

Main Article

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Presented at British Academic Conference of Otolaryngology, 10–12 January 2021, online.

Cite this article: de Cates C, Jashek-Ahmed F, Bohara RB, Salter C, Youngs R. How chronic ear disease affects quality of life: a qualitative research study in Nepal. *J Laryngol Otol* 2023; **137**:390–397. <https://doi.org/10.1017/S0022215122001050>

Accepted: 12 April 2022

First published online: 29 April 2022

Key words:

Ear Diseases; Hearing Loss; Quality Of Life; Nepal; Public Health; Qualitative Research; Global Burden Of Disease

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How chronic ear disease affects quality of life: a qualitative research study in Nepal

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Abstract

Objective. Hearing loss is the third leading cause globally for ‘years lived with disability’. The majority of those affected live in low and middle-income countries.

Method. This study used qualitative research methods to explore the impact of chronic ear disease on quality of life in Nepal. Twenty face-to-face semi-structured interviews were conducted during a visiting ear camp at the Britain Nepal Otolaryngology Service Ear Care Centre in Nepal. Interviews were recorded, transcribed and translated with thematic content analysis performed manually by two researchers.

Results. Chronic ear disease has a significant impact on social interactions, emotional well-being and functionality. Barriers to surgery are cost, accessibility, reputation, gender and fear of complications.

Conclusion. This study provided valuable new insight into patient perspectives on living with chronic ear disease in Nepal. Patients with chronic ear disease experience discrimination and stigmatisation across all levels of personal, family and social life, with their function across all domains being directly limited by symptoms.

Introduction

A total of 5.4 per cent of the world’s population, or 430 million people, currently live with disabling hearing loss.² Over 90 per cent of those affected live in low and middle-income countries in South Asia, Asia Pacific and sub-Saharan Africa where there is extremely limited, if any, access to an ENT specialist. The burden of untreated disease is therefore very high, and hearing loss ranks third in the 2019 Global Burden of Disease rankings for ‘years lived with disability’.¹

Chronic suppurative otitis media (CSOM) describes chronic inflammation of the middle ear that is characterised by a perforated tympanic membrane and persistent or intermittent discharge, with or without cholesteatoma, with the latter being more likely to also present with life-threatening complications. It typically manifests as otorrhoea and hearing loss. If left untreated, infection in CSOM may spread extracranially (causing mastoiditis or facial paralysis) or intracranially (causing a cerebral abscess or meningitis).³

The negative effects of living with chronic disease are well documented and on a personal level can affect physical, emotional, social and financial well-being. These in turn can impact public health on a larger scale through reduced productivity, increased unemployment and reduced gross domestic product. The World Health Organization (WHO) estimates that the annual global cost of unaddressed hearing loss is currently approximately US\$ 980 billion.²

Hearing impairment has been linked to greater poverty, reduced educational attainment and higher unemployment rates in the USA.^{4,5} In developing countries with pre-existing high unemployment and poverty levels these issues are likely to be amplified; ‘children with hearing loss and deafness rarely receive any schooling’, and of the adults who are in work, they are likely to be ‘in the lower grades of employment compared with the general workforce’.⁶

Quality of life (QoL), once described as ‘the missing measurement in healthcare’,⁷ is now increasingly regarded as a key component in understanding social determinants of health and estimating the burden of disease. It is defined by the WHO as ‘an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns’.⁸

To date, a number of quantitative studies have explored the links between QoL and chronic ear disease or hearing impairment. There is however a dearth of qualitative literature on the topic, and to our knowledge there has only been one such study previously conducted in Nepal.⁹ Qualitative research is particularly useful for exploring QoL as it places emphasis on the experiences and views of the participants in a way that quantitative research cannot.¹⁰

The Britain Nepal Otology Service has been providing a community-based ear programme in Western Nepal since 2006.¹¹ The programme is largely delivered by community ear assistants who are non-physician healthcare workers who have undergone intensive training in the prevention, diagnosis and treatment of ear disease. Two to three times a year this service is augmented by visiting surgical teams composed of British and Nepali otologists, anaesthetists, nurses and audiologists who undertake intensive 'ear camps'. During an 'ear camp' approximately 120 major middle-ear operations (myringoplasty, mastoidectomy and stapedotomy) are undertaken over a two-week period in the Britain Nepal Otology Service Ear Care Centre in Nepalgunj for patients who would otherwise be mostly unable to afford the surgery.¹² Nepalgunj is a city in the Terai region of Nepal near the southern border with India, and the Britain Nepal Otology Service Ear Care Centre is a modern centre providing facilities for ear surgery. This ethos of providing high level specialist care in the ear camp setting has been shown to be safe and effective with outcomes linked to pathology and number of years running.

This study, which took place at the 64th Britain Nepal Otology Service ear camp in March 2019, aimed to use qualitative research to explore the impact of chronic ear disease and hearing impairment on quality of life in Nepal.

Materials and methods

Recruitment

This study was carried out during the 64th Britain Nepal Otology Service ear camp at the Britain Nepal Otology Service Ear Care Centre, Nepalgunj, Nepal in March 2019. The study was approved by the institutional review board of the Britain Nepal Otology Service and the Britain Nepal Otology Service Ear Health Community Service in Nepal.

Patients attending the ear camp had been recruited from the Britain Nepal Otology Service outreach programme. Patients were recruited through simple random sampling on the day of surgery from the pre-operative waiting room. The following inclusion criteria were applied: (1) age equal to or greater than 16 years and (2) chronic ear disease awaiting surgery. Recruitment took place over four days. Informed written consent was obtained from each participant using a professionally translated consent form. The study and consent form were explained and read aloud by a Nepali community ear care worker to patients who were unable to read themselves.

Procedure

Face-to-face semi-structured interviews took place in a private room in the clinic on the day of surgery. These were conducted by one of the principal researchers (FJ-A or CdC) and translated in real-time by another researcher (RBB), a native community ear care worker who is fluent in English. Interviews lasted 15–40 minutes and were modelled on the interview guide (Appendix 1) with the aim of exploring the themes of: life with family and friends, school, work, and health expectations. Basic patient demographic information was also recorded. The interviews were audio-recorded, translated and transcribed contemporaneously.

After the first 10 interviews, a preliminary review of the results was conducted to ensure the appropriateness of the methodology. Although none of these interviews were subsequently excluded and no changes were made to the interview

guide, the interviewing methodology was changed, and the Nepali speaking researcher (RBB) conducted the remaining interviews. These were still translated contemporaneously, allowing the other researchers to follow the interview guide and prompt if required. A second translator, a Nepalese doctor who was fluent in English and independent of the interviews and data analysis, reviewed three of the audio files and transcripts to ensure accurate and reliable translations.

Data analysis

Data analysis was performed manually by the principal researchers (FJ-A and CdC) and included the following. (1) Familiarisation with data: transcripts and audio recordings were re-reviewed and preliminary ideas and concepts were noted. (2) Identification of preliminary themes: deductive and inductive approaches were used by two of the researchers (FJ-A and CdC) to identify preliminary themes based on both the predetermined concepts of life with family and friends, school, work, and health expectations, and new concepts identified during data familiarisation. (3) Open coding: themes were then refined into a set of codes by one of the authors (FJ-A) and reviewed by a second author (CdC). (4) Framework construction: a working thematic framework was established by grouping codes with similar content into themes and sub-themes. (5) Indexing: the codes were then applied across and within the whole dataset by both FJ-A and CdC independently, and any discrepancy between the authors was resolved through discussion. This was then indexed into the framework to allow reading across and interpretation of the entire dataset. There was no blinding of the study, and all researchers were involved in the study.

Results

Participants

A total of 20 participants were recruited to the study and included in the data analysis. The median age was 35 years (range, 16–54 years), and 11 participants were male. The median travel distance was 140 km (range, 5–1580 km, rounded to nearest 5 km). They had travelled from a total of 13 districts, some remote and mountainous, as well as from across the border in India. Included participants all had a diagnosis of unilateral or bilateral chronic otitis media. Patient characteristics are presented in [Table 1](#).

Thematic analysis

Thematic analysis identified five themes: impact on social interactions, emotional impact, functional impact, health-seeking behaviour and attitudes to surgery. Within the themes, a number of sub-themes were identified ([Table 2](#)). We have presented some quotations to further illustrate these. Further verbatim quotations can be found in [Appendix 1](#).

Theme 1: impact on social interactions

Participants described the impact of chronic ear disease in family, social, work and school environments.

Frustration of others

Participants described the frustrations of friends and family at having to repeat what they say over and over again. This

Table 1. Participant characteristics*

Parameter	Value
Sex (<i>n</i>)	
– Male	11
– Female	9
– Age (median (range); years)	35 (16–54)
– Distance travelled to nearest 5 km (median (range); km)	140 (5–1580)
Symptoms (<i>n</i>)	
– Unilateral	12
– Bilateral	8
Education (<i>n</i>)	
– Completed secondary school (class 10)	2
– Not completed secondary school	14
– Unknown	4
Employment (<i>n</i>)	
– Farmer	7
– Housewife	3
– Barber	2
– Shop assistant	2
– Teacher	1
– Kitchen assistant	1
– Aluminium worker	1
– Student	1
– Driver	1

**n* = 20

frustration even extended to verbal abuse, anger and in one case physical violence:

‘I only went to school for 10–15 days. My teacher beat me because I didn’t listen properly and then it happened again the next day. That’s the reason why I left school’ (participant 14, age 16, male).

Anticipated stigma

Female participants exclusively were worried about how their symptoms, especially ear discharge and hearing loss, would affect how others would behave towards them. One participant mentioned:

‘If I have discharge they will think I am dirty and not sit with me’ (participant 1, age 20, female).

Another participant was so worried about what other people would think that she was hesitant to attend social gatherings in case she met new people. One participant, who married into a higher caste was so afraid about what her husband and in-laws might say that she hid her symptoms for 21 years. This sub-theme did not arise in any interviews with male participants.

Impact of ear discharge

Ear discharge was described as a driver for teasing, with one participant reporting:

‘My friends used to tease me about smelly ear discharge’ (participant 16, age 30, male),

Table 2. Themes and sub-themes

Theme	Sub-theme
1. Impact on social interactions	Frustration of others
	Anticipated stigma
	Impact of ear discharge
2. Emotional Impact	Positive social interactions
	Sadness
	Burden to others
3. Functional Impact	Fear
	Activity limitation
4. Health-seeking behaviour	Coping mechanisms
	Previous healthcare interactions
5. Attitudes towards surgery	Barriers to previous surgery
	Motivations for surgery
	Funding surgery
	Aspirations

and another mentioning negative behaviour from her husband.

Positive social interactions

However, many participants also described positive social interactions, especially with their family, and described their spouses and children as being understanding, by speaking louder for example. Furthermore, many of the patients described incidences of relying on others (see coping mechanisms), hearing about the Britain Nepal Otolaryngology Service and the ear camps from others (see motivations for surgery), and receiving financial aid from friends, relatives and communities for the operations (see funding for surgery).

Theme 2: emotional impact

Sadness

Many participants described the feeling of sadness in relation to their symptoms with one participant commenting that his ‘general life is bad and difficult due to hearing loss’ (participant 2, age 19, male). In some cases these feelings had been present persistently since childhood and in others only when the symptoms were particularly troublesome. The sadness was often attributed to the feeling of being different from others and having to make functional adjustments, such as a driver who struggled to hear people sitting on his left-hand side meaning he had to stop his car to hear. Some participants also mentioned sadness from having to endure teasing and cruel behaviour.

Burden to others

Participants described finding it difficult or worrying to ask others to adapt their behaviours to help them hear. One participant reported how frustrated people get when he asked them to talk slowly or repeat things. Other participants mentioned their teachers getting angry or how they felt bad for using sign language.

Fear

Some participants expressed fear of health complications, such as developing a brain abscess, and one participant believed she might die without the operation, saying

'Someone told me I might die without an operation' (participant 15, age 40, female).

Theme 3: functional impact

Activity limitation

Almost all the participants described examples of how their chronic ear disease had been limiting in environments such as the workplace, school or community gatherings.

School

Although a number of participants said they left school because of ear related problems, it is also important to highlight that some female participants never attended school at all, and other participants left school for other reasons. One participant explained how he left school in part because of his hearing loss.

Work

Participants gave varied reports of the way in which their symptoms affected work. These included regular but manageable disruptions, such as cleaning their ear all the time. Some participants experienced limiting career progression because of their hearing loss, with one participant being unable to benefit from training at work, saying:

'I have difficulty hearing when they give training for farmers on how to grow vegetables' (participant 8, age 54, male).

Some participants even had to stop work or change career because of safety concerns.

Community and social

Participants described reluctance to attend community or social gatherings because of their symptoms. One participant told us how he was putting off marriage because of his ear problem. A female participant explained that she would not go to group meetings because she could not hear, and another relied on friends to tell him what was said at them.

Coping mechanisms

Coping mechanisms included those that allowed participants to hear better, such as asking others to speak louder, slower, repeat things and change position, those that treated the problem itself, such as medicines or cleaning the ears, those that allowed the participant to hide their symptoms and those that relied on the assistance of others.

Augmented communication skills

Several participants explained ways in which they augmented communication skills. For example, one participant mentioned:

'I have to ask people to talk slowly and repeat things again' (participant 14, age 16, male)

and another mentioned sitting at the front in the classroom.

Masking the problem

This was another area that showed some gender imbalance where only female participants described attempts to hide their ear problems. One explained:

'I used to cover my ears with my hair so that people wouldn't see' (participant 11, age 35, female),

and another talked about being clever to conceal the ear discharge. One female participant even sat away from her friends because she was so worried about the foul-smelling discharge.

Reliance on others

Several participants reported how reliant they were on others for support. One participant who worked in a hotel kitchen would ask his colleagues to send voice-notes because he could not hear properly, and another participant also worked with the help of sign language.

Theme 4: health-seeking behaviour

Previous healthcare interactions

Participants described a range of healthcare seeking behaviours. Two participants (both women) had never previously sought medical help for their symptoms. Some mentioned community remedies:

'I've been to different hospitals and clinics in both India and Nepal. In the village, many people said that if you put pigeon blood inside [the ear] it may help. They also suggested alcohol in the ear to help with discharge. I also tried this. And I also tried crushed marigold flower in the ear. These were all tried when I was much younger in class 6/7 by my parents' (participant 11, age 35, female).

Where some had only ever attended their local medical post, others had seen multiple health professionals in both primary and secondary care, and several described visiting clinics in India. One patient, who had gone to Saudi Arabia for work, sought medical help there.

Barriers to previous surgery

Several participants had previously been told they would benefit from an operation. The most cited barrier to previous surgery was cost. Participants also mentioned fear of the operation and its complications, such as one participant who said:

'10 years ago the doctor at the hospital advised an operation but someone told me my face would be paralysed as a complication, so I was scared' (participant 9, age 44, female).

A lack of faith in the healthcare professionals or hospitals, a lack of treatment facilities and conflicting medical opinions were other reasons for having avoided surgery previously.

Theme 5: surgery with Britain Nepal Otology Service

Motivation for surgery at the ear camp

The main motive for surgery at the Britain Nepal Otology Service ear camp was symptom control. Many participants had heard of the Britain Nepal Otology Service via recommendations from friends or relatives, whereas others, especially those from Surkhet and Kailali, had not previously heard of the ear camp but were recruited through the outreach programme. Participants also cited health concerns and gaining independence as motives for surgery, with one even reporting the fear of a brain abscess being her motivation.

Funding surgery

Participants commented on the cheaper cost of surgery at the ear camp compared with other institutions, and for one participant they could only afford to have the surgery because it was cheaper at the Britain Nepal Otology Service.

They funded the operation in a number of ways; for example, for those who came from Surkhet, the operation was paid for by a local political organisation. Others could afford to pay for the operation through their work, their husband's work or by selling animals.

Some participants borrowed the money from either friends, family or communities. For example, one mentioned

'In my area, there is a family group where we pay 100 rupees each month. If there are any problems you ask from that fund and after the operation you pay the money back with interest' (participant 9, age 44, female).

Aspirations after surgery

Many participants hoped that their work life would improve post-surgery, with one participant hoping to be able to hear a whistle so that he could operate the cranes in his workplace and another saying:

'If I hear better after the operation I will do business ... then I can help my children study in school ... All my family members rely on me' (participant 13, age 38, male).

Others hoped that they would feel happier, be more accepted, develop independence, get married or further their education. When asked what one participant hoped would improve following the operation, she replied

'I would love more love from the family' (participant 15, age 40, female).

Discussion

The findings of this study provide some understanding of the impact of chronic ear disease on QoL from the perspective of patients living in rural communities in Western Nepal (and in some cases India). Five QoL themes emerged from this study (Table 2). Chronic ear disease has a significant impact on patients' QoL affecting their social interactions, emotional well-being, education and ability to work and participate in community events, and patients employ a number of coping mechanisms. Healthcare seeking behaviour is varied, and some areas have seemingly no access to secondary care. A huge barrier to surgery seems to be cost; however, access to healthcare, reputation of the institution and fear of complications appear to also impact the decision to proceed. For patients, surgery is a means of achieving symptom control, which in turn seems to be associated with a better life across all domains.

Comparison with previous literature

To our knowledge there has only been one previous qualitative study exploring QoL in patients with chronic ear disease in Nepal.⁹ The study reported on the high levels of stigma faced by these patients, particularly commenting on enacted and felt stigma, non-disclosure (patients attempting to disguise their symptoms), and barriers as a result of these. Although each of these themes also appeared in our own analysis, some differences have been noted.

Stigma

The narratives of being teased about hearing and discharge, mixed reactions from the community and feelings of 'hurt

and upset from the stigma' are common to both this study and the study by Skilton *et al.* (2016).⁹ However, Skilton *et al.* reported that none of their participants 'recounted teachers displaying negative or stigmatising behaviour', whereas our participants gave mixed answers on this topic.⁹ Some teachers were described as supportive, allowing students with hearing impairment to sit at the front of class, whereas others engendered an anxiety that made students 'worry that the teacher would get angry', and in one case an act of physical violence was described:

'The teacher hit me because I didn't listen properly' (participant 14, age 16, male).

The experience of bullying in the workplace described by Skilton *et al.* did not emerge in our analysis.⁹ Although most of our participants commented on the difficulties faced at work, these were largely related to the logistical implications of having to stop work and deal with ear discharge or the functional implications of not being able to hear. Our participants described a number of situations where their colleagues were supportive, such as by using voice notes, sign language, speaking loudly and attending meetings on their behalf. These differences may be explained by differing patient populations, differing work environments or even a reduction in stigma over the last five years.

Non-disclosure

The study by Skilton *et al.* explores the idea of discreditable stigma and 'the act of 'covering', a commonly used strategy where the stigmatised try to disguise their condition from others.⁹ Although this also emerged as a coping strategy for many of our patients, we found that this was restricted to women. Although men and women commented equally on feeling sad, being a burden on others and being teased for their symptoms, the men did not describe any examples of concealment, whereas women did. Smart and Wegner suggested that while concealment is a legitimate coping strategy, those who conceal their stigmas may actually be struggling more than it initially appears.¹³ It is worth considering this in the context of Nepal's patriarchal culture where women are expected to marry, rear children and contribute to family life. A study by Devkota *et al.* exploring societal attitude and behaviours towards women with disabilities in rural Nepal commented that 'it is much harder for women with disabilities than their disabled male counterparts'.¹⁴ They found that 'women with disabilities face significant challenges from family and society in every sphere of life' with many people believing that 'a disabled woman's impairment, no matter what type of impairment, would be transmitted to her baby' and 'that pregnancy and childbirth of women with disabilities were often viewed as an additional burden for the family and society'.

Barriers

The difficult experiences of patients in social, school and work environments, described by Skilton *et al.* as 'barriers', are also supported by our own analysis.⁹ By exploring social interactions, emotional impact and functional impact as separate themes we have been able to explore these in greater detail with sub-theme analysis and build on this existing knowledge base. Both this study and the study by Skilton *et al.*⁹ found that hearing loss itself, the frustration of others and anticipated stigma were key barriers to social interaction. Those

participants experienced embarrassment, worried about being a burden to others and experienced general sadness; they mentioned that their symptoms not only made work and school life difficult but, in several cases, caused them to leave school or change their line of work. We also describe previously unexplored sub-themes, such as fear of both medical complications and surgery, how ear discharge in particular appears to be linked with teasing and bullying, and the multitude of coping mechanisms employed by patients.

Health-seeking behaviour and surgery attitudes

To our knowledge this is the first qualitative study to specifically explore health-seeking behaviour and attitudes towards surgery in this population.

Our participants described a range of health-seeking behaviours, ranging from never having previously sought medical attention to visiting multiple health professionals across primary and secondary care in Nepal, India and in one case Saudi Arabia. By exploring both within and across the dataset, we have once again identified a gender bias. Our female participants were less likely to seek medical attention from either primary or secondary care or cross the India–Nepal border for a medical consultation than their male counterparts; both the participants who had never previously sought any medical help were women.

We also noted that the majority of the participants who had previously only attended primary healthcare facilities, such as local health posts or pharmacies, were from the Kailali District. These same participants had not sought specialist help, treatment or surgery although they described many of the same social, emotional and functional issues as participants from other areas. For many of them, despite living with chronic ear disease since childhood, the first time they had been made aware that they might need an operation had been through the Britain Nepal Otology Service outreach programme. This is not unexpected as Nepal is one of the least developed nations in the world, ranking 142nd in the United Nations Human Development Index along with a poorly developed healthcare infrastructure.^{15,16} It is worth noting that a previous study by Maile *et al.* (2015) showed an improvement in QoL, as judged by the Glasgow Benefit Inventory scale, following surgical intervention for patients in Nepal with chronic ear disease.¹⁷ They also highlighted that there is a lack of suitable QoL measures for the developing world, and therefore this requires development to guide health interventions and is something our study begins to tackle.

The majority of participants, however, described multiple prior health consultations at various institutions, ranging from local medical posts to government hospitals and specialist clinics. The prescription of ear drops and antibiotics is well described from all institutions, and the majority of those who had been seen in secondary care had previously considered an operation. The most commonly described barrier to surgery was affordability, followed by fear of the operation and its complications, no access to facilities and a lack of faith in the institution. Interestingly, many of these themes, namely affordability, proximity of services and a lack of appropriate, high-quality providers also emerged from an American study exploring ‘the impact of hearing loss and barriers to care’ in the rural Appalachian region of Kentucky.¹⁸ Although these populations are not directly comparable in terms of wealth, education and objective access to healthcare, it is interesting that from the patient perspective, access to ear-related healthcare poses similar barriers for rural communities worldwide.

Although symptom control was the main motive for surgery and linked to aspirations of career progression, independence, reduced sadness and improved social and family life, patients were also motivated by health concerns, such as disease progression into brain abscess or death, and the recommendations of family and friends. These recommendations came mainly from two cohorts of people: friends and relatives who were residents of Nepalgunj (the town where the hospital is based) or those who worked in the healthcare industry and provided us with some insight into the importance of reputation.

Implications for practice

Patients with chronic ear disease experience discrimination and stigma across all levels of personal, family and social life, and their function across all domains is directly limited by symptoms. Although the stigma associated with hearing loss is well recognised, the additional factors of chronic ear disease add another dimension, particularly related to ear discharge and fear of complications. Effort should be made to improve education and awareness across communities to encourage health-seeking behaviour, early diagnosis and reduce stigma. Outreach programmes can provide specialist care to otherwise unknowing communities and should continue to be supported.

Strengths and limitations

Although focus groups are the ‘gold standard’ for qualitative research, our semi-structured questionnaire was devised by reviewing existing literature and in consultation with an expert in qualitative research methods (CS). We reviewed and adjusted our interview technique after 10 interviews, and a number of methods were employed to ensure credibility and transparency of the study (constant comparison techniques, independent coders and a clear, reproducible framework).

We must also consider a number of limitations. Firstly, we must be aware that a sample size of 20, taken from a cohort of patients who have already consented to surgery, may not be representative of the wider population. Furthermore, patients may overemphasise their symptoms more on the day of surgery. There may have also been a level of discomfort at having two foreign non-Nepali speaking doctors from the visiting surgical team in the room at the time of interview and a desire to please when discussing motives for surgery. Of course, there may have also been subtle inaccuracies or variations between the Nepalese language and the English translation.

We tried to combat these by introducing ourselves to the patients and explaining the process and consent in detail before starting the interviews. We also changed our lead interviewer to our local researcher as we felt this may make the participants feel more at ease and improve the flow of conversation. To ensure accuracy of translations, we used a second independent translator to review three of the transcripts to ensure accurate translations.

- A total of 5.4 per cent of the world’s population currently live with disabling hearing loss
- Over 90 per cent of those affected live in low and middle-income countries where there is extremely limited, if any, access to an ENT specialist
- There is little previous work exploring the disease-specific quality of life (QoL) of patients with chronic ear disease in South Asia
- This study used qualitative research methods to explore the impact of chronic ear disease on QoL in Nepal

- This is the first qualitative study to explore health-seeking behaviour towards surgery in this population and barriers are cost, accessibility, reputation, gender and fear of complications
- This study provided novel insight into patient perspectives on living with chronic ear disease in Nepal

Conclusion

In conclusion, our study provided valuable and novel insights into patient perspectives on living with chronic ear disease in Nepal. In a region where access to surgery is limited, and in some areas unheard of, we must be careful not to impose our own ideas about QoL. The first step must be to listen: to explore the ideas, concerns and expectations from the perspective of patients in the context of their real living situation, and only then can we start to understand the true burden of disease and deliver healthcare that is need-specific. This study hopes to provide a springboard for further and necessary work in this domain.

Acknowledgements. The authors would like to thank all of the participants who made this study possible, alongside all the staff at the Britain Nepal Otolaryngology Service Ear Care Centre Hospital, Nepalgunj. We also thank the Britain Nepal Otolaryngology Service Camp 64 Team who allowed us to join their surgical ear camp and Dr Shreya Shrivastav for her assistance in translating transcripts. We give particular thanks to Professor Charlotte Salter for her invaluable guidance on qualitative research without which this paper would not have been possible.

Competing interests. Mr Robin Youngs is a trustee of the Britain Nepal Otolaryngology Service.

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Appendix 1. Themes, sub-themes and verbatim quotations

Themes	Sub-themes	Verbatim quotations
1. Impact on social interactions	Frustration of others	'In my family they call me 2–3 times. When I can't hear them, they stop asking' (participant 10, age 44, female).
	Anticipated stigma	'I am embarrassed ... Even though I'm invited [to social gatherings such as weddings], I am reluctant to go in case I meet new people and I can't hear properly or talk properly and then they think things' (participant 4, age 24, female).
		'If I put cotton wool in my ear then people will know there is a problem. If I have discharge they will think I am dirty and not sit with me' (participant 1, age 20, female).
		'I didn't tell anyone. I have been married for 21 years. I was afraid of what he [husband] might say and that he would marry someone else. I married into a higher caste family and if they found out they would be angry. I am afraid of them' (participant 15, age 40, female).
Impact of ear discharge	'My husband says the discharge is very foul-smelling' (participant 11, age 35, female).	
Positive social interactions	'I have no problems at home. If I don't understand, they will speak louder' (participant 17, age 21, female).	
2. Emotional impact	Sadness	'If I didn't have the hearing problem, I wouldn't have to deal with this. It makes me sad and angry' (participant 18, age 35, male).
		'I have been very sad from childhood until now. In childhood my friends used to laugh at me' ... I used to think, why are they laughing at me?' (participant 13, age 38, male).
		'When someone sits on my left-hand side, I have problems hearing what they are saying so I have to stop the car. This makes me feel sad' (participant 20, age 38, male).

(Continued)

Appendix 1. (Continued.)

Themes	Sub-themes	Verbatim quotations
	Burden to others	'I have to ask people to talk slowly and repeat things again. They get frustrated that they have to repeat things again and again. This makes me sad' (participant 14, age 16, male).
	Fear	'The doctor advised me that if I didn't have an operation there may be more complications such as a brain abscess. This made me ready for an operation.' (participant 18, age 35, male). 'Someone told me I might die without an operation' (participant 15, age 40, female).
3. Functional Impact	Activity limitation	
	Work	'When I go to the farm I have to clean my ear all the time' (participant 15, age 40, female, farmer). 'I work with aluminium. I can't hear my colleagues and I can't operate the cranes because I can't hear the whistle' (participant 16, age 30, male, aluminium worker).
	Community/social	'I find it difficult to understand so another friend tells me what is said' (participant 12, age 45, male).
	School	'There are two reasons why I dropped out [of school] – the hearing loss disturbing school and even though I wanted to study my parents told me I needed to be a farmer to help them' (participant 12, age 45, male).
	Coping mechanisms	
	Augmented communication skills	'It was difficult to understand if I sat at the back so I asked the teacher if I could sit at the front [at school]' (participant 17, age 21, female).
	Masking the problem	'I became clever so that no one would know there was ear discharge...I used to clean the pus and didn't tell anyone' (participant 15, age 40, female).
	Reliance on others	'I send someone else [to the womens' group] because of the ear. They collect the money' (participant 10, age 40, female).
3. Health-seeking behaviour	Previous healthcare interactions	'I've had ear discharge since childhood but I've never been anywhere for treatment. I told my husband about my ear problem... [he] said I can't understand the Nepalese language so if I take you to the hospital I won't be able to understand anything' (participant 10, age 40, female).
	Barriers to previous surgery	'The doctor told me I needed an operation to prevent further progression but I didn't have money at that point' (participant 19, age 35, male).
4. Attitudes towards surgery	Motivations for surgery	'I didn't know about BRINOS. When the team went there they convinced me to come to the ear hospital' (participant 8, age 54, male). 'The foul-smelling discharge is worse so I'm ready to have an operation. My life will be saved and I will be happy and will be saved from that complication [brain abscess]' (participant 9, age 44, female).
	Funding surgery	'The money is not an issue. I just came because of the reputation' (participant 20, age 38, male). 'I paid together with my husband. [He] sold the goat and milk from the cow. It takes 3 months to collect the money. Money is nothing – we can earn. The main problem is the ear' (participant 7, age 40, female). 'It is cheaper when BRINOS are here' (participant 1, age 20, female). 'My husband works for the Red Cross and he earns some money – not enough [for elsewhere] but if I have the operation here he can manage it' (participant 4, age 24, female).
	Aspirations	'I have big expectations after the operation. I am hoping that if I can hear the whistle I can operate the cranes and move forward in my career' (participant 6, age 30, male).

BRINOS = Britain Nepal Otology Service