

**An examination of the counselling experiences of a
sample of patients in Ireland before undergoing total
laryngectomy surgery**

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**This thesis is submitted to the University of Limerick, Ireland, in fulfilment of the
requirements for the award of the degree of Masters of Science**

1st March 2018

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Abstract

This study was designed to examine the pre-operative counselling experiences of patients undergoing a total laryngectomy (complete removal of the larynx) for treatment of head and neck cancer (HNC), together with their carers and Speech and Language Therapists (SLTs) in Ireland.

People undergoing a total laryngectomy surgery require pre-operative counselling to prepare them for physical and psychological changes arising from treatment. To date there is no written consensus about the content or format of counselling, nor is there a standardised approach from SLTs.

International research about counselling remains limited, with the few studies published being of poor methodological quality, and mainly representing expert opinion. However, from those published studies, there are persistent reports of shortfalls in clinical practice.

We collected, described and analysed the pre-operative counselling experiences of a representative sample of total laryngectomy patients in Ireland, their carers, and specialist SLTs, to characterise current practices and to identify deficiencies.

Purposefully recruited patients, carers and SLTs attended three focus groups (FGs). Data were collected and interpreted and convergent/divergent themes were identified. Marked deficiencies were identified in pre-operative counselling practices for this sample of laryngectomy patients and carers.

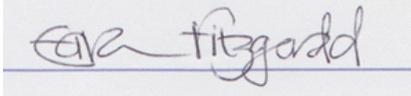
SLTs identified themselves as the main information providers for patients but could not identify any unique contribution. Patients' and carers' views were largely aligned and they clearly identified key information that should be provided for future patients and carers.

This is the first study from Ireland to examine pre-operative counselling experiences of HNC patients and carers. Further research is required, as it would be useful to reproduce this study internationally, across different healthcare systems. We identify a need to improve the counselling skills of SLTs working with the Irish HNC population to improve the lived experiences of patients and carers.

Declaration:

I declare that this thesis has been composed by myself and that it has not been submitted, in whole or in part, in any previous application for a degree. Except where stated otherwise, by reference or acknowledgement, the work presented is entirely my own. The data presented is data that I have gathered personally and is original to this thesis.

Signed:

A handwritten signature in blue ink that reads "Eavan Fitzgerald". The signature is written on a light blue horizontal line. The name "Eavan" is written in a cursive style, and "Fitzgerald" is written in a more formal, slightly cursive style.

Ms. Eavan Fitzgerald

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Introduction:

I have worked as an SLT in Ireland for the last fourteen years, mainly with adults referred with ear, nose and throat (ENT) disorders and, specifically, people with HNC. I worked as a senior clinical SLT at the South Infirmar-y-Victoria University Hospital, Cork from 2006 to 2012 and at St. James's Hospital, Dublin from 2012 to 2014. Both positions involved managing speech and swallowing disorders in patients who underwent surgery and/or (chemo) radiotherapy treatment for HNC.

Background:

The incidence of HNC varies worldwide, but is of low prevalence compared to, for example, breast or prostate cancer. However, patients with HNC are complex because of the profound changes that can result, initially from their cancer and then from their HNC treatment.

My main experience was with people who had undergone a total laryngectomy, providing them first with pre-operative education and then, post-operative rehabilitation of voice. Total laryngectomy surgery results in extensive physical, psychological and socio-emotional changes for patients and their families.

From my experience, I identified a need for suitable pre-operative counselling so that patients would have realistic expectations of their post-operative performance and functional outcome. However, I also became concerned about referrals to the SLT service and about the pre-operative counselling practices which I observed in clinical settings.

At a service level, there was a lack of consistency in referrals to SLT services. It frequently depended on an ENT consultant's decision about whether to refer to a professional service or not, and this might depend on the availability and timing of a hospital bed before surgery. Multi-disciplinary team structures were either absent or poorly developed, with a notable gap in clinical psychology that reflected a lack of funding for these services by the Irish Health Service Executive (HSE).

In terms of SLT practices, my colleagues and I had no standardised approach when providing pre-operative information to patients. I noted that patients were presenting with more co-morbidities if they were scheduled for a total laryngectomy after undergoing unsuccessful organ-preservation protocols (involving combined chemotherapy and radiotherapy treatment). Total laryngectomy was being reserved as a salvage option, so patients were often very unwell by the time their total laryngectomy surgery was undertaken.

My proposed solution to address these issues was to design an information programme for patients and their carers. At this stage I discussed these issues with Prof. Alison Perry, Head of the Department of Clinical Therapies at the University of Limerick from 2011-2014 and an acknowledged expert in rehabilitation of speech and swallowing with HNC patients.

From our conversation I realised the need to establish an evidence-based intervention, rather than proceeding with only my own opinion of what was required.

I read the 'Menzies Handbook for Allied Health Professionals' (Perry, Morris & Cotton, 2009) to learn about how to conduct clinical research studies and then registered on the Clinical Therapies' MSc (Research) programme in February 2014, with Prof. Perry as my Primary supervisor.

I undertook a systematic literature review to establish what was known about pre-operative counseling with people undergoing a total laryngectomy. The working title for that study was, 'What are the informational needs of patients pre-laryngectomy?'

I designed a concept map using a Population, Intervention, Comparison, Outcome (PICO) search strategy. The Faculty of Education and Health Sciences (FEHS) librarians advised me on how to conduct a systematic search and I attended formal workshops covering strategies for undertaking a literature review.

From my database searching, it became clear that there were few published papers and that those that were published were out-dated. The inter-library loan service in the Glucksman Library at UL proved essential in acquiring these journal articles. I read and catalogued the literature, assessing the methodological rigour and statement of purpose of each paper. I allocated each paper a level of evidence, using the Joanna Briggs Institute's (JBI) schema because that provides more detailed descriptors of papers with lower levels of evidence (The JBI Approach, 2014), as were evident in this body of literature.

I submitted the systematic review as a paper to the Journal of Laryngology & Otology (JLO) in June 2015. This journal was chosen because it is widely-read by ENT surgeons in UK and Ireland, whom I wished to influence. The paper was accepted for publication in August 2015 and now follows:

Paper 1 (Published):

Title:

Pre-operative counselling for laryngectomy patients: a systematic review.

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Abstract:

Objectives: To undertake a systematic review of the literature about pre-operative counselling for laryngectomy patients, identifying both practices and patient/carer perceptions.

Methods: A search strategy was formulated using a concept map and PICO schema.

All types of publications from 1975-2015 that had reports of pre-operative counselling for laryngectomy patients were included. Papers were retrieved, underwent critique, and those included were assigned a level of evidence (Joanna Briggs Institute schema).

Results: Fifty six papers were retrieved and 21 included. Literature is limited; studies demonstrate bias and are of poor methodological quality. There are clear and persistent reports by patients and carers of shortfalls in clinical practice.

Conclusion: Studies about pre-operative counselling for laryngectomees are flawed in design and represent weak levels of evidence. There is no operationalising of pre-operative 'counselling,' which results in differing paradigms being examined. Aggregation of data/results is not possible and the veracity of many studies is questioned.

Keywords

head and neck cancer, laryngectomy, counselling, information

Introduction

There is a need for good quality information for cancer patients, as they try to understand their immediate diagnosis and treatment and adapt to living with a long term uncertainty of their disease progression.¹ Evrard et al,² report that, in surgical oncology where the latitude for accepting or refusing surgery is limited, most patients want detailed information before consenting to treatment, especially details about potential complications.

Patients with a specific diagnosis of head and neck cancer (HNC) have increased challenges, with a prospect of profound changes to their physical appearance, speech and/or swallowing,^{1,3} so these patients may have specific needs beyond those who have other cancer types.⁴

HNC patients are characteristically a vulnerable group, with high levels of tobacco and alcohol consumption, often of low socio-economic status, with a lack of social support mechanisms and a low level of education, all of which combine to marginalise them from necessary health supports.^{1,5} Predominantly men, HNC patients may not actively engage in health information-seeking behaviour,⁶ so they pose a challenge for health professionals as many of them require support to access health information and to use it effectively.⁷

Schall⁸ was one of the first physicians to acknowledge that the ‘mental outlook’ of patients must be considered, and it was later recognised by Greene⁹ that a patient’s emotional state may negatively impact on their rehabilitation outcome. Many authors since have stated the importance of patients being provided with information prior to their surgery so that they are fully aware of their likely post-operative status.¹⁰⁻³¹

Materials and methods

To examine current pre-operative counselling practices with patients and their carers before laryngectomy and their perception of such services, the published literature was reviewed using a systematic search strategy, with a concept map and a PICO schema (Population, Intervention, Comparative Interaction and Outcomes).³² Articles in English were sourced from Scopus, Medline, PubMed and Google Scholar databases. All online sources were searched with a forty year date limit applied, 1975-2015. The reference lists of included articles were hand-searched and evaluated, as were pamphlets and handouts from the Irish Cancer Society and from Macmillan Cancer Support.^{33,34}

The following MeSH terms were used; cancer, head and neck cancer, head and neck neoplasms, laryngeal cancer or neoplasms, laryngectomy or total laryngectomy, alaryngeal speech, counselling, rehabilitation, survey and information. These were supplemented by additional terms from papers located and by author-generated terms; laryngectomy patient or laryngectomees, preoperative education, preoperative counseling or counselling, patient support, carer support, information needs, patient information.

All types of studies that included reports of pre-operative counselling for patients before they underwent a total laryngectomy and/or patient and carer perceptions were included in this review.

Results and analyses

Fifty-six papers were initially retrieved and 35 were discarded for the following reasons: there was no reference to pre-operative counselling practices (N=23); the studies involved surveying of carers only (N=4); and/or the studies described intervention for patients in the post-operative phase only (N=8). Twenty-one publications met the inclusion criteria. These included one paper in which total laryngectomy patients were surveyed along with patients who had a diagnosis of other HNC. All papers were analysed and then allocated a level of evidence, using the Joanna Briggs Institute's definitions (Fig 1) with the "best" evidence being Level 1 ("The JBI Approach," 2014).³⁵

Levels of Evidence - Effectiveness	
Level 1 – Experimental Designs	Level 1.a – Systematic review of Randomized Controlled Trials (RCTs)
	Level 1.b – Systematic review of RCTs and other study designs
	Level 1.c – RCT
	Level 1.d – Pseudo-RCTs
Level 2 – Quasi-experimental Designs	Level 2.a – Systematic review of quasi-experimental studies
	Level 2.b – Systematic review of quasi-experimental and other lower study designs
	Level 2.c – Quasi-experimental prospectively controlled study
	Level 2.d – Pre-test – post-test or historic/retrospective control group study
Level 3 – Observational – Analytic Designs	Level 3.a – Systematic review of comparable cohort studies
	Level 3.b – Systematic review of comparable cohort and other lower study designs
	Level 3.c – Cohort study with control group
	Level 3.d – Case – controlled study
	Level 3.e – Observational study without a control group
Level 4 – Observational – Descriptive Studies	Level 4.a – Systematic review of descriptive studies
	Level 4.b – Cross-sectional study
	Level 4.c – Case series
	Level 4.d – Case study
Level 5 – Expert Opinion and Bench Research	Level 5.a – Systematic review of expert opinion
	Level 5.b – Expert consensus
	Level 5.c – Bench research/ single expert opinion

Fig. I
The Joanna Briggs Institute Levels of Evidence, 2014

The Joanna Briggs’ schema was selected because it offers more extended descriptions/sub-divisions for papers at the lower levels of evidence. No retrieved papers for this study were of Level 1 evidence.

Literature and Study Designs

Published studies were from the 1970's (N=4),²⁸⁻³¹ the 1980's (N=7),²¹⁻²⁷ the 1990's (N=5)¹⁶⁻²⁰ and the 2000's (N=5),^{10-13,15} with the most recent published in 2006.¹⁰ Most papers were from the USA,^{10,13,16,18,21,23,25-31} although there was one report from Australia,¹² four from the U.K.,^{11,15,17,22} one from Norway,²⁴ one from France,¹⁹ and one from Switzerland.²⁰ Authors were mainly either Ear, Nose & Throat (ENT) surgeons (N=10) or Speech & Language Therapists (SLTs, N=8).

Study designs were predominantly quantitative^{10,15,16,20,21,23-25,30} although some mixed method designs were used^{12,17,22,28,29} with data collected from postal questionnaires,^{12,15,17,23,25,30} from interviews,^{20,22,24} or from both postal questionnaire and interviews.^{21,28,29} Some researchers used face-to-face questioning¹⁶ or questionnaires completed online.¹⁰ Sample sizes varied significantly. Smaller studies had participant numbers ranging from N = 18²² to N = 72.³⁰ Larger studies (>100 participants) had sample sizes ranging in size from N = 115²⁵ to N = 332.²⁰ In the main, only summary statistics (number, percentage, frequency count) were reported and in only two published studies^{21,24} were statistical analyses performed.

A chi-square analysis was used to assess differences in the counselling needs of male and female laryngectomees in one study,²¹ and to assess the quality of pre-operative counselling in another study and to determine its influence on patients' post-operative rehabilitation and adjustment.²⁴ As there were no comparable quantitative data collected that could be synthesised, a critique and narrative review was undertaken, and the following issues were identified.

A lack of operationalising of pre-operative counselling

The main deficit in the literature was that ‘pre-operative counselling’ was nowhere defined, which led to lack of clarity about what this constituted. Nevertheless, this term was used by seventeen of the twenty-one authors.^{10,12,13,16,18,20-31}

A definition of ‘counselling’ from the Dictionary of Counselling,³⁶ is; *‘a principled relationship characterised by the application of one or more psychological theories and a recognised set of communication skills, modified by experience, intuition and other interpersonal factors, to clients’ intimate concerns, problems or aspirations. Its predominant ethos is one of facilitation rather than of advice-giving or coercion. It may be of very brief or long duration, take place in an organisational or private practice setting and may or may not overlap with practical, medical and other matters of personal welfare. It is both a distinctive activity undertaken by people agreeing to occupy the roles of counsellor and client and it is an emergent profession.... It is a service sought by people in distress or in some degree of confusion who wish to discuss and resolve these in a relationship which is more disciplined and confidential than friendship, and perhaps less stigmatising than helping relationships offered in traditional medical or psychiatric settings.’*

Although the term ‘counselling’ was widely used, authors did not operationalise the activity according to the above definition. By not using a clear definition, further issues arose:

‘Counselling’ was largely provided by ENT Surgeons and/or SLTs, rather than by a person trained in psychological medicine or in counselling, although one author described counselling from the perspective of a medical social worker (MSW) whose training might have included instruction in counselling.¹⁸ Also, the ‘counselling’ described in the pre-operative period was limited to patients meeting and receiving information from members of a multi-disciplinary team (MDT) and /or possibly from a laryngectomised visitor.

In two papers, both from the U.K., authors referred more accurately to ‘information giving’ pre-operatively^{11,17} and Ward et al.,¹² who were Australian authors from a ‘pre-operative counselling’ group, used two terms; ‘pre-operative counselling’ and ‘information dissemination’- which they also defined as ‘information giving’ in their paper. Stafford et al,¹⁵ surveyed ‘information giving’ practices of ENT surgeons in order to develop a pre-operative ‘counselling’ package for patients. In 1995, Depondt and Gehanno from France¹⁹ referred to ‘patient education’ but they actually meant ‘informing’ patients about surgery.

As with pre-operative ‘counselling,’ there was no operationalising of the term ‘information giving’. A dictionary definition of ‘give’ is, ‘*freely transferring the possession of (something) to (someone)*’ and ‘information’ is, ‘*facts provided or learned about something or someone.*’³⁷ In combining these as ‘information giving,’ there are clear differences between this term and ‘counselling.’

In summary, ‘information giving’ best represents what most authors described, despite their use of different terminology. ‘Pre-operative counselling’ and ‘information giving’ were applied inter-changeably and synonymously across the literature, which may lead to confusion when accurately describing this service to patients.

Defining the content of pre-operative counselling or of information giving

As there was no distinction made between the terms pre-operative ‘counselling’ and ‘information giving,’ so there was no agreement about the content of such information - whom it should involve; who should provide such information; when it should occur and/or in what format (face to face conversation, pamphlets, video and/or CDs).

Seven authors outlined the content of pre-operative ‘counselling’^{13,18,23,24,26,27,31} but this was based on their own professional opinion and experience (Level V evidence), with no underpinning research to support the claims made.

As examples of this, in 1983, Natvig²⁴ suggested that pre-operative counselling should contain three important elements; *explanation* about the disease, *advice* about surgery and survival and *information* on the consequences of surgery. In 2002, Cady¹³ outlined several aspects of care to be discussed with patients pre-operatively, including *physical aspects* such as stoma care and nutrition; *symptom management* of dysphagia and of secretions; *speech therapy* to discuss available voice options; *safety issues* relating to a lack of sense of smell and changed resuscitation, and *psychosocial considerations*, such as the feasibility of returning to work and/or providing support for substance abuse (nicotine, alcohol).

In 1980, Baker and Cunningham²⁷ provided a checklist for pre-operative counselling about vocal rehabilitation, to include an explanation of the anatomy and physiology of the laryngeal area, a brief explanation of different methods of speech production available post-operatively and supplying printed information.

Applying the earlier definition of pre-operative *counselling*, the suggestions made by these authors really refers to ‘information giving’ as there is nowhere a ‘*principled relationship*’ between the patient and information provider with a ‘*predominant ethos..*’ of ‘*..facilitation.*’³⁶ Feber¹⁷ referred to ‘information giving,’ when evaluating a written information pack given to patients before they underwent a total laryngectomy at a hospital in Leeds, UK. The content of the pack included practical information about laryngectomy, obtaining supplies, general cancer support, details of the local laryngectomy club and information about financial benefits. All patients reported that the pack had been useful.¹⁷

Poor methodological rigour

A number of issues contributed to weak rigour in all the studies reviewed.

Studies were observational and descriptive (Level IV evidence) using data from surveys of people with a laryngectomy,^{10,17,20-22,25,28,30} of their carers,^{11,12,16,24} of ENT surgeons,^{15,23} or of all three groups.²⁹

Many studies were from single centres,^{12,16,17,22,28,30} although some researchers surveyed across wide geographical areas of the USA,^{10,21,23,25,29} across more than one centre in the U.K.,^{11,15} and one survey was across Norway,²⁴ and one across Switzerland.²⁰

In six studies, a clear sampling bias was evident as the laryngectomees and/or carers were recruited through laryngectomy clubs, support groups and/or when they attended laryngectomy conferences.^{10,12,16,20,21,29} Participants recruited from such settings are likely to be highly motivated, usually have good communication following surgery, are well adjusted and comfortable in social situations, so they are not wholly representative of the population.

In all instances, participants were asked to reflect on their past experiences, although retrospection has known limitations as it relies on subjective judgement³⁸ and on the accurate recall of patients – some of whom may have had a psychological burden at the time of their treatment.²

Participants' length of time since surgery was reported in six studies and they differed markedly, so it was not possible to aggregate these data. For example, Blanchard²⁵ surveyed a sample of laryngectomees up to 12 months post-operatively; Craven and West²² surveyed patients up to 36 months post-operatively and Minear and Lucente²⁸ from 2 – 48 months post-operatively. In 1978, Keith et al.³⁰ surveyed post-operative patients from the preceding 4 year period and, in another study by Lehman and Krebs,²⁰ patients were surveyed at 1-20 years post-operatively, while Ward et al.,¹² studied patients who had surgery over a 10 year period (between 1990-2000). As

HNC patients are known to be at risk of developing significant psychosocial problems which may persist for 2 to 4 years post-treatment,³⁹ caution is needed when interpreting findings from data collected at an early post-operative phase. Although surveying patients in the early post-operative period may elicit a more immediate recall, other variables may confound an accurate recall of events. For example, patients and their carers who have recently experienced a total laryngectomy may be contending with feelings of shock and distress while working through recovery, dealing with changed function (speech, swallowing, coughing) and grappling with their psycho-social adjustment.

Some papers were, 'expert opinion' pieces (Level V evidence) written by professionals such as an SLT,³¹ oncology nurses,^{13,27} a medical social worker,¹⁸ or a group of ENT surgeons.^{19,26}

Perception of pre-operative counselling

In addition to the lack of operationalising of pre-operative 'counselling' or of 'information giving' and the methodological flaws in the published studies, a common finding was that **pre-operative counselling was not considered adequate by laryngectomees and/or their carers.**^{10-12,16,17,20-22,24,25,28-30}

In a survey from the USA by Keith et al,³⁰ 13% of 72 patients reported that it had not been explained to them that they would not be able to speak after surgery, while 19% reported not being informed about any voice rehabilitation. In another USA study of 120 laryngectomees, 38% of females (N=50) and 41.2% of males (N=68) stated that they had not received any counselling,²¹ which was a high percentage of that sample.

Zeine & Larson (1999)¹⁶ wished to determine whether pre-operative counselling had improved since the study by Keith et al.,³⁰ in 1978. In their study, 153 laryngectomees and their spouses

were surveyed across the USA and 21% of respondents reported that they were unaware that they would be unable to speak post-operatively.¹⁶

Although these authors stated that pre-operative counselling was increasingly being undertaken, significant gaps in information – specifically about loss of voice and rehabilitation options - were identified. Overall, the authors noted that patients' reports about the inadequacy of pre-operative counselling meant that this had not improved significantly over the prior 20 years.¹⁶

A more recent study from the USA in 2006 highlighted persistent issues raised by 150 laryngectomees who completed an online survey, with 20% (N=30) of participants stating they were not made aware that they would lose their voice, and only 40% (N=60) stating that they had any pre-operative contact with a Speech and Language Pathologist (SLP).¹⁰

In a UK study of 29 HNC patients, dissatisfaction was expressed with the information that they had received from their ENT surgeon and the participants further reported a difficulty in absorbing details because treatment was discussed at the same time as their cancer diagnosis.¹¹

Johnson et al., (1979)²⁹ reported a disparity between the opinions of ENT surgeons and those of patients and their carers about the adequacy of pre-operative counselling, with ENT surgeons indicating that patients should be, and are, well informed pre-operatively and patients reporting that they required further counselling.

Patient dissatisfaction may be partly explained by the ENT surgeon imparting bad news, as poor recall may be associated with the shocked reaction that such major surgery was necessary to treat their cancer.

Pre-operative laryngectomised visitors

Having a pre-operative meeting with an established and well-adjusted laryngectomised person is offered at many centres. From a national UK audit of HNC oncology nurses working in laryngectomy services between 2008 and 2009, in 53 of 56 regions patients were always offered a pre-operative patient visitor service.⁴⁰ Attempts were made to match the patients on gender, age, interests, and on their planned surgery or anticipated post-operative speech type.⁴⁰ However, in one USA survey of 60 laryngectomees, several patients expressed strong feelings about *having a choice* whether or not to meet a laryngectomised visitor at the pre-operative stage.²⁸ This issue therefore needs careful consideration when designing pre-operative meetings for patients.

Summary

Across published papers, there was no operationalising of pre-operative ‘counselling’ with people undergoing a total laryngectomy, despite the term being frequently used. In applying the dictionary definition of ‘counselling’³⁶ it is clear that such an activity rarely occurs pre-operatively.

Pre-operative ‘counselling’ was a term used interchangeably and synonymously with ‘information giving.’ There was no agreement on either the content or the format of pre-operative counselling with people before total laryngectomy. All published studies had significant flaws in design and sample biases that were not addressed, resulting in a low evidence base. However, laryngectomy patients and their carers all complained of persistent shortfalls in pre-operative counselling practices^{10-12,16,17,20-22,24,25,28-30} so this issue demands further examination.

Discussion

Pre-operative counselling for total laryngectomy patients remains variable, with the published studies being of poor methodological quality^{10-12,15-17,20-25,28-30} and often representing expert opinion (Level V evidence),^{13,18,19,26,27,31} rather than being studies underpinned by good research evidence. An underlying and persistent problem remains the lack of an agreed definition of counselling and of what this involves.

There is a need for clarity in definition and for further research to audit and evaluate current pre-operative counselling practices and laryngectomy patients' experiences, expectancies and preferences in order to address the persistent reports of shortfalls in clinical practice.^{10-12,16,17,20-22,24,25,28-30}

This is a topical debate; members of the Australia & New Zealand Head and Neck Cancer Society (ANZHNCS) in 2015 were surveying their membership to determine the accessibility and quality of HNC cancer education, examining the type/variation of resources available across Australia and New Zealand and how such tools might be improved. This work needs to be replicated across the UK and Ireland.

A prospective, well designed study to enable information provided by clinicians to be compared with the information understood by a patient cohort would help direct future research and clinical practice.¹²

We also need to scope the experiences of current laryngectomy patients, their carers and clinicians, using a well-established qualitative methodology such as Grounded Theory,³² to understand their experiences and needs.

We plan to undertake such a study, using a topic guide grounded in the literature with a purposefully recruited sample of patients, carers and SLT clinicians. A series of focus groups

(FGs) will be used to map recurrent views (both convergent and divergent) across and within these groups.

From examination of such data, recurring themes will be identified and reported. This may include, but will not be restricted to; reported gaps in services provided, desired information (content), optimal time, place and person(s) to deliver such information, and the preferred format(s) to be used. By obtaining such data, proactive and principled services for patients and their families that are grounded in their needs and requirements, can be developed.

Conclusion(s)

Total laryngectomy surgery results in extensive physical, psychological and socio-emotional changes for patients and their families. It has long been recognised that people preparing for this surgery require suitable pre-operative counselling. To date, there is no consensus on what this means and/or what or who should be involved. Literature remains limited, with reported studies demonstrating selection bias and being of poor methodological quality. There are nevertheless clear and persistent reports by patients and carers of shortfalls in clinical practice that need to be addressed through undertaking rigorous research studies.

Acknowledgements

This work was completed as part of Eavan Fitzgerald's MSc (Research) degree from the Department of Clinical Therapies at the University of Limerick (2014/2015).

Conflicts of Interest

None

Summary

- People undergoing total laryngectomy surgery require suitable pre-operative counselling but there is neither a consensus definition of this process, nor what it should involve.
- Literature remains limited with studies conducted to date being of poor methodological design and of low quality.
- We propose that a prospective, well-designed research study is undertaken, using an established qualitative methodology, to scope the experiences of current laryngectomy patients, their carers and clinicians, as a first step in addressing the persistent reports by key stakeholders of shortfalls in clinical practice.

References

1. Semple CJ, McGowan B. Need for appropriate written information for patients, with particular reference to head and neck cancer. *J Clin Nurs* 2002; 11: 585-593
2. Evrard S, Mathoulin-Pelissier S, Larrue C, Lapouge P, Bussieres E, & Tunon De Lara C. Evaluation of a preoperative multimedia information program in surgical oncology. *Eur J Surg Oncol* 2005; 31: 106-110
3. Ackerstaff AH, Hilgers FJM, Aaronson NK, Balm AJM. Communication, functional disorders and lifestyle changes after total laryngectomy. *Clin Otolaryngol* 1994; 19: 295-300
4. Semple C. The role of the CNS in head and neck oncology. *Nurs Stand* 2001; 15: 39-42
5. Wallen V, Webb VP. A survey of the background characteristics of 2,000 laryngectomees: a preliminary report. *Mil Med* 1975; 140: 532-534
6. Chewing B, Sleath B. Medication decision-making and management: a client-centered model. *Soc Sci Med* 1996; 42: 389-398
7. Christmann S. Health literacy and internet: recommendations to promote health literacy by the means of the internet [Internet]. 2005 [cited 2014 Apr 2]. Available from: <http://eurohealthnet.eu/content/health-literacy-and-internet>
8. Schall LA. Psychology of laryngectomized patients. *Arch Otolaryngol* 1938; 28: 581-584
9. Greene JS. Speech rehabilitation following laryngectomy. *Am J Nurs* 1944; 49: 153-154
10. McColl D, Hooper A, Von Berg S. Preoperative counselling in laryngectomy. *Contemp Issues Commun Sci Disord* 2006; 33: 147-151
11. Newell R, Ziegler L, Stafford N, Lewin RJ. The information needs of head and neck cancer patients prior to surgery. *Ann R Coll Surg Engl* 2004; 86: 407-410

12. Ward EC, Hobson TK, Conroy A. Pre- and post-operative counselling and information dissemination: perceptions of patients undergoing laryngeal surgery and their spouses. *Asia Pac J Speech Lang Hear* 2003; 8: 44-68
13. Cady J. Laryngectomy: beyond loss of voice – caring for the patient as a whole. *Clin J Oncol Nurs* 2002; 6: 1-5
14. Chan Y, Irish JC, Wood SJ, Rotstein LE, Brown DH, Gullane PJ, et al. Patient education and informed consent in head and neck surgery. *Arch Otolaryngol Head Neck Surg* 2002; 128: 1269-1274
15. Stafford ND, Lewin RJP, Nash P, Hardman GF. Surgeon information giving practices prior to laryngectomy: a national survey. *Ann R Coll Surg Engl* 2001; 83: 371-375
16. Zeine L, Larson M. Pre- and post-operative counselling for laryngectomees and their spouses: an update. *J Commun Disord* 1999; 32: 51-71
17. Feber T. Design and evaluation of a strategy to provide support and information for people with cancer of the larynx. *Eur J of Oncol Nurs* 1998; 2: 106-114
18. Renner MJ. Counseling laryngectomees and families. *Semin Speech Lang* 1995; 16: 215-220
19. Depondt J, Gehanno P. Laryngectomized patients' education and follow up. *Patient Educ Couns* 1995; 26: 33-36
20. Lehman W, Krebs H. Interdisciplinary rehabilitation of the laryngectomee. *Recent Results Cancer Res* 1991; 121: 442-449
21. Salva CT, Kallail KJ. An investigation of the counselling needs of male and female laryngectomees. *J Commun Disord* 1989; 22: 291-304

22. Craven A, West R. Counselling and care of laryngectomees: a preliminary study. *Br J Disord Commun* 1987; 22: 237-243
23. Berkowitz JF, Lucente FE. Counseling before laryngectomy. *Laryngoscope* 1985; 95: 1332-1336
24. Natvig K. Laryngectomees in Norway. Study No. 2: pre-operative counselling and postoperative training evaluated by the patients and their spouses. *J Otolaryngol* 1983; 12: 249-254
25. Blanchard SL. Current practices in the counselling of the laryngectomy patient. *J Commun Disord* 1982; 15: 233-241
26. Gates GA, Ryan W, Lauder E. Current status of laryngectomee rehabilitation: IV. Attitudes about laryngectomee rehabilitation should change. *Am J Otolaryngol* 1982; 3: 97-103
27. Baker BM, Cunningham CA. Vocal rehabilitation of the patient with a laryngectomy. *Oncol Nurs Forum* 1980; 7:23-27
28. Minear D, Lucente FE. Current attitudes of laryngectomy patients. *Laryngoscope* 1979; 89: 1061-1065
29. Johnson JT, Casper J, Lesswing NJ. Toward the total rehabilitation of the alaryngeal patient. *Laryngoscope* 1979; 89: 1813-1819
30. Keith RL, Linebaugh CW, Cox BG. Presurgical counselling needs of laryngectomees: a survey of 78 patients. *Laryngoscope* 1978; 88: 1660-1665
31. Curran MF. The psychological aspects of becoming a laryngectomee. *Am Arch Rehabil Ther* 1975; 23: 8-14
32. Perry A, Morris M, Cotton S, editors. *Handbook for Allied Health Researchers*. Australia:

Menzies Foundation; 2009

33. Understanding cancer of the larynx. Dublin: Irish Cancer Society; 2011
34. Understanding cancer of the voicebox (larynx). London: Macmillan Cancer Support; 2013
35. The JBI Approach [Internet] 2014 [cited 2014 Sep 6]. Available from:
<http://joannabriggs.org/jbi-approach.html#tabbed-nav=Levels-of-Evidence>
36. Feitham C, Dryden W. Dictionary of Counselling. London: Whurr; 1993
37. Oxford Dictionaries [Internet] 2015 [cited 2015 Apr 19]. Available from:
<http://www.oxforddictionaries.com/definition/english/information>
38. Pruyne JFA, de Jong PC, Bosman LJ, van Poppel, JWMJ, van den Borne HW, Ryckman RM, et al. Psychosocial aspects of head and neck cancer – a review of the literature. Clin Otolaryngol 1986; 11: 469-474
39. De Boer MF, McCormick LK, Pruyne JFA, Ryckman RM, van den Borne BW. Physical and psychosocial correlates of head and neck cancer: a review of the literature. Otolaryngol Head Neck Surg 1999; 120: 427-436
40. Bond L, Hamilton DW, Birchall MA. (2010). National audit of UK laryngectomy services 2008-2009. Clin Otolaryngol 2010; 35: 238-256

Results from the scoping study:

From the literature review, it was evident that there was a paucity of published literature worldwide about pre-operative counselling for patients before total laryngectomy. Specifically, there were no studies published from Ireland. In terms of methodological rigour, the published studies were observational and descriptive and thus only represented evidence Levels IV or V (The JBI Approach, 2014).

The key issue identified was that there was no consensus in operationalising the term ‘pre-operative counselling,’ despite this being the key term used by all authors. Definitions came from professional opinion / experience, with no research evidence to support (sometimes sweeping) definitions.

There was no agreement about the type or extent of pre-operative informational counselling required for someone undergoing a total laryngectomy and their carers - i.e., what this should entail, to whom it should be directed, or who should provide the information. There were no published reports of SLT pre-operative counselling practices.

However, there were persistent shortfalls in clinical practice reported by total laryngectomy patients and their carers (Blanchard, 1982; Craven & West, 1987; Feber, 1998; Johnson Casper & Lesswing, 1979; Keith, Linebaugh & Cox, 1978; Lehman & Krebs, 1991; McColl, Hooper & Von Berg, 2006; Minear & Lucente, 1979; Natvig, 1983, Newell, Ziegler, Stafford, & Lewin, 2004; Salva & Kallail, 1989; Ward, Hobson & Conroy, 2003; Zeine & Larson, 1999).

There was a need to examine practices in Ireland and to document stakeholder perspectives, so a vanguard study was designed and implemented.

A qualitative research methodology - grounded theory – was applied, with data collection at three FGs involving patients, carers and specialist SLTs. The study protocol was designed to document the pre-operative counselling experiences of a sample of patients who had

undergone a total laryngectomy in Ireland, together with their carers and the pertinent specialist SLTs.

This purpose of the study, 'an examination of the counselling experiences of a sample of patients in Ireland before undergoing total laryngectomy surgery' was to characterise the pre-operative counselling experiences of a sample of patients in Ireland who had undergone surgery within the last ten years, to describe the experiences of their carers, and to document the practices of a sample of sub-specialist SLTs. The data captured from each of the three FGs was compared and contrasted to underpin a suitable model of pre-operative counselling.

Approval was obtained from the ethical research committees at three (of four) Dublin hospitals where total laryngectomy surgery is performed. I recruited a consultant psychiatrist and a clinical psychologist as facilitators to run the FGs. A topic guide was designed for each group of participants. Each topic guide was grounded in the available literature from the systematic review completed. A pilot session with a volunteer laryngectomy patient was used to test the content and clarity of the topic guide, amended it as necessary, and then finalise it for use at the FGs.

Patients, carers and SLT participants were purposefully recruited to ensure representation of key characteristics (see 'method' in following paper).

The FGs were each held over a three week period through June and July 2015 at a Dublin hospital. Four participants attended the SLT FG, six attended the patient FG and four attended the carers' FG.

I attended all FGs as an observer and note-keeper. All three FGs were audio-recorded and data were transcribed as soon as possible after each session. The transcripts were then sent to all participants for verification and amending (modified Delphi) and consensus was obtained after one round. Professor Perry and I then independently carried out content analysis to identify key

themes from each group and to identify concordant and discordant views. We then met and compared our findings.

In March 2018 the study was submitted as a paper to the International Journal of Speech and Language Pathologists. This journal was chosen because it is widely-read by SLTs. The outcome of their review is pending. The submitted paper follows:

Paper 2 (In submission):

Title:

Pre-operative counselling of patients undergoing total laryngectomy surgery in Ireland: three different perspectives

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Declaration of Interest:

None of the three authors has any conflict of interest to declare.

Abstract:

Primary Objective: To collect, describe and analyse data about the pre-operative counselling experiences of a sample of total laryngectomy patients in Ireland, with their carers and specialist Speech and Language Therapists (SLTs), in order to characterise current practices and identify deficiencies.

Research Design: Qualitative, using grounded theory

Methods and Procedures: Data were collected at three focus groups (FGs) of purposefully recruited patients, carers, and SLTs. Participants were audio-recorded and data were transcribed and analysed post-hoc. A modified Delphi approach was used to establish participant consensus. Data were interpreted, and convergent / divergent themes were identified, compared and contrasted.

Main Outcomes and Results: Although SLTs identified themselves as, ‘the main information providers for patients and carers’ they could not describe any unique contribution that they made to pre-operative counselling. Clear differences emerged from the themes elicited from SLTs, compared to those of patients and carers. Patients and carers could identify key information that should be provided for future patients and carers and described key shortfalls in current practices that are necessary to address.

Conclusions: We have identified marked deficiencies in pre-operative counselling practices, as reported by laryngectomy patients and carers in Ireland. Improvement in provision of information is needed and SLTs need to more clearly operationalise their pre-operative role in information giving and counselling with this population.

Main Text:

Introduction

In the Republic of Ireland, the provision of health and personal social services for residents is the responsibility of the Health Service Executive, or HSE (*Feidhmeannacht na Seirbhíse Sláinte*) using public funds. The HSE is frequently portrayed in the Irish media as an inefficient, top-heavy and excessively bureaucratic organisation and has been the subject of criticism by the national media for financial cutbacks and service cancellations.

Across Ireland, cancer services are provided by designated hospitals in four main urban areas (Dublin, Galway, Cork and Limerick) with treatment for head and neck cancer (HNC) centered in Dublin and Cork.

There is a clear gap between the rhetoric of policy on cancer care (National Cancer Forum, 2006) and the reality of HNC clinics run by the HSE. For example, there are no accepted clinical guidelines for the treatment of HNC in Ireland. The multidisciplinary team (MDT) structure is currently not defined although, according to the National Cancer Forum (2006, pp. 47), *'the provision of cancer care by specialist teams needs to be developed as a consistent feature of care across the various types of cancer within each Managed Cancer Control Network.'* Staffing of MDTs remains inadequate and inequitable across Ireland as a result of many years of embargo on public sector recruitment during economic recession.

Further, professions such as SLT are relatively 'young' to the HSE, so these staff members often do not have an established position within an MDT structure.

Together, these factors result in a fragmented and poorly co-ordinated service for many HNC patients in Ireland.

This is a significant problem as, with a recorded population of 4,753,054 people in 2017 (Worldometers, 2017), Ireland had over 500 new HNCs registered annually between 2010 and 2012 (Cancer trends No. 24: Cancers of the head and neck, 2014). Laryngeal cancer was the second most common site, with a difference in male: female ratio of 7:1 (Cancer trends No. 24: Cancers of the head and neck, 2014), so the numbers of people with a diagnosis of HNC are significant.

Current treatments for laryngeal cancer include surgery, radiotherapy and/or chemotherapy (Sendur & Aksoy, 2015). Combined modality treatment may also be offered, depending on the site and stage of the cancer. In the last decade there has been a move towards organ-preservation, following advances in early cancer detection using MRI-PET scanning, in trans-oral laser surgery, in radiotherapy-delivery techniques and with the addition of new chemotherapy drugs to treatment regimens. However, for patients who do not respond to organ-preserving treatment for locally advanced laryngeal cancers, who develop a recurrence, or who present with locally advanced disease at diagnosis, total laryngectomy surgery (removal of the entire larynx) remains the treatment of choice.

Pfister et al., 2006 p.3693, state that a, '*total laryngectomy is widely recognised as one of the surgical procedures most feared by patients.*' Commonly, physical changes after total laryngectomy surgery lead to negative psychological, social and emotional changes (Ward, Hobson & Conroy, 2003).

HNC patients usually obtain information about their diagnosis from members of a hospital's multi-disciplinary team (MDT). People often have little background knowledge at diagnosis, reflecting the public's lower awareness of HNC compared to other types of cancer (Luryi et al., 2014).

Like all cancer patients, those with HNC need clear information to understand their diagnosis, their planned surgery and its sequelae, and how to live with the long term uncertainty of their disease (Semple & McGowan, 2002). Bozec et al., 2010 p. 73, stated that, ‘...*providing HNC patients with adequate information is essential to their confidence and satisfaction regarding medical care.*’ They also describe the need for comprehensive and personalised information, as patients with HNC face a significant impairment to vital functions (speech, swallowing and respiration) that may reduce their quality of life (Bozec et al., 2016).

We recently published a systematic review of the literature about pre-operative counselling for patients about to undergo total laryngectomy surgery to treat advanced laryngeal cancer (Fitzgerald & Perry, 2016). There were clear differences in operationalising of pre-operative ‘counselling’ and there was no consensus about the process, nor agreement about which member(s) of the MDT should provide patients with informational counselling before they undergo a total laryngectomy.

Overall, literature on the subject of counselling for people with HNC is very limited and published studies had low levels of evidence - levels IV and V using The Joanna Briggs’ schema (The JBI Approach, 2014). Importantly, there have been persistent reports of shortfalls in clinical practice by patients and their carers (Blanchard, 1982; Craven & West, 1987; Feber, 1998; Johnson Casper & Lesswing, 1979; Keith, Linebaugh & Cox, 1978; Lehman & Krebs, 1991; Minear & Lucente, 1979; McColl, Hooper & Von Berg, 2006; Natvig, 1983, Newell, Ziegler, Stafford, & Lewin, 2004;; Salva & Kallail, 1989; Ward, Hobson & Conroy, 2003; Zeine & Larson, 1999).

The aim of this study was to analyse the pre-operative counselling experiences of a sample of total laryngectomy patients, their carers and SLTs in Ireland in order to characterise current practices, identify any shortfalls and make informed suggestions for improvement to services.

Method

This was a naturalistic, observational study to document the experiences and views of a purposefully sampled group of total laryngectomy patients (Group 1), their carers (Group 2) and their SLTs (Group 3) in Ireland, using an established qualitative research methodology, Grounded Theory. This investigative research method is suitable where there is no pre-conceived hypothesis and it involves continual comparative analysis of data. It is a powerful methodology, suitable for collecting and analysing data where little/none of the content area is known or understood (Ke & Wenglesky, 2010). This was particularly relevant to this study as there is no published research from Ireland about counselling of HNC patients.

Ethical approval for the study was granted a priori by the Human Ethics Committees of the three Dublin hospitals where patient participants were registered.

Procedure

A sampling grid was designed to recruit participants who, together, represented key characteristics of their respective populations (see Tables 1-3 in Results).

Representation from patients included gender (*male, female*); age (*middle-aged, retirement age, old age*); timing of surgery (*primary, or secondary to other 'failed' modalities*); voicing method (*TEP, artificial larynx; oesophageal speech*); time since surgery (*< 2 y, 2-5 y, > 5 y*); and socio-economic status (*employed, unemployed, retired*).

Carer recruitment addressed gender (*male, female*) and relationship to the patient (*spouse, partner, child*).

SLT participants characteristics included the length of time as a qualified clinician (*5-10 y, >10 y*); length of time working with HNC patients (*0-2 y, 2-5 y, >5 y*); engaging in pre-operative counselling of laryngectomy patients (*Y, N*); and the number of new total laryngectomy patients treated annually (*<5, 5-10, >10*).

Where possible a patient and carer were recruited as a dyad, although some individuals, such as a patient or a carer alone, were also recorded and included.

After reviewing the literature about pre-operative counselling, a set of questions for each focus group (FG) was devised.

For the patient participants, five questions were posed: (i) *can you each describe any counselling that you had (if you had any) before you had your total laryngectomy?* (ii) *before surgery, were there any gaps in information you were given? If so, what additional information do you think should have been given?* (iii) *In your opinion, what information is necessary for patients to have before total laryngectomy surgery?* (iv) *If you were advising another patient before surgery, what three things do you think they need to know, perhaps in order of importance?* and (v) *should specific information be given to carers/family members before surgery? If so, what would this information consist of?*

For the carer participants, their five questions were: (i) *can you each tell me what you were told before your (husband, partner or mother) underwent his/her total laryngectomy?* (ii) *is there anything that you did not know before the surgery that you think should have been told?* (iii) *what are the key pieces of information you think your (husband, partner or mother) should have been told before surgery?* (iv) *in your opinion, what information should be given to carers before*

surgery? and (v) If you were advising another carer, what three things do you think they need to know before surgery, perhaps in order of importance?

The SLT participants' five questions were: (i) *can you each describe your philosophy and methods of pre-operative counselling patients before they undergo total laryngectomy?* (ii) *are there any particular resources that you routinely use?* (iii) *do you think there are key pieces of information that are important for patients to hear before surgery? If so, can you describe these, perhaps in order of importance?* (iv) *has your approach to information-giving changed with an increase in clinical experience? If so, how?* and (v) *should specific information be given to carers before surgery? If so, what would this information consist of?*

An examination of the patients' questions with one volunteer laryngectomy participant was undertaken before finalising their content and format. That patient had no suggestions for change and clearly demonstrated that he understood, and could respond to, all the questions asked of him.

Inclusion criteria for all FGs included that (i) participants could provide informed consent and (ii) they were able to travel to and attend an hour-long focus group alone.

Additionally, Group 1 (patient participants) had to have undergone total laryngectomy surgery during the past 10 years (2004 – 2014). All participants had sufficient visual and hearing skills to be able to actively participate, and Group 3 (SLT) participants were fully qualified SLT clinicians, currently practising in Ireland at a designated HNC unit.

Exclusion criteria for all FGs included participants who could not provide informed consent and/or those with a visual or hearing impairment, such that they could not actively participate in

a FG. For Group 1 (patients), those who had undergone a partial laryngectomy surgery and/or who communicated using non-verbal means (such as writing) were excluded.

Patient and carer participants were purposefully recruited through SLTs at three Dublin hospitals where total laryngectomy surgery is performed, while SLT participants were recruited by either the researcher (EF) contacting them directly, or via an SLT service manager. Identified participants were sent a written study pack that included the study description, a consent form to sign and return, and a demographic information form to be completed and returned to the researcher (EF).

A series of three, one hour-long FGs was then held at weekly intervals at a Dublin hospital, facilitated by a consultant psychiatrist and a clinical psychologist.

Each session was audio-recorded for post-hoc transcription and analysis. The researcher (EF) attended each FG as an observer and note-keeper, documenting non-verbal information, body language and other features or events which might not have been captured by audio-recording.

Each session was transcribed by the researcher (EF) as soon as possible after the FG finished and a summary report was compiled and sent by post to each participant to check, verify and/or change the content and return to the researcher (a modified Delphi approach).

After one round, consensus was reached across each group about the accuracy of the data collected and its interpretation. This process ensured rigour and transparency, as well as confirming the accuracy of the data collected (Linstone & Turoff, 2002).

The FG transcriptions were independently examined, scrutinised and coded by the researcher (EF) and primary supervisor (author three), using the principles of grounded theory. This was done by hierarchical coding, with the most detailed level being line-by-line to ensure that the data, *'are truly grounded and that higher-level categories... actually emerge from the data.'*

(MH Education n.d., p. 73). This analysis elicited recurring and separate themes, within and across the three groups, by the two coders, who then met to compare and discuss their findings.

Results

Using our purposeful recruitment strategy, key participant characteristics were met. See sampling grids for all three FGs below.

Table 1: Patient Participant Sampling Grid

Patient ID	Gender		Age			Type of Surgery		Voicing method			Time since surgery			Socio-economic status		
	M	F	MA	ER	OA	PT	ST	TEP	E/L	OES	<2y	2-5y	5-10y+	EM	UN	RET
P1	x		x			x		x			x			x		
P2	x				x		x	x					x			x
P3		x		x			x		x				x			x
P4	x		x				x	x				x			x	
P5		x			x		x	x				x				x
P6	x			x			x	x					x			x

Key: Gender:

M: Male

F: Female

Age:

MA: Middle Aged (40-60y)

ER: Entering Retirement (60y+)

OA: Old Age (70y+)

Type of surgery:

PT: Primary Treatment

ST: Secondary Treatment (after failed primary modalities)

Voicing method:

TEP: Tracheoesophageal Puncture Speech

E/L: Electrolarynx

OES: Oesophageal

Socio-economic status:

EM: Employed

UN: Unemployed

RET: Retired

Table 2: Carer Participant Sampling Grid

Carer ID	Gender		Relationship to patient				
	M	F	S	P	F	S	C
C1		X		X			
C2		X	X				
C3 (pair)		X	X				
C4 (pair)	X						X

Key: Gender:

M: Male

F: Female

Relationship to patient:

S: Spouse

P: Partner

F: Friend

S: Sibling

C: Child

Table 3: SLT Participant Sampling Grid

SLT ID	Time since qualified			Time working in HNC			Involved with pre-op counselling		Number new laryngectomy patients seen annually		
	<5y	5-10y	>10y	I	M	V	Y	N	<5	5-10	>10
SLT 1		X		X			X				X
SLT 2		X				X	X		X		
SLT 3			X			X	X				X
SLT 4		X			X		X		X		

Key: Time working in HNC:

I: Inexperienced (0-2y)

M: Moderately Experienced (2-5y)

V: Very Experienced (>5y)

Involved with pre-op counselling:

Y: Yes

N: No

Group 1: Patient focus group

A total of six patients who had undergone a total laryngectomy attended. In the data presented below participants are identified as P1-6.

Although all had received pre-operative counselling, there were differences about who had provided this, as well as how, when, and where it occurred. No participant could provide a detailed account of the information they received, although they all remembered receiving details about their surgery and the immediate post-surgery effects. For some participants the ENT surgeon was the main point of contact and for others it was the nursing staff;

'... I would like to say that through the course of all the seven weeks that I was there that the nurses played a huge part ... in giving me information and telling me what would happen and I found them ... brilliant.' (P1)

The majority of participants thought they had received 'sufficient information' pre-operatively. One participant commented that his recall was limited by the length of time since his surgery.

Three key pieces of information that these participants suggested that future patients should receive pre-operatively included, *being told they would survive*; having an *understanding of the physical changes arising from surgery*; and that in time *there could be a good life post-operatively*, as the following quotes demonstrate;

'I suppose what to me was most important that I was going to survive ... they told me that I'd lose ... my sense of smell and taste. That became very irrelevant at that stage.' (P6)

'The mucous, they never tell you about the mucous that comes up out of your neck, it's awful embarrassing.' (P5)

'I'm as independent as I was prior to the operation which is important to me.' (P4)

An ENT consultant, a Clinical Nurse Specialist (CNS) and/or ward nurses were identified as the MDT members who were best to deliver this information. Participants also stated that *psychological support should be made available for patients* (to mitigate likely post-operative depression). They thought that clear information should be given to patients about a week pre-operatively and again, on admission to hospital.

Group 2: Carer focus group

Four carers attended this FG. In the transcripts presented below they are identified as C1-4. They had contrasting experiences of/views about/ pre-operative counselling. Regardless of the amount of information they received, all carer participants said they had not been prepared for the person's changed physical appearance post-operatively, nor for the mental health problems which developed. These were identified as the key gaps in information provided. Mention was made of *'encouraging involvement by other family members;*

'...we knew the voice was goin' to go and when we went in to see me Ma [mother] in intensive care, it was a shock but it was a major surgery you know. It was major, there was pipes and tubes everywhere and bruising everywhere ... it was just a shock.' (C4)

'I don't think anybody prepares you for the depression that the person feels afterwards or the change in the whole family or in the.. you know, dynamic of the whole thing.' (C3)

Three key themes that emerged from the carers were *shock; hard on everyone;* and *life-changing surgery*. Carer participants reported their shock at seeing the patient's physical state post-operatively and of other people 'being afraid of' the patient on their return home. Reference was made to patients being 'in denial' pre-operatively.

'A huge change, but she's still here you know, thank God but eh ... it was just so hard for her. It's still, it's still hard up to this day like the, the nebuliser and everything else, everything is a big change.' (C4)

'I don't think you get prepared psychologically for the whole thing, for what life is going to be like after.' (C3)

Carers all stated that the whole experience was difficult for both patient and family. They referred to major changes in the patient, such as their loss of voice. All reported practical challenges in meeting a patient's daily care, for example in obtaining medical supplies and in dealing with the person's depression.

'It is very hard going and even to this day em things magically appear, a new voice prosthesis magically appears in our house (laughs) and all the, all the filters just magically appear..you know..the Santa Claus or somebody brings them. (laughs) He has no idea where they come from.' (C3)

The carer participants stated that total laryngectomy surgery *was a life-changing event for the patient - but also for the carer*. They outlined the multiplicity of new roles that a carer adopts, how these are often invisible, and that the work they do may not often be recognised and/or attributed to them.

All participants stated that the patient and family members should have been given realistic information about the likelihood and feasibility of a return to work.

Participants stated that future carers need to be informed of how life-changing the surgery will be for them too, and that they will require provision of practical information to manage day to day

issues for the patient. They identified nurses as the best MDT members best to deliver these messages.

Group 3: SLT focus group

Four SLTs attended this FG. In the transcripts presented below they are identified as SLT1-4. None could identify their unique contribution to the process of pre-operative counselling with patients. Despite this, they stated that they were the *main information provider for patients* and they *adopt a multiplicity of roles*.

Two key themes that emerged were *providing reassurance* and *realism*. SLTs said they *provided reassurance* to patients by, '*being positive about outcomes from surgery*' and '*helping (them) to adapt to post-operative changes*.'

'I find for them to get reassurance because, what they hear, I think, what they take most of, what patients have told me after is, a permanent hole in the neck and that's kind of a terrifying term for them. Em.. but even to reassure them that they're not going to be walking around with the hole exposed for everyone to see.' (SLT3)

They said that their ability to reassure improved with increased clinical experience as this enabled them to recount anecdotes from other patients' experiences. SLTs said they provided practical information to patients, giving them realistic expectations of surgery by discussing potential outcomes and complications. Speaking about her ability to provide information to patients, SLT1 noted,

'I think it's a skill em, I certainly think when I was em starting out in the area, I had, it was almost like a tick the box, I need to talk about this, this and this - but now I think I can tailor it a lot more to the patient's needs and priorities. Em.. so I definitely think it's

something that evolves and, you know, you do kind of get better at it with experience.'

(SLT1)

There was some alignment of content with the patients' wishes, with the SLTs stating that they provided, *'information about the physical changes arising from surgery.'* The involvement of a laryngectomy visitor pre-operatively was highlighted by these SLTs as being important, in order to provide a realistic account of life changes post-operatively.

'I think I'm more realistic as well, I suppose I've mentioned about the change in treatments and the impact that's had ... I do talk to the patient about the, the risk of fistulae and the possibility that they may not be swallowing, whereas ... you know, there is a fine line; obviously you don't want to deter someone from surgery who's decided to go for that, but you know, you want them to have a realistic expectation, you know, and not to be disappointed or, you know, extremely upset with the outcome.' (SLT4)

The key themes from the three groups are summarised in table 4 below.

Table 4: Summary of Key Themes

Participant FGs	Themes		
Patients (Group 1)	Survival	Changed Quality of Life	Physical Changes after Surgery
Carers (Group 2)	Shock	Hard on everyone	Life-changing surgery
SLTs (Group 3)	Reassurance	Realism	

The results showed clear differences in the themes that emerged from the three groups.

SLT participants identified themselves as the main information providers for patients, but they could not define their unique contribution. There were clear differences in the themes elicited from SLTs, compared to the patients and carers - who were largely aligned.

Patients and carers could clearly identify what information is required pre-operatively and had views about who should provide it.

Discussion

In this study we examined the experiences and views of three different groups in Ireland who were involved with people undergoing a total laryngectomy; laryngectomy patients themselves, their carers, and the specialised SLTs who worked with them.

Although the sample size is small, our purposeful recruitment (see Tables 1-3) resulted in key population characteristics being represented across all three groups, giving us confidence in the validity ('truthfulness') of the data that were collected.

We had anticipated obtaining data to underpin the design of a model of pre-operative counselling. However, although our data provide some premises and principles to underpin intervention, more consideration and research is required before evidence-based practices can be reliably formulated.

Patient themes included obtaining pre-operatively *information about surgery*; *survival* of the actual procedure; and knowing the expected *physical changes after surgery*.

Perhaps it is not surprising that patient participants identified the two healthcare professionals most involved in their care at the time of surgery - ENT consultants and nurses - as their preferred providers of pre-operative information.

This preference may also reflect the generally conformist attitudes of the Irish population, where primacy is afforded to the more established healthcare professionals - doctors and nurses.

All patients recommended that clear information about surgery and its outcome should be provided pre-operatively, which are two principles that may underpin the design of informational counselling, although the detail of practice (i.e., which professional should do this? when? and how?) still needs to be ascertained in a future framework.

Patients were concerned about life beyond the surgery and wished for pre-operative counselling to address their *changed quality of life*. Participants stressed that future patients should know that quality of life this would be negatively impacted, with the possibility of a resulting low mood/depressions and a difficulty in adjusting, but that generally these will improve with time. Information about these topics and available assistance had not been available to these participants, perhaps reflecting the absence of clinical psychologists in MDTs in Ireland. Carer themes were similarly focused on the need for pre-operative *information about the surgery*; preparing for the *shock* of the patient's post-operative physical state; and how total laryngectomy is a *life changing surgery*.

Carers were ill-prepared for the immediate surgical aftermath of surgery. Nurses were named as 'best' providers of key information, perhaps because they were the main healthcare professionals with whom the carers had regular contact in the critical care setting. These carers may also be placing a greater value on established healthcare staff (rather than the SLTs), as did the patients. Like the laryngectomy patients, carers talked about *life after the surgery*. Dealing with a patient's low mood and difficulty in adjustment was *hard on everyone* especially given a lack of formal psychological supports and the varying roles that carers had to adopt.

By contrast, SLT themes were focused on *reassurance* for patients and carers and providing *realism* through the information provided. When comparing with the patient themes, theirs would appear to align with patients' need to be told they would survive and that their quality of life would improve with time.

However, on closer inspection, the SLTs predominantly reassured patients by discussing the 'positives' post-operatively, such as the potential for improved swallow function and the ability to cover the permanent 'neck hole' or tracheostoma. SLTs discussed the need for patients to have

‘realistic information’ that included post-surgical functional changes such as the loss of taste and smell. However, one patient observed, that this level of detail about issues which they could not understand or process pre-operatively seemed ‘irrelevant.’

As well as establishing the key themes elicited, it is important to consider **who** provides pre-operative information to patients and carers, as any model for intervention needs to ascertain this and action accordingly.

SLTs were included in this study as they typically are the people who provide pre-operative counselling for laryngectomy patients given the changes to speech and swallowing.

The role of a specialised SLT with laryngectomy patients is supported by clinical guidelines from some professional bodies internationally, although these primarily describe the SLT role in voice rehabilitation post-operatively (RCSLT, 2010; SPA, 2013).

SLTs are usually involved with laryngectomy patients in the pre-operative phase although the consistency and timing of this can vary, as was the case with the patient participants in this study. Given this, it was notable that patients and their carers both remembered, and highly valued, the input and expertise of an ENT consultant or nurse, rather than an SLT, at the pre-operative stage.

The SLTs indicated that they felt best placed to counsel patients because of their knowledge and expertise in total laryngectomy and in speech and swallowing function. However, they admitted that this responsibility likely fell to them because of a lack of clinical psychology and/or social work staff in the MDTs in which they operate. They each acknowledged and expressed concern about their lack of formal training in counselling.

Our findings indicated a clear gap between patients' and carers' perceptions of the role of SLTs in providing pre-operative counselling and the SLTs' own perceptions of their role.

This sample of patients and carers thought that ENT consultants and/ or nurses were best positioned to provide the reassurance they required about surviving the surgery and their likely post-operative physical state, which was the extent of information they wanted pre-operatively. The SLTs did not provide sufficient detail about the acute post-operative phase that patients and carers had wished for – perhaps because these SLTs saw their pre-operative role more broadly, providing 'reassurance' and 'realism.'

The views of these patients and carers about the pre-operative function of an SLT may have been influenced by SLT being a relatively new profession in the Irish acute health system, resulting in 'professional positioning' which sometimes occurs as SLTs seek space and recognition among more established members of a clinical team. SLTs may thus operate within a HNC service but without a clear role definition. To compound this, some new(er) MDTs in Ireland have not yet become fully established or effective in their operation. This can result in a lack of defined roles and responsibilities, with overlap in some areas and neglect of others, resulting in confusion for patients and carers – and sometimes for the clinicians themselves.

It would be useful to interview ENT consultants and clinical nursing staff, who were identified as key information providers in this study, to document their views about their roles in pre-operative counselling and who they consider best positioned to provide information for patients and carers.

Replicating this study in other countries to compare healthcare systems and outcomes would be useful, as this would provide a benchmark for developing 'best practice' (in pre-operative counselling of laryngectomy patients) in Ireland.

One core issue remains: there is no agreement about pre-operative ‘counselling’ for laryngectomy patients (Fitzgerald & Perry, 2016) and this results in a mis-match across patients, carers and professionals’ expectancies and experiences.

A lack of any agreed definition of ‘pre-operative counselling’ and any description of practice may have an impact on the ability of SLTs to provide ‘effective’ counselling in an Irish context. Patients and carers may have unrealistic expectations of what they will obtain from pre-operative ‘counselling’ and may then deem the process unsatisfactory in terms of personnel encountered and information content obtained.

The purposeful recruitment of participants gives validity to the results from this study but we acknowledge that there are limitations.

Requesting patients to recall events from their past creates difficulty. In this study patients had undergone surgery up to ten years previously, and one stated that his recall was reduced because his surgery had taken place eight years previously. It would seem optimal to interview patients as early as possible post-operatively to ensure accuracy of their recall. However, we know that people treated for HNC (including laryngectomy patients) may experience significant negative psychosocial sequelae in their early post-operative years (DeBoer et al., 1999). Therefore, caution is needed when interpreting data from patients at this stage of recovery. Patient and carer participants made multiple references to dealing with post-operative depression during this study, and one carer referred to a patient being in denial even at the pre-operative stage. We consider that obtaining the views of patients at varying stages post-surgery is most useful to fully capture their experiences, but length of time since surgery must be taken into account when interpreting the findings.

A further issue involves choosing a suitable methodology for data collection. FGs were chosen for this study because these participants had shared similar experiences. However, attempting to group the participants in FGs may result in an over-representation of dominant views, possibly from people with the 'best' recall of events. Conducting face to face interviews singly may have allowed for more individual opinions and experiences to emerge, but this was not feasible, given the time constraints of this thesis.

It is evident from this study that patients and carers can tell us much about their experiences and what information they require pre-operatively. This can provide a clear direction and highlight current important gaps in service provision, for example, a lack of psychological support and timely provision of information, which need to be addressed.

Patients and carers highlighted that information and opinions were imposed on them by healthcare professionals such as SLTs, resulting in negative experiences for both service users and clinicians. There is an urgent need for clinical psychologists to be employed in cancer healthcare teams in Ireland if pre-operative counselling is to be made more effective.

SLTs would benefit from reviewing their involvement with this patient group and attend recognised courses to develop their counselling skills to improve the pre-operative experience for patients and carers.

Summary & Conclusion:

This is the first study to explore the pre-operative counselling experiences of laryngectomy patients and carers in Ireland. Further engagement with a larger sample of patients and carers would be desirable to verify our findings. We would also need to incorporate views of other HNC MDT members before proposing a model of pre-operative counselling for laryngectomy patients.

From this study, we have identified the premises and principles that should underlie a model of pre-operative counselling practices, and we now know the key information that patients and carers wish to receive pre-operatively.

What remains to be ascertained: the specifics of who (professionally) should deliver such information and counselling; how to do this (via pamphlets, oral means, telephone, online etc) and when (at what time) pre-operatively. This remains work for future studies.

Acknowledgements:

This work formed part of Eavan Fitzgerald's MSc (Research) thesis at The School of Allied Health, University of Limerick (initially submitted in March 2018).

We thank the laryngectomy volunteer who participated in the pilot study; the patients, carers and SLTs for freely giving up their time so freely to attend the focus groups; the consultant psychiatrist and clinical psychologist, who gave expert input to the study and facilitated the FGs.

We also thank the SLT staff at the three Dublin hospitals for their assistance with the study recruitment.

References:

- Blanchard, S.L. (1982). Current practices in the counselling of the laryngectomy patient. *Journal of Communication Disorders, 15*, 233–241.
- Bozec, A., Schultz, P., Gal, J., Chamorey, E., Chateau, Y., Dassonville, O., Poissonnet, G., Santini, J., Peyrade, F., Saada, E., Guigay, J., Benezery, K., Leysalle, A., Santini, L., Giovanni, A., Messauodi, L., Fakhry, N. (2016) Evaluation of the information given to patients undergoing head and neck cancer surgery using the EORTC QLQ-INFO25 questionnaire: a prospective multi-centric study. *European Journal of Cancer, 67*, 73-82.
- Craven, A., & West, R.(1987). Counselling and care of laryngectomees: a preliminary study. *British Journal of Disorders of Communication, 22*, 237–243.
- De Boer, M.F., McCormick. L.K., Pruyn. J.F.A., Ryckman. R.M., van den Borne. B.W. (1999) Physical and psychosocial correlates of head and neck cancer: a review of the literature. *Journal of Otolaryngology - Head & Neck Surgery, 120*, 427-436.
- Edwards, D. (1997). *Face to face: Head and neck cancer services* London: King's Fund.
- Feber, T. (1998) Design and evaluation of a strategy to provide support and information for people with cancer of the larynx. *European Journal of Oncology Nursing, 2*, 106–114.
- Fitzgerald, E., & Perry, A. (2016) Pre-operative counselling for laryngectomy patients: a systematic review. *The Journal of Laryngology & Otology, 130*, 15-20.

Johnson, J.T., Casper J. & Lesswing N.J.(1979) Toward the total rehabilitation of the alaryngeal patient. *Laryngoscope*, 89, 1813–1819.

Ke, J., & Wenglensky, S. (2010). *Grounded theory – handout*.

<http://avantgarde-jing.blogspot.ie/2010/03/grounded-theory.html> accessed 25th September, 2015.

Keith, R.L., Linebaugh, C.W., & Cox B.G. (1978) Presurgical counselling needs of laryngectomees: a survey of 78 patients. *Laryngoscope*, 88, 1660–1665.

Lehman, W., & Krebs, H. (1991) Interdisciplinary rehabilitation of the laryngectomee. *Recent Results in Cancer Research*, 121, 442–449.

Linstone, H. A., & Turoff, M. (Eds) (2002) *The Delphi Method: Technique & Applications*. Boston: Addison-Wesley Publishing.

Luryi, A.L., Yarbrough, W.G., Niccolai, L.M., Roser, S., Reed, S.G., Nathan, C.A., Moore, M.G., Day, T. & Judson, B.L. (2014) Public awareness of head and neck cancers: a cross-sectional survey. *JAMA Otolaryngology – Head & Neck Surgery*, 140, 639-646.

McColl, D., Hooper, A., & Von Berg, S. (2006) Preoperative counselling in laryngectomy. *Contemporary Issues in Communication Science and Disorders*, 33, 147–151.

MH Education. (n.d.) *UK: Chapter 7 - Grounded Theory Methodology*.

<http://www.mheducation.co.uk/openup/chapters/9780335244492.pdf> accessed 13th November, 2017.

Minear, D., & Lucente, F.E. (1979) Current attitudes of laryngectomy patients. *Laryngoscope*, 89, 1061–1065.

National Cancer Forum. (2006). *Ireland: A Strategy for Cancer Control in Ireland*.

http://www.hse.ie/eng/services/Publications/HealthProtection/Public_Health_/National_Cancer_Control_Strategy.pdf accessed 15th October, 2016.

National Cancer Registry of Ireland. (2014). *Ireland: Cancer trends No. 24: Cancers of the head and neck*. http://www.ncri.ie/sites/ncri/files/pubs/head%20and%20neck_trends_report13.pdf accessed 15th October, 2016.

Natvig, K. (1983). Laryngectomees in Norway. Study No. 2: preoperative counselling and postoperative training evaluated by the patients and their spouses. *Journal of Otolaryngology*, 12, 249–254.

Newell, R., Ziegler, L., Stafford, N., & Lewin, R.J. (2004) The information needs of head and neck cancer patients prior to surgery. *The Annals of the Royal College of Surgeons of England*, 86, 407–410.

Pfister, D.G., Laurie, S.A., Weinstein, G.S., Mendenhall, W.M., Adelstein, D.J., Ang, K.K., Clayman, G.L., Fisher, S.G., Forastiere, A.A., Harrison, L.B., Lefebvre, J.L., Leupold, N., List, M.A., O'Malley, B.O., Patel, S., Posner, M.R., Schwartz, M.A., & Wolf, G.T. (2006) American society of clinical oncology clinical practice guideline for the use of larynx-preservation strategies in the treatment of laryngeal cancer. *Journal of Clinical Oncology*, 24, 3693-3704.

Royal College of Speech and Language Therapists (2010). *Prosthetic surgical voice restoration (SVR): the role of the speech and language therapist*.

https://www.rcslt.org/docs/svr_policy_document accessed 14 May, 2018.

Salva, C.T. & Kallail, K.J. (1989) An investigation of the counselling needs of male and female laryngectomees. *Journal of Communication Disorders*, 22, 291–304.

Semple, C.J. & McGowan, B. (2002) Need for appropriate written information for patients, with particular reference to head and neck cancer. *Journal of Clinical Nursing*, 11, 585-593.

Sendur, M.A.N. & Aksoy, S. (2015). Current Systemic Therapy Options for Head and Neck Cancers. In Beyzadeoglu M., Ozyigit G., & Selek U. (Eds) *Radiation Therapy for Head and Neck Cancers*. (pp 17-31) Springer International Publishing AG: Switzerland.

Speech Pathology Australia (2013). *Laryngectomy Clinical Guidelines*.

http://www.speechpathologyaustralia.org.au/library/Laryngectomy_Clinical_Guidelines.pdf

accessed May 14, 2018.

The Joanna Briggs Institute (2014). *The JBI Approach*. <http://joannabriggs.org/jbi-approach.html#tabbed-nav=Levels-of-Evidence> accessed 15 October, 2016.

Ward, E.C., Hobson, T.K., & Conroy, A. (2003) Pre- and post-operative counselling and information dissemination: perceptions of patients undergoing laryngeal surgery and their spouses. *Asia Pacific Journal of Speech, Language and Hearing*, 8, 44-68.

Worldometers (2017). *Ireland: Ireland Population Live*. <http://www.worldometers.info/world-population/ireland-population> accessed 15th August, 2017.

Zeine, L. & Larson, M. (1999) Pre-and post-operative counselling for laryngectomees and their spouses: an update. *Journal of Communication Disorders*, 32, 51–71.

Results of the Vanguard study:

Key themes were identified from each participant group:

The SLT themes were '*reassurance*' and '*realism*.' They identified themselves as the main information providers for patients undergoing a total laryngectomy. They stated they adopted a variety of roles, but their unique contribution to pre-operative counselling was not defined, nor was there any patient choice about meeting with them. They stated their approach with patients was *to provide realistic information* and *to give reassurance by being positive*.

The patient themes were '*survival*', '*changed quality of life*' and '*physical changes after surgery*.' All participants had received pre-operative counselling but there was no standardisation of the process and their reported experiences varied considerably.

Patient participants said that it is important for pre-operative patients to be told that they *will survive the surgery* and that, with time, their *quality of life will improve*. They also said that patients should be told about the *physical changes from the surgery*. Patients identified the ENT consultant and CNS or ward nurses as the MDT members who should provide them with information, with no mention of SLTs, and they did not refer to wanting reassurance at this point. There was some alignment in purpose with the SLTs who stated they, '*provide information about the physical changes arising from surgery*,' as the patient participants indicated that this was important information for them to hear pre-operatively.

Carer themes were '*shock*', '*hard on everyone*' and '*life-changing surgery*.' They reported varied experiences from pre-operative counselling. They said that total laryngectomy surgery was *a life-changing experience* for both the carer and the patient, which echoes with the patients who described negative changes to their quality of life. The carers said they *had not been prepared* for the *shock* of the patient's immediate post-operative physical changes. They described how the whole experience was *hard for the patient and carers*, which echoes the patients'

description of negative changes to their quality of life. The CNS or ward nurses were again identified as the MDT members who should be providing information to carers. Carers did not say that they were seeking reassurance at this stage; rather they said they wanted the provision of practical information.

The findings of this study indicated clear differences in the views of SLTs, compared with those of patients and carers. SLT participants identified themselves as the main information providers for patients, but any unique contribution was not able to be defined. Patients and carers were largely in agreement about pre-operative informational counselling. They clearly identified key information they thought important for future patients and carers to have and could describe important shortfalls in current practices.

This is the first study from Ireland to explore views about counselling with HNC patients and carers. Further research is required to establish the views of ENT consultants and nurses. There is a need to reproduce this study internationally, to examine and compare findings from different healthcare systems.

I made the latter suggestion after my oral presentations at the World Congress on Larynx Cancer in Australia in 2015, at the 30th World Congress of the International Association of Logopedics & Phoniatics (IALP) in Ireland in 2016, and again at the 10th International Head and Neck Cancer Quality of Life Conference in England in 2016. Although some delegates at each session expressed a strong interest, to date no-one has undertaken a similar study for comparison.

In Ireland, a framework for management of HNC patients remains to be agreed and established. National guidelines for cancer treatment are not yet in place. The publication of such guidelines will likely support the development of multi-disciplinary team (MDT) structures.

There is a clear need to listen to the views and experiences of patients and carers who have undergone the experience of a total laryngectomy to guide development of a suitable model for pre-operative counselling.

We need to improve the counselling skills of SLTs who work in HNC cancer units, if they are to more effectively meet the pre-operative needs of total laryngectomy patients and their carers.

The findings from the vanguard study were discussed in detail with the consultant psychiatrist and clinical psychologist facilitators, as well as with their departmental colleagues. All expressed surprise at the findings; specifically, the clear inconsistency in patient experiences and the lack of available psychological support.

It was agreed that there is a clear need for continuing professional development (CPD) to support current staff, specifically SLTs, in their role of pre-operative counselling of HNC patients and carers.

Future Directions:

If I were to continue this work under the FEHS sPhD programme, I would choose to work with Prof. Perry (School of Allied Health) and Dr. Oliver McGarr (School of Education) as my supervisors as, together, they have the requisite expertise in research methodology, in HNC rehabilitation and in pedagogy.

From the issues raised by my research to date, I would choose to address the issue of SLTs lacking the necessary skills to provide effective pre-operative counselling for patients and carers. There is a clear need for an online CPD module on counselling skills for qualified SLTs who are working in HNC rehabilitation in Ireland. The design and content of this module would involve collaboration and wide consultation with my psychiatry and psychology colleagues.

For a quality result, it would be important to consult with experts in online education design, under Dr. McGarr's guidance, to ensure that any such module was underpinned by sound pedagogical principles.

An online module providing interactive distance learning may work best, given the constraints of HSE funding and the lack of opportunity for SLTs in Ireland to attend CPD events.

By SLTs engaging with such training, a community of 'expert practitioners' could be developed across SLTs working with HNC patients in Ireland. There would be enormous benefit from developing peer-support and networking opportunities.

It would also promote the development of good counselling skills in SLTs working with HNC populations and such a module would enable qualified SLTs to better support and counsel patients and carers in the pre-operative phase, giving a more structured approach than the current 'scattergun' practice.

The counselling skills developed could be then extended to improve post-operative interventions with patients and carers, which occurs as relationships develop over time while vocal rehabilitation continues.

Other MDT members, such as surgeons, nurses, dietitians and physiotherapists, may also benefit by undertaking such a CPD programme, to enhance their counselling skills with HNC patients.

A CPD module would also provide a framework that could be adapted and transferred to SLTs working with adults and children who have other disorders.

Finally, the development and use of such a module could help better define the roles of the MDT members who engage with total laryngectomy patients and their carers. Specifically, it may be helpful in better defining the roles and responsibilities of SLT professionals.

Personal and professional gain from the experience of undertaking research:

Embarking on the MSc (research) programme at UL in 2014 meant my return to academic life after 11 years of full time clinical work.

I availed myself of the supports and learning opportunities at UL, which included completing C-STAR courses on questionnaire design (January 2014), the use of SPSS (April 2014), basic statistics for researchers (May 2014), a critical appraisal and systematic review workshop (August 2014) and use of N-VIVO (November 2014). I also attended a course on systematic reviewing at NUI Maynooth (July 2014).

Being in an academic environment gave me a fresh perspective on my clinical work. I began the post-graduate programme by thinking that I knew what patients and carers required from pre-operative counselling.

From challenging discussions during supervision, I quickly recognised that this was possibly a naïve viewpoint, based on my own opinion, rather than on any quality research or review of current literature.

I have developed a more respectful view of data analytics after learning about study design and research methodologies. Most importantly, I have developed a different, more evidence-based, approach with patients and believe I am a more skilled clinician as a result.

I encountered many challenges during this programme. As I undertook the MSc in a part-time capacity, I had to balance study with the demands of a busy clinical practice. Being based in Cork, travelling to UL was sometimes challenging. I have considerably developed my scheduling and time-management skills during this course of study.

If I was to proceed to the sPhD programme I would enjoy being part of a class and having peer support. During completion of the MSc (Research), my only formal academic contact was with my supervisor. I particularly would look forward to the taught core modules of a sPhD to support and structure my independent learning. I had planned to reduce my clinical hours and protect my study time, which would have been essential for sPhD enrollment.

Due to *profound and unexpected health issues*, I am unfortunately not able to register on the sPhD programme but know that I have established useful and ongoing University links that would be reactivated, should my circumstances change and I am in a position to re-engage.

I have valued the opportunity to meet other researchers internationally; specifically, some key members of the Australian and New Zealand Head & Neck Cancer Society (ANZHNCs) who conducted a survey in Sept 2014 to determine the accessibility and quality of education and resource material for HNC patients across Australia & New Zealand, with view to improving their care.

At a conference in July 2015, I met colleagues from Curtin University in Perth, Australia who were conducting a national survey of professionals' views about the supportive needs of HNC patients and families, to then make suggestions for intervention and scope future research priorities.

This indicates the international interest in the informational needs of HNC patients and carers, and that many practitioners wish to improve their clinical practices. My links to other researchers have enabled me to have a wider profile for my work and to generate international interest. I hope that these links will prove useful in the future, should I be in a position to return to this area of study.

I have valued the time and opportunity to read and think around this topic and conclude with a reference list that has influenced my own thinking.

References:

- Blanchard, S.L. (1982). Current practices in the counselling of the laryngectomy patient. *Journal of Communication Disorders, 15*, 233–241.
- Craven, A., & West, R.(1987). Counselling and care of laryngectomees: a preliminary study. *British Journal of Disorders of Communication, 22*, 237–243.
- Feber, T. (1998) Design and evaluation of a strategy to provide support and information for people with cancer of the larynx. *European Journal of Oncology Nursing, 2*, 106–114.
- Johnson, J.T., Casper J. & Lesswing N.J.(1979) Toward the total rehabilitation of the alaryngeal patient. *Laryngoscope, 89*, 1813–1819.
- Keith, R.L., Linebaugh, C.W. , & Cox B.G. (1978) Presurgical counselling needs of laryngectomees: a survey of 78 patients. *Laryngoscope, 88*, 1660–1665.
- Lehman, W., & Krebs, H. (1991) Interdisciplinary rehabilitation of the laryngectomee. *Recent Results in Cancer Research, 121*, 442–449.
- McColl, D., Hooper, A., & Von Berg, S. (2006) Preoperative counselling in laryngectomy. *Contemporary Issues in Communication Science and Disorders, 33*, 147–151.
- Minear, D., & Lucente, F.E. (1979) Current attitudes of laryngectomy patients. *Laryngoscope, 89*, 1061–1065.
- Natvig, K. (1983). Laryngectomees in Norway. Study No. 2: preoperative counselling and postoperative training evaluated by the patients and their spouses. *Journal of Otolaryngology, 12*, 249–254.

Newell, R., Ziegler, L., Stafford, N., & Lewin, R.J. (2004) The information needs of head and neck cancer patients prior to surgery. *The Annals of the Royal College of Surgeons of England*, 86, 407–410.

Perry, A., Morris, M., & Cotton, S. (Eds.). (2009). *Handbook for Allied Health Researchers*. Australia: Menzies Foundation.

Salva, C.T. & Kallail, K.J. (1989) An investigation of the counselling needs of male and female laryngectomees. *Journal of Communication Disorders*, 22, 291–304.

The Joanna Briggs Institute (2014). *The JBI Approach*. <http://joannabriggs.org/jbi-approach.html#tabbed-nav=Levels-of-Evidence> accessed 15 October, 2016.

Ward, E.C., Hobson, T.K., & Conroy, A. (2003) Pre- and post-operative counselling and information dissemination: perceptions of patients undergoing laryngeal surgery and their spouses. *Asia Pacific Journal of Speech, Language and Hearing*, 8, 44-68.

Zeine, L. & Larson, M. (1999) Pre-and post-operative counselling for laryngectomees and their spouses: an update. *Journal of Communication Disorders*, 32, 51–71.

Appendix 1: Topic Guide for Patient Focus Group

Focus Group Topic Guide – Patients

Q1. Can you each describe any counselling that you had (if you had any) before you had your total laryngectomy?

Prompt with the following if not offered:

- (a) Who did you meet (professionals, another patient etc)?
- (b) What information was given?
- (c) How was the information delivered, in what form?
- (d) When did the counselling occur?
- (e) Where did the counselling occur?
- (f) Were your carers/family members involved?

Facilitator to briefly summarise group discussion before moving to the next question.

Q2. Before surgery, were there any gaps in information you were given? If so, what additional information do you think should have been given?

Facilitator to summarise group discussion before moving on to the next question.

Q3. In your opinion, what information is necessary for patients to have before total laryngectomy surgery?

Prompt with the following if not offered:

- (a) Who should provide this information?
- (b) In what form should information be given?
- (c) When should this information be given?
- (d) Where should the information be given?

Facilitator to summarise group discussion before moving to the next question.

Q4. If you were advising another patient before surgery, what three things do you think they need to know, perhaps in order of importance?

Facilitator to summarise group discussion before moving to the next question.

Q5. Should specific information be given to carers/family members before surgery? If so, what would this information consist of?

Prompt regarding 'who', 'how', 'when' and 'where' if not offered.

Facilitator to summarise group discussion before moving to close the discussion.

Appendix 2: Topic Guide for Carer Focus Group

Focus Group Topic Guide – Carers:

Q1. Can you each tell me what you were told before your husband, partner or mother underwent his/her total laryngectomy?

Prompt with the following if not offered:

- (a) Who did you meet (professionals, another patient etc)?
- (b) What information was given?
- (c) How was the information delivered, in what form?
- (d) When did the counselling occur?
- (e) Where did the counselling occur?

Facilitator to summarise discussion before moving to the next question.

Q2. Is there anything that you did not know before the surgery that you think should have been told?

Facilitator to summarise group discussion before moving to the next question.

Q3. What are the key pieces of information you think your husband, partner or mother should have been told before surgery?

Facilitator to summarise group discussion before moving to the next question.

Q4. In your opinion, what information should be given to carers before surgery?

Prompt with the following if not offered:

- (a) Who should provide this information?
- (b) In what form should information be given?
- (c) When should this information be given?
- (d) Where should the information be given? With patient or without?

Facilitator to summarise discussion before moving to the next question.

Q5. If you were advising another carer, what three things do you think they need to know before surgery, perhaps in order of importance?

Facilitator to summarise group discussion before moving to close the discussion.

Appendix 3: Topic Guide for SLT Focus Group

Focus Group Topic Guide – SLTs

Q1. Can you each describe your philosophy and methods of pre-operative counselling patients before they undergo total laryngectomy?

Prompt with the following if not offered:

- (a) Are there other professionals/patient visitor involved?
- (b) What information is given?
- (c) How is the information delivered, in what form?
- (d) When does the counselling typically occur?
- (e) Where does the counselling typically occur?

Facilitator to briefly summarise group discussion before moving to the next question.

Q2. Are there any particular resources that you routinely use?

Facilitator to briefly summarise group discussion before moving to the next question.

Q3. Do you think there are key pieces of information that are important for patients to hear before surgery? If so, can you describe these, perhaps in order of importance?

Facilitator to briefly summarise group discussion before moving to the next question.

Q4. Has your approach to information-giving changed with an increase in clinical experience? If so, how?

Facilitator to briefly summarise group discussion before moving to the next question.

Q5. Should specific information be given to carers before surgery? If so, what would this information consist of?

Prompt with the following if not offered:

- (a) What is that information?
- (b) Who should provide this information?
- (c) In what form should information be given?
- (d) When should this information be given?
- (e) Where should the information be given?

Facilitator to briefly summarise discussion before moving to close the session.

Appendix 4: National, International Oral Presentations

1. Irish Association of Speech and Language Therapists (IASLT) Biennial Conference 2015
25th & 26th May 2015 – Dublin, Ireland

Title: *An examination of the counselling experiences of a sample of patients in Ireland before undergoing total laryngectomy surgery*

(Abstract submission – declined)

2. World Congress on Larynx Cancer 2015
27th July 2015 – Cairns, Queensland, Australia

Title: *Pre-operative counselling for laryngectomy patients: a systematic review*

(Conference abstract published)

3. Pint of Science (aka Science in the pub)
25th May 2016 – Limerick, Ireland (A Science Week activity to engage the public further in science)

Title: *Stick your NECK out I get aHEAD of cancer*

4. 30th World Congress of the International Association of Logopedics & Phoniatics (IALP)
22nd August 2016 – Dublin, Ireland

Title: *Pre-operative counselling of patients undergoing total laryngectomy surgery in Ireland: three different perspectives*

(Conference abstract published)

5. Psychiatry and Clinical Psychology Departments in St. James's Hospital
4th November 2016 – Dublin, Ireland

Title: *Pre-operative counselling of patients undergoing total laryngectomy surgery in Ireland: three different perspectives*

6. 10th International Head and Neck Cancer/ Quality of Life Conference
11th November 2016 – Liverpool, England

Title: *Pre-operative counselling of patients undergoing total laryngectomy surgery in Ireland: three different perspectives*