Going where other methods cannot: A systematic mapping review of 25 years of qualitative research in Otolaryngology

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Presentations

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Abstract

Objective

To map the use of qualitative methods within otolaryngology, providing examples and identifying gaps in the literature.

Design

Systematic mapping review of journal-based literature from 1990 to 2015 using Medline, Embase, PsycInfo and CENTRAL. Included studies were categorized according to clinical sub-specialty, research aims and qualitative approach.

Results

Of 4,061 identified articles, 388 were deemed relevant to qualitative research in ENT. The number of qualitative publications has risen markedly over the last 25 years ($r=0.802$), particularly since 2010. The most commonly used method was semi-structured interviews 62.1% (241/388). Head & neck cancer (41.8% (162/388)) and otology (40.2% (156/388)) publish more qualitative research than rhinology (7.0% (27/388)) and laryngology (6.7% (26/388)).

Conclusions

Qualitative research in otolaryngology has increased over time, but laryngology and rhinology remain under-represented. Most studies use interviews, underutilising the strengths of other qualitative methods. There is considerable scope for further application of qualitative methods in otolaryngology.

Key words (MeSH):

Otolaryngology, qualitative research, patient care, patient reported outcome measures, decision making

Five succinct key points:

- 1) Use of qualitative methods in published ENT research has increased over the last 25 years.
- 2) This increase has not been equally distributed across the subspecialties.
- 3) Semi-structured interviews are the most commonly used qualitative methodology, potentially indicating lack of use of other methods which have their own unique strengths.
- 4) Much of the literature currently explores patient experience, but it is surprisingly deficient in important themes such as understanding decision-making.
- 5) There are numerous barriers facing the ENT surgeon planning to conduct qualitative research. We describe 5 exploratory case studies and offer advice to facilitate use of qualitative methods in ENT research.

Introduction

Historically, research in otolaryngology has been predominantly quantitative in nature, employing approaches such as the randomised controlled trial, case-control studies and structured surveys. However, in the twentieth century and beyond there has been increasing recognition of the patient not only as a biological entity but as a social being (1) and of the implications that this has for prevention, management and living with illness. Alongside this has been the growth of the disability rights movement, the development of the patient as an equal partner in healthcare decision making and the recognition that some experiences are not easily captured by quantitative methods (2). These changes brought a desire to access patients' accounts of their experiences of illness and health care from their own standpoint, rather than based on categories pre-determined by researchers. Health researchers began to turn to qualitative research, an approach originating in the social sciences, to find new ways of understanding and engaging with health problems.

Qualitative research is not a single approach but a range of methods underpinned by different theoretical frameworks. In a similar way to quantitative research, there are a range of methods of collecting data (examples include, but are not limited to; semi-structured interviews, focus groups, observational methods, document analysis) and analysing data (such as, but not exhaustively; framework analysis, grounded theory, interpretive phenomenological analysis, conversation analysis). Although qualitative research is broadly concerned with words rather than numbers, it is perhaps more helpfully defined in terms of its aims and objectives. If quantitative research addresses "how much" questions, qualitative research is more concerned with questions of "what", "how" and "why". Where quantitative research can tell us, for example, how many people have hearing loss, measure this in decibels, and quantify the impact of hearing loss using a patient reported quality of life measure, qualitative research can ask: "What does hearing loss mean to you?" or "Why do some people wear their hearing aids consistently but others choose not to?". Detailed introductions to qualitative methods and to qualitative health research have been provided by a number of other authors (3) (4) (5).

Growing appreciation that qualitative research offers a different and helpful perspective on health problems; complementing rather than opposing quantitative

research, has seen the increasing use of this research approach. In health research, qualitative research may be used alongside quantitative research in “mixed methods” studies. Mixed methods studies combine aspects of both qualitative and quantitative methodologies to provide a more comprehensive understanding than would be possible using the two approaches in isolation. For example, mixed methods studies have been used to help researchers to better understand the findings of randomised controlled trials (6) (7) (8) and to develop patient-reported outcome measures (9).

Following the spread of qualitative methods from their initial uptake in nursing and primary care to areas such as dentistry and surgery, maps have been provided of their use in some areas of health research (10) (11). To date, however, little is known of qualitative research in otolaryngology. The practice of otolaryngology provides the physician with readily observable anatomy and treatments have a potentially significant impact on function, quality of life and cosmesis; all notoriously difficult notions to quantify (12). Qualitative research in otolaryngology should be of great interest to ENT surgeons. To show how qualitative research can be used in ENT, to map current use of qualitative research in ENT and identify areas where further research could enhance patient care, we conducted a systematic review of qualitative research in ENT over 25 years from 1990 to 2015.

Materials and methods

A systematic mapping review of journal-based literature was conducted by a team including two otolaryngologists (DH, MM), an information specialist (SR), and a social scientist (NR). Medline, Embase, CENTRAL and PsychInfo were searched for papers published between 1990 and 2015 (we chose 1990 as our cut off as an initial scoping search indicated very few qualitative papers in ENT prior to this date). Initial electronic database searches were conducted in August 2013, and an updated search was conducted in June 2015. ENT research was identified using the Cochrane ENT group search strategy as a guide and was limited to English language articles only. Search filters which limited results to qualitative studies only were also applied (13) (14). The results of the initial search were checked to ensure that known qualitative ENT papers were included among those papers identified – changes were made to broaden the qualitative search terms as a result of this check (see appendix A for final medline

search strategy). Duplicate references in different databases were identified and de-duplication conducted.

An initial screening process based on the abstract was conducted by NR, DH and MM. Studies were classified as in/out and unsure – those in the unsure category were reviewed by a second person and discussed if necessary. Studies were excluded if it was felt that the primary focus was not otolaryngology. An example of this was papers about the experiences of people with deafness in education. Also excluded were articles which did not present original qualitative data (editorials, for example), meta-syntheses (though the individual papers within the synthesis could be included), and PhD theses (published papers resulting from PhD work were included). Mixed methods studies were included where the qualitative component was described in detail and qualitative data presented. In keeping with other systematic mapping reviews, which aim to categorise research across a broad topic area rather than provide in-depth critical analysis of a more focused clinical question, there were no in/exclusion criteria relating to the quality of identified papers (15) (16).

During the screening process, an initial coding frame for the included papers was developed based on iterative examination of the literature and researcher experience. DH and NR cooperatively developed lists of codes. Some codes were agreed with little difficulty (e.g. sub-specialty), others (particularly those within primary purpose of research) took a number of iterations before the final list of codes was confirmed (an example is the “access to healthcare” code which combined earlier codes including “early detection” and “help seeking”). Categories for coding were: primary purpose of research (e.g. to understand patients’ experiences of a condition); primary method (e.g. semi-structured interview); country in which research was conducted; sub-specialty of otolaryngology (e.g. laryngology). After an initial period in which the coding frame was refined and consistency of coding was checked between coders, coding was applied to each paper by DH and NR. In most cases coding was performed on the basis of the abstract, however where necessary reference was made to the full published paper. During the coding process, closer examination of papers meant that some previously included papers were deemed to fall out with the inclusion criteria for the study. Upon completion of coding, coded data was exported to Microsoft Excel™ for data analysis (MM).

Results and analysis

After deduplication 4,061 articles were identified from the database search. After screening of abstracts and application of inclusion criteria 388 studies were deemed relevant and included in our analysis (fig.1).

Changes in qualitative literature over time and by geography

There was a strong positive increase in the number of qualitative studies published over the last 25 years (from only 2 studies in 1990, to 53 in 2014; $r=0.802$, excluding incomplete 2015 data), as can be seen in figure 2. We found that the publication rate of qualitative research in otolaryngology varies greatly by country. As might be expected given the English language inclusion criteria, the UK and USA dominated the literature (25.8% [100/388] and 24.2% [94/388] respectively), followed by Sweden (9.5%, 37/388), Canada (9.2%, 36/388), and Australia (8.0%, 31/388). No other individual country made a relative contribution of greater than 3%.

Predominant research themes and methods

Studies were categorised according to their primary purpose (fig. 3). The largest category of studies (136 of 388 papers (35.1% of all papers)) addressed questions concerning the patient or carer's experience of a particular health condition. Other common themes in the literature included how patients experience healthcare (18.8%; 73/388), evaluation of interventions (10.1%; 39/388), and questionnaire development (8.8%; 34/388). Less common was the use of qualitative research in intervention development (4.1%; 16/388) or for understanding trial processes (1.0%; 4/388).

The most frequently utilised method was the semi-structured interview (62.1%; 241/388) followed by focus groups (10.8%; 42/388), and mixed method studies (8.5%; 33/388). Rarely were documentary (3.6%; 11/388) or observational studies (1.8%; 7/388) employed (fig. 4).

Qualitative research by subspecialty

Publication rates varied greatly between ENT subspecialties. Qualitative articles were, by far, more common in head & neck cancer and otology at 41.8% (162/388) and 40.2% (156/388) respectively. Rhinology (27/388) and laryngology (26/388), by contrast, only represented 7.0% and 6.7% respectively.

Discussion

The overall publication rate of qualitative research in otolaryngology has increased over the last 25 years and head & neck cancer and otology were the sub-specialities most frequently employing this approach. The most commonly utilised methodologies were semi-structured interviews, but there are multiple other methods with unique advantages that are presently underutilised in ENT (such as analysis of documentary evidence and observation data). The majority of studies come from either the UK or the USA, providing scope for more research in other countries which might face unique challenges. Laryngology and rhinology are relatively deficient in qualitative studies and represent unexplored avenues to understand and improve patient care.

Changes in literature over time

Our data indicate a dramatic rise in the publication rate of qualitative studies in otolaryngology from 1990-2015. This interval was selected to provide an overview of recent historical trends. Even before the millennium, the rise of qualitative studies in other fields, such as psychology (17), palliative care (18), infectious diseases (19), and intensive care (20) has been noted. More recently in 2011, output analysis of nine major health services and management journals found that qualitative research comprised 9% of research articles (21).

Such trends are likely reflective of the increasing recognition of the strengths of qualitative research, and their uses in healthcare (22). As we have demonstrated in this paper, qualitative methods allow researchers to develop complex interventions, assess them more thoroughly and identify barriers to their implementation. As surgery is often a complex intervention itself with many competing variables in its delivery and outcome, the discipline stands to benefit greatly from the advantages that qualitative research brings. Increased interest in qualitative methods in medical practice more generally may also reflect a renewed effort to address calls to combine qualitative and quantitative research, in order to compensate for the deficiencies created by using individual methods alone (23) (24).

Qualitative research themes in otolaryngology

The majority of qualitative research in ENT is evaluating human views; such as how patients feel about either their disease or their experience of healthcare. Such

research tasks are exploratory and, although quantitative analysis might follow such studies, the open-ended nature of qualitative methods allow for discovery of patient opinions (25). For example case study 1 (26) demonstrates use of qualitative methods to improve our understanding what patients think of professionally-derived guidelines. The results of this study were felt to be so impactful they went on to change national guidelines, improving existing management recommendations.

Although extensive research investigating patient experience is to be commended, our results indicate under-utilisation of qualitative research for other important research themes such as informing trial processes, understanding decision-making and questionnaire development. These concepts are clearly important, but together these three categories comprise less than 15% of the qualitative ENT literature. It is also notable that relatively few studies examined the views of healthcare professionals.

A good example of how qualitative research can optimize trial processes is the investigation of poor recruitment of patients to the EaStER (Early Stage glottic cancer: Endoscopic excision or Radiotherapy) trial (8). This paper, outlined in case study 2, highlighted study protocols, logistical issues, and training of recruiters as barriers which, if overcome, will enable more effective recruitment. This study was also relatively unusual in employing additional qualitative methods as well as interviews – recording and analyzing trial recruitment conversations so that the detail of the interaction between clinician and patient and its impact on study recruitment could be understood.

Other neglected research themes include decision-making; both of patients and of clinicians. Understanding decision-making is of vital importance in ENT, for example demonstrating which factors are important to a patient in refusing a laryngectomy or investigating why some consultants prefer certain tonsillectomy techniques. A good example of where one such study added to our knowledge is described in case study 3 (9). This qualitative investigation into decision-making regarding whether or not to accept a bilateral cochlear implant used semi-structured interviews to inform clinicians that parents often do value a second implant, and provided information that will be useful in counselling patients prior to surgery and in managing expectations of the technology.

Qualitative methods can also be used to as a tool to design and develop, rather than evaluate or assess. For example in case study 4 Morris et al. use semi-structured interviews to create a novel, robust, self-reported measure to assess outcomes following vestibular rehabilitation in patients with dizziness (9).

Qualitative methods can also inform the development and implementation of new healthcare interventions, helping to design technologies and services which are acceptable to patients and clinicians and feasible to implement, for example highlighting unforeseen negative impacts of surgical safety checklists on staff routines in the operating theatre (27), or studying the integration of robotic surgery into routine care (28). Further examples of the use of qualitative research in otolaryngology are shown in table 1.

Publication of qualitative studies in ENT by subspecialty

Laryngology and rhinology have relatively low publications rates of qualitative research but stand to significantly benefit from this method of enquiry. Laryngology involves disorders of voice which can be relatively easily quantified such as by volume (Db) and frequency (Hz). However, the human experience of voice is often complex and therefore qualitative research has a role in improving our understanding of how disease of the vocal cords and larynx can affect the functionality of a patient's voice and their quality of life.

Similarly, the practice of rhinology is heavily linked with the perception of cosmesis but was identified as making a relatively small contribution to the qualitative literature. Cosmesis is notoriously difficult to quantify, and therefore it is likely that further qualitative research will be beneficial in this subspecialty. An example of such a study, by Gulbas et al. (case study 5), investigated the effect of patient race on motivating a decision to undergo cosmetic surgery (29). A mixture of cultural domain analysis and qualitative interviews elucidated the complex relationship between race and cosmetic surgical preferences, and can be used to help inform patient decision-making in surgical consultations.

Utilisation of qualitative methods - barriers and advice

As in a quantitative paradigm, differing qualitative methods have differing strengths and weaknesses, therefore, some are better suited to answering particular kinds of

questions than others. In case study 1 Richardson et al. used focus groups to enable patients to comment together on clinical guidelines (26). Their investigation provided essential insight into how to apply these guidelines in the context of patient-centered medicine to make decisions with a patient rather than for them (30).

Almost two thirds of studies in our analysis were conducted using semi-structured interviews, with most other methods scarcely used. A similar dominance of semi-structured interviews over other qualitative data collection methods was found in surgery and dental research (10) (11). Semi-structured interviews provide a method of gathering rich data about individuals, thoughts, and understandings; however, these are not suited to all types of research question. Although most people are familiar with a range of interview forms, being asked to explain their thoughts and actions remains an unnatural situation for many people which can be potentially compounded by cultural or power imbalances between interviewer and interviewee. It is also rarely a good way of establishing the detail of what took place during any particular event (although it is an excellent way of obtaining insight into how people felt about those events). Direct observation, e.g. through video or audio recording, enables a closer examination of naturally occurring events, such as patient-clinician interactions, proceedings on an in-patient ward, or in theatre (31). For example, analysis of audio-recordings of trial recruitment conversations in case study 2 revealed that the language used to describe the trial interventions was an important factor in patient decision making. Narrative inquiry analysis of documentary evidence could also be employed in ENT, for example examination of patient feedback diaries to help understand issues that arise in clinical consultations, or to identify aspects of a patient's pathway from hospital admission to discharge that could be improved.

Wider collaboration between ENT clinicians and social scientists could encourage diversification in the range of qualitative methods available in ENT research. We did not attempt to assess who was driving the investigations that we identified (social scientist, clinician etc.). There may be a tendency for social scientists to produce work which is more academic and theory-informed, and for clinician-led research to be more practice-orientated, which itself may be secondary to the research methods they are exposed to during their training. Close and active collaboration, ideally also involving patients in research design, should lead to more research that is both rigorous and relevant.

Limitations of study

Whilst this study has provided a summary of the state of the literature, several limitations to this systematic review exist.

Firstly, our search only considered articles in English language, which potentially underestimates the prevalence (and selection) of qualitative research methods in ENT globally.

Secondly, whilst we searched multiple electronic databases in our original literature review, there is the distinct possibility of missing studies; again, underestimating the use of qualitative methods in ENT. In particular, allied health professionals have traditionally played a leading role in qualitative health research and including the CINAHL database might have identified additional nursing and allied health professional research relevant to ENT. Similarly, the categories developed in our analysis may reflect the interests and priorities of the research team which included otolaryngologists and social scientists but not nurses or allied health professionals.

Thirdly, we were only able to assess published qualitative research, however this is unlikely to encompass all qualitative research that has occurred. It is well recognized that qualitative research can face challenges when seeking publication (22). It is also possible that much qualitative research exists in 'grey literature', which was not analysed in this review. This indicates our summary may provide an underestimate of the prevalence of qualitative research. It may also help explain the historically low numbers of qualitative studies, as shown in figure 2.

As far as we are aware this is the first published attempt to systematically map the qualitative literature in ENT but this is not the only potential summary of the qualitative data in this field and we hope that other researchers will use our findings as a starting point for their own research. We also recommend that they consult with experienced qualitative researchers; particularly social scientists and experienced allied health professionals within their multidisciplinary teams.

This paper did not attempt to assess the quality of included studies or their potential for impact and patient benefit (32). These and other dimensions could usefully be explored in future research.

Conclusion

The use of qualitative research in ENT is rapidly increasing, however it remains underutilized in potentially fruitful areas of research (such as understanding patient and clinician decision making, improving trial processes and development of new healthcare interventions) and certain clinical subspecialties (such as rhinology and laryngology). Otolaryngology stands to benefit greatly from qualitative research given the invasive nature of some of its interventions, important cosmetic and functional implications, the implications on the senses. In particular, the strengths of methods other than semi-structured interviews, and exploration of healthcare professional views, have yet to be fully realized. In this review we have highlighted the potential of qualitative research to augment well-established quantitative techniques in this specialty and encourage researchers to exploit the strengths of qualitative and mixed methods studies to improve patient care and outcomes.

Case studies

Case study 1: Getting the full picture – understanding what the patient thinks

Richardson, A., Lee, L. & Birchall, M. 'Learning from patients with cancer and their spouses: a focus group study'. Journal of Laryngology & Otology (2002) **116**: 1028-35.

Summary: Richardson et al. ran focus groups with Head & Neck cancer patients and their carers to investigate their opinion on professionally-derived standards of care, in order to improve patient participation in guidelines development.

What this paper added: Focus groups, especially when re-convened on more than one occasion, allow patients to meaningfully share their views on professionally-derived standards and can contribute to guideline development. National (BAO-HNS) standards were modified as a result.

Case study 2: Understanding processes – where do things go wrong and why?

Hamilton, D., W., De Salis, I., Donovan, J., L. & Birchall, M. 'The recruitment of patients to trials in head and neck cancer: a qualitative study of the EaStER trial of treatments for early laryngeal cancer'. European archives of oto-rhino-laryngology (2013) 270(8):2333-7.

Summary: Hamilton et al. sought to understand barriers to recruitment to a clinical trial through the use of semi-structured interviews, focus groups and audio recordings involving trial staff.

What this paper added: An understanding that important factors in trial recruitment include; agreement amongst clinicians of trial protocol, logistical issues at individual centres, and lack of appropriate training for recruiters.

Case study 3: Development and evaluation of clinical tools

Morris, A., E., Lutman, M., E. & Yardley, L. 'Measuring outcome from Vestibular Rehabilitation (VR), Part I: Qualitative development of a new self-report measure'. International Journal of Audiology (2008) 47(4):169-77.

Summary: Morris et al. identified that all then existing tools to assess treatment outcomes following VR had limitations. They interviewed patients undergoing VR sought to identify themes that were important to patients in terms of outcome on quality of life.

What this paper added: This study identified 64 themes of which 35 were selected for use as a new tool in evaluating outcomes after VR. A quarter of these items addressed issues not covered by previous tools.

Case study 4: Development and evaluation of clinical tools

Fitzpatrick, E. M., Jacques, J., Neuss, D. Parental perspectives on decision-making and outcomes in pediatric bilateral cochlear implantation. *International Journal of Audiology* (2011) 11;50(10):679-87.

Summary: Using semi-structured interviews this study informed clinicians that parents often do value a second cochlear implant.

What this paper added: This paper highlighted a number of important factors to counsel parents of patients about pre-operatively and helps clinicians manage expectations.

Case study 5: Evaluating concepts difficult to quantify

Gulbas, L. 'Embodying Racism: Race, Rhinoplasty, and Self-Esteem in Venezuela'. *Qualitative Health Research* (2012) 23(3) 326-355.

Summary: Gulbas investigates the multifaceted relationship between race and a woman's decision to undergo aesthetic rhinoplasty in Caracas, Venezuela. Qualitative methods included domain analysis and thematic analysis of qualitative interviews.

What this paper added: This work generated a new understanding of how Venezuelan women view their bodies in terms of race and how this links to their choice to undergo rhinoplasty.

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Inclusion	Exclusion
<ul style="list-style-type: none"> • Focus of paper is relevant to a sub-specialty of ENT (laryngology; otology, head and neck cancer; rhinology) • Journal article reporting original qualitative or mixed methods research • Journal article referenced in Medline, Embase, CENTRAL, PsychInfo • English language • Published between 1990-2015 	<ul style="list-style-type: none"> • Primary focus is not ENT (e.g. experiences of people with hearing loss in education) • Paper mentions a qualitative study component but presents no qualitative data. • Editorials, meta-syntheses, PhD theses (though related individual journal articles were included)

Box 1: Inclusion and exclusion criteria for literature search

Figure 1: Flow diagram of literature review process

Figure 2: Change in publication of qualitative articles over time.

Figure 3: Predominant qualitative research themes in otolaryngology

Figure 4: Methods of qualitative research used in ENT

Table 1: Uses of qualitative research in ENT with relevant case examples.

Research theme	Example study
Assessing access to healthcare	Post-treatment care pathway in long-term survivors of head and neck cancer with oral and/or facial prosthesis (33)
Decision making	Specialty group differences over tonsillectomy: pediatricians versus otolaryngologists (34)
Experiences of healthcare	When expectation meets experience: parents' recollections of and experiences with a child diagnosed with hearing loss soon after birth (35)
Intervention development	A proposed new model of follow-up for patients with head and neck cancer (36)
Intervention evaluation	Conversation repair and adult cochlear implantation: A qualitative case study (37)
Patient or carer health experience	Quality of life after total glosso-laryngectomy (38)
Practitioner experience or understanding	A qualitative analysis of faculty motivation to participate in otolaryngology simulation boot camps (39)
Questionnaire development	The development and validation of a quality-of-life questionnaire for head and neck cancer patients with enteral feeding tubes: The QOL-EF (40)

Trial processes	The recruitment of patients to trials in head and neck cancer: a qualitative study of the EaStER trial of treatments for early laryngeal cancer (8)
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