

A lifeworld interpretation of tinnitus

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Abstract

Lifeworld-led care provides a route through which research and practice can navigate the ‘biopsychosocial’ allowing us to overcome the shortfalls of the medical model and enabling us to prioritise humanity in the care of people living with tinnitus. In this article we sought to explore qualitative descriptions of life with tinnitus. We aimed to address the question ‘what it is like to live with tinnitus?’ In doing so we examined qualitative studies and provide suggestions about key themes that seem consistent. This is a narrative, thematic overview of the way lifeworld has been conceptualized and explored in tinnitus research.

Background

Tinnitus challenges biomedical understandings of health and illness. Whilst in some cases it is a symptom of a pathology and a target for medical treatment, chronic tinnitus is a subjective condition, experienced through the lens of an individual life. What is more it is a heterogeneous experience, affecting a huge proportion of humanity (estimates vary from 3% to 30%, increasing with age)¹. Alongside this heterogeneity there is variation in healthcare responses to tinnitus with a wide variation in care provided². Current UK Good Practice Guidance for commissioning tinnitus services recommends treating tinnitus related distress via information and education, hearing aids, counselling and psychological support, relaxation therapy, cognitive behavioural therapy, sleep management and sound enrichment. The use of antidepressants, anxiolytic and night sedation may also be required in some cases³. Recent development of a patient decision aid has provided a resource for clinicians and patients to enable shared decision making in tinnitus care⁴.

Without clear mechanistic process or pathology underpinning the tinnitus perception, the concept of a ‘cure’ remains ambiguous. There have been forays into surgery⁵ and medical devices⁶ but with no long term reduction in tinnitus perception.

The British Tinnitus Association has focused their research strategies on finding a cure⁷, cure remains a preference for people affected by tinnitus.⁸ Yet consistently the most effective interventions for tinnitus target coping rather than cure⁹. The switch between symptom eradication

and building coping mechanisms is one that challenges scripts used by clinicians¹⁰. Clinicians must communicate uncertainty about causal factors, while offering evidence based options for care that rely on psychological adaptation¹⁰. This is a common experience with invisible conditions and subjective health experiences¹¹. People presenting for help with complex symptoms create feelings of frustration, inadequacy and powerlessness in clinicians¹¹. In turn this leads to barriers in communication and reduced shared decision making¹⁰.

Making tinnitus ‘true’

We have a limited understanding of tinnitus perception from the view of the perceiver. Instead, to conceptualise individual subjective perception, clinicians and researchers have employed objective measures. Tinnitus pitch & loudness matching tests are used, and more recently fMRI studies have provided proxy measures of brain activity¹². In pitch and loudness matching tests patients indicate when a clinician or researcher has identified a sound that shares some qualities with the sound that they are perceiving at that time¹². Thereby turning the tinnitus into objective fact e.g. an observable measurement. This risks missing the opportunity to explore the subjective and meaningful aspects of the tinnitus. It risks communicating to the patient that there is a separation between valid, measurable signs and their experienced symptoms. Furthermore, it dehumanizes people with tinnitus by reducing their experience to mechanics¹³. As a result there is a disconnect between the clinical view, based on biomedical markers of tinnitus, and the ‘insider’ perspective¹³. Understanding the ‘insider’ view and the nature of ‘insiderness’ for people with tinnitus is important in humanizing healthcare¹³. For example, people with tinnitus may seek help only to be told ‘there’s no cure’ or worse, ‘there’s nothing we can do’. These remarks may strictly speaking be true in that a persistent symptom with no obvious pathophysiology does not lend itself to medical treatment. Yet the consequences of these remarks are that people feel dismissed⁸. What is more there are treatments that are effective at reducing the distress associated with the perception. Cognitive behavioural therapy, mindfulness, and acceptance and commitment therapy have demonstrably reduced tinnitus distress^{9,14}. These approaches depend on individualised reinterpretation of bodily signs (tinnitus) and symptoms (bodily markers of stress). There is

tremendous social pressure on validating tinnitus as an externally ‘true’ experience for researchers, clinicians and patients. But this is social pressure. It reflects the hierarchy of illness that our culture condones¹⁵.

Quantifying the tinnitus helps validate the ‘sick role’¹⁶ which is socially sanctioned only if symptoms are seen as pointing to a valid illness. The lack of visibility compromises this socially sanctioned role as does the questionable element of mental, rather than physical, illness. It is risky for those with tinnitus to honestly describe their psychological suffering. There is a risk that the patient experience is pushed to one side in favour of statistically driven generalizations about population average mechanisms and treatments¹⁷.

The importance of understanding the ‘lifeworld’

We know very little about what it is really like to live with tinnitus. Interpretivism proposes that dualism is inherently meaningless within the human realm¹⁸ where experience is regarded as unique, and constructed, based on individual learning, cultural and psychological perspectives. The perception is inseparable from the perceiver¹⁹.

There is a growing understanding that ‘lifeworld’ contrasts with the medical world view²⁰. Lifeworld is the descriptive term for the individualised world view and individualised embodied sense. It is inherently subjective and unique. It is also infused with important meanings and clues about what matters to the individual. Lifeworld is a concept attributed to Edmund Husserl (1859-1938). It is ‘the construct of a universal, ultimately functioning, subjectivity’²¹. This distinguishes lifeworld from the notion of scientific objectivity and places lifeworld as the fundamental starting point for all enquiry within the human realm.

Surprisingly, given the inherently subjective nature of tinnitus, there have only recently been a handful of studies which acknowledge the lifeworld of tinnitus. Such studies have captured the contrasts between the medical model and the concept of the lifeworld during clinical encounters and help-seeking¹⁰. There are in depth descriptions of adjustments in thinking as coping changes

and matures in the presence of tinnitus²². Patient preferences for treatments have been modelled⁸. Dauman et al 2017 aimed to capture and describe ‘tinnitus induced disablement’ and provide in depth insights into the lived experience of tinnitus²³. This growing body of qualitative research, using a variety of methods from individual and focus group interviews to ethnographic observations, has informed our understanding of not only what the tinnitus experience is but how and why tinnitus is experienced in particular ways.

Qualitative research offers important new insights in both emancipating the patient voice and bringing the patient view into research discourse. It lends new insight into the inherent ‘felt sense’ of tinnitus²⁴.

The embodiment of tinnitus

The concept of ‘felt sense’ is intrinsically linked to the notion of ‘feeling tone’²⁰. These terms encapsulate the way that a feeling is experienced not simply as a separate and discrete emotion, but one that permeates the lifeworld. Any situation is infused with ‘feeling tone’ which may or may not be articulated. This may provide helpful insight into the mechanisms behind coping processes offering a rich new understanding of how a perception is experienced and what mechanisms are important in determining how it is experienced. In order to explore tinnitus it is vital that we understand the experience of the perceiver rather than extricate the perception from the perceiver.

A simple PubMed search for ‘tinnitus and treatment’ yields 7665 hits. The literature utilizing qualitative methods is sparse. Of 65 results containing qualitative aspects, all but 14 articles are using ‘qualitative’ to mean a description of the tinnitus sound heard. There are very few articles exploring patient experience beyond this. Of those that exist, two elicit views of treatment²⁵, one explores general attitudes to leisure noise²⁶. One explores trauma distress and adaptation in a related condition for which tinnitus is a symptom with a focus group interview²⁷. Watts et al (2018) used qualitative methods to list the problems associated with tinnitus²⁸. Patient preferences for treatments and outcomes have also been examined⁸. These provide useful background and

information but do not address the lifeworld perspective, in the sense of telling us what living with tinnitus is like.

To address the lifeworld perspective we have explored further 9 remaining studies that focus on what it is like to live with tinnitus. The studies included used qualitative methodologies including ethnography, grounded theory and phenomenology to generate new understandings and insights into the lifeworld of tinnitus. Whilst not a systematic review, this narrative review synthesises the rich data generated in explorations of the lifeworld of tinnitus. We have carried out an interpretative synthesis to generate a set of themes which summarise the patterns of lifeworld experience that are present in these published accounts. This was based on exploring the findings for commonalities in the presented categories and themes (from the grounded theory informed studies) and the descriptive themes from the ethnographic and phenomenological studies. All themes were listed and grouped into common categories following the procedures of thematic synthesis²⁹. This was an interpretative synthesis which generated a set of new themes representing the included studies. Finally the researchers applied summary labels to the themes.

Table 1 summarises characteristics of the studies.

Table 1: Characteristics of papers reviewed

Paper authors and title	Methodological framework and purpose	Data collection methods	Data analysis methods	Contribution summary
Pryce & Chilvers, 2018. Losing silence, gaining acceptance: the role of thoughts in adult patients with subjective tinnitus. ²²	The study explored the thinking patterns described by clinical help-seeking participants.	13 people with tinnitus participated in semi structured interviews	Data were analysed in line with grounded theory methods.	Patterns of thinking associated with distressing tinnitus were identified. The core category was 'sense-making' and there were 8 themes around this.
Thompson, Pryce, El Refaie. 2011. Group or individual tinnitus therapy: what matters to participants? ²²	A grounded theory approach was taken to explore the experiences through which individual or group therapy supported coping.	8 clinical help-seekers participated in open ended interviews	Constant comparison of data categories	Experiences of tinnitus improved by mechanisms of information and social comparison

<p>Dauman, Erlandson, Albaracin and Dauman. 2017. Exploring Tinnitus-Induced Disablement by Persistent Frustration in Aging Individuals: A Grounded Theory Study.²³</p>	<p>A grounded theory based study which sought to enlighten variability in tinnitus-induced disablement using a qualitative approach</p>	<p>12 people with tinnitus participated in 3 interviews each exploring 'tinnitus induced disablement'.</p>	<p>Data were analysed following grounded theory methods</p>	<p>4 main themes: Tinnitus as a persistent frustration, losing body ownership, lacking perspectives and persevering through difficulties</p>
<p>Adams, Verrier, Walsh and Lind. 2010. Adults' perceptions of their tinnitus and a tinnitus information service.³⁰</p>	<p>Study aiming to identify key motivations for adults seeking tinnitus advice, how those services are perceived and insight into help-seeking behaviour.</p> <p>Grounded theory methodology underpinned data</p>	<p>Semi structured interviews with 13 participants informed by grounded theory.</p>	<p>Category development and description.</p>	<p>Descriptive categories were 'empowerment through education' and 'If you can't cure me I'll cope'</p>

	gathering and analysis methods.			
Wheeler and Hopwood 2015. Tinnitus: a Deaf/hearing phenomenon ³¹	Auto ethnography providing descriptive account of the authors' experiences of tinnitus with and without profound deafness.	Author and her cousin describe their experience with tinnitus from a Deaf and hearing perspective	This takes the form of a brief, descriptive set of postings.	A description of impacts of tinnitus from a Deaf and hearing perspective.
Greenberg and Leigh 2018. Loss meaning making and reconstruction of narratives in adults enduring tinnitus exacerbated by exposure to sound ³²	A qualitative survey of written responses to 3 open –ended questions.	418 volunteer participants from English speaking world responded to 3 open ended questions	Conducted thematic analysis of 418 unique responses	5 themes were identified: loss, psychological impact, inadequate understanding, crisis of meaning, and solutions.

<p>Marks, Smith & McKenna 2019. Living with tinnitus and the healthcare journey: an interpretive phenomenological analysis.³³</p>	<p>An IPA study with a sub sample participating in a randomized controlled trial.</p>	<p>A sub sample of 9 participants under going a randomized controlled trial into Mindfulness Based Cognitive behavioural therapy undertook interviews</p>	<p>IPA analysis</p>	<p>Descriptions of the distress inherent in the tinnitus experience and the role of clinical encounters in increasing distress.</p>
<p>Andersson and Edvinsson 2008. Mixed feelings about living with tinnitus: a qualitative study.³⁴</p>	<p>Grounded theory informed study Purpose; to explore patients' views of tinnitus and their treatment</p>	<p>7 purposefully sampled participants participated in semi-structured interviews</p>	<p>Based on grounded theory categorization methods</p>	<p>3 main categories labelled: Consequences, Treatment experiences and tinnitus identity</p>

Colagraso, Fournier, Fitzpatrick and Hebert. 2018. A qualitative study on factors modulating tinnitus experience ³⁵	As part of a mixed methods investigation,	27 participants discussed their tinnitus through semi-structured interview and journal entry.	Thematic analysis of verbal and written accounts.	3 themes were identified: participants' appraisal of their tinnitus, factors modulating tinnitus experience and consequences of tinnitus. Attention is considered to have particular importance in regulating tinnitus distress.
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Three dominant themes were identified: 'losing body ownership', 'living with invisible weakness' (themes originally described by Dauman et al²³ and 'tinnitus as an embodied experience of distress'.

'Losing body ownership'

Tinnitus entails a loss of control over auditory perception which impinges on free will, losing the ability to switch off sound and experience quiet at will. Participants refer to 'being invaded by inescapable noise'²³. Terms such as 'invasion' and 'intrusion' communicate a sense of an external force removing body ownership. Participants describe coping processes by acquiring control over their thoughts about the persistent presence of sound. This was achieved by re-framing the comparison³⁰ with other problems and re-evaluating the impact²². Understanding tinnitus helps to bring back a sense of ownership³⁰ to their experience²². Sound therapies have value as exerting control rather than removal of the tinnitus perception³². In an autoethnographic account there is a description of fear of this loss of ownership and control over bodily experience³¹. Greenberg and Leigh's participants report similar loss of ownership and autonomy³²: 'It's the most awful thing...it just takes over your life'.

The presence of accompanying hearing loss is noted to worsen this loss of body ownership for example a participant reports 'even the most basic things have been spoiled' as communication is compromised³³. The loss of body ownership is described as 'something that is in control of me'. ³³

'Living with invisible weakness'

The invisibility of tinnitus makes it a challenge for others to understand³⁴. It is an inherently individualised experience²² and as such brings a sense of separating individuals from those closest to them. Finding a language to describe the tinnitus is also therefore challenging³². There are

concerns about ‘sounding crazy’³². The lack of language is also a feature of the clinical encounter. The accounts include complaints about lack of clear information and explanations that would help them interpret the tinnitus³³.

Tinnitus as an embodied experience of distress

Descriptions of distress²³ are interwoven with accounts²² about tinnitus³³. Participants describe restricted social lives, anxieties about the long term consequences of hearing tinnitus and sleep difficulties³³. This distress is attached to a sense of loss.³⁵

Colagraso et al.³⁵ refer to the physical state embodied with tinnitus which can include feeling physically unwell, fatigue and auditory strain. These descriptions are echoed elsewhere.²²

Contributions from the lifeworld of tinnitus

These themes highlight the human experience in which tinnitus perception and tinnitus perceiver are one. Important features of life with tinnitus are a sense of loss of body ownership, negotiating the invisibility of this experience and managing psychological distress. In a lifeworld perspective these themes encompass the embodied meaning that tinnitus has. Meanings that extend far beyond content descriptions of the tinnitus perception itself (loudness, pitch etc) to describing a sense of loss of ownership and autonomy (identity). As a result the experience is inherently distressing (mood), in part because of the invisibility of it. Individual lifeworld descriptions are by definition subjective and unique, by examining these patterns of description there are insights and clues about what matters to the people affected by tinnitus. This insight is vital in developing patient centered interventions that respond to the impact of the tinnitus on the lifeworld. The perceiver experience has only been fully realized through interpretivist research approaches.

These insights provide new paradigms and models to understand the mechanisms and processes behind tinnitus and associated distress (e.g. thinking processes).²² Qualitative research provides insight into the important features of the experience to target clinical interventions.³⁰ It leads us to providing tools to inform and share information with people with tinnitus⁴. Qualitative accounts also prioritise the patient voice, bringing the role of the perceiver back, rather than simply focusing on

the perception³² , thus enabling emancipation through research. This ‘lifeworld turn’ opens up opportunities for re-humanizing healthcare¹³, for adjusting care so that it prioritizes the well-being of patients, and for busting the myth of the ‘mind-body problem’. This move from object to subject is a crucial shift in redressing the dualist and reductionist dominance in tinnitus research.

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