop their own competencies.

#### 5.4.1.1 Subtheme 3.1: Becoming aware

The IWL and primary supporter participants described how gaining knowledge and skills was crucial but reported that the acquisition process was often inconsistent and poorly supported. The IWL said they felt supported when education was provided in a timely and competent manner, and vulnerable if there was a lack of information. The health professional participants also emphasised the importance of education but described issues related to IWL and their supporters' readiness to absorb information. For example, Edward, the surgeon interviewed, described how the delivery of information to a patient was important:

> *Some patients need more information; others don't want to hear, they get freaked out with the news. I think you just have to tell them and involve their family members because they need support.*

The senior speech pathologist, Tessa, described how her relationship with patients was different to other members of the MDT because she was able to spend more time explaining things. It appeared that the IWL and their primary supporters took in information differently and at different times. One of the primary supporters, Colin, 77 (partner), reported that he got information from the surgeon and watched some education videos. In Pieter's case, he could not recall if he had pre-operative counselling from a speech pathologist but explained that his wife gathered a lot of information. He also stated that he had not wanted to get information from the Internet and later said he taught himself because he felt he was getting inconsistent messages:

> *I'm pretty sure she did but I don't remember. ... it doesn't matter how much they tell you or how little they tell you, nothing can prepare you.*

As mentioned under subtheme 2.3, very few of the IWL reported using the Internet to gain information. The participant socio-demographics suggested this pattern could change as future generations develop increased levels of digital literacy. However, it highlighted the complexity of education and information counselling in the early stages. Many of the IWL described how they trusted the information they received from the MDT but some reported they did not always get well-supported opportunities to learn and the reassurance they needed at critical times. They explained that education should be well-timed and tailored to a patient's needs. For example, Lyn described her shock at seeing for the first time sputum coming from her neck after coughing:

> *When I was well enough to get up I went in the mirror and I looked in there and I coughed and sputum came out of my neck, I nearly died. ... No one told me that that was going to happen. So you really need people trained, around you, that is going to say this is what's going to happen and here is a mirror, have a good look because you don't know what you look like.*

The primary supporter participants also described feeling vulnerable immediately after surgery. They reported that gaining information about the surgery and its consequences resulted in increased confidence and competence with the new situation. These participants valued having a health professional demonstrate, guide and support the practice of tracheostoma care. They said they were better equipped to provide both emotional and physical support when they had grasped the issues and could trouble shoot problems as they arose. This is explored further in subtheme 6.4.

It appeared that competence development made primary supporters more confident. However, the health professional participants reported that some partners never assisted with tracheostoma care. It was difficult to gain further information about this because I was only given second-hand accounts. One such account came from Tessa, a senior speech pathologist, who reported that some partners were repelled by the tracheostoma. This was not the case for Rachael (partner). She explained she found it helpful to learn about her partner's changed anatomy and the risks associated with neck breathing. She described it as *a real eye opener* and *if it went down the wrong way he'll drown.* She said a nurse taught her this when her partner was recovering and that she now teaches others.

Interestingly, there appeared to be an ongoing issue for primary supporter

participants about having to educate others. Julie, 63 (partner), described how her knowledge of her partner's situation sometimes made her appear complacent in others' eyes. She said sometimes her partner would choke when eating and this disturbed other people, but not her. She reported she often reassured others that it was OK. Cilla (partner) agreed that this also happened to her:

> I'm not taking any notice and there might be this, "Is he all right?" "He's fine", you know, "he's not going to choke. He can still breathe". So people get freaked out.

The IWL and primary supporter participants discussed another example of the process of becoming aware when they described the benefits and challenges of benchmarking the experience to others in a similar situation (e.g. laryngectomy support visitor or incidentally meeting an IWL). For example, Kath said:

> The closest I got was a man at the [local] shops and he had one of these and he spoke and it scared me.

Sonia (partner) revealed that a visit from another IWL helped her partner realise what he might be able to achieve with his TE speech. She also said he had met another IWL and that this has been really good for his morale, education and adjustment. She described her partner's reaction when he met a laryngectomy support visitor:

> He was quite surprised how well he could speak and how he could understand him because he had just had the operation and to actually get to that stage where this bloke was, ...that was not in his sight at that point but when he came and seen him, that was in his sights, knowing that one day he'll be able to do that. That was fantastic.

The issue of the suitability of a laryngectomy support visitor was identified. It related to the shortage of suitable candidates and individuals' readiness. In Pieter's case, he decided not to have surgery initially because of his experience meeting another IWL. He said the visitor:

> ... kind of freaked me out a bit, you know, speaking like this. He didn't seem very much at ease with himself. I said to my wife, "I'll never do that, it's not going to happen", so I said, "look, I'll take the radiation and the chemo and whatever goes but I'm not having a hole in my neck.

Unfortunately, he had no choice when the disease returned.

There also appeared to be differences of opinion amongst the health professional participants about the benefits of laryngectomy support visitors. When discussing the merits of this, Edward the surgeon referred to it as being an important part of the care approach, whereas Josephine, senior speech pathologist, identified that *it can be difficult to organise a laryngectomy visitor* so it is not always offered. She

explained that:

> *... trying to match someone appropriately and finding someone that hasn't just had a horrendous experience can be quite difficult.*

There were mixed responses from the IWL when I discussed the usefulness of a support group. There was no longer a support group available in Adelaide and the consensus was that it lacked diversity of membership, or perpetuated the image of difference or unwellness:

> *If you have laryngeal cancer there is the New Voice Association, which I went to a couple of their meetings but it was all men and it really wasn't a support group, it was some people running it but no one talking to you, it's like everyone knows what is best for you that you don't say anything, but they don't exist any more. Lyn, 63*

> *I don't know that those things work because it is like ... putting all the broken down horses together. I don't think it would work. Kath, 72*

> *You think, "Well why should I go to a room full of people who are crook like me?" Hugh, 57*

It appeared from Hugh's comment that it would also be effortful for him to participate in a group due to his communication difficulties.

Some participants reported that the gathering of knowledge about TL was often haphazard rather than by design. This may have reflected the participants' readiness to absorb information. The IWL and primary supporter participants reported that having things explained and demonstrated by a health professional was reassuring and helped in the process, but there appeared to be conflicting data related to the benefits of being exposed to other IWL or the need to join a support group. Generally, however, consistent and sensitive guidance, reassurance that things would improve and that IWL and supporters would get through it, were highly valued. The data suggest that supportive and competent health professionals were an important validating influence and made a significant difference to how the IWL and primary supporters managed the experience.

### 5.4.1.2 Subtheme 3.2: Learning skills and troubleshooting

This subtheme pertained to the development of functional abilities such as learning an audible ACM, managing nutrition orally and understanding the imperatives of airway management. It inter-relates with subthemes 3.1 and 3.3, and is closely tied with the other categories. It was not surprising that restoration of verbal communication was an important turning point for most of the IWL. However, it was evident that

proficiency with an audible ACM did not fully substitute an individual's pre-laryngectomy communicative competence. It appeared that this was not immediately apparent to the IWL in this study. The health professional participants described how surgical voice restoration (SVR) could be very positive. For example, Josephine, senior speech pathologist, reported *the miracle of the new voice* as one of her professional pleasures. She said this resulted from placing the voice prosthesis for the first time for a patient after SVR.

Rose (partner) reported that her husband getting his voice prosthesis was a positive development because he went from writing messages to being able to talk:

> *Well to start with, until he had the valve put in he just used to write things down. I bought him one of those boards, you know you write on it and wipe it off, one of those things, but once he had the valve put in he talked and then he just kept talking.*

The process of acquiring an ACM was not always straightforward for some of the participants. Rachael (partner) stated that *learning to talk again, communicate* was the biggest adjustment her husband faced. Many of the IWL did not learn to use an audible ACM immediately, which appeared to impact their adjustment and relationships. This has been explored in Categories 1, 2, and is further explored in Categories 4 and 6.

The health professionals also described how developing competency with self-care was part of a deliberate strategy to facilitate discharge. They perceived that self-care and stoma management were important skills for individuals who may be faced with an emergency or reduced supports. Thus, they played an important role in providing education and support for individuals and their families. The health professionals were very clear that an IWL's motivation and ability to self-manage affected the way they worked with that person. For Maria, senior head and neck nurse, the development of self-care was a learned process in which IWL had to be educated and supported. She was very clear that she sometimes had to be quite assertive with patients so they would become independent. She reported that she had all her patients with adequate manual dexterity learn to self-manage their stoma. She emphasised that *the key is communication … and explaining*, and stated that IWL and their supporters often had *no idea of the anatomy*. For example:

> *… they've got no idea that's the back of their throat down into their stomach, their oesophagus.*

> *…We get the mirror, we get the (tweezers), we get the torch and we make them do it*

*in front of us … it's mandatory. They have to do it. … because something could happen to their partner.*

Josephine, senior speech pathologist, reiterated the importance of social support and self-care prior to discharge and how this influenced decision making about treatment options. She said that SVR was offered if a person could self-manage or had support. The issues of social support are explored further in Category 6.

Matilda, senior dietitian, reinforced that having poor manual dexterity could be problematic for independent stoma care. She stated that patients who do not have *steady hands or have really bad arthritis struggle with their stoma care.* This issue alone could delay discharge and *the longer someone's in hospital the more chance they have of catching another germ.* The issues related to the timing and stages of care were captured by Category 5.

The senior speech pathologist, Josephine, reflected on supporting people who *aren't able to self-manage.* She had recently assisted an IWL who had a mild intellectual disability and very little home support, and reported that there were no community supports for this person so her team provided ongoing support. The main health issue was that his stoma would get congested with dried secretions between visits. His progress learning to clean his tracheostoma was slow and resource intensive. Josephine stated that she used a paramedical aid to:

*… [provide extra support for] short bursts of treatment …on a daily basis, even if it's just helping them wipe their stoma or look at their electrolarynx.*

This narrative highlights the vulnerability of some IWL who have additional health or disability concerns, and demonstrates the complexity of service provision for health professionals. Access to these kinds of narratives, including information about co-existing conditions such as arthritis, would have been unlikely if data collection had ceased after Stages 1 or 2 because IWL faced with these issues are less likely to volunteer and participate in research such as this.

There was a trend in the data for female partners to maintain an active role in assisting IWL with tracheostoma care. Interestingly, several partners reported that they continued to do a lot of the caring when their loved one was discharged. They also felt they did not know when to stop assisting. For example, Rose (partner) said her partner was dependent on her for his stoma care *for ages* until he decided he wanted to go camping again. She thought that she had created this dependence because she felt it was difficult for him to do using a mirror:

> *... because he goes camping with one of his brothers and he'll go for a week and he has to do it himself, so now he'll come in out of the bathroom and just do it himself, which is wonderful.*

Later in Category 6 there is evidence that the TL journey was quite burdensome for primary supporters. There appeared to be an ad hoc approach to how health professionals supported primary supporters. In addition, there appeared to be conflicting messages from health professionals and primary supporters to IWL about developing independence.

The health professional participants with a practical interest in the patient's care (e.g. the speech pathologist, nurse and dietitian) reported that mastery of care of the tracheostoma, and if relevant, the voice prosthesis or feeding tube, involved the ability to troubleshoot issues as they arose. Josephine, senior speech pathologist, stressed it was important that an IWL learned to become self-reliant. She believed that IWL needed to have self-efficacy and be motivated to manage and solve a laryngectomy-related problem, but that it was really helpful to also have another person to provide support. She described the complexity of the issues, saying an IWL may be *resourceful* and *can deal with something* but:

> *... if something goes wrong, having someone else there that also reinforces the right course of action or gives ... a hand or holds the torch, or whatever, just gives you that extra level of confidence in being able to manage things.*

It was evident that an IWL's ability to self-manage had several implications, including:

1) improved wellbeing, confidence and resilience

2) decreased primary supporter burden and strain.

Generally, it appeared that competent self-care resulted in independence and boosted confidence but there were some exceptions. Well-timed, tailored education and strong but judicious social support appeared to facilitate competency development. Increased independence enabled IWL and primary supporter participants to troubleshoot difficult situations and teach others. More data related to the experiences of partners providing support is reported under Category 6.

### *5.4.1.3 Subtheme 3.3: Teaching others*
The data suggest that education is not one way. Both IWL and primary supporter participants reported that they often educated health professionals. It was evident that due to a general lack of public awareness, both IWL and primary supporter

participants needed to educate others frequently and randomly. Issues arising from poor awareness were raised in Category 2 and are discussed further in Category 6.

The IWL and primary supporter participants described the role and responsibility of educating inexperienced health professionals as bemusing, frustrating and necessary. For example, Helena (partner) reported that she had had to train her GP about her partner's voice prosthesis. Annie had to do the same with the local ambulance officers. The community speech pathologist, Samantha, also talked about how one of her IWL patients helped inexperienced staff to learn about his prosthesis. Helena (partner) lived in a rural area and reported that *it's been a bit of a learning curve for [the local medical staff] to a great degree but they're getting there slowly*. She described how she had to show them some of the equipment (e.g. a catheter) and found that they reacted strongly:

> *... they were horrified, they really weren't sure what's going on. ...*

> *I actually know more than they do at the present moment regarding the voice prosthesis and how to cope with that because the speech pathologist taught me.*

There were many examples from other primary supporter participants who had taught less experienced hospital staff. These primary supporters reported that this responsibility was a source of strain, an issue described more extensively in the subthemes 6.1, 6.4 and 6.5. Fay, for example, said:

> *I did everything for him so they didn't have to do anything. In fact, they came and asked me how to do things for him. ... it's obviously a lack of teaching or whatever. Fay, 77 partner*

Rachael (partner) also reported that once she had been educated she was able to teach others, but the experience of this process had been less straightforward for Annie. She lived in a rural area and identified the need for a trained health professional to help her when something goes wrong with her voice prosthesis, such as when it falls out. She said she had been asked to train the local ambulance officers about her voice prosthesis but that it was later deemed *illegal* for them to manage it.

In another rural setting, the community speech pathologist, Samantha, described how one of her patients was very willing to help train others:

> *... He's really comfortable with his laryngectomy and really happy to talk to people about it and happy for new staff to give changing his prosthesis a go and... supportive in that way.*

It appeared that the demand on IWL and their families to educate others was closely

related to Category 6 and the subthemes 3.1 and 3.2.

The IWL in this study faced a range of functional limitations and competency issues after their surgery. Their rehabilitation was affected by temporal factors, their general physical wellbeing and factors beyond their control such equipment and breathing status. The narratives suggest that the confidence of IWL and primary supporters is strengthened with mastery, self-efficacy, resourcefulness and social support. In many cases, it appeared that developing competence was motivating for the IWL; it assisted them to come to terms with their changes and embrace new roles and ways of doing things. There were, however, stories where setbacks and persisting competency issues were difficult to accept, and had social and clinical implications.

### 5.4.1.4 Category 3 summary

| Category 3 – Developing competence | |
|---|---|
| **Subtheme 3.1 Becoming aware**<br>The acquisition, timing and retention of information via education, researching and experiential learning. This experience affects all the participants and also implies readiness to learn | *I very frequently get told, "You're the first person that's actually explained what's going on. The doctors don't have time for me. This is too overwhelming". I definitely think that the doctors do what they can and in that early stage people are bouncing and it's in one ear and out the other. Tessa, senior speech pathologist*<br><br>*...if it doesn't affect you directly you tend to not absorb all the medical bits and pieces that are very important but don't appear to be that important at the time because other things take priority, like, "Is he going to live?" Pieter, 61* |
| **Subtheme 3.2 Learning skills and troubleshooting**<br>Developing independence, having ability or support to problem solve as issues arise. Tied with resilience and clinical decision making | *...we have a strong role in trying to encourage and reassure and educate people, and I think we're quite good at stepping people forward in a way that is appropriate for their level of learning. Josephine, senior speech pathologist*<br><br>*I know what to do. Like if the valve comes out I know I've got to stick the ... I've got all the equipment to stick it in and then we have to go to Adelaide but thank God that's never happened. Rose 65, partner* |
| **Subtheme 3.3 Teaching others**<br>Having developed competence, now able to teach others, this relates to IWL and primary supporters | *The way the guy explained ... how ... when you look at the side of the neck you've really got ... this part that goes down to here and the other part that goes down to the tummy, ... to eat, so there's two parts, and I never knew that and I tell people and people don't realise that. Rachael 53, partner* |

### 5.4.2   Category 4: Building resilience

The IWL described how it was stressful being diagnosed with a life-threatening disease and having a TL, which resulted in disablement, disfigurement and stigma.

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They reported that some of their regular activities and routines had been disrupted. This category demonstrates the crucial process of building resilience and explains the variation in the data regarding how participants appeared to adjust to the complex multi-level changes they faced. It builds on Categories 1 and 2, which highlighted the personal costs, social impacts and changes to self-identity. In many cases, social engagement and participation were affected. Participants described both explicitly and implicitly their loss of independence and competence in many areas of their lives. They described how they grieved for the loss of their pre-laryngectomy self, experienced vulnerability and managed the post-TL changes to their social roles. Their ability to manage change appeared to be influenced by how they reframed their post-laryngectomy identity.

Category 4 explores how IWL and their primary supporters coped with the losses and challenges, how they felt about their situation, whether they perceived they were appreciated, and had purpose, self-efficacy and the capacity to learn. Many reported that their return to independence was slow and context-dependent. This category is also closely linked with Category 3, which highlighted how the process of developing competence assisted the process of building resilience.

The data suggest a number of personal factors intrinsic to each IWL that influenced adjustment and acceptance of the post-laryngectomy identity. The important and validating influence of a person's relationships and supports from a partner, family or friends, while discussed here are also discussed in Category 6. The suggestion that building resilience took time for many of the participants, and was not a linear or fixed process, closely links this category to Category 5.

### 5.4.2.1 Subtheme 4.1: Coping with the losses and challenges

It was evident from the narratives that the IWL responded differently to their individual circumstances; they had unique capacities to face the adverse situations they encountered. Some of the participants spoke explicitly of their difficulties to adjust and how they mourned their losses. Others were less expressive but resolved to live with their circumstances and reported they were happy to be alive. Several described how they avoided certain situations as a way of coping. Adjustment required considerable mental effort and perseverance for many, and this process appeared to be fatiguing. There also seemed to be strong evidence that participants felt they had to be in control of their own adjustment process but this sometimes

resulted in feeling distressed if they were not able to manage their situation. In some instances, people's hobbies or livelihoods were affected. Some of the issues described were transient and resolvable. Others were persistently disruptive and affected a person's ability to return to their old lifestyle or ways of doing things.

Pieter discussed how he self-managed and decided to do things his way. He saw this as a positive part of his recovery and self-development. He also articulated, like many of the other IWL, that he had to use considerable mental effort to overcome his difficulties:

> *I think you're your own best healer and create a proper mental model of who you are now compared to what you were, but also … that process of discovery, makes your life so much richer and makes you so much more capable of maybe coping with any other challenges that might come in the future.*

Like Pieter, Christopher and Kath described the adjustment and recovery from the surgery as an active and validating process wherein they made decisions about what they wanted. I asked them both about their experience after the surgery. Christopher, 61, who reported he had been suicidal before the surgery, said he did not experience *depression,* and stated *I tried to survive and gain my health back.* He did this by surrounding himself with the *kind of people you know, they know you, but they speak for me and I speak for them,* and being guided by Buddhism. Kath reported she was *terribly, terribly depressed* and thought about *jumping off the roof of the hospital.* She felt this was very unlike her. She described how, after a period of staying at home and sleeping a lot, she pushed herself *to get on with it* and that walking her dog *everyday… miles and miles* really helped her *come to terms with it.*

Lyn also talked about her personal struggle for 10 years after her surgery. She described why she did not accept taking anti-depressants when she was feeling depressed and said the stoicism related to her Irish heritage:

> *Oh yeah, "Pull yourself together girl!" Very Irish, very ebullient … and the thought of having any [anti-depressants or anything in my family go back … you don't do that, you get over it, just get over it … So that's what I do.*

The data suggest that the IWL found it emotionally effortful to adjust to their physical changes and needs – altered appearance (tracheostoma, reduced neck muscles and/or teeth), alaryngeal communication, neck-breathing, eating and tracheostoma care. It was reported that it took time and energy to build confidence and accept the post-laryngectomy self. It seemed that, for some of the participants, this confidence was at times tenuous and easily destabilised by negative experiences. This destabilising

effect appeared to contribute to the burden and strain the primary supporter participants experienced. These experiences, highlighted in Categories 1 and 2, described the challenges of social interaction due to the poor reliability and versatility of alaryngeal communication.

A few participants like Jack discussed how previous life experiences and health scares had assisted them to cope with the demands of a TL. Jack had had a serious motor vehicle accident:

> *I think … that experience which I wouldn't recommend to anyone, did teach me to be patient and a timeframe of healing etc. and perseverance, you've got to show or exercise. It is still with me from that day in that regard. I suppose that helped me have some of the attitude like that.*

Mary reported she had experienced family members getting cancer but still did not believe it could happen to her. She also remarked about her daughter's worry of getting laryngeal cancer. Mary's illness had led her daughter to give up smoking. Other participants reported the need to move forward, and to start accepting and adjusting to the new situation:

> *I have still got a normal life. … I do everything … I can still talk from the mobile. … I've had no regrets. It had to be done it. … It was that or I'd be kicking up daisies, let's put it that way. Bill, 70*

Pieter identified that the TL had changed him personally, and that he had been committed to turning it into a positive and character building experience. He said he had learnt to cope with the inevitable *peaks and troughs.* Helen, senior social worker, reported that some IWL have coping strategies they cannot use to help them recover, particularly in the early transition stage. Many of the IWL reported they gave up smoking before the surgery:

> *The typical patient whose coping skills are drinking and smoking and going to the pub. If those things are taken away from them then they don't cope well, as well as the fact that they've often burnt bridges and don't have much social support.*

An important challenge described by all participants was medically-related setbacks and how they impacted their recovery trajectory, resilience building, and medical and psychosocial support needs. The health professional participants identified that the patients who experienced setbacks tended to have poor pre-operative health (physical and mental health issues), be malnourished and have poor social support. They explained that tissue viability for surgery and healing was important. Some of the IWL reported they experienced wound healing problems, weight loss, depression and

anxiety, particularly in the first year, which resulted in longer hospital stays. The health professional participants reported that difficulties such as these were often intensified if a person had previously had chemo-radiation treatment.

The head and neck nurse, Maria, reported that some patients had comorbidities and alcohol or drug dependencies that also affected recovery. The senior dietitian, Matilda, highlighted two factors that assisted a *smoother* recovery. These were, *how healthy they go into the surgery* and *how much support they have at the other end.* Edward, the surgeon, described the first year as a *bit rough* for IWL due to the likelihood of complications and setbacks. The health professionals predicted that two thirds of their patients faced difficulties and needed further clinical support. It was also reported that setbacks were becoming more common because of the increased number of salvage procedures.

Another important observation from the study was that setbacks were described as emotional experiences and not just related to medical issues. Several participants described how specific events and social experiences had affected them emotionally. There was variation in the narratives about the timing of these emotional setbacks but some participants, such as Lyn and Valerie, described how they were still experiencing them many years after their surgery.

It was also evident in the data that setbacks were more common in the transitioning stage but also occurred much later after surgery and contributed to the care burden and strain. This was particularly noticeable for those primary supporter participants from a remote or rural location due to diminished supports and isolation. Another primary supporter, Tom (partner), described how his wife had experienced multiple problems with her tracheostoma and had required multiple procedures, which he described as taking an emotional and financial toll on him and his partner.

A few of the IWL, such as Jack and Lyn, talked about their need to live near the hospital where they got their care. After an emergency situation with his breathing, Jack and his wife moved to be closer to the hospital:

> *... well to be honest that caused such a fright that this place we are living in now became available brand new and we moved from ... about a half hours travel to the [hospital's name] to about 10 minutes which is a little more self-assuring. Jack, 69*

The IWL described how they chose different courses of action as they tried to adjust and get back to their pre-laryngecomy self and lifestyle. It appears that they were very active in trying to construct meaning related to the extent of their changed self-

identity, which was an ongoing process for them, even many years after their surgery. These constructed meanings were impacted by other factors such as social acceptability, social interaction, support levels, personal levels of achievement (e.g. education or occupation), timing in life, feeling responsible for the cancer and an individual's own interpretation of situations. Broader cultural issues also appear to impact their experiences. These are considered in more detail later in Category 6.

#### 5.4.2.2 Subtheme 4.2: Having mixed feelings (grateful, responsible, overwhelmed, resigned)

This was an important subtheme because the IWL reported a range of feelings about their situations. They felt:

- grateful for being treated and still being alive or having survived
- responsible for the illness due to smoking or the opposite if the diagnosis was not due to smoking
- overwhelmed and destabilised by the experience
- guilt or a sense of resignation.

The data suggest that these feelings changed at different times along the journey or in different circumstances. It was also evident that all participants did not experience all of these emotions. For example, Kath and Brian appeared to be stoic about their situation. Kath, like a few others, was a little uncertain about whether her smoking had caused her cancer, but later in the conversation she stated *[I] accept the fact that I brought this onto myself.*

Brian did not feel his laryngeal cancer diagnosis was different in essence to his lung cancer diagnosis and tried to accept his situation. He was also pragmatic about what treatment he needed to get better. He described his wife's reactions to her melanoma diagnosis and treatment as different, stating, *she took it a lot harder.* He said he advised her:

> *... well if it's got to be done it's got to be done; that's it, it's got to be fixed.*

Mary stated, *I just wanted to get (through) it to be alive*, and Annie said, *I was glad to be alive.* Like a few other participants, Annie was also philosophical about her situation:

> *They just say I take it good. I'm always happy. I've always got a smile. ... I just keep going on with my life. There is a lot worse than me love. No legs, no arms.*

Brian, who had been resolute in his responses about his situation and how he had adjusted, was asked if anything good came out of the surgery and he responded:

> *I don't think that you can have anything good come out of it. Well, you know, you've lost your throat and that but the only good thing is I save a bit of money now not smoking.*

Lyn reported that her TL was shocking and had a long-term effect upon her. She became emotional in the interview when she was asked to describe her feeling after the surgery. This part of the interview took over a minute and was characterised by long pauses. I prompted Lyn to describe if she had used strategies to help her cope. She described the efforts she had taken but had not been able to really come to terms with her situation. The disruption to Lyn's life and social roles appeared to have profoundly affected her over a long period of time:

> *I bought a book, when I was really bad, really bad and I didn't think that I was going to make it, I planned suicide a lot of times. I thought I would write a book and write it down. When I started to write, why am I doing this? ... I couldn't, I think I was too angry to write ... just my emotions get blocked. You lock yourself in the house, you don't answer the phone, you don't talk to anybody if you've got to go shopping, you don't do anything, you stay at home for weeks and weeks.*

Valerie also described it had been difficult and she even joked *it would be a blessing* if she stopped breathing at night-time due to poor positioning, but quickly added, *see now Colin gets annoyed with me when I say that.* She then berated herself and compared her situation to a public figure with profound disability, stating, *I still have a life compared to her.* Interestingly, throughout her interview, Valerie made contradictory statements such as these. She also provided details of positive and negative social interactions in her journal. I interpreted that the ambivalence in her statements and about her predicament were context-dependent and tied to a destabilised sense of self.

Hugh, on the other hand, seemed resigned to the changes he experienced. He said that he would rather not participate in a support group due to the effort involved with communicating.

> *Things become an effort. ... I would find it better to sit here and read a book. I really, really would. Isolation is the better of the options because it requires no effort. Hugh, 57*

The study results suggest that the level of ambivalence the IWL felt about their situation affected their resilience levels and abilities to cope with the losses and changes they experienced. The timing and stages of recovery were important factors

but so were context and social experiences. This important subtheme is discussed further in relation to the other subthemes in this category and Category 5. It has already been discussed in Categories 1 and 2.

### 5.4.2.3 Subtheme 4.3: Resuming meaningful activities

It is clear from the narratives that the resumption of hobbies or meaningful activities was in many cases an important turning point in the recovery journey. All the IWL described how they attempted, in one way or another, to return to activities that gave them self-expression and reconnected them to their pre-laryngectomy lives. Resuming meaningful activities was a strong and important theme in the data. It was also linked closely to Categories 1, 3 and 6.

Several of the IWL described a resolute sense of self and wanted to resume their lives soon after they were discharged from hospital. For example, Jack reported he could only communicate using a pen and paper but still wanted to go to his local RSL[4] for a drink:

> Well I tried to live my life as normal ... for example on the Thursday after I was discharged from the [hospital name], I said to my wife or wrote it, I think I will go to the club tonight which I normally do of a Thursday night.

Josephine, a senior speech pathologist, described how mastery of tracheostoma care could prompt an IWL to resume a hobby. She described one of her patients as taking a long time to recover and adjust emotionally to the changes. She stated that once he could care for his tracheostoma, he gained the confidence to go fishing again. Several of the IWL described how attempting to reclaim their pre-laryngectomy life was challenging. It was also evident that resuming certain activities or doing things as they had done them previously resulted in some realising their limitations, which caused them to grieve and feel demoralised. Thus, this subtheme can be linked with subtheme 3.1, Becoming aware:

> I have tried as I have said. I did go away not long after my cancer. I decided to go away, so my sister and I and my niece went overseas to England and I was fine until we got over there and three is a bad number to go away with ... because those two were talking all the time but you get left out. ... I was very much the third person and I think that was the time that I realised ... that was when the depression set in, and said that six months after I had the operation. Lyn, 63

This subtheme highlights the importance for the IWL of the ability to resume meaningful activities in relation to reframing their altered identity. It appeared that

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[4] Returned Services League (RSL) clubs provide support and meeting places for returned and active services personnel (army, navy, airforce etc) and their families in Australia.

many were very motivated to become independent again but it was difficult to predict when they would be physically and emotionally ready. It was also evident that the resumption of meaningful activities had been traumatic for some individuals. There was evidence that some experienced a destabilised or resigned sense of self when they could not resume all their pre-laryngectomy activities. This was an important observation regarding the reframing of the self after TL and has been explored in Category 1.

### 5.4.2.4 Subtheme 4.4: Finding purpose

There were a number of stories in the data where the IWL described the important and validating influence of being appreciated by others and finding purpose. This need for appreciation after a TL seemed apparent to some participants and tacit to others. It also seemed to be a source of frustration. Some participants described how they had sought meaning by volunteering, supporting other IWL or cancer patients, or becoming lobbyists and activists. Others described how they were pleasantly surprised when they were complimented on the intelligibility of their speech. A few reported how important it was for them to feel valued and needed by their friends and family. For example, Jack, Valerie, Brian and Lyn all said they had volunteered and/or supported other IWL or cancer patients. Both Jack and Pieter explained they had been politically active, with Jack stating he had joined a class action against some tobacco companies:

> *... after my laryngectomy operation I said to my GP and [surgeon's name] independently that I was joining a class action for [law firm's name] against the cigarette companies and I was going to ask for some medical evidence but they interrupted me and said, "Any medical evidence you want Jack in relation to your claim, don't hesitate to ask us we will supply it to you". Jack, 69*

Pieter described how he had lobbied his local MP regarding the expensive dental treatment he had endured after his TL and stated his concern that other IWL would not be able to afford it. Hugh described how he would have liked to be able to voice his opinion on many issues of the day, for example on talkback radio, but could not due to his unreliable communication. This was a concern also articulated by Pieter, who said he would like to lobby more but found his communication unreliable.

Many of the IWL appeared to be in supportive relationships. A few who were single described their need for *being needed*. This was an important and revelatory theme for Lyn, who described how her sense of purpose and resolve returned after

being *depressed* for a long time. A turning point for her was feeling that someone (her son and later her sister) needed her. She said it was at this time she decided to prepare her house for sale and move:

> *It has been 10 years and it wasn't until last year my son's marriage breakup and it was like I snapped out of this sleep that I had been [in] so long, it was something because, all of a sudden somebody needed me because up until then nobody needed me.*

Lyn candidly discussed the level of support and recognition she got from her family, and compared her situation with her sister who had just been diagnosed with breast cancer. She said that she had empathy for her sister's situation and wanted to provide her with the emotional support she had never had. Valerie described how appreciative she was for being asked to babysit her grandchildren, even though, for many years post-TL, she had decided not to do this because she felt self-conscious.

The narratives provide evidence that the IWL found meaning in their post-laryngectomy lives when they pursued certain activities such as supporting others, and when other appreciated them. The more isolated participants described the reassurance and certainty they felt when others appeared to need them. This theme is linked to the other categories.

### 5.4.2.5 *Category 4 summary*

| *Category 4 – Building resilience* | |
|---|---|
| **Subtheme 4.1 Coping with the losses and challenges** Developing strategies over time to cope with the changes and challenges, including setbacks. Considerable mental effort and both intrinsic and extrinsic validation required to re-establish meaning | *So it's really about saying, "Okay, I never knew that about myself" and you don't know until you're faced with it. How do you cope when your doctor turns around and says, "You know what, you've got less than 50 percent chance of survival?" You go, "Okay, so we've got to do our wills"; "What are we going to do if I die?" You know, "What are we going to do with the kids?". ... These are very confronting things. ... I managed to do that every step of the way by simply putting one foot in front of the other. Pieter, 61* |
| **Subtheme 4.2 Having mixed feelings (grateful, responsible, affected, resigned)** Experiencing a range of emotion related to illness, recovery, survival and personal involvement. Feelings at times contradictory and circular | *You said there was one man who said there was nothing good about this operation, except I would have been dead without it. I am so grateful for the 2 extra years I have had, you look at life so very different, when you have been through that experience. Kath, 72 journal entry* <br> *I don't know how to interpret that, it's been anger, it's been "Why me?" It's been the full gamut of emotions and depression. Lyn, 63* |

| | |
|---|---|
| **Subtheme 4.4 Resuming meaningful activities**<br>Attempting to return to pre-laryngectomy life and move forward | *… he was convinced that he would never fish again – how would he ever go out in a boat – but once he learnt to be able to manage his own valve, once he had come to grips with the emotional changes and was in a better place emotionally, he was able to make a constructive decision about, "Well, fishing's important to me so, you know, I'll wear my life jacket but I understand the risk and I'm still going to fish", so for him that was a turning point about, "Well, I'm going to still embrace things that are important to me in my life".*<br>*Josephine, senior speech pathologist* |
| **Subtheme 4.5 Finding purpose**<br>Taking on alternative and meaningful roles involving support, activism and awareness-raising. Tied to self-efficacy | *I joined the [hospital volunteers]. … I'm probably working harder now. I spend more time in there than I ever thought or imagined I would. Jack, 69* |

## 5.5    Part 3: The context

### 5.5.1    Category 5: Timing and turning points in the journey

A number of themes emerged from the narratives relating to temporal factors and the trajectory of recovery and adjustment. An important theme reported by the IWL was the timing of their TL in their lives and how this impacted them psychosocially. The data also suggest distinct intervention and recovery stages in the TL journey. These are explored here and represented by Figure 9. The personal and emotional journeys experienced by IWL and families were parallel to these stages, but not always synchronised across the different participants' stories. These phenomena are examined across several categories. It is helpful to view the data with the distinct care stages in mind because many of the stories relate to experiences at particular times of the journey. The changes participants experienced were multi-level and dynamic, and required differing levels or intensities of support at different stages.

**Timing and stages of the total laryngectomy journey**
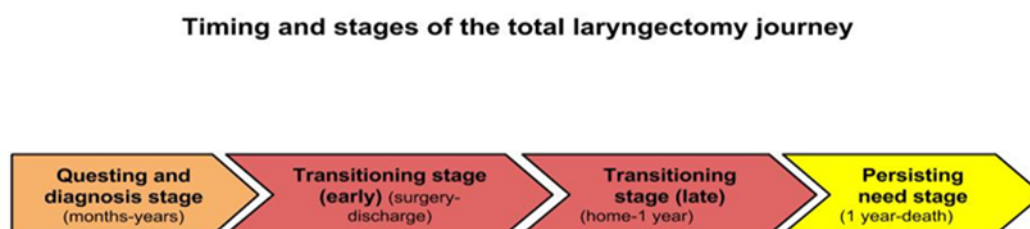


**Figure 9:    Timing and stages of the total laryngectomy journey**

Turning points in the journey relate to specific times in the recovery process where progress, adjustment or setbacks were experienced. They were characterised by physical, functional or emotional changes, and often impacted a person's psychosocial wellbeing. As discussed in Category 4, the resumption of meaningful activities and hobbies signified important turning points and increasing independence, and were validating for a person. Recovery and turning points appeared to be influenced by both intrinsic and extrinsic factors. The intrinsic factors related to the IWL's health status, and their ability to develop competence and build resilience. These issues have been explored in Categories 3 and 4. The extrinsic factors included experiencing the understanding of others and competent, responsive and adequately resourced care from primary supporters and healthcare providers. These themes are further explored

in Category 6.

### 5.5.1.1 Subtheme 5.1: Timing in life

Some of the IWL in this study reported that their age and career stage at the time of the TL was important to them. Many viewed a TL as something that occurred to people later in life and not earlier. There were comments such as, *I was only 50,* and *fairly young,* and *my wife was only 27 when she had it*. Age factors also appeared to frame the experience. Younger participants described how they had been unable to find and connect with peers to share their experiences, and had been subjected to looks of surprise by health professionals and others because they did not typify the common age demographic for TL.

Lyn's experience highlights that *age* is one of several biopsychosocial factors that influenced a person's experience. She said that a TL was a lonely experience because *there was nobody my age and the women I have met have always been older than me.* Lyn also described how she felt judged by others because she did not fit the typical presentation of a person who undergoes TL. She said it was a *male cancer,* affecting the *elderly* and individuals who had smoked. These stereotypes are discussed further in subtheme 6.5.

A number of the IWL described how they had derived a lot of personal meaning from their employment or certain activities, and the timing of surgery had a detrimental effect on their ability to work and their self-identity:

> *I was rocketing. It's kind of like someone takes an axe to your knees. Pieter, 61*

> *I did business in Melbourne and Sydney. ... I used to drive to Broken Hill, to the Barossa Valley. I might do that every month ... there was no problems at all. But now I don't like going out of my element, that is why I call it a very lonely cancer. You ... shut your emotions off, you shut everything off. Lyn, 63*

Valerie described how the surgery had affected her life and outlook. She appeared to indicate that the surgery had transitioned her to retirement:

> *No it has just affected my life I guess. I mean when people speak to me, they don't always say, "Did you smoke?" They will say, "What happened?" ... and I will say, "I retired". I call that retirement because that is when it happened. ... I mean it just changed the whole outlook.*

The impact of the disruption of the surgery on participants' social role has also been explored in Category 1.

### 5.5.1.2 Subtheme 5.2: Questing and diagnosis stage

In this stage, the IWL described their quest to get an explanation for hoarseness or breathlessness. In many cases, this took a long time (several months to several years). This distinct stage is highlighted in Figure 9 as the first important stage of the TL journey. Establishing a diagnosis involved a range of individuals and there was often a period of not knowing. This subtheme can be tied to subtheme 3.1. Many of the IWL and primary supporter participants reported that when they made initial contact with a GP, the IWL were frequently treated with antibiotics to manage hoarseness or steroids to manage breathlessness. Participants were sometimes given several courses of treatment or experienced ambivalence from the GP due to their smoking history before being referred to an ENT specialist for further investigation. The data suggest that many GPs did not have the expertise to refer promptly. For example, Jack described how he had a *raspy voice* for several months and was treated with several courses of antibiotics before he requested another opinion due to worsening symptoms:

> I said to my GP, "Look this has gone on for 2-3 months and all due regards I think I had better see someone else about this one because it is getting worse". So he made a phone call and ... I went and saw ... Dr [surgeon's name] at the Royal Adelaide who inspected me and said that I had tumour and that he would like me to return ... the following Thursday for x-ray scans etc. and then come back the following Monday for the results. I went and on the second one he didn't even say "G'day", he said, "Did you bring your toothbrush because I want to operate at 7am in the morning?"

Similarly, Lyn experienced symptoms that affected her breathing. After a *scary* episode of breathlessness, her GP misdiagnosed her symptoms and treated her for a few months with antibiotics for a chest infection. She and her doctor were surprised a benign tumour caused her airway obstruction.

The IWL and primary supporter participants described how the long wait for the diagnosis was starkly contrasted by the rapid action and *sudden* interventions that followed. Becoming a patient of the hospital system occurred quickly, with little room for negotiation due to the urgent and critical nature of the diagnosis. Some reported that they were told to go and have their planned holiday or complete a project. However, most had the radical surgery straight away due to advanced disease. The IWL said they found themselves in the care of a highly specialised group of people and that the treatment they received was aimed at preserving their life but was not without risk. This experience is explored more comprehensively in Category 6.

Some of the IWL and the primary supporters reported it was their first

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experience with specialist medical care. Many of the IWL and primary supporters in this study had not heard of the procedure and thus had little background knowledge about what it entailed or what the consequences were. Some reported that they had the benefit of a partner or family member with healthcare experience such as nursing or having looked after a sick relative. Others described multiple health issues that had brought them into contact with the healthcare system.

Understandably, the diagnosis resulted in shock and grief. Many of the IWL described how they had little time to fully comprehend the veracity of the situation or the changes that subsequently occurred. It seemed that the development of trust was really important for the success of the treatment and recovery process. For example, Jack said he felt his surgeon was realistic and this helped his decision making. Brian reported he was also confident the doctors would help him with his laryngeal cancer. Len said he really had no choice but to have the surgery:

> *They more or less told me that I got to have surgery… I didn't care as long as they bloody cleared it up.*

Rose (partner) described how she and her husband remained determined to *beat* the

cancer:

> *I said to [husband's name], "We'll beat it" and he'd say, "Yeah, we'll beat this bloody thing", and hopefully so far we have. I think being positive is half the battle. … I think I'd fight it until the bitter end.*

Bill was shocked when he was diagnosed but quickly accepted it because in his mind a cancer diagnosis was so prevalent. He responded to the news by inviting a group of friends to his caravan (home) to have a few beers. In contrast, the diagnosis was traumatic for Christopher. He described how he had contemplated suicide but that his son had talked him out of it. He had other serious health problems at the time of his laryngeal cancer diagnosis:

> *… it was a lot of persuasion, … I had my rope in my garage. My stool with broken legs. Deliberately I broke legs not to have any chance to you know climb, survive … I was so serious, I remember well. … one of the boys or at least one said, "Dad try". … "What do you have to lose?"… He didn't say, "Try for Mum", "try for us" or "try for yourself", just simply "try". I never before [sic]. I'm always curious person, I was curious what will happen to me.*

Lyn, Valerie and Kath also mentioned that they had suicidal ideation but that these thoughts came later after their surgery.

This subtheme highlights the emotional vulnerabilities experienced by both

the IWL and the primary supporter participants. It was an important stage because it signalled the beginning of the disruption from the pre-laryngectomy to the post-laryngectomy self. It also marked the beginning of the relationship with the health professionals who provided the specialist head and neck cancer care.

### 5.5.1.3  Subtheme 5.3: Transitioning stage (early and late)

The data suggest that the immediate post-operative care phase was a distinctive and important period. It involved the acute hospital recovery period and marked the beginning of the transitioning period in which individuals had to learn to live their lives without their larynx. This transitioning period appeared to occur over the first year after surgery and could be further distinguished into early and late stages, as highlighted in Figure 9.

*Early transition*

In the early transitioning stage, the IWL described how they experienced a lengthy procedure and intensive medical care needs during the early recovery stage. The health professional participants reported that the treatment often involved multiple specialist surgical teams if reconstruction was required (e.g. head and neck surgery and plastic surgery), and that there was a hierarchy of care needs. They reported that airway and wound management were the two areas which received the most attention in the early stages of recovery, followed by swallowing, then communication and emotional needs. The issues of shock, dignity and communication difficulty that characterised this period have been discussed in the earlier Categories 1 and 2. The IWL and primary supporter participants described the experiences of IWL being dependent for even their basic needs, and having multiple tubes for waste and nutrition purposes. They reported they felt vulnerable and uncertain at this early stage:

> *I was absolutely bloody terrified because as I came out of the anaesthetic, I couldn't breathe and I couldn't speak to tell them. Hugh, 57*

> *It is a dreadful operation. It's such a big operation. Your throat is cut right across. Kath, 72*

The primary supporter participants described how their loved ones appeared swollen and disfigured in this early stage, with staples in sutures. They reported they were alarmed, shocked and disturbed by this, particularly on the first visit. The IWL reported they often requested family and friends to stay away at this time.

After the long, all-day operation, Rachael reported her shock when she saw a very

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different looking person to the one she had left in the morning sitting having a cigarette:

> *I didn't know what to expect. You know, the recovery room and – and I think the look ... on my face made him look worse because I was just, "Oh", because ... you've got all these ... tubes and everything and it was scary. Rachael, 53 partner (group interview)*

Pieter reported that he was more concerned for his wife and daughter than for himself. After the surgery, some participants described their realisation that they had no capacity to voice or communicate like they used to. Some reported that they were unprepared and may or may not have received pre-operative education about the experience. Pieter, 61, stated *nothing prepares you,* and Jack described his initial shock. In Category 1, some of the IWL highlighted the significant impact and experience of helplessness related to not being able to communicate in the early stages of recovery. They gave examples where health professional staff did not implement even simple 'yes/no' systems.

There also appeared to be a range of other issues the IWL faced in this study at this critical time. For example, Annie described the time after her surgery where she not only had to get used to her appearance and communication difficulties but also physical disability. She explained how she adapted her showering due to nerve weakness in her shoulder. The nerve damage had resulted from the surgery.

The IWL reported that when they were physically able, there was a period where they could only communicate using basic methods (pen and paper); a period during which they often felt their needs or wishes were ignored. Interestingly, in subtheme 1.1, Edward the surgeon explained that time factors often affected his interactions with his patients and he found this frustrating. The data suggest that this period lasted for varying lengths of time for each of the IWL and was dependent on when they acquired an audible ACM. It also indicates that this was a particularly difficult time for those who lacked supports. The health professionals described this as a period of intense training and development of competence in relation to self-care, and referred to many factors affecting discharge. These issues have been discussed in Category 3 and will be discussed further in Category 6.

*Late transition*

It appeared that after discharge from hospital, IWL and primary supporter participants experienced new and different challenges, particularly in the first year after the

surgery. The late transitioning stage occurred from the time of discharge home and encompassed the rest of the first year after surgery. In this stage, some of the IWL described how they had more treatment, for example radiotherapy or corrective procedures such as dilatation for strictures affecting swallowing. The issue of setbacks has been explored under subtheme 4.1.

Rose (partner) described how her partner was readmitted to hospital several times in the late transitioning stage because he started chemotherapy but experienced a drop in platelets, so he commenced radiotherapy. She said her partner's mood improved after being discharged home:

> *He hated that, ... towards the end he'd cry before he went in to have it; it was just too much... He'd come home for a couple of days and then he'd go downhill and say, "I want to go back". It was almost like a comfort thing for him to be back there. Rose, 65 partner*

The data indicate that during this stage, expressive communication continued to be problematic for some of the IWL. This subtheme is tied with the earlier subtheme 3.2. The IWL reported that they experienced months, and perhaps a year, without verbal communication. Jack described it was almost a year before he had SVR and could talk verbally. In another narrative, Helena described how her partner had been discharged from hospital with persisting trouble with his voice prosthesis. She described how he had accepted this and that his social group had also accepted his communication difficulties:

> *Since we've been home [loved one's name] enjoys having a drink so he goes down to the hotel with his little board and all the rest of it and everybody ... they've been wonderful, absolutely marvelous. They talk to him and they have a conversation with him on the board and ... it really has been terrific. Helena (nk), partner*

Other late transition issues for some of the IWL included swallowing problems. However, many problems tended to resolve or become more manageable after the first year. Alternative feeding may have continued for part or all of the first year. During this stage, the health professional participants explained that there was a need for ongoing education of the patient and their family. They reported that this was because individuals often did not fully absorb information in the earlier stages of care due to information overload or grief and loss reactions. The issue of education and raising awareness have been discussed more comprehensively in Category 3.

### 5.5.1.4 Subtheme 5.4: Persisting need stage

The final stage in the TL journey, represented beyond the first year after surgery, is

highlighted in Figure 9. This was the long-term stage when the health of the IWL continued to be monitored or needed further rehabilitation, equipment or emotional support. Several primary supporters described their ongoing supportive role; an important theme that is also explored extensively in subtheme 6.4. Fay, for example, described how she ensured the availability of her partner's voice equipment, saying she takes in her *handbag ... all our junk with us* for the *speech box.* Tom (partner) described how his partner had ongoing health issues and how this impacted their relationship:

> *[partner's name] and I ... find it really hard to sort of feel happy in our lives at the moment. Nothing seems to be going right for us and, with my job, that's just put more pressure on us, and with [partner's name] going to hospital on Monday. ... I think ... she needs a Fly Buys card for hospital ... I kind of get a bit sick of going to hospitals all the time.*

Another issue was related to the acceptance of the physical changes and how this impacted others long-term. Pieter discussed how he perceived his wife accepted the ongoing reminders of his physical changes:

> *I know sometimes my wife tends to ... look the other way or she'll go and do something else. ... I have a feeling that it makes her slightly uncomfortable ... So I think it's more that she's thinking, "I wish he didn't have to put up with this" rather than "I'm upset by the stoma itself".*

Another feature of this stage strongly represented in the data was that community care was limited and often the IWL relied on being able to see specialist health professionals; a situation reported to be problematic for individuals who lived remotely. The data suggest that it was the surgical team and the speech pathologist who maintained the longest contact with IWL and their families. These issues also impacted primary supporter support and are explored more extensively in Category 6. It appears that long-term adjustment in this stage related to all the other categories as well as socio-cultural factors such as gender, age and geographical location.

### 5.5.1.5 *Category 5 summary*

| Category 5 – Timing and turning points in the journey | |
|---|---|
| **5.1 Timing in Life**<br>Age and stage of work career | *... she was pretty young, 27, so she would be one of the youngest to have that procedure done. Tom 36 (partner)*<br><br>*But all gone. I've been pensioned off, literally. I just basically sit around here do a bit of reading, work on my model. Hugh, 57* |

| 5.2 Questing and diagnostic stage<br>Knowing something is wrong,<br>waiting and getting the diagnosis | *Questing*<br>*I'd been in a few months before to see a doctor and she told me that I had a chest infection, if not ... asthma. So I had lots of antibiotics. ... I was still short of breath, I thought I'd got a bit of asthma. ... It started to get really bad ... so I saw a doctor and he said ... "No you haven't got asthma". He sent me for an x-ray. They said you had better get straightaway to the doctor and go straight down and have an MRI, so I did. I was in hospital that afternoon because I was breathing through the size of a straw, that's how big my airway was and that is why I was getting so short of breath ... and ... I just thought it was asthma. Lyn, 63*<br>***Diagnosis***<br>*I tried to be as realistic in the current circumstances as possible and one I had to have an operation and ... I had no option but to put 100% faith in the outcome of the operation. Jack, 69* |
|---|---|
| **5.3 Transitioning stage**<br>Recovery after surgery, getting home, managing<br>ongoing issues | *Early transition*<br>*Initially, a hell of a shock when I came out of the operation and wanted something and I thought, it just hit me then ... I can't talk. ... Prior pre-op I hadn't given it much thought. Because really when you think about it, it all happened so quick and possibly that it's a good thing 'coz I never had time to procrastinate or think about outcomes or anything. Jack, 69*<br>***Late transition***<br>*... he'd be really grumpy and I'd go to put his food in his PEG and he'd crack up. It's really hard. ... I could have killed him sometimes. Not literally, but I'd just get so mad with him ... The day he could actually get rid of it and start to eat properly was just like a celebration. Rose, 65 partner* |
| **5.4 Persisting need stage**<br>Ongoing dependence on health professionals and others, maintenance of health and audible ACM | *I mean we didn't expect troubles with the prosthesis but we've got them so now we've got to cope with that. So you can't really make plans at this stage until everything settles down. Helena (nk), partner* |

### 5.5.2  Category 6: Being supported

In this category, I explore how extrinsic supports were external validating influences for the IWL as they adjusted to their changed circumstances. These supports related to getting competent care, perceiving holistic care, having strong social networks and experiencing adequate resources, and general awareness. The role of others in the care continuum and more generally in the lives of individuals is also be explored here.

In general, the IWL and primary supporter participants described mixed experiences of care support and the acceptance of others in relation to the TL journey.

They contrasted quality care experiences with those of poor care and described how, whilst some people had been very accepting of the changes, others (including friends) had not. Reports of better care and social acceptance seemed to be related to expertise, empathy, understanding, the development of trust and resourcing. It appeared that the primary supporter role was significant during the entire TL experience but that some particular stages were described as being more demanding, as highlighted in Category 5. The factors impacting the primary supporter experiences are also discussed.

### 5.5.2.1 Subtheme 6.1: Getting competent care

This subtheme was a large and important one in the data. IWL and primary supporter participants described their vulnerabilities in needing the competent care of specialist health professionals who became very significant in their lives and had a profound influence. The frustrations these participants reported related to poor awareness and reduced competency displayed by some health professionals. It was evident that the health professionals interviewed were well aware of some of the issues patients faced but were frustrated by competency and resourcing issues, which prevented patients accessing optimal care. These issues are explored extensively in the subthemes 6.2 and 6.5.

Collectively, the health professionals interviewed had 70.9 years' experience working with this clinical population and were representative of the typical MDT at each tertiary hospital in Adelaide. The group included a head and neck surgeon, a nurse, two speech pathologists, a dietitian and a social worker. In addition, I interviewed a community-based speech pathologist. The health professionals reported that other disciplines typically present in the MDT were plastic surgery, radio-oncology, medical oncology and dentistry. All the health professional participants emphasised the importance of the specialist MDT approach to TL care. However, there appeared to be consensus that the MDT provided intensive support for physical and functional needs, but less support for emotional issues. This is explored more extensively in subtheme 6.2.

Many of the health professional participants referred to the need for joint effort and collaboration across disciplines to successfully care for IWL. They reported that this occurred in the two settings where they were based. However, Samantha, the community-based speech pathologist, felt this less strongly because she was not a member of either MDT. Samantha, along with the IWL and primary supporter

participants, perceived the MDT health professionals as the experts who provided optimal care. Samantha indicated that her ongoing involvement was valued but that she felt peripheral to the MDT in relation to the management of IWL. Interestingly, the data also suggest that the stakeholders within the MDT also experienced different levels of contribution and decision making about a patient's care. The MDT was reported to be hierarchical, with the head and neck surgery team taking the lead coordinating role. The other team members (allied health professionals and nurses) were described as being complementary to surgeons. For example, Maria, senior head and neck nurse, stated *nothing's nurse initiated, it's all doctor initiated.* She discussed the approach to the complex care for this clinical group, describing the specialist nursing available on the ward she worked in:

> *We have a protocol – day one, day two, day three and … I know automatically…. To have the ideal patient would be fantastic and the ideal pathway but then as incidents occur we have to deal with it.*

It was clear that the health professionals were very motivated to support IWL and that they did this in different ways. For example, the surgeon described how he prioritised the treatment due to the life-threatening nature of the disease, strongly desired success and tried to minimise risk, striving for cure and good outcomes. All health professionals agreed that they adapted their care for each client due to different care needs. In many cases, all participant cohorts appeared united in *fighting* the cancer or health issues but that it was a *big commitment* for all sides. As already discussed in subthemes 3.1, 5.2 and 5.3, many of the IWL and primary supporter participants described how they trusted their surgical team and MDT to suggest the right treatments and assist them to manage their health crisis.

All participants described how *communication* was critically important amongst team members, and between the MDT, the patient and their family. The participants who were members of a MDT described how they liaised throughout a patient's care in both formal and informal ways. Scheduled meetings and ward rounds enabled incidental discussions and they regularly participated in case meetings. These structured discussions were perceived as crucial and facilitated a culture of *open* dialogue. The MDT participants reported that the team approach promoted investigation, evaluation, troubleshooting, problem solving, decision making, care coordination, risk management and discharge planning. They appeared to use specific and technical language but reported they endeavoured to develop a relationship with

each client. Overall, the data suggest the health professionals in the MDT attempted to inform and present a realistic picture. Tessa, senior speech pathologist, stated this could only be achieved by all team members providing a *consistent narrative*. She explained that the complexity and nature of care meant people would develop long-term relationships and possible attachments with many of the health professionals in the specialist team and vice versa: *you just build relationships and I think you just become quite attached.*

The IWL and primary supporter participants also commented upon the importance of good communication, accessibility, attitude, knowledge and skills:

> *The head and neck surgeon. I don't know whether he's pre-eminent but he is pre-eminent to me. ... if my wife was there she would ask questions and he would get back to her and explain all the things. He's probably the most caring man I've ever met. Pieter, 61*

> *Most days the doctors would come round but a lot of the time it was a student. They were all very good and if I had any questions or anything I'd ask them and they'd explain it to me or they'd get the dietitian or speech pathologist to come down and ... they were very good. Rose 65, partner*

It appeared that this ability to build relationships was reliant on the health professionals demonstrating competent skills in TL care. The specialist health professional participants described how they used their clinical judgement and knowledge to support their practice. They said they often predicted and planned care for patients by using clinical reasoning and their previous experiences with other IWL. These participants identified that to build trust and provide assurance and guidance to patients they needed a range of generic as well as discipline-specific skills. These included being a *skilled listener* and communicator; being able to provide basic counselling; being pragmatic and flexible; using clinical reasoning; being reflective practitioners; being able to problem solve and troubleshoot; and having perseverance, knowledge and technical understanding:

> *Then there's the high level of troubleshooting when things aren't straightforward. Josephine, senior speech pathologist*

> *Oh it's a huge role. It starts from the day they're admitted to the day they're discharged and lots of nursing interventions, lots of education, lots of reassurance. Maria, senior head and neck nurse*

A very important issue for all participants was the relationship of competent clinical care to knowledge acquisition. Few of the health professionals reported they had received undergraduate training. It appeared that there was a novice-expert continuum

where in-depth knowledge, exposure and thresholds of experience with laryngectomy care assisted development. The speech pathologists who were interviewed reported they preferred structured, on-the-job training and mentoring to acquire the relevant skills but this was not always available, particularly outside the tertiary system. They also described the importance of maintaining skills and knowledge, and said this was tied to thresholds of exposure and resourcing levels.

The data suggest that many non-specialist health professionals were also involved with the care of the IWL during their treatment and later when other health issues needed to be managed. The IWL and primary supporter participants reported they could easily determine a health professional's level of competence and were frequently subjected to incompetent care. They stated that this was a source of significant frustration, worry and burden for them, and affected the morale of some, particularly in the early stages of recovery. The impact of perceived incompetent care is explored further in subthemes 6.2 and 6.4.

The IWL and primary supporters described how they frequently encountered health professionals in all healthcare settings (e.g. GPs, emergency physicians, nurses and temporary staff) who had a poor understanding of TL and the breathing needs of an IWL, and found it difficult to provide effective assistance. Examples included health professionals who tried to apply an oxygen mask to the face or asked a person to cough from their mouth, or who did not provide sensitive or empathetic care:

> *Some of the nurses were, really good, really compassionate when they were cleaning out the stoma, before you do it yourself, but some were really not. They didn't understand that when you poke around in there it kind of makes you feel, at least in the early stages - and even today it feels really strange. So, you know, didn't have that level of empathy that I thought would have been really helpful. Pieter, 61*

In the case of GPs or other health professionals, this lack of understanding may persist well beyond the acute recovery phase and first year after surgery. According to the surgeon interviewed, Edward, the education of GPs regarding TL is *limited to training as medical students in ENT unit*. Despite this lack of experience, the expectations of GPs are high. They are expected to counsel people to stop smoking and to refer to ENT early if hoarseness is suspected.

The specialist health professionals reported on how they mentored, educated and trained inexperienced health professionals, primary supporters and community practitioners. The senior speech pathologist, Josephine, reflected upon the way in which things had changed and that there was much more support for inexperienced

staff now:

> *I think a lot of work has gone into developing junior clinicians now. ...we have some laryngectomy competencies that we've developed. We have quite a structured, supervisory type approach to laryngectomy now.*

Maria, senior head and neck nurse, identified that inexperienced nurses needed on-the-job training because they had not learnt to apply their university-based knowledge:

> *I say to them, "You need to know your anatomy and the functions of your epiglottis, your larynx, your thyroid's attached – and your trachea".*

Josephine, who worked in a smaller unit than Maria, identified that speech pathologists in her team often had to retrain nurses to ensure appropriate care. She also identified this as a resourcing issue. This is explored further in subtheme 6.5.

The community speech pathologist, Samantha, described how managing an IWL was challenging from a competency perspective. She said:

> *It's a tiny area for us and especially only having one person that's consistently coming to get it changed here.*

Samantha described how she and her colleagues needed the specialist health professionals in Adelaide to support them but that there were issues relating to staff retention. Josephine, senior speech pathologist, described how difficult it was trying to support people after they leave hospital, particularly if they live regionally:

> *Trying to support people in their region can be challenging. Obviously we have the expertise and it is an area that people do need to feel comfortable with, but trying to support 'speechies' out in the country can be more difficult, or trying to support the patients so they don't have to be coming back to [hospital's name] all the time.*

Several of the specialist health professional participants identified that advances in telecommunications had meant they could troubleshoot issues using expert forums, provide training to other health professionals or telehealth to IWL in remote/rural locations.

All participants identified the importance of expertise in TL management. However, the development of competence in TL care was described as complex and resource-intensive. There was evidence that expert care provided the IWL and primary supporter participants with reassurance and important guidance. However, there was a level of concern that the care provided was not always holistic, and that there were a number of inexperienced health professionals who did not have accurate knowledge of TL and were not confident with managing airway issues post-TL. This

was explained in part as a resourcing issue. Subtheme 6.5 will explore these issues in greater depth. The next subtheme, 6.2, further expands the important role health professionals appear to play in supporting IWL to adjust and build their resilience over time.

### 5.5.2.2 Subtheme 6.2: Perceiving holistic care

This subtheme related to the importance of care extending beyond physical and functional support. It highlights a perceived need for increased psychosocial support and barriers to this. The identified barriers included resourcing, appropriateness of services, and individuals' attitude or readiness to receive supports. While this subtheme appears to be linked closely with subtheme 6.1, it suggests that receiving competent care was only part of the picture. The data clearly establish that the relationship between the IWL, the primary supporters and the treating health professionals was a really important validating influence. However, there appear to be some issues preventing consistent and holistic care.

A few health professional participants reported that the timing of the first meeting, the stage of treatment, the intensity of contact and the length of involvement over time influenced their relationship with each patient. Some described the benefits of seeing a patient and their family in the questing and diagnosis stage. However, the nurse and dietitian described how they often did not get to meet a patient before surgery. They explained that this was problematic due to the communication limitations experienced post-surgery making it difficult to establish clinical baselines, support needs and rapport:

> *I think if you haven't met the patient beforehand you don't have a sense of them as a person. I think the lack of communication can change your perspective because the person can't communicate themselves freely so they are reliant on someone else to be their voice or laboriously writing out everything that people want to know. I think you are able to interact with them more easily having had that previous experience with them. Josephine, senior speech pathologist*

> *… best practice care from my perspective would be to see them all pre-operatively, to do a baseline assessment because doing that assessment post-operatively with the lack of communication is difficult. Matilda, senior dietitian*

In Categories 1, 2, 3 and subtheme 6.1, the IWL highlighted that they experienced limited empathy and psychosocial support from some health professionals. They said these experiences were usually the result of poor knowledge and skills or resourcing but also related to bedside manner. These competency-related issues were discussed

more comprehensively in subtheme 6.1. The participants described how these experiences made them feel isolated, demoralised and stigmatised. They identified a need for further training. The IWL reported that reduced support from health professionals also resulted in their need for additional support from their social networks, which increased the burden and strain experienced by the primary supporter participants, as described later in subtheme 6.4:

> *I think they are of necessity, and I guess time-wise, focused on making sure that your body gets through the process so you get the painkillers but you don't get the counselling. ... Just that little bit of time and background. A bit more holistic approach. Pieter, 61*

> *I think if there was nurses who had some sort of course or some sort of training and able to say, "I'm laryngectomy accredited". So therefore they would have a bit of insight and they won't treat you like an oddity. Lyn, 63*

The health professional participants identified that they also needed to allow for their patients' emotional experiences, and to a lesser extent the emotional experiences of the primary supporter. However, they often felt that they could not, and that this situation would only improve with increased funding for counselling services and a specialist head and neck nurse. The surgeon, Edward, said *having specialised nurses* and *a nurse practitioner would really help.* He identified that:

> *... accessibility for the patient, patient education, support would really help and said that doctors don't really provide that very well.*

Josephine, senior speech pathologist, reiterated the need for:

> *... a head and neck cancer nurse that could see people, inpatients and outpatients, to try and take on some of that coordination role and education role and have a presence on the ward.*

She also identified that *early* rather than *reactive counselling* and a *really strong source of equipment* were important.

Interestingly, several participants described how they did not expect health professionals to really understand their emotional needs. This appeared to relate to subtheme 4.1 and the approaches individuals use to cope with their situation:

> *... the patient and the people around them have to find their own mechanism for support for each other. ...at times I felt I was carrying my own weight as much as my [family's] because there was so much pressure on [them] I think any real interference in that cycle is probably more likely to be counterproductive than anything else. Pieter, 61*

> *When I was having troubles the speech pathologist recommended me to a psychologist ... but I didn't find her any help at all, well she was very sympathetic ... she kept saying, "How did that make you feel?" Well it made me feel terrible, that*

This subtheme reinforced the importance of the development of a trusting and collaborative relationship between the treating team and the IWL and their primary supporters. However, it appeared that whilst specialist services were provided there were gaps related to the type, timing and consistency of care. The IWL and primary supporter participants wanted all the health professionals they encountered to be empathetic, pragmatic, knowledgeable, genuine and reasonable in their practice. However, it was reported that experiencing empathy and psychosocial support was an inconsistent experience. There also appeared to be some reticence amongst a few IWL regarding the role of health professionals in providing psychosocial support.

The health professional participants identified that gaps in providing holistic care related to competence and resourcing. There appeared to be strategies in place to manage some of these issues and a desire for expanding specialist services to include a nurse practitioner. Additional discussion regarding resourcing is provided in subtheme 6.5. Finally, the data suggest that experiencing empathy and having needs understood has a validating and reassuring effect on individuals. In other words, an empathetic and holistic approach communicates to individuals that their needs are important and they are being taken seriously.

### 5.5.2.3 Subtheme 6.3: Having social capital

The health professional participants described the significance of a person's close relationships and social supports during the TL journey. The data suggest that the role of a close and supportive partner or primary supporter is important, and was highly valued by the IWL and health professional participants. The primary supporter participants detailed their loyalty, sense of duty and stoicism during the experience. It appeared that they were witness and companion to the experience. These concepts are explored more extensively in subtheme 6.4. It also appeared that the attitude, level and type of support (e.g. emotional and physical) a partner, family members and friends provided were very important and influential for the IWL.

The following quotes provide evidence of how the health professional participants judged the influence of social capital for an IWL's outcome:

> *I probably need to be less involved with them because they do have better coping skills; they have better support systems. They will often have a spouse. The other ones often have a lot of burnt bridges. … I would imagine that they would have better outcomes because of the psychosocial aspect. Helen, senior social worker*

> *The ones who do well are those with good family support. Those who have got none or minimal family support or continue to smoke and drink alcohol, they won't do well. Edward, surgeon*

Senior dietitian Matilda believed the level of education and social circumstance (e.g. family and friends) could perpetuate negative lifestyle choices:

> *It's not uncommon for the patient to be in hospital post a total laryngectomy and the wife's coming in reeking of cigarette smoke and obviously they're going to go back home to that environment where that's happening around them.*

The IWL in this study presented with varied social circumstances. Some had very little extended family or were estranged from their families. Others had large families with adult children, brothers and sisters, and grandchildren. Most of the participants perceived social capital as advantageous, even those who did not have a partner or other primary supporter. For example, Lyn, who did not have a partner, said she thought individuals with partners experienced more support because the partner could assume some of the roles. Christopher also described how being single required more mental effort because he had to be prepared for the worst-case scenario should his chronic back problems incapacitate him.

The IWL reported a range of reactions from their families, with some being very supportive and others less so. These responses appeared to be external validating influences for them. A few participants described negative experiences with family members and friends where they felt misunderstood, stigmatised or shunned. Some of the difficulties faced related to reduced understanding or fear, for example some grandchildren did not react well to the changes, or other family members did not modify their expectations or situations to accommodate the difficulties the IWL experienced. For example, Lyn described how she found family gatherings challenging and often chose not to go. She discussed how her family were all young adults with their own busy lives and not much time for her:

> *If my family would have been more supportive, just to say … to me, "How are you going?" Rather than treat me like nothing has happened. … I don't go to family get-togethers or anything, they're noisy. [They] don't even say to me, "Why aren't you going?" I have told them that they don't seem to make any allowances.*

IWL and primary supporter participants also described the importance of close friends during the journey. It appeared in some cases that friendships assisted the IWL to build their resilience and had a validating influence. For example, a few IWL reported that one of their motivations to resume a meaningful activity after discharge, such as going to the pub, was to see their friends again:

*...as soon as I had this done I went to the pub and seen all my mates and they're giving me stick and having a joke. ... there was no big deal. Brian, 59*

Unfortunately, the data suggest that not all of the IWL enjoyed this level of social success. The primary supporter participants described how some friends were very supportive and others had been less understanding. Some of these issues have been described in Categories 1 and 2. It appeared that distant friends were less reliable and more likely to drop away, and some participants reported that the IWL experienced reduced contact, fewer visits and were no longer invited to participate in social events. Some of the data representing this change of circumstance was provided earlier in subtheme 1.2.

Having social capital was an important and multidimensional theme to emerge from the data. Many of the IWL described a range of social supports but it was clear that the TL impacted some relationships. A few participants reported that they experienced a lack of empathy from family and friends, and this affected them. This has been explored more deeply in Categories 1, 2 and 4. The role of a primary supporter as an important source of social support is explored more extensively in the next subtheme.

### 5.5.2.4 Subtheme 6.4: Being there

The narratives suggest that this subtheme, which highlights the supportive and valued role of the primary supporters, is an important phenomenon throughout the TL journey. Like expert care, support from a partner or close confidante appeared to be another important external validating influence during the TL journey. The data suggest that the primary supporter participants provided unwavering, flexible and dynamic support on many levels; emotional, physical, protective and social. There appeared to be a pattern of these participants 'being there, taking charge and then pulling back' over the journey in relation to the communication and other physical limitations their loved one experienced. The extent of the emotional impact of the experience for the primary supporter participants is also explored in this subtheme and has been discussed in Categories 1, 3 and 5.

In subthemes 3.3, 5.5 and 5.4, I explored how the primary supporter participants often assumed a lot of care and social responsibility. They said they were frequently educators and demonstrators for inexperienced health professionals. They described how they were a calming, comforting influence or had a *perking* effect at

the time of diagnosis and during a hospital admission. This view appeared to contrast with the IWL describing how some primary supporters were upset by the diagnosis and in need of emotional support. There were obvious emotional impacts on partners and families of IWL like Pieter and several others. The accounts suggest that the partner's experience contrasted with their own acceptance and ability to cope. Pieter said he had to support his wife emotionally whilst supporting himself pre-operatively and during early recovery *because she was suffering very heavily under the strain. So it becomes a double whammy.*

Other IWL described how the diagnosis affected them and their partners. There appeared to be a notable difference in the quality of the experiences:

> *To be honest I think it affected her more than it affected me. … I think she was more scared of the outcome and the unknown. Where conversely you could say I was in a fool's paradise. I tried not to let it worry me and … I just sort of somehow accepted that I got it and had to get rid of it. Jack, 69*

The data suggest that the primary supporter participants were aware of their own uncertainties and emotions during the journey. Subtheme 3.1 highlighted that many of these participants were initially daunted by the anatomical changes from the TL and were not prepared for the magnitude of the experience. However, education and support helped them develop confidence and teach others. For example, Rose (partner) described her initial shock and disorientation: *Looking back now it just seems like I went through it in a trance.* A number of primary supporters described how, in the early stages, they tried to just take it *one day at a time*.

There appeared to be evidence of a phenomenon of supervigilance in the data. This can be linked to subtheme 6.1. It typically occurred in the early transition stage. For example, several primary supporter participants reported they did some of the nursing duties because they were concerned about their partner's care, such as suctioning, showering and enteral feeding. They described how they compensated if they felt the care of their loved one was compromised, for example they stayed all day and all week for weeks at the hospital, or felt that the nurses wanted them to be there. Fay (partner) reported, *that was the most worrying time for me.* Like Rachael (partner), she spent all day at the hospital:

> *I was there from eight o'clock in the morning until seven o'clock at night. … he had good nurses and he had some terrible nurses. I'd clean his valve. I changed his feeding thing because some of the nurses didn't know how to do it. … so I said, "I'll do it". "Oh, could you, please?" Rachael, 53 partner*

Primary supporter participants also reported that they provided important support, particularly with the discharge home and late transition stage:

> *Then he even got to the stage where he wouldn't have a shower. I'd go … in the morning and shower him and the nurses would say, "We can't get him to shower", and I'd say, "Oh I'll do it", and then he'd do it. Rose, 65 partner*

The data imply that the resourcefulness of the primary supporter was important and related to the individual's own resilience levels rather than their gender. The primary supporter participants described how they changed their plans, roles and social lives to accommodate their loved one's changing support needs. For example, in the questing and transitioning stages, couples had to change and adjust plans such as travel. In the persisting need stage, the primary supporter participants reported how they reduced or adapted their social activities:

> *You can't prepare, I don't think; you've just got to take it as it comes. …I mean we had plans, of course that's all been put on the backburner. We're just sort of going with the flow and coping with things as they come up because I think that's the only way you can do it because everything changes at the drop of a hat. Helena (nk), partner*

Many of the primary supporter participants reported that their loved one remained reliant on them in social and emergency situations during the persisting need stage. However, primary supporters also described how they *pulled back* from taking charge, which for some meant they shared the care of the stoma and prosthesis, while for others it meant they changed a few roles to help their loved one regain independence. For example, one primary supporter reported that she had always done the accounts but her partner does them now.

The primary supporter participants described the ongoing importance of respecting their loved one's decisions, and supporting and accepting their determination and self-sufficiency many years after the treatment. However, they also said they remained an advocate or frontline person in their relationships. Examples included taking and making all telephone calls, assisting with breathing issues, informing family and friends of the issues and ensuring that stoma equipment was always available:

> *I have to do pretty much most of the phone calls for her so … if I get her appointments wrong then she tends to get a bit annoyed with me. Tom 36, partner*

Rachael (partner) described the practical support she provided her husband, which resulted in changes to her role:

> *I've got authority to do things ... and if they need him to hear it I just put it on the speaker phone.*

Fay (partner) described the emotional and practical support she provided her husband:

> *I think if they know someone is there to love them and to care for them – he does everything for himself now. He even goes out and cuts wood, etcetera, however he loves me to be there and to see to his voice prosthesis because it gets blocked up.*

The primary supporter participants talked about how they had maintained some time for themselves whilst their partner's needs were high. This persisted beyond the early transition stage and translated into maintaining social connections or a job, keeping a diary, and taking short breaks from the hospital. They all reflected that their perspectives about life had been challenged/changed:

> *It's a little cleaning job at the caravan park and I really, thoroughly enjoy the interaction with the people. I am a people person. I look forward to going to work and I'm home by lunchtime every day that I do work. That just gives me that little bit of me time and I really enjoy the job. Helena (nk) partner*

Despite efforts to have some personal time, there were many examples where primary supporters had changed their behaviour to accommodate the changes to self-expression and health experienced by their loved one. There was evidence that their partners remained very dependent on them:

> *This is the problem with one of those complete laryngectomies, they have to always have someone there in case, you know, and at times you feel a little bit trapped, however when it is your husband and you love them you just make those sacrifices because we've always done things together and it's not so painful to stay with them, if you know what I mean? It's different if it would be a stranger, if you had to stay with them day and night. Fay, 77, partner*

Other experiences included primary supporters preparing and eating the same food (e.g. soft textured or blander food), and avoiding going out socially due to eating and communication difficulties. Rachael (partner) described how she would go to the local café at lunchtime whilst her partner was in hospital. It was partly because she did not want him to see her eating what he couldn't and also to have some time to herself. She said:

> *I just went down there [café]. It was good to get out and about.*

Jack described how his wife had accommodated his need for a specific diet:

> *Since there's two of us, rather than cook something for me different ... she just accepts I will eat what he is eating. I am just thinking that she might have to adjust her life. ... there could be other things I haven't even thought of.*

A few of these participants described how their ability to provide emotional support

was dependent on their own levels of resilience. The primary supporter participants reported varied utilisation of support services such as counselling provided by a local cancer support agency. For example, Tom (partner) recognised that his own grief process had affected his ability to support his wife:

> ... even my attitude has changed since my parents and grandfather were killed as well. I've sort of become a little bit more selfish. I don't sort of help out others as much. I know that I don't help out [partner's name] as much as I should.

Sonia (partner) described the disruption her partner's TL had created for her and the difficulties she had even getting in to see him in the hospital. She described the bus ride as stressful because she suffered mental ill health but she did not want to burden friends to take her each day:

> I don't like to burden friends with it because it's a choice that I have made, to stay and be with him, and I don't want them getting angry at him because he's being unappreciative ... that's what made me ring the Cancer Council and do that and have someone to talk to. ... That was good.

Rose found having to move to Adelaide for a few months whilst her husband was in hospital a lonely experience. She stayed with someone she had only known for a short time. When she was recalling this experience in the interview, she became, in her own words, *emotional*. She spoke to some professionals and used a counselling service. Her husband's ongoing care needs on discharge were also significant for her.

Tom described issues related to his personal grief and the persisting chronic conditions experienced by his wife. He had not pursued counselling because he had not found it helpful:

> I went to a counsellor when my parents ... passed on but ... I find that they sort of helped but not really. ... I don't really understand how [partner's name] feels because I'm not in her situation and she doesn't understand how I feel because of what's happened to my parents, so it's really hard.

In this study, it appeared that primary supporters experienced variable recognition of their efforts by loved ones, some family members and health professionals. Some of the IWL reported they valued their partner's support, but that it was usually with the benefit of hindsight they recognised their partner's devotion and the prioritisation of their health concerns. There appeared to be evidence that in the early stages the situation was so demanding for both that many had little time to really process or empathise with the primary supporter. In some cases, this acknowledgement did not occur and partners were afforded little support of their own:

*I think it was more after I got my speech back I realised how selfish I had been, not that I could do anything about it. Jack, 69*

*My wife… was absolutely wonderful friend and supporter [sic]. She slept with me every night the 28 days in the hospital. She was fantastic, the best carer … and friend I had. Christopher 61*

*The final straw was when he got his results back that he had all clear of cancer. He didn't turn around and say to me, "Thank you for helping me through all this" or "let's go out and celebrate". He just upped and he went to the pub and I'm left sitting, thinking, "Well, where did I go wrong? What else could I have done to help any better?" Sonia, 59 partner*

In this subtheme, primary supporters appeared to be proactive, flexible and vigilant throughout the TL journey even when they experienced disruption to their lives, roles and routines. It seemed that many tried to accept the situation and get on with life. However, this acceptance was tied to a grief and loss process, resilience levels and past life experience of mortality. The primary supporters described how they assumed a lot of responsibility and that the persisting needs of their loved one really did affect them. The extent of the burden and strain they experienced seemed to relate to intrinsic and extrinsic factors, which included their own competency and confidence levels. The extrinsic factors were identified as:

1) the level of their loved one's dependence and persisting needs

2) the timing of the care

3) episodes of poor care, which were more prevalent in non-specialist settings and with temporary healthcare staff

4) poor exchange of information between health systems

5) the need to travel or live near to specialist care, which was challenging for partners living a long way from the hospital or reliant on public transport

6) post-operative complications and subsequent care.

Categories 3 and 5, and subthemes 6.1, 6.2 and 6.5 also relate to this subtheme.

### 5.5.2.5 Subtheme 6.5: Resourcing and awareness

All participant cohorts raised the issues of resourcing and general awareness many times, particularly in subthemes 3.1, 3.3, 6.1, 6.2 and 6.4. One possible explanation is that the complex care needs and small numbers of TL procedures completed locally resulted in a concentration of specialist knowledge in two of Adelaide's large tertiary hospitals. The accessibility and availability of specialised care were described as important because there was limited expertise in the broader community. However,

this was problematic for people living in rural/remote locations and placed resource demands on the specialist teams to train inexperienced health professionals. Some discussions emphasised how laryngeal cancer and laryngectomy were poorly understood more generally across the South Australian community.

The health professional participants perceived that comprehensive healthcare involved a clear and supported pathway characterised by good surgery, treatments that improve QoL afterwards, and the provision of timely and adequate supports needed for recovery, including financial support and home support. The surgeon, Edward, stated that IWL should:

> *... have their treatment in a timely manner, have speech therapy, nursing, enough social work support and resources so that the patient can just concentrate on their cancer and their treatment without having to worry about other things until six months down the track.*

Edward later identified that, even though South Australians have access to universal healthcare, long public hospital waiting lists resulted in delayed consultation. He considered that seeing people early resulted in much better outcomes. Helen, senior social worker, also recognised that:

> *... [community] services are tailored around the over 65 year olds who are frail, not around the people who are emotionally needing help. ... best practice there would be someone you could hand over to the community for these people ... important having allied health involved from the initial diagnosis.*

The speech pathologists and dietitian in this study provided other examples of reduced resources and fragmented services affecting care for IWL. In subtheme 6.2, it was reported that they were often not involved from the beginning due to staffing issues or delineation of care (e.g. inpatient versus outpatient). They also described their practice as being affected by the rationing of services, for example length of stay pressures, rationing of outpatient services, the absence of a cancer care coordinator, limited community services for individuals under 65 years or individuals living remotely. They believed there were often many barriers to obtaining appropriate community care and this affected discharge. They reported that forecasting and planning were required during a patient's hospital stay, and explained that there was pressure regarding discharge and the types of care a person might need after discharge.

> *If the patient isn't managing their treatment themselves ... need extra training, need funding. So a lot of residential care facilities don't take patients like that. ... it's around the confidence and them feeling able to manage their trachies. Helen, senior social worker*

The health professional participants said that community-based services were inconsistent and affected by staffing levels, levels of expertise and resources but there appeared to be a range of community and other auxiliary supports available to the IWL and primary supporter participants. These included community nursing, generic cancer support services, support or social groups and general community supports such as Meals on Wheels and respite care. As described more extensively in subthemes 3.1 and 6.4, the data suggest differences amongst IWL and primary supporter participants regarding their wish to access certain services such as the Cancer Council's Head and Neck support group or the telephone counselling service.

The issue of location of services was a recurring theme. In subtheme 5.2, it was highlighted that many of the IWL from both metropolitan and rural locations felt it was difficult to get prompt referral to appropriate services. Once referred, the rural participants experienced the need to travel to Adelaide for most specialist appointments. Mentioned in subtheme 4.1 was that some IWL reported the importance of living near the specialist hospital for their ongoing care needs. Other participants discussed the impact on their lives of having to be in Adelaide for appointments and treatment, and to access equipment.

Community services to manage and teach individuals how to care for their stoma were identified as patchy and problematic for this clinical group. For example, Annie described how she lived remotely from Adelaide and there was no one near her with expertise to change her prosthesis. She said her visits to Adelaide were problematic because she was reliant on patient transport, and could not get support from the local ambulance officers after her prosthesis dislodged for the third time because they did not have the expertise. When I interviewed her, the voice prosthesis was leaking and causing her to cough:

> *I can't drive because I can't turn my neck and I thought I'd be a road hazard. ... I can't get home. ... And because I have got to have my bed ... I can't stay down in the nurses' quarters. Annie, 65*

It appears from the data that discharge home often disrupted the continuum of developing competency with self-care, as described in Category 3. Josephine, senior speech pathologist, reported that this placed extra demand on her service to community-based clinicians with limited experience:

*Well the few times that it's been organised it's come back to us because, depending which region the patient's going to, there are some regional speech pathologists that have experience and are happy to support and in other areas they don't have the experience.*

Samantha, community speech pathologist, reported that there were very few community-based speech pathologists in South Australia who could manage an IWL's voice prosthesis. She was one of the few and worked remotely 300km from Adelaide. She explained how she tried to be prepared for the next voice prosthesis change but sometimes the equipment did not arrive and her patient might be waiting a week before she could replace the valve. She said there was no funding for her to have her own supply of equipment:

*When we change one we contact [hospital's name] … and we wait for it to arrive. Sometimes it doesn't come and then we're calling when he's here or when it's leaking or something. I've tried to get a backup stock … It's on a list of things we need but no funding to pay for it.*

There appeared to be several larger community issues affecting this group of participants, which could be interpreted collectively as external validating influences for IWL. They related to the provision of suitable public spaces to manage their disability, suitable financial and healthcare supports to support their recovery and adjustment, and adequate general public awareness of the issues they experience.

The primary supporter participants described how there are very few appropriate public conveniences for people who need to tend their stoma, valve or feeding tube. Often, public toilets are unhygienic and unsuitable. Sonia (partner) stated that with her partner's voice prosthesis they frequently had to clean it, so she encouraged him to take hand sanitiser and use the disabled toilets:

*When you go out … the toilet … that's the only place you've got. I said to him, "Go into the, I don't like to call it the handicapped toilet. Nine times out of ten that would be more hygienic because there's not that many that use it.*

A few participants reported that a person's financial status could affect the provision of services. The health professional participants reported that communication aids, including voice prostheses, were supplied by the hospital but extra equipment, including humidifiers and heat moisture exchange items, were not. Helen, senior social worker, explained she sometimes applied to certain charities for rehabilitation equipment but people needed have a low income or be receiving welfare support to be eligible.

In Australia, there are variations in the healthcare system, for example public

versus private care, healthcare card or gold card status for war veterans. Some equipment has to be self-funded while some is provided. The IWL and primary supporter participants described how these variations posed some issues and led to unfortunate experiences, for example where care such as suctioning to alleviate breathing problems would cost *A$385.00* or ongoing dental bills were very expensive with high out-of-pocket costs. Pieter was concerned about the cost of his healthcare, stating he could afford the dental work but he assumed that many other IWL would not be able to.

The narratives suggest there was little awareness about this type of condition in the South Australian community due to the low incidence of laryngeal cancer. It was also perceived as a lifestyle disease related to smoking that affected mainly middle-aged men with poor social supports and a modest education level. This was true in many cases but there were some where it was not. In this study, three IWL had never smoked, five were women, five were in supportive relationships and five had tertiary level education:

> *Well, all think that you smoke. "Oh goodness you must've been a very heavy smoker?" ... I say, "No, I've never smoked in my life", and sometimes I just ... go along with it. You know, it is easier just to say, "Yeah that is right" rather than sort of talk about it. Lyn, 63*

The participants reported that there was a lot of public media attention and fundraising efforts for certain cancers and health conditions such as breast cancer. They made stark comparisons between the supports available for breast cancer sufferers and laryngeal cancer sufferers. Several of the participants believed that the reduced recognition of laryngeal cancer affected resourcing, funding and public understanding:

> *I think breast cancer sufferers now have the kind of visibility by the government that gives them good all round care but I'm a guy, I don't necessarily get breast cancer. This is far more life-changing than breast cancer will be and just as dangerous because I had less than 50 percent chance of survival. That's not to say that breast cancer isn't important, of course it is, as are all the other cancers, colon cancer, all the others, but I think the focus on one particular type at the exclusion of all the others is a little bit one sided. Pieter, 61*

> *It's hardly recognised. ... You can't raise funds. ... it doesn't have a public image. It's not sexy. Edward, surgeon*

The senior head and neck nurse, Maria, remarked that due to public awareness and laws such as plain packaging with warnings and graphic images of head and neck cancers on tobacco products, there had been *one positive thing*; the reduction in

smoking and *[no] smoking in the pubs.* Despite this, many participants remained concerned that many people do not know about laryngeal cancer.

Helen, senior social worker, described how she liked the *challenge* of working with this group of IWL because they were *poorly represented* and often judged – *you brought this on yourself* – and they didn't get the level of services they needed. Bill described how he had experienced discrimination after his TL. He was having a cigarette and a man brushed it from his mouth. He said he was upset at this because he was not inhaling the smoke, only trying to partly experience what he could no longer do:

> *I used to have a sly smoke every now and again and people used to look down their nose at me. And one bloke came over, come up and knocked my bloody cigarette out of my hand. I wasn't very happy about him. Because if I had a smoke now and again ... I don't inhale it. You're ... just tasting and blowing. To inhale it, you've got to put it in there (gestures to stoma). And I don't put it in there ... because tobacco stands for cancer, no way!*

This raises the important issues of advocacy and raising awareness.

The data suggest that the small TL population and complexity of care needs partly explain the problems associated with resources and poor public awareness. A number of subthemes and categories were also relevant to this, including Category 5 and subthemes 6.1 and 6.2. These highlighted how the care pathway (medical, nursing, rehabilitation) needs to be flexible to manage the ongoing medical care, complications and long-term maintenance requirements experienced by IWL.

### 5.5.2.6 *Category 6 summary*

| *Category 6 – Being supported* | |
|---|---|
| **Subtheme 6.1 Getting competent care** <br> The complex multidimensional care needs require expert care and a MDT approach. A lack of competent care can be frustrating for IWL, their families and specialist professionals | *I think some of that comes down to the knowledge and experience of the nursing staff with this population so that they can anticipate what the patient might need or what might be required. Josephine, senior speech pathologist* <br><br> *... my GP kept saying he was getting all this information from the doctors ... and frankly I don't think he understood most of it, so his ability to help me is limited by his understanding of what actually happens and he was asking me some very fundamental things like "Are you breathing through this now?" Shouldn't he know that? Pieter, 61* |

| Subtheme 6.2 Perceiving holistic care<br>The provision of well-timed and empathetic holistic care to address the physical as well as the psychosocial needs | *Because everything that is done is geared towards the medical condition, nothing that's done is geared towards the person. Pieter, 61*<br><br>*Nursing staff, I mean they are very busy, god you can't change them. In ENT, the speech pathologist, you know you are the most sympathetic and understanding of the lot. Lyn, 63* |
|---|---|
| **Subtheme 6.3 Having social capital**<br>Perceiving the support of others, experiencing some loss and some gain of support | *I'm always concerned if someone doesn't have a strong network of support. It doesn't mean that they're not necessarily going to do well but it means that they have to be more resilient themselves and be more independent. Josephine, senior speech pathologist* |
| **Subtheme 6.4 Being there**<br>The role of a primary supporter for some IWL is very important. The TL journey can result in changes to role, routine and plans. It can often be an isolating, disrupting and fatiguing experience | *I was with him from first thing in the morning until they kicked me out at night. Helena (nk), partner*<br><br>*I really don't know how I got through that, but it's just I have a lot of good friends and I do craft things, like I knit and I make dream catchers. Sonia, 59* |
| **Subtheme 6.5 Resourcing and awareness**<br>The TL experience is also affected by the availability and accessibility of services, and general public awareness | *... it's very limited supportive care in the community for laryngectomies and tracheotomies. One is the fear side and also the equipment. ... Lots of care facilities don't have suction or oxygen; you have to have portable, and humidification and the funding and staff training. Maria, senior nurse*<br><br>*... with breast cancer they have ... pink ribbon day, they are very much out there and they talk about it and there is support groups whereas if you have laryngeal cancer there is the New Voice Association ... but they don't exist any more . ... breast cancer at least you do get support, you've got other females. Lyn, 63* |

## 5.6  Conclusion

The results presented here confirm that each TL journey is different and unique for every individual and their supporters. However, all IWL experience the phenomena of changes to self-expression and related competencies, which can affect social roles and require IWL to negotiate and navigate interaction and situations. The new reality can pose all sorts of challenges. There appear to be a number of key processes involved with how the IWL in the current study adjusted. These were development of a range of competencies, and building resilience to cope with the complex physical changes and difficulties related to breathing, swallowing and communicating.

A number of contextual factors have also been identified as important. The first was the timing of diagnosis, treatment and recovery, which have been defined as

distinct care stages. Significant time points were highlighted as critical for psychosocial adjustment, and there was the important context of having appropriate, well-timed and well-resourced social and clinical support. Finally, embedded across all the categories, personal factors and socio-cultural influences emerged as important to recovery and the level of psychosocial supports a person requires. In the next chapter, I expand on these categories and conceptualise the substantive theory of *Validating the altered self after TL* that has emerged from the analysis.

# 6  A substantive theory: Validating the altered self after total laryngectomy

## 6.1  Introduction

In this chapter, I further integrate and conceptualise the six categories and related subthemes that emerged from the data (which were presented in the previous chapter) into the core concept *Validating the altered self after total laryngectomy (TL)*. This concept is discussed as the substantive theory of the significant psychosocial process to emerge from the data. A *Model of validation* is used to illustrate relationships between the categories. Consistent with a constructivist grounded theory approach, the theory and model represent the participants' embodied views, which are as close to the experience as possible. An exact replication of the participant experience is not possible but reflexive methods have been utilised to enhance the credibility of the theoretical constructions.

Earlier, in Chapter 3, I discussed the use of an interactionist theoretical framework to examine how the data represented many themes related to self-identity due to loss of self-expression. Interestingly, many of the IWL described how they interpreted their experiences and what their subsequent actions were. It appears that social interaction and communication were more challenging for them post-laryngectomy and were also challenging for others. Thus, 'interaction' became an important unit of analysis. Using symbolic interactionism (SI) meant I perceived that "Interpretation and action arise from interaction whether we address the reconstructed past, lived present, or imagined future" (Charmaz, 2014, p. 265).

My intention here is to describe the substantive theory, which entails a more explicit exploration of the categories using additional examples and further analysis of material presented in Chapter 5. Each category is discussed as representative of the phenomena, an underlying process, or part of the context of the embodied experience. I discuss the significant role that the construct 'the altered self' appears to play in IWL actions and interactions after their surgery. Here, 'the altered self' is interpreted as a construction that arose in response to the TL experience. It also represents the interactive influences of the significant and generalised other (Mead, 1934). I describe the four reframing patterns of 'the altered self' that are evident in the current data set, then discuss the intrinsic and extrinsic factors that appear to have contributed to validation of 'the altered self' for the IWL.

## 6.2 Overview of the substantive theory

This substantive theory proposes that it is the event of the health crisis, the subsequent TL and resultant physical, functional and psychosocial changes that triggers changes to an IWL's identity and selfhood. These changes lead to the construction and reframing of 'the altered self'. An important social and psychological process after TL is the validation of 'the altered self'. This can be described as the process of feeling or being validated. It highlights that an individual's relationship to themselves and others is strongly predicated on their capacity for self-expression and meaningful social roles in their lives. Impaired self-expression, in part, entails subtle communication difficulties where individuals can no longer shape or influence interactions or others in the same way. This results in a change of status or position for IWL, thus affecting their identity; they view their 'identity' differently, as do others. After a TL, individuals navigate and negotiate interactions and situations in a range of ways. These actions appear to relate to how they reframe 'the altered self'. The validation of 'the altered self' appears to be influenced by intrinsic and extrinsic factors. Self-validation is an intrinsic process affected by developing competence, building resilience and personal factors. It occurs when individuals evaluate their altered self-expression (e.g. communicative or swallowing competence), interpret the likely outcome of a situation or interaction, and make choices about engagement. This decision making is often influenced by their prior knowledge and experience of their pre-laryngectomy self. For example, IWL may attempt to avoid being excluded by sometimes excluding themselves. Validation by others and the cultural environment are extrinsic processes experienced through interaction and context, and can symbolise social legitimacy and acceptance. Examples of these include perceiving successful social participation, being able to engage meaningfully in interactions and experiencing competent care; in other words, individuals feel understood and have their needs met. There are also notable turning points and distinct stages in the TL journey, which influence the construction and patterns of reframing of 'the altered self'. An individual's resilience can change over time and be impacted by a wide range of factors, including their own perceived competencies, beliefs about survival, feeling needed, ability to develop independence, support levels and broader social acceptance.

I intend to maintain the language used by Mead (1934) in relation the social construction of the self when discussing the construction and reframing of 'the altered self'. A more detailed analysis of the construct has been provided in Chapter 3. However, I am aware that the terms 'identity' and 'self-identity' are extensively discussed and analysed in the health literature (Butler, 2013; Muenchenberger, Kendall, & Neal, 2008). These terms appear to be used interchangeably and may reflect the use of other theoretical frameworks.

The proposed theory explicates the relationship between psychosocial adjustment after TL and the extent to which changes to post-laryngectomy self-expression affect individuals on a day-to-day, situation-to-situation and interaction-to-

interaction basis. In these theoretical constructions, I refer to the self as both object and subject. For example, when interpreting the data, I regarded the construct 'the altered self' as the subjective vehicle the IWL used to "experience themselves in relation to others", and I interpreted it as "an object" that each individual managed as they felt appropriate (Elliott, 2008, p. 32).

Further examination of the literature in relation to disruption of self and identity due to illness or acquired communication impairment is undertaken in Chapter 7, in which I also discuss how these findings and the substantive theory relate to the current literature; answer the research questions; and extend our current understanding of the psychosocial needs of individuals and their primary support networks after TL.

## 6.3   The embodied experience of validating 'the altered self' after total laryngectomy

The core concept *Validating the altered self after TL* is an important and complex social and psychological process requiring extensive elaboration. It highlights the multidimensionality and context-dependent nature of the TL experience. The emergent six categories of the core concept can be further defined by three groupings: the central phenomena; the underlying processes; and the context. Figure 10 (next page) illustrates the expanded coding tree. A colour-coded key highlights the three broad category groupings. The coding tree shows the categories and their relationships with one another and the core concept representing the participants' constructed meanings and actions central to their experiences. It also highlights the role of others. This is not a deterministic representation of the phenomena at hand but an attempt to explain the constructions, interpretations and actions (behaviours) the IWL shared with me about their experiences of having, and living with, a TL.
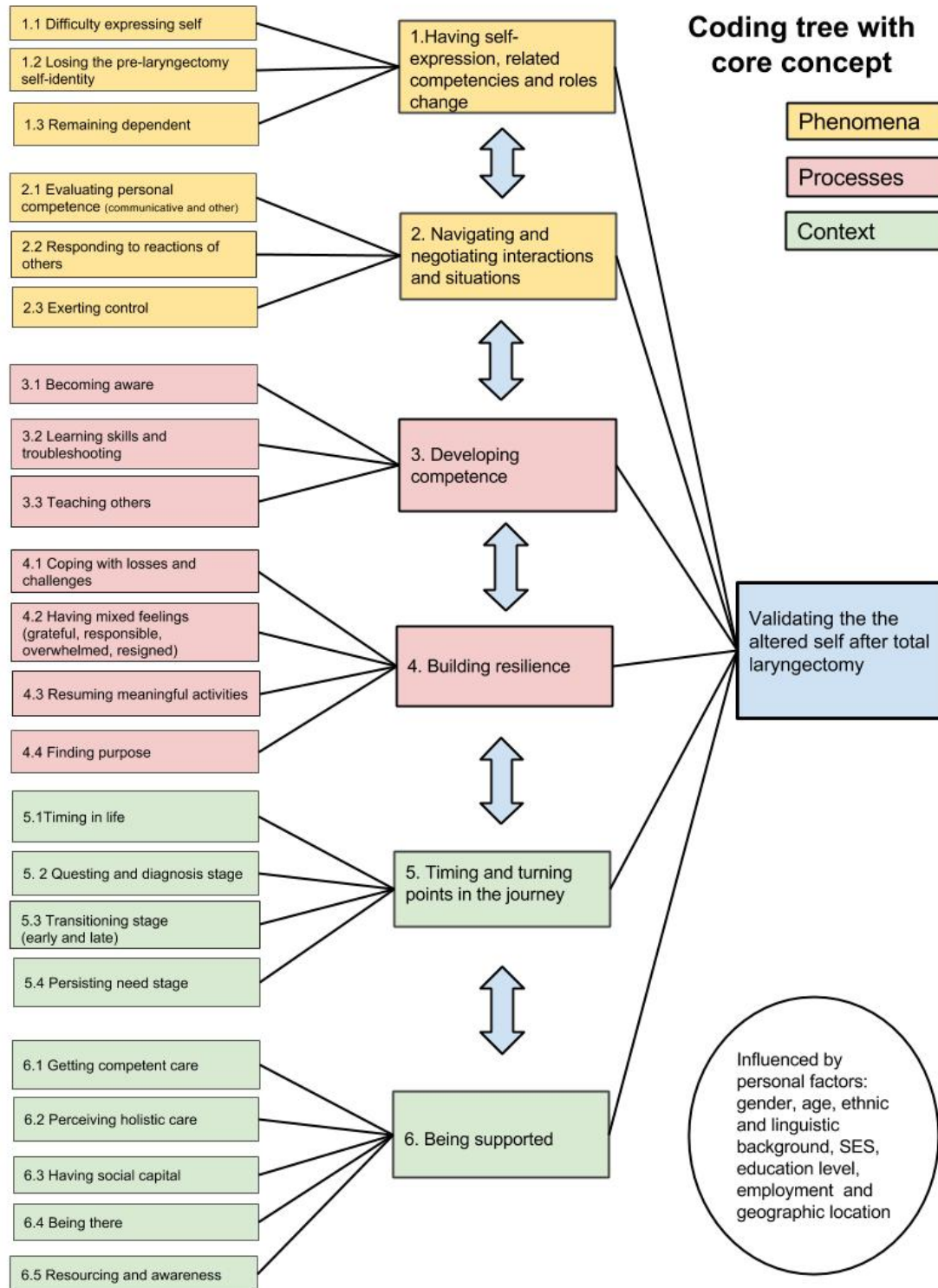
**Figure 10: Coding framework with core concept**

The inter-relationships of the elements constituting the embodied experience are further represented in Figure 11. This diagram illustrates how the phenomena central to the construct 'the altered self' relate to how individuals navigate and negotiate

interactions and situations due to the disruption of their self-expression, related competencies and roles (Categories 1 and 2). It indicates that adjusting to these disruptions is influenced by the intrinsic validating processes of developing competence and building resilience (Categories 3 and 4). In addition to these phenomena and processes, 'the altered self' is highlighted as being influenced by several contextual factors, including the timing and turning points of the journey, and the extrinsic validating influence of being supported (Categories 5 and 6). Personal factors are also contextual and embedded across all the categories.

An embodied experience of 'validating the altered self after total laryngectomy'

The Processes (how?) **VALIDATING**

The Context (when and why?) **AFTER total laryngectomy**

The Phenomenon (what?) **The ALTERED SELF**

Category 3. Developing competence

Category 4. Building resilience

Category 1. Having self-expression, related competencies and roles change

Category 2. Navigating and Negotiating interactions and situations

Category 5. Timing and turning points in the journey

Category 6. Being supported

＊ Personal factors

**Figure 11: Categories and their relationship to the core concept**

After illustrating the coding tree (Figure 10) and the inter-relationships of the elements constituting the embodied experience of the TL journey (Figure 11), I discuss the three constituent areas and relate the categories more explicitly to the two significant constructs that form the core concept; 'the altered self' and 'validation'. The construct 'validation', representing the important underlying social and psychological process of acceptance, is described in terms of intrinsic and extrinsic validation. I then discuss the personal factors.

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### 6.3.1 The phenomenon: Validating the altered self

Categories 1 and 2 (phenomena) highlighted the phenomenon of 'the altered self' throughout the TL experience. The IWL described how they were affected on physical, functional and psychosocial levels. All participants perceived that the TL procedure was a dramatic and heroic intervention, which afforded all of them a longer, disease-free life. However, it was not without significant personal and social cost. The narratives strongly suggest that the experience affected the participants' sense of who they were. These categories also indicated variations in how individuals interpreted their experiences. A wide range of factors influenced how they reframed their altered self after their surgery. In other words, the construct 'the altered self' embodied the notion that the TL and others' reactions affected the selfhood of all the IWL in the current study. However, the extent to which these influences affected their acceptance and led them to change their lives, actions and beliefs about themselves varied significantly. These variations are explored further when I examine the important roles of Categories 3-6 to the construct 'validation', and acceptance.

#### 6.3.1.1 Validating influences

The validation of 'the altered self' was an important construct underpinned by the psychosocial process of acceptance. It signified both self-validation and validation by others. The data suggest that self-validation was an intrinsic process characterised by re-engagement with meaningful activities and social situations without remarkable consequences, and/or perceiving that the experiences had been character building. The development of competence and the building of resilience also appeared to assist individuals to manage the post-laryngectomy experience of 'the altered self'. It is important to reiterate that the perception of competence appeared to vary greatly amongst individuals. It also seemed strongly connected with pre-laryngectomy abilities and a continuum of function.

Validation by others and the socio-cultural environment were extrinsic validating factors. These related to social legitimacy, as explicated in Category 6, which encompassed care experiences, levels of social support a person experienced, and larger cultural factors related to levels of resourcing, location and broader societal attitudes to the health-related issues associated with laryngeal cancer. Further exploration of these issues occurs in section 6.3.3 related to context.

### 6.3.1.2 *Construction of 'the altered self'*

Before discussing the changes to selfhood after a TL, it is important to revisit the theoretical assumptions used to examine the experiences of 'the altered self' as described by the participants. Using an interactionist lens, I viewed the IWL as deriving meaning from their actions and the actions of others in social interaction. Thus, their interpretations of these experiences were influenced by their pre-laryngectomy constructed self, but also may have been shaped and reframed by their post-laryngectomy constructed self; 'the altered self'. This perspective suggests that all the IWL experienced a continual and reflexive dynamic because they were capable of thought, symbolic interaction and role-taking (Blumer, 1969; Mead, 1934). The data strongly suggest that rather than individuals experiencing continuity of their selfhood, the TL resulted in disruption to it. The data also suggest that individuals were faced with significant issues of adjustment due to this disruption. Charmaz (2014) eloquently described how disruption to selfhood could be precipitated, stating: "People construct new meaning, or reconfirm past meaning through acting. Problematic actions and events interrupt the taken for granted flow of experience and subsequently result in reassessment" (p. 271).

In this data set, the 'problematic event' appeared to be the near death experience and TL. This, along with the resultant physical and functional changes affecting self-expression, related competencies and roles, appeared to have a profound impact mentally, emotionally and socially. All the IWL were faced with survival, disfigurement and long-term disablement. I interpreted that construction of 'the altered self' was the response to these disruptions and others' reactions. The areas of disruption identified in the data included:

1) an appearance-altering tracheostoma
2) losing meaningful forms of self-expression
3) having to express themselves in an alternative way
4) altered interactions, reduced acceptance and occasions of stigma
5) having survived as a different person; one with disabilities and disfigurement.

The following quote from Hugh described his experience of losing his voice and how he perceived it as being an important part of his self-identity. He described his expressive communication as being significantly altered and socially limiting. He reported that acceptance of his altered self was difficult:

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> *I've lost ... my voice ... I've lost part of my character, part of my personality ... and that is very difficult, you know. ... For a long time I used to dream of still being able to speak properly… it's gone finished, that expression has gone. ... it can be very distressing if I dwell on it.*

Several other participants also reported the significant personal loss of losing their self-expression. Lyn described what it meant to her to lose her larynx:

> *Well my life really is over and it was over, so quickly, so early, it happened overnight and you didn't have time to think about it, ... I never thought you couldn't ... talk, like I thought you could talk even if you were feeling terrible but if I feel any emotion, any emotion at all, I can't talk. So therefore you go from being very social, I was going out to lunch. I was in the business-world, I was going to Melbourne and Sydney or Queensland doing business everywhere and it died overnight, like what happened? You know everything ... my job, my voice, my friends, my social life.*

Goffman (1963) described different patterns for interpreting the impact of stigmatisation on selfhood during a lifetime. The IWL in this study experienced stigma related to their TL later in their lives. This is an important observation because according to Goffman, people who experience disruption to their selfhood later in life have developed social and cultural expectations about what is acceptable long before they perceived they no longer met these expectations. The IWL reported they needed to reframe their post-laryngectomy self, not their pre-laryngectomy self, and there was significant individual variation regarding the extent of the difficulties in doing so.

Seeking to further understand the relationship between 'the altered self' and adjustment after TL, I now discuss how I viewed selfhood as socially-constructed phenomena, based on de Laine's (1997) excellent interpretative model of Mead's social construction of the self (Mead, 1934), which was provided in Chapter 3. The analysis suggests that the construction and reframing of 'the altered self' is a psychosocial process because it is both a personal and relational experience. The IWL described many occasions when they had personally reflected about their situation but had also found support from others important and reassuring. There is evidence that others had a negative effect on the IWLs' experiences, and that broader socio-cultural factors also affected them.

The findings of the present study appear to confirm the following two premises of symbolic interactionism described by (Elliott, 2008). The first, that "language and communication are pivotal to the fabrication of personal identity and the self", and the second, that "the development of self-consciousness is intimately interwoven with taking on the role of others" (p. 37). The subthemes for Category 2

illustrate this. It appears that for this group of IWL, it was social situations and others' reactions consistently brought two 'objects' of change affecting their identity into view; changed self-expression and changed social roles. These were the objects the IWL had to learn to manage and accept, resulting in individuals questioning their identity and selfhood on a symbolic level. An important aspect of this identity reframing was these participants' ability to role-take and perceive others' 'point of view', particularly when they interacted.

It also appears that loss of self-expression was an important mediating factor in how the IWL navigated and negotiated interactions and situations. In other words, they reported they were no longer competent communicators. They said they experienced intact language skills but that their communication skills were impaired. They described how they were always aware of comprehending social situations, reading social cues, and interpreting others' reaction or rejection. This process occurred daily in most social interactions but the IWL described how interaction was different for them because they no longer had their pre-TL subtle level of linguistic and paralinguistic ability (e.g. reliability and versatility affecting tone, loudness and patterns to word stress). These impairments meant they could not influence the interaction and others in the same way, and subsequently lost their role or status in an interaction; a change in status or position that led the IWL and others to view their identity differently. They then reacted to these perceptions and changed themselves. The persisting nature of the disabilities, the unreliability of an ACM to support function and the context in which interactions occur all appear to influence 'the altered self' over time.

### 6.3.1.3 *Patterns of reframing 'the altered self' after TL*

In trying to further understand the TL experience and adjustment responses, I analysed how the IWL reframed their altered self. My analyses were tied closely to Category 4 (Building resilience), and subtheme 4.1 in particular (Coping with losses and challenges). Participants appeared to describe four distinct patterns of reframing:

1) destabilised self
2) resigned self
3) resolute self
4) transformed self.

These reframing patterns provided an important unit of analysis from which to examine the constructions the participants appeared to make after their TL. The patterns also enabled analysis of how they influenced an individual's interpretations and responses to particular situations and interactions. In addition, the patterns were critiqued in relation to how support, resilience and levels of competence influenced them, which provided some insight into how psychosocial interventions and supports may be improved.

There was no evidence to suggest a linear progression or specific time points for experiencing the different patterns, even though the narratives were snapshots in time and all participants were interviewed at least one year after their surgery. Nevertheless, it seemed that many of the participants had experienced a 'destabilised self' during the questing and transitioning stages, but only a few continued this way many years after their surgery. Another finding was that some participants appeared to experience either one or a combination of these changes to selfhood, suggesting that adjustment to a TL was dynamic and influenced by a range of validating factors.

Here, I examine the four reframing patterns and how each one appeared to provide each of the IWL with a way of framing, interpreting and coping with their experiences. This examination will enable me to discuss in more detail the relevance of these reframing patterns to adjustment for IWL, giving me an enhanced understanding from which to critique how important a deeper understanding of self-identity after TL is to the provision of psychosocial supports. A summary of each pattern is provided as Table 9 at the end of this section. I have provided several participant stories in Appendix 10 to illustrate each of the patterns. Each story provides detail about how each individual felt the TL had changed their lives and them.

*Destabilised self*

Several of the IWL and a few of the primary supporters described how a TL and subsequent altered self had greatly impacted their lives, or the lives of their loved one. Two participants appeared to experience a persisting 'destabilised self'. They described significant personal loss and grief related to their altered abilities. It also seemed that participants presenting with this reframing pattern found it difficult to find purpose in their lives, experienced a lot of ongoing anguish and felt let down by others. The data suggest that these individuals were sophisticated communicators with

high levels of communicative competence prior to their TL. They appeared to use their highly developed communication skills to actively appraise their own abilities and others' responses when communicating. They described how they consciously evaluated all situations and chose to retreat from, or avoid, social interaction where possible, including using the telephone. This avoidance behaviour can be viewed as strategic because they reported poor success in interactions and often felt stigmatised by others. It also appeared that at times they were distressed by others' responses or discomfort, and chose not to engage. Unfortunately, this resulted in feelings of isolation and exclusion. They appeared to have a highly developed ability to evaluate the reaction of a communication partner, and were likely to judge poor responses or rejection negatively. They also seemed to be affected by health professionals' communication behaviour because they expected higher levels of awareness and empathy.

Valerie and Lyn's stories illustrate how changes to communicative competence and self-expression significantly impacted their participation and engagement. They were both articulate and fluent TE speakers, but reported that they used more mental effort and strategy during interactions and situations than they did prior to their TL. They also said they rarely experienced the positive self-efficacy they needed to manage the social difficulties they experienced. They seemed to be very sensitive to social rejection and the challenges faced when communicating, and described a lot of self-doubt. It appears that the loss of subtle verbal and non-verbal communication skills was detrimental for them. The data suggest that social support was a protective factor, which assisted individuals with their adjustment but did not completely scaffold a person from experiencing a 'destabilised self', nor did it result in complete acceptance of 'the altered self'.

Lyn described how her emotions had overwhelmed her and that the path to acceptance had been a very difficult and treacherous one. The following excerpt could be interpreted as Lyn experiencing a 'destabilised self' and finding it very difficult to establish a stable self. She recognised that the influence of her communication difficulties with others had affected her ability to reconstruct a stable self:

> *I don't talk about it and I don't go out of my way to see anybody else because, ... you can't talk about it because the words just don't come out ... and sometimes ... you feel ... you are not even alive and if you ... start to feel good about yourself someone might take that away from you and feeling so terrible all the time. At least I know I am alive because I am feeling something.*

The extent to which a person experienced a 'destabilised self' seemed to relate to how highly a person valued their communicative competence and self-expression prior to a TL, and how much their disabilities disrupted their social roles. The maintenance of a 'destabilised self' appeared to be negative; it prevented the resumption of meaningful activities and engagement. Earlier I mentioned that the pattern of a 'destabilised self' appeared relevant to all the other participants in the early stages of the TL journey. However, unlike Lyn and Valerie, there was evidence that most of these participants experienced a stabilising of their self when they developed functional communication and swallowing. This suggests that temporal factors, the developing of competence and the building of resilience did affect the reframing of 'the altered self'. The individuals who did not experience a stabilising of the self were female, suggesting that personal factors such as gender may also influence the reframing of the self. Having said this, the small sample size prevents identification of gender as a specific determiner of this reframing pattern.

*Resigned self*

Four of the 12 participants appeared to experience a 'resigned self'. This term was used when participants described tolerating their disabilities but seeming reluctant to challenge the status quo because they believed they were fortunate to be alive. In many cases, their significant disabilities affected their social participation. They avoided some social situations or changed their behaviour because they did not feel confident or socially accepted. They also seemed to judge that preventing others' discomfort was more important than their own social needs. In some cases, these behaviours appeared maladaptive and several of the participants were socially isolated. It was difficult to determine whether these beliefs affected overall motivation for improving functional outcomes. In other words, participants may have been motivated to change but did not know how. In this group, three of the participants experienced very poor audible ACM proficiency, which appeared to relate to a number of intrusive factors, including disruptive breathing, poorly-fitted voice prosthesis and poor mastery of an electrolarynx. This contrasted with pre-laryngectomy abilities where they reported moderate to high levels of communicative competence and participation.

Several participants, including Hugh, Christopher, Mary and Annie, described how they accepted their circumstances because they had survived their cancer. Hugh,

Mary and Annie said they avoided going out to public places, preferring to stay either at home or, for Mary, in the residential care home. They described how they could not rely on their audible ACM and experienced other difficulties, including uncontrollable coughing, poor mastery of their communication device, needing PEG feeds or a leaking voice prosthesis:

> *I don't fancy my chances out in the big wide world. Although I did go shopping with my son and (that was a change). I was a bit scared. Mary, 75*

Annie said she avoided going out and chose not to eat out because her voice prosthesis often leaked and could cause an embarrassing coughing episode. Christopher reported that he would go out in public but did not think he was attractive anymore, and felt that it was unlikely anyone would be attracted to him. He talked at length about these issues but said he accepted it because it was part of the experience.

The reframing of 'the altered self' as a 'resigned self' appeared to influence how individuals managed social experiences and accepted poor functional and quality of life outcomes. The belief that one should accept poor functional outcomes due to the narrative of survival appeared to result in maladaptive coping for this group. These individuals seemed to be reluctant to accept, or not expect, extra support, and appeared less affected by health professionals' poor communication or reduced competence.

The interaction of the processes of developing competence and building resilience appeared to be important here. The individuals who experienced a 'resigned self' were both male and female, but were more likely to be single and without a partner. This suggests that personal factors such as social capital may influence the reframing of the self. However, the small sample size prevents the identification of social capital as a specific determiner of this reframing pattern.

*Resolute self*

Another group of IWL discussed how they had come to terms with their changes and embraced new roles and ways of doing things. They are described here as presenting with a 'resolute self'. They were proactive and maintained social participation, but in a modified way (e.g. choosing to socialise in smaller groups or using alternative means to communicate such as texting). However, other participants in this group reported being determined to maintain the status quo and resume their old ways as soon as they were able. All these participants appeared to distance themselves from

others' discomfort stemming from their TL-related difficulties. They presented with variable communication abilities and reported unreliable audible ACM due to breathing, health or anatomical issues. They also reported having moderate-to-high levels of pre-laryngectomy communicative competence and communicative participation, and seemed less affected by health professionals' poor communication or competency behaviour.

Jack's story represented an example of an IWL who had been able to adjust and accept his circumstances. He described how he did not take very long after his TL to stabilise his altered self. It appeared he was resolute about his situation and made attempts to reclaim his former life despite considerable functional difficulties. For example, he resumed meaningful activities as soon as he was discharged from hospital and communicated by writing until he had his SVR many months later. He reported that even though he experienced occasional stigma, he did not perceive he was to blame or that he was fully responsible for all that occurred in an interaction. Bill, Kath and Brian were other examples of participants achieving a 'resolute self' after TL:

> *I am doing the same things that I was doing when I had my voice. … you have still got your voice. Bill, 70*

I explored this further with Bill because he described some physical limitations and impediments to his ability to work. However, his journal revealed he was grateful for the extra time his TL had afforded him.

The use of humour, social engagement, participation, willingness to interact with strangers, using the telephone and resuming pre-laryngectomy roles were all suggestive of a resolute self. This reframe also meant that participants often justified that they were leading their lives as if they were *normal*. Category 2 highlighted that the IWL frequently made judgements about themselves and the social acceptability of their situation. Despite, their descriptions that there had been little change in their life, it was apparent that the TL had been disruptive and continued to pose challenges for them. These participants described a range of actions and interpretations they made in relation to their TL. They reported that they consciously attempted not to draw unnecessary attention to themselves by wearing clothing to cover their tracheostoma, or opting out of social situations or activities. However, they were frequently subjected to situations where they could no longer participate or experienced reactions

from others, which highlighted their differences. The 'resolute self' reframe seemed to promote individuals to see the positives of their situation and cope with the challenges they experienced. Three of the four participants presenting with this reframed self were male. They all described reasonable levels of social capital but only two had a partner.

*Transformed self*

A final example of a reframed altered self could be drawn from a few participants who explicitly stated that the TL had resulted in positive changes to their lives and personalities. They described how they were experiencing a 'transformed self', explaining how the positive changes in their lives had affected their outlook on life and their relationships had changed for the better. They reported that they had experienced significant health issues and ongoing disruptive breathing affecting their TE speech. Both reported highly developed communicative competence and communicative participation prior to their surgery. They described how they had used their communication skills in occupations where they had significant responsibility. These individuals displayed high levels of resilience in the face of adversity and appeared to distance themselves from others' discomfort during interaction. They demonstrated the ability to evaluate the perspective of a communication partner and were less likely to judge poor responses or rejection negatively. There appeared to be one exception, however, and this related to health professionals' communication behaviour; they expected higher levels of awareness and empathy.

Both participants continued to socialise despite experiencing social rejection or significant functional limitations. They said they had found purpose and meaning in other things. For example, Pieter described how the experience had been *transformative* to his life. He did not achieve this new sense of self immediately but spoke at length about how he had tried to use the experience in a positive way. He said he viewed things quite differently than he had prior to his TL. He described how this change in him helped him to adjust and had improved his relationships. Len reported a similar situation, in which he felt his personality and outlook had changed positively as a result of the experience:

> *I think I appreciate life better. I don't get irate with stupid things now and again. I can't stand stupidity. I used to get very irate with people at work if things were not done right or my way. Since I've had this done I'm more placid, I've found I'm more relaxed. Len 75*

Despite these participants experiencing significant disruption to their lives, the meaning they gained from the TL experience appeared to strengthen their ability to cope with it. Both these participants were male, had very supportive partners and described how their resilience had built over time.

The four reframing patterns of 'the altered self' are presented in Table 9).

**Table 9: Examples of the participants' reframing patterns**

| Changes to self (private world) | Example | Social impact |
| --- | --- | --- |
| **Destabilised**<br><br>The disability and subsequent changes are overwhelming | I don't socialise like I used to. … even with family, but you know you get used to it. … and sometimes it doesn't affect you and other times it does affect you, it upsets you. Valerie, 74 | Distressed by others' discomfort or responses<br><br>Isolated, feels excluded<br><br>Proficient ACM usage, high levels of pre-TL communicative competence/participation |
| **Resigned**<br><br>I've survived so I am prepared to put up with the disabilities and social changes | Well, … I just don't get to see them anymore. … Because, I don't go down to the pub. … you end up, becoming more and more insular. Hugh, 57 | Concerned for others' discomfort<br><br>Isolated, chooses to be excluded<br><br>Variable ACM usage, moderate-high levels of pre-TL communicative competence/participation |
| **Resolute**<br><br>I am going to live my life as though little has changed | It's one of them things; you've got to get on with it and that's it. Brian 59 | Distances oneself from others' discomfort<br><br>Engages in a similar way<br><br>Variable ACM usage, moderate-high levels of pre-TL communicative competence/participation |
| **Transformed**<br><br>It has been an existential experience | It goes down to a really deep personal level … a little bit of soul searching. …Transformative is a very good word I think, almost a sea change in the sense that it teaches you about yourself. It teaches you who you really are when everything else is stripped away and that is really a valuable experience. Pieter, 61 | Balanced view of the discomfort of others<br><br>Observes a positive difference in engagement<br><br>Variable ACM usage, High levels of pre-TL communicative competence/participation |

These reframing patterns demonstrate variation in adjustment to the changes rendered by TL. The formation of these constructions appears to relate to how individuals

experienced their changed self-expression subjectively and how they tried to manage the changes objectively. These reframes stabilised over time, and appeared to influence how these IWL responded to adverse situations and during interactions. Conceptualising these patterns was useful for interpreting the IWLs' actions and behaviours. It was clear that several of these patterns (e.g. destabilised and resigned) were detrimental to adjustment and posed longer-term health risks to participants due to social isolation and acceptance of poor functional outcomes.

I have highlighted how the development of competence and building resilience were underlying interactive processes affecting reframing. Contextual issues, such as temporal factors, levels of support and personal factors also need to be considered. I explore these processes and contextual factors later in this chapter.

### 6.3.1.4 'The altered self' and its relationship with altered self-expression

I used Mead's (1934) 'I-Me' phases of 'the self', as discussed in Chapter 3, to further critique how altered self-expression affected the construction of 'the altered self'. I viewed each participant with a TL as having a 'private self', representative of the 'I', and a 'public self', representative of the 'me'. Later, I explore how the 'other' (e.g. significant other and generalised other) influenced both these phases of the Meadian self. An important assumption was that the 'private self' acted on itself, and, in a relationship with the 'other', continuously modified the 'public self'. The data suggest fluidity between these aspects of each participant's 'self'.

It appears that the post-laryngectomy experience involved constant interaction and states of modification of the 'public self' in relation to the 'private self' and the 'other'. Figure 12 illustrates the dynamic relationship between self-expression and 'the altered self' after TL.

**Self-expression and the altered self after total laryngectomy**

**Pre-laryngectomy self**

**PRIVATE world**

Stabilised self

Competent communicator & swallower

Appearance unaltered

Presentation, participation & roles maintained

**PUBLIC world**

Identity maintained

**Phenomena**

Having self-expression, related competencies & roles change

Navigating & negotiating situations & interactions

| Processes | Context |
|---|---|
| Developing competence | Timing & turning points in the journey |
| Building resilience | Being supported |
| | Personal factors |

**Post-laryngectomy self**

**PRIVATE world**

Destabilised, Resigned, Resolute or Transformed self

Alaryngeal communicator & swallower

Appearance disfigured

Presentation, participation & roles changed

**PUBLIC world**

Identity restricted/changed

**Figure 12: Self-expression and 'the altered self' after total laryngectomy**

Figure 12 represents a holistic view of self-expression. It shows the importance of losing pre-laryngectomy communication abilities and indicates that loss of self-expression also encompasses appearance and style, food preferences, hobbies and occupations, and social roles. Figure 12 suggests that pre-laryngectomy, the IWL perceived themselves as being competent communicators and swallowers, with an unaltered appearance. In many cases, their presentation, participation, roles and public identity were maintained. It is important to state that this perception may have been tacit rather than overtly understood. The data suggest that recognition of these pre-laryngectomy constructions appeared to come with the benefit of hindsight. Thus, after TL when the IWL found themselves as alaryngeal communicators and swallowers, with a disfigured appearance and changed or restricted presentation, participation, roles and public identity, they inevitably compared themselves to their pre-laryngectomy identity. I now discuss how altered self-expression appeared to impact these IWLs' private and public selves, and influence how they navigated and negotiated interactions and situations.

*Alaryngeal communicator*

The change from a competent communicator to an alaryngeal communicator is

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represented in Figure 12. All the IWL in this cohort experienced changes to their linguistic and respiratory systems, both of which interacted with the changes to the phonatory system and subsequent ACM. The performative aspect of their linguistic and paralinguistic capacity in discourse regardless of ACM impacted their symbolic interaction in a number of ways. Category 1, subtheme 1.1 (difficulty expressing self) described how, as alaryngeal communicators, they no longer had their previous versatility, flexibility or acceptability when communicating. For example, they could not sustain long utterances, speak quickly, flexibly or spontaneously, converse in the way to which they were accustomed (e.g. tell jokes, establish repartee, be heard in noisy environments), or be confident that their new way of communicating would be reliable and acceptable. They also described the impact of their TE speech or EL speech no longer being a marker of their gender, age or emotional state. In other words, respiratory and phonatory issues affected production (e.g. style, rate, form, reliability, vocal tone, loudness and quality), with linguistic and social consequences.

The participants also reported that as alaryngeal communicators, their non-verbal communication had been affected and added to the overall disruption to their expressive communication ability. For example, ACM such as TE speech and EL speech may require the use of one hand for occluding the tracheostoma or holding the electrolarynx. Subsequently, participants had to limit their hand gestures and activities requiring two hands. Both methods were symbolically unusual to the dominant method of hands-free oral communication, and could be potentially disruptive to interaction and signify difference. Category 2, subtheme 2.1 (evaluating personal competence) provides evidence that the experiences of these changes were strongly connected to context and the perception of being able to communicate competently to an acceptable situated and socio-cultural standard. These evaluations were related to prior knowledge of interaction from pre-laryngectomy experiences and the capacity for role-taking as described by Blumer (1969) and Mead (1934). Subtheme 2.1 also illustrated the dynamic interaction between an individual's 'private' and 'public' worlds, and the 'other'. The way the IWL reframed their altered self influenced how they responded to their changed identity as alaryngeal communicators, as well as to others' reactions.

*Alaryngeal swallower*
Figure 12 also represents the contrast between being a competent swallower and an

alaryngeal swallower. The impact of swallowing difficulties has been described extensively in Categories 1, 2, 3 and 4. Swallowing problems were reported to be worse during the transitioning stage but in some cases persisted and became chronic. A number of IWL reported that swallowing problems were challenging and felt like a loss of expression. Some described how they experienced a transient or persisting difficulty requiring dietary modification or slower rate of eating. These changes contrasted starkly with their former diet and eating habits, and had socio-cultural ramifications because they could no longer enjoy eating out. The narratives suggest that these participants wanted to return to their former ways of eating and drinking because of their strong desire to socialise at a public venue, or to socialise over a meal or a drink. It appeared that this was an important aspect to both the IWL and primary supporters' lives. There was also evidence in these accounts that other people, such as their friends, had difficulty accepting the eating and drinking difficulties associated with TL. It appeared that the primary supporter participants were more accepting, empathetic and accommodating. However, these difficulties seemed to have an associated care burden. Finally, there seemed to be some tension between the IWL and significant others in relation to swallowing ability. Many of the IWL and primary supporter participants described how individuals were frustrated by having dietary restrictions prescribed by health professionals as well as functional difficulties. Several health professional participants also appeared to be affected by these issues, describing issues of concordance with recommendations.

*Altered appearance*

Figure 12 indicates that expressing personal taste and style was another important form of self-expression for the IWL, which was affected by changes to appearance. Categories 1 and 2 highlighted that these changes affected both male and female participants, who reported having lost some control over how they presented themselves and what they could wear. For example, they were advised to cover the tracheostoma for humidification or opted to wear clothing to conceal the disfigurement. Some of the participants described how they attempted to exert control by making deliberate choices about how to conceal or not conceal their disfigurement. They described how the stoma was often a source of unwanted attention and stigma. The female and younger male participants appeared to be most affected by their appearance.

*Changed roles and participation*

Figure 12 highlights that many of the IWL described changes to their social roles, livelihood or lifestyle. These themes were strongly articulated across the categories. Some said their capacity to work had been affected by their communication and physical limitations. These participants described how their work had been an important expression of who they were. Only a few of the younger participants described how they had to give up work due to their communication limitations. Certain hobbies involving water (e.g. fishing) or two-hands (e.g. wood-turning) were no longer possible for a few participants, who felt this was a loss of personal expression. Another theme to emerge from the data was how the primary supporter took over some social roles at the time of the surgery. These changes were perceived as impacting the nature of participants' relationships. It was identified that the changes had increased dependence and, in some cases, the care burden.

*Navigating and negotiating interactions and situations*

Another important part of self-expression relates to Category 2, which described the processes and actions involved during interactions and certain social situations for the IWL. It highlighted that during interactions, individuals were often reminded of their limitations and differences. These social reminders occurred randomly and were governed by socio-cultural norms related to gender, appearance, alaryngeal communication, breathing and eating. In this study, social situations were defined as those settings where participants were required to interact with others one-to-one or in a larger group, either face-to-face or using technology such as a telephone. Social situations also encompassed a range of different social actors and a continuum of intimacy, for example significant others and distant others (acquaintances or strangers). A range of environmental factors and issues related to the generalised other also influenced social situations.

The IWL described how it took them considerable mental effort, confidence building and planning to negotiate their social roles and navigate their changed self-expression. Subsequently, some participants reported they found interaction a fatiguing process. They reported that they frequently made decisions in interaction about initiating or continuing conversation, or whether it was better to save face and maintain silence or anonymity. Many of the choices they made about a situation were based on their previous experiences of similar situations. There was a strong tendency

to avoid highlighting differences in interactions and participants reported a range of strategies they drew upon to appear *normal* and minimise attention. However, this was not always possible due to their functional limitations.

It appeared that the altered signals and symbols of self-expression experienced by this cohort of IWL also impacted their "non-symbolic interaction" and ability to establish and sustain "joint conduct" with others (Blumer, 1969, pp. 66-67). They provided many examples where they encountered a non-empathetic response from another person during interaction. Thus, they evaluated their own personal communicative competence, predicted the outcome of interactions based on different situations and environments, and altered their behaviour accordingly. Context and how the participants reframed their altered self appeared to affect navigating these changes. The different reframes appeared to affect how individuals situated their changed abilities with their desires for self-expression, participation and engagement. The following journal entries from Valerie, 74, provide a powerful illustration of the nature of a situated altered self in relation to significant others.

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*Valerie's journal*

Entry 1
You were right. When you left I sat down and realised yes! I am a bit traumatised then lo and behold my grandson rang. He …wanted to visit for lunch with his friends. Hey Presto I had to move myself and prepare for lunch, no time to mope. I actually spent 4 lovely hours with 6 teenagers. Conversation was all about computers, which fortunately I am computer literate, so there you go they accepted me as I am. Which to me was all the counselling I needed.
Entry 2
Went to birthday for our son-in-law and had a lovely time. Only 8 of us at the tea party, but still with family only members there I gave up about 3 times trying to talk as everyone was talking at once. Almost as soon as I opened my mouth, including my husband. It is as if they know I am going to talk. Don't want to hear what I have to say. Only joking about that of course. BUT at the time that is how I feel.
Entry 3
Went to an 80th birthday party today… on my own. Not a problem I said. Wow! Was that a lie. … I got a couple of strange looks (which I am used to). One lady did ask me about my problem but whether she was slightly deaf or something …I don't know, but she never spoke to me again and neither did the others, so I sat there for about an hour smiling and pretending enjoyment 'til I felt like I was going to embarrass myself by bursting into tears, so I made my excuses and left much to my disgust.
Obviously, I am no good on my own without my husband's support. I cried all the way home. When I finally calmed down (next day), I realised I am lucky to have my husband. I know quite a few laryngectomees who don't have that support and I feel for them.

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I interpreted that overall, Valerie presented with a destabilised self. She appeared to find most social interactions challenging. Her first entry reflects how she responded after I interviewed her. At the end of the interview, I voiced my concern that she appeared upset and I suggested that she speak to a counsellor to help her process her feelings. Soon after I left her, she entertained her grandson and his friends. In this situation, she felt accepted and was able to establish common ground in relation to computers. In the final two entries, she reflected upon feeling alienated from the group in which she had tried to participate. She described how she did not feel valued or supported by those with whom she was communicating. Her embarrassment was acutely felt at the birthday party because she experienced isolation from her peers and did not have the social protection of her husband to support her.

This example also demonstrates how the IWL in this study often felt singled out as being different, and used strategies to predict and plan how to respond. It highlights that a TL could be a *lonely* experience even when surrounded by family and friends. The limitations to self-expression often disempowered individuals in interactions and certain situations, and disrupted their independence. It also resulted in negative social experiences in which they felt stigmatised and demoralised. The data suggest that individuals presenting with a 'resigned self' were likely to avoid social situations like the birthday party Valerie attended. The individuals presenting with a 'resolute' 'or 'transformed self' would attend a social occasion such as the birthday party and would more likely perceive that communication partners were jointly responsible for making an interaction successful.

In summary, the IWL described how these experiences persisted throughout the post-laryngectomy experience and took different forms and shapes. The degree of difficulty with communication, breathing and swallowing as well as changes to appearance seemed to directly impact an individual's social activity, concordance with recommendations and their self-worth. It appeared that levels of adjustment and participants' reactions and responses in interactions were influenced by how they reframed their altered self. It was clear that this reframing also related to both intrinsic and extrinsic validating influences.

### 6.3.2   *The processes: Intrinsic factors influencing validation*

There was evidence in the data that the process of 'validation' was an important and

influential aspect of the reframing of 'the altered self'. It occurred in a number of different ways and contexts. The overarching process of intrinsic validation was characterised by the sub-processes of Categories 3 and 4; 'Developing competence' and 'Building resilience'. Each of these processes described how the participants managed, and adapted to, their post-laryngectomy functional skills. These categories are closely linked with both the phenomena and the contextual factors.

*Developing competence and Building resilience*

In many instances, motivation, the development of both competence and independence, and being able to resume meaningful activities affected adjustment for this group of IWL. However, it seemed that adjustment to TL was a more complex picture than intrinsic motivation. Managing the physical changes and functional difficulties was challenging for participants and their supporters. They were demanding on physical, emotional and social levels. It appeared that the development of knowledge through 'becoming aware' (subtheme 3.1) and 'learning skills' (subtheme 3.2) impacted an individual's confidence and mastery. However, competence with tracheostoma care, an audible ACM and swallowing issues was countered by ongoing and significant functional difficulties. The IWL and the primary supporter participants described how they had to learn to adapt to these persisting problems. There also appeared to be a continuum of perceived competency for each functional area of self-expression.

Josephine, senior speech pathologist, described how turning points in coping related to the development of skills and the perception of competence:

> *... the first thing ... is someone's ... emotional state and there's a certain level of readiness to accept the changes and that can be at any stage for a patient. ... then there is that ability to move forward and deal with the changes in a more constructive way. Some of it is practical, feeling independent in being able to self-manage.*

There appeared to be temporal influences affecting the development of competence and resilience levels. A few IWL reported that they realised over time how much their competencies had disrupted their social roles, and that longer-term acceptance was far more challenging. A good example of this was Lyn, who reported she managed the early transition stage without too many difficulties. She described how she attempted to accept her situation and get on with her life. She decided to have a holiday in Europe six months after her TL to help this process. However, she found that her ability to participate in three-way conversations was greatly affected, and she could

no longer engage and communicate as she had done in the past. She felt that this is when her mental health suffered.

Category 4 contained a number of important subthemes related to coping skills, and beliefs about self and situations. The data suggest that while the development of resilience occurred over time for most of the IWL, for a few their resilience was situated. For example, some participants, like Valerie in her journal entries, described how they felt resilient in some situations and not others. Evidence of resilient coping was an important indicator of acceptance and adjustment post-TL for the IWL. Evidence of resilience also indicated how individuals reframed their altered self. The participants who demonstrated the strongest levels of resilience described a 'resolute' or 'transformed self'. The participants with poorer levels of resilience described a 'destabilised' or 'resigned self'.

There also appeared to be a relationship between support levels (Category 6) and levels of resilience. Firstly, having good levels of support did not mean that all the IWL in this study demonstrated resilience. Similarly, having low levels of support did not mean a participant had poor resilience. However, the narratives suggest a trend that individuals with limited social support required increased health professional support. For example, individuals with a partner were more likely to describe a 'resolute' or 'transformed self' ($n=4/6$) and individuals without a partner were more likely to describe a 'destabilised' or 'resigned self' ($n=5/6$). Finally, personal factors such as gender, age and geographical location were relevant to the development of competence and resilience building. I expand on their relevance in the next section.

### 6.3.3  The context: Extrinsic factors influencing validation

The phenomenon of *Validating the altered self* must be contextualised in relation to when and why it is happening. Several important contextual factors were represented as Categories 5 and 6. In addition, personal factors were embedded across all the categories and were also important contextual factors. Category 6 in particular highlighted the extrinsic validating role of supports. It demonstrated that the interactions experienced by individuals could be viewed from the perspectives of both the significant and generalised other, or socio-cultural context.

*Timing and turning points in the journey*

An important contextual factor was the timing and recovery trajectory of the TL. In

this study, the mean age was 66 years (range 59-75 years) and the mean time post-TL was 6.5 years. This was similar to the average timing reported in the literature for IWL (Eadie & Bowker, 2013; Singer et al., 2014). Most of the participants in this study had the surgery later in their lives. I stated earlier that the accounts suggested they experienced well-established selfhoods and related social identities (e.g. personal relationships, employment and lifestyle) prior to their surgery. Some underwent a transition from employment to retirement associated with their laryngectomy. The data suggest that the nature of the retirement, forced or planned, was an important consideration because it potentially raised other identity issues for a person. Subtheme 6.5 highlighted that a person's age at the time of their surgery impacted access to community-based supports and resources, with fewer supports for individuals under 65 years old.

The data also suggests that the TL experience has a beginning but no clear ending. The participants likened it to a *journey*. A few IWL experienced long and difficult recoveries from their TL, which in many cases affected their mood. The discharge home was difficult for many participants. The IWL also described how they experienced many emotions during their journey, including grief, loss, frustration, anger and distress (e.g. suicidal thoughts). The intensity of these emotions appeared to be greatest in the questing and transitioning stages but had persisted for some participants. It was also identified that specific turning points along the path of recovery often related to improved health or increased competence and independence.

*Being supported*

Category 6, 'Being supported', was another contextual factor important to the TL experience. Several of this category's subthemes appeared to provide important extrinsic validation of 'the altered self', and assist the IWL to accept and adapt to their post-laryngectomy experiences. It is important to highlight that issues of not being supported or externally validated also characterised this category and seemed to affect the participants' sense of social legitimacy at different stages of their journey.

Firstly, the data suggest variation across the participants in the intensity of support they needed from significant others and their social support networks at the different stages of their journey. It was evident that the IWL and primary supporter participants felt they needed to build trust with their healthcare providers and have strong social networks. The relationships with the specialist health professionals were

often described as *validating* and *reassuring*. The benefits of a responsive and resourceful primary supporter were also clearly defined and identified as other important validating phenomena. The health professional participants said that reduced social support increased the care burden on them and on the IWL. Interestingly, the primary supporters identified that reduced health professional support increased their burden and strain, particularly in the questing and transitioning stages. The data suggest that support providers had to be accepting, competent, empathetic and flexible. They also needed to promote a person's independence whilst being sensitive to the grief and loss experienced.

The support from a significant other such as a partner was described as beneficial and protective. Its relationship to the phenomenon *Validating the altered self after TL* deserves further exploration. The primary supporter participants reported that they understood the importance of their role in supporting their loved one but found the experience demanding, particularly as a result of communication limitations. Alternative means of communicating in the 'early transition' stage placed extra demands on the communication partner. Some of these problems persisted because of the unreliability of equipment or the poor social acceptability of audible ACMs (e.g. avoidance of telephone). Several participants who did not have a partner reported that living with the extent of their communication and other changes was very challenging. All the IWL described how they found some responses of others validating. For example, some participants described how having positive feedback about their audible ACM helped them:

> *Actually, I have had compliments. Because. … I am English and my cousin rings me up and she couldn't get over when I had it, how clear I was. Annie, 65*

Other sources of support outside a person's social network included clinical and community supports. The health professional participants identified that IWL need a lot of psychosocial support to complement clinical support. However, they acknowledged that their capacity to provide psychosocial and practical support was reduced, and that specialist psychology services were poorly utilised.

The IWL, primary supporter and less experienced health professional participants identified how physical and psychosocial support and resourcing for IWL could improve. It was identified that improved accommodation of communication difficulties, stronger interaction skills and more preparation, education and planning

could help the IWL feel validated and more secure. The data suggest that these processes were likely to assist IWL to better manage the adverse situations they faced over the trajectory of their TL experience.

Skilled, well-timed care was validating for the IWL. However, they provided many stories where they often felt peripheral in an interaction with health professionals. This reinforced their sense of marginalisation rather than legitimacy. Pieter reported that he *deliberately disassociated* himself after he was discharged and did not want assistance or rehabilitation:

> *I don't think the system is set up to assist with recovery, I think it is set up to meet my medical needs but not the needs for my recovery.*

The experience of having inexperienced health professionals meant that the IWL often felt health professionals undervalued the specialist attention they needed. This was illustrated when Lyn stated that some health professionals *flip you off.* Experienced health professionals were also described as having reduced empathy. Some of the health professional participants identified this as a time and resourcing issue. Under subtheme 1.1, I provided a quote from Edward, the surgeon, who described how he often did not have the time to communicate with IWL because the interactions were lengthy, which resulted in IWL trying to negotiate difficult interactions and educate health professionals despite their expressive communication difficulties. It also emerged that primary supporters often felt they had to be *supervigilant*, particularly during the early transition stage because they were not confident their loved one would get the care they needed.

Another important contextual factor related to the validating influence of the generalised other or the broader socio-cultural experience. In many of the participants' minds, they had specific needs for support and understanding but were often subjected to poor resourcing and poor awareness. The IWL also described how they experienced social stigma and variable care due to their geographical location, gender, age, welfare or private insurance status. For example, Christopher, an EL speaker, said his interactions with strangers were at times difficult, and he was stigmatised due to his appearance and audible ACM:

> *I felt totally alone and lonely. ... I moved to private accommodation ... many people ... react to my speech. ... some were patient, some were not. [On the] phone [people would say] "Oh you freak", "Do you come from the universe?" "Are you from this planet?" "Speak normally". When I talk to people ... if they want to sell you something, if you ask them for something [they say], "I'm sorry I don't have time to*

*sort this out". So apart [from this]... many people are very nice and compassionate.*

*... suddenly you are different and it is very detectable. ... You are [at the] church and shop. So [you] have to use different tactics because if you [talk] people [are] scared. (gestures to electrolarynx). Maybe the device to spray you, kill you or harm you. So have to be very carefully [sic]. "Hello, hello, hello". I am talking like this. I have experienced many in the 10 years many different reactions. ... So it's, if people [who] teach you how to behave.*

All the participant cohorts compared the TL support with other cancer support services. The provision of adequate and tailored care was identified as more coordination of care, for example a specialist nurse practitioner and the increased use of specialised psychosocial supports.

The IWL in this study reported that they often felt isolated from others but wanted to be understood and accepted for who they were. However, they described how their situation was poorly understood in the broader community and this was reflected in poor provision of services and ignorant attitudes. Resources and resourcing did not solely determine the validation of 'the altered self' after TL. However, issues of competency and adequate care were important to IWL and their supporters. Consistent expertise and care alleviated undue stress and provided the certainty needed when individuals were experiencing a lot of uncertainty. The data suggest that the IWL needed to be reassured, well supported and valued by those around them, including the larger systems they encountered, for example the health system, to recover and overcome the challenges. How an individual reframed their altered self influenced how they interpreted and responded to negative experiences. Thus, understanding and acceptance by others, and the broader socio-cultural values they faced, appeared to have a strong validating influence on how much some of the IWL accepted their altered self. This appeared to be most relevant to those participants who described a 'resigned' or 'destabilised' altered self.

*Personal factors*

The personal factors influencing the phenomenon of *Validating the altered self* appeared to relate primarily to gender, age, and to a lesser extent SES and geographical location, and were closely related to Category 6. It appeared that participants younger than 65 years or female were more likely to experience a 'resigned' or 'destabilised self', and these patterns occurred more commonly in the female participants than the male participants. Individuals who were partnered and male were more likely to describe a 'resolute' or 'transformed self'.

*Model of Validation*

A *Model of validation* representing the TL experience constructed from the data was developed to conceptualise the substantive theory *Validating the altered self after TL.* The model is shown as Figure 13.

The *Model of validation* represents the interplay between a range of intrinsic and extrinsic factors influencing the process of constructing, reframing and *Validating the altered self after TL.* These factors relate to the phenomena of having disrupted self-expression, related competencies and social roles, and how individuals navigate and negotiate these changes. They also capture the underlying processes impacting these phenomena, the development of competence and the building of resilience.

Contextual factors are the third important part of this model, and include the timing and stages, being supported and personal factors. The IWL described how they felt validated when they experienced successful social participation, were able to engage meaningfully in interactions, experienced competent and adequate care, and felt accepted. They reported they frequently evaluated their self-expression (communicative and/or swallowing competence, and appearance) and made choices about engagement in relation to a particular social interaction or situation. They did this to mitigate the risk of not experiencing validation and therefore social legitimacy.
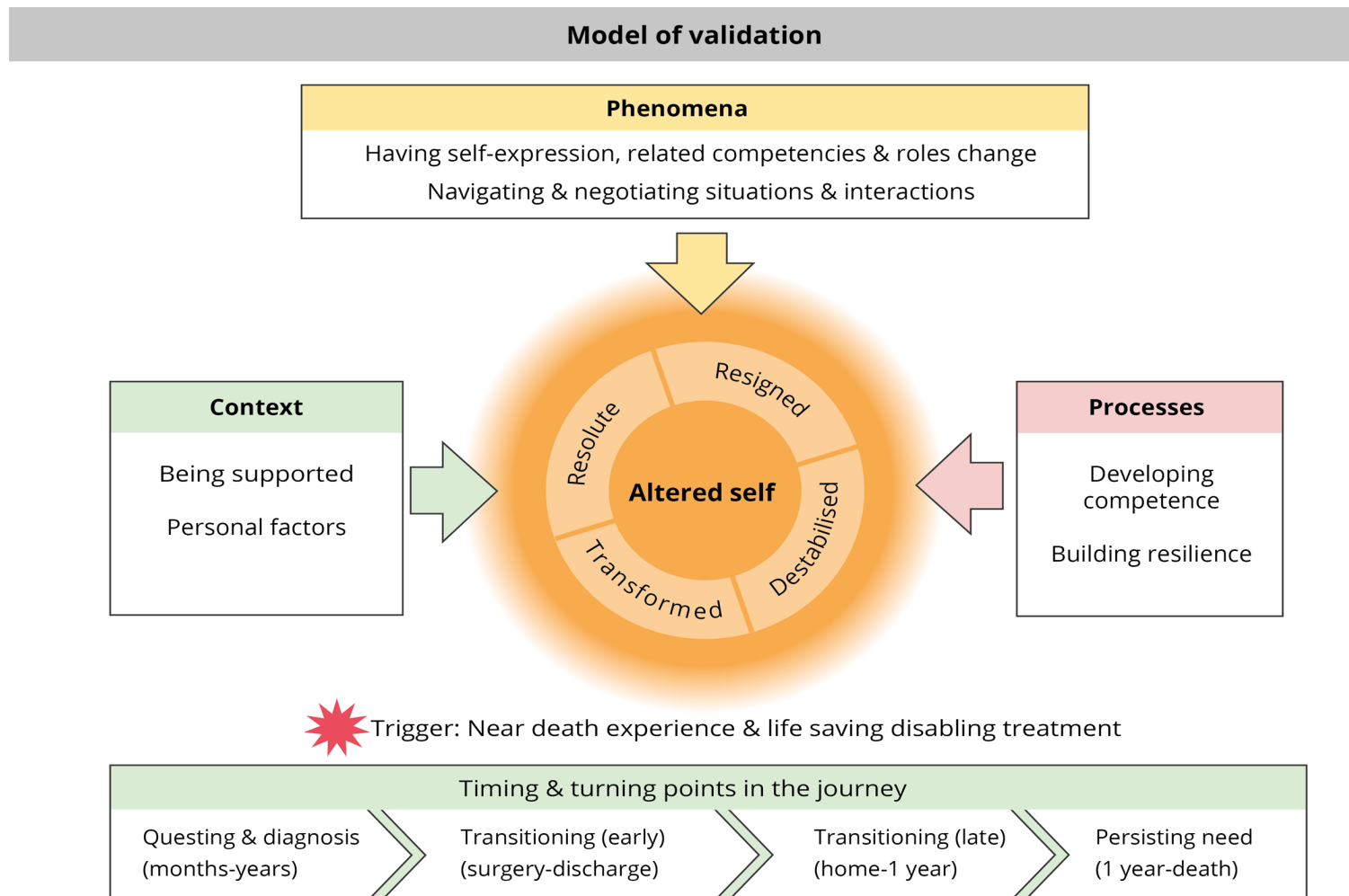
**Figure 13:  Model of validation**

Knowledge of the pre-laryngectomy self and temporal factors was also important here. A person's communication capacities affected the ability to navigate and negotiate interactions and situations, and differed throughout the TL journey. The data suggest there were particular moments, occasions or turning points in the journey where participants either perceived validation or non-validation. These experiences appeared to have a lasting impact on the IWLs' ability to cope with their changed circumstances. The results indicate that the participants' resilience changed over time and was impacted by a wide range of factors, including their beliefs, feeling needed, ability to develop independence, support levels and broader social acceptance.

## 6.4 Conclusion

In this chapter, I have discussed how the data suggest that self-expression and related competencies for this cohort of IWL were tied to the construction and reframing of 'the altered self' after TL. The IWL derived meaning from the relationships they had, the work they did and the activities they participated in. All of these facets of their lives were contingent on their self-expression. The theory suggests this was broader than expressive communication ability. It also encompassed swallowing ability, appearance and the capacity to express personal tastes, style and preferences. Numerous intrinsic and extrinsic validating factors related to each individual influenced their reframing and acceptance processes. The substantive theory, *Validating the altered self after TL,* conceptualised the physical, functional, emotional and psychosocial changes experienced by all IWL as a result of their TL. A near death experience, and altered self-expression and related competencies meant that all individuals experienced the world and social interaction differently.

There was a range of responses to these changes, and evidence that all IWL made personal decisions, and evaluated the reactions of others and the cultural context. They appeared to do this in all social interactions to determine how they felt about their situation and what course of action to take.

The substantive theory provides a finer-grained analysis of how a group of IWL appeared to construct meaning related to their TL experiences, and the influence of biopsychosocial factors on this process. In this chapter, the understanding gained from this analysis has been used to answer the study's first research question (How do people construct meaning in relation to the experience of having and living with a total laryngectomy?) and partly answer the second question (How do biopsychosocial

factors such as gender, age, family structure/constellation, support networks, SES, level of education, employment situation and geographical location, and/or cultural and linguistic factors such as ethnicity, attitudes, beliefs, practices and linguistic diversity influence the psychosocial adjustment of IWL?). The theory is firmly grounded in the data and conceptually rooted in a well-established theoretical framework.

In the following chapter, I use the theory to continue answering the second research question, and to answer the third and fourth research questions, illustrate how the theory resonates or extends our current understanding regarding acquired communication impairment and selfhood, and discuss it in relation to the literature pertaining to the TL psychosocial experience.

# 7 Discussion and recommendations

## 7.1 Introduction

In this chapter, I discuss how the current study provides new insights related to the meaning of the TL experience from the perspective of IWL, and those of the primary supporters and health professionals. In the previous chapter, I presented the substantive theory *Validating the altered self after TL*, which assisted me to answer the first research question about how IWL construct meaning about their TL, and partly answer the second research question related to the biopsychosocial factors that influenced the IWLs' psychosocial adjustment to TL. I now expand this discussion by examining the substantive theory in relation to other theories of selfhood during other illnesses and other types of communication impairment. In doing so, I draw on a range of theoretical constructs and empirical evidence from several disciplines, including sociolinguistics, speech-language pathology, second language acquisition, psychology and otolaryngology. This leads to discussing the psychosocial experiences described by the participants in this study. I have maintained the structure used in the previous two chapters – the phenomena, the processes and the context – to assist this discussion and enable a more in-depth examination of how acceptance of a TL appears to relate to situated competence, communicative participation, resilience building and influential contextual factors. The discussion provides the groundwork for continuing to answer the second research question regarding contextual and biopsychosocial factors influencing psychosocial adjustment, the third question relating to the ways health professionals routinely address psychosocial issues, and the fourth question relating to the kinds of professional practices that will provide better psychosocial supports to IWL (the recommendations).

## 7.2 The phenomenon: Validating 'the altered self'

The substantive theory and associated model presented in the previous chapter were grounded in the data presented in Chapter 5. Categories 1 and 2 emerged as central phenomena and highlighted that a TL is a deeply personal and existential experience in which IWL are actively engaged in constructing meaning to reframe and accept their altered self. The substantive theory is consistent with the current TL and HNC literature, and also expands our knowledge. In Chapter 2, numerous studies were reported that described difficulties with social functioning and role disruption for

individuals who undergo TL. Several of these studies discussed these phenomena but few theorised what may be underpinning them (Singer et al., 2014; Swore Fletcher et al., 2012). The relationship between functional communication ability, social functioning and social support has been reported but there has been little critical exploration of how loss of self-expression is tied to the disruption of identity, relationships and roles.

In the present study, the data and subsequent analysis of the constructs 'the altered self' and 'validation' have illuminated why some of the participants seemed to adjust more quickly than others. These constructs suggest the types of behaviours indicative of specific reframing patterns, and the types of experiences that served to validate or delegitimise individuals as they tried to live with their changed circumstances. The constructs highlight the cognitive, communication and psychosocial challenges individuals faced along the trajectory of their experience. More theoretical understanding of these constructs has enabled a detailed examination of the psychosocial issues faced, and the enablers and barriers to adjustment over time. I explored the published literature to further understand the constructs in relation to the experiences of identity reconstruction after other illnesses or communication impairments. Theories of 'Communicative competence' and 'Communicative participation' appeared to be useful in further understanding the TL experience described by the participants in the present study, as did self-efficacy theory (discussed in depth in section 7.3.2). I now discuss the relevant literature and critique these theories for their usefulness in guiding and developing future person-centred practices with this clinical group.

### 7.2.1 *Exploration of theories of selfhood arising from other illnesses or communication impairments*

It has been theorised that humans experience a continuous sense of self unless a significant life event such as a health crisis or problem changes their lives and forces a re-examination or redefinition of their identity (Goffman, 1963). This has been referred to as "biographical disruption", experiencing a "disrupted self" or "loss of self" (Bury, 1982, 2001; Charmaz, 1983, 1995). The substantive theory describes that the IWL experienced a life-threatening illness, requiring treatment, which resulted in long-term disability. They perceived their altered self-constructions subjectively but also appeared to relate to them as 'objects' they could interpret and manage or

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reframe. It was evident that symbols of their pre-laryngectomy life and self-identity were taken for granted but changed overnight, for example plans for the future and daily routines, relationships, occupations, appearance and functions such as being able to breathe, speak and swallow. The construct 'the altered self' conceptualised how the IWL perceived the changes to their physical, functional and psychosocial sense of self after TL. It also represented how this was a socially-constructed entity, impacted by the perceptions and actions of others and the broader socio-cultural context.

The overarching construction of 'the altered self' and the four reframing patterns (resigned, destabilised, resolute and transformed) provided a more nuanced description of the IWL experience than the terms 'disrupted' or 'continuous self'. The substantive theory described how each of the reframes was a response to the "biographical disruption" described by other authors. The extent and length of time individuals experienced disruption differed. A range of processes and contextual factors contributed to this. The *Model of validation* highlighted the situated nature of 'the altered self'. In other words, people reframed their 'altered self' differently over time or in different situations. This model promotes a person-centred view and does not suggest a fixed or linear progression of reframing patterns. For example, the construct 'the resolute self' suggested some individuals attempted to continue their lives as they had previously and did not recast themselves in any significant way. There is evidence that these individuals, while experiencing a period of destabilisation or resignation in the questing and early transition stages, attempted to resume meaningful activities that their 'altered self' stabilised after discharge and during the late transition stage. Some participants reported they were 'resolute' when discharged but later experienced situations where their communicative competence and social roles had changed so significantly that they experienced a 'destabilised self'. The *Model of validation* suggests that in the longer-term, the reframing patterns stabilise but continue to be influenced by both intrinsic and extrinsic validating factors. At the time of data collection, most of the IWL appeared to interpret their experiences through the lens of one of the reframing patterns described.

The findings of the current study are consistent with the HRQoL literature, which suggests that psychological comorbidity (anxiety and depressive symptoms) in this clinical population are elevated in the questing and transitioning stages, but the prevalence reduces over the first year (Armstrong et al., 2001; Gibson & McCombe,

1999; Haisfield-Wolfe et al., 2009; Singer et al., 2014). In the current study, HRQoL status was not screened, but the narratives and the *Model of validation* suggest that these stages were high risk, distressing times for the IWL. The study also confirmed that ongoing reframing of 'the altered self' and related psychological distress could occur in the persisting need stage many years after the surgery. These findings seem consistent with studies examining long-term quality of life (Boscolo-Rizzo et al., 2008; Metreau et al., 2014; Terrell et al., 1998).

As I identified in Chapter 2, many studies using HRQoL instruments have identified mild-moderate communication and social difficulties, but not functional difficulties such as communication or swallowing problems, as the main predictors of reduced quality of life in the longer-term (Maclean et al., 2009a; Perry et al., 2015; Terrell et al., 1998). Despite a growing number of studies exploring the TL experience and adjustment, very few have explored issues related to self-identity reconstruction and acceptance after laryngectomy, and how these may change over time. This suggests a limitation in using only self-report tools and the dominant positivist approach in TL and HNC research.

Other dramatic and life-changing health events such as diabetes, traumatic brain injury and stroke can lead people to re-evaluate their lives and feel they have gained some valuable insight or personal growth (Gelech & Desjardins, 2010; Hinojosa, Boylstein, Rittman, Sberna-Hinojosa, & Faircloth, 2008; Muenchenberger et al., 2008; Paterson et al., 1999). These studies describe how illness prompted some individuals to report they felt they had changed and related to others differently. In some cases, the illness experience was not perceived negatively; it was constructed as transformative and worthwhile. Swore Fletcher et al. (2012) described HNC as a "blessing and a curse" (p. 126), and found that some of their subjects described existential experiences after their HNC. In the current study, a few participants reframed the TL experience as transformative. However, the majority did not describe this experience.

There is a small body of literature exploring the impact of acquired communication impairment and self-identity stability (e.g. traumatic brain injury) (Douglas, 2015; Gelech & Desjardins, 2010; Muenchenberger et al., 2008), hearing impairment (Hogan, 2001; Kovarsky, Duchan, & Maxwell, 1999), voice impairment (Charmaz, 2014; Rosen & Sataloff, 1997), aphasia (Armstrong, Ferguson, &

Mortenson, 2010; Brumfitt, 1993) and stuttering (Butler, 2013; Kathard, Norman, & Pillay, 2010; Plexico, Manning, & Levitt, 2009). Authors such as Hogan (2001), and Maxwell, Poeppelmeyer, and Polich (1999) also used social constructivism to examine self-identity formation and maintenance experienced by adults with hearing impairment. Hogan (2001) described how this specific group of people frequently experienced breakdowns in interactions as confidence-eroding and disorientating to their sense of self. Maxwell et al. (1999) reported that deafness resulted in people being observers rather than full participators in an oral language world. However, the experience of full participation in a social interaction via conversation could be experienced with other deaf people when using sign language. This full participatory experience affords a person a range of social identities rather than their social identity being defined as only an observer.

There are similarities between the psychosocial experience of 'deafness' described by Hogan (2001) and the TL experience represented in the current study. For example, IWL have constructed their self-identity over a lifetime and self-expression is an integral part of that self-identity formation. When the TL occurs, individuals have difficulties expressing themselves in the way they have come to know. They also hear themselves differently and some people react to them differently. Interpreting the reactions of others has a validating influence on individuals. This new experience has the potential to destabilise the self and adjusting to 'the altered self' can pose many challenges.

Like hearing impairment (Hogan, 2001), a TL can result in the loss of valued roles, relationships, intimacy, opportunities and a social life. However, unlike hearing loss, IWL also face the stigma of what Goffman (1963) described as a "spoiled identity". This is symbolised by disfigurement, problems associated with disruptive coughing and excessive phlegm production, and poor social acceptance of the audible ACMs such as TE and EL speech. The current study highlights it is critical for health professionals to consider that individuals responded to these factors and reframed their post-laryngectomy self, and whether these reframes were maladaptive and posed risks to longer-term health and social wellbeing. For example, it appeared that 50% (*n*=6/12) of the IWL in the current study presented with a 'resigned self' or 'destabilised self' longer-term. These reframes were indicative of poor coping and social isolation.

Traumatic brain injury (TBI) is another situation where a person is faced with considerable disruption and loss. Communication impairment can be just one change alongside a range of cognitive difficulties. Gelech and Desjardins (2010) reported that the dominant discourse in TBI is one of a "lost" or "shattered self". They described the conflict between the "inner" and "public" aspects of selfhood for individuals with TBI, and how others perceive the "public self" as lost because an individual's visible social identity and social roles are disrupted. However, Gelech and Desjardins' study participants with TBI reported a continuity of their 'inner self' after their injury. This created conflict for them because their belief was repeatedly delegitimised by significant others such as health professionals and family and friends who considered them different and less capable. They described being treated as a "disabled" person rather than a unique individual, and this was distressing (pp. 62-74). Gelech and Desjardins (2010) suggested that individuals experienced personal growth despite changes to their social identities. The substantive theory also highlights the importance of relationships, and how people perceived themselves and others in relation to their changed identity. The IWL had all experienced stigma and interaction difficulties but there were clear differences in how participants responded to these adverse situations. This was because they reframed their altered self differently.

Another acquired communication impairment affecting symbolic and non-symbolic interaction is a voice disorder. Charmaz (2014) described the devastating impact on one of her research participants who lost her vocal ability due to cancer. The event meant this participant could not pursue a singing career. The value of the 'voice' for this person was so significant that she could not see a meaningful life without it. Charmaz (2014) theorised that in this case, the "voice and self merge". It took the participant many years to regain a "valued self" (p. 164). The narratives of the IWL in the current study confirm that vocal ability was part of their overall self-expression and represented part of their personality. It was evident that the loss of these abilities impacted individuals differently. The narratives also suggest that the IWL lost more than their physical voice; they also lost the ability to express who they were intellectually, socially, emotionally and even spiritually. They described issues related to gender confusion, and both female and male participants expressed cultural alienation.

The communication disorder 'stuttering' has also been examined in relation to

identity construction and maintenance. Plexico et al. (2009) explored how people who stutter use a range of coping techniques to manage communication acts. These included 'problem focused' and 'emotion focused' strategies, and were aimed at protecting both the listener and the speaker from the social disruption experienced as a result of dysfluency. The genesis of these strategies appeared to have some resonance with the data in the current study. For example, the IWL presenting with a 'resigned' or 'destabilised self' described how they were most concerned by their own evaluations of performance and that of others' experiences. They reported they often avoided situations or changed how they communicated in response to others' actions. Butler (2013) identified that people who stutter also experience "randomised identity conflict" due to the stigma associated with their stutter. She described this conflict as being rooted in how individuals assess socio-cultural and personal influences in conjunction with "locus of control". She described this as "identity work" and labelled the consequent process "identity cloaking" (p. 1117). These constructs provide a deeper understanding of how individuals with communication impairment such as a stutter construct and manage themselves and social situations.

Kathard, Pillay, Samuel, and Reddy (2004) also explored positive and negative self-identity formations in relation to stuttering. They described these as "Able" and "DisOther" formations, which could co-occur, compete or affiliate with "personal, social and temporal" processes, rendering the stuttering experience complex and varied, and impacting self-identity formations (p. 57). Again, it is important to highlight that whilst IWL do experience stigma associated with communication impairment in a similar way to individuals with a stutter or a hearing impairment, they face the wider issues of altered appearance, disruptive breathing and communication aids, all of which result in gender confusion or have an *alien* quality.

The current literature contains little critical analysis or theoretical discussion related to self-identity constructions after TL. I and my colleagues published preliminary findings of this study (refer to Appendix 11), but data collected from primary supporters and health professionals, as well as further analysis has resulted in a deeper understanding of the subjective experiences reported by the IWL (Bickford et al., 2013). The impact of the loss of self-expression on an individual should be viewed holistically and examined more comprehensively at a range of time points. The findings suggest that loss of self-expression and social participation impacted

how the IWL reframed their altered self. In part, communicative competence and communicative participation were underlying factors.

### 7.2.2 *Relating theories of communicative competence and communicative participation to the substantive theory*

The current study confirms that evaluations of successful acquisition of an audible ACM must also include social impacts, assessment of participation restrictions, and the influence and perceptions of the 'other' (significant and generalised) in interaction. In Chapter 2, I highlighted that recent research has focused on participation restriction due to communication impairment and how to measure it (Baylor et al., 2011; Noonan & Hegarty, 2010; Rodriguez et al., 2012; Swore Fletcher et al., 2012). This is an important shift in TL and HNC research because much research to date has measured communication impairment from a deficit, activity limitation and global QoL perspective (Eadie, 2007; Haisfield-Wolfe et al., 2009; Murphy et al., 2007; van As, 2001; van der Molen et al., 2013).

The substantive theory suggests that social and emotional impacts are significant for IWL, and that self-identity constructions should be considered when evaluating their level of acceptance and providing support to assist them to adjust. The theory highlights that changes to self-expression affect both the 'public' and 'private' aspects of the self. It also indicates the importance of the 'other' in social interaction and the reframing process.

In seeking to further critique these issues, I examined a range of theories and interpretative frameworks related to communicative competence, situated competence and communicative participation. These theories have been further developed in communication disability and second language acquisition (SLA) research (Baylor et al., 2011; Celce-Murcia, 2007; Kovarksy, 2014; Kovarsky, Culatta, Franklin, & Theodore, 2001; Kovarsky et al., 1999; Lafford, 2007). I now discuss some of the constructs presented by these theories and how they aided my analysis and interpretation of the issues at hand. By using these theories, I continued to examine the experiences described in the current study from a social constructivist and interactionist viewpoint (Firth & Wagner, 1997; Hymes, 1972).

#### 7.2.2.1 *Communicative competence*

In the current study, Categories 1 and 2 highlighted that the IWL made a lot of

decisions and acted according to their evaluations of their own communicative competence and that of others. The construct 'Communicative competence' was theorised by linguist and ethnographer Dell Hymes (1972), and provided a useful framework to view the communication experiences described by the IWL participants. Hymes viewed communication as a situated and contingent accomplishment, stating:

> … a normal member of a community has knowledge with respect to all these aspects of the communicative systems available to him [sic]. He [sic] will interpret or assess the conduct of others and himself [sic] in ways that reflect a knowledge of each (possible, feasible, appropriate), done (if so, how often). There is an important sense in which he [sic] would be said to have a capability with regard to each. (Hymes, 1972, p. 282)

This is further elaborated by the following premise that the IWL in the current study decided "when to speak, when not, and as to what to talk about with whom, when, where, in what manner" (Hymes, 1972, p. 277). These participants reported they spent a lot of their time and mental effort doing just as Hymes described. It appeared that these experiences were qualitatively different from their pre-laryngectomy experiences; they no longer had complete control over the manner in which they spoke. There was also little evidence in the data to suggest that significant others and other people routinely allowed or compensated for the changes experienced by IWL during interactions, apart from general support. It appeared that this was a source of disappointment for some of the IWL in the current study. This is an important observation and enabled me to explore the kinds of practices that may assist interaction with an IWL, including the responsibility of the communication partner. A theoretical understanding of communicative competence will assist with these explorations.

Communicative competence relies on participants having the communication capacity to organise their communication for "socially defined purposes" and to be sensitive to the rules of situations (Hymes, 1972, p. 292). Therefore, competent communication is dependent on the communicative competence of both the speaker and listener. Individuals also develop and use context-dependent strategies to manage communication.

### 7.2.2.2 *Situated competence and communicative participation*

There is emerging literature in speech-language pathology linking the importance of

communicative competence with identity formation and social interaction. Kovarsky, Duchan, and Maxwell (1999) extensively explored these themes and developed a 'situated' framework. Later, a 'communicative participation' framework was proposed with five inter-related elements that can be evaluated independently, but may interact and affect each other (Kovarksy, 2014; Kovarsky et al., 2001). Table 10 provides a summary of these constituent elements.

**Table 10: Communicative Participation framework**

| 1) | **Lifeworld participation** | Moments of cultural focus that reveal the importance of communication in experience of value or disvalue. Among other things, these experiences have the potential to include or exclude in ways that impact on identity and relationships, and on an individual's sense of place, involvement or belonging in the social world. |
|---|---|---|
| 2) | **Participant structure** | Different and culturally embedded values expected in interaction in a particular setting |
| 3) | **Participant roles** | Speakers (sender) e.g. authors, animators and principals of the messages they convey. Hearers (receiver) e.g. primary or secondary recipients of a message or bystanders |
| 4) | **Participant accommodation** | How messages are designed to meet the needs of the listener. Turns at talking can contribute to how meaning is constructed in interaction. |
| 5) | **Participant resources** | A range of communicative means in order to participate in discourse including spoken, written, signed, gestural (the kinetics of the entire bodies in movement included), temporal and special resources that function to affect communicative meaning. (Kovarksy, 2014, p. 82) |

The framework emphasises cultural or situated context, and enables a closer examination of socio-cultural issues impacting interaction for individuals with communication disability. The elements promote examination of multiple perspectives (speaker and listener) during communication and interaction (Kovarksy, 2014; Kovarsky et al., 2001; Kovarsky et al., 1999). The framework has enabled an explicit examination of the phenomenon *Validating the altered self after TL*, and provided a more detailed interpretation of how the IWL managed communicative events, interaction and social identities after their surgery. In addition, it has enabled critique of the influence of context and the role of the 'other' in the form of communication partners. In the current study, the primary focus has been 'significant others', the primary supporter or health professional, although the IWL did describe how others had affected them.

An important underlying assumption of the 'situated' framework is that

identity is constructed in a flexible and situated manner through interaction (Kovarsky et al., 1999). Kovarsky et al. cited Carbaugh (1996, pp. 213-214), who commented:

> Identities [are] something created and subjected to particular conversational dynamics… From this vantage point the question 'who am I?' depends partly on where I am, 'with whom I am', and [material and symbolic] resources that are available to the people there.

The framework also emphasises socio-cultural influences, and prompts evaluation of the role of communicative competence in the construction, maintenance and reframing of 'the altered self' after Kovarsky et al. (1999) theorised that evaluations of competence "pervade, influence, and grow out of ordinary social interactions" (p. 5). Thus, there is a dynamic process of building up, negotiating and revising these competency evaluations, as illustrated by Kovarsky's (2014) description of how co-constructed evaluations are also socio-culturally situated and reflect the practices of a specific community:

> Communicative participation refers to how individuals participate in a range of discourse activities in contextually situated ways that in turn, reflect on the manner of their involvement in culture. (p. 76)

The narratives in the current study highlight that the IWL participants perceived that they, significant others and the wider social context subject them to frequent competency evaluations. There is a tacit assumption in both frameworks that all participants in an interaction use communication devices and strategies, both linguistic and paralinguistic, in conjunction with their socio-cultural knowledge. Collectively, these form an individual's "potential communication repertoire" (Kovarsky et al., 1999, p. 7), and underpin communicative competence (Hymes, 1974; Kovarksy, 2014; Kovarsky et al., 2001; Kovarsky et al., 1999).

Blumer (1969) described a naturally occurring sequence, which resonates with the experiences of the IWL in the current study. It appears that this process either validated or cast doubt on the legitimacy of 'the altered self' in interactions:

> In a new and different situation a person has the need of carving out a new line of activity. He [sic] has to size up the situation, get cues, judge this or that, and piece together some line of activity that will enable him [sic] to fit the situation as he sees it. The situation will pose new demands and present new possibilities. (p. 96)

Using the Communicative Participation framework proposed by Kovarsky et al. (2001), it appears that the IWL in the current study were describing how limitations to self-expression were significantly impacting their 'lifeworld participation'. These

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limitations related to the 'participant resources' of timing, intonation, gesture and movement when communicating. It seems from the narratives that they experienced a lack of adaptation of 'participant structures' or 'participant accommodation' to compensate for these limitations. Collectively, these things influenced and impacted the construction of communicative meaning as well as the 'participant roles' and 'participant accommodation' for the participants (p. 1). The concept of 'positioning' in communication and interaction was also highlighted by these frameworks (Kovarsky et al., 1999, p. 11). It appeared to impact the 'participant roles' and 'participant accommodation' experiences of the IWL (Kovarsky et al., 2001).

The following section provides a further discussion of the constituent elements of the Communicative Participation framework in relation to the findings from the current study.

*1) Lifeworld participation*

This element provides a focal point for examining why personal evaluations of altered expressive ability and socio-cultural acceptability can lead to the phenomenon of *Validating the altered self after TL*. Validation pertains to personal acceptance and social legitimacy in interactions and relationships. An individual may perceive they are legitimate but can also gauge the verbal and non-verbal responses of their communication partner to reinforce or refute this sense of legitimacy.

Hymes (1972) theorised that language use is situated and that evaluation of the appropriateness of communication is not only dependent on the linguistic form but also constrained by what is socially or culturally permissible in a given context. Socialisation enables us to develop the assumptions, beliefs and attitudes we use to evaluate our own communicative competence and that of others. Hymes expanded the interactionist position related to 'role-taking', believing that the ability to role-take and perceive the situation from a communication partner's perspective contributed to socio-cultural competence; an important aspect of communicative competence. In the substantive theory, I have discussed how role-taking in interaction also influences the construction of the self, and how interpretations may influence and shape participant actions in an interaction (Blumer, 1969; Mead, 1934). Category 2 in the current study supported that the IWL actively interpreted others' responses and shaped their actions accordingly. However, their physical limitations also affected their abilities. It also suggested that all forms of alaryngeal communication were often not fully accepted or

accommodated. The participants used their knowledge of socio-cultural norms, built over their lifetime, to assess the appropriateness of their symbolic communication for a situation. For example, prior to a TL, individuals may have had a highly developed social competence with which they successfully interacted with others because they were motivated, confident, displayed empathy and had skills to manage social challenges. However, it appears from the narratives that very few communication partners were able to empathise with the post-laryngectomy changes to self-expression. This suggests, perhaps, that for many communication partners their ability to comprehend the changes to significant symbols evidenced by audible ACMs affected their ability to role-take, thus affecting their understanding and ability to accommodate the communication experiences of an IWL.

The role of communication partners in laryngectomy communication deserves further analysis. It appears that there is potential positive therapeutic effect in developing meta-awareness of the impact and influence of communication partners in interaction to support IWLs' acceptance of, and adjustment to, their communication changes.

*2) Participant structure*

The Situated framework highlights that every interaction is impacted by a local situation with specific conditions. The substantive theory explicated that these were very real issues described by the IWL during interaction. It also highlighted that certain contexts influenced and constrained interactions, and that evaluations were often influenced by standards and expectations, just as Kovarsky et al. (1999) suggest. In the current study, the healthcare environment was reported to be problematic for individuals, and often resulted in the primary supporter playing an important role and compensating for these difficulties. Subsequently, the care burden increased and remained significant. These issues are evaluated further under the subheading 'participant accommodation'.

It has been postulated that "situated evaluations" can have varying impacts on individuals (Kovarsky et al., 1999, p. 17). However, multiple and accumulative negative evaluations about communicative competence may have significant effects on self-identity over time, and result in powerlessness (Hogan, 2001; Kovarsky et al., 1999). This is an important observation for the IWL population because it has been consistently identified that in the longer-term, a subset of IWL experience poor

coping and reduced psychological wellbeing (Eadie & Bowker, 2013; Perry et al., 2015; Terrell et al., 1998).

Another important finding of this study was that judgements of communicative competence appeared to be different between the different participant cohorts. For example, the IWL appeared to be affected by how much their audible ACM compensated for their pre-laryngectomy communication abilities, disrupted their social roles or was socially acceptable, whilst the primary supporter participants were concerned with functionality and the impact of the communication changes on their partner's independence. The IWL reported that health professionals consistently rated their communication better than they did. These ratings appeared to be related to intelligibility rather than communicative participation indicators. Singer, Wollbrück, et al. (2013) reported that objective measures and subjective perceptions of speech intelligibility after TL were only partially correlated and not dependent. In other words, an IWL will judge their performance according to what they used to be like and what their expectations for recovery are, whereas significant others such as a speech pathologist will judge performance according to their expectation of attainment for that particular ACM.

*3) Participant roles*

The IWL described how their 'participant roles' had changed because they found it difficult to position themselves in conversation, and on many occasions they felt peripheral rather than central during interactions. These difficulties were problematic because they frequently resulted in social exclusion and affected participation. Kovarsky et al. (1999) raised the issue of 'positioning', stating: "evaluations are issued and interpreted by interactants from particular positions" (p. 11). They argued that both speakers and listeners in an interaction take up positions in relation to one another and the situation at hand.

The 'participant resources' of timing and intonation are also important here. Categories 1 and 2 explicated that the IWL often experienced poor airway control, and poor versatility and reliably of their audible ACM. The resultant effect included difficulty sustaining discourse or having the flexibility to engage in conversation. There is very little documented in the broader literature regarding these interaction difficulties for this population. The current study not only highlighted the issue of 'positioning' as being significant for alaryngeal communicators, but it also showed

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that for many of the IWL 'positioning' resulted in changes to social roles and relationships. It was clear that IWL 'lifeworld participation' was impacted by issues related to positioning. The findings also illustrate the situational nature of this issue and how a setting's 'participant structure' often excluded participation. However, the IWL learned to manage their difficulties with 'positioning', and described how they were very active in communication and attempted to exert some control to ensure successful communication. However, these attempts were not always successful and impacted their identity. They described using verbal and non-verbal strategies or situation avoidance to circumvent experiencing stigma or communication breakdown. These strategies are forms of "strategic competence", a construct previously described by second language acquisition researchers (Celce-Murcia, 2007, p. 50). The methods the IWL described included attempts to engage with their communication partners and inform them of their difficulties. The participants reported that it was physically and mentally effortful to maintain these strategies because the problems were subtle and chronic in nature. The majority described experiencing frustration and disappointment. Some reported that they reframed how they perceived others' actions in interactions to manage these challenges. These reframes were often accepting of the poor understanding or empathy displayed by a communication partner. However, for the participants presenting with a 'destabilised' or 'resigned' altered self, the issue of 'positioning' when communicating was an important concern. It appeared to be linked to social status and role.

*4) Participant accommodation*

Another significant difficulty for the IWL in this study related to 'participant accommodation', which needs to be considered across the trajectory with different communication needs at different stages. Categories 1, 2 and 6 indicated that the IWL found it difficult to accommodate the needs of their listeners due to their communication difficulties, and vice versa. The narratives suggested that many of their communication partners did not empathise with their communication changes or limitations. Thus, they did not modify their behaviour to support communication changes. Some of the IWL described how they interpreted this as an extrinsic validation of their competence and legitimacy as communicators. For example, the IWL and primary supporter participants acknowledged how these communication difficulties impacted interaction with busy health professionals. A commonly reported

dynamic was for a primary supporter to be available as much as possible in the early stages of recovery to compensate for the IWL due to communication difficulties. Primary supporters were also reported to assume social roles to reduce the communicative demand for IWL. The IWL described how they were often relegated to a peripheral position in conversations with health professionals. They described this as difficult because the conversations were about them. Several of the health professional participants acknowledged these issues and said they supported their patients to express their needs. However, from the participants' perspective, this approach appeared to be inconsistent and tied to professional competence and empathy levels.

The findings of the current study appear to be consistent with issues raised by Rodriguez et al. (2012) who described the sudden loss of speech, and the issues of dignity and safety experienced in the early stage of recovery from HNC. The IWL experienced sudden speechlessness randomly across the TL journey due to a range of physical and functional reasons. These experiences caused significant concern for the IWL and reinforced their need for empathetic communication partners. The related safety issues and care burden effects have received little or no attention in the current literature. However, spouses have reported an increase in adverse events in hospital related to communication breakdowns for people with aphasia (Hemsley, Werninck, & Worrall, 2013).

The IWL with partners acknowledged the communicative, emotional and physical support they received from them throughout the entire experience. The primary supporter participants also reported the significant and prevailing support they provided. Both participant groups reported that communication breakdowns occurred and this was stressful at times. There was no evidence that partner training to improve communicative participation for IWL had been instigated as part of the rehabilitation plan.

There is a paucity of information in the TL literature regarding the cognitive and emotional demands of interaction and social participation, particularly in relation to communicative or situated competence. The Baylor et al. (2011) study begins to provide some important evidence regarding communicative participation and the nature of interference; those factors, both intrinsic and extrinsic to a person, that interfere with participation. In other studies, psychological constructs such as

avoidance coping, active coping, distancing, positive self-efficacy, and adaptive and maladaptive behaviours have been described as pertaining to IWL populations (Aarstad, Lode, et al., 2011; Blood, Simpson, Raimondi, et al., 1994; Eadie & Bowker, 2013; Perry et al., 2015; Relic et al., 2001). Conceptualising the communication experience described by the IWL in the current study in purely psychological terms fails to capture the social construction elements underpinning communication and interaction between individuals. Questions arise about interaction passivity and how it relates to the communication difficulties and socio-cultural experience, and whether passivity is adaptive or maladaptive. In addition, it may be useful to examine more rigorously how IWL use their communicative competence to manage their communication disability and stigmatised condition. The current study clearly highlights the issues of 'participant accommodation' for all the participant cohorts, but most importantly for the IWL.

*5) Participant resources*

Very few studies have critically explored how audible ACMs can identify individuals as different and affect them during social interaction. The substantive theory highlights that significant symbolic communication markers, including timing, intonation and movements to manage a communication aid are a few elements that identify laryngectomy communication as different. These significant symbols are frequently subjected to social judgements and stigma, resulting in a change in the dynamic of an interaction. Often, these judgements are related to evaluations of competence and result in frustration for an IWL because they no longer have access to the significant symbols they did prior to their surgery.

Timing

Timing issues for IWL can be dissected in a number of ways and are dependent on the ACM. The data suggest that IWL experienced a range of difficulties with prosody with both audible and non-audible ACMs. Kovarsky et al. (1999) have described how the "rhythm, tempo and rate" of speech utterances can impact communication (p. 9). Similar issues have been identified for other augmentative communication users (Clark, 1996; Higginbotham & Wilkins, 1999). TE speech and 'mouthing' preserve these capacities more than the other methods. However, the TE speakers in the current study reported that initiation and maintenance of timing in conversation was

problematic, even for a TE speaker. Kovarsky et al. (1999) described how a delay in response could be perceived as "reticence or incompetence" (p. 9). Their data suggested that the IWL observed that some communication partners appeared to have made these judgements about them.

<u>Intonation</u>

The current study captured the perspectives of TE speakers and EL speakers. These groups experienced very different intonation patterns post-laryngectomy due to the nature of their ACM. However, both groups identified that intonation was an important and key paralinguistic feature of their communication style and social identity. They all described difficulty with their intonation due to problems with vocal pitch, loudness and quality. All the IWL reported gender confusion, and difficulties communicating face-to-face and using the telephone. These problems suggest that even with visual cues, listeners could experience confusion or misjudge an alaryngeal communicator due to the intonation of their voice. These findings are consistent with Laver (1980), who described the significance of voice quality and stated that "the importance of an individual speaker's voice in everyday social interaction, as an audible index of his [sic] identity, personality and mood could hardly be overstated" (p. 1).

There is some evidence that intonation post-laryngectomy has been linked to moderately impaired VRQoL and that listeners find audible alaryngeal speech less acceptable, but this can be context dependent (Doyle & Eadie, 2005; Evans et al., 2009; Hughes & Gabel, 2008; Kazi et al., 2007; Stam et al., 1991). The current study's findings are consistent with the consensus that TE speech is more socially acceptable than EL speech (Eadie, Day, Sawin, Lamvik, & Doyle, 2013b; Moukarbel et al., 2011). The narratives provide further evidence that female TE speech is less socially acceptable than male TE speech, which others have suggested (Eadie, 2007), and support the established view that some female TE speakers have poorer psychosocial adjustment outcomes (Kazi, Kiverniti, et al., 2006; Lee et al., 2010).

The current study results can be viewed in terms of how intonation impacted the IWLs' 'lifeworld participation'. For example, they described how they perceived stigma because of their synthetic electrolaryngeal voice or low pitched and rough sounding tracheoesophageal voice, and as a result changed their interactive behaviour. This appeared to be further influenced by socio-cultural attitudes related to voice

quality, gender and, to a lesser extent, social status. Several IWL described how a lack of intonation was frustrating for them because they could not convey emotion. Doyle (2009) has outlined how IWL have difficulty conveying emotion such as laughter and crying due to the constraints of loudness, pitch and quality of audible ACMs. Another interesting finding was how emotion appeared to disrupt the communication of some IWL. They described similar physiological issues as those experienced by individuals with functional voice disorders (Roy, 2008). The current study extends current understanding by suggesting that the flow of conversation or interaction, and the feedback IWL received from communication partners about these differences, reinforced their altered identity. Participants presenting with a 'destabilised' and 'resigned self' appeared to experience the most difficulties managing the issues associated with intonation.

Movement and gesture

The paralinguistic feature 'movement' was problematic for the TE speakers and EL speakers in the current study. Typical movements associated with these methods include using one arm to either digitally occlude their tracheostoma or hold the electrolarynx when talking. The IWL described how this limited their verbal and non-verbal communication, for example the use of gesture, or talking whilst undertaking activities requiring the use of both hands. Several IWL described how they altered or avoided communicating in some situations because they perceived that their movements attracted attention, they felt stigmatised and the flow of conversation was disrupted. Despite the absence of OE speakers in this study, issues of 'movement' can also be described as the audible clicking of ingested air for speech production for this group of laryngeal communicators. Kovarsky et al. (1999) wrote that differences in 'movement' have been identified as having "evaluative effects" in interaction (p. 10). The current study has provided more understanding about how gesture required for some audible ACMs impacts socio-cultural conventions and was perceived by the IWL as disruptive and stigmatising. However, there is little or no discussion in the wider literature about these impacts.

## 7.3   The processes: Intrinsic factors influencing validation

The substantive theory, *Validating the altered self after TL,* involved two important inter-related processes: Category 3, 'Developing competence'; and Category 4,

'Building resilience'. These categories highlighted a range of intrinsic factors influencing acceptance and adjustment outcomes for IWL.

### 7.3.1 The role of developing competence

In the previous section, I discussed the importance of communicative competence in identity reframing after a TL. In the *Model of validation,* the process 'Developing competence' related in part to these issues but also captured other issues of competence affecting IWL, including self-care and management of a communication aid such as a voice prosthesis. The current study has reinforced that competency issues do not always render someone socially isolated, but others can perceived them wrongly, resulting in stigma. It is also important to highlight that the narratives suggest that others' incompetence is stressful, frustrating and disappointing. It appears that the IWL required high levels of self-efficacy to reframe a situation, and frequently made decisions about their own competence and the competence of others before deciding to act. This seemed to take significant cognitive effort. It was also reported that social support could both enhance and inhibit competency development. Another important observation was that competence developed over time and was contingent on scaffolding.

These processes described how individuals came to understand the changes to their functional abilities and how these changes impacted them socially. It appears that a poor recovery in the early stages did not predict poor acquisition of an audible ACM or independence in other functional areas. However, other studies have documented that functional and QoL outcomes improve with time (Eadie & Bowker, 2013). There is very little in the broader literature about the timing of competency development in a range of domains, for example self-care, and prosthesis management for both IWL and primary supporters. Nor does it seem that there are mechanisms to evaluate or scale competency for particular domains.

There is evidence in the general health literature, however, that if a person perceives they have mastery and agency of situations, they will experience better health outcomes than individuals who feel powerless (Baker, Ben-Tovim, Butcher, Esterman, & McLaughlin, 2013; Blane, 2006; Marmot & Wilkinson, 2006). The IWL in the current study had to adjust to obvious disfigurement and functional limitations that affected multiple modalities (e.g. communication, swallowing and breathing). They also had to develop new skills to regain their independence. They were still

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dependent on others in some areas of their lives many years after their surgery. Category 3 highlighted that the development of understanding about a TL was important, and was linked with the development of independence for both the IWL and primary supporter participants. While informational or pre-operative counselling has been described as an important part of the management approach, it is an under-researched area of clinical practice (Lawson & Ward, 2014; Ward, Hobson, et al., 2003; Zeine & Larson, 1999). There appeared to be inconsistent perceptions amongst IWL, primary supporters and health professionals about the timing, need and extent of information counselling. There were likely to be a number of factors contributing to this finding, including the ability of individuals to absorb and retain information. This issue has been documented previously in the literature (Ziegler et al., 2004).

The health professional participants reported they routinely provided education and information both verbally and in written form to their patients and families. This was a practice consistent with clinical guidelines (Roland & Paleri, 2011; South Australia Department of Health, 2013). Also in this study, many of the IWL and primary supporter participants felt that information had to be well-timed and accessible, but their preferences for how they wanted to learn varied considerably. Participants described learning and developing knowledge as *taking time* and a *personal experience*. Some participants reported they wanted the facts and some described being overwhelmed by too much information. Others did not recall any formal information counselling but described how their partner had received it. This phenomenon has also been described for this clinical group in earlier studies (Zeine & Larson, 1999; Ziegler et al., 2004).

In addition, it appears from the current study that many of the IWL downplayed their need for information. They said the MDT guided them, whereas the primary supporters identified that they sought out more information and support than the MDT provided. This phenomenon has also been reported by Penner (2009). Another Australian study showed that a higher number of spouses compared to IWL reported that pre- and post-operative information or support was inadequate (Ward, Hobson, et al., 2003). A recent study examining the communication between nurses and HNC patients and their partners suggests that nurses are able to respond effectively to information needs but are less effective in responding to emotional cues (de Leeuw et al., 2014).

Care burden and strain, and the need for further support have been identified in the TL, HNC and cancer literature (Blood, Simpson, Dineen, et al., 1994; Goldstein et al., 2004; Penner, 2009; Richardson, Broadbent, & Morton, 2015; Ward, Hobson, et al., 2003). The extent to which 'Developing competence' impacts adjustment, carer burden and strain was previously poorly understood. An important observation in the current study was that the primary supporter participants described being motivated to get information and specific training. They said the acquisition of knowledge reduced their apprehension and assisted them to provide more supportive care. They also described how they were often educators of others (e.g. family and friends and health professionals) and how this responsibility did add to their sense of burden and strain. There was no evidence in the data of strategies or assessments being used by health professionals to evaluate and support primary supporters affected by these increased demands. This appears consistent with other published studies (Penner, 2009).

The under-recognised phenomena of 'being there' and the associated psychosocial costs in both the transitioning and persisting need stages, were described by many of the primary supporters and a few IWL in the current study. Only recently have other researchers reported this phenomenon for primary supporters of HNC patients. In one study, caregivers described the need for "just being there" in the early stages of care and their perceptions appeared to impact the HNC sufferers' quality of life (Richardson, Morton, & Broadbent, 2015, p. 288). In the current study, there appeared to be conflicting reports regarding how the primary supporters coped. The IWL reported that in the early stages, at diagnosis and surgery, they had to provide significant support to their partner. Some of the primary supporter participants described the opposite. Interestingly, the primary supporter participants described seeking more external supports than the IWL to assist them to cope.

The findings of the current study also suggest primary supporters and health professional participants experienced some conflict about how much ongoing care they should provide IWL. It was reported that in some cases the supportive care from a primary supporter discouraged the development of self-care and independence, which can have obvious psychosocial benefits. There is also increasing evidence that task burden in the short and longer-term for the primary supporters is both unexpected and draining. In fact, the perceptions of primary supporters in relation to their partner's HNC illness have been described as impacting negatively on patients

(Penner, 2009; Richardson, Broadbent, et al., 2015).

Gibson and McCombe (1999) described the risk to intimate relationships as one partner assumed a significant care role after TL. They also described the need for staged discharge to alleviate the stress experienced by IWL and primary supporters at this time. The current study suggested that gender factors underpinned the issue of carer burden, with female partners adopting a care role more easily than male partners. However, there were exceptions to this pattern. The more important observation was that there appeared to be an ad-hoc approach to promoting self-care and independence, but there was evidence that the development of self-care promoted psychological stability and wellbeing for both the IWL and their primary supporter. A systematic review by Ziegler et al. (2004) highlighted the need for multimodal (verbal and written) information giving.

Another influencing factor for 'Developing competence' in the current study was the IWLs' support-seeking behaviours. Despite clinical recommendations and the emphasis placed on this by the health professionals interviewed (Roland & Paleri, 2011; South Australia Department of Health, 2013), several participants were ambivalent in their responses about the need for support groups, laryngectomy support visitors and psychosocial supports from health practitioners. Participants held conflicting views about the benefits of a laryngectomy support visitor to assist with the development of competence. These differences seemed to relate to timing and suitability. Matching a visitor for age, gender and temperament was described as problematic. The laryngectomy support group was also scrutinised for its relevance and helpfulness.

One of the inherent problems with the South Australian TL population is that it is small and heterogeneous, and there is no local support group. In the current study, some of the IWL reported they would not pursue a support group, while others had found meeting other IWL really helpful and supportive for their recovery. Younger male and female participants were more reluctant than others to consider a support group. The health professional participants seemed to be aware of these reservations but were also constrained by a limited pool of potential candidates to provide support. There is very little critique of these issues in the broader literature. Kwok and Ng (1999) described similar support-seeking behaviours amongst a population of IWL in Hong Kong, and Lawson and Ward (2014) provide guidelines for managing

laryngectomy support visitors, stating that due consideration must be given to a person's suitability. In addition, very few of the IWL in the current study reported that they accessed information or support using digital technologies. This was most likely a generational issue. However, this is something that could be further explored as online forums and telemedicine becomes more widely used (Burns et al., 2014).

### 7.3.2 *The role of building resilience*

In the *Model of validation,* Category 4, 'Building resilience', is an important underlying process. It appears that resilience factors are crucial in an individual's acceptance of their post-laryngectomy identity. The data suggest that resilience did build over time for the majority of participants and was related to the development of competence, levels of support and personal factors. However, it also appears that resilience fluctuated for some individuals and was impacted by age, gender, level of support, and how social acceptance and participation levels affected their reframed altered self.

Earlier, I mentioned that the current study's findings were consistent with the HRQoL literature regarding the trajectory of self-reported psychological comorbidity in this clinical population, with it being elevated in the questing and transitioning stages, and reducing over the first year. Also consistent with the literature was that some of the participants experienced long-term adjustment issues. The development of resilience is important in TL care, and there is a large body of literature discussing its health protecting benefits (Muller, Ward, Winefield, Tsourtos, & Lawn, 2009). We are also beginning to see more studies describing different styles of coping and self-efficacy in adjustment to, and acceptance of, TL (Eadie & Bowker, 2013; Perry et al., 2015).

An important feature of Category 4 appears to be that an individual's attitudes and beliefs affected how they reframed their altered self, and how this impacted their coping style and general acceptance of their situation. For example, it seems that the narrative of "survivorship" assisted some of the IWL to accept their functional and social difficulties because they felt lucky to be alive. Survivorship appeared to be a form of stoicism evident in the narratives of the IWL who had either a 'resolute', 'resigned' or 'transformed' altered self. This phenomenon has been described in other HNC populations (Cartmill, Nund, & Ward, 2014, p. 525), with one study terming it "focusing on the positive" (Eadie & Bowker, 2013, p. 959).

Stoicism in HNC patients and cancer patients in general has been reported widely (Breetvelt & van Dam, 1991; Murphy et al., 2007; Swore Fletcher et al., 2012). Earlier, I mentioned that some researchers such as Murphy et al. (2007) are concerned that HNC patients under-report their symptoms due to the phenomenon called 'response-shift' (Breetvelt & van Dam, 1991). These researchers suggest that this is maladaptive because it can give rise to late health effects. In the current study, it appears that participants who experienced the poorest functional and social outcomes described a 'resigned' or 'destabilised self'. The 'resigned self' group seem to be the ones at most risk of under-reporting late effects, inadequate functional verbal communication and subsequent social isolation. It has been mentioned in the literature that HNC patients experience persisting worry regarding the return of their cancer (Eadie & Bowker, 2013; Ramírez et al., 2003). In the current study, only a few participants raised this as a concern. This may reflect that seven of the twelve IWL were at least five years post their surgery. In other health literature, it has been observed that beliefs and attitudes to illness can influence adjustment. For example, Hinojosa et al. (2008) found that up to a third of the individuals over 65 years of age who experienced stroke used discursive beliefs related to age, religion and self to assist their adjustment. Interestingly, very few of the IWL in the current study described having 'religious belief' but some said they had 'self-belief' and they could help themselves.

Self-efficacy theory (Bandura, 1977, 1982) offers some useful constructs for interpreting and contexualising the adaptive and maladaptive behaviours described by the IWL in the current study. This theory is part of a socio-cognitive framework that views personal adjustment as being affected by three distinct domains: cognition; emotion; and behaviour. These domains inter-relate and can affect each other. Thus, adjustment problems can be understood by evaluating specific examples of particular problem behaviours, cognitions and emotions in certain contexts (Maddux, 1995). In self-efficacy theory, "context" relates to situational demands and social norms contingent in social settings, and applied in social settings (Wakefield, 1992). It is important to contextualise adaptive and maladaptive behaviour, cognition and affect (Maddux, 1995). A sense of mastery, control and agency are very important aspects of healthy psychosocial functioning, whereas the sense of loss of control over one's life and environment can result in a demoralised state (Maddux, 1995). In the face of

stressful life events such as TL, a strong self-efficacy has been hypothesised to impact psychological stability, wellbeing and HRQoL outcomes. However, a recent study (Perry et al., 2015) suggests that psychological state rather than self-efficacy is associated with QoL and social relationship outcomes. In fact, the participants perceived higher levels of self-efficacy than normative samples. Interestingly, population bias was cited because all the participants were members of a laryngectomy support group and 54.2% ($n = 45/83$) reported they had a partner. It could be argued that these participants were demonstrating reasonable self-efficacy by seeking to be involved in the support group.

In the current study, the IWL reported perceived loss of mastery of their self-expression, reduced control in social interactions and disruption to roles. Their loss of self-expression affected their agency to a greater or lesser extent, resulting in increased dependency on others. The results also indicate a spectrum of adjustment amongst the participants, with the timing of critical turning points in adjustment varying significantly between them. It appears that participants developed positive self-efficacy when they mastered their self-care, breathing, speaking and swallowing through the acquisition of knowledge and skills, and the resumption of meaningful activities. However, a cause and effect relationship was not always evident. This finding appears to be partly consistent with previous studies that have demonstrated that psychological comorbidity, not reduced function, is a better predictor of global HRQoL (Maclean et al., 2009a; Perry et al., 2015). For example, the IWL who presented with a 'destabilised self' perceived they had developed reasonable mastery of the basic functions but continued to experience disruption of their higher level functioning, which affected their full communicative participation. Also, it was how they perceived their communicative competence and social roles that resulted in a loss of personal meaning and self. The narratives highlighted that social support did not buffer the negative experiences and social interactions appeared to lead to diminished self-worth. These findings are consistent with Devins et al. (1994), who found that IWL with higher levels of perceived illness intrusiveness and stigma had poorer psychosocial adjustment.

Another group of IWL in the current study who were observed to have poor functional mastery over their audible ACM and self-care presented with fluctuating self-efficacy. Most of these participants could be described as having a 'resigned self'

and experienced social isolation. Finally, a few of the IWL reported they experienced variable to poor functional communication skills, but perceived they had reasonable self-efficacy and presented with a 'resolute' or 'transformed self'. Other TL and HNC populations have also been found to adapt positively to their situation (Eadie & Bowker, 2013; Murphy et al., 2007; Swore Fletcher et al., 2012). The current study confirms that adaptation to losing self-expression after TL must be viewed within a person's context.

Self-efficacy theory also provides explanation for the impact of longer-term functional limitations. The data from the current study provide examples of a range of experiences. Some of the IWL described how they perceived they lost their self-efficacy due to repeated failure to overcome or ameliorate their functional disadvantages. Other participants described their perception of low self-efficacy at the beginning and development of stronger self-efficacy over the TL journey. It appears that the participants with a 'resolute' or 'transformed self' displayed the strongest perceived self-efficacy. The participants with a 'resigned' or 'destabilised self' had lower perceived self-efficacy. Another interesting observation was that some participants described how their affective state (e.g. panic attacks) and their feelings about their abilities impacted their verbal communication, and on occasion made it worse. There is little discussion of this phenomenon in the literature. However, it is well-established that emotion can impact voice production (Rosen & Sataloff, 1997). The complex integration and balance of systems (e.g. respiration, phonation, resonance and articulation) are all involved with producing TE speech, just as they are with laryngeal voicing. Even with a different vibratory source, as is the case for TE speech, disruption of any of these systems can disrupt voicing.

The processes of 'Developing competence' and 'Building resilience' appeared to be closely tied to the development of self-efficacy. This understanding can be used to explore the role of self-efficacy further. It can also be used in conjunction with evaluations of self-efficacy to assist with appropriate design and better targeting of support for a person's behaviour and cognitive or affective states. The role of contextual factors in adjustment to altered identity after TL is now discussed.

## 7.4   The context: Extrinsic factors influencing validation

The *Model of validation* highlighted Category 5 'Timing and turning points of the TL journey' (temporal factors) and Category 6 'Being supported' as important contextual

factors. The relationship between these categories and personal factors is now explored. How these contextual factors influenced adjustment outcomes is also discussed.

### 7.4.1   *Temporal factors*

It was important to consider temporal factors to be able to evaluate the role of the other constituent factors related to the TL experience, for example the processes and other contextual factors. The stages defined in the current study are similar to the time periods described in the TL literature (Armstrong et al., 2001; Singer et al., 2014; Terrell et al., 1998). However, the terms used to describe the temporal phenomena in this study match the experiences reported by the study participants and reflect the themes grounded in the data.

The current study describes how each stage has its own unique characteristics and demands for all the participants. It explicates the issues the IWL faced in getting their diagnosis, and the difficulties experienced by loved ones during the questing and diagnosis, and transitioning stages. The data suggest that these stages were highly risky for participants' health and wellbeing, and also profoundly impacted the primary supporters' lives. Other studies have confirmed that HRQoL and care burden is greatest at the time of surgery, at time of discharge and during the first six months, but that there is gradual improvement, with some individuals experiencing a return to pre-surgical HRQoL levels (Armstrong et al., 2001; Gibson & McCombe, 1999; Singer et al., 2014).

The *Model of validation* describes the first year after surgery as a year of transition for both the IWL and the primary supporters. This period appeared to be complicated by a person's health status and their ability to adjust. It was also a period when dependency behaviours were likely to develop, adding to the worry and strain for primary supporters. The current study provides a more detailed account of how this first year can be defined as early and late stages, and how the needs of individuals and primary supporters differ for each stage. It also suggests that individuals who experienced high levels of self-reported stress at diagnosis or during the early transition stage (e.g. suicidal ideation) were able to overcome these issues and adjust to their situation. This finding is inconsistent with studies that have found psychological comorbidity pre-surgery to be predictive of poor outcomes in the longer term (Armstrong et al., 2001; de Leeuw et al., 2014).

'Persisting need', the descriptor for the final stage, emphasises the ongoing issues of dependence, symptom and care burden. These issues have been highlighted by others (Haisfield-Wolfe et al., 2009; H. M Mehanna & R. P Morton, 2006; Murphy et al., 2007), while some studies have noted improvement in longer-term HRQoL (Woodard et al., 2007). The terms used to describe the different stages of the TL journey in the current study do not appear as descriptors in any other studies. This is another indication of the dominance of the biomedical view of the TL experience in the current literature. Finally, in the current study, the concept of 'a journey' emerged as important in the data because it represents the physical, cognitive, social and emotional experience of TL. It was marked by a clear beginning and followed often by an unknown and unexplored path, and often with no end to the experience.

### 7.4.2    Levels of support

Direct and indirect support from others and the socio-cultural context more generally appeared to be extrinsic validating influences for the current study's IWL cohort. Category 6 provides some important information to assist answering the third research question related to the types of psychosocial supports health professionals routinely provided IWL over the entire TL journey. Here, I relate the relevance of these findings to the role of the health professional and MDT approach in treating and managing the physical and functional needs of IWL throughout the recovery trajectory. This provides the opportunity for me to discuss how issues relating to resourcing and wider cultural awareness appear to impact the provision of support and the role of the primary supporter. I highlight the finding that there appears to be conflicting views about this important issue. Finally, I explore other professional practices that may optimise psychosocial support for IWL and their support networks.

#### 7.4.2.1  The MDT approach and person-centred care

In the current study, satisfaction with the support provided by health professionals varies. Some of the issues appear to relate to setting and expertise. A number of other key areas are highlighted as affecting the provision of quality person-centred care for IWL. These include failure to be referred early for specialist care, safety concerns, reduced communication between the MDT and other practitioners, communication breakdown, recruitment and retention issues, and limited time for specialist team members to provide additional support and training.

The results suggest that despite the availability of the South Australian Head and Neck Cancer (SAHNC) Pathway, there were different models of care in place and resourcing issues that resulted in fragmented service delivery and reduced services (South Australia Department of Health, 2013). In addition, the concentration of specialist services in the acute hospital setting was reported to be problematic for generalist hospital staff as well as community or rural-based clients and clinicians. There is clear evidence in the data that the MDT approach in the specialist tertiary settings was an integral part of the management of this population. This reflected practice guidelines, and external and clinical evidence that this group warrants the input of many disciplines due to their complex needs and treatment trajectory (Goldstein, Genden, & Morrison, 2008; Lawson & Ward, 2014; Roland & Paleri, 2011; South Australia Department of Health, 2013). The results suggest that the concentration of specialist services resulted in pressure on hospital staff to communicate and provide training to less experienced health professionals. There appeared to be some tension here due to competing demands and economies of scale whereby the small numbers of patients lead to rapid skill decay and succession issues. The MDT model of care occurs throughout the Australian healthcare system and is replicated in many other countries (Goldstein et al., 2008; Lawson & Ward, 2014; Ward, Burnett, et al., 2014). However, there is little documented in the broader literature regarding how this model of care, in a country like Australia, is also a barrier to the provision of person-centred care for IWL due to geographical isolation and poor provision of community-based services. The development of some pilot telehealth programs to overcome some of these issues is testament to these problems (Burns et al., 2012).

All the health professionals interviewed were very experienced in TL care and said they attempted to provide flexible and individualised care for each person. They acknowledged the importance of the MDT structure in building relationships with other health professionals, and with the patients and their primary supporters. The large membership of the MDT offered flexibility as issues arose. The data suggest that the relationships were hierarchical and transactional, with the surgeons, and specialist and generalist health professionals providing the care. The current study raised the ethical issue of all the health professionals in the MDT having adequate time to talk with their patients, particularly with IWL experiencing profound changes and

subsequent difficulties with communication.

Many of the IWL and their partners were happy with the support they received from their specialist teams but raised issues such as reduced access to the team when they had concerns. This appeared to be worse for rural/remote participants. The IWL and primary supporter participants identified that flexible care and regular contact promoted trust and certainty, but was not always available to them. This was an important theme and identified the health professionals' validating influence. Positive interactions with health professionals were described as confidence-boosting and helpful. Negative interactions with health professionals were described as frustrating, discriminating, disappointing and unhelpful. They also reported that very few health practitioners outside of the MDT had specialist knowledge, and this was problematic for competent care, training, care burden and strain. General hospital staff or community-based practitioners were identified as having limited expertise, and consequently lacked empathy and awareness of key issues.

Fortunately, there have been recent attempts to address competency issues and remote access to care with telehealth services to support patients and clinicians (Burns et al., 2014; Burns et al., 2012). However, the current study suggests that the success of such services is dependent on the availability of health professionals to reciprocate and manage patients in their rural/remote locations. In addition, there is very little in the current literature evaluating the importance of the relationship between the MDT, the IWL and their support networks.

Interestingly, all the participants in the current study described person-centred care as optimal practice. However, consistent and timely person-centred support was described as deficient due to resourcing issues. In the SAHNC Pathway (South Australia Department of Health, 2013), person-centred care is described under the umbrella term "Coordinated care", which captures both "Clinical care" and "Supportive care". The guideline states:

> The provision of coordinated care can involve clinical and/or supportive care components, and requires:
>
> - highly developed communication and psychosocial skills to recognise a patient's non-clinical needs as well as problems directly associated with cancer treatment
> - a strong knowledge base in the management of head and neck cancers
> - knowledge of the system in order to streamline timely referrals, and focus on support and care for the patient throughout the head and neck

cancer journey. (South Australia Department of Health, 2013, p. 23)

Some of the health professional participants identified that it was important to meet a patient prior to surgery to establish a baseline, facilitate decision making and get to know a person before their communication skills changed irrevocably. This is also recommended in the SAHNC Pathway and other HNC literature, but did not appear to be routine practice for some of the disciplines (e.g. nursing, dietetics and social work) due to a lack of resources (South Australia Department of Health, 2013; Zeine & Larson, 1999; Ziegler et al., 2004).

Earlier, I discussed issues related to 'communicative participation' and 'participant accommodation', in particular that IWL reported some difficulties communicating and interacting with health professionals across the care journey. Issues of frustration, isolation, inconsistent scaffolding of communication, and increased care burden and strain were identified. Similar phenomena have been described in the literature. Rodriguez et al. (2012), for example, reported the safety issues and higher likelihood of prolonged hospital admission for HNC with communication difficulties.

### 7.4.2.2 *Focus of support*

Part of the difficulty the IWL experienced in communication and interaction was attributed to the focus of treatment and care. The health professional participants described a hierarchy of physical care needs over functional and psychosocial needs. The IWL and primary supporter participants confirmed that health professionals were very focused on patients' physical needs and focused to a lesser extent on the psychosocial issues patients were experiencing. This appeared to be a source of frustration and disappointment for all parties. All participant cohorts explained it as being a resourcing or geographical issue. It seemed to result in heavy reliance on primary supporters and social supports. Several other researchers have also identified a general reluctance amongst clinicians to use HRQoL tools to identify psychosocial needs at specific time points (Mehanna & Morton, 2006; Murphy et al., 2007)

The SAHNC Pathway identifies that supportive care and well-timed, targeted psychosocial support are important features of coordinated care for HNC patients. It states:

> Supportive care addresses the physical, emotional and practical needs of the cancer patient. Supportive care requires generalist and specialist health

services to provide support to people with cancer and their families and/or caregiver/s.

Collaboration between all members of the multidisciplinary team is essential, and all needs must be addressed in a culturally and linguistically appropriate manner. (South Australia Department of Health, 2013, p. 25)

The SAHNC Pathway recommends regular assessment of a person's psychosocial status and suggests rather than mandates the use of the NCCN Distress Thermometer screening tool throughout the patient's journey (Hoffman, Zevon, D'Arrigo, & Cecchini, 2004; South Australia Department of Health, 2013). The current study suggests there is an inconsistent approach to psychosocial assessment and measurement by health professionals. It was reported that routine objective assessment of IWLs' psychological state rarely occurred. It appeared that formal psychological assessment was only instigated if a person's affective state and behaviour were disruptive or impacted discharge. This reactive rather than proactive practice seemed to mirror the literature, where few patients with psychological comorbidity received appropriate psychiatric screening or support (Keszte et al., 2013; Murphy et al., 2007; Penner, 2009; Ziegler et al., 2004). This is despite strong evidence in the literature that the diagnostic and transition stages are high risk times for psychological comorbidity (Armstrong et al., 2001; Gibson & McCombe, 1999; Murphy et al., 2007), that increased psychosocial issues increase care burden and strain (Penner, 2009; Richardson, Morton, et al., 2015), and that there is a risk of persisting depressive and anxiety symptoms (Singer et al., 2014; Terrell et al., 1998). The current study supports these findings. There was disturbing evidence that some of the participants had experienced suicidal ideation, with one describing his attempted suicide prior to surgery. As I have discussed previously, this remains an under-reported phenomenon because some studies excluded participants with suicidal thoughts (Duffy, Ronis, et al., 2007; Gibson & McCombe, 1999).

The current study highlights the variation in support needs over time for the IWL. A concern raised earlier when discussing Category 4 was that some individuals had reframed their altered self as a 'resigned self', whilst others experienced a 'destabilised self' many years after their surgery. These participants reported persisting issues regarding social isolation and/or poor mental health. There appears to be a distinction between the groups, with the participants with a 'resigned self' having accepted social isolation and participation restriction as part of the experience because

they had survived. Some of these participants presented with poor outcomes (poor command of an audible ACM or unreliable functional communication). The participants presenting with a 'destabilised self' appeared less accepting of their functional difficulties and reported high levels of self-perceived distress. Previously, when discussing resilience and self-efficacy, I raised the issue that researchers such as Murphy et al. (2007) are concerned that the acceptance displayed by the 'resigned self' group is maladaptive and results in poor reporting of longer-term problems or late effects. There is currently little evidence of monitoring and support for these issues.

### 7.4.2.3 *The provision of psychosocial support*

In the current study, the health professional participants reported they wanted to provide a coordinated approach to psychosocial support but had neither the time nor the skills. They described the recent availability of specialised cancer care psychology services but interestingly, they were unanimous that these services were a valuable resource but continued to under-utilise them. These participants also said that both patient care and the MDT would benefit from the implementation of a specialist nurse model, similar to the MacMillan Nurse model in the United Kingdom (Sullivan & Elliott, 2007). In this model, a nurse practitioner coordinates patients' care needs, provides well-timed education, is a source of support throughout the TL journey, and is the link between the MDT, community practitioners and the patient. This model fosters psychosocial support and is used in other cancer care areas (Farrell, Molassiotis, Beaver, & Heaven, 2011).

Another important theme identified was that some of the health professional participants appeared to view reluctant behaviour or failure to take on advice as an issue of concordance rather than one of adjustment. These issues have been described more generally for HNC populations, with psychological comorbidity such as depression or anxiety being attributed to concordance (Purcell & Turner, 2014). When the issue of psychosocial support was raised with the IWL, reactions were mixed. Some said they did not think health professionals could do much more, whilst others wanted more understanding and empathy. A few participants had sought counselling but did not feel it met their needs. Others were determined to face their difficulties on their own, suggestive of a stoicism reported in other cancer patient groups (Breetvelt & van Dam, 1991). Being able to access a team member and receive flexible care was

identified as assisting participants and their families. The primary supporter participants described being more proactive in seeking support from the Cancer Council hotline or their GP.

### 7.4.2.4 *Social capital and primary supporter role*

Health professional participants described the importance of a patient's social support network in recovery. This sentiment is supported by the literature (Avramika et al., 2011; Blood, Simpson, Raimondi, et al., 1994; Eadie, 2007; Gibson & McCombe, 1999; Howren et al., 2013; Ramírez et al., 2003; Relic et al., 2001). However, the current study suggests that the quality of these relationships and the pre-laryngectomy roles are important. The health professional participants also identified that they provided increased support for IWL with low levels of social support. As I have mentioned previously, it appears that they did not routinely evaluate care burden, strain or distress despite this being reported in the literature (Blood, Simpson, Dineen, et al., 1994; Penner, 2009). This is an area deserving of further evaluation.

### 7.4.2.5 *Resourcing and public awareness*

The issues of resourcing and its relationship with competent care and the provision of psychosocial support have been explored above. In the current study, the IWL younger than 65 years or from remote locations experienced the most difficulty accessing appropriate care within the community. All participants perceived that awareness about TL and laryngeal cancer in the broader community was poor, and resulted in stigma and reduced resources. The participants reported that social messaging about laryngeal cancer and TL was narrow, exclusive, judgemental and at times blaming. A similar experience was reported by individuals with lung cancer who took part in another study (Chapple et al., 2004).

Some of the participants in the current study described how the lack of funding for resources and research related to the aetiology of the disease and the typical demographic associated with this diagnosis. This was despite evidence that a TL could affect people who were younger than 50 or older than 75 years, and affect women and those with tertiary level education. There is very little in the broader TL or HNC literature critiquing the social and structural basis for these issues. In summary, issues of support emerging from the data were:

1) Health professionals experienced conflict because they wanted to provide more psychosocial support but were constrained by resources.

2) Primary supporters provided extensive physical and emotional support because health professionals and others did not provide enough, but often felt underprepared until they received practical and emotional guidance.

3) IWL both received and provided support from/to their loved ones. They either did not perceive the need for counselling or found the counselling methods deficient. They also wanted more empathy from others, including health professionals, family and friends.

Figure 14 highlights the issues and relationships described by all of the participant cohorts in relation to the provision of adequate psychosocial support.
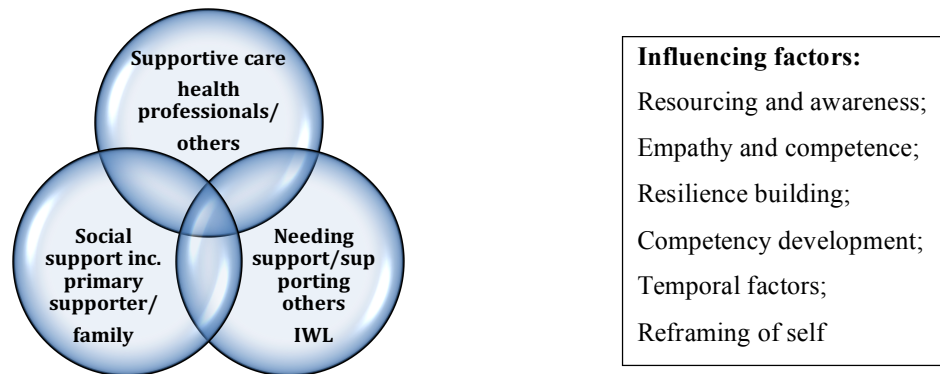


**Figure 14: Psychosocial support issues**

This illustrates the interactive nature of support provision, competency development and resilience building identified in the current study.

### 7.4.3   Personal factors

A number of personal factors appear to have influenced the way the IWL in the current study perceived their situation, and also how others responded to them. These factors included gender, age, ethnicity, linguistic background, SES, education level, employment and geographical location. It also seems that multiple biopsychosocial and cultural factors combined with levels of support, health status and the ability to develop and perceive competence influence resilience building and identity reframing.

### 7.4.3.1 Gender

The present study captures the direct experiences of five women and the indirect experience of another woman via one of the primary supporter participants. The findings support other research relating to poor HRQoL outcomes for women because

of the importance of vocal quality and appearance in conveying feminine identity (Kazi, Kiverniti, et al., 2006; Lee et al., 2010). The male participants also reported difficulties accepting their alaryngeal voice, loss of their pre-laryngectomy voice and their altered appearance. In addition, several of the women (both TE speakers and primary supporters) suggested they would find the use of any audible ACM very difficult and disruptive to their selfhood. The women using TE speech described how they were frequently affected by the stigma experienced due to their ACM. Also, more women than men in the sample had a poor command of their audible ACM or did not use one, whereas more men than women described how their unreliable TE speech frustrated them. Finally, only one of the five women described a 'resolute self'. The others described a 'destabilised' or 'resigned self'. This contrasted with the men, who appeared to be more positive, with two describing a 'transformed self', three describing a 'resolute self' and two describing a 'resigned self'.

### 7.4.3.2 Age

In the current study, the age of a person at the time of their surgery was an important contextual factor. The age range and median age for the IWL was consistent with other studies (Eadie & Bowker, 2013; Metreau et al., 2014; Singer et al., 2014). This study provides information about how IWL perceived their age as affecting their situation. Some described TL as a procedure that occurred in the elderly and usually with men. Some of these issues have been discussed earlier as relating to resourcing and general awareness. In general, the younger participants found it harder to adjust and accept their altered self than the older participants, but there were exceptions. The younger participants described greater social isolation, changed roles and forced early retirement due to lost employment, although a few reported reasonable levels of adjustment. Some of the older women also described changed roles and social isolation despite being well supported by significant others. These findings, despite the exceptions, are consistent with other studies confirming poorer post-TL adjustment outcomes for younger people than older people (Bindewald et al., 2007; Haisfield-Wolfe et al., 2009; Moukarbel et al., 2011).

In other illness literature, Hinojosa et al. (2008) found that having a stroke does not necessarily result in a perceived disruption of the self one month after the event. Approximately a third (*n* = 39/122) of the participants (male North American veterans) in their study were found to describe 'continuity of the self'. It is important

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to note that none of these participants experienced stroke-related communication impairment. The researchers theorised that it was the participants' discursive beliefs about 'age' and 'religion' which assisted them with their post-stroke constructions of themselves.

### 7.4.3.3 *Ethnicity and linguistic background*

The current study was designed to attract individuals from diverse ethnic and linguistic backgrounds, however it was constrained by the clinical populations of the two recruiting hospitals. Consequently, the majority of the participants recruited were of Caucasian origin, a trend cited in other TL and HNC literature (Eadie & Bowker, 2013; Haisfield-Wolfe et al., 2009; Singer et al., 2014). Interestingly, two-thirds (*n*=8/12) of the participants were first generation immigrants from Great Britain and Europe. Several participants described how their cultural heritage assisted them to cope against adversity, describing stoicism as being part of this response. Only two of the participants reported that English was their second language. Both demonstrated proficient English language skills and did not report barriers to accessing healthcare related to their language.

### 7.4.3.4 *Socio-economic status, education level and employment*

The literature suggests that individuals from lower SES backgrounds are more likely to require a TL due to late presentation for treatment (Gourin & Podolsky, 2006; Thorne et al., 1997). The recruitment strategy for the present study resulted in all IWL who were receiving treatment from either major hospital being notified of the study. This resulted in interviews with a cross-section of individuals with a range of SES and levels of education. The majority of the participants had completed secondary schooling and were either retired or unemployed. This was consistent with another Australian study (Perry et al., 2015).

Even though the sample was small, it appeared that participants with lower levels of education found it very difficult in the early stages, particularly at diagnosis and during the early transition stage. This finding was consistent with a study by Blood, Simpson, Raimondi, et al. (1994). The findings of the current study suggests that the IWL with higher levels of education or SES struggled longer-term and presented with a 'destabilised' or 'resigned self'. There were, however, exceptions where several individuals appeared to have reframed a 'resolute' or 'transformed self'.

*7.4.3.5 Geographical location*

In the current study, another important contextual factor related to the setting of the surgery and specialist services. Some of the IWL and primary supporter participants were from remote/rural locations. Very few studies have captured this particular demographic. The experiences were described as 'contrasting'. The burden of travelling to the city for treatment was significant and there was evidence that some individuals had moved to be closer to services. The provision of services in rural areas was described as poor. This has been further critiqued in relation to Category 6. Participants also described different levels of social acceptance in these smaller communities. Some reported excellent support and acceptance, whilst others described the opposite.

## 7.5 Exploration of other professional practices and recommendations that may optimise psychosocial support

In the previous section, I examined the main psychosocial issues identified in the data and appraised their relevance to the external and clinical evidence. I now use these findings to address the final research question and discuss how professional practices and services may optimise psychosocial support and improve the provision of person-centred care for IWL. I do this by describing how supportive care can be provided across three levels: individual; social; and socio-cultural.

### 7.5.1 Individual level

The current study reinforces the need for sensitive, competent care and timely education. Like Purcell and Turner (2014), these findings endorse how important it is for health professionals to recognise that IWL and their families experience many emotions during the TL journey. IWL experience significant physical, functional and psychosocial changes, and it can take time for them to make sense of their experiences and changed abilities. Primary supporters also experience significant changes and role disruption. Issues of concordance may relate to a person's grief and loss reaction, and feelings of disempowerment. Increased awareness of these issues will support the provision of person-centred care.

Well-timed and tailored education is key to supporting individuals and their support networks to realise that a TL is a journey; adjustment is not a predictable or linear process. The year after surgery should be viewed as a period of transition

characterised by important time points relating to physical and psychosocial wellbeing. The development of competence and independence with self-care and other areas, such as communication and swallowing, should be promoted as soon as possible because people need validating and confidence building experiences in a supportive environment. Education can lead to resilience building, turning points and alleviation of caregiver burden and strain.

All health professionals should acknowledge there is grief and loss associated with becoming dependent and losing self-expression (communication ability, swallowing ability, appearance, roles); it is destabilising, and difficult to cope with, and adjust to. It is important to be sensitive to the existential nature of the experience and the fact that individuals have to reframe their sense of self. All behaviour should be viewed as meaningful and an expression of a grief and relating to lost identity and role disruption. For example, a person may try to maintain some control as they rebuild their personhood and attempt to understand their altered post-laryngectomy identity, or be prepared to tolerate poor functional outcomes because they have survived. The monitoring of these responses is important because some individuals may be at risk of maladaptive adjustment and significant 'late effects' (Eadie & Bowker, 2013; Mehanna & Morton, 2006; Murphy et al., 2007).

Routine use of a standardised screening tool such as the NCCN Stress thermometer (Hoffman et al., 2004) is recommended to evaluate psychological distress. This tool could be used consistently during peak anxiety-provoking times, for example diagnosis, seeing self for first time post-surgery, seeing loved one for first time post-surgery, realising "I can't speak", and preparing for, and going through with, discharge. There are also a number of new tools available to evaluate voice disability-related coping and communicative participation. These include the Voice Disability Coping Questionnaire (Epstein, Hirani, Stygall, & Newman, 2009) and Communicative Participation Item Bank (Eadie et al., 2014). Such tools could be used to identify the degree to which a person's communication disability may be influencing their coping style and communicative participation.

The data strongly suggest that intensive and skilled psychosocial support is required by IWL because a TL is a deeply personal and frightening experience. However, it is important for health professionals to acknowledge that IWL will have different coping styles during the journey, for example situation avoidance or

distancing. These coping styles may also be affected by competency, resilience and support levels. Additionally, IWL are similar to other HNC populations in that they may be stoic in their responses and downplay the extent of their feelings due to beliefs about surviving or responsibility for illness (Purcell & Turner, 2014).

The SAHNC Pathway recommends the use of diaries and relaxation techniques such as meditation to alleviate stress (South Australia Department of Health, 2013). A diary could be used over the course of the experience or at particular times such as during the transitioning stage. Well-trained health professionals and consistent care could also alleviate some of these issues by educating patients and their supporters that there will be challenging times, and what supports they may access. The health professionals could also recognise and tend to worries and concerns in a timely and empathetic way (Purcell & Turner, 2014).

A range of psychological, behavioural and sociological approaches may be used to support transition or assist people longer-term (Perry et al., 2015; Purcell & Turner, 2014). However, what this study elucidates further is that it is important to complement these approaches with explicit examination of a person's communicative competencies and their constructed beliefs about their own abilities. Very few intervention studies have targeted communicative participation and communication behaviours for IWL. In a RCT study by de Maddalena and Pfrang (1993), it was found that IWL who received psychological training to manage their communication difficulties had better rehabilitation outcomes than the participants who did not receive intervention support. These researchers later conducted a prospective study examining the influence of early speech rehabilitation for IWL in the early stages of recovery. They found that the group receiving early rehabilitation achieved better outcomes but there were also participants with good speech intelligibility who were anxious about discharge in anticipation of stigmatisation (de Maddalena, 2002).

In addition, the beliefs of others should be evaluated. This is important because IWL need to be encouraged to validate the changes, and reframe a more positive and strengths-based view of 'the altered self' and interaction. A clinical emphasis on communicative participation would promote the following:

1) consistent and representative pre-operative meetings with patients
2) honest and empathetic information counselling and preparation regarding functional deficits post-surgery

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3) augmented early communication and utilisation of alternative communication systems

4) use of strategies the patient may use to compensate for communication limitations in the postoperative period, for example prepare written messages for health professionals

5) development of meta-awareness of interaction and how it is impacted after TL for all stakeholders (individual, supporters and health professionals)

6) support for the education and acquisition of skills for individuals and primary supporters

7) monitoring the development of competence and resilience, and promote independence early on

8) recognition and management of safety issues associated with reduced communicative competence

9) routine provision of simple user-friendly written information about a TL for dissemination to others who may not be aware of the issues.

The data suggest some of these practices were in place but there appears to be room for enhancement and value adding. There also appears to be a need for increased training and education for all involved within the care triad. Innovation and novel ways of delivering care and supportive participation are important.

### 7.5.2   *Social and relationship level*

There are a number of areas where clinicians could further support individuals during interaction and provide support to others, including primary supporters and other professionals. The current study reinforces that communication and interaction with IWL should be central to care; a valued part of clinical practice that can be perceived as potentially therapeutic or harming. Optimal practices would consider and address issues related to safety, dignity, and care burden and strain. It should be acknowledged that communication is effortful and tiring for all concerned, but particularly strenuous for IWL. Earlier, I presented several frameworks that enabled comprehensive critique of the IWLs' narratives related to communicative competence. In particular, the 'situated' framework (Kovarsky et al., 1999), which highlights the roles of communication partners in interaction, prompts clinicians to critically view themselves as 'situated' or in a particular 'position' in an interaction.

This 'situated view' could impact their ability to evaluate the competencies of another person, such as a client or student. The underlying premise of the framework is summarised succinctly as follows:

> A situated self draws from a variety of communication resources to evaluate competence from some position, occasioned by something, about something, in comparison with a set of expectations, and with potentially long-lasting and profound effects. (Kovarsky et al., 1999, p. 7)

This approach highlights the importance of health professionals taking joint responsibility for interaction success. It also promotes reflexive practices (Higginbotham & Wilkins, 1999). There appears to be scope for health professionals working with IWL to further develop their own communication and interaction skills.

Important goals for successful communication or swallowing intervention include emphasising intelligibility or safe oral consumption, but these ignore the social elements required for interaction success and adjustment. This focus potentially reinforces areas that are really challenging for IWL, whilst overshadowing their other competencies. Focusing only on impairment may lead to an individual's coping strategies being interpreted as maladaptive rather than mechanisms to manage the communicative interference they are experiencing. There appears to be scope for health professionals such as speech pathologists to explore the value of raising broader meta-awareness of communicative competence and participation amongst IWL and communication partners. This approach may incorporate communication partner training.

There is also room for more comprehensive support for primary supporters who often experience grief, loss and role disruption whilst simultaneously coping with their partner's health and psychological needs. Routine evaluation of primary supporter distress, even in the longer-term, is highly recommended. The provision of early comprehensive education for primary supporters is very important for their emotional wellbeing and their ability to competently support their partner.

The current study endorses linking IWL with appropriate social support but it is important that this support is suitable and accessible. It may need to be broader than a laryngectomy support visitor or group. The current study participants reported they wanted to be matched with peers (gender and age) rather than someone with the same condition. A similar approach could be considered with primary supporters. In the following section, I discuss how this might be addressed on a broader socio-cultural

level.

Finally, the issue of expert and non-expert care needs to be addressed. It is important that the health professionals who hold the specialist knowledge continue to take leadership in this area. However, it is also important that they are supported to do so. Currently, support is provided to less experienced practitioners but this is resource intensive, costly and often ad-hoc. There needs to be innovation regarding the transfer of specialist knowledge to those with less knowledge such as GPs, community practitioners, and nursing staff in general wards or residential care. Perhaps the utilisation of electronic technologies and telehealth can go some way to assisting these processes.

### 7.5.3  *Socio-cultural level*

A number of areas where clinicians or their professional bodies can support individuals and their supporters on a broader socio-cultural level include:

1) Developing more awareness amongst health professionals, for example GPs, particularly for early detection of laryngeal cancer and the safety issues associated with neck breathing.

2) Supporting and developing public education, awareness-raising and advocacy targeting social stigma and the stereotypical messaging associated with laryngeal cancer and audible ACM usage.

3) Supporting the development of a national database of people (IWL, significant others including primary supporters and health professionals) willing to provide support or mentoring to IWL and their support networks.

A range of possible measures and strategies, as discussed above, could be used to optimise the provision of psychosocial support to IWL and their supporters. Some of these could be implemented without the need for increased resources. Others, such as sufficient clinical training and specialist coordinated care, would be easier to implement with additional resources. In the following chapter, I discuss possible future directions for care and research based on these suggestions.

### 7.6  **Conclusion**

It is widely accepted that person-centred care should be sensitive to the psychosocial, cultural and ethical needs of patients, and is a critical aspect of healthcare provision.

Recovery and adjustment after a TL can persist long-term. However, small clinical populations and limited specialist services have resulted in a narrow understanding of these processes. This study attempts to understand the perspectives of individuals directly affected by TL and the contributions they have made to their adjustment. These individuals have articulated how changes to self-expression and related competencies are complex and have significant psychosocial impacts on their daily lives many years after their surgery. Contextual factors have been shown to interact with the way individuals perceive themselves and behave socially. Examination of the perspectives of significant others such as primary supporters and health professionals have been used to continue building a theoretical understanding of life after TL. A range of ways to enhance current supports has been presented and discussed. In the final chapter, I summarise the study and its findings, discuss the strengths and weakness of the study design, and propose future directions for research.

# 8  Conclusion

## 8.1  Introduction

I conclude by providing an overview of what this study adds to our current understanding of the TL experience and acquired communication impairment. I then examine the strengths and limitations of the study design, and future directions for further research.

## 8.2  Overview of the study

This study has provided rich data from multiple perspectives relating to the experience of having, living with, and supporting a person after their TL. A number of important findings have emerged in relation to how clinical care and professional practices may be enhanced for those involved.

       The substantive theory, *Validating the altered self after TL,* and the *Model of validation* have been developed from the data and reflect a range of experiences and abilities amongst individuals who undergo TL. The theory and the model represent the reality that a TL marks a change from a pre-laryngectomy self to a post-laryngectomy self. The subsequent changes, including those of self-expression, have varying impacts and require some emotional processing to assist adjustment. The current study highlights that post-laryngectomy identity reconstructions can influence how IWL navigate and negotiate their experiences and interactions. There appears to be a range of reframes, as described by the study's participants. The evidence shows that competency development and resilience building, time, direct and indirect support, and personal factors affect the nature of these reconstructions. An individual's perception of their competencies and the support they receive from their primary support network, the health professionals they encounter and the broader socio-cultural milieu also appear to be validating influences.

       The substantive theory and model emphasise that IWL actively construct meaning about their experiences before their surgery in response to significant personal and social change/upheaval. The theory and model highlight that individuals frequently have to manage themselves and others during times of great vulnerability and loss. The different reframing patterns of 'the altered self' aid our understanding of these constructed meanings and explicate possible behavioural responses during interactions. The theory also enables us to view and evaluate the validating influences

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of the 'other', both significant and generalised. The substantive theory provides a critical analysis of the roles and relationships provided by primary supporters and health professionals.

Assuming a social constructivist view enhances our understanding of psychological phenomena such as coping behaviours. The issues pertaining to communicative competence and communicative participation demonstrate more comprehensively the extent to which individuals experience social disruption, and the kinds of reframes and behaviours they use to manage their situation. The theory suggests that developing competence and building resilience are interconnected but not necessarily co-dependent. It emphasises that individuals have their own perception of communicative and personal competence, and this is usually influenced by their pre-laryngectomy ability, the extent of disruption to their social roles and how they perceive their survival. It appears that the IWL's perception of their communicative competence and social roles influenced how their loss of personal meaning and self-identity was manifested.

The theory proposes that maladaptive reframing poses long-term health risks and social isolation. It highlights the interrelationship of different reframes with contextual factors, including timing, supports and personal factors. The different stages in the TL journey have been developed to reflect the experiences described by the IWL and the primary supporters.

The current study expands the established literature that claims a TL results in mild-moderate communication impairment. The focus of research and practice, until recently, has been the functional acquisition of an audible ACM or adapting to swallowing problems. However, the results of this study suggest this approach requires expansion. There is consensus that these methods and approaches have provided IWL with some important benefits. However, more attention related to how these ACMs and adaptations have altered pre-operative and post-operative communicative participation is needed.

The substantive theory proposes that the role of a communication partner is an important validating influence, and emphasises the need for consistent and competent care and education. Issues of safety, ethics, dignity, education and reassurance are important. It also puts a spotlight on the role of the primary supporter, their emotional experience, and the need for timely and adequate education. The substantive theory

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emphasises that issues relating to resourcing and general awareness are also important. It can be used to critique current practices and develop new lines of research.

Some of the findings are indicative of a need for increased resourcing, but many are not. The MDT approach would benefit from the additional role of a specialist care nurse or practitioner to coordinate patient care. However, there are some areas that could be addressed within the current structure. Central to all care should be the importance of interaction and communication, relationship building, well-timed and suitable education and learning opportunities for all involved, awareness and sensitivity to the grief and loss experience, and ongoing monitoring and competent support. Further analysis of these is provided under section 8.4, 'Future directions'.

## 8.3   Strengths and limitations of the study

One of the strengths of the current study is that all the participants were willing to discuss their experiences and perspectives, and despite the communication difficulties experienced by the IWL, rich data were obtained. The study captured the experiences of individuals from wide geographical locations and had reasonable representation of men and women. However, due to the limited pool of potential participants, the sampling favoured individuals with similar age, ethnicity and social situations. This was similar to other studies. Further exploration of the views of individuals from diverse ages, SES, cultural and linguistic backgrounds, is needed for deeper understanding of the issues.

The subjective experience of identifying with 'the altered self' after TL has been presented here with a primary focus on IWL. A more in-depth understanding was obtained by collecting the perspectives of primary supporters and health professionals. For example, these participants significantly broadened the narratives and provided details of additional IWL who were unlikely to participate in a research project of this kind, for example patients with intellectual disability or significant mental health issues.

The study's design and methodology promoted the use of rigorous grounded theory methods for data collection and analysis. These methods fostered deep analysis of the experience of having, and living with, a TL, and supporting IWL. The themes, categories and emergent concepts presented here were firmly grounded in the data

(Charmaz, 2014). Criteria for judging the quality of a constructivist grounded theory study described by Charmaz (2006) include credibility, originality, resonance and usefulness. I now discuss each criterion in relation to the current study.

### 8.3.1 Credibility

The study explored the TL experience from multiple perspectives. It has provided an opportunity for those with first-hand knowledge to participate and describe how the TL experience affected them. The aim of gathering contextualised data related to the nature of the TL experience whilst attempting to generate detailed and integrated analyses was achieved. These analyses also involved "relating individual events and interpretations to larger meaning systems and patterns" (Liamputtong & Ezzy, 2005, p. 2). Rich and in-depth data were captured using semi-structured interviews, participants' journals and group interviews. The criteria for participation in the study were intentionally broad. Provision was made to facilitate the participation of a diverse representation of the potential population. This included methods to assist a range of alaryngeal communicators, primary supporters and health professionals to participate. It also guided the sampling of individuals from a range of biopsychosocial, cultural and linguistic circumstances, including gender, age, SES, ethnicity and geographical location, professional disciplines and levels of expertise, from two institutions.

The overall intention of the study was to provide understandings of the studied life as constructions of the TL experience from those close to it, rather than providing objective truths about the experience. This premise was consistent with constructivist grounded theory (Charmaz, 2014). The dependability of the findings and the substantive theory were enhanced by the implementation of a variety of methods and techniques during the entire project to ensure transparency regarding my own interpretations and constructions of the data.

Throughout the data collection and analysis stages, I used methods and reflexive techniques to ensure rigour and the credibility of the work. An important feature of this research was to maintain the participants' voices in the foreground. Minimising the early review of the literature, preparing verbatim transcripts for each interview, repeated listening and reviewing of interview data, using sifting, sorting and verification techniques, including the opportunity for participants to review and update transcripts or comment on themes, were the methods used to keep the

emergent themes, categories and substantive theory firmly grounded in the participants' narratives (Charmaz, 2014). I also acknowledged my position within the research by implementing a field diary to capture observations during interviews and consultations not otherwise captured, and by extensive memo writing during the theme and theory development phases. As documented throughout this thesis, I used other triangulation techniques to assist the credibility process (Liamputtong & Ezzy, 2005). The implementation of all of these strategies enables the reader to determine whether there is sufficient evidence of reflexivity and rigour to support the interpretations and constructions provided (Charmaz, 2006; Giles, King, & deLacey, 2013; Popay, Rogers, & Williams, 1998; Tracy, 2010).

### 8.3.2   Originality

The study adds to the collective knowledge available regarding the psychosocial impacts of TL. It provides detailed accounts of the impact of TL on primary supporters, and how the provision of support to this group of people is affected by factors such as small numbers of patients, concentration of services, competency issues and general public awareness. There have been very few studies using qualitative methodology with this specific population and fewer examining the experiences of supporters. This research has attempted to provide these groups with a stronger voice in the research literature, a factor that reinforces the originality of the work. There is little evidence in the literature regarding the constraining factors for sampling alaryngeal communicators, so I have discussed the issues faced.

The substantive theory offers original insights into the TL experience and the role others play in supporting individuals to adjust. Prior to this study, little theoretical work had been done regarding the reframing of self-identity and its relationship to losses of self-expression after TL. The study provides significant conceptual understanding of the subjective experiences from which current healthcare practices can be appraised and improved. It has also added to the understanding of acquired communication impairment and the importance of a social constructivist view when evaluating communicative behaviour. Finally, it provides impetus to improve general public awareness and strengthen advocacy efforts.

### 8.3.3   Resonance

The study's conceptual interpretations attempt to capture the meaning of the TL

experience for IWL, primary supporters and health professionals. These multiple perspectives provide a multidimensional picture of the TL journey, beginning prior to diagnosis and continuing up to the present day. Attempts were made to represent a range of participants from diverse social backgrounds, which was achieved apart from diverse ethnicity. The research reveals the participants' constructed meanings from a broad range of experiences. Its design enabled in-depth analysis of these constructed meanings in relation to the other participants and the literature. There is evidence that some of the constructs that have emerged have broader application to other IWL. The following quote describes issues of loss of self-expression and identity as experienced by others who have had a TL:

> I endured the consequences of radiation, repeated surgeries, and prolonged hospitalizations. I confronted medical errors in my care, discrimination following loss of my vocal cords, and the hardships of regaining my ability to speak. Perhaps most importantly, I struggled to find a new meaning to my life… (Brook, 2011)

Brook's comments are particularly powerful because he is a physician who, prior to his TL, had some previous work experience of laryngeal cancer. There are other examples in the HNC literature that also resonate with the findings of the current study (Diamond, 1998).

### 8.3.4   Usefulness

The substantive theory developed here can be perceived as useful in a number ways: it provides a theoretical explanation for the phenomena of adjustment and support needs after a TL experience; it can assist IWL and their loved ones during the journey; it can assist health professionals to evaluate their practice when working with this specific group of patients; and it increases understanding of the difficulties faced by IWL, primary supporters, family, friends, inexperienced health professionals and the general populace. Knowledge of this theory may influence the provision of healthcare to this group, and reinforce the need for greater advocacy and community awareness for individuals faced with communication impairments and other acquired disabilities and disfigurements.

Another strength of this research was the use of symbolic interactionism (SI) as an interpretative framework during the data collection and analysis phases. This approach assisted the development of concepts and understanding of the social phenomena 'identity' and 'interaction' after TL that emerged from the data. The aim

of this study was to provide theoretical constructions rather than definitive understandings of the social processes and patterns of the socio-cultural determinants of health and wellbeing after TL. The themes generated from the interviews were used to develop theoretical constructs and substantive theory relating to the phenomena of TL from multiple perspectives. Further research is required to verify the generalizability of these constructs to a wider population of individuals who undergo TL. Conceptual development is also dependent on the development of theoretical saturation (Charmaz, 2003). Not achieving theoretical saturation was a risk for this study, given the small population of potential participants. However, as discussed in chapters 3 and 4, a number of recruitment and data collection strategies were implemented to assist this process.

A criticism of SI is that while the construct *society* exists in symbolic interactionism literature, some psychologists, ethnomethodologists and other researchers argue that it is an underdeveloped theory. Critics also suggest that SI fails to attend to broader influences such as how social class and structure, gender, race, ethnicity and power differentials affect the *self* (de Laine, 1997). Blumer (1969) stated that:

> A network or an institution does not function automatically because of some inner dynamics or system requirements; it functions because people at different points do something, and what they do is a result of how they define the situation in which they are called on to act. (p. 19)

Structuralism and postmodernist thought have challenged the relevance of SI to critique social phenomena. There was a period where it was not a popular framework to apply in social research (Gusfield, 2003; Ritzer, 2007). Despite this, contemporary uses of the framework have emerged in a wide range of disciplinary settings such as education, architecture and health. Symbolic interactionism is often applied now in conjunction with structuralist/postmodernist frameworks such as feminist theory and critical theory. For Denzin (1992), the postmodern era has resulted in important interactionist concepts such as 'symbol', 'social object', 'social act' and 'self' being viewed through a prism that is conscious of gender and class. In the current study, personal factors relating to gender and SES were considered and critiqued.

## 8.4 Future directions

It is clear that a number of questions and recommendations for further research are required at the conclusion of this study. Further verification of the substantive theory could occur by examining the experiences of individuals within the first year of their surgery. The length of time and extent to which some individuals experience destabilisation of their self-identity during the transitioning stage are not known. There is also scope to further explore the TL and HNC experience of diverse populations. Prospective ethnographic studies are warranted to provide a more holistic view of the subjective experience of TL. This would assist with the development of a middle range and grand theory related to how acquired communication impairment affects identity.

The current study, having provided a comprehensive theoretical analysis of the impact of communicative competence on identity reframing after TL, raises the opportunity to explore and evaluate the factors affecting decision making regarding the acquisition of an audible ACM. The issue of difficulties with interaction could be explored further. Observation of interaction and dialogue between IWL and conversation partners in a range of settings could be facilitated using a method and framework such as conversational analysis (Wilkinson, 2014). This approach has been used to examine a wide range of communication disorders and how they impact interaction, including dysarthria (Bloch & Wilkinson, 2009). This level of critique could provide additional support for the theory that communicative competence and communicative participation are important mediators of interaction for IWL. It may also enable the interpretation of the reframing patterns in relation to interaction challenges, for example positioning, and how they might be influencing interaction, participation and engagement. This form of critique may provide observable data that IWL experience diminished control or ability to repair communication breakdown. Conversational analysis would allow evaluation of the roles communication partners play in compensating or accommodating these difficulties in a range of communicative situations and contexts. It may also elucidate for IWL and their communication partners strategies they can use to examine their competency and enhance participation. In addition, the different audible ACMs and their impacts could be examined more extensively.

Another possible direction for further research could be additional critical

analysis of TL communication and how it is influenced by socio-cultural context. There remain some unexplored areas, such as why women appear to experience poorer functional and wellbeing outcomes than men. The current study suggests that communication outcomes form part of these women's difficulties. Although only a small number of individuals were sampled, it was very clear that the women had the most difficulty managing social situations and interactions.

Critical discourse analysis has been recommended as a useful analytic approach to examine communication disorders and how they are socially constructed. It has been used to examine and further understand the difficulties experienced by individuals with aphasia, and the public awareness of aphasia (Ferguson, 2014). In the case of the IWL in the current study, the disruption to self-expression clearly impacted the individuals and some people's perceived attitudes. General public awareness of TL and audible ACMs was reported to be poor. These issues concerned all the participating cohorts in this study. A critical discourse analysis may provide the necessary tools and analytic framework to deeply explore them.

Another area of research could be to evaluate the effectiveness of therapeutically targeting communicative competence to support participation, quality of life and psychosocial wellbeing in the short, medium and longer-term for IWL. Further critique of how the reframes, coping styles and self-efficacy levels interact over time is warranted to achieve this. These rehabilitation strategies may also focus on greater individual empowerment through the early provision of effective communication aids, the development of meta-awareness of the communication issues and emphasis on the development of community networks to reduce social isolation.

Increasing the empowerment of all stakeholders in the TL triad is another potential area for research. While the provision of timely education and support was identified, a number of barriers were also described. The development of other competencies such as self-care and swallowing are deserving of attention. For example, rigorous evaluation of the consistency, intensity, type and timing of education for all stakeholders could provide more transparency and lead to innovative practices.

The current study endorses individualised and sensitive care to be implemented and evaluated. It appears that the primary supporters are a group in need of more guidance and support to alleviate the effects of the strain and burden of care.

The health professionals also need to establish ways in which to effectively educate and support a broader understanding and awareness of TL care and needs. Other needs are for greater reflexive practice amongst health practitioners and greater awareness of the impact of communication impairment on individuals. Research examining novel ways of using online technologies to support the care effort, social engagement and the promotion of both independence and awareness may be useful. These may include education tools tailored for all stakeholders, and a national database or support forum where people could be matched with others of the same gender, age and background.

Future research could also target the development of more reliable and sensitive surgery and technology. The current study has highlighted the unsatisfactory issues of the low Fo of TE speech for female IWL. The development of SVR techniques and voice prostheses with a higher Fo may assist. In addition, the practical issues of voice prosthesis reliability need to be enhanced with anti-phlegm technology so that prostheses do not get blocked and communication is not disrupted. The current heat-moisture exchange and hands-free valve systems remain inaccessible for many individuals for both suitability and cost reasons. These findings also provide further support for continued development and research for laryngeal transplant (Luu & Farwell, 2014). The current study highlights the need for development in these areas because current systems are clearly unsatisfactory for many in the long-term.

Finally, a mechanism whereby health professionals could evaluate the effects of self-identity constructions after TL at different time points could be developed and trialled.

## 8.5   Conclusion

In this thesis, I have presented a research study that has attempted to gain a rich understanding of the TL experience. The narratives and analyses have yielded some important findings in relation to further understanding acquired communication disability, communicative participation, optimal person-centred healthcare practices and well-targeted psychosocial supports for IWL. The study reinforces the ongoing need for advocacy and education about the important roles people play during interaction. It has strongly emphasised the experiences of those with communication impairment, however, it became clear that the role of communication partners was

crucial. Unfortunately, this is an area that has received little attention in the health literature. There needs to be much more attention to, and evaluation of, how a person with communication impairment may be optimally supported in a range of settings and at all structural levels—personal, social and socio-cultural. In the first instance, consistent and person-centred communication and interactions must prevail throughout the care journey.

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# Appendices

## Appendix 1: Sample of literature search

**Journals@ Ovid Fulltext, Ovid Medline (R), PsycInfo, HaPI (Health and professional instruments) 22/12/09, 19/03/10 and 19/05/15**

| Search Sequence | Search terms | Results 1990-2010 | Relevant 1990-2010 | Results 2010-2015 | Relevant 2010-2015 |
|---|---|---|---|---|---|
| 1. | Laryngectom* and quality of life | 820 | | 949 | |
| | Total laryngectom* and quality of life | 462 | | 233 | 101 |
| 2. | Total laryngectom* and qualitative (removed duplicates) | 48 | 12 | 8 | |
| | Total laryngectom* and quality of life and qualitative (removed duplicates) | 17 | 8 | 10 | 6 |
| 3. | Laryngectom* and lived experience | 0 | | 0 | |
| | Total laryngectom* and quality of life and qualitative and lived experience | 0 | | 0 | |
| 4. | Laryngectom* and adjustment | 173 | | 55 | 36 |
| | Total larygectom* and adjustment | 56 | | 36 | 26 |
| | Total laryngectom* and qualitative and adjustment | 6 | n.b all were in search 3 | 0 | |
| 5. | Laryngectom* and psychosocial | 161 | | 65 | 53 |
| | Total laryngectom* and psychosocial | 80 | | 39 | 31 |
| | Total laryngectom* and qualitative and psychosocial | 7 | | 3 | 2 |
| 6. | Laryngectom* and social support | 61 | | 31 | 18 |
| | Total laryngectom* and social support | 20 | | 13 | 12 |
| | Total laryngectom* and qualitative and social support | 2 | 2 | 1 | 1 |
| 7. | Total laryngectom* and qualitative and women | 10 | 4 | 9 | 3 |
| 8. | Quality of life and head and neck cancer and review (removed duplicates) | 224 | | 1210 | |
| | Quality of life and head and neck cancer and review and laryngectomy and 2010 - 2015 only (removed duplicates) | | | 100 | 80 |
| 9. | Total laryngectom* and systematic review | 14 | 4 | 33 | 10 (non-surgical/ medical) |
| 10. | Systematic review and qualitative and women and cancer and psychosocial | 173 | 30 | 301 | 77 |

**Appendix 2: Samples of advertisements**

Invitation to participate in a research project

# Are you a Health Professional?
# Do you support people who have
# had a total laryngectomy?

Do you have approximately 60 minutes
to spare out of your busy work schedule?
If yes, please read further....

**Ms Jane Bickford** (Principal Investigator, Department of Speech Pathology and Audiology, School of Health Sciences at Flinders University) and her supervision team are undertaking research about the psychosocial experience of living without a larynx (total laryngectomy).

We are seeking health professionals with experience caring for patients who have had a total laryngectomy to volunteer to assist in this project. Indepth, semi-structured interviews will be conducted one on one either face-to-face or over the phone. The interviews could last between 60-90 minutes.

Any information you provide will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting publications – i.e. your name or identity will not be revealed in subsequent reports and publications.

We will seek your consent in participating in the research at the time of the interview. You are free to discontinue your participation at any time.

**Any enquiries you may have concerning this project should be directed to Ms Jane Bickford 08 82045955 or jane.bickford@flinders.edu.au**

Figure has been removed due to Copyright restrictions.

This study has been approved by the Southern Adelaide Clinical Human Research Ethics Committee

CRICOS No. 00114A

# Appendix 3: Sample of Letter of Introduction

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CRICOS Provider No. 00114A

**Letter of Introduction**

Date

Dear

My name is Jane Bickford. I am a speech pathologist and Research Higher Degree student at Flinders University. I am interested in finding out more about how people manage after having a total laryngectomy. Your own speech pathologist, Ms. Stephanie Martin has suggested that you might be interested in participating in the research project I am conducting called ***Experiences of living without a voice box after surgery (total laryngectomy).*** Included in this information pack is a Participation Information Sheet providing more details about the study, a reply slip and a sealable reply-paid envelope.

This project will specifically focus on the personal experiences of people after having a total laryngectomy. It is an interview study, which aims to provide an opportunity for people to describe their experiences of total laryngectomy in their own words.

The overall aim of this study is to provide information that will enable health professionals to better care for the needs of individuals who have a total laryngectomy. Involvement in this study will include an interview of approximately 60-90 minutes, the keeping of a personal journal for a month and, at a later date, a review of the researcher's summary interpretations of your interview and journal, to check that my interpretations match what you wanted to say.

If you are interested in participating in this project, please return the reply-slip either in the reply-paid enveloped or mail directly to Ms Jane Bickford, Speech Pathology and Audiology, School of Medicine, Flinders University, GPO Box 2100, Adelaide, 5001. If you have any questions about my study, please phone me Monday, Tuesday or Thursday of each week on 82045955 or with email at jane.bickford@flinders.edu.au

Yours sincerely,

Ms Jane Bickford
Research Higher Degree student

# Appendix 4: Sample of Participant Information form

Miss Jane Bickford
Lecturer/Chief Investigator
Faculty of Health Sciences
Speech Pathology and Audiology
GPO Box 2100
Adelaide SA 5001
Tel: 08 8204 5955
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CRICOS Provider No. 00114A

Southern Adelaide Health Service / Flinders University
Flinders Clinical Research Ethics Committee

## PARTICIPANT INFORMATION FORM

### *Experiences of living without a voice box after surgery (total laryngectomy)*

You are invited to participate in an in-depth interview and to keep a short-term journal exploring your personal experiences of having a total laryngectomy. Both the interview and journal keeping will form part of a study aimed at furthering health professionals' understanding of how factors such as gender, age, social supports, location and cultural background influence an individual's ability to cope and adjust to total laryngectomy.

The in-depth interview will last approximately 60-90 minutes and can occur either in your home or at Flinders Medical Centre. The keeping of a personal journal will be for one month. You will also be asked to look over the researcher's summary interpretations of your interview and journal, to check that interpretations match what you wanted to say. Interviews will be occurring between March 2010 and March 2011.

This study is being conducted by Ms. Jane Bickford, lecturer in Speech Pathology and Research Higher Degree student at Flinders University. Her co-investigators and supervisory team at Flinders University include Professor John Coveney, Public Health, Associate Professor Janet Baker, Speech Pathology and Dr Deborah Hersh, Public Health.

Your speech pathologist Ms. Stephanie Martin has agreed to contact people such as yourself, to see if you may be interested in being interviewed about your experience of having a total laryngectomy. Your decision to be involved is entirely up to you. Whether you take part or not, the speech pathology services you receive from Flinders Medical Centre will not be affected in any way.

Your participation is entirely voluntary and you have the right to withdraw from the study at any time without giving a reason. If you decide not to participate or if you withdraw, you may do so freely, without affecting the standard care or treatment you will receive. Participants will also be informed of the results of the study and, if necessary, participants (including those who withdraw) can contact the chief investigator to debrief about the results.

To indicate you would like to be involved in the study return the reply slip in the prepaid

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addressed envelope provided. You will be contacted by telephone by Ms. Jane Bickford and she will discuss with you the inclusion and exclusion criteria of the study. If you meet the inclusion criteria a mutually suitable time and place for the interview will be determined. Please note: that the interview data analysis for each participant can take time and you may not be offered an interview immediately. The interview can occur at your home or at Speech Pathology and Audiology, Flinders Medical Centre. You will be reimbursed for reasonable travel costs for visits made, which were related to the study. You will also be offered a small fee of $40.00 to compensate you for volunteering your time to participate in this study.

The interview will be audio-recorded but you may also be asked permission for the interview to be video-recorded. The recording is an important part of data collection because the interview will be transcribed word for word for analysis. The transcribed interview will be returned to you for comments. At the end of the interview you will be asked to complete a brief form identifying socio-demographic information such as your age, address, family details and average annual income. This information will be stored and reported in a way that all your personal details are not identifiable to maintain confidentiality and your privacy. After the interview, you may also be given a blank notebook and asked to keep a journal of your experiences of the total laryngectomy for a month. It is also possible that you may be asked whether you would mind being interviewed again for clarification on certain matters raised in the first interview or the journal.

Your involvement in this research project may not directly benefit you. However, a possible benefit may include an opportunity for you to talk about your experiences of total laryngectomy openly and frankly to someone who is not your family or one of your health care workers.

It is unlikely that the interview or journal keeping will result in adverse risk or injury. Participants in this study are insured under the Flinders University. If you suffer injury as a result of participation in this study, compensation might be paid without litigation. However, such compensation is not automatic and you may have to take legal action to determine whether you should be paid. Additionally, the personal nature of the interview may raise things that you find upsetting. If you find this is the case then you will be advised on where you can access some immediate help from local and telephone based counselling services provided by community health and privately based counsellors. Some of these services are free, whilst others charge a fee. Details of these services will be provided to you as a written sheet at the time of the interview. Additionally, Associate Professor Jan Baker (co-investigator) is a qualified Family Therapist and would also be willing to offer counselling to you.

All records containing personal information will remain confidential and no information which could lead to your identification will be released, except as required by law. All your data will not be identifiable to maintain your privacy and it will be stored in a lockable filing cabinet in the office of the chief investigator at Flinders University during the duration of the study. It will then be housed in a locked storeroom in Speech Pathology and Audiology, Flinders University for at least five years after publication of results of the project. The project outcomes may be published in conference papers, scientific journals or other venues as appropriate. It is possible that the results may not be published for scientific or other reasons.

For further information about participation and the project; contact the chief investigator Ms. Jane Bickford, Speech Pathology and Audiology, Flinders University, phone number 8204 5955 or email jane.bickford@flinders.edu.au. The principal supervisor for a this project is Professor John Coveney, Public Health, Flinders University, phone number 7221 8419 or email john.coveney@flinders.edu.au

***This study has been reviewed by the Flinders Clinical Research Ethics Committee. If you wish to discuss the study with someone not directly involved, in particular in relation to policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the executive officer on 8204 4507 or email research.ethics@health.sa.gov.au***

## Appendix 5: Sample of Consent form

**Government of South Australia**

SA Health

**Flinders**
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### CONSENT TO PARTICIPATION IN RESEARCH

I, --------------------------------------------------------------------------------------------
*(first or given names)*                                    *(last name)*

give consent to my involvement in the research project

***Experiences of living with and/or supporting someone without a voice box after surgery (total laryngectomy).***

I acknowledge the nature, purpose and contemplated effects of the research project, especially as far as they affect me, have been fully explained to my satisfaction by

--------------------------------------------------------------------------------------------
*(first or given name)*                                    *(last name)*

and my consent is given voluntarily.

I acknowledge that the detail(s) of the following has/have been explained to me, including indications of risks; any discomfort involved; anticipation of length of time; and the frequency with which they will be performed:

1. This study involves a focus group interview of approximately 60-90 minutes about my experiences of living with and or supporting someone who has had a total larygectomy (removal of your voice box). Some of the things talked about may be of a personal nature and could result in me feeling upset.

2 I agree to audio/video recording of my information and participation.

3 I agree to complete a socio-demographic information form.

...........

I have understood and am satisfied with the explanations that I have been given.

I have been provided with a written information sheet.

I understand that my involvement in this research project may not be of any direct benefit to me and that I may withdraw my consent at any stage without affecting my rights or the responsibilities of the researchers in any respect.

I understand that counselling services are available.

I declare that I am over the age of 18 years.

I acknowledge that I have been informed that should I receive an injury as a result of taking part in this study, I may need to start legal action to determine whether I should be paid.

Signature of Research Participant : _____ Date: _____

I, _____ have described to _____
the research project and nature and effects of procedure(s) involved. In my opinion he/she
understands the explanation and has freely given his/her consent.

Signature: _____ Date: _____
Status in Project:_____

# Appendix 6: Sample of Counselling information

Miss Jane Bickford

Lecturer/Chief Investigator

Faculty of Health Sciences

Speech Pathology and Audiology

GPO Box 2100
Adelaide SA 5001

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CRICOS Provider No. 00114A

## Counselling Services Information Sheet

Thank you for spending time talking to me about your experiences of having a total laryngectomy. I hope you found this interview a useful opportunity to reflect and share your experiences with someone else. If you feel that you need to discuss your experiences further, I encourage you to do so. A trusted family member or spiritual leader may be your choice. Below I have included a list of some of the counselling services available in Adelaide, their cost and approximate waiting period. If you have found any part of the interview distressing, it is important that you seek further help.

### Telephone Counselling Service
**Lifeline: 131114**
This service offers a 24 hour confidential service conducted by trained counsellors. Please keep trying if you do not get through the first time. This service may be very useful to you if you are on a waiting list to see a counsellor face-to-face at one of the organisations below. For further information look up the website: www.ucwesleyadelaide.org.au/lifeline

### Cancer related counselling and support services
**Cancer Council South Australia**
**Helpline: 131120**
Free counselling service for people diagnosed with cancer, their partners, family or friends experiencing distress. The service aims to build on a person's coping skills and provide them with additional information, emotional support and practical help as needed to reduce cancer related distress. A social worker and two counsellors are available to talk to between 9.00am and 5.00pm Monday to Friday by appointment.
Cancer Council SA also provides a range of support groups, publications and other services. Refer to the website for more details www.cancersa.org.au

### Community Health Centres
Please contact the centre nearest you (under "Community Health Centres" in the Whitepages). The centres closest to Flinders Medical Centre are:

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**Inner Southern** ph. 82772488. Provides a general counselling service. No Charge. Waiting list currently (September, 2009) 3-4 weeks

**Noarlunga** ph. 8384 9266. Provides a general counselling service. No Charge. Intake for an initial appointment can occur Monday-Friday 9am-1pm and people can drop in or telephone. There is no waiting time for an initial appointment. Subsequent appointments are managed case by case and may incur a waiting time.

## Community Welfare Organisations

**Centacare** ph. 82108200. Provides relationship counselling and other counselling services in a range of metropolitan and regional centres including Whyalla, Pt Augusta and Mt. Gambier. Cost = Sliding scale depending on your income, no fee for unemployed or concession card holders Waiting list is variable (September). Centacare also offer a range of employee assistance services. Visit the website for further information www.centacare.org.au

**Loss and Grief Centre** ph 81313400

Kent Town and an outreach service to Elizabeth. Loss and grief counselling run jointly by Anglicare and Flinders University. 2 counsellors and social work students from Flinders University. Can opt to see counsellor only. Fees range from $10 for Healthcare card holders to $25 for employed people. Telephone counselling is also available. There is currently no waiting list.

## Private practices

**Bower Place** ph. 82216066

Private practice providing psychology (Catherine Sanders) and family therapy (Malcolm Robinson) counselling services. This is also a training school for counselling students learning the "Bower Place Method" which integrates family therapy, psychology and counselling approaches.

*Low fee clinic*- run by students under supervision on Wednesday afternoons and evenings and Thursday evenings.

*Practitioner* costs vary between $120-$600 depending on service provided. Waiting lists also vary.

**Dulwich Centre** ph. 82233966

Provide narrative Therapy. Cost approximately $80 per hour. A consultant may be seen within 2-4 weeks (September, 2009)

**Australian Counsellors Association**

The website **www.theaca.net.au** provides a list of private practitioners who can provide counselling services.

## Other options

Contact your GP surgery to find out whether it offers a counselling service. Alternatively, visit your GP, which is billable on Medicare with a possible small co-payment. Some GPs can provide counselling themselves, or could ask for a referral to another medical practitioner who can help. For example, some psychiatrists are experienced counsellors and their consultation fees will largely be covered by Medicare.

There are also many other counselling services operating in South Australia with a range of costs and waiting periods. Consult the Yellowpages for a list. Please contact the people you feel most comfortable in seeing.

# Appendix 7: Sample of Interview guide

**Stage 3 Interview questions**
**Explain a little about the study and why we are interested in the experiences of health professionals supporting people who had a total laryngectomy.**

| Theme | Question | Sub-questions/probes |
|---|---|---|
| Icebreaker | Tell me about your role when working with people who need or who have had a TL. e.g. pre-operative, post-operative and longer-term. | What do you routinely do? |
| | Tell me about a client you remember working with. | What worked and why? What didn't work so well and why? \*Probe the key things generated here. Sequence the following questions according to what occurs here, may have to use structured questions later if particular things don't naturally come up (such as guidelines or outcome measures). |
| Recovery | For you, what factors constitute a successful recovery from a total laryngectomy? For you, what factors contribute to an unsuccessful recovery from a total laryngectomy? | Are there specific socio-cultural, psychological and biological factors e.g. gender, age, SES, employment status, geographic location, linguistic background, social capital, health status, level of education that you think assist recovery? Give examples Are some of these more important than others? Which of the above factors are priorities, based on your experience and particular caseloads? |
| Services/team role | For you, what constitutes optimal/best practice healthcare for a person who undergoes total laryngectomy? If time and funding allowed, what kind of further training or support to enhance your expertise in this area would be helpful for you and or your team? | Who are important members of the multidisciplinary team and why? How might a best practice approach be achieved? How does the multidisciplinary approach facilitate or detract from optimal care? |

| | | Describe whether your clinical practice and that of the multidisciplinary team is informed by clinical practice guidelines? |
|---|---|---|
| | What are the pressures affecting laryngectomy care provision in your setting? | Note and comment on possible pressures generated e.g. Professional boundaries Funding/system schemas Service delivery issues e.g. waiting lists, hospital (biomedical) focused, minimal community care to support psychosocial adjustment |
| | In your experience and setting, how are laryngectomy services similar/different to other cancer services e.g. breast, prostate, bowel? | Are these pressures prioritised and do these factors interact with one another - i.e. professional boundaries and the functioning of multidisciplinary teams - or funding schemas and service delivery issues - i.e. waiting lists.

What is your perception of the multidisciplinary, specialist team? (ask both specialist team members and community-based practitioners) |
| Support needs | What do you think are the psychosocial needs of a person who undergoes TL? In your mind, do these needs vary across the treatment pathway?

How is patient psychological distress assessed and supported in this clinical population?

Describe your role in providing psychosocial support for people who have TL.

Describe the multidisciplinary team's role in providing psychosocial support. How do you think people are personally affected by the alaryngeal communication method they use?

How are people supported with persisting disabilities such as swallowing problems, breathing issues, communication difficulties? | How and when is patient psychological distress measured along the diagnosis/treatment trajectory?

What do patients report as being the day-to-day impacts of alaryngeal communication? |

| | | |
|---|---|---|
| | Describe and comment on any particular groups of patients you perceive as being more needy/vulnerable after TL, e.g., Rural, elderly, female, isolated, young, NESB<br><br>A laryngectomy visitor or a support group are often recommended. What are your thoughts/experiences about these recommendations?<br><br>Comment on the health literacy and health awareness of this clinical population. Are there similarities or differences amongst groups? What factors are at play here? | *Probe1:10 smokers don't link smoking as a cause of illness and half of all smokers surveyed could link lung cancer to smoking. Victorian Cancer Council Survey 2014 |
| Carer role | What role do family/friends play in the adjustment to laryngectomy?<br><br>How is carer strain/ burden managed in your setting?<br><br>How do you think the multidisciplinary, specialist team is perceived by the client and their loved ones/family? | |
| Future healthcare | What do you see as the future healthcare development /trends in laryngectomy care? | |

## Appendix 8: Sample of Socio-demographic information form

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## Socio-demographic information form

Stage 2 Participants

Interview date:

| Participant details | | |
|---|---|---|
| Name: | | |
| Age: | Gender: | Marital status: |
| Residential address including postcode: | | |
| Country of birth: | | If not born in Australia, how long have you lived here? |
| Predominant language spoken: | | Other languages frequently spoken: |
| Highest level of education: | | Religion: |
| **General health history** | | |
| Personal history of cancer? | | |
| History of cancer in the family? | | |
| Smoking and alcohol consumption? | | |
| **Social details** | | |
| Partner, relative or friend's name: | | |
| Partner, relative or friend's age: | | |

| Only complete if you are a partner or relative. |
| --- |
| Family members and ages (immediate and extended) |
|       How many children do you have? |
| |
|       Children (first names and ages) |
| |
|       Grandchildren (first names and ages) |
| |
|       Siblings (first names and ages) |

## Occupation details

| Occupation (fulltime/part-time) |
| --- |
| Previous occupation/s (length of time, roles) |
| Retirement date: |

Income support: Yes/No

Average yearly combined family income $A (circle):

| A | 0-6000 | D | 35001-50000 | G | 80001-100000 |
| --- | --- | --- | --- | --- | --- |
| B | 6001-20000 | E | 50001-60001 | H | 100000+ |
| C | 20001-35000 | F | 60001-80000 | | |

## Laryngectomy details

| When was your partner, relative or friend diagnosed with laryngeal cancer? |
| --- |
| What has been the course of treatment to date? |
| Where did the treatment take place? |
| Who was the treating head and neck surgeon? |
| Who is the treating speech pathologist? |
| How does your partner, relative or friend communicate with you?<br>-voice prosthesis<br>-servox<br>-oesophageal speech<br>-other, please specify |

*Thank you for taking the time to complete this form.*

## Appendix 9: Sample of Initial and focused coding

| Interviewer: Interviewee: | Initial codes | Focused codes |
|---|---|---|
| **So you weren't given a lot of preparation for the surgery?** Absolutely none. It was explained to me why it had to be – he had to be taken by the doctor – well, not exactly, the doctor needed to take him and there was no explanation as to – there wasn't any time for any explanation or anything as to what – all it was, that he was going in for an emergency surgery. The surgery wasn't explained or anything. There was nothing explained as to when I walked in to see him or anything like that there. | Lacking information Needing emergency surgery Being there | Questing information |
| **So after his surgery, his tracheotomy, you didn't get any nurse or anybody come in and just telling you what had happened?** No.  **And when he got to – did he go to [ward name]?** Yes, he did.  **Was there more explanation about the laryngectomy and what that meant?** No. Well, I actually asked for information as to – but one of the nurses I did ask and he was great, he said about – because the centre part of the tracheotomy, well, you know, it comes out and he asked me whether I wanted to watch or go out of where my partner was and I said 'no, I'm better off to see what actually needs to be done because if I'm going to be around I need to know what to do', so that was great but he was the only one that actually had – yeah | Asking for information Being educated Wanting to learn and care Taking responsibility | Becoming aware Being there Developing competence |
| **Given you that time?** Yeah and that's when I asked him if there was any information that I could take home and read about it and all that, and that's when he got me that. | Asking for information | Becoming aware |
| **And did you search for any other information anywhere else, the Cancer Council or the internet or anything like that?** No, I had to just take it in for what was – because at that point it was a laryngectomy and we knew that the doctor was going to have another talk because there was a biopsy and that done. Weren't sure whether it was just the – well, that's where my head went, I just thought 'well, is this going to be a permanent thing? By the sounds of it, it could be' and at that point we didn't know so it wasn't much use in me feeding in information on everything else, just on the pamphlet to take in the – what needed to be known at that point. **At that point in time, yes.** Yeah. | Feeling uncertain Waiting for diagnosis Avoiding too much information | |
| **So you said immediately after the surgery you walked into the room; so how did you feel at that point?** I really felt for him because I could see in his eyes 'what the hell's going on?' and I couldn't explain anything to him because I didn't know and it was, yeah, very frustrating for him because he woke up and he couldn't speak. | Feeling for partner Experiencing shock and frustration (partner) | Experiencing shock Early transition Lacking education |

| | | |
|---|---|---|
| He went to try to speak but he couldn't speak. Like I say, nothing was explained to him and even if a doctor was to explain to him – I mean that sort of explanation for anybody that's just gone through that surgery is going to go right over their heads, you know? | Waking up with no speech Lacking speech and comprehension Reasoning lack of information | |
| **Yes, that's right, and it's giving small amounts of information often really rather than a lot.** That's exactly it. I mean, yeah, I can only hope – I mean it wasn't about me and what I was going through at that point, it was just to get him through the – yeah, I just put my 'it's not about me, it's about him' you know? | Putting partner's needs first | Being there |
| **Sure. Tell me about that trying to communicate. So as things settled and he was in hospital for such a long time what other methods did you use?** That was very frustrating because when the actual stoma was – what do you call it, created or – they had to take a skin graft and the vein from his right arm and he's right handed and he couldn't write properly. That's all there was; there was just bits of paper and that there that he was writing on. They gave him a piece of paper with the alphabet on so it could be pointed to what letter and he was just getting frustrated. Whatever nurse, they lost that piece of paper and all this, you know, and it was just total frustration. Like him and I – I don't know. I don't know whether it's me reading his mind or whatever, it was just that I had the sixth sense to understand what he was saying without him writing anything so he didn't go through that frustration. | Finding communication frustrating Having difficulty writing Using AAC Losing communication sheet Predicting needs Providing support Empathising | Difficulty expressing self Experiencing frustration  Being supported |
| **That would have been very exhausting.** Yeah, well, it was for both of us. This is where I actually asked whether – you know, like even with today's technology, you know, a tablet that – I don't know how many of these operations are performed – a patient to have a tablet to tap on, you know, and then to push a button and it speaks; I know I've seen them somewhere and I thought that would be ideal. It still gives them the satisfaction of actually – even though it's not their voice but they're actually hearing what they've written down or pointed on this –yeah. | Asking for communication aid | Replacing communication Using technology |
| **And also, like you said, his right hand was out of action; he could tap.** That's it as well and he had to learn how to write with his left hand. **As things settled did he end up learning to use something like a Servox or a valve or anything like that?** I'm not understanding what you mean? You mean the voice prosthesis? **Yes, voice prosthesis** He has a voice prosthesis now. **And when did he get that?** He got that basically straightaway. Yes, it was straightaway because when he was in hospital he had a tube going down there and then when he turned around and told them he was leaving – I can't remember the woman's name; It wasn't [speech pathologist's name]. One of the women actually came in and put in a voice prosthesis on his leaving. **So it was probably about five or six weeks without anything?** Yes. | Trying to solve issues Hearing communication Getting feedback Losing use of dominant hand Learning to write Getting prosthesis early on Leaving hospital Having tube and then valve placed Spending 6 weeks without voice | Trying to help Hearing self  Having to compensate Getting voice prosthesis early  Being discharged Being voiceless for 6 weeks |

| | | |
|---|---|---|
| **And how's that going? Does he get good voice from that? I beg your pardon?**<br>**Does he communicate well with that?** He communicates very well but he doesn't think he does.<br>**Does he have problems with breathing and it getting all clogged up or anything like that?**<br>Yes he does but he – oh, that's an ongoing battle between him and I. I've got my way of doing it and I show him the way I do it in the mirror because he doesn't seem to clear it as well as what I do. That's not blowing my own trumpet but, you know, I said to him he had to twist it round and then pull the brush out but he finds it – and then it works but by – he just gets so frustrated; it's like he's talking underwater, that's what it sounds like. | Perceiving voice<br>Breathing difficulties<br>Experiencing tension<br>Cleaning stoma<br>Acknowledging skills re: stoma care<br>Advising<br>Being frustrated<br>Speaking affected | Perceiving TE speech<br><br><br>Managing self-care<br><br>Being frustrated<br><br><br>Noting poor reliability |
| **And so you sometimes take it out and clean it and things like that or does it stay in?**<br>It's got to be changed every four weeks or every two weeks. He had trouble there with Candida so he's on the anti-fungal tablets for that so that's no longer the problem it used to be. We did have trouble at the beginning because when he cleaned it, cleaned out the stoma, he would actually pull out the prosthesis so he had to have one of those tubes that go down until we got to see [speech pathologist's name]. | Having trouble<br>Treating candida<br>Cleaning stoma/prosthesis<br>Experiencing a different process<br>Seeing the speech pathologist | Experiencing tension, frustration<br>Being there<br>Helping<br>Showing<br>Maintaining prosthesis |
| **So like a little stent to keep it open?**<br>No, it's actually a feeding tube from the hospital, but one of those long ones that go actually down to his stomach, and all I did was clogged up the top of it with cotton wool and put tape over the top so it wouldn't – his food and stuff wouldn't come out the top of it and (then) put more tape on it than needed. | Supporting care<br>Finding solutions | Supporting care<br>Finding solutions<br><br>Managing tube |
| **Now this is all quite messy stuff; how's it been for you, getting to know wall this?**<br>Well, once again, nothing was explained to us, only that he had to – if difficulties come up that tube had to go in no matter what or the fistula would close over, so basically for us it was trial and error because we'd done what we were told and to put the tube in but there was nothing said to us about putting a knot in the top of the feeding tube. That wouldn't have mattered any – well, we didn't even know that until I had put the cotton wool in the end of it and put the tape around the top and then just taped it up to his shoulder because when he coughed he actually sometimes coughed the tube out so that automatically had to go back in. Yeah, that was – you know, [speech pathologist's name] realised that we had it under control if that was going to happen again; she was quite satisfied with that. | Receiving little information<br>Having some support<br>Finding out by trial and error<br>Checking back | Feeling underprepared/ educated<br><br><br><br>Checking back |

| | | |
|---|---|---|
| **You don't mind the cleaning? Some people actually find that more of a challenge.**<br>No, not at all. I mean this is – well, I don't mind at all. [My partner] finds it sometimes frustrating because everything's just so time consuming. It's like the constantly having to clean it, like you don't know who's going to ring on the phone and you don't know who's going to come to the door or anything like that and when you go out and then – I mean hygienically it's not the sort of place to clean it, in the toilet, but that's the only place you've got. Like I said to him, I said 'go into the – I don't like to call it the handicapped toilet but that's what they put – 'go in there'. Nine times out of ten that would be more hygienic because there's not that many that use it and to have that hand sanitiser on him, you know? | Accepting situation<br>Observing frustration<br>Time consuming<br>Having to constantly clean it<br>Being unreliable and uncertain | Being there<br>Supporting<br><br>Experiencing uncertainty, disruption |

## Appendix 10: Sample of Participant stories

*Examples of a 'resigned self' reframing pattern*

Hugh's story

Hugh was a 57 year old gentleman who had his TL four years before I interviewed him. He casually described himself as *pensioned off* due to his TL and heart problems. Hugh was living in a small inner urban ground floor flat, in an affluent area. He was my fourth interviewee and I had not met him before. In many ways he surprised me. He was a former truck driver with a history of heavy smoking and alcohol consumption and living alone. He did not communicate any prior or current attachments and seemed quite isolated. He described how he visited his brother but that *socially things have collapsed* since his TL. Prior to his surgery he enjoyed going to the pub to socialise but now he spent most of his time staying in his *little dog box* and focused on his hobbies. In his flat there were large and intricate model sailing ships (18th Century British Navy warships) and in his courtyard, his beloved vintage-style motorbikes. His love of history was expressed through his hobbies and story telling. He described how his life had changed and that *things can become a bit mundane but…, I'd rather that than struggling in a pub or wherever,… I'd rather just do my (boat).*

Hugh was highly social, articulate, political in his views and enthusiastic about my visit. He spoke frankly about his experiences of TL and how it had impacted his life. During the course of the interview, it became apparent that he experienced a lot of functional issues with his airway and TE speech. He had to stop frequently to cough or clear his airway. This was very disruptive to the conversation and clearly a source of frustration for him. Hugh articulated two important aspects of 'the altered self' experience, the loss of his voice and the loss of his communicative competence. He identified his 'voice' as a distinctive part of himself, his character and his personality and that it had '*gone*'. He described the loss of this valued part of himself as being distressing and irreplaceable. He talked about the yearning for it to return, the struggle to accept the change, whilst stating that '*you never get used to it*' and that his individuality had been deeply affected.

> *…everybody has a distinct voice. … … it is part of you gone. Part, …of you has been*
> *amputated …and that is difficult to …. get along with, you know.*

Many of the IWL interviewed, attached meaning to how they sounded and connected

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its importance to their social identities. This was illustrated by Hugh's comments about the attractiveness of his pre-laryngectomy voice and how the voice is a '*distinctive*' part of a person. He described it as '*sort of deep, sort of mellow*'

> *One woman told me it is just so mellow and reassuring.*

> *Your voice ...can be ...the most seductive part about someone. It can be, can't it? ......I used to hear it 'I know that voice'. ...I used to get that a lot. ...but all gone and it was nice. Girls used to often come and 'I love your voice'. Oh dear (laughs).*

For Hugh, his tracheosophageal voice was a stark contrast *it just sounds… rough as guts and no personality, closer to a robot.* The other aspect to 'the altered self' Hugh identified was the change to his communicative competence. He gave numerous examples of the extent these changes had impacted him on many levels. He also conveyed his concern about not being able to communicate at all should the cancer return.

> *...the thing… is having this speech handicap ... now knowing how difficult this can be, even with my ability to speak to you, the thought now of not being able to speak at all, should this come back or something or whatever happens, not being able to even answer the phone or nothing, I really don't [know] (gestures a raspberry).*

Hugh reported that his communication issues also affected his participation and agency.

> *Do you know what really pisses me off? ... I listen to ABC radio. You know there is often enough I would like to ring up, in with my two bobs worth, but I can't! Hugh, 57*

Hugh's changed voice and verbal expression marked the difference between his pre- and post-laryngectomy selves. He perceived his pre-laryngectomy self *spoke properly*. The meaning he attached to speaking properly was situated in the context of his experiences and he felt his current abilities did not measure up. He exclaimed

> *I would imagine that anyone who has this done would dream of being able to speak properly again, ...I haven't had those dreams for a long time now. I would think that ...may be some indication that at least you were coming to accept it.*

The attachment Hugh had to his voice and communicative competence and how he observed they were part of his identity might explain why it was hurtful and stigmatising for the IWL when their alaryngeal voice was mocked, ridiculed or the brunt of poor humour by being described as a *robot*, *Dalek* or *Donald Duck.*

Christopher's story

Christopher was a very talkative interviewee and our interview was the longest at 2

hour and 25 minutes. His laryngectomy affected him on a number of levels. His descriptions of appearing a *freak* to others for both his EL speech and his altered appearance showed that he had tried to empathise with how others see him but had experienced many difficult encounters, particularly with strangers. He had excellent command of his EL but needed to stop at times to drink water and to replace the batteries in his device. His story was full of rich descriptions about his experiences and also his opinions on many topical issues. His experience of having multiple health issues, being an immigrant to Australia and becoming estranged from his family after his surgery, had all impacted the way he perceived his difficulties. He was initially shocked by his diagnosis when he was 51 years old and perceived this as a relatively young age. He recalled his attempt at suicide. Details of this were given in chapter 5. However, he resolved to have the surgery and reported that he subsequently adapted to the challenges of his altered life and self. He was the only person I have encountered who could use his electrolarynx as if it is a musical instrument and make it sound like a didgeridoo.

At 61, Christopher was similar in age and social circumstances to Hugh. He also reported that he used to dream *a lot* of being able to use his former voice and how it made him feel happy. At the interview, he said he was now dreaming of himself as an alaryngeal communicator using EL speech rather than his pre-laryngectomy self. This altered perspective in dreams suggests that there is a transition in how individuals perceive themselves and adds further to the notion that the 'voice' and self-expression are an integral part of one's self. There is also suggestion that the pre-laryngectomy self is judged as the 'normal' self and the post-laryngectomy self as 'different' or 'abnormal' and therefore 'altered'.

> *I was conscious in the dream I shouldn't talk because… I have trache but with my power of something inside me I was able to communicate …in a dream absolutely normally and I woke up so happy and the (earth shook), it was a dream.*

I also asked Christopher how he felt about the appearance of his neck, in particular the stoma, the altered skin tone and irregular shape from the radiotherapy and the radical neck dissection. His descriptions were also negative like other participants including Valerie and Lyn. He discussed the challenges of being 'different' and having a *very visible* tracheostoma. He felt he lost his manly appearance when the surgery resulted in reduction of the muscle bulk in his neck. This was a big contrast for him because he

used to be very strong and have a muscular neck. He said he was embarrassed by his appearance but tried to use humour and described himself as a *holey man.* Christopher had also been creative with his stoma cover. He had bought himself a top-grade silver-plated metal and had it inscribed with the Buddhist symbol for 'om'. He proudly described the lengths he had gone to acquire the silver and having it made. He also said he had grown his hair.

Christopher said poor social acceptance of his appearance was similar to the reactions of others to his verbal expression. He used the analogy of being at a football match. He said at a match he could express himself by *'waving, clapping, jumping'* and because it is loud *nobody can hear.* However, as soon as someone tried to converse or ask a question such as *'what do you think about this player?'* With the tracheostoma and alaryngeal communication Christopher said:

> *You are not [an] average person suddenly. Suddenly you are like a different caste. Different…. Definitely not normal.*

This change influenced the way Christopher thought about himself and ability he had to form relationships, particularly an intimate one. Christopher was frank about how he found starting up a new relationship very difficult because of his concerns about his appearance. He did not experience unattractiveness with his ex-wife but said that his disfigurement discouraged him from sexual intimacy with another person. He said

> *with other people… I'm not brave enough (to) initiate contacts and if that other person initiate [sic]. I always try to have a long discussion 'will you not be afraid, when we?' [sic] 'Do you think you will have nightmare to have intimacy with such a different person?' and 'what kind of position?'. It is such a big subject and it absolutely is very difficult.*

He said that perhaps it was also related to his age. He stated that if he was younger he may well have tried to overcome his inadequate feelings. He reasoned that he would have liked to have a companion to share his life but that his practice of hatha yoga assisted him to accept his situation.


### *Examples of a 'destabilised self' reframing pattern*

<u>Lyn's story</u>

For Lyn aged 63, the change was far more brutal and transformed her life in such a way that she lost meaning, her sense of place in the world and her social standing. Lyn had been a former patient of mine and our relationship had always been open and supportive. From someone who had never had a *sick day in her life* she had become

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someone dependent on ongoing healthcare. She has experienced multiple post-operative complications and has struggled with a hypersensitive TE speech, so changing her voice prosthesis had never been easy. She laughed when she quipped, *(Treating hospital's name) and I are married because we will always be very closely connected to the rest of my life.*

Lyn has three adult sons and a larger family of siblings. She is the eldest and often took on caring responsibilities for her younger siblings when her father died, when she was a teenager. She was really engaged with the interview and it was as though she could finally tell her story. She was honest about her difficulties coming to terms with her surgery, subsequent changes and the challenges she experienced. Her sadness filtered through as she described her experiences but there was also evidence of renewed optimism in her story. Her non-smoking-related chondrosarcoma disrupted her life at a time where she had found autonomy and real direction. She was no longer caring for her siblings or her kids and she was running her own business and loving it. She expressed herself through her work and her relationships with her family and friends. Verbal communication was of paramount importance and a significant part of her identity. She described how her alaryngeal speech let her down time and time again, and if she was emotional it worsened.

Lyn talked about her battle with what she described as *depression* for 10 years after her surgery. Her 'destabilised self', coloured everything she did and her loneliness was reinforced by her not being able to express her difficulties to others. She described many occasions where her communication problems inhibited her ability to participate and connect socially. Interestingly, a 'destabilised self' did not occur initially but as time progressed she realised the extent of her communication difficulties and this significantly affected her ability to resume meaningful activities, and eroded her confidence and self-efficacy further.

> *…I had always been on committees, social committees, I've done everything social and then all of a sudden you know your life stops so … that has been the hardest to adjust to and if I go out and I get scared or if I get …panic attacks, I think that is what it is. … I lose my voice because I think 'oh, am I in the right place?' Anything at all, any… nervousness, anything and I can't talk.*

Lyn was circumspect about her experience. She felt that being a single woman and also one that had always been in '*charge*' or '*looked up to*' had made things more difficult for her. Her gender and her age were also factors that alienated her even further. She reported that she felt there had been a strong tacit assumption by others in

her family that she should accept her situation.

> *They don't see that, that side of me. I am the oldest of five and in a lot of ways I bought up those five children. My dad died when we were fairly young and I've always been the oldest. My mum worked full-time and I always, I was the one that did everything for those kids. They don't see me upset. That's what my family has always done, 'So Lyn has had cancer', 'so she is home', 'well get on with it, get over it'. And you do on the outside but not on the inside.*

Lyn talked about how her self-image had changed and this was tied to practical issues and her identity. She said there was a lack of choice regarding clothing style and she was changing her hairstyle for practical reasons.

> *... I don't care anymore, I really don't. That is why I've gone grey and I don't care and I'm only letting it grow because it will be less work and I'm just going to wear it up in a bun...I don't care.*

Even though Lyn described these changes as if they didn't distress her, there was a resignation in her tone. These remarks did occur at a time when she was experiencing a turning point in the way she felt about her situation.

## Valerie's story

Valerie was a 74 year old, lady living with her husband in a coastal retirement estate located about 75 kilometres from the capital. She described herself as middle class and was a first generation immigrant from the United Kingdom. I met with Valerie and her husband and she described how her change in appearance and expression had really affected the quality of her life, in the nine years since her TL. Valerie had been a smoker and had experienced vocal change before her laryngeal cancer was diagnosed. She described how she had always been complimented for her phone manner when she used to work in a call centre, until one day when she was mistaken for a man due to her low pitched voice. Her friendly and 'feminine' manner and low-pitched voice confused a male customer and he accused her of being a *poofter*. This was Valerie's first experience of being insulted about her voice. This was not the last upsetting experience and some have had a more lasting effect than others. Valerie said she still found it difficult to not internalise and take some things personally such as having people *hang up* on her and call her an *idiot* if she answered the phone. Valerie reported that she was a very social person with a very supportive partner in Colin, who said in social situations *I like to be in control. ...well I used to.* In response to this her husband Colin described the social change the TL had for both him and

Valerie.

> *Well if we had a party Val was the life and soul of the party she was the one saying you do this you do that, you do that and you do the next thing and she was the centre of the stage you know everything had to be organised. But ...since this has happened I have taken over. And I was usually the quiet one who wouldn't say anything. Colin, 77 partner*

Valerie said that her whole outlook changed when she had her TL and she entered retirement at the time of the surgery. Ten years after her surgery, she was still experiencing a lot of grief and disruption socially. She disliked her appearance, could no longer participate as she was accustomed and had felt lonely as a result of her communication difficulties. When asked how she feels about her TL she said *I hate it… I do hate it with a vengeance.* I also asked her whether she felt she had experienced depression and she said:

> *even now I have my down days… I can have my days where I sit in my dressing gown and watch that (pointed to TV) … but I don't call that depression. ...I mean I still make the beds, tidy up, prepare dinner. To me if you are depressed. You don't do anything. ...I honestly don't think I am depressed. I'm not happy but I'm not depressed.*

Valerie described how her changed voice has even resulted in change to her role as a grandparent. She stopped babysitting her grandchildren because she did not want to read bedtime stories with her TE speech. She also reported that she did not like her appearance and changed her behaviour according to how she felt about her image for a specific situation. She said she will never *get used to it* and blamed her feelings on *personal pride.*

Valerie's acceptance also seemed to be affected by the extent to which she could no longer dress herself the way she used to. This was another form of self-expression affected by a TL. She was asked how she felt about wearing a bib-like stoma cover and she stated '*I hate those things. I really do I hate them'.* They have a white webbed cover and look clinical. She said she prefers to make her own clothes and tailors items to have a neck to conceal her stoma.

### Example of a 'resolute self' reframing pattern

Jack's story

I interviewed Jack, 69 first. He had been very supportive of the study and was happy to be the 'key informant'. I conducted the interview in his home and he described his experiences in great detail. He had previously had a car accident and he described

how he thought this experience assisted him to face his TL. Jack had a supportive relationship and he and his wife spent much of their week volunteering. He became interested in volunteering after his surgery and is frequently asked to go and speak to people in hospital who are going to have a TL. He was also the former president of the laryngectomy support group (now defunct).

> *I volunteered without a voice, to drive a car for the hospital which they accepted Initially I did ward work to get a general feel and learn about the functioning of the [hospital's name] and then I went onto the driving hospital vehicles which now almost 11 years later I am still doing.*

Jack described how it took over a year for him to acquire his TE speech but he was keen to return to his social activities such as going to the pub to socialise as soon as he was discharged. He used a pen and pad to communicate for about a year after his surgery and reported *I tried to live my life as normal.*

He developed independence with his voice prosthesis quickly and hadn't let it prevent him from expressing himself. Aside from his volunteering he lectures university students, is a justice of the peace and takes on office bearing roles on committees. He has also been involved with a class action against a tobacco company. Jack mentioned that his life has been altered considerably and he does find occasions when he is not socially accepted but he described how what used to bother him didn't anymore.

> *I never object or…. show intolerance to anyone who can't understand what I'm saying or ask me to repeat it and I'm glad when they say 'I am sorry I never got it, could you say it again or repeat it'? I like them to do that.*

Jack was reflective during his interview. He described the importance of the support his wife had provided him, particularly in the early stages, when he could only communicate by writing and needed all his food prepared so it was soft and easy for him to eat.


### Example of a 'transformed self' pattern

*Pieter's story*

Pieter aged 61 had been working at an executive level for an international company and had been living in Europe, when he was diagnosed. He was semi-retired at the time of our interview because he could not see how his communication impairment and breathing issues would ever allow him to resume the work duties he previously performed. Pieter was enjoying a reasonable work funded pension and had a very

supportive wife and family. He reported that whilst the diagnosis and surgery had been very difficult for him and his family, he believed the experience had been challenging but that it had also been *transformative* in a positive sense. Despite his deficits in verbal expression he had been able to find meaning in other forms of expression and indicated that the TL had given him the opportunity to really get to know himself. He reported the following

*I've become much more mellow. I think I've become more philosophical about not only my life but also other people's lives,...illnesses and death.*

With very little prompting, he explained that the change was not straightforward but he felt *transformed*.

*I think last year some time my wife and I were discussing something ...and I said if I had the choice to go back and not have this I wouldn't take it simply because of the learning experience about me when everything else was stripped away and the additional richness that it's put into my life.*

Pieter was very clear that he treated the experience as though it was a process and that he used a number of strategies to assist his adjustment.

## Appendix 11: Manuscript from article

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***Living with the Altered Self*: A qualitative study of life after total laryngectomy**
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Running head: The Altered Self after Total Laryngectomy

**Abstract**

Total laryngectomy (TL), a life-preserving surgery, results in profound physical and communication changes for the individual. Physical and psychosocial adjustment to a TL is complex, and quality of life (QoL) measures have provided useful knowledge to assist clinical management. However, many tools were developed without considering the perspectives of people who have experienced TL. To improve understanding of the phenomena of living with TL, a qualitative study was conducted and explored the views and experiences of seven men and five women from a range of ages, geographical locations and social situations who had undergone a TL. Data were collected through in-depth, semi-structured interviews, journals and field notes, and analysed using a constructivist grounded theory approach and symbolic interactionism. The emergent concept was *identifying with the altered self after TL* as reflected in dynamic multi-level changes (physical, communication and psycho-emotional) continuously interacting with intrinsic and extrinsic interpersonal factors including personal and socio-cultural constructs e.g., age, gender, resilience, beliefs and supports. This process affected the strategies these individuals used to negotiate their social experiences. The extent to which communication changes disrupted social roles affecting a person's sense of self appeared to relate to long-term adjustment.

**Introduction**

A total laryngectomy (TL) is a radical, complex surgical procedure used to treat advanced laryngeal carcinoma. In Australia, laryngeal cancers form 22.8% of malignant head and neck carcinomas (Australian Institute of Health and Welfare & Australian Association of Cancer Registries, 2007). The 5-year survival rate is high and was reported in approximately 67% of individuals treated with TL (Hall et al., 2003). The significant physical and functional changes after TL primarily affect respiration and airway management, swallowing and verbal

communication. This altered or loss of function can have considerable impact on an individual's quality of life (QoL) (Armstrong et al., 2001). Consequently, adjustment outcomes are poorer for TL compared to organ preserving treatments (Terrell, Fisher, & Wolf, 1998) and necessitate extensive specialist multi-disciplinary team pre-operative support and post-operative rehabilitation (British Association Otorhinolaryngologists Head and Neck Surgeons (BAOHNS), 1998). The role of the speech-language pathologist in assisting individuals to obtain optimal communication outcomes usually lasts for the rest of a person's life (Doyle, 1994; Eadie, 2007).

Lifestyle factors such as heavy tobacco smoking and alcohol consumption are the main risk factors for developing laryngeal carcinoma (Doyle, 1994). However, socio-cultural factors are also significant determiners, including low socio-economic status (SES) in conjunction with low levels of educational achievement, aging and gender. Diagnosis usually occurs in or after the 5$^{th}$ decade of life, with men 7 times more likely to be diagnosed than women in developed countries (Doyle, 1994; Saunders, Coman, & Guminski, 2007; Stewart & Kleihues, 2003). Despite this typical clinical picture, a range of other aetiologies e.g., trauma, benign pathology and airway disease may result in a TL. This, combined with diverse socio-demographics e.g., younger people, women, non-smokers and people with higher SES, means that healthcare provision must be flexible and sensitive to the needs of all individuals (Hughes, Bamford, & May, 2008). Understanding the psychosocial effects of a TL can assist with the provision of such healthcare.

*Psychosocial adjustment*

Due to small clinical populations, an understanding of the effects of TL has come from small to moderately sized research studies, clinical reports and clinical guidelines. These have highlighted significant adjustments required by individuals and their 'significant others' in

dealing with communication and swallowing problems in the first year after surgery (Armstrong et al., 2001; Blood, Simpson, Dineen, Kauffman, & Raimondi, 1994). Several studies have indicated that issues of stress and burden related to levels of disablement may persist in subsequent years for some individuals. Terrell et al. (1998) conducted a longitudinal randomised control trial of different treatments for advanced laryngeal cancer and found that 28% (n=9/32) of subjects had persisting depression post TL. A larger study by Singer, Herrmann, Welzel, Klemm, and Heim (2005) found 23% (n=43/189) of the study participants with TL had mental health issues e.g., alcohol dependence, affective disorders, depressive symptoms.

Ferrer Ramírez et al. (2003) reported that the timing of supports was critical in alleviating psychological distress after TL. However, more research is needed to examine the issues affecting the implementation of person-centered healthcare. To date many studies, which have examined psychosocial outcomes after TL have recruited participants using self-selection criteria and under-represented those who have experienced significant mental health difficulties (Strojan & Zwitter, 2005). Healthcare service constraints have also been reported. In Australia, a multi-disciplinary specialist approach is typical practice, however geographical distance restricts access to specialist services for some people (Ward et al., 2007).

*Consequences of alaryngeal communication*

Rehabilitation of alaryngeal communication (AL) has been identified as assisting post-surgical adjustment. AL methods e.g., electrolaryngeal speech (ELS), oesophageal speech and tracheoesophageal speech (TES) have been discussed extensively by Van As (2001). These methods are characterized by reduced ability to alter the volume of the pseudo-voice making projecting or whispering difficult; and prosodic features of speech, which convey emotion through vocal tone, are more difficult to achieve. The expressions of laughter and crying will also have a different quality to the pre-surgical state (Doyle, 2009). In comparison to the

other techniques, TES (which requires surgical voice restoration (SVR)) results in more naturalistic fluency, pitch, quality, speech rate and inflection (Bień et al., 2008; Van As, 2001) and therefore offers the most desirable clinical outcome.

Issues of pre-morbid suitability and gender can influence the clinical success of TES. Some individuals are not anatomically or cognitively suited to SVR and may require the use of another AL method temporarily or permanently. Additionally, a frequent complaint is that women who use TES experience a significant reduction in fundamental frequency (the acoustic correlate of pitch), and can be mistaken for being male. This, combined with altered appearance due to a surgically created tracheostoma in the neck, had been found to result in poorer adjustment and acceptance for women (Kazi et al., 2006; Lee, Gibson, & Hilari, 2009). Interestingly, Evans, Carding, and Drinnan (2009) reported a study in which all male alaryngeal speakers regardless of their method, experienced similar voice-related QoL outcomes and moderate voice handicap. Finally, the impact of TL on non-verbal communication has not been widely evaluated.

*Quality of life*

Recovery from a TL is a multi-factorial and difficult process. Our clinical understanding of psychosocial adjustment has been built from studies examining health-related quality of life (HR-QoL) outcomes. Some validated HR-QoL instruments used with head and neck cancer populations have identified the role played by gender (Lee et al., 2009), age (Singer, Merbach, Dietz, & Schwarz, 2007) and social status, educational achievement and social supports (Blood, Simpson, Raimondi, et al., 1994; Eadie, 2007) in promoting psychosocial well-being following TL. For example, one study showed higher levels of depression in women than men were associated with disfigurement but that these effects seemed to have been buffered by higher levels of social support (Katz, Irish, Devins, Rodin, & Gullane, 2003). Pre-morbid physical and mental health, and coping styles also influence

adjustment outcomes (Eadie, 2007).

The limitations of widely used head and neck cancer specific HR-QoL questionnaires include limited adherence to guidelines for questionnaire development and inadequate pilot testing (Pusic et al., 2007), over-reliance on general health rather than domain specific reporting (Rogers, Ahad, & Murphy, 2007), failure to contextualize environmental and personal factors (Eadie, 2007), a bias towards those with high literacy skills (Eadie & Doyle, 2005) and poor participation from low SES groups or those from ethno-culturally and/or linguistically diverse backgrounds. Moreover there have been contradictory findings on whether specific impairments (e.g., impairments related to voice, appearance, swallowing) can affect overall HR-QoL (Farrand & Duncan, 2007; Herranz & Gavilán, 1999; Vilaseca, Chen, & Backscheider, 2006).

*The need to understand the subjective experience of the impact of TL*
With clinical understanding of adjustment to TL currently based on small clinical population studies and QoL instruments with inherent limitations, there is an identifiable need for further research. Exploring and understanding the patients' subjective experience is an important step in assisting health practitioners in their roles in treating cancer to provide appropriate psychosocial supports, timely rehabilitation and longer-term supports. Interpretive rather than deductive methodologies can be used to explore the views and experiences of individuals affected by TL from a range of social factors e.g., gender, age groups, geographical locations and socio-economic backgrounds.

The paucity of qualitative research in TL is surprising given the large body of research examining patient perspectives and the psychosocial impact of other major illness resulting in disfigurement, disability and/or life changes such as breast cancer (Oxlad, Wade, Hallsworth, & Koczwara, 2008), diabetes (Paterson, Thorne, Crawford, & Tarko, 1999) and chronic

illness (Charmaz, 1990). The impact of TL has also received far less attention than that of other acquired communication problems including aphasia (Davidson, Howe, Worrall, Hickson, & Togher, 2008; Hersh, 2009; Parr, 2001) and acquired brain injury (Gelech & Desjardins, 2010), conditions which have been shown to significantly affect self-concept and social connectedness (Davidson et al., 2008; Parr, 2001). Gelech and Desjardins (2010) sensitively examined the subjective experience of the so-called 'post-injury self' and discussed the need for a holistic appreciation of personhood by health practitioners.

Grounded theory is a useful approach to help health practitioners understand people's beliefs and actions (Charmaz, 1990) and is applied in this study to explore how people from diverse socio-cultural backgrounds experienced TL and negotiated its psychosocial impact from their own perspectives. Concepts relating to the lived experiences and adjustment will be described with some reference to the influences of social factors (e.g., gender, age, family structure/constellation, support networks, socio-economic status, level of education, employment situation, geographical location) and cultural factors (e.g., ethnicity, beliefs and linguistic ability). This research is ongoing and future papers will explore the perspectives of caregivers and health practitioners regarding their role in addressing and responding to psychosocial issues following TL.

**Method**

The primary objective of the study was to examine the views and experiences of people from diverse backgrounds and demographics who have had a TL. A qualitative research design was adopted as little is known about contributions individuals may make in their own acceptance of, and adjustment to TL. Ethics approval for this study was granted by Flinders Clinical Research Ethics Committee: Application Number 333/09 and The Royal Adelaide Hospital Ethics Committee: Protocol Number 091205.

*Design*

The study was exploratory, applying a constructivist grounded theory approach (Charmaz, 2003). Symbolic interactionism (Blumer, 1969; Mead, 1962) was also used to examine how participants made sense of their experiences associated with their 'altered identity' after TL and to further understand the socio-cultural phenomena at hand. In line with the interpretative framework and the role of reflexivity in this research it is important to recognize that the first author (subsequently to be described as 'the researcher') is a speech-language pathologist with expertise working with people who have had a TL.

The design enabled data to be collected and analysed progressively from a range of sources to assist with data triangulation e.g., in-depth, semi-structured interviews with participants and journal keeping by participants. All the data were collected by the researcher and reported back regularly to the co-researchers. Rigour and reflexivity (Mays & Pope, 1995) was achieved with comprehensive memo-writing of all methodological and analytical decisions, member checking techniques, inter-rater coding and joint appraisal of coding structure, theme and conceptual development with the co-researchers. The researcher also maintained a detailed field diary to assist with reflection and interpretation of the data.

*Sampling*

Sampling was conducted purposively to represent a diverse range of demographic variables such as gender, age, support networks, socio-economic status, level of education, employment situation, geographical location, ethnicity, religious and linguistic diversity. A combination of *criterion* and *maximum variation* techniques were used initially and as data were analysed and themes emerged, *theoretical sampling* determined inclusion of the final two participants (Liamputtong & Ezzy, 2005).

Participants were recruited through two tertiary hospital speech-language pathology services

in a large metropolitan Australian city. All participants were at least one-year post surgery, over 18 years, used AL methods and were proficient communicators. Potential participants were excluded if they had been diagnosed and treated for other head and neck cancer/s, neurological and or cognitive impairments.

*Procedure*

Participants took part in individual interviews at home or at the university clinic. In one interview, the participant's partner was present for some of the time. An interview schedule was piloted in the first interview and subsequently modified and updated after each interview to reflect the development of themes emerging in the data. Interview length averaged 90 minutes and each interview was audio-recorded using a high quality digital recorder.

All the interviews were transcribed verbatim; the first 10 by the researcher and the remainder by a professional transcriptionist. Participants were invited to keep a journal of their experiences of TL for one month and if they agreed they were provided with a blank journal and a prepaid envelope to return it. Two levels of member checking were implemented; *in situ* checking during the interviews to clarify meaning and interpretation with participants and each participant was invited to check the accuracy, make comments or alter their transcript. Socio-demographic data was also collected at the end of each interview.

*Data Analysis*

Interview transcripts and participant journals were read and re-read to elucidate the ideas coming through from the participants. Participants' ideas and concepts were coded and described as themes using the open coding, axial coding and core category analysis continuum (Corbin & Strauss, 2008). Researcher field-diary entries were read and re-read to contextualize the interactions with participants. Discussion and agreement of the emerging themes between the researcher and the co-researchers occurred routinely throughout this stage

of the study and themes were constantly compared with the data. Alternative views from negative cases were considered when developing the emergent theory.  To ensure a constructivist grounded theory approach the researcher used field diary notes and meetings with the co-researchers to reflect on, and examine interpretations of the data iteratively. Participants were given the opportunity to refute or alter their interview transcripts but no disputations were received.

QSR Nvivo ® software was used to assist with the mapping of a coding structure. Initial codes were generated directly from the interview data. Participants described their experiences and perspectives before and after having a TL. After the second interview, themes relating to self-concept and communication ability were emerging. The impact of changes in communication ability in social interactions, engagement and participation appeared strongly in the data. Symbolic interactionism was used to further interpret major themes because it provided a theoretical framework to examine how meaning and self-concept are constructed through language. Participants described how social experiences highlighted their altered language abilities and subsequently affected their self-concept and decision-making.  A coding map of analysis levels is provided in figure 1.

**Findings**

The data provided rich detail of the lived experiences and perspectives of the participants from a range of socio-cultural circumstances. The participants recruited were males and females from urban and rural locations whose ages ranged from 57 to 75 years, some were in relationships and others were single, three were non-smokers, several had to stop working, the majority were pensioners and all had their TL after mid-life. Table 1 contains participant details.

An important emergent concept from the data was a continuous process of *identifying with the*

*altered self after TL,* particularly associated with social situations. The data also highlighted the fact that long-term psychosocial adjustment is impacted by dynamic multi-level physical, communication and psycho-emotional changes interacting with the intrinsic and extrinsic interpersonal influences surrounding a person. Thus, the three major themes related to this concept were *dynamic multi-level changes, negotiating experiences, interpersonal influences.* Biographical details of some of the participants will be described to contextualize the extracts used to represent the core concept and related themes. The use of '….' in the quotations indicates that some words in the quotes have been omitted. The brackets indicate interpretation of what was said (Dresing, Pehl, & Schmieder, 2012).

*Core concept: Identifying with the Altered Self after TL*

*Identifying with the altered self after TL* encapsulates how social experiences reminded individuals of their post-surgical physical state and communication changes. These changes demand significant psycho-emotional and social adjustments. Individuals described a range of experiences, and in particular their actions and reactions to these experiences. In most cases, the need for surgery was sudden and dramatic. Participants described little time to adjust to their diagnosis or the potential consequences of their treatment. Hugh, aged 57, was the fourth participant interviewed. He was one of the youngest participants and lived alone in a small inner-suburban apartment. He reported other health problems but his communication disability was the cause of his social isolation. He could no longer frequent the pub and found it difficult to maintain conversation due to his breathing difficulties. Hugh intimated how the loss of his voice and the change to TES had affected him in relation to his self-concept:

> I've lost my voice ...I've lost part of my character, part of my personality ... And that is
> very difficult, you know. ...for a long time I used to dream of still being able to speak
> properly...that expression has gone... it can, …be very distressing, if I dwell on it.

Many participants also described a need to be self-reliant and seek their own pathway to support themselves with the changes. Some individuals described the transformative and positive effects a TL had had on their lives. Pieter, a 61 year old semi-retired business consultant was open and articulate when he described his personal experiences:

> transformative is a very good word …almost a sea change in ...in the sense that it teaches you about yourself. ...who you really are when everything else is stripped away and that is really a valuable experience…and the additional richness that it's put into my life …I've become much more mellow with life.

Although Pieter reported he did not avoid social situations like Hugh, he did admit that social interactions had changed and that his communication disability had effectively forced him into semi-retirement.

Len, aged 75 and a retired engineer also reported that his communication and breathing issues affected him but he had accepted this because he was still alive. He described how he could not express anger in a way that would be taken seriously. He felt this was a positive change as he had become more "mellow" after the surgery.

Three major themes emerged that supported the concept of 'Identifying with the altered self after TL':

*Theme 1. Dynamic multi-level changes*

All the participants remarked on how *physical, communication and psycho-emotional changes* e.g., communication competence, appearance, swallowing, respiratory function, social and emotional behaviours were interconnected and affected them daily. Hugh, Valerie, Kath and Lyn described how they could no longer interject, be humorous, sustain conversation or be heard in noisy environments.

…things aren't spontaneous anymore. ...You can't have the quick sort of stab... Particularly, if you are looking for a laugh and if you miss that split second it is gone…which of course with this (laryngectomy) ...there is every likelihood that you are not going to be heard.  Hugh, 57 years

Participants reported ways in which they interpreted the responses of others during interaction, as impacting their behaviours when communicating. They described surprised reactions, insensitive comments, overcompensations and misinterpretations by others.  They recognized that these disruptions or breakdowns in *social interactions* occurred because their pseudo-voice failed to convey their intended meaning. Unlike their pre-surgical selves, they now experienced limited capacity to alter their communication to clarify their meaning and elicit a desired response from their listener. Lyn, a 63 year old retired business-woman, described how she interpreted the reactions of others during the physical act of digitally occluding her tracheostoma to produce TES.

> I am ...very embarrassed ...well people don't ask you questions because they are embarrassed to talk to you …you've only got to see someone's face ...when you talk to them ...and you put your hand-up and the voice comes out... They treat you differently straightaway.

The importance of a conversation partner having an empathetic understanding of AL was widely reported. Brian and Kath described that they would not like to use ELS because of the marked difference in vocal quality. However, Brian's experience of TL had exposed him to different communication methods and he demonstrated some empathy for those individuals who had to use ELS.

> ...when I go to the clinic …there's people …with an electric thing and it's …like a

dalek, like a robot… I daresay they have that because they don't have their own

laryngectomy *(sic)*…Brian, 59 years

... Hate it. ...it sounds like a robot...(when I) do it at the shops, everybody turns around

... to see it. Kath, 72 years

*Theme 2. Negotiating experiences*

Participants were observed to have different psycho-emotional responses to their AL

communication and described different methods of *negotiating* daily situations and

*navigating social interactions*. Some described the uneasiness felt with a stranger who had

little understanding of their situation. A strategy Lyn used was to avoid speaking at all.

…if people talk to me at the checkout at the supermarket …I don't even talk to them…I

just nod or put my hand up and say yes.

Others also chose limited verbal interaction with strangers or even family and friends both

face to face and over the telephone.

When we get visitors, I hate if they come into the kitchen and I'm cooking because you

can't talk. I've tried to explain that to them…I can't cook and talk...but they find it hard.

Valerie, 74 years

Pieter described the importance of not assuming what a conversational partner might be

thinking even if their behaviour appeared patronising.  He described his years of working as a

consultant had assisted him not to make assumptions. Conversely, Kath reported being

confrontational if she felt ill-judged.

The odd people who think that because you can't talk you are stupid.  There is this lad in

Coles, he treated me like some sort of simpleton ... I said to him I am not deaf and I

have a very high IQ, I just can't talk… It got to me …but that is not many people.

Kath and Mary, both in their seventies had poor command of their ELS. This complicated their interviews because they preferred to mouth and write. They reported difficulty learning to use the electrolarynges and it appeared that their dislike of the sound of their ELS was the disincentive for becoming proficient users. They both reported experiencing social isolation as a result of their communication difficulties.

Sixty-one year old Christopher described how he frequently warned communication partners that his electrolarynx was a communication device and not a "weapon". He also described how he has to think ahead to get the help he needed.

I have to, think about it, predict and even very gently ask and direct people who helped me to help me better.

Christopher's experiences were like other participants who described ongoing *mental engagement* regarding their changed circumstances. Participants constantly experienced the need to mentally prepare and compensate for their changed communicative competence. Prior to their surgery they had taken for granted their communication abilities and after surgery they had realised how much their communication skills were part of their personality and social selves.  This increased need for mental engagement prior to and during social experiences could also be related to the notion of *temporality*. For example, participants described how things had not improved with time. It seemed that participants had expected that their situation would improve with time. However, constant reminders of their former selves, their changed communication abilities and negative responses from other people only served to amplify their loss. These themes were also inter-related with the personal and resilience factors described later under Theme 3.

*Theme 3. Interpersonal influences*

Participants were affected by a combination of interpersonal influences categorised as intrinsic or extrinsic factors. Intrinsic factors included *personal factors* e.g., age, gender, SES, level of education; *resilience factors* e.g., beliefs/attitudes, coping skills, locus of control and *roles and agency* e.g., partner, parent, employee, retiree. Extrinsic factors related to *supports* e.g., social, professional and community and *society* e.g., socio-cultural norms and beliefs, policy and location. This third theme is important as it highlights how interpersonal factors interact with the dynamic and multi-level changes after TL to affect social behaviours and psychosocial adjustment. These intrinsic and extrinsic interpersonal influences contextualize an individual and are used to explain differences in how participants had adjusted to TL. A few examples are provided of the data supporting the emergence of this major theme.

Intrinsic interpersonal influences such as *Personal factors* e.g., gender and age, were discussed in many of the interviews. Mistaken gender for female participants using both TES and ELS was common, particularly on the telephone. Annie reported being called a "stupid man" when she rang a cosmetic consultant due to her low pitched TES. Valerie described how she was often ridiculed.

> a friend once called me Donald Duck. Now that has never left me … I often think about it when I'm talking and it puts me off.

Both women had responded to their experiences differently. Annie in her sixties and former nurse did not perceive her pseudo-voice as a social disadvantage. She reported that her lack of social participation was due to her poor voice prosthesis maintenance and subsequent swallowing problems. Other health issues precluded her from traveling 3 hours to receive specialist support. Local support was not available to her. Valerie, like Lyn, had been

profoundly affected by her communication difficulties and this had influenced her social participation despite being a proficient TES user.

Pieter also experienced gender confusion. He had been mistaken for a woman due to his 'thin' neck. The removal of lymph nodes in the neck at the time of a TL can alter the appearance of the neck. Several participants described how they felt self-conscious of their neck and tracheostoma and deliberately covered it. Alternatively, Bill felt strongly that if he covered his tracheostoma he would draw attention to himself and that he'd rather appear "bloody normal".

Participants used *resilience factors* e.g., coping skills, attitudes and beliefs and attitudes developed over a lifetime to *negotiate* the complexities in which they found themselves. For example, some participants described a resoluteness to be content with their situation because they were alive and had "survived". They described the need to return back to routine as soon as possible and were *proactive* in seeking social situations. Others were sometimes overwhelmed by the extent of their functional impairments. Social situations seemed to amplify their difficulties and their losses, particularly the loss of social status. For these individuals *avoidance* of social interaction was important.

Brian, Jack, Len and Bill all desired quick resumption of their old social routines. Participants from rural locations reported increased social acceptance compared with the urban dwelling participants. Brian said

> …when I first got home from here, I went and seen them and there was no big deal…you've got to get on with it and that's it.

Len and Jack also described how resuming "bridge" and going back to the "Returned Service League" social club had been really important to them in the early stages despite having

marked communication difficulties to cope with.

Lyn on the other-hand described periods of extended depression during the 10 years since her TL. She could no longer run her business and felt she couldn't communicate effectively in group or family situations and with strangers.

> …my life really is over … it happened overnight and you didn't have time to think about it …it died overnight ...everything ... my job, my voice, my friends, my social life. I don't go… anywhere! …if I do I go…like my children's birthdays, …I do the cooking; you don't have to talk to anyone …you are just part of the furniture and … meld into the background.

The data suggested that changed *roles* were inevitable after TL and affected a person's sense of *agency*. In some situations this was difficult for individuals to adjust to, whilst others had developed new roles such as being volunteers to assist other people who undergo TL. Changed role was notable for those participants who were grandparents. For example, Valerie reported she would not baby-sit her grandchildren because she could not read them bedtime stories due to the sound of her pseudo-voice.

> I used to do lots of babysitting … I dropped off from that ....it upset me... I couldn't read bedtime stories like I used to. ... Pride is a terrible thing.

Mary had also experienced reduced interaction with her grandchildren. She chose not to speak to her grandchildren living inter-state over the telephone and also had a different relationship with one granddaughter who was now shy of her.

> she is frightened... because we used to have a lovely relationship her and I. We used to dance and sing, but not anymore. …She is really shy about it all. (She doesn't understand).

The extrinsic interpersonal factors included *supports* provided by 'significant others' such as partners, family friends and health practitioners. Participants were perceived as being both being supported and unsupported by the situations they described. The unsupportive situations usually related to communication breakdown and impacted on a person's self-worth and meaning.

> Now and again you get a bit annoyed. If I've got my two arms full my wife will say something to me, not thinking, …I can't answer her and then …she'll say "don't answer then" and ….(when I can) …the wife just says… "well don't get mad about it". Brian, 59 years

The supportive situations were perceived particularly from a social perspective. Valerie provided insight about her reliance on her husband to assist her in social situations. She described candidly in her journal about a birthday party she went to without her husband.

> Went to an 80th birthday party today… on my own. Not a problem I said. Wow! Was that a lie. …I got a couple of strange looks (which I am used to). One lady did ask me about my problem but whether she was slightly deaf or something …I don't know, but she never spoke to me again and neither did the others, so I sat there for about an hour smiling and pretending enjoyment 'til I felt like I was going to embarrass myself by bursting into tears, so I made my excuses and left much to my disgust.

The supports health practitioners had provided were many and varied and most participants reported positively on their experiences. Issues related to communication breakdown and reduced supports in remote locations were also described. For example, Pieter discussed his experiences in hospital where he could not speak and the procedure of cleaning his tracheostoma was difficult.

…some of the nurses were …really quite harsh about it saying "well, it's got to be cleaned out". …didn't have that level of empathy...I thought would have been really helpful.

Annie said she showed the paramedics in her rural town what to do if her voice prosthesis dislodged. Hugh could not see a role for health practitioners assisting him with coming to terms with the loss of his voice and when prompted said:

…everybody has a distinct voice. ....it is part of you gone…Part, … of you has been amputated ...and that is difficult ....Well I don't suppose they (health practitioners)…really have to….. Hugh, 57 years

Hugh, Pieter and others were stoic in their descriptions of psychosocial adjustment. Culturally, it appeared more acceptable to participants to suggest they were coping than to seek or expect help from support groups or health practitioners. Health practitioners, whilst appreciated for the work they had done in treating the cancer and managing the physical sequelae appeared to have a mechanistic rather than psychosocial role in the minds of participants.

Few participants had sought a support group or internet information. Kath did not go to a support group to be "with other broken down horses". Lyn went to a laryngectomy support group but found her experience unhelpful on the basis of gender and age.

…I went to a couple of their meetings but it was all men and it really wasn't a support group, ...breast cancer at least you do get support you've got other females. …this, I find is a particular male cancer ….there are a …few females and they seem to be elderly. I was only 50 when I got it …there was nobody my age.

**Discussion**

The narratives in this study highlighted the fact that psychosocial adjustment to TL is a complex process where individuals are often faced with sudden and dramatic life-preserving physical changes they must live with for the rest of their lives. The physical disfigurement and associated communication impairment demanded individuals to identify with, and accept their altered selves. Despite advances with AL rehabilitation, adjustment appeared to take time, and for some was a painful experience. This study provided contextualized insights related to the subjective experiences of TL that general and discipline specific HR-QoL tools and clinical guidelines have not captured.

The impact of the multi-level physical and communication changes after TL should not be under-estimated. The real-life accounts demonstrated the effects of permanent loss of the voice and how the acquisition of AL communication had affected an individual's communication competence and social behaviours. These observations reflected the acknowledged importance of voice and vocal tone as symbolic tools in constructing meaning (Mead, 1962). Laver (1980) stated that 'the importance of an individual speaker's voice in everyday social interaction, as an audible index of his identity, personality and mood could hardly be overstated' (p. 1). As discussed, the paralinguistic and acoustic signals of the voice collectively convey emotional status, health/well-being, age and gender of a person to a listener. Therefore, a loss of commonly recognised significant symbols such as tone of voice, results in an impression of a speaker having reduced empathy, causing possible confusion in the 'other' actor participating in the interaction (Mead, 1962).

Participants in this study reported that they frequently experienced reduced shared meaning with others due to their vocal tone and limited communication abilities. This demanded them to think about altering or avoiding social engagement. Participants' choice of negotiation strategies and acquisition of AL communication were influenced by many interpersonal

factors. These factors interacted and affected an individual's adjustment in different ways. Younger participants described greater social isolation, changed roles and forced early retirement due to lost employment. Similarly, some of the older women also described changed roles and social isolation despite being well-supported by significant others. It appeared that resilience factors were crucial in an individual's successful identification with and acceptance of their altered selves. These factors are similar to the contextual factors affecting participation levels described by Eadie (2007). Finally, support-seeking behaviours were limited. Participants were stoic in their responses about the need for support groups and psychosocial supports from health practitioners despite clinical recommendations (BAOHNS, 1998).

What constitutes successful acquisition of AL needs to be examined further. Whilst the findings of this study support other research relating to poor QoL outcomes for women because of the importance of vocal quality in conveying feminine identity (Lee et al., 2009), the male participants also reported difficulties accepting their AL and loss of their 'old' voice. Despite technical advances with TES, it, along with other forms of audible AL, remained alien to both women and men who participated in this study. Subsequently, some participants were not motivated to use or master an AL method. Consequently their social participation and sense of agency were affected.

The personal accounts from participants about their communication impairment has furthered our understanding of the impact AL communication has on social competence, self-concept, the ability to maintain and develop relationships and participate in some social roles or activities. They have also highlighted the role paralinguistic features play in constructing meaning and this has not been explored widely in the broader acquired communication impairment literature.

*Strengths and limitations of the scope of the study*

Participants were willing to discuss their experiences and perspectives and despite their communication difficulties, rich data were obtained. Whilst the study captured the experiences of individuals from wide geographic locations, due to the limited pool of potential participants the sampling favoured individuals with similar ethnic and social situations. For deeper understanding of the issues, further exploration of the views of individuals from diverse ages, SES, cultural and linguistic backgrounds is needed. The subjective experience of identifying with the altered self after TL has been presented here with a primary focus on AL. However, the effects of other sequelae of TL and the perspectives of significant others and health practitioners require further exploration.

*Clinical implications*

This study reinforces the notion that communication (linguistic and paralinguistic) plays an important part in constructing a person's sense of self and has a role in reassuring an individual, and others who they are. It also provides evidence that despite advances in technology, altered communication ability, AL methods and altered appearance have significant social consequences for people who have TL. The findings suggest that contextual information relating to interpersonal influences are important factors in long-term adjustment and could be used to support clinical decision-making, resource allocation and the provision of timely education for future patients and their families. This information, in conjunction with further understanding of roles of 'significant others', health practitioners and the impact of society in adjustment, could be used to develop a comprehensive tool to evaluate the functional implications of TL and the need for psychosocial supports over time.

**Conclusion**

It is widely accepted that person-centered care should be sensitive to the psychosocial, cultural and ethical needs of patients and is a critical aspect of healthcare provision. Recovery

and adjustment after a TL can persist long-term. However, small clinical populations and limited specialist services has resulted in a narrow understanding of these processes. This study has attempted to understand the perspectives of individuals directly affected and the contributions they have made to their adjustment. These individuals have articulated how their acquired communication disability and associated impairments are complex and have significant impacts on their daily lives many years after their surgery. Contextual factors also have been shown to interact with the way individuals perceive themselves and behave socially. Wider examination of the perspectives of significant others and health practitioners will be used to continue building a theoretical understanding of life after TL to further assist well-timed and sensitive clinical supports.

**Declaration of interest**

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Table 1. Participant Details

| Pseudonym | Age | Gender | Communication method | Smoking history | Years since surgery | Relationship status | Ethnicity | Location | Education level | Income support | Journal completed |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Jack | 69 | M | TES | Y | 11 | M | AAb | M | T | P | Y |
| Lyn | 63 | F | TES | N | 10 | S | AAb | M | HS | IP | N |
| Len | 75 | M | TES | N | 5 | M | AAi | M | T | P | Y |
| Hugh | 57 | M | TES | Y | 4 | S | AAi | M | HS | P | N |
| Kath | 72 | F | ELS, O | Y | 2 | S | AAi | M | PS | P | Y |
| Valerie | 74 | F | TES | Y | 9 | M | AAi | R | HS | P | Y |
| Mary | 75 | F | ELS, O | Y | 2 | W | AAi | M | T | P | Y |
| Christopher | 61 | M | ELS | N | 10 | S | EAie | M | HS | P | N |
| Bill | 70 | M | TES | Y | 11 | S | AAi | R | HS | P | Y |
| Annie | 65 | F | TES | Y | 9 | W | AAi | R | T | P | N |
| Pieter | 61 | M | TES | Y | 4 | M | EAie | M | T | IP | N |
| Brian | 59 | M | TES | Y | 3 | M | EAi | R | HS | P | N |

*Key:* Male (M), Female (F); Electrolaryngeal speech (ELS), Tracheoesophageal speech (TES), Other (O); Yes (Y), No (N); Married (M), Single (S), Widowed (W); Anglo-Australian born (AAb), Anglo-Australian immigrated (AAi), Euro-Australian immigrated, English as second language (EAie), Euro-Australian immigrated (EAi); Metropolitan (M), Rural (R), Primary school (PS), High school (HS), Tertiary (T); Pension (P), Income protection (IP).
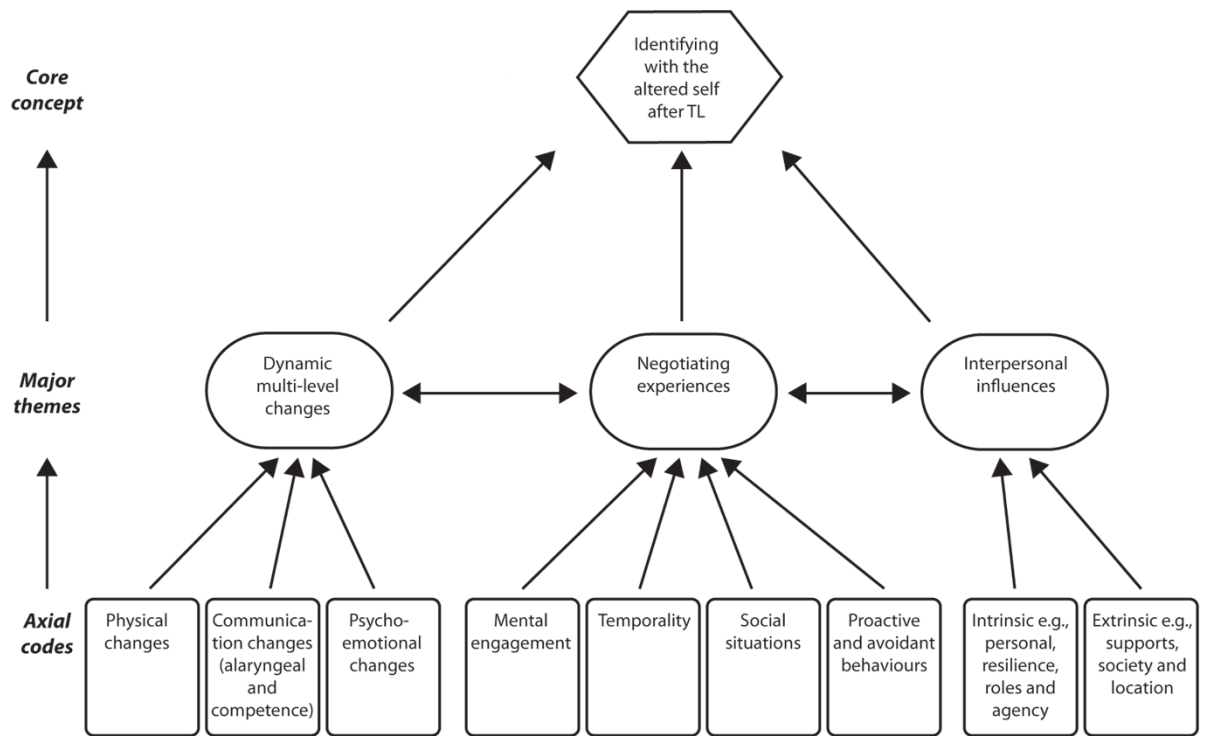
Figure 1. Coding map