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Reflections and perceptions of chronic tinnitus during childhood and adolescence.

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ABSTRACT

Objectives: To enhance understanding of the lived experience of tinnitus during
childhood/adolescence from the reflections of adults who experienced tinnitus during
childhood/adolescence and the perceptions of primary carers and clinicians who care for
children/adolescents who experience it. Secondly to develop a conceptual framework to
better describe the experience of chronic tinnitus during childhood/adolescence and to
guide approaches to assessment and management.

Design: Using a concept mapping approach, participants from two stakeholder groups
generated statements describing what chronic tinnitus sounds and feels like to
children/adolescents who experience it. Participants subsequently grouped and rated the
statements to reveal key concepts. The first stakeholder group consisted of adults who had
experienced chronic tinnitus as a child/adolescent and parents of children or adolescents
who experience chronic tinnitus. The second stakeholder group consisted of clinical
professionals who provide care for children/adolescents experiencing chronic tinnitus.

Results: Participants identified 102 different descriptions of what chronic tinnitus sounds and feels like to children/adolescents, across five concepts: 1) Sounds of tinnitus; 2) Descriptions of tinnitus; 3) Perceptions of tinnitus; 4) Emotional responses to tinnitus and 5) Physical responses to tinnitus.

Conclusions: The experience of chronic tinnitus during childhood/adolescence is heterogenous and multifaceted. It may involve the perception of sound, emotions and physiological sequelae. How a child/adolescent experiences their tinnitus will be influenced by the interplay between the sound they perceive, the number of accompanying senses involved and their interpretation of the sound. As well as the emotions and physical effects they experience.

Key Words: Tinnitus, children, adolescents, concept mapping qualitative analysis

1. INTRODUCTION

Chronic tinnitus experienced by children/ adolescents, described hereafter as tinnitus, refers to the perception of sound in the absence of external acoustic stimulus for five minutes or longer and for a period of three months or longer as experienced by children/ adolescents [1-3]. The occurrence of tinnitus during childhood /adolescence has been

4.7 to 54.7% recorded, peaking between the ages of 16 and 19 years [5, 6]. Debate regarding the impact and associated distress continues, as the numbers of children/adolescents presenting clinically with troublesome tinnitus is fewer than the numbers of adults. Furthermore, children/adolescents rarely spontaneously report or complain about tinnitus [2, 7, 8].

Although, the occurrence of tinnitus in children/adolescents is established, little is understood about the lived experience of children with this condition. There is a general perception that children/adolescents who experience tinnitus are not troubled by it [9]. This pervasive perception may have arisen from both the low numbers of children/adolescents seeking medical assistance for their tinnitus and from methodological differences in studies investigating paediatric tinnitus distress. This may lead to the experience of distress in association with tinnitus not being evaluated or of it being misinterpreted [2, 10, 11]. Like adults, children/adolescents who experience tinnitus may be affected to varying degrees, with some being significantly troubled [12, 13]. As with adults who experience tinnitus, a strong association with mental health concerns such as anxiety and depression have also been reported in children/adolescents who experience tinnitus [14, 15]. However, unlike adults, a child/adolescent's experience of tinnitus may be heavily influenced by the interplay of their developmental stage, maturity and concurrent symptoms such as hyperacusis and the sensory nature of their tinnitus. Anecdotal reports suggest that it can be accompanied by emotions such as fear and / or perceived physical

A child's experience may also be influenced by the support they receive at home, at school, from treating specialists as well as a family history of the condition [15-18].

Tinnitus in children/adolescents has been associated with the following anxiety-based symptoms such as difficulties with sleep, concentration, attention and listening, learning difficulties, irritability and emotional distress (especially anxiety) [19]. These issues may have a pervasive impact on a child/adolescent's emotional well-being, social and family relationships as well as their academic progress [19, 20]. Recognising the interwoven impact of paediatric tinnitus within a family unit is imperative for effective intervention. When a child/adolescent experiences tinnitus, other family members may be affected by the child's experiences and reactions. Parents' concerns and experiences can also impact upon their child's assessment of their tinnitus and the coping strategies they employ. They can also influence the parents' preparedness to seek assistance on behalf of their child.

Subsequently, assessment and management approaches to tinnitus during childhood/adolescence may be required for parents as well [15, 20].

Improving awareness and understanding of the distress children/adolescents with tinnitus may experience is essential for improving the support and treatment they receive. It may also assist to improve assessment and management of tinnitus in this population and subsequently reduce the impact of tinnitus upon a child/adolescent's development, education, and quality of life.

1 This study is the first to explore the retrospective lived experience of tinnitus in
2 children/adolescents. It does so based on the reflections of adults who experienced chronic
3 tinnitus as a child/adolescent and the perceptions of the primary carers and clinical
4 professionals involved in the care of children/ adolescents currently experiencing tinnitus. It
5 aimed to better understand the experience of tinnitus in children/adolescents and is part of
6 a larger study which sought to explore the impact of chronic tinnitus during childhood and
7 adolescence, as well as the methods of management and barriers to treatment. The findings
8 of the second and third components of this larger study will be reported separately. The
9 study in its entirety also sought to develop a conceptual framework to express the lived
10 experience of tinnitus during childhood and adolescence and identify key aspects of the
11 experience which contribute to distress and may be amenable to treatment. Insights gained
12 from this framework may enhance the accessibility of services or improve the clinical
13 management.

15 2. MATERIALS AND METHODS

17 Concept mapping techniques were employed to establish a conceptual framework for
18 understanding the lived experience of tinnitus during childhood/adolescence from the
19 viewpoints of key stakeholders.

1 Concept mapping is a participatory mixed methods approach which combines two stages of
2 qualitative data collection with two quantitative data analysis approaches, to produce visual
3 representations of how the participants involved view the topic of interest [21-24].

4 The qualitative approaches to data collection are brainstorming, grouping and rating.

5 Brainstorming involves the generation of statements by the individual participants in
6 response to an open-ended question. Grouping involves each participant grouping the
7 statements generated by all participants into groups in a manner which makes sense to
8 them. Rating involves each participant rating each statement against a scale pertaining
9 to the topic under investigation. These processes allow participants to share their

10 experiences and perceptions without preconceived limitations and boundaries from
11 examples, classifications or predetermined descriptions established by researchers [22-28]

12 The quantitative data analysis methods assist in the identification of key themes and
13 relationships from these participant insights by involving them in the initial data synthesis
14 processes of statement grouping and rating. Involvement of participants in these stages also
15 assists to reduce the potential for influence from researchers on data analysis. It is the
16 participants who contribute to the identification of themes and relationships with the
17 researchers determining the number of themes that best reflect the participants' data. This
18 improves the validity of a study's findings compared to other qualitative research methods
19 [26].Through this method, researchers become better able to understand the context

20 surrounding the topic under investigation, identify interrelationships as perceived by
21 affected individuals and groups, and improve the applicability of actions and plans arising

22 from the data interpretation and analysis [21, 22, 26]

Concept mapping as a research method has been recommended for evaluating and improving healthcare services and, more recently, has been applied to audiology for client clinician interactions for hearing aid adoption[22, 23, 30].

This study in its entirety involved three questions 1) What does chronic tinnitus sound and feel like to children and adolescents who experience it? 2) What parts of children's and adolescents' lives are affected by chronic tinnitus? 3) What is done to reduce the impact of chronic tinnitus on children's and adolescents' lives? The participants were recruited to participate in all three components of the overall study

An online concept mapping system (Concept Systems Inc., Ithaca, NY, USA) was used as an online portal for participants, for data entry for data collected offline, and for some of the data analysis. Statements were generated either via an online portal or via teleconference. Grouping and rating tasks were undertaken either via the online portal or via postal packs.

2.1 Participants

In the present study the views of participants from two stakeholder groups; a tinnitus group and a clinicians' group were sought. The input from various stakeholder groups promotes the generation of diverse and comprehensive insights [24, 27, 28]

The tinnitus group, comprised of two subgroups: Adults who had experienced chronic

adolescent who had experienced chronic tinnitus. Both the adults who had experienced tinnitus during childhood/adolescence and the primary carers were grouped as they both have a firsthand view of the patient experience.

The clinicians group consisted of clinicians who were involved in or had been involved in the provision of care to children and adolescents who experience chronic tinnitus. Clinicians who care for children and adolescents with tinnitus have a unique perspective of the lived experience of tinnitus during childhood and adolescence.

Adults who experienced tinnitus during childhood/adolescence were chosen to inform this study as several studies have shown that adults are able to reliably recall salient and autobiographical events from their childhood such as illness and that their responses are likely to be more detailed, longer and have greater narrative coherence than the recollections of children [31-33]. Additionally, Smith (2009) found that their recollections were neither significantly coloured by time nor impacted by later events. While this decision presents some limitations in regards to the general reliability of the findings of the study, it was deemed more appropriate to include adults who had experienced tinnitus during childhood and adolescence than children or adolescents currently experiencing tinnitus for whom this data collection method may have been onerous and to prevent any perceived influence on a child/adolescents current experience of tinnitus.

1

2 **2.2 Recruitment**

3

4 Participants were recruited via university, professional and clinical networks in Australia and
5 internationally, utilising emails, word of mouth, and online chatrooms and forums. All
6 clinicians were asked about their experience to ensure that they had adequate familiarity
7 with the subject under investigation.

8

9 Two rounds of recruitment were undertaken. The first occurred for the brainstorming stage.
10 The second occurred for the grouping and rating stage and was undertaken to increase
11 participant numbers, reduce participant burden (Figure 1).

12

13 Approval for the project was received from the Human Research Ethics Committee, The
14 University of Western Australia (RA/4/201/4274). All participants provided informed written
15 consent prior to participating.

16

17 **2.3 Procedures**

18 *2.3.1 Brainstorming:*

19 Participants were asked to generate statements in response to the question: What does
20 chronic tinnitus sound and feel like to children and adolescents who experience it?

1 The wording of the question was carefully chosen by three researchers (ST-Q, RJB & RHE)
2 and pilot tested on eight clinicians, friends and adult patients of an affiliated clinic who
3 reported having experienced tinnitus during childhood or adolescence. The pilot testing
4 took into consideration the participants to be recruited bearing in mind that the question
5 would be understood, that the question was not leading, and it was worded such that it
6 encouraged the generation of statements focussing on the lived experience of chronic
7 tinnitus in childhood and adolescence.

8
9 Brainstorming was offered as either a group or individual task, although none chose the
10 group option for reasons of convenience. Thus, all participants completed the brainstorming
11 tasks online or via a teleconference. Rosas & Kane (2012) demonstrated that there is no
12 negative impact on the validity or reliability of the concept maps generated when multiple
13 brainstorming participation methods are used in a study design Inclusion of multiple
14 participation methods facilitated the involvement of stakeholders from multiple geographic
15 locations.

16
17 When brainstorming was undertaken via teleconference, the question was voiced in a
18 neutral tone, and the participants were not prompted further than having the question
19 repeated using the same wording when there were pauses in the generation of statements.

20 The participant's answers were transcribed by one researcher (ST-Q) during the session.

21 When brainstorming was undertaken online, participants entered their statements into the
22 portal generating as many statements as they could.

The statements were pooled across all participants groups. Three members of the research group (ST-Q, RJB & RHE) refined the statements. A duplicated statement was removed when the meaning of two statements provided the same information even if the wording was slightly different [34], e.g. “affects concentration during exams” and “can’t concentrate during quiet work at school”. Irrelevant statements were removed when the information in the statement did not pertain to the focus question. The remaining statements were edited for clarity to ensure that they were not written in the first person and could be used to reflect the input from participants from any of the three participant groups thus ensuring anonymity and encouraging participants to group and rate the statements in a manner without bias or influence.

2.3.1 Grouping and rating:

Participants then played a vital role in data synthesis by grouping and rating the brainstormed statements. These activities generated a conceptual framework which illustrated both the relative importance of each concept and the relationships between the concepts and identified clusters of concepts.

To reduce participant burden, each participant was allocated randomly to the task of grouping and rating statements for one of the three questions of the larger study. Once a participant completed their tasks for their allocated question, they were invited to complete the grouping and rating tasks for one or both of the other questions. Grouping and rating

was conducted through the online portal, or via postal packs; two participants utilised the second option.

During the grouping stage, all participants were asked to group the statements in a way that made sense to them. They were told that there was no right or wrong way to group the statements. However, they were asked 1) to ensure that each statement was placed in only one group, 2) to create a minimum of five groups, 3) that a statement may form its own group if they felt that it was unrelated to any other statement, and 4) that a miscellaneous group could not be created. Upon completion of the grouping task they were asked to formulate a title for each group that summarised the content of that group.

Participants then rated the individual statements given their perception as to the degree of distress it would likely cause: "Rate each statement according to the degree of distress associated with the sound or feeling described." The rating was provided using a 5-point Likert scale, where 0= low distress; 1= mild distress, 2 = minor distress, 3 = moderate distress, 4 = significant distress, 5 = high distress.

2.4 Data Analysis and Interpretation:

Data was entered into the Concept Systems portal, and, it was checked to ensure that each participant's grouping and rating responses were coded according to their initial participant

Multidimensional scaling was undertaken to generate a point map presenting each statement as a single point and in a two-dimensional space. The position of the points graphically illustrates the relationship between the statements by depicting how closely the statements are situated relative to one another. Statements that were frequently grouped together by participants appear close to each other on the point map; conversely statements which were rarely grouped together by participants appear further apart in the two-dimensional space. A stress index was computed for the multidimensional scaling, providing a measure of the goodness of fit of the grouping data. Kane and Trochim (2007) suggest that stress index values between 0.205 and 0.365 are acceptable but lower scores are more desirable.

Key concepts were identified through a process of hierarchical cluster analysis, wherein cluster configurations are analysed based on the participants grouping data. These cluster configurations illustrate different options for clustering the statements to identify key concepts. The shape and size of each cluster illustrates whether the cluster represents a narrow or broad conceptual area and is calculated based on the frequency with which the participants grouped the individual statements [26]. Three of the authors (ST-Q, RJB and RHE) reviewed various cluster map configurations to establish which map best represented the data. This decision was informed by the statements within each cluster and the bridging scores between the clusters. Bridging scores indicate how frequently the statements in a cluster are grouped together. Lower bridging scores indicate that the participants grouped those statements more frequently. Higher bridging scores suggest that the statements were

which statements in a cluster are key or anchor statements and which statements are bridging between different clusters within the map.

After the cluster maps were reviewed, the reliability of the map was established by undertaking a Spearman-Brown coefficient split-half reliability test of unequal lengths for the data representing both participant groups individually and then for the participants split randomly into two groups to ensure that a single five-cluster map solution represented the thoughts and experiences of both participant groups. Split-half reliability tests provides an indication of the reliability of the concepts generated by measuring the consistency of participant grouping [29]. Internal consistency for the final cluster map was established using SPSS to calculate Cronbach's alpha for the rating data generated by the participants in each cluster. A pattern matching graph, which compares the average cluster ratings between cohorts in a ladder styled graph was produced to display the differences in the average cluster distress ratings between the tinnitus group and the clinicians. A pattern matching graphs displays how the two groups rated the statements and establishes where they rated them similarly and where they rated them differently.

Once the final map was produced, external representational validity was obtained by presenting the cluster map back to the participants and seeking their comments.

Participants were asked to review the concept map and consider whether the concepts conveyed in the map were reasonably informed by the statements, as well as considering whether the names and descriptions of the presented clusters reasonably represented the

3. RESULTS

Thirty adults participated in the initial brainstorming phase and 25 (23 original participants and 2 subsequent participants) completed the grouping and rating tasks. There was a predominance of females in both the adults who experienced tinnitus during childhood/adolescence ($n=10$) included three males and seven females and were aged between 19 and 62 years (mean 34.9, SD 15.14). The age of their tinnitus onset ranged from four to 18 years and they were Australia, Portugal and the USA. At the time of data collection all ten described still experiencing tinnitus, four reported that their tinnitus was less troublesome and six reported that it fluctuated. Five reported having sought help for their tinnitus as a child/adolescent but only one reported that the help they had received was useful. The primary carers ($n=10$) included one male and nine females, with ages ranging from 28 to 55 years (mean 44.73, SD 7.67). They were in Australia and the United Kingdom.

The clinicians ($n=12$) included one male and 11 females, with ages ranging from 34 to 56 years (mean 46.8, SD 7.99). They were in the United Kingdom, Denmark and Australia. The clinicians represented three different professions: one Ear Nose and Throat specialist, one Psychologist, and ten Audiologists. Their experience ranged from less than five years to over 20 years of experience working in the field of paediatric tinnitus.

The participants generated 156 raw statements these were reduced to 102 individual statements after refinement (Appendix 1).

During the grouping and rating tasks the individual participants grouped the data to produce between three and 23 separate groups of statements (mean 7.12, SD 4.22). It was determined that a five-cluster map optimally represented the data. (Figure 2).

The five-cluster concept map had a stress index of 0.1985 indicating that the cluster map generated accurately reflected and represented the groupings undertaken by the participants [29, 35]. Two Spearman-Brown coefficient split half reliability tests were undertaken. The first compared the two cohorts and produced a score of 0.854. The second compared the participants randomly split into two groups and produced a score of 0.916. These scores demonstrated that the map was representative of all participant groups and that there is good correlation between how the individuals grouped the data and how their effects were represented. They also indicated that the single map had a high degree of reliability [36, 37].

A five-cluster map was deemed to best represent the views of the stakeholders. Each cluster represented a specific concept relating to the research question. Within this map there were two clusters which were considered to describe the domain of sounds; *Sounds of tinnitus* and *Descriptions of tinnitus*, and three clusters the domain of feelings; *Emotional responses to tinnitus*; *Perceptions of tinnitus* and *Physical reactions to tinnitus*.

3.1 Domain of sound.

3.1.1 Sounds of tinnitus (25 statements): Statements within this cluster tended to represent sounds that are perceived without linking an emotional response to the tinnitus sound or without including emotional content in the sound description. These tended to focus on simple descriptions of the tinnitus sound such as “A ringing and whistling sound” or “Motor”. Several statements also incorporated a familiar sound, such as “Constant high pitch noise with air behind it: a whoosh” or “Like a shell over the ear”. As a concept, *Sounds of tinnitus* had the lowest average distress rating for both the tinnitus group (mean 2.29, SD 0.38) and clinicians (mean 1.43, SD 0.21). This suggested that both participant groups perceived that when a child/adolescent experiences tinnitus as a sound without additional emotional, sensory or physical associations it may be less distressing than when the sound has additional associations or experiences. The statement associated with one of the lowest degrees of distress, as determined by the average rating score ascribed to it by the participants, notably “Enjoyable friendly bees”, was included in this concept. This concept was associated with a very low bridging score (0.14) suggesting that these statements were frequently grouped together. This concept was geographically close to the other concept within the sound domain *Descriptions of tinnitus*. Two statements, statement 26 “footsteps” and statement 46 “repetitive animal noises” bordered the two concepts.

3.1.2 Descriptions of tinnitus (12 statements): This concept included statements where the tinnitus sound description was accompanied by an emotional response such as “Like

included a positive emotion, “Happy sounds e.g. angel noises”. This statement was also one of the two statements associated with the lowest distress rating scores. The rating order of this concept was similar for both the tinnitus group (mean 2.78, SD 0.62) and clinicians (mean 2.67, SD 1.22). This suggested that both participant groups regarded this concept similarly compared to the other concepts. This concept had a bridging score of 0.41.

3.2 Domain of feelings:

3.2.1 Emotional responses to tinnitus: This was the concept with the largest group of statements (n=34). Statements included in this concept centred on the emotional sequelae of tinnitus with statements such as “Distress caused by thinking something is wrong but not being able to talk about it” and “Scary and frightening, the more it is listened to the scarier or more frightening it becomes.” Professionals ordered this concept as the most distressing (mean 3.36, SD 0.53) while the tinnitus group ordered this concept as the second most distressing concept (mean 3.16, SD 2.25). This concept had a very low bridging score of 0.07 indicating that these statements were frequently grouped together by participants.

Emotional responses to tinnitus was most closely associated with the concept *Physical response, whole body*.

3.2.2 Perceptions of tinnitus: This concept described physical presentations or feelings

associated with the tinnitus. Many of the statements (n=25) within this concept localised

hearing other sounds while it grows stronger” or “Vibration in head”. Statements within this concept also introduced the concomitant existence of tinnitus and hyperacusis for some children with statements such as “Associated with decreased sound tolerances”. Physically, this concept was the largest of the five concepts even though it only contained 25 statements because the statements within this concept were not grouped together as frequently as the statements within the other concepts. This was evidenced by the relatively high bridging score of 0.64. This concept was ordered by both the tinnitus group and clinicians as the second least distressing concept. The tinnitus group attributed a mean distress rating of 2.68 (SD 0.24) to this concept and the clinicians attributed a mean distress rating of 2.19 (SD 0.45) to it.

3.2.3 Physical Responses to tinnitus (6 statements): This concept described bodily sensations and the systemic responses associated with the experience of tinnitus with descriptions such as “Tiring”, “Stomach churns” and “Brain fog getting in the way of thinking about anything else.” The tinnitus group ordered this concept as being the most distressing of the five concepts with a mean distress rating of 3.19 (SD 1.14). However, it was not statistically different to the distress ratings for *Emotional response to tinnitus*. The clinicians also rated this concept highly in regard to associated distress (mean 3.26, SD 0.06). The *Physical responses to tinnitus* concept had a bridging score of 0.40 which indicates that the six statements were not grouped together as frequently as the statements in the other concepts.

3.3 Participant Ratings

The participants' median rating scores for the degree of distress associated with the sound or feeling described in each statement varied from 0 to 5 (SD 1.10). The mean rating scores for each statement across all participants varied from 0.68 to 3.84 (SD 0.82). The lowest distress ratings were associated with three statements "Happy sounds e.g. angel noises", "Enjoyable 'friendly bees'" and "Sometimes feels as if it changes from ears to brain with jaw and temple movements." The greatest degree of distress was associated with two statements "Causes a huge amount of distress" and a sense of having "Ruined self for life."

These results suggest that most of the statements, even those that appear to have a positive description are associated with a degree of distress albeit minor for some statements.

Although the clusters appeared to be presented in order of distress on the pattern matching graph (Figure 2) there was no statistically significant difference ($p > 0.05$) between the two participant groups for the mean distress ratings of the three concepts of *Emotional response to tinnitus*, *Physical response to tinnitus* and *Descriptions of tinnitus*. Statistically significant differences ($p < 0.05$) were found between mean distress ratings of the two groups for the concepts *Sounds of tinnitus* and *Perceptions of tinnitus*, with the tinnitus group rating these clusters more distressing than the clinicians. Internal consistency for each cluster was established by calculating Cronbach's alpha from the rating data generated by the participants and high values were achieved for each cluster [38]: *Sounds of Tinnitus* ($\alpha = 0.980$); *Descriptions of Tinnitus* ($\alpha = 0.950$); *Perceptions of Tinnitus* ($\alpha = 0.983$); *Emotional Response* ($\alpha = 0.991$) and *Physical Response* ($\alpha = 0.983$). These show a high degree of

Eight participants (n= 4 tinnitus experiencers; n= 4 clinical professionals) provided an external validation of the final cluster map. Seven participants supported both the clusters derived from the data, the cluster names and their descriptions with none requesting or suggesting that any changes be made. One participant, a clinician suggested that the data would be better divided into three concepts; 1) auditory descriptions, 2) physical sensations and responses, and 3) emotional sensations and responses, however, the grouping and rating data and concept mapping software did not support this division.

4. DISCUSSION

The purpose of this study was two-fold: firstly, to explore what tinnitus sounds and feels like to children/adolescents who experience it from the reflections and perceptions of those who experienced chronic tinnitus as a child and/or adolescent and from those who care for them; secondly, to enhance our understanding of the experience of tinnitus during childhood/adolescence and build a conceptual framework which describes it.

Through this study of participant's reflections and perceptions it became apparent that the sounds and feelings experienced by children/adolescents with tinnitus are multifaceted. It involves the perception of sound, emotions and physiological sequelae. Sounds are diverse and the interpretation and personification of these sounds may influence how a child/adolescent experiences their tinnitus. Both the tinnitus group and clinicians used similar language and descriptions to describe how tinnitus sounds and feels as is evidenced

suggest that the clinicians who assist children/adolescents with tinnitus and their families are sensitive to and well informed about the experiences of those they assist.

Terms such as noises, ringing and buzzing are used frequently to describe the sounds of tinnitus in adult tinnitus literature. However, the applicability of these terms for some children/adolescents may be limited, non-representative and unfamiliar. Of the 102 individual statements describing how tinnitus sounds and feels, generated during this study, 30 different sound descriptions were identified. Four statements involved *“buzzing”* and eight involved *“ringing”*. Descriptions using a sense of speech such as *“screaming and yelling,” “speech”* and *“screeching”* were identified seven times. These results concur with a study involving 102 children/ adolescents with tinnitus where eight different tinnitus descriptions were identified [39]; as well as another study [40] which identified 12 different sound descriptions. Sound personifications were another common means of describing or explaining the sounds perceived by children with tinnitus, [19]. In a retrospective study of children attending a hospital psychology department for assistance with tinnitus the authors described how children with tinnitus may personify their noises, reporting terms such as ‘scary monster’[19]. Personification and sensory descriptions were also found in this study. In addition to terms such as ringing and buzzing, more vivid and sensory descriptions such as *“A lady singing,” “Repetitive animal noises”* or *“Mumbling / muttering noises; not distinct words that disagree with the person who hears them”* were described. Other researchers [41] discussed how children may use examples of associations within their everyday

of object identification within the experience of tinnitus during childhood/adolescence. In the clinical setting it is important that clinicians are aware of the potential plethora of descriptions used by children/adolescents with paediatric tinnitus. Many of the statements generated during this study show that children/adolescents process and evaluate their experiences with tinnitus and intense feelings of isolation and despair may arise. This study also illustrated the difficulty children/adolescents may experience verbalising their experiences and perceptions and, consequently, may be wary of sharing them [19]. As such, it is important that clinicians do not limit, diminish, or exclude a child/adolescents' experience by providing a sound example of "ringing" or "buzzing". Instead, it is vital they ask more open-ended question to encourage the child/adolescent to share their experience. For example, it would be prudent to ask whether "they hear any noises in their ears or head that they think others can't hear?" in a natural questioning manner. It is then necessary to remain open and accepting of the descriptions that follow.

This diversity of descriptions and experiences of tinnitus has implications for the manner in which people seek help for tinnitus during childhood/adolescence, and the assessment methods used. The myriad of descriptions and experiences associated with tinnitus during childhood/adolescence may contribute to the high prevalence rates contrasted with low clinical attendances noted in previous studies [2, 8, 11, 16]. The statements generated during this study illustrate the variety of language used to describe the multisensory and multifaceted experience of tinnitus during childhood and adolescence. Many of the

1 *laughed at during initial attempts to discuss with others*". Many children/adolescents who
2 experience tinnitus are dependent upon their parents or carers becoming aware of their
3 tinnitus, seeking assistance and advocating on their behalf. However, parents need to be
4 more knowledgeable about tinnitus if they are to be relied upon to recognise behaviours, or
5 interpret experiential language descriptions as pertaining to tinnitus, so they may seek
6 assistance on their child's behalf. Many children/adolescents who experience tinnitus, and
7 who may benefit from clinical intervention and assistance [42], may not be identified and
8 brought in for medical assessment and management [2, 9, 20]. As such, it is essential to
9 raise parents' awareness about tinnitus during childhood/adolescence, its prevalence, the
10 signs and symptoms as well as potential ramifications.

11
12 Exploring how a child/adolescent experiences their tinnitus, and which aspects of their
13 experience are more and/or less distressing, is crucial for understanding their experience of
14 tinnitus and is essential for facilitating the development of appropriate management
15 strategies. Twenty statements from this study provided direct examples of how tinnitus
16 during childhood/adolescence, may be perceived and experienced with physical and
17 esoteric symptoms: as well as the perception of sound. These include statements such as
18 *"Brain fog getting in the way of think of anything else"*, *"As if head would explode"* or *"Feel*
19 *as if hearing has switched off"*. Other statements illustrated how tinnitus may be perceived
20 as single discrete sounds: *"A beating noise"*, multiple combinations of discrete sounds
21 *"Overlay of multiple high pitched tones"* as well as combinations of personifications, familiar

1 *unable to hear when tinnitus is present*” or constant “*Constant hum that gets louder and*
2 *softer*”. Statements within this study that involved personifications and familiar object
3 identification illustrate the complex nature of tinnitus during childhood and adolescence. It
4 also illustrated how the experience of tinnitus may be influenced by degrees of imagination
5 – reality confusion. This may be associated with the child/adolescent’s level of multisensory
6 integration and neuropsychological development [18, 43-45]. Clinicians need to be mindful
7 of the possible sequelae of tinnitus and how a child’s developmental phase may contribute
8 to how tinnitus sounds and feels to them.

9
10 The integral role of the feelings associated with the experience of tinnitus during childhood/
11 adolescence was highlighted by this study. Emotional, physical, and esoteric feelings were
12 all linked to the perception and experience of tinnitus and warrant further investigation.
13 Statements identifying an association of the perceived sound with an emotion, a
14 personification or a familiar object reinforce the applicability of tinnitus models such as
15 Jastreboff’s (1975) neurophysiological model to tinnitus during childhood/adolescence. This
16 study illustrated that participants reflected on or perceived sound descriptions such as
17 “*Happy sounds e.g. angel noises*” and “*Enjoyable friendly bees*” as associated with lower
18 rating scores consistent with lower degrees of distress. Conversely statements such as
19 “*Ruined self for life*” and “*extreme panic*” from the emotional response concept were
20 associated with high rating scores consistent with higher degrees of distress.

tinnitus as a child/adolescent involving sound personification, familiar object identification and by statements where the sound was associated with an emotion or physical sensation. They illustrate how a child may interpret and experience their tinnitus and how the strength of that experience can be carried through to adulthood [46]. When tinnitus is interpreted and associated with fear and/or anger, the limbic system becomes involved[47]. Involvement of the limbic system contributes to establishing negative emotional responses and the memories associated with the sound, as well as a subconscious automatic flight and fright response from the autonomic nervous system[47]. The autonomic nervous system's response promotes, the memories and emotions evoked by the perception of tinnitus. They may interact to reinforce the importance and potential distress associated with the sound and may, in part, contribute to many of the associated sequelae of tinnitus during childhood/ adolescence. These include lying awake being too scared to go to sleep; feeling as though one's "stomach churns", and avoiding situations that may trigger their tinnitus [48]. Incorporating a child/adolescent's tinnitus descriptions for what tinnitus is, how it develops, its association with many of the symptoms experienced and methods for managing the tinnitus may improve the applicability and suitability of the explanations [46].

Several studies exploring tinnitus during adolescence have noted an association between the experience of tinnitus and poor mental health outcomes, higher levels of stress, anxiety, depression and even suicidal ideations [14, 49-51]. In a study of tinnitus and mental health in 15 and 16-year-olds, Brunnberg et al. found that adolescents who experienced tinnitus

Statements within the *Emotional Response / Impact of tinnitus* cluster provide reflections of and perceptions of the intense thoughts and feelings of isolation and despair that many adolescents/children with tinnitus may experience but have difficulty verbalising. Many of these statements supported the findings of a study which described how children/adolescents process and evaluate the tinnitus sound and its implications but may have difficulty articulating what they are experiencing[19]. The manner in which children/adolescents evaluate their tinnitus may be informed by several factors including their experiences, familial and early messages about tinnitus, illness and/or coping styles and strategies; their personality type and their developmental level. Adolescence is a time of great upheaval and change in a young person's life [49]. The physical and emotional changes within this period can be turbulent enough without additional stresses associated with perceiving tinnitus and dealing with the potential sequelae. While several studies have discussed the link between the experience of tinnitus during childhood/adolescence and poor mental health, few provide an exploration around the contributing factors. This study provides a greater insight into the type and complexity of feelings which could contribute to poor mental health in association with the experience of tinnitus during childhood/adolescence. It also and highlights the need for further research in this area.

5. Limitations and Future

Participants for this study were recruited through a variety of channels and were heterogenous in nature with regards to the stakeholder group represented. This took into

child/adolescent who was troubled by their tinnitus, or clinicians who interact with those who are troubled by their tinnitus. Therefore, the statements that they generated and ratings they provided may have been skewed or biased towards greater distress or may not capture the experience of children/adolescents with non-distressing tinnitus. The high levels of distress recorded for some of the statements within this study suggest that distress may well be associated with the experience of tinnitus during childhood/adolescence. In addition, the incidence and degree of distress may be greater than the levels reported in a number of studies examining tinnitus in children where high prevalence rates, but low distress rates, are reported [8, 11, 16]. However, specific tinnitus distress was not formally assessed during this study, as a validated method of assessing tinnitus distress within a paediatric tinnitus is yet to be developed.

This study was also limited by not including a subset of children/adolescents currently experiencing tinnitus. However, the demands of a concept mapping approach to research this field was considered onerous for children/adolescents and the authors wished to ensure that there was no perceived influence on a child/adolescents experience through exposure to the experience of others. However, adults who had experienced tinnitus during childhood/ adolescence were considered appropriate for informing this study as adults are able to effectively recall salient autobiographical childhood events such as the experience of tinnitus during childhood or adolescence and are likely to provide responses of greater length and detail.

1 This study may also have been limited by the combined grouping of adults, who experienced
2 tinnitus during childhood/adolescence, together with the primary carers of children or
3 adolescents who experienced chronic tinnitus in the patient cohort. Ideally, the insights
4 from these two groups would be analysed separately to generate independent perspectives.
5 However, there was good consistency between the groups and combining them as a single
6 patient cohort because of the sample size provided valuable and valid insights that have
7 assisted the development of a conceptual framework for improving our understanding of
8 how tinnitus sounds and feels to the children/adolescents who experience it.

9 Several of the statements included in the study were double-barrelled, meaning in that they
10 combined a descriptor of the sound, as well as a physical impact or associated symptom.
11 These combinations may have increased the complexity of both the grouping and rating of
12 statements. Whilst efforts were made to reduce the number of these statements, many
13 were generated during the brainstorming stage and were deemed to illustrate an important
14 feature about how tinnitus sounds and feels to the children/adolescents who experience
15 tinnitus. Therefore, complete removal would have been detrimental.

16
17 It has been noted that many studies investigating tinnitus during childhood/adolescence
18 employ discrete descriptions of tinnitus sounds, and equate distress in terms of its presence,
19 volume or duration. Some studies employed questionnaires such as the Tinnitus Handicap
20 Inventory that have been validated for adults, but not for children/adolescents. The
21 statements generated during this study highlight that the experience of tinnitus in

Consideration needs to be given to how the experience of chronic tinnitus in children/adolescents is assessed and further research into developing a validated assessment tool for paediatric tinnitus is required.

6. CONCLUSION

Through this study, participants described the diverse nature of the sounds and feelings that may be experienced by children/adolescents with tinnitus. The experience of chronic tinnitus during childhood and adolescence is heterogenous, multifaceted and multisensorial. How a child/adolescent experiences their tinnitus will be influenced by the interplay between the sounds they perceive, the number of senses involved, and the emotions and physical effects they experience. Clinicians need to be mindful of the possibility of tinnitus manifesting during childhood/adolescence, and that a child's developmental phase may contribute to how tinnitus sounds and feels to them. Consequently, it is vital to ask open ended questions that allow the child or adolescent to describe their experiences without limitation. The participants' reflections and perceptions enabled the development of a conceptual framework to facilitate a better understanding of the retrospective lived experience of paediatric tinnitus.

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Figure 1. Diagram illustrating the study's recruitment process

Figure 2. Concept map of the five clusters describing what tinnitus sounds and feels like to children and adolescents who experience it. Each concept's bridging score (provided in

1

2 Figure 3. Pattern match graph comparing the Tinnitus Group and Clinical Professionals'
3 ratings of the degree of distress associated with the themes of "what does tinnitus sound
4 and feel like for children and adolescents who experience it?" The medial rating scores (and
5 standard deviations) are provided in brackets, with some scores ranging from (0 = low
6 distress to 5 = high distress)

7

8 Table 1. Five concepts describing how tinnitus sounds and feels to children and adolescents

9

10 Appendix 1. 102 Statements describing what tinnitus sounds and feels like to children and
11 adolescents as generated by study participants.

12

Table 1. Five concepts describing how tinnitus sounds and feels to children and adolescents.

Domain	Concept name (number of statements & bridging score)	Concept description	Example statement number and statement (bridging score)
Sound	Sounds of tinnitus (25, 0.41)	Description of tinnitus sounds with low emotional association	56. Constant high pitch noise with aid behind it; a whoosh (0.10) 101. High pitched whining or buzzing (0.10) 67. Buzzing (0.10)
Sound	Descriptions of tinnitus (12, 0.41)	Descriptions of tinnitus sounds, including emotional associations and sound personification	2. Screeching (0.23) 22. Happy sounds e.g. angle noises (0.29) 44. Speech (0.32)
Feeling	Perceptions of tinnitus (25, 0.64)	Physical presentation of tinnitus and triggers	41. Brief humming noises that go into brain; can occur at any time but worse in quiet (0.33) 72. Fluctuating (0.41) 31. Vibration in head (0.43)
Feeling	Emotional response to tinnitus (34,	Emotional responses to and impact of tinnitus— scared and frightened	21. Causes a huge amount of distress (0.00) 47. Upset (0.00)

Feeling	Physical	Negative physical	50. Tiring (0.22)
	responses to	responses to tinnitus	91. Exhausting because it is
	tinnitus (6		constantly there (0.22)
	(0.40)		37. Stomach churns (0.36)

Q1: Sound and Feeling	Q2: Impact	Q3: What is done
Brainstorming Tinnitus Group n=20 Clinicians n=10		
Grouping and Rating Additional Recruitment		
Tinnitus Group n=13 Clinicians n=12	Tinnitus Group n=11 Clinicians n=12	Tinnitus Group n=11 Clinicians n=12

Appendix 1.

Cluster	Statement
1. Sounds of tinnitus	
	1 Like a shell over the ear.
	4 Water rushing, whooshing, ringing.
	9 Sensory or language experiences e.g. 'Someone blowing in my ear' or 'train chugging'.
	11 Sound of the stars at night.
	13 Grating sensation in middle of skull.
	17 A continuous ring that is forgotten about after a while.
	18 A ringing and whistling sound.
	23 High pitched noise for short periods of time.
	26 Footsteps.
	27 A lady singing.
	40 High pitched hissing and high / medium tones.
	42 Enjoyable 'friendly bees'.
	46 Repetitive animal noises.
	51 A high pitched noise that comes on loudly but then fades after a short while.
	53 Constant hum that gets louder and softer.
	55 Loud buzzing that keeps getting louder.
	56 Constant high pitch noise with air behind it; a whoosh.
	60 A beating noise.
	65 High pitch and ringing.
	67 Buzzing.
	87 Motor
	90 Pulsatile.
	98 Various noises; ringing is most common but other noises too e.g. Blowing in ear, buzzing, beepir
	100 Overlay of multiple high pitched tones.
	101 High pitched whining or buzzing.
2. Descriptions of tinnitus	
	2 Screeching.
	6 Distressing ringing.
	7 Like screaming and yelling.
	22 Happy sounds e.g. angel noises.
	33 Like screaming which is scary at night.
	44 Speech.
	57 All sorts of sensations.
	64 Emotional sounds e.g. angry bees.
	66 Lots of different noises that come and go suddenly, unable to hear when tinnitus is present.
	68 Angry voices; can't hear what is being said but it feels as if someone is angry.
	70 Mumbling/muttering noises: not distinct words that disagree with person who hears them

- 3 A sound fog that decreases hearing other sounds while it grows stronger.
- 5 Really loud and scary when combined with recreational drugs.
- 10 Sometimes feels as if it changes from ears to brain with jaw and temple movements.
- 12 Louder when it is noisy.
- 24 Feels more intrusive in quiet.
- 30 Something going on in head.
- 31 Vibration in head.
- 32 Louder in one ear than the other.
- 34 Always there.
- 36 Gets louder with caffeine and alcohol.
- 41 Brief humming noises that go into brain; can occur any time but worse in quiet.
- 43 Difficult to localise (head, left or right ear).
- 45 Tries to match pitch to that of other sounds.
- 49 Whole body affected.
- 58 Just there in the background.
- 61 A ringing noise, which starts when classrooms are too noisy.
- 72 Fluctuating
- 73 Set off by other sounds.
- 77 Always more prominent in quiet.
- 79 Feels as if hearing has 'switched off'.
- 83 As if ears are blocked.
- 86 Louder after gigs and drums.
- 94 Some specific sounds are no longer tolerable because they set the tinnitus off.
- 96 Associated with decreased sound tolerances.
- 102 Ringing and can temporarily lose hearing in one ear for a short time.

4. Emotional responses to tinnitus

- 8 Shocking.
- 14 Distracting.
- 15 Very overwhelming; can focus away from it but it comes back when it is quiet.
- 16 Feelings of being annoyed and then a bit down and miserable.
- 19 Fear of mentioning it to anyone as it was laughed at during initial attempts to discuss with other
- 20 Thought that it was strange.
- 21 Causes a huge amount of distress.
- 25 Ruined self for life.
- 28 Knowing that hearing things that others don't is bad.
- 29 Extreme panic.
- 35 Fear due to not knowing what it is.
- 38 Great distress.
- 39 Out of person's control.
- 47 Upset.

- 59 Self-blame.
- 62 Different because others don't hear it.
- 63 Wondering why ears ring.
- 69 Confronting.
- 74 Scarred.
- 75 Guilt that tinnitus may have been self-inflicted.
- 78 Feeling it there and knowing nothing can be done about it.
- 80 Initially scary; didn't know what it was.
- 82 Scary or frightening, the more it is listened to, the scarier or more frightening it becomes.
- 85 Not distressed by the sound but distressed by the associated symptoms.
- 88 Isolated because others don't hear it.
- 89 Frightening.
- 92 Psychologically painful.
- 93 Fear permanent damage has been done.
- 95 Confusing.
- 97 Distress caused by thinking something is wrong but not being able to talk about it.
- 99 Annoying.

5. Physical responses to tinnitus

- 37 Stomach churns.
- 50 Tiring.
- 71 As if head would explode.
- 76 Brain fog getting in the way of think of anything else.
- 84 Painful.
- 91 Exhausting because it is constantly there.