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## article

# Advocating for carers: a qualitative study exploring the needs of UK carers of patients with an acoustic neuroma

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Research on the impact of caring for patients with an acoustic neuroma is scarce. Findings from 12 interviews with primary carers of this patient population highlight six key themes: life disruption, support, well-being, the carer role, lessons learned and the impact of COVID-19. Carers need more practical information and emotional support, starting from the diagnosis stage through to recovery. Recommendations include routine carer assessments, early signposting to auxiliary services and information materials about recovery. This study contributes to the UK literature gap of this under-studied population and demonstrates the importance of carer assessments, as set out in the Carers Act 2014.

**Key words** carer needs • informal carers • acoustic neuroma • non-malignant brain tumour

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## Introduction

### *Well-being of carers*

Carers are those who look after family (Monroe and Oliviere, 2011), friends or neighbour's due to ageing, disabilities or health conditions that impact their ability to look after themselves (Caring Together, 2020; Department of Health and Social Care, 2021). Carers are unpaid and are sometimes referred to as 'informal carers', providing personal or emotional care (Carers Trust, 2018). In the UK, carers play an integral role in reducing the burden on the National Health Service (NHS) and social care services, and are entitled to a carer assessment (Department of Health and Social Care, 2021). However, carers are not routinely recognised by the NHS

as having well-being needs of their own, which can lead to a decline in carer health and increased health inequality (Carers UK, 2021).

Carers of brain tumour patients may experience anxiety (Petruzzi et al, 2012; Andrewes et al, 2013) or depression (Petruzzi et al, 2012). In addition, prolonged length of time as a carer, higher carer burden and depression have been linked to a decline in carers' physical health (Pinquart and Sorensen, 2007). High levels of long-lasting stress have been found to be prevalent in carers (Bennett et al, 2012), and chronic stress can lead to health problems, such as disruption of the immune system (Groër et al, 2010), as well as anxiety (Fink, 2016). Carers who take a less passive approach and who hold a sense of control have been found to cope better with their role (Smeets et al, 2012), and those who accept their new role show significantly more ability to adapt (Kim et al, 2007). Furthermore, carers who have higher resilience have also been found to have lower anxiety and depression from their caring role (Simpson et al, 2015).

### *Well-being of carers of brain tumour patients*

Across various international contexts, carers of patients with malignant brain tumours experience significant life changes, often with an abrupt transition into the carer role (McConigley et al, 2010), which can be highly distressing (Petruzzi et al, 2012). Carers can have trouble receiving timely information following diagnosis (McConigley et al, 2010) and can feel unprepared when there is a lack of practical information (Morris and Thomas, 2001; McConigley et al, 2010). Additionally, carers of malignant brain tumour patients can experience a reduced quality of life (Petruzzi et al, 2012). Globally, studies show that the needs of carers of malignant brain tumour patients are for: one-on-one therapy; more information on what to expect (Morris and Thomas, 2001; Andrewes et al, 2013); and more information on how to cope (Andrewes et al, 2013). Similarly, carers of patients who received treatment for non-malignant brain tumours have expressed a lack of information and support in the early stages of recovery or could not remember what support they were offered, indicating disconnection from healthcare providers (HCPs) (Cornwell et al, 2012). This reflects the findings by McConigley et al (2010), suggesting that carers of patients with non-malignant brain tumours are facing similar challenges to those of patients with malignant tumours. However, there are limited data on the experiences of carers of patients with non-malignant brain tumours. Looking exclusively at this population, a systematic review carried out by Gilchrist (2020) found a gap in research for this population. Of 183 studies dated from 2005, 27 were identified as focusing exclusively on carers of adult patients with a brain tumour, omitting patient perspectives. Of these, none were found to focus on non-malignant brain tumours.

### *UK context: carers of patients with an acoustic neuroma*

Brain tumours can be malignant (cancerous) or non-malignant (benign) (Woehrer et al, 2014). While non-malignant tumours may grow, they do not spread to other areas of the body and may be considered less disruptive than malignant tumours (Woehrer et al, 2014; Patel, 2020). However, non-malignant brain tumours can be fatal (McKinney, 2004), potentially compressing the brain, resulting in life-changing side effects or death (Brainstrust UK, 2019).

Acoustic neuromas, also referred to as ‘vestibular schwannoma’ (Carlson and Link, 2021), are non-malignant brain tumours (Nikolopoulos et al, 2009 [1998]). Acoustic neuromas develop from the eighth cranial nerve, containing the balance and hearing functions (Linkov et al, 2017). Acoustic neuromas contribute to a decline in hearing on the affected side (Foley et al, 2017), tinnitus, vertigo, difficulty with balance or facial numbness (Mooney et al, 2017), as well as fatigue, eye issues and headaches (Brooker et al, 2013). Additionally, acoustic neuromas can compress the brainstem and lead to hydrocephalus (Campione et al, 2019). Despite being non-malignant, acoustic neuroma tumours can severely impact a patient’s well-being and can be life threatening (Nikolopoulos et al, 2009 [1998]).

Treatment for acoustic neuromas include the wait-and-scan approach, radiosurgery and surgery (Carlson and Link, 2021). Wait and scan involves periodically scanning using MRIs to monitor for growth and is common in the early period following diagnosis (Carlson et al, 2020). Radiosurgery and surgery are both considered when the tumour shows signs of growth (Carlson et al, 2020). However, surgery is physically invasive and disruptive (Rutkowski et al, 2014). Despite prioritising post-operative quality of life (Rutkowski et al, 2014), the onset of single-sided deafness, post-operative headaches or injury to the facial nerve can occur (Mooney et al, 2017). Furthermore, patients may experience balance dysfunction, anxiety or depression (Pritchard et al, 2004). Lack of balance can be prolonged and result in the patient needing help with personal care (Cohen et al, 2002); ultimately, patients may come out of surgery with a decreased quality of life (Nikolopoulos et al, 2009 [1998]). As such, patients may count on family for emotional and practical support (Mayo Clinic, 2021).

### *What we already know about carers of non-malignant brain tumour patients*

UK research on carers of brain tumour patients under the age of 18 has looked at: carers’ experiences and their unmet needs (Nicklin et al, 2021); predictors of parenting stress (Bennett et al, 2012); and the provision of rehabilitation for paediatric brain tumours, including carers’ perspectives (Treadgold et al, 2019). Broadly, these studies found that unmet patient and carer needs can continue for years following a brain tumour diagnosis (Nicklin et al, 2021), as well as high stress in parents where a child had a brain tumour diagnosis (Bennett et al, 2012). Recommendations include stress screening, coping interventions (Bennett et al, 2012) and improved rehabilitation access (Treadgold et al, 2019).

### *Research gaps*

While Nicklin et al (2021), Bennett et al (2012) and Treadgold et al (2019) explore the experiences of carers of patients with non-malignant brain tumours, none of these studies consider carer experiences where the patient is an adult. Nor do they exclusively explore carer experiences without patient or HCP input, or where the patient has an acoustic neuroma. Further to this, a systematic review carried out by Boele et al (2019) found limited effectiveness for carer well-being interventions where adult patients had a brain tumour. Collectively, these studies highlight a gap in UK literature for understanding carers’ experiences of supporting adult patients with an acoustic neuroma.

Considering the lack of research on carers of patients with an acoustic neuroma (Gilchrist, 2020) or successful interventions for carers of non-malignant brain tumour

patients (Boele et al, 2019), a qualitative approach was an ideal starting point to gather valuable information on this under-studied population. To the research team's knowledge, this is the first qualitative study exploring the experiences of carers of patients with an acoustic neuroma diagnosis. It thus offers new empirical findings not only for acoustic neuroma patients and their carers, but also for healthcare professionals. The primary aim of the study was to identify the needs of carers of acoustic neuroma patients in relation to the diagnosis, approaching surgery and recovery stages of the condition. The secondary aim was to establish what interventions or support may be beneficial to this carer group in order to address any gaps and provide recommendations for future carers. The study addressed three main questions throughout the research process:

- What are the needs of carers of patients with an acoustic neuroma diagnosis?
- Do the needs of carers change as patients move through the diagnosis-to-recovery pathway?
- What recommendations can be given to help future carers?

## Methods

### *Approach*

For reader transparency and context, this study was carried out for a student MSc research project, where the student was a previous patient who received surgery to remove an acoustic neuroma (Dodgson, 2019). The following methods are presented in line with the Consolidated Criteria for Reporting Qualitative Research (COREQ) 32-item checklist to ensure relevant research steps were followed (Tong et al, 2007). A qualitative approach, underpinned by grounded theory, was used to explore carers' experiences of looking after patients with an acoustic neuroma. This would not have been possible with quantitative research due to the constraints of such materials as questionnaires (Braun and Clarke, 2013). While critics would argue that the interpretation of qualitative data is subjective, this approach was key to understanding carers' interpretation of their experiences, and it was felt that the merits outweighed the drawbacks. Furthermore, a cross-sectional design was used to allow for experiences to be recalled from a set point in time (Sedgwick, 2015).

### *Ethical processes*

The study protocol and materials were approved by University College London's Ethics Committee prior to participant recruitment (ethics number 17479/001). The researchers adhered to key ethical principles in research, such as voluntary participation, an informed consent process, anonymity and the confidentiality of the data. Consideration was given to the participants' well-being, as they may have discussed experiences that raised upsetting emotions for them. Where such cases arose, the participants were signposted to relevant support services by the researcher.

### *Recruitment process*

Participants were recruited from the British Acoustic Neuroma Association (BANA) and via the British Acoustic Neuroma Support Group on Facebook. On behalf of

the research team, the chief executive officer of BANA emailed the information sheet and consent form to members, asking for volunteer participants. The British Acoustic Neuroma Support Group Facebook page allowed the research team to post recruitment messages directly on the group page. All participants were provided with the researcher contact details to find out more. All participants were provided with an information sheet at least 24 hours prior to the interview and provided a signed consent form before the interview commenced.

### *Sampling*

The study followed a purposive sampling approach, where potential participants are approached to take part in the study as they comply with pre-established categories. In the case of this study, participants had been, or were at the time, primary carers of patients with an acoustic neuroma. All participants were 18+ years old and resided within the UK at the time they were carers. The study design purposefully excluded patients as participants for two reasons: first, so that patients did not influence the carers' responses (Tong et al, 2007); and, second, it was felt that as one of the researchers had been an acoustic neuroma patient, interviewing patients may generate biased results via the comparison of experiences or as being interviewed by a previous patient may impact how the participant feels (Berger, 2015). To facilitate the cross-sectional design, we ensured the recruitment of participants from each stage of the pathway: diagnosis, wait and scan, approaching surgery, and recovery. This was so that participants were not asked to look back retrospectively over what may have been a long period of time, mitigating the need for follow-up interviews, which the research time frame did not allow for. As such, for the purpose of this study and time frame, the sampling frame outlined in Table 1 was used.

### *Data collection*

A brain tumour diagnosis can be distressing (Goebel et al, 2011). Therefore, it was anticipated that difficulty may occur when recruiting carers for recently diagnosed patients. As such, a six-month window from diagnosis was initially selected to allow scope to recruit enough participants. However, it was noted that this strategy missed a proportion of the population – those on wait and scan – and so an amendment was approved by University College London's Ethics Committee to extend this group to those diagnosed within the last ten years. Furthermore, as the patient moves from diagnosis to awaiting surgery, carers' needs may change. To capture these changes, a group of patients within three months of their surgery date was

**Table 1: Sampling frame for recruitment criteria and numbers recruited**

Group	Criteria	Participants
1	Carers of patients diagnosed within the last ten years <sup>a</sup>	3
2	Carers of patients undergoing surgery within the next three months	1
3	Carers of patients who underwent surgery within the last six months	1
4	Carers of patients who underwent surgery within the last ten years	7

Notes: <sup>a</sup> One participant was a carer for a patient diagnosed eight years prior and on 'wait and scan' at the time of interview. The remaining two were diagnosed within one year prior to interview.

**Table 2: Recruitment response and outcome**

Response/outcome	Participants
Enquired	23
Excluded (criteria not met)	7
Excluded (numbers met)	1
Forms sent, no response	3
Interviewed <sup>a</sup>	12

Notes:  $n = 23$ . <sup>a</sup> One participant was interviewed with their wife, who was also a carer for the same patient; therefore, 11 interviews were carried out with 12 participants.

**Table 3: Participant demographic profile**

Demographics	Participants	Relationship
Carers' relationship to patient	1	Sister
	5	Female partner/wife
	3	Mother/father <sup>a</sup>
	3	Husband
Sex of participant	8	Female
	4	Male

Notes:  $n = 12$ . <sup>a</sup> One father was interviewed with the mother of the same patient.

included. The treatment modality selected for review in this study was surgery, as recovery can be prolonged (Cohen et al, 2002). As such, groups within six months and ten years since surgery were chosen to capture the different stages of recovery, ensuring opportunity to gather immediate and long-term effects. A total of 23 potential participants enquired about the study; 11 were excluded based on the sampling frame criteria and 12 were interviewed (see Table 2). While the number of interviews was driven by the number of participants who met the criteria, data were reaching saturation at 11 interviews. Reasonable steps were taken to recruit participants evenly across the four groups, though not at the expense of fewer participants, and a conscious effort was made to recruit an even distribution of male and female participants (see Table 3).

Semi-structured interviews were carried out to maintain consistency while allowing the carers to expand on their experiences (Adams, 2015). Interviews ranged in length, allowing participants opportunity to tell their story in their own words, without being rushed or capped by a time limit. While this added to the transcribing and analysis workload, it was necessary not only to allow adequate time for the participants, but also to respect the sensitivity of the topics discussed and to comply with ethical guidelines of not causing undue distress (British Psychological Society, 2014). An added merit to this approach was the immediate therapeutic benefit (Sieber, 2009) that some participants expressed by being able to talk about their experiences to another person.

Topic guides were designed specifically to explore four key stages – diagnosis, wait and scan, approaching surgery, and recovery – based on the three research questions. Interviews were carried out by the researcher via Skype, in accordance with University College London's ethical guidelines on Skype use (UCL, 2020). Interviews were

video-recorded, and the collected data remained confidential. No participants or other persons were deemed at risk of harm (British Psychological Society, 2014). The researcher transcribed ten of the 11 interviews and one was transcribed by a third-party transcription service, arranged through the research supervisor.

### *Analysis approach*

Thematic analysis was carried out on the interview data. All transcripts were read, and data related to the research questions were highlighted for easy reference. Following this, all transcripts were read again to ensure familiarisation, and memos were added in the form of electronic comments. From the memos, codes were developed by systematic, inductive coding; all the codes were logged on a spreadsheet and were cross-checked by a second researcher. From the collective codes, themes of key, shared concepts were created by reflecting on the raw data and the codes, and searching for potential relationships between codes (Nowell et al, 2017). The researchers developed themes that they felt could describe these groups of codes. This multi-level approach is deemed to have added rigour to the thematic analysis, allowing the reader to understand where the findings derived from and judge whether they have the same interpretation (Thomas and Harden, 2008). Thematic analysis also allowed researchers to maintain a grounded theory approach by drawing themes from the data (Charmaz, 2014).

### *Analysis limitations*

For transparency and reflexivity (Dodgson, 2019), a potential concern was that of researcher bias. In this case, one researcher (Katie Gilchrist) had had an acoustic neuroma tumour removed by surgery and had preformed views of the diagnosis to recovery pathway. To protect against bias and ensure that codes and subsequent themes were derived from the interview data rather than researchers' internal dialogues (Archer, 2007), this researcher personally conducted all interviews and transcribed all but one. Following this, the researcher reread all interview data, highlighting relevant information, and included memoing to help mitigate bias (Goodell et al, 2016). This supplementary step of highlighting prior to memoing added a further level of familiarisation and opportunity for reflexivity and internal deliberation (Archer, 2007). Where personal experiences were triggered in the researcher, a bracketing process was carried out, using reflection to ensure that they did not influence the results (Braun and Clarke, 2013). Transcripts were not returned to participants for review, as the time frame for the study did not allow for this. To remain trustworthy, data interpretation was cross-checked by a second researcher (Cecilia Vindrola-Padros), who had no prior knowledge of the condition. Furthermore, codes and themes were discussed between both of the two researchers to ensure that agreement was reached (Roberts et al, 2019).

## **Results**

### *Life disruption*

Carers' experiences through the pathway consisted of a lot of fear, uncertainty and change that was interpreted to be life disrupting: "We just wanted some answers. It, it wasn't, it wasn't good, it wasn't good for us to wait that long. We're not, we're not



the sort of people who are particularly good at just kind of like forgetting about it. It was taking over our lives” (P6, husband).

### *Fear*

Patient survival, post-operative quality of life and the side effects of surgery were expressed as main concerns by nine of the carers, across all stages of the diagnosis to recovery period: “We didn’t even know if he was likely to survive the operation or what the risks were, you know. There was so little time to gather information and get your head round it” (P1, sister). Concerns of side effects included facial paralysis, single-sided deafness or brain damage:

‘Lasting damage to his eye or his face, erm, err, he was, the main concern. I mean, yes, I was very, very distressed that his hearing was going to go, erm, was very distressed, because he loves singing, he loves music, erm, yeah, very, very upset, you know. It is awful to see a child go through something so traumatic; it is not very nice.’ (P4, mother)

### *Uncertainty*

Many patients experienced long waiting times between first seeking help from HCPs and getting diagnosed, with difficulty watching the patient’s prolonged distress. As patients began their approach to surgery, carers experienced uncertainty and distress where the waiting time was unknown or prolonged, with one saying: “We just lived under this perpetual kind of uncertainty” (P9, partner).

### *Support*

All but two of the 12 participants talked about having some form of support from either friends and family, charitable services (referred to as auxiliary support), or the NHS or private healthcare system. Support generally came in the form of emotional, peer or informational support.

#### *Friends and family*

All but three carers talked about support from either family or friends. The three carers that did not tell family or friends about the patient’s diagnosis did not feel that they wanted to burden them: “She’d rather not, erm, open up too much with our, with our daughters because, you know, they’ve got jobs, they’ve got young kids. They’ve got enough on their plate without worrying about their mum” (P5, husband).

#### *Auxiliary support*

Auxiliary support refers to any HCP or service that is not part of the public or private healthcare system. A complex relationship with auxiliary support was apparent, particularly with charity organisations and Facebook support groups. Nine of the 12 carers knew of an acoustic neuroma charity or Facebook support group. However, five of them did not come across these until after the patient had undergone surgery.



Four were advised of the charity by HCPs before surgery, with three engaging at this stage. Three carers either did not mention charity organisations or support groups, found them to be a negative experience, or chose not to engage: “It was all such doom and gloom” (P10, wife), and one was not sure what support for carers existed:

‘Somehow find a mechanism, a way for caregivers to share their strategies so that we’re not working in isolation ... erm, now, as I say, it could be that there is a system in place which I’m just oblivious to, but if I’m oblivious to it, why am I oblivious to it? Perhaps it’s my fault for not exploring it, I don’t know, but, erm, yeah, I would, I would say that.’ (P5, husband)

Of those who engaged, whether on the charity website or acoustic neuroma Facebook groups, eight found them to be mostly helpful. When asked if the charity helped emotionally, one carer replied, “I thought it was brilliant ... it helped me understand, you know, it can happen to anybody” (P4, mother). Overall, the level of engagement with auxiliary support remained similar through the approaching surgery and recovery stages.

### *HCPs*

At the diagnosis stage, seven of the 12 carers described having had a positive experience with HCPs and having received enough support and information at that point. One carer recalled having had all their questions answered, even though “Sometimes, the answer wasn’t what you wanted to hear” (P8, husband). However, three carers found HCPs’ support around the diagnosis stage difficult. One described that the weight of the condition was not fully explained by the HCPs. Instead, it was described as a “swelling” (P9, partner), and at one point, they were told it would not be an acoustic neuroma. Another carer and patient were initially told the patient would be referred to a cancer clinic shortly after being told it was non-malignant.

As patients approached surgery, carers’ experiences of HCPs became mixed, experiencing similar amounts of positive and negative experiences. Those that felt the HCPs supported them as the patients approached surgery generally had positive experiences of the diagnosis stage. Despite feeling that it was a “lose-lose” situation, one carer stated: “We were made aware of very much all the risks, all the possibilities, all the potential outcomes” (P8, husband). However, all four of the carers who expressed dissatisfaction with HCPs’ support approaching surgery described not feeling they received enough information on what to expect as the patient went through surgery, the immediate period after and the recovery at home. These carers expressed feeling unprepared to look after the patient or did not realise they would become a carer: “It didn’t occur to me that there was going to be problems after the surgery. I just thought that we had to get through the surgery and then it’d be fine. So, I didn’t think I was going to be any kind of carer” (P9, partner).

At the recovery stage, of the seven carers who felt supported during the diagnosis and approaching surgery stages, two also felt supported during recovery. Of the three carers that described a negative diagnosis experience, two also felt unsupported through recovery for the same reasons: lack of support with becoming a carer; limited information on what to expect; and limited information on how to help the patient. These carers found it challenging to know who to approach for help and what questions to ask.

### *Well-being*

During the interviews, eight of the 12 participants verbally described experiencing worry, stress, anxiety or feelings of being alone following the diagnosis. In addition to this verbal communication, five participants presented with body language indicating that they were recalling a stressful period of their life, with actions such as crying or holding their hands to their head. Collectively, these are considered to contribute to carers' overall well-being (Department of Health and Social Care, 2021).

### *Mental health*

During the diagnosis stage, four carers experienced guilt or regret for not noticing or realising what the patient's symptoms meant. One carer felt that the diagnosis was taking away the happiness of their pregnancy, triggering negative emotions. Another carer, where the patient was on wait and scan, found it hard to watch the prolonged symptoms of the patient and, on occasion, felt alone or unable to know what to do to help. Emotional distress for the carers was apparent in the approach to surgery. While three carers were able to cope with minimal impact to their mental health, others described being "worried sick" (P4, mother) about the patient's post-operative quality of life. One carer felt extremely abandoned by the HCPs and described feeling in "freefall" (P9, partner), expressing: "I just couldn't cope, erm, yeah. He wasn't, he wasn't in a good way, and I was struggling too probably, but I hadn't realised that I was struggling with my own mental health at that point" (P9, partner).

Of the eight carers where the patient had undergone surgery, all but two had had little or no impact to their mental health throughout the recovery period, though they did express ongoing worry about the patient's quality of life and whether their recovery was going well. However, of those that were impacted, it was to a large degree. Two carers were diagnosed with post-traumatic stress disorder, with one receiving ongoing trauma therapy. One experienced being in a long-term "constant state of alert" (P2, wife), with persistent transition between normality and post-operative complications, as well as describing "death anxiety" (P2, wife) and panic attacks over the fear of losing a loved one. Another felt they were heading for an emotional breakdown and went on sick leave from work to deal with the mental health impact.

### *Coping strategies*

Six of the 12 carers attributed their coping abilities to their own resilience. Carers also leaned towards emotion-focused coping, that is, reducing emotional responses (Ben-Zur, 2017), or problem-focused coping, that is, reducing the cause of the stressor (Carroll, 2013) (see Table 4).

There were varying degrees of coping among participants. Coping levels were not measured during this study; however, from the discussions that took place, it was viewed that nine of the 12 carers were able to cope moderately to well: "You just get on with it and I don't think I thought about it a lot; it was just a coping mechanism" (P1, sister). One carer had felt able to cope but was visibly upset when asked how they felt about the patient's upcoming surgery: "I suppose, a bit upsetting [cries]" (P3, wife). In addition, there were three carers who described barely being able to cope and that they "were just trying to survive" (P9, partner), with another considering some respite and experiencing times where they felt they could not cope. The carers

**Table 4: Coping strategies used by participants in the present study: emotion-focused, problem-focused and resilience**

Emotion-focused coping	Problem-focused coping
Carer and patient supporting each other	Researching the condition
Connecting with others with similar experiences	Focusing on goals and making plans
Positive reframing	Drawing on own coping mechanisms
Distractions: hobbies, dog walking, family and so on	Maintaining your own good health
Focusing on life returning to normal	Drawing on previous experiences
Not dwelling on the negative aspects	Got on with the practical elements
Acceptance that life may be different	Maintained routine throughout recovery
Acceptance of a 'new normal'	Taking it one step at a time
Conscious decision not to worry too much	
Conscious decision does not rule life	
<b>Resilience: an individual adapts positively to adversity (see Masten and Obradovic, 2006)</b>	
Drew on resilience for coping	
Carers without resilience or coping mechanisms could really struggle	

experiencing the most difficulty coping had been doing so the longest, with diagnosis taking place between 2012 and 2018. One carer deemed to have coped moderately had been doing so since diagnosis in 2017, and for the remaining seven carers, the patients were diagnosed between 2019 and 2020. The exception was one participant whose wife was diagnosed in 2018, where the carer coped well. This carer was also a carer by profession and felt equipped with skills to deal with the situation.

### *Carer role*

A total of 12 carers were interviewed: eight females, who consisted of four wives, one partner, two mothers and one sister; and four males, including three husbands and one father. Ten of the carers reported providing emotional care, which included all male participants; two females did not describe providing any emotional care. A total of 11 participants reported providing practical care; one male, where the patient was on 'wait and scan', did not describe any practical care requirements of them (see Table 5).

### *Practical*

Overall, practical care at or before the diagnosis stage consisted of attending appointments with the patient. On approach to surgery, carers provided more practical support, getting the home ready for the patient's return. During recovery, carers provided a wide range of practical support (see Table 6).

### *Emotional*

Emotional support was a key part of the carers' role; however, it was sometimes tricky for them to navigate. Some patients were deeply impacted by the diagnosis, and emotional support came from the carer, continuing in the approach to surgery and increasing during recovery. Some carers were supporting patients with severe

**Table 5: Carer role and support provided**

Sex of carer	Relationship to patient	Practical support	Emotional support	Tasks carried out
Female	Sister	Y	N	Meals, medication, stairs
Female	Wife	Y	Y	Emotional support, appointments, caring for newborn, adjusting hospital bedding, communication with family, bringing items to hospital, emptying catheter, toileting, communicating with HCPs, shaving, showering
Female	Wife	Y	Y	Emotional support, preparing home for recovery
Female	Mother	Y	Y	Emotional support, also carer for husband, appointments
Male	Husband	N	Y	Emotional support
Male	Husband	Y	Y	Emotional support, appointments, communicating with HCPs, communicating with family, toileting, bathing, preparing home for recovery, walking dog, meals, stairs, teeth, hair, dressing
Male	Father	Y	Y	Emotional support, meals, laundry, shower support for balance, walks for rehab, keeping house
Female	Mother	Y	Y	Emotional support, meals, laundry, keeping house
Male	Husband	Y	Y	Emotional support, appointments (patient managed daily activities)
Female	Partner	Y	Y	Emotional support, financial support, keeping house, physical care, meals, cleaning, communicating with HCPs, medication
Female	Wife	Y	N	Appointments
Female	Wife	Y	Y	Emotional support, set up second home so patient could isolate

**Table 6: Examples of practical tasks carried out in the carer role**

<b>Practical caring</b>
Keeping house
Assisting patient up and down stairs
Driving patient to appointments
Showering and personal care
Preparing meals
Assisting with walks out
Communicating with HCPs
Tracking medication
Walking the dog
Assisting with vestibular therapy
Taking over household bills
Helping patient in and out of bed

post-operative complications, exhibiting depression, stress, anxiety and suicidal thoughts: “The longer he was in hospital, the more he became anxious” (P2, wife). In three cases, carers were the only source of emotional support to the patient, adding a great burden on the carers. Carers expressed not always knowing what the right balance of emotional support was, impacting their confidence to give care. Struggling to decide on a “tough love” (P6, husband) approach or an “arm around the shoulder” (P6, husband) or doubting their caring skills were some obstacles.

### *Carer status*

For four carers, the realisation that they were a carer came during the approaching surgery or recovery periods, and after they began to take on more tasks and provide more emotional support to the patient. Four expressed not having considered themselves to be a carer, which coincided with when the experience had been short or with minimal disruption to their life:

‘The only thing I struggle with a little bit is the term ‘caregiver’ because, I suppose, I don’t really see myself as that; I’m just a family member looking after his, looking after her brother. So, but yes, I suppose, in realistic terms, that is what I’ve ended up being, but, but, I, it, it feels strange to be described like that ... the hospital didn’t say at any point, either to him or to us, “Who’s going to look after you afterwards? Have you got someone to take care of you?” So ... that wasn’t even a question that was raised, erm, so, yeah, it’s, it’s, it’s an interesting kind of concept really.’ (P1, sister)

Further to this, one carer described going in and out of the carer role for a prolonged period as the patient experienced multiple complications, while another stated that they were a carer but did not want to be.

### *Lessons learned*

Lessons learned came down to two elements, with the first being advice for future carers with the luxury of hindsight (see [Table 7](#); for supporting quotes, see [Table 8](#)). The second element of lessons learned constituted carers’ suggestions to HCPs and auxiliary services, which formed three key areas: information, skills support and emotional support. As previously mentioned in the support theme, information was particularly lacking at the approaching surgery and recovery stages, and for two of the carers, the impact was detrimental. These carers felt a loss of trust in, or abandoned by, HCPs. Collectively, the suggestions outlined in [Table 9](#) were strongly recommended (for supporting quotes, see [Table 10](#)).

### *Impact of COVID-19*

The COVID-19 pandemic directly impacted four carers. Communication with HCPs was minimal, reducing the opportunity for carers to ask their own questions, with one saying “It’s really difficult because, obviously, it would have been nice to have had some support, but because of COVID, it’s made such a big difference to

**Table 7: Lessons learned: advice for future carers, with the luxury of hindsight**

Carer advice (to future carers)	
Practical	Emotional
Discuss with the patient before surgery what personal care they are comfortable being given and whether the carer is comfortable doing it	Taken more self-care and look after your own mental health and well-being
Would have asked more questions if they knew what questions to ask	Nothing can prepare for unexpected complications
Ensure you are fit to care for somebody and get help if you can	Talking to friends, family or charities more may have helped
Have in place a trusted GP	Keep doing things you enjoy
Ensure as a carer you are aware of what you are facing physically and emotionally	

**Table 8: Lessons learned: advice for future carers with the luxury of hindsight – supporting quotes**

Carer advice (to future carers)	
Practical examples	Emotional examples
"I think what's really important is discuss ... well, firstly is to discuss with the person that you're going to be looking after what they want and what you feel like they are going to need ... the last thing you want to do is have to make, have an awkward discussion about that sort of thing when you're, the person you're caring for is in pain or agony" (P6, husband)	"I'd kind of spend that time on my own and try and process those things on my own. Erm, which, which in hindsight, I would have tried to probably find a couple of friends or a couple of family members to do that with. That would have definitely, I think, been better for me" (P6, husband)
"We would have probably asked more questions ... it's knowing what those questions would be, though; that's the problem" (P7, mother)	"The only thing that I ... looking back, that I should have done was looking after myself more" (P2, wife)
"You're no good to them if you're not in, if you're not fully fit, if you're not healthy, if you've not had a good night's sleep. If you're not eating properly ... try and make sure you have either someone to help you help that person ... or something in place so that you can at least get a little bit of rest yourself" (P6, husband)	"I YouTubed some people's recovery but they ... didn't ... prepare me for what I was about to go through. Obviously, X had a very rare ... erm, complications and everything, but they didn't prepare me" (P2, wife)
"We found a good supportive, understanding GP who believed the mental health" (P9, partner)	"Don't feel guilty about going, going off and doing something for yourself" (P6, husband)
"Making sure you as a carer are fully aware of what you could be faced with" (P6, husband)	

things" (P3, wife). In addition, delayed tests and surgery created a lot of uncertainty and frustration.

## Discussion

As the first known of its kind, this study explored the needs of carers looking after patients with an acoustic neuroma diagnosis. It is argued that a limitation of qualitative research is the complexity of compiling findings and drawing meaningful conclusions

**Table 9: Lessons learned: carer suggestions on how HCPs and auxiliary services can help future carers**

Carer suggestions (to HCPs and auxiliary services)		
Information	Skills support	Emotional support
Access to more information, particularly on the recovery period	Carers would benefit from resilience building	Ask the carer how they are
HCPs to be more forthcoming with information about recovery	Carers would benefit from learning skills on how to work with people	Carers need to be able to access support if they want or need it
More touch points with HCPs in recovery period to assess patient progress	Live chat or some forum where carers can share strategies	In-person sessions by charities and online support groups just for carers
Signposting to charities and support groups earlier in the process	Leaflets with hints and tips on how to deliver care practically and how to cope with patient and carer emotions	Mental health assessment for carer and patient at diagnosis

from data that have the potential to be summarised in multiple ways (Braun and Clarke, 2013). This argument is true of the present study, as there were many meaningful stories, albeit that some were on a smaller scale than the narrative reported on. While tempting to report on all possible findings, the scope of this article was narrow. As such, final conclusions were those considered to be the points that would generate the most benefit to future carers. The findings show a clear picture of carers’ needs being the following:

- at diagnosis, practical information and emotional support; and
- when approaching surgery and recovery, consistent and adequate practical information explaining the immediate post-operative period and the recovery at home.

### *Diagnosis*

Carers who expressed great struggle also described a lack of practical information and emotional support at diagnosis. This is similar to findings by McConigley et al (2010), where carers of malignant brain tumour patients expressed a need for practical information at diagnosis. Cornwell et al (2012) also found that carers of patients with non-malignant brain tumours found it difficult to know what services were available to support them. As such, carers in the present study may have experienced fewer difficulties had they been offered carer assessments and signposting to relevant auxiliary services at the diagnosis stage in order to fulfil their need for information and support.

### *Approaching surgery and recovery*

By the time patients approached surgery and recovery, some carers had been through a long stressful period of unknown causes of symptoms, delayed or incorrect diagnosis, and long waiting times. Those who found this period the most difficult expressed a lack of practical, post-operative information, which is reflective of studies of carers looking after malignant brain tumour patients (Andrewes et al, 2013). Additionally,



**Table 10: Lessons learned: carer suggestions on how HCPs and auxiliary services can help future carers – supporting quotes**

Carer suggestions (to HCPs and auxiliary services)		
Information	Skills support	Emotional support
“For us, we didn't know what she would be doing or not doing ... or we might have to do as a result. Erm, there was, I thought that was the point where there seemed to be a ... a gap, a void of information from the, if you like, the surgery and just before that, the preparation for that” (P7, father)	“I do have coping mechanisms and that type of things, which was helpful. I can imagine if somebody didn't, this would be really, really hard for them, really difficult, you know” (P8, husband)	“A way for caregivers to share their strategies ... so that we're not working in isolation.... Now, as I say, it could be that there is a system in place which I'm just oblivious to, but if I'm oblivious to it, why am I oblivious to it. Perhaps it's my fault for not exploring it” (P5, husband)
“I think there ought to have been more, we would have liked more information coming out to us and to the patient erm ... than, than existed” (P7, father)	“I think a lot of people would benefit from some sort of support about how to, to work with people, you know” (P8, husband)	“At one of the BANA conferences, couldn't it ... there could be a session when, when the carers get together” (P5, husband)
“There appeared to be no support ... system, erm, post-operative support system, other than there, there would be, erm, two or three appointments at, you know, sort of certain intervals” (P7, father)	“There must be lots of other people in my situation who are, who are living with someone with an acoustic neuroma. Erm, they must have come up with strategies and ideas that help them ... and if those ideas were shared ... it, you know, if there were sort of, I don't know ... like a live chat or something” (P5, husband)	“Nobody looks at us ... at, at the carer and go, 'But how are you ... how are you coping?’” (P2, wife)
“I found the online support group, I think, only after he had gone into hospital, so, erm, actually having, if I, I found, if we'd had enough time to think about it beforehand and prepare, then hearing other people's experiences, erm, would have been very reassuring” (P1, sister)	“Could a booklet be written or something ... by somebody who's an expert in this field ... on how to cope, how, how to remain patient?” (P5, husband)	“I think both of us should have had counselling, mental health support from the beginning” (P9, partner)

like other studies, there were more female than male carers (Bennett et al, 2012; Treadgold et al, 2019; Nicklin et al, 2021). Although, help provided by the carers, with daily activities, did not differ greatly between male and female carers. Nor was there a significant difference in tasks carried out by relationship status to the patient.

### *Coping*

This study demonstrates that despite the stressors of the caring role, many carers coped well and had coping mechanisms in place. Carers in the present study leaned towards emotion-focused and problem-focused strategies, even if they themselves did not identify them as ways of coping. In addition, resilience was a common response when asked what got them through the situation. This is comparable to findings by

Simpson et al (2015), who conclude that higher resilience may be linked to lower anxiety and depression in carers. While there are obvious differences to these carers' experiences and needs, there is one clear observation: those who experienced the caring situation and the stressors longer and with the least support expressed the most unmet needs. Moreover, one carer for a patient who was on wait and scan for a prolonged period experienced adverse psychological effects. This indicates that the duration of caring is not determined by where the patient is on the pathway, in line with findings from Pinquart and Sorensen (2007).

### *Implications and recommendations*

It would be an oversight to assume that carers of patients with an acoustic neuroma have no needs and will cope well following surgery. While many successfully cope and navigate the uncertain territory, those who struggle may experience catastrophic impacts on their mental health. Consequently, we make the following recommendations for HCPs and future work.

### *Diagnosis*

From a social policy perspective, we recommend that these carers are systematically recognised and assessed as carers at diagnosis, and that HCPs practise consistent signposting to relevant auxiliary services. While this will not avoid all of the negative impacts of being a carer, it will allow carers to access practical information and emotional support that may prevent a decline in their own health (Carers UK, 2021). Bennett (2016) found that, generally, carers were signposted to relevant services, yet 65 per cent did not receive a carer assessment. Under the Carers Act 2014, carer assessments are to be carried out to assist carers with their well-being (Department of Health and Social Care, 2021). Here, we demonstrate the importance of early assessments of carers to evaluate their coping skills and resilience and potential interventions. Since the duration of caring has also been linked to carer health and well-being (Pinquart and Sorensen, 2007), as shown by the carers in this study, we recommend post-operative follow-up assessments to ensure that carers' needs are being met during recovery.

### *Approaching surgery and recovery*

Carers indicated that their needs were met with adequate information regarding the risks of surgery. However, gaps lay in practical information regarding what to expect after surgery. Specifically, carers need more information from HCPs on patient outcomes for the days in hospital following surgery and what care the patient will need once home. Therefore, we suggest informational materials on practical and emotional carer tips and patient recovery, such as those found in Tables 7, 8, 9 and 10, as well as advice on coping techniques. Equipping carers with relevant skills to be a carer may instil a sense of control and reduce stress, anxiety and depression (Smeets et al, 2012).

### *Future work*

Being the first-known qualitative study exploring this population, conclusions may be used as reinforcement for funding applications by charity organisations seeking

support for their carer programmes. Furthermore, it may be useful to undertake studies on other non-malignant brain tumours, exploring whether those populations have similar needs, in order to build up the gap in this under-researched population. [Brainstrust UK \(2019\)](#) recommends that models of support are developed specifically for patients of non-malignant brain tumours. Authors of the present study support this notion and recommend that it is extended to include the carers of these patients.

## Conclusion

This study contributes to the literature gap around the needs of carers of patients with acoustic neuromas by concluding that the needs of this population are not being consistently or adequately met. Carers need practical information and emotional support at diagnosis, as well as consistent and adequate practical information at the approaching surgery and recovery stages. HCPs are in the prime position to offer carer assessments, signpost carers to relevant auxiliary services and provide consistent and adequate post-operative information that may help carers feel prepared, assisting their ability to cope. Overall, there is much to be learned from all the carers in this study, as they have demonstrated that their collective experiences are not of those who coped or did not cope, but of those who are on a spectrum of two extremes.

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## Conflict of interest

The authors declare that there is no conflict of interest.

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