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Patients' experience of necrotising otitis externa: a qualitative study

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Abstract

Background. Necrotising otitis externa is a serious infective condition. Patients are typically frail, diagnostic delay is common and severe pain is a key feature. This study aimed to qualitatively analyse patient-centred data to identify key themes in the patient's experience.

Methods. Open-ended questionnaires were sent to 28 patients. Responses were qualitatively analysed using a grounded theory approach. Iterative cycles were used to develop codes using a constant comparison technique. Emerging categories were refined to identify core themes.

Results. Four main themes emerged: severe pain, mental health, quality of life and diagnostic delays.

Conclusion. This is the first study to explore patients' perspectives in necrotising otitis externa. It indicates a need to raise awareness of necrotising otitis externa, and to improve symptom management, pain control and quality of life. This valuable information can be used to identify research priorities, guide service improvements, improve clinical care and feed into the development of a Core Outcome Set for necrotising otitis externa.

Main Article

Dr E Stapleton takes responsibility for the integrity of the content of the paper

This paper was presented orally at the British Society of Otology free papers meeting 30th June 2021, where it won the prize for best presentation by a medical student.

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Introduction

Necrotising otitis externa is a serious infection of the external auditory canal and temporal bone that can have debilitating consequences. Severe pain is a key feature of necrotising otitis externa and delayed treatment can have devastating effects for patients.[1]

Patients are typically immunocompromised, elderly or diabetic.[2] Necrotising otitis externa characteristically presents with symptoms of severe otalgia and otorrhoea. Patients typically report severe, deep-seated otalgia, which is worse at night,[3] and headaches in the temporal and occipital region.[4] If left untreated, necrotising otitis externa can lead to cranial nerve palsies, compromised hearing, and, less frequently, meningitis[5] and intracranial abscesses.[6] Facial nerve palsy is the most common cranial nerve palsy, because of its close anatomical location to the ear canal;[2] it has been documented to occur in up to 15 per cent of patients.[7] Palsies of the glossopharyngeal, vagus, accessory and hypoglossal nerves can also occur, albeit less frequently.

On examination, patients with necrotising otitis externa have oedema and granulation tissue in the base of their external auditory canal.[8] It has been reported that 78 per cent of patients with necrotising otitis externa will suffer some degree of hearing loss[5] because of this granulation and oedema. Diagnostic criteria for necrotising otitis externa were published by Cohen and Friedman in 1987.[9] However, current literature reports the use of a diverse range of diagnostic criteria amongst experienced clinicians, and there is no recent, universally recognised and established diagnostic criteria. Alongside clinical findings, radiological investigations, microbiology and histological analysis are also used to confirm diagnosis in published case series.[6]

Treatment of necrotising otitis externa requires aggressive intravenous (IV) antibiotic therapy, which is often empirical,[10] followed by culture-guided antibiotic therapy. Prompt treatment can reduce mortality[5] and decrease the likelihood of serious consequences.[1] Recurrence rates have been reported to be up to 20 per cent.[11] Antibiotic resistance is an increasingly common issue that clinicians should be aware of when treating necrotising otitis externa.[12,13] Surgical management of necrotising otitis externa is sometimes employed, including surgical debridement,[8,14] although current literature questions the worth of surgical management.[13,15] It has been suggested that 85 per cent of patients with necrotising otitis externa have diabetes mellitus.[16] It is therefore also important that diabetics with necrotising otitis externa maintain good glycaemic control to improve outcomes and reduce mortality.[17] Although pain is a key feature of necrotising otitis externa, analgesia features in a minority of published treatment protocols.[18]

No previous publication has ever explored the patient's experience of necrotising otitis externa. It is essential to understand the patient's journey, and to consider the impact that this condition – with such severe symptoms, potentially life-threatening consequences and prolonged treatments – has on their life and well-being. There has been a large increase in the number of hospital admissions associated with necrotising otitis externa

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in recent years,[19] and so it is increasingly important to gather a detailed assessment of patients' experiences of their disease and its treatment.

The primary aim of this qualitative study was to explore the patient's experience of necrotising otitis externa. Secondary aims included the identification of potential improvements to treatment pathways and the recognition of research priorities for future work on this theme.

The patient's experience is a crucial aspect of medical care. It is important to understand and report on patients' experience to assess quality of care, and to drive improvement in quality of care. The National Health Service (NHS) has defined eight domains with the goal of guiding measurement of patients' experience. Examples of these domains include: respect for patient-centred values, physical comfort, emotional support, communication and access to care.[20] The questionnaire used in our study incorporated aspects of these NHS patient experience domains in an effort to give patients a chance to state their viewpoint on how necrotising otitis externa has affected them. It is imperative that the findings from this study are incorporated alongside research and robust scientific evidence regarding necrotising otitis externa, to improve the quality of patients' experiences.

There are no published studies in the literature exploring the patient's experience of necrotising otitis externa. In light of the increase in incidence of necrotising otitis externa,[15,19] the severity of symptoms and sequelae, and the lengthy treatment regimen, it is important to fill this gap in the literature. Therefore, it is hoped that this study will help to guide future management and care, and identify themes important to patients that may not be immediately apparent to clinicians. This study is the first to explore necrotising otitis externa from a patient-centred perspective. It aimed to elicit their viewpoints regarding their experience of necrotising otitis externa and its treatment, and to learn about the impact it had on them.

Materials and methods

All living adult patients who completed treatment for necrotising otitis externa in our Trust between 2018 and 2020 inclusive were identified via clinical coding and cross-checked via electronic patient records. All included patients were diagnosed with necrotising otitis externa on the basis of their clinical history, clinical examination findings, radiological findings and granulation biopsy results. All received IV antibiotic therapy in the hospital setting initially, followed by longer term management in the community by an expert outreach team, and regular ENT clinical follow up for a minimum of six months to ensure clinical resolution of disease. As this study focuses on qualitative patient experience, granular clinical details are not included.

The research sponsor approved the protocol as a service review not requiring full ethical approval. Twenty-eight patients were sent an open-ended questionnaire (Table 1) via post, with an approved patient information letter. This letter explained the study aims, and stated that participation was voluntary, and that their clinical information and questionnaire responses would be treated as confidential.

Participants were assigned a unique study identification number. Qualitative analysis was conducted by the main author (EO), who independently read and coded the questionnaire responses through careful interpretation using a grounded theory approach.[21] Several iterative cycles were used to develop preliminary codes using a constant comparison technique, alongside discussion and input from another author (ES). Emerging categories from the codes were refined to identify core themes. Dedoose™ software was used for all qualitative analysis.

Table 1. Open-ended questionnaire sent to patients

Patients' experience of necrotising otitis externa
1. How was your experience of necrotising otitis externa?
2. Please tell us about your treatment & care that you received for necrotising otitis externa
3. How did necrotising otitis externa initially impact your daily life & well-being?
4. Does necrotising otitis externa continue to impact your daily life & well-being? If so, how & why?

Results

Sixteen participants responded, representing a response rate of 57 per cent. Four key themes emerged following qualitative analyses of the questionnaire responses. These themes were: pain, mental health, quality of life and diagnostic delays. Descriptions of the themes are presented in the following subsections. From each main theme, subthemes were also explored. An overview of the main themes and subthemes, with sample quotes, is shown in Table 2.

Theme one: pain

All patients mentioned pain in their questionnaire responses. Patients described unbearable, agonising pain, and wrote very emphatic responses regarding the extreme pain they endured. The pain theme can be broken down into subthemes, including: inadequate analgesia, nocturnal pain, head pain, jaw pain and pain on eating, ear pain, and pain elsewhere in the body.

Inadequate analgesia

This was a common subtheme, whereby inadequate analgesia compounded the pain that patients experienced, because they were not receiving adequate pain relief. Patients attributed this mostly to diagnostic delays in the primary care setting, which meant they had to use over-the-counter pain relief. Patients reported using large amounts of self-administered analgesia at home, but that this made no difference to the pain they were in, leaving them with feelings of hopelessness, and the risk of overdosing.

> 'It totally made me house bound, I was in the most terrible pain I've ever encountered. I once took 4 co-codamol. I knew I was taking too many tablets but when you're in so much pain you just did not care' (patient 2).

'Initially I was advised to use over-the-counter pain relief and use a hot water bottle for comfort but as the infection progressed so did the pain. By the time I was admitted to hospital, I felt desperate' (patient 5).

Nocturnal pain

Patients described nocturnal pain that affected their ability to sleep, causing fatigue, and this contributed to their poor quality of life.

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Table 2. Overview of themes and subthemes, with example quotes

Theme	Subtheme	Example quote
Pain	Inadequate analgesia	'No amount of painkillers would stop the pain' (patient 8)
	Nocturnal pain	'Pain stopped me sleeping, so I felt tired' (patient 9)
	Head pain	'I felt really depressed due to limited action and confinement and feeling very unwell. It was painful and my head felt heavy' (patient 4)
	Pain on eating & jaw pain	'It was the most painful experience I've ever had; it was constant pain; I could not eat (only jelly). I could not chew any solid food as I could not open my jaws' (patient 2)
	Ear pain	'The initial ear infection was painful. As time progressed, the pain worsened and seemed to radiate from my ear upwards towards my eye and downwards to my jaw and towards the back of my head' (patient 5)
	Pain elsewhere in body	'I had severe pain to my head, ear, jaw and teeth and all down my left side of [my] face' (patient 8)
Mental health	Depression & low mood	'I would like to have died. I didn't want my family to see me so depressed and in pain. I felt so depressed. I could not sleep. The pain! Then I could not eat or drink. I wanted to die. I was a burden on my family' (patient 11)
	Wanting to die	'I contemplated suicide I felt no doctors took notice of the severity of it so I phoned for ambulance' (patient 8)
	Anxiety about potential relapse	'I am worried it will come back as I am diabetic. I get anxious when I have a headache or feel an itch. But it is better, and I am grateful. It took a long time' (patient 13)
Quality of life	Poor quality of life	'I wanted to die. I had no quality of life. I couldn't sleep or eat, then the medicine for months. I couldn't leave the house. I still don't leave the house, but I am 86' (patient 7)
	Interrupted sleep	'I used to come downstairs at night to give my wife a chance to sleep. I honestly felt suicidal after weeks of terrible pain and very little sleep' (patient 2)
	Other symptoms that impacted life	'Short concentration in the things I love, jigsaws and bingo. Still have some pain in my ear and popping, at times discomfort. I had to lie down during the day – it made me feel better. Bending to get anything caused me to become dizzy' (patient 4)
	Home antibiotic therapy	'It is better to be at home for antibiotics, in your own home it is better. I don't think my ear is right. It will never be right. It's better than it was. I hate to go into hospital. I want to be free from all this' (patient 14)
	Impact on family & loved ones	'I was so low. I couldn't care for my husband. I could not cook him dinner. I had no appetite, and I could not keep food down' (patient 12)
	Feeling better &/or grateful for care	'The NHS saved my life. They are brilliant' (patient 3)
Diagnostic delays	Delays in primary care	'Went to my GP practice and saw five doctors on different days, first doctor suggested ear syringe. Went private, only to be told infection too bad, went back to GP surgery!' (patient 2)
	Delays in secondary care	'Even at A&E it was so hard to explain to [the] doctor how much pain I was in. I start to think if I had a brain tumour. It affected my family and home life. I thought I was never going to get well' (patient 8)

NHS = National Health Service; GP = general practitioner; A&E = accident and emergency department

'Headache and pain at night was bad and it took another two months to improve. Painkillers did not touch it. It affected my quality of life very badly' (patient 16).

Head pain

Head pain or headache was the most frequently reported type of pain. This was described as severe and intractable by the majority of patients, affecting their quality of life.

'My head hurt mostly, I had to go and lie down during the day, it was the only thing that made me feel better' (patient 4).

Pain on eating and jaw pain

Because many patients had pain that radiated to their jaw, they struggled to eat and chew food. The inability to eat contributed negatively to the overall well-being and health of these patients. Some patients reported they were unable to eat solid food because of jaw pain, likely indicating involvement of their temporomandibular joint by their disease.

'My jaw hurt when I eat. It was hard to keep my diabetes under control when I couldn't eat properly' (patient 10).

Ear pain

As expected, patients commented on extreme pain that they localised to their affected ear.

'My ear felt blocked, then turned very painful' (patient 3).

Pain elsewhere in body

In addition to frequent reports of ear, head and jaw pain, facial and neck pain were also reported.

'The pain was the worst pain in the middle of my head and in my neck and jaw' (patient 14).

Theme two: mental health

The majority of patients reported a decline in their mental health during their experience of necrotising otitis externa and its treatment. Three mental health subthemes emerged: depression and low mood, wanting to die, and anxiety about potential relapse.

Depression and low mood

Patients openly discussed how necrotising otitis externa made them feel depressed and low in mood, attributing this to

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intractable pain, lack of sleep, an inability to eat and an inability to perform everyday activities. The fact that many patients also had long diagnostic delays and received inadequate analgesia interplayed with their feelings of depression and low mood.

> 'The pain for so long made me depressed. I thought I was going to die. The pain in my ear, in my neck, in my head at night. I thought it would never get better' (patient 12).

> 'I felt so weak. Made me feel so low. Six months of treatment took its toll on me' (patient 4).

> 'I was in severe pain and unable to do day-to-day activities and [had] sleep disturbance. Which led to feelings of anxiety and depression' (patient 6).

Wanting to die

Over half of the patients in this study commented that they wanted to die or had suicidal intentions, attributing this to intractable pain, lack of sleep, and diagnostic delays.

> 'I honestly felt suicidal after weeks of terrible pain and very little sleep' (patient 2).

> 'Felt like I'd rather die at one point. It was depressing to be ignored for so long' (patient 10).

> 'From first having the severe pain I didn't have no sleep for nearly three weeks day or night and no painkillers to take my pain away. I contemplated suicide. I felt no doctors took notice of the severity of it' (patient 8).

Anxiety about potential relapse

Some patients shared feelings of worry and anxiety regarding potential relapse.

> 'I am worried it will come back as I am diabetic. I get anxious when I have a headache or feel an itch. But it is better, and I am grateful. It took a long time' (patient 13).

> 'I get anxious when I have a headache or feel an itch' (patient 14).

Theme three: quality of life

This theme describes the impact that necrotising otitis externa had on patients' quality of life. Quality of life can be defined as factors that affect physical well-being, material well-being, social well-being, emotional well-being, and development and activity.[22] This theme incorporates six subthemes. The predominant overarching subtheme was the patients reporting a poor quality of life. Other subthemes included: interrupted sleep, additional symptoms, impact on family and loved ones, and home antibiotic therapy. Many patients reported feeling better and expressed thanks for the care they had received.

Poor quality of life

The majority of the respondents elucidated that their experience of necrotising otitis externa had a negative impact on their quality of life.

> 'My quality of life was so much worse. I already have other problems. My ear problem got ignored. The pain was terrible. My diabetes was worse. I could not eat' (patient 10).

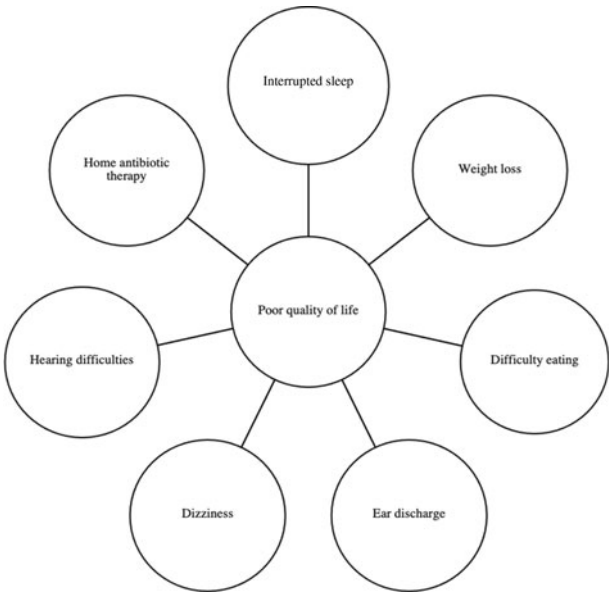


Fig. 1. Factors that led to patient-reported poor quality of life.

There were a number of common attributing factors that patients described as contributing to this poor quality of life; an overview of these is provided in Figure 1. Unsurprisingly, there was some overlap with theme two: mental health.

Impact on family and loved ones

One noticeable subtheme that contributed to the patients' experience was how necrotising otitis externa impacted their loved ones and family. This subtheme describes how patients felt like a burden to their family, and how necrotising otitis externa not only impacted their lives, but the lives of their families.

> 'Having pain and a leaking ear for a year was embarrassing and I did not want to go out and see my family' (patient 9).

> 'I would like to have died. I didn't want my family to see me so depressed and in pain. I felt so depressed. I could not sleep. The pain! Then I could not eat or drink. I wanted to die. I was a burden on my family' (patient 11).

> 'I was so low. I could not care for my husband. He is 91' (patient 12).

Interrupted sleep

Interrupted sleep was a factor that greatly affected patients' lives. Patients described an inability to sleep, because of pain that stopped them from falling asleep or woke them up during the night. This resulted in tiredness, fatigue and the inability to perform everyday tasks.

> 'I had a discharging ear for a year then it became painful and bled. The worst thing was the pain and headache, it stopped me sleeping. The antibiotics made it better, but I had been ill for over one year… pain stopped me sleeping so I felt tired' (patient 9).

> 'As the ear infection worsened, so did its effect on my life. I was constantly in pain, particularly at night and woke up on a number of occasions very tearful because of the pain' (patient 5).

Other symptoms that impacted life

Participants commented on numerous other symptoms and factors that also impacted their life. These are shown, with sample quotes, in Figure 2.

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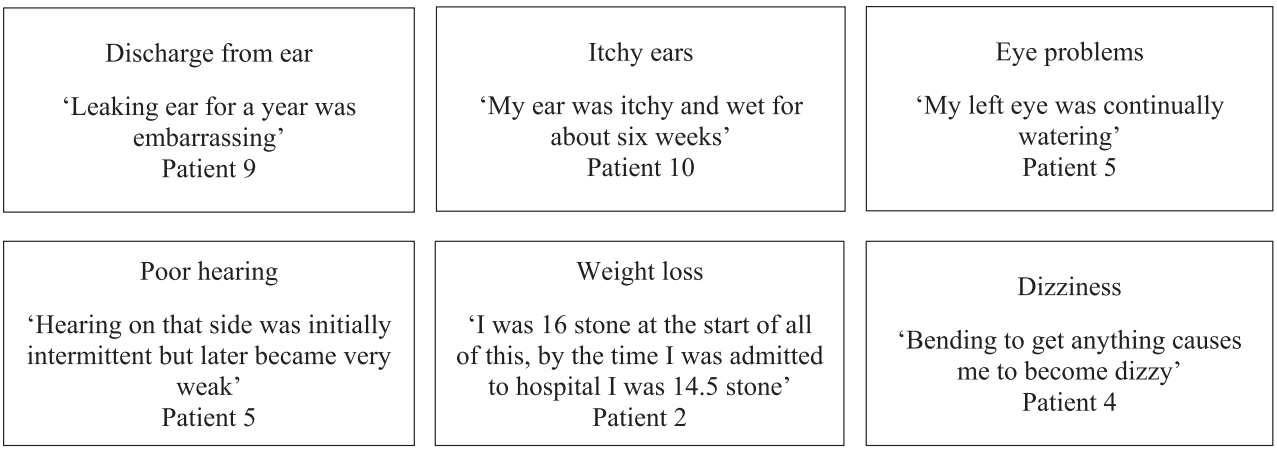


Fig. 2. Other necrotising otitis externa symptoms that affected patients' quality of life.

Feeling better and grateful for care received

Several patients commented that they now felt better and were grateful for the care they had received.

> 'It is better, and I am grateful. It took a long time' (patient 13).

> 'The doctors and nurses were wonderful. I was kept well informed [of] what was happening and what procedures they were going to perform. I always felt I was in safe and experienced hands' (patient 2).

Home antibiotic therapy

Aggressive antibiotic treatment is crucial in necrotising otitis externa cases. Patients commence IV antibiotics as an in-patient, completing an extended course at home via the community team. Patients reported having nurses visit every day to deliver the antibiotics for six or more weeks. Although it was an inconvenience to have treatment for so long, patients were pleased that they could receive treatment at home, as they would rather be in the comfort of their own home than in hospital.

> 'Antibiotics [were] given through a needle in my arm which I found irritating. My skin became very sensitive and sore too. Nurses were excellent and patient with me especially when I was feeling very low in mood' (patient 4).

Theme four: diagnostic delays

Diagnostic delays were a common theme described, both in primary and secondary healthcare settings. Patients reported having their symptoms ignored, and experienced delays before they received a diagnosis. Patients described being frustrated by this, largely because of the pain they were in.

Delays in primary care

Over half of the patients described diagnostic delays by their general practitioner, explaining that general practitioners ignored their problem, did not take their pain seriously, and that they saw the general practitioner repeatedly before getting referred to ENT. Furthermore, patients commented that the general practitioners did not take their diabetes into account, perhaps reflecting a learning need in primary care.

> 'I saw the GP [general practitioner] about eight times, he gave me antibiotics that did not touch it. Eventually I came to ENT and they kept me in hospital for treatment' (patient 15).

> 'GP was useless. Like a chocolate teapot. Honestly just ignored my problem and said it would get better' (patient 16).

> 'I went to my GP practice and saw five doctors on different days, first doctor suggested ear syringe. Went private, only to be told infection too bad, went back to GP surgery! Prescribed different ear drops and antibiotics all of which did not ease the tremendous pain I was in. I personally felt the problem was in my jawbone behind my ear. I think the doctor did not take into account my history of type 2 diabetes and therefore I endured many weeks of terrible pain. The GPs finally sent me to hospital, where in tears I begged to be admitted' (patient 2).

This theme links with the subtheme of inadequate analgesia. Patients reported that because of the delays in diagnosis and not being taken seriously, they suffered a lot of pain, and were not given adequate pain relief. In addition to this, patients repeatedly commented that they were prescribed antibiotics by their general practitioner, which did not improve their symptoms.

Delays in secondary care

Though not as commonly reported as delays in primary care, delays in secondary care (regional district general hospitals) were described, including receiving incorrect diagnoses such as temporal arteritis, being discharged prematurely, and hospital clinicians not taking the patients seriously.

> 'I was admitted to the hospital several times, given antibiotics and discharged. On the last admission I was on IV antibiotics for a few weeks as an inpatient and then at home for about eight weeks' (patient 6).

> 'I reported to [the] consultant about severe headaches and his answer: headaches are not my job in ENT' (patient 1).

Discussion

The primary aim of this qualitative study was to explore the patient's experience of necrotising otitis externa. Secondary aims included the identification of potential improvements to treatment pathways, and the recognition of research priorities for future work on this theme.

The study results demonstrate an in-depth insight into ways in which necrotising otitis externa affects patients' lives, via the four main themes that emerged from our qualitative analysis: pain, mental health, quality of life and diagnostic delays. No studies have previously explored the patient's experience of necrotising otitis externa, and our study has revealed

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important findings in keeping with its aims. The benefit of qualitative research is that it allows for diverse and varied responses, concentrating on patients' needs and priorities.[23]

Our response rate was 57 per cent; however, because this was a single-centre study, the sample size was small ($n = 16$). This is the main limitation of the study. Conducting a multicentre study with a larger cohort of patients would be beneficial. A further limitation was the use of qualitative data. This yields rich, patient-centred data, but relies on patient-reported symptoms and diagnoses. For example, whilst many patients reported mental health symptoms such as anxiety and depression, these diagnoses were not clinically confirmed by a psychiatrist.

Patients were emphatic regarding the pain they were suffering and explained that it affected multiple aspects of their lives. All patients mentioned pain, including headache, ear pain, jaw pain, and neck and face pain. Jaw pain led to difficulties in eating. This had negative repercussions on patients' overall health associated with weight loss, anhedonia and difficulties with diabetic control, putting patients at risk of additional co-morbidities.[24,25] This emphasises the importance of involving multidisciplinary teams in the care of necrotising otitis externa patients,[18] including pain, dietetics and endocrinology teams.

Nocturnal pain resulted in interrupted sleep and difficulty sleeping, leading to high levels of fatigue, and lack of concentration. This lack of sleep placed a heavy burden on patients' quality of life, not only affecting them physically, but mentally as well. Lack of sleep and insomnia has been associated with increased mortality.[26] Adequate analgesia and sleep quality could be usefully addressed to improve patients' experience of necrotising otitis externa.

Inadequate analgesia was a further factor that exacerbated patients' pain. Patients reported ineffective over-the-counter analgesia, especially during the early days of their infection when they were being managed by primary care. This could have negative implications, including the risk of overdose. These findings highlight the need for an effective analgesia protocol for patients with necrotising otitis externa. Furthermore, disproportionate pain in a diabetic patient with an ear infection should be recognised by primary and secondary care physicians as a 'red flag' for necrotising otitis externa, requiring referral to a specialist secondary care setting.

Patients commonly reported delays in their diagnosis of necrotising otitis externa, despite them knowing something was not right. These delays were predominantly in the primary care setting, but they also occurred in secondary care. Chawdhury *et al.*[15] demonstrated via a survey of UK clinicians that there is variation in necrotising otitis externa diagnosis. Some clinicians use the Cohen criteria[9] to diagnose necrotising otitis externa,[4] whilst others view these criteria as obsolete and use a modified version.[27,28] Diagnostic delays in secondary care indicate the need for a recognised diagnostic protocol. Regarding diagnostic delays in the primary care setting, our study highlights that primary care physicians may require education regarding necrotising otitis externa, especially amongst patients with diabetes. Greater awareness of necrotising otitis externa in the primary care setting would improve patients' care and their experience, largely through quicker recognition and referral to hospital for appropriate treatment. Not only would this improve patients' outcomes, but also their quality of life.

The impact that necrotising otitis externa had on patients' reported mental health is concerning. Patients described feeling depressed, worried, anxious and hopeless. This must not be underestimated. Over half of the patients in our study commented that they wanted to die, or considered suicide, whilst suffering from necrotising otitis externa. Our study suggests there is a need for emotional and psychological support to be provided for patients with necrotising otitis externa. There is an important relationship between physical health and mental health. Necrotising otitis externa not only impacts patients physically, causing intractable pain, but the impact on their quality of life is clearly traumatic. Patients with necrotising otitis externa are typically elderly with other co-morbidities; it is therefore important to mitigate the adverse mental health effects of necrotising otitis externa. The depression and anxiety experienced and reported by patients is multifaceted; however, given that this is the first ever paper exploring the patient's experience of necrotising otitis externa, the findings highlight a need to explore this theme further, and to manage these patients more holistically. There were high levels of anxiety described regarding relapse. This anxiety may be better managed if patients experienced fewer diagnostic delays and were given effective analgesia.

- Necrotising otitis externa is a serious infection that can have debilitating consequences
- This is the first study to explore the patient's experience of necrotising otitis externa
- Four main themes emerged: pain, quality of life, mental health and diagnostic delays
- All patients described intractable pain; this and other symptoms negatively affected quality of life and mental health
- Patients experienced diagnostic delays; this could be improved via physician education and enhanced awareness of necrotising otitis externa
- The themes identified in this study can be used to guide service improvements and identify research priorities in necrotising otitis externa

It is clear that necrotising otitis externa places a heavy burden on patients' lives. The cause of the decline in quality of life was multifactorial. Aspects included intractable and nocturnal pain, an inability to sleep, an inability to eat, low mood, anxiety and an impact on their relationship with family. Furthermore, delays in diagnosis and inadequate analgesia aggravated the impact that necrotising otitis externa had on patients' lives. Meta-analyses have shown that a better health-related quality of life is linked with a lower mortality risk.[29] Prolonged antibiotic therapy is essential in necrotising otitis externa cases,[30,31] and although patients have a better quality of life at home than in hospital, this treatment can affect their ability to live their normal life, potentially leading to feelings of social isolation. Despite the decline in patients' quality of life whilst suffering from necrotising otitis externa, there were some positive findings. Patients reported their life improving, they expressed thanks and were grateful for the care they had received.

Conclusion

This is the first published study to explore the patient's experience of necrotising otitis externa; there is no similar work in the literature. Four major themes emerged from our qualitative study of patients' experiences of necrotising otitis externa: pain, impact on quality of life, impact on mental health and diagnostic delays. These are explored in detail, and they consistently highlight the importance of a patient-centred approach in educating primary and secondary care physicians, improving care pathways, and identifying research priorities. The NHS patient experience framework outlines crucial elements that are pivotal in the patient's experience.[20] All these

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elements should be considered when guiding improvements in patient care. It is our hope that the results of this study will be used to guide service improvements, improve clinical care, guide future research, and feed into a Core Outcome Set for necrotising otitis externa.

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