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REVIEW ARTICLE

Pre-operative counselling for laryngectomy patients: a systematic review

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Abstract

Objectives: This study aimed to undertake a systematic review of the literature about pre-operative counselling for laryngectomy patients, identify its practice and patient and (where possible) carer perceptions.

Methods: A search strategy was formulated using a concept map and a Population, Intervention, Comparative Interaction and Outcomes ('PICO') schema. All publications from 1975 to 2015 reporting pre-operative counselling of laryngectomy patients were included. Papers were retrieved and critiqued, and those included were assigned a level of evidence (according to the Joanna Briggs Institute schema).

Results: Of the 56 papers retrieved, 21 were included in the review. The literature is limited: studies demonstrate bias and are of poor methodological quality. There are clear, persistent reports by patients and carers of shortfalls in clinical practice.

Conclusion: Studies on pre-operative counselling for laryngectomees are flawed in design and represent weak levels of evidence. Pre-operative counselling has not been operationalised, resulting in differing paradigms being examined. Aggregation of data and/or results is not possible and the veracity of many studies is questioned.

Key words: Head and Neck Neoplasms; Laryngectomy; Counseling; Information Services

Introduction

Cancer patients need good quality information to help them understand their immediate diagnosis and treatment and adapt to living with long-term uncertainty about their disease progression.[1] Evrard *et al*. reported that in surgical oncology where the options for accepting or refusing surgery are limited, most patients want detailed information before consenting to treatment, especially about potential complications.[2]

Patients with a specific diagnosis of head and neck cancer have more challenges, including the prospect of profound changes to their physical appearance, speech and/or swallowing.[1,3] Therefore, these patients may have specific needs beyond those with other cancer types.[4]

Head and neck cancer patients are a vulnerable group, characterised by high levels of tobacco and alcohol consumption and often a low socio-economic status, with a lack of social support mechanisms and a low education level, which combine to marginalise them from necessary health supports.[1,5] They are predominantly men and may not actively engage in health information seeking behaviour.[6] Therefore, they pose a challenge to health professionals because many require support to access health information and use it effectively.[7]

Schall was one of the first physicians to acknowledge that the 'mental outlook' of patients should be considered.[8] It was later recognised by Greene that a patient's emotional state may have a negative impact on their rehabilitation outcome.[9] Many authors have since stated the importance of providing patients with information prior to surgery so that they are fully aware of their probable post-operative status.[10–31]

Materials and methods

To examine the current pre-operative counselling practices regarding patients and their carers before laryngectomy and their perceptions of these services, the published literature was reviewed using a systematic search strategy comprising a concept map and a Population, Intervention, Comparative Interaction and Outcomes ('PICO') schema.[32] English language articles were sourced from the Scopus, Medline, PubMed and Google Scholar databases. All online resources were searched within a 40-year range: 1975–2015. Reference lists of the included articles were hand-searched and evaluated, as were pamphlets

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and handouts from the Irish Cancer Society and Macmillan Cancer Support.[33,34]

The following Medical Subject Headings ('MeSH') were used as search terms: 'cancer', 'head and neck cancer', 'head and neck neoplasms', 'laryngeal cancer' or 'laryngeal neoplasms', 'laryngectomy' or 'total laryngectomy', 'alaryngeal speech', 'counselling', 'rehabilitation', 'survey', and 'information'. These terms were supplemented by the following terms taken from the identified papers and by author-generated terms: 'laryngectomy patient' or 'laryngectomees', 'pre-operative education', 'pre-operative counseling' or 'pre-operative counselling', 'patient support', 'carer support', 'information needs', and 'patient information'.

Studies included in this review reported pre-operative counselling of total laryngectomy patients and/or patient and carer perceptions of such counselling.

Results

A total of 56 papers were initially retrieved and 35 of these were discarded for the following reasons: no reference to pre-operative counselling practices ($n = 23$), studies involved in surveying carers only ($n = 4$), and/or described only post-operative intervention for patients ($n = 8$). Twenty-one publications met the inclusion criteria. These included one paper in which total laryngectomy patients were surveyed along with patients diagnosed with other head and neck cancers. All papers were analysed and then allocated a level of evidence using the Joanna Briggs Institute's definitions (Table 1), in which the best quality evidence is categorised as level 1.[35] The Joanna Briggs' schema was selected because it provides extended descriptions and subdivides the lower levels of evidence. No retrieved papers contained level 1 evidence.

TABLE I

THE JOANNA BRIGGS INSTITUTE LEVELS OF EVIDENCE, 2014

Level	Description
1	Experimental designs
– 1a	Systematic review of RCTs
– 1b	Systematic review of RCTs and other study designs
– 1c	RCT
– 1d	Pseudo-RCTs
2	Quasi-experimental designs
– 2a	Systematic review of quasi-experimental studies
– 2b	Systematic review of quasi-experimental and other lower study designs
– 2c	Quasi-experimental prospectively controlled study
– 2d	Pre-test – post-test or historic / retrospective control group study
3	Observational–analytic designs
– 3a	Systematic review of comparable cohort studies
– 3b	Systematic review of comparable cohort and other lower study designs
– 3c	Cohort study with control group
– 3d	Case–controlled study
– 3e	Observational study without a control group
4	Observational–descriptive studies
– 4a	Systematic review of descriptive studies
– 4b	Cross-sectional study
– 4c	Case series
– 4d	Case study
5	Expert opinion and bench research
– 5a	Systematic review of expert opinion
– 5b	Expert consensus
– 5c	Bench research / single expert opinion

RCT = randomised controlled trial

Literature and study designs

Published studies included were from the 1970s ($n = 4$),[28–31] the 1980s ($n = 7$),[21–27] the 1990s ($n = 5$)[16–20] and the 2000s ($n = 5$),[10–13,15] with the most recent being published in 2006.[10] Most papers originated from the USA,[10,13,16,18,21,23,25–31] although there was one report from Australia,[12] four from the UK,[11,15,17,22] one from Norway,[24] one from France[19] and one from Switzerland.[20] Most authors were ENT surgeons ($n = 10$) or speech and language therapists ($n = 8$).

Study designs were predominantly quantitative[10,15,16,20,21,23–25,30] or used a mixed methods design.[12,17,22,28,29] Data were collected from postal questionnaires,[12,15,17,23,25,30] interviews[20,22,24] or both.[21,28,29] Other studies involved the use of face-to-face questioning or online questionnaires.[10,16] However, sample sizes varied significantly: smaller studies included 18–72 participants[22,30] and larger studies had sample sizes of 115–332.[20,25] In general, only summary statistics (e.g. number, percentage, frequency) were reported; statistical analyses were performed in only two published studies.[21,24] The chi-square test was used in one study to assess differences in the counselling needs of male and female laryngectomees and in another to assess the quality of pre-operative counselling and determine its influence on patients' post-operative rehabilitation and adjustment.[21,24]

As there were no comparable quantitative data across studies, a critique and narrative review were performed, which identified the following issues.

Lack of operationalising of pre-operative counselling

The main deficit in the literature was that the term 'pre-operative counselling' was not defined, which led to lack of clarity about what this constitutes. Nevertheless, this term was used by 17 of the 21 authors.[10,12,13,16,18,20–31]

A definition of 'counselling' taken from the Dictionary of Counselling 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'.[36]

Although the term 'counselling' was widely used in the studies, authors did not use the definition shown above, and this led to further problems. Counselling was largely provided by ENT surgeons and/or speech and language therapists rather than by a person trained in psychological medicine or counselling. However, one author described counselling from the perspective of a medical social worker, which may represent a more accurate use of the terminology, given their training.[18] Moreover, pre-operative counselling was limited to patients meeting and receiving information from members of a multidisciplinary team and possibly from a laryngectomised visitor.

In two UK papers, authors referred more accurately to pre-operative 'information giving'.[11,17] Ward *et al.* (Australian authors from a pre-operative counselling group) used two terms in their paper: 'pre-operative counselling' and 'information dissemination' – also defined as 'information giving'.[12] Stafford *et al.* surveyed the 'information giving' practices of ENT surgeons to develop a pre-operative counselling package for patients.[15] In 1995, Depondt and Gehanno from France referred to 'patient education', but simply meant 'informing' patients about surgery.[19]

As found for pre-operative counselling, the term 'information giving' was not operationalised in the literature. A dictionary definition of 'give' is 'freely transferring the possession of (something) to (someone)' and a definition of 'information' is 'facts provided or learned about something or someone'.[37] There are thus clear differences between the terms 'information giving' and 'counselling'.

In summary, 'information giving' is the term that best represents what most authors described, despite their use of different terminology. The terms 'pre-operative counselling' and 'information giving' were applied interchangeably and synonymously across the literature, which may lead to patients' confusion about this service.

Defining the content of pre-operative counselling or information giving

As for the terms 'pre-operative counselling' and 'pre-operative information giving', there was a similar lack of agreement about the content of such information i.e. whom it should involve, whom should provide such information, when it should occur and/or in what format (face-to-face interview, pamphlets, videos and/or CDs).

Only seven authors described the content of pre-operative counselling but this was based on their own professional opinion and experience alone (level V evidence), with no research underpinning their claims.[13,18,23,24,26,27,31] For example, in 1983, Natvig suggested that pre-operative counselling should contain three important elements: an explanation about the disease, advice about surgery and survival, and information on the consequences of surgery.[24] In 2002, Cady outlined several aspects of care that should be discussed with patients pre-operatively, including physical aspects such as stoma care and nutrition, symptom management for dysphagia and of secretions, speech therapy and the available voice options, safety issues related 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 (e.g. nicotine, alcohol).[13] In 1980, Baker and Cunningham provided a checklist for pre-operative counselling on vocal rehabilitation that included explaining the anatomy and physiology of the laryngeal area, briefly explaining the different methods of speech production available post-operatively, and supplying printed information.[27]

However, by 'pre-operative counselling', it is clear that these authors really mean 'information giving' because there is not a 'principled relationship' between the patient and the information provider with a 'predominant ethos' of 'facilitation'.[36] Feber referred to 'information giving' when evaluating a written information pack given to patients before they underwent total laryngectomy at a hospital in Leeds, UK.[17] The pack content included practical information about laryngectomy, obtaining medical 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

Several factors contributed to the poor rigour of all studies under review. Most studies were observational and descriptive (level IV evidence) using data from surveys of laryngectomees,[10,17,20–22,25,28,30] their carers,[11,12,16,24] ENT surgeons[15,23] or all three groups.[29] In addition, 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] or involved more than one UK centre,[11,15] with one survey performed across Norway[24] and one across Switzerland.[20] In six studies, there was a clear sampling bias because laryngectomees and/or carers were recruited through laryngectomy clubs and support groups and/or when attending conferences.[10,12,16,20,21,29]

In all instances, participants were asked to reflect on their past experiences, despite retrospection being limited by its reliance on subjective judgement[38] and the accurate recall of patients – some of whom may have had a psychological burden at the time of treatment.[2] The length of time since surgery was reported in six studies and these differed markedly, so it was impossible to aggregate these data.[12,20,22,25,28,30] Blanchard performed a survey of laryngectomees up to 12 months post-operatively,[25] Craven and West up to 36 months post-operatively,[22] and Minear and Lucente from 2 to 48 months post-operatively.[28] In 1978, Keith *et al.* surveyed post-laryngectomy patients from the preceding four-year period.[30] In another study by Lehman and Krebs, patients were surveyed 1–20 years post-operatively,[20] while Ward *et al.* studied patients who had undergone surgery over a 10-year period between 1990 and 2000.[12] As head and neck cancer patients are at a risk of developing significant psychosocial problems which may persist for 2–4 years after treatment,[39] caution is needed when interpreting findings from data collected at an early post-operative phase.

Some papers were 'expert opinion' pieces (level V evidence) written by professionals such as a speech and language therapist,[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 operationalisation for pre-operative counselling or information giving and the methodological flaws in the published studies, pre-operative counselling was commonly considered inadequate by laryngectomees and/or their carers.[10–12,16,17,20–22,24,25,28–30]

In a US survey by Keith *et al.*, 13 per cent of 72 patients reported that it had not been explained to them that they would not be able to speak after surgery, while 19 per cent reported not being informed about voice rehabilitation.[30] In another US study of 120 laryngectomees, 38 per cent of women ($n = 50$) and 41.2 per cent of men ($n = 68$) stated that they had not received any counselling.[21]

Zeine and Larson (1999) investigated whether pre-operative counselling had improved since the 1978 study by Keith *et al.*[16,30] In a survey of 153 laryngectomees and their spouses across the USA, 21 per cent of respondents reported that they had been unaware they would be unable to speak post-operatively.[16] Although these authors stated that pre-operative counselling was increasingly being provided, significant information gaps were identified, specifically about voice loss and rehabilitation options. Overall, the authors noted that patients' reports of inadequate pre-operative counselling showed that this had not significantly improved in the intervening 20 years.[16]

A more recent US study in 2006 highlighted persistent complaints of 150 laryngectomees who completed an online survey: 20 per cent ($n = 30$) stated they were not made aware that voice loss would occur, and only 40 per cent ($n = 60$) stated that they had pre-operative contact with a speech and language pathologist.[10]

In a UK study of 29 head and neck cancer patients, many were dissatisfied with the information they had received from the ENT surgeon and further reported difficulty in absorbing details of the conversation because treatment options were discussed at the same time as their cancer diagnosis.[11] In 1979, Johnson *et al.* reported a difference in opinion between ENT surgeons and patients and their carers on the adequacy of pre-operative counselling: ENT surgeons indicated that patients should be, and are, well informed and patients reported that further counselling was required.[29] Patient dissatisfaction may be partly explained by poor recall associated with a shocked reaction to the bad news that major surgery is necessary to treat their cancer.

Pre-operative laryngectomised visitors

A pre-operative meeting with a well-adjusted laryngectomised person is offered at many centres. A national UK audit of head and neck oncology nurses working in laryngectomy services between 2008 and 2009 reported that in 53 out of 56 regions patients were always offered a pre-operative patient visitor service.[40] Attempts were made to match the patients by sex, age, interests and their planned surgery or speech type.[40]

However, in one US survey of 60 laryngectomees, several patients expressed strong feelings about having a choice about whether or not to have a pre-operative meeting with a laryngectomised visitor.[28] This issue therefore needs careful consideration when planning pre-operative meetings for patients.

Summary

In the published papers, there was no operationalisation of pre-operative counselling for total laryngectomy patients, despite the term being frequently used. When the dictionary definition of counselling was considered, it was clear that this activity rarely occurred pre-operatively.[36]

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

Discussion

Pre-operative counselling for total laryngectomy patients remains variable. Published studies are of poor methodological quality[10–12,15–17,20–25,28–30] and often provide expert opinion (evidence level V),[13,18,19,26,27,31] rather than good research evidence. An underlying and persistent problem remains the lack of agreement on the definition of counselling and what this comprises.

There is a need for clear definitions and further research to audit and to evaluate current pre-operative counselling practices and the experiences, expectancies and preferences of laryngectomy patients to address persistent reports of shortfalls in clinical practice.[10–12,16,17,20–22,24,25,28–30]

This is a topical problem: the Australia and New Zealand Head and Neck Cancer Society is currently surveying their members to determine the accessibility and quality of head and neck cancer education. They are also examining the types and variation of resources available across Australia and New Zealand to determine how such tools might be improved. This work needs to be replicated across the UK and Ireland.

A prospective, well-designed study to compare the type of information provided by clinicians with the type of information understood by a patient cohort would help direct future research and clinical practice.[12] Current laryngectomy patients and their carers and clinicians should also be surveyed using a well-established qualitative methodology such as Grounded Theory for understanding their experiences and needs.[32] We are currently undertaking such a study, using a topic guide based on the literature with a purposely recruited sample of patients, carers, and speech and language therapists. This will include consulting a series of focus groups to reveal recurrent themes (both convergent and divergent) across and within these groups. Themes may include reported gaps in services provided, desired information (content), the optimal time, place and person(s) to deliver such information, and the preferred format(s). These data will enable the development of proactive, principled services designed to address the needs and requirements of patients and their families.

Conclusion

Total laryngectomy results in extensive physical, psychological and socio-emotional changes for patients and their families. It has long been recognised that suitable pre-operative counselling is necessary to prepare patients for this surgery. However, there is no consensus on the meaning of this term, what it should comprise or who should be involved. Literature on this topic remains limited, with reported studies being of poor methodological quality and demonstrating selection bias. There are nevertheless clear, persistent reports by patients and carers of shortfalls in clinical practice that need to be addressed by rigorous research studies.

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