

## **Reflections on how tinnitus impacts the lives of children and adolescents**

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## ABSTRACT

**Objectives:** To generate a conceptual framework describing which aspects of children's and adolescents' lives are affected by chronic tinnitus.

**Design:** Views and experiences of 32 participants from two participant groups informed this study: i) a tinnitus group consisting of adults who had experienced tinnitus during childhood and/or adolescence, and primary carers of children/adolescents with tinnitus, and ii) a clinicians' group, consisting of clinicians who provided care for children/adolescents with tinnitus. Participants produced statements describing aspects of children/adolescents' lives which may be affected by chronic tinnitus. Key concepts were identified through the processes of sorting the statements and rating them for degree of associated impact.

**Results:** Participants identified 118 unique aspects of the lives of children/adolescents that may be affected by chronic tinnitus. These were clustered into four concepts: 1) *Emotional Wellbeing*; 2) *Academic Performances*; 3) *Social/Relational* and 4) *Auditory/Cognitive Processing*. At a group level, participants rated the impact of tinnitus as above a slight degree but below a moderate degree of impact. However, individual participant's ratings indicated a range of perceived impact for each statement.

**Conclusions:** The experience of chronic tinnitus during childhood and adolescence extends beyond the mere perception of sound. The perception of tinnitus may impact a child's *Emotional Wellbeing*; *Academic Performances*; *Social/Relational* and *Auditory/Cognitive Processing*. The impact of tinnitus in one aspect of a child's life may influence other aspects of their life. While at a group level, participants regarded the impact of tinnitus as "somewhat more than mild" to "less than moderate", individual participant's ratings indicate that the impact from chronic tinnitus may be highly individual and highlighted the

importance of individual assessment and management. Clinically, tinnitus management during childhood and adolescence may be improved if clinicians consider the impact and manifestation of tinnitus within each child's daily life, and tailor tinnitus education and management strategies accordingly.

## **INTRODUCTION**

Chronic tinnitus is the perception of a sound in the absence of external stimuli for episodes of five minutes or longer for three months or longer (Baguley et al., 2013; Hall et al., 2011; Holgers & Juul, 2006; Viani, 1989). It is a common and often distressing phenomenon (Yetiser et al., 2002) for both adults (Sindhusake et al., 2003) and children (Coelho et al., 2007; Kentish et al., 2000; Rosing et al., 2016). Tinnitus is associated with psychological and somatic symptoms which can compromise the quality of life for both those who perceive the tinnitus and their family members (Mancini et al., 2018; Yetiser et al., 2002).

How tinnitus impacts an individual's life is highly variable and may be influenced by factors separate from the acoustic characteristics of the sounds perceived but which interplay with the perception of tinnitus to compound the impact (Bhatt et al., 2017; Gopinath et al., 2010). Adults with chronic tinnitus often report that their tinnitus is associated with feelings of sadness, worry, frustration and anger. These feelings can lead to difficulties sleeping, relaxing and concentrating, may negatively impact relationships at work and impair participation in social settings (Gopinath et al., 2010; Moroe & Khoza-Shangase, 2014).

However, the impact of tinnitus on children and adolescents, hereafter referred to as children, has been less closely studied. Some studies report that children are less likely to report tinnitus than adults, may be less troubled by it and more readily distracted from it

(Mills et al., 1986; Mills & Cherry, 1984; Viani, 1989). Others report children being significantly distressed by their tinnitus (Kentish et al., 2000). Children have reportedly experienced symptoms such as poor sleep in association with tinnitus, which may contribute to difficulties with concentration, attention and fatigue (Adegbiyi et al., 2018; Smith et al., 2019, Szibor et al., 2017). They can suffer social exclusion, poorer mental health and physiological symptoms like dizziness and headache (Brunnberg et al., 2008; Kentish et al., 2000; Martin & Snashall, 1994; Szibor et al., 2017).

In an earlier study, we explored what tinnitus sounds and feels like to children through the reflections of adults who had experienced tinnitus during childhood as well as the perspectives of the primary carers and clinicians who care for them (Tegg-Quinn et al., 2020). Findings from that study indicated that the perception of tinnitus extends beyond the mere perception of sound to include both emotional and physiological manifestations. The study also found that children experience tinnitus in a manner different to adults, in that it is influenced by their interpretation of the sounds (Tegg-Quinn et al., 2020). Subsequently, it is imperative to establish how tinnitus impacts the lives of the children.

The joys and demands of childhood are different from those of adulthood, and as such, it is essential to understand the impact of tinnitus during these ages specifically. Applying assessment and management strategies designed for adults to children without modification may be unsuitable if delivered in a manner that is not suitable or appropriate for children and does not address those areas of impact important to them. Therefore, we must establish how tinnitus impacts children's lives to manage and ameliorate the negative impacts of tinnitus. The knowledge gained may improve tinnitus awareness during

childhood, assist in developing assessment tools and appropriate management techniques, and improve access to and the quality of care for children who experience tinnitus.

This study aimed to identify:

- 1) Aspects of a child's life that are impacted by the experience of chronic tinnitus; and
- 2) The degree of impact associated with these aspects.

## **METHODS**

This paper presents the findings of the second research question from a larger project seeking to develop a conceptual framework facilitating an improved understanding of the experience of chronic paediatric tinnitus. It does so from the reflections of adults who experienced tinnitus during childhood and the perspectives of the primary carers and clinicians who care for them. The first question explored what tinnitus sounds and feels like to the children who experience it. The second question explored which aspects of children's lives are affected by chronic tinnitus and is reported here. The third question explored what is done to assist children who experience tinnitus and will be reported separately.

This study used concept mapping, an inclusive mixed-methods participatory research method that combines group research processes of brainstorming, grouping and rating with multivariate statistical analysis (Rosas & Kane, 2012; Rosas & Ridings, 2017; Trochim & Kane, 2005). Concept mapping as a research technique has been cited as suitable for studies that strive to gain insights into the patient experience and unveil topics of interest in fields where research is scant (Burke et al., 2005; Trochim & Kane, 2005; Trochim, 1989). This

study's methodologies follow those described previously (Tegg-Quinn et al., 2020) and are summarised below.

## **Participants**

Two groups of participants were recruited: (i) a tinnitus group which incorporated adults who had experienced tinnitus during childhood, as well as the primary carers of children with tinnitus, and (ii) a clinician group consisting of clinical professionals who care for children with tinnitus. Diversity was sought in participants in terms of age, country of origin and experiences to generate comprehensive and diverse insights (Rosas & Camphausen, 2007; Schiller et al., 2013; Trochim, 1989). Both the adults who had experienced tinnitus during childhood and the primary caregivers were regarded as patients given both had different lived experiences of paediatric tinnitus, the patient journey, as well as their interactions with clinicians. However, parents were asked for their perspectives on their child's experience. Adults who had experienced tinnitus during childhood were chosen as participants for this study rather than children currently experiencing tinnitus because it is perceived that asking children about their experience of tinnitus may unduly influence them. There was also concern regarding the participant burden associated with concept mapping. Previous studies support the decision to explore the reflections of adults who had experienced tinnitus during childhood. Several studies have shown that adults can recall and relate autobiographical and salient childhood events, such as childhood illness, with great detail and that these recollections are not impacted or altered by time or later experiences (Bauer & Larkina, 2016; Haas & Bishop, 2010; Smith, 2009). The inclusion of the three

participant groups sought to provide a balanced perspective of the experience of tinnitus during childhood.

Participants were recruited through emails and word of mouth through university, professional and clinical networks in Australia and internationally and through online chatrooms and forums. People who wished to participate, and who met the eligibility criteria provided written consent prior to participation.

Thirty-two adults participated in the initial brainstorming phase, and 25 (23 original participants and two subsequent participants) completed the grouping and rating tasks.

There was a greater number of female participants in both groups. A minimum of between 10 and 20 participants is recommended to ensure that both a variety of insights are captured and that data saturation is achieved (Guest et al., 2006; Trochim & Kane 2005).

Saturation refers to the point at which no more new insights, themes or information emerge and is often achieved within the first 12 interviews (Guest et al., 2006)

The adults who experienced tinnitus during childhood (n=10) included three males and seven females 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 resided in Australia, Portugal and the USA. At the time of data collection, all ten participants described still experiencing tinnitus; four reported that their tinnitus was less troublesome than during childhood and six reported that it fluctuated. Five reported having sought help for their tinnitus as a child, but only one reported that the help they had received was useful. The primary carers (n=10) included one male and nine females, ranging from 28 to 55 years (mean 44.73, SD 7.67). They resided in Australia and the United Kingdom. At the time of data collection, nine of the ten primary carers had sought tinnitus assistance for their children.



The clinicians (n=12) included one male and 11 females; their ages ranged from 34 to 56 years (mean 46.8, SD 7.99). They participated from the United Kingdom, Denmark and Australia. The clinicians represented three different professions: one Ear Nose and Throat specialist, one Psychologist, and ten Audiologists with their experience working in paediatric tinnitus ranging from less than five years to over 20 years. All clinicians had assisted a minimum of five children with tinnitus; nine clinicians had assisted more than 20 children with tinnitus, one had assisted between five and ten children, and one had assisted five children.

Human ethics approval was granted through the Human Research Ethics Office, The University of Western Australia (RA/4/201/4274).

## **Procedures**

The concept mapping process involved four stages: (i) brainstorming, (ii) grouping, (iii) rating, and (iv) data analysis and interpretation (Kane & Trochim, 2007).

*Brainstorming:* During brainstorming sessions, 32 participants were asked to generate statements in response to the question: “What parts of children’s and adolescents’ lives are affected by chronic tinnitus?” The brainstorming sessions occurred via an online portal (Concept Systems, Version 4; Concept Systems Incorporated 2011) or via teleconference with researcher ST-Q. A face-to-face brainstorming session was also offered, but no participants chose this option. When participants elected the teleconference option, the instructions were given using a neutral tone, and they were not prompted beyond presenting the question again or asking for clarification if a response was not heard clearly. All statements were accepted and transcribed to promote participation and the generation

of ideas, beliefs and experiences. All statements gathered offline were entered into the online concept mapping software portal. When participants chose to use the online portal, they were presented with the same instructions as participants participating via teleconference, but their responses were directly entered into the portal. These responses remained anonymous but could be viewed by other participants. Multiple participation methods promote heterogeneity of participation, thereby enhancing the breadth and depth of the insights gathered without compromising the validity and reliability of the study (Rosas & Camphausen, 2007; Schiller et al., 2013; Trochim, 1989).

Upon completing the brainstorming activities, the participants' statements were pooled and refined by three research group members (ST-Q, RJB & RHE). The statements were refined to ensure that participants had a list of clearly written statements for the grouping and rating tasks. Irrelevant or duplicate statements were removed. An irrelevant statement did not relate specifically to the prompting question such as *Many little ones just put up with it*. A duplicate statement presented the same information as another statement, even if the wording differed slightly (Poost-Foroosh et al., 2011). For example, *Lose hearing in that ear when the tinnitus is there which is distracting and you can't hear* and *When it blocks the hearing in one ear it is very distracting and distressing*. These two statements were combined into one statement which conveyed both the words and sentiments of the original statements, *When tinnitus blocks hearing in one ear it can be distracting and distressing*. Double-barrel statements or those statements which presented more than one concept were where possible split to present each perceived impact (Jackson & Trochim, 2002). For example, *Worries about what might be e.g. That might miss what is said because of tinnitus, that tinnitus may get worse in certain environments so avoids them*, was split into smaller concepts of 'worry', 'missing what is heard' and 'avoiding environments'. These

were then combined with other statements that stated similar concepts: statement 18:

*Worrying about which soft sounds might not be heard because of the tinnitus;* statement 30:

*Stop being able to do the things one wants to,* and statement 39: *Worry about triggering the*

*tinnitus is overwhelming.* All statements were edited to ensure that they were clear, non-

identifiable and written in the first person.

*Grouping and rating:* Following the brainstorming stage participants were randomly allocated to the grouping and rating tasks for one of the three questions in the larger study. The random allocation was undertaken to reduce participant burden. Once each participant had completed the grouping and rating tasks for their allocated question, they were invited to undertake the grouping and rating tasks for one or both remaining questions.

Twenty-three participants (21 original participants and two subsequent participants) sorted the final set of statements into groups they believed identified a common theme. In the third stage, the individual statements were rated for their degree of impact associated with the statement using a 6-point Likert scale: 0 = “low degree of impact”, 1 = “minimal degree of impact”, 2 = “slight degree of impact”, 3 = “minor degree of impact”, 4 = “moderate degree of impact” and 5 = “high degree of impact”.

The grouping and rating activities were undertaken via the online portal or via postal packs.

## **Data Analysis**

Data analysis involved multidimensional scaling and hierarchical cluster analysis undertaken both within the concept mapping software and using SPSS (IBM Corp. Released 2017. IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp.). The relationships between the individual statements were graphically displayed using a point map. This

displays each statement as a point, with the points appearing closer to each other when statements are grouped frequently and further apart when statements are rarely grouped. As such, the distance between points illustrates how frequently individual statements were grouped.

In the concept mapping process, the outputs of the grouping tasks of the individuals are synthesised to produce options for clustering the statements.

The cluster map illustrates key concepts highlighted through the process of hierarchical cluster analysis. The cluster boundaries define which statements are in the cluster, and their relative locations illustrate how they are associated with each other (Jackson & Trochim, 2002). While multiple cluster maps may be created for any data set, establishing which cluster map best represents the participants' views is determined by the researchers. This is guided by both the content of the clusters and the bridging scores of each cluster. Bridging scores provide information regarding how frequently statements are grouped, which statements form the anchor statements for each cluster, and which statements bridge between the clusters. Lower bridging scores indicate that the statements within a cluster are frequently grouped. High bridging scores indicate that the statements within a cluster are grouped less frequently and suggest that consideration be given to increasing the number of clusters (Jackson & Trochim, 2002).

#### *Validity and reliability estimates*

The validity of the grouping tasks and multidimensional scaling is established through calculating a stress index. Stress indices between 0.205 and 0.365 indicate an acceptable level of reliability or goodness of fit and lower scores being more desirable (Kane & Trochim, 2007).

The reliability of the final concept map was investigated through split-half reliability tests conducted in two ways: (i) comparing the grouping data of the tinnitus and clinician cohorts, and (ii) comparing two groups into which all participants' grouping data were randomly allocated (Rosas & Kane, 2012). The split-half reliability tests establish whether there is a consensus in how the statements are grouped among cohorts and participants (Trochim, 1993).

Internal consistency for each cluster was established by calculating Cronbach's alpha for each cluster separately for both the tinnitus group and the clinicians' group.

External representational validity was explored by presenting the cluster map and the list of statements in each cluster to the participants. Participants were asked to review the concept map and then consider whether the statements reasonably informed the concepts and whether the names and descriptions of the presented clusters reasonably represented the statements within each cluster. The participants' responses determined whether any adjustments were required.

## **RESULTS**

Participants generated 194 raw statements which were refined to produce 118 statements (Appendix 1). The individual participants grouped the data to produce between seven and 17 separate statements (mean 8.6, SD 4.1). Following the hierarchical analysis, the research team determined that a 4-cluster map best represented the data (Figure 1).



bridging score (0.68); (iv) *Auditory/Cognitive Processing* included statements describing interference with listening and cognitive processing, contained the smallest number of statements (n=15) and had the highest bridging score (0.71).

As two clusters had relatively high bridging scores, the five and six cluster options were revisited. However, as these did not provide additional insights and the bridging scores did not improve, the four-cluster representation was retained.

Internal validity of the four-cluster map was determined firstly by calculating a stress index. The stress index for the four-cluster map was 0.26, indicating that the cluster map accurately reflected and represented the groupings undertaken by the participants (Kruskal, 1964; Rosas & Kane, 2012; Trochim, 1993).

Reliability of the cluster map was determined using the Spearman-Brown coefficient of unequal lengths split-half reliability tests. With the participants split into their tinnitus and clinician cohorts, the score was 0.89. When the participants were randomly split into two groups (Rosas & Kane, 2012), the score was 0.92. These scores indicated that the final four-cluster map was representative of the two participant groups and displayed good correlation between how the individuals within the groups sorted their data and how their effects were presented (Hinkle et al., 1988).

Cronbach's alpha was calculated for both the tinnitus and the clinicians' groups to establish internal consistency for each cluster. The results were consistent with very high levels (>0.8) for all clusters (Rosas & Kane, 2012; Trochim, 1993) (Table 1).

The participants' group mean rating scores for the impact associated with each statement varied from 1.67 (slight to minor degree of impact) for statement 15 *Physical reaction times are slower* to 4 (moderate degree of impact) for statement 42 *Sleep, as the tinnitus is*

*associated with nightmares and scary thoughts*. Individual participant's rating scores varied between 0 (low degree of impact) to 5 (high degree of impact) for each statement.

The participants viewed the degree of impact associated with each cluster similarly. The mean rating scores varied from 2.69 for the impact of the *Auditory/Cognitive* processing cluster to 3.03 for the *Academic Performances* cluster on a 0 to 5 Likert scale. These cluster ratings are consistent with a perceived degree of impact well above a "slight degree of impact" and just above a "minor degree of impact."

Eight participants (tinnitus group n=4; clinicians n=4) participated in the external validation of the final cluster map. The participants supported both the clusters derived from the data, the cluster names and their descriptions; no changes or adjustments were suggested or requested.

## **DISCUSSION**

During this study, the participants' statements, groupings and rating results highlighted four distinct areas of children's lives affected by the experience of chronic tinnitus. While participants rated the impact associated with each of the four areas similarly, the impact associated with *Emotional Wellbeing* and *Academic Performances* were described more frequently. As will be described below, they also illustrated how the impact associated in one area of a child/adolescent's life might contribute to difficulties in other aspects of their life such as their education, social engagement and family relationships. This study also identified that sleep disturbance is often described as an effect of tinnitus and that both groups perceived the impact associated with tinnitus during these life stages as being above "slight" but below "moderate" on a 0 to 5 Likert scale with significant individual variation



noted. This variation highlights the importance of individual assessment and of avoiding generalisations regarding the experience of tinnitus during childhood when working in the clinical setting. These findings will be discussed further below.

#### *Four distinct areas of children's' lives impacted by tinnitus*

Participants indicated that tinnitus might affect children's *Emotional Wellbeing*, their *Academic Performances* and *Social/Relational* aspects of their lives and cause *Auditory/Cognitive Processing* interference. These findings concurred with and extended the findings of a scoping review reporting tinnitus-related problems experienced by children and how they impact upon physical health, emotional health, cognitive health, hearing and listening abilities, a sense of being different or isolated, and quality of life (Smith et al., 2020). The participants in the present study grouped the statements in a manner that highlighted similar areas of impact; however, the content of the statements often provided insight into why tinnitus may have the impact described. For example, statement 10: *Give up studying because of difficulty concentrating* provides insight into how the experience of tinnitus during childhood can impact upon schooling. These insights explain how childhood experiences of tinnitus can be similar to and also different from those described by adults who experience tinnitus. They are similar to adults, in that adults who seek assistance for their tinnitus often describe difficulties with concentration, sleeping, hearing and communication as well as an association with anxiety and depression (Andersson, 2002; Bartels et al. 2008; Langguth, 2011; Westin et al., 2008). Yet, they differ from adults, in that the impact experienced by children can be compounded by their developmental age and stage, by not knowing what they are experiencing and by having difficulty expressing or

communication what they are experiencing (Dionne-Dostie et al., 2015; Kentish et al., 2000; Tegg-Quinn et al., 2020). The experience of tinnitus does not occur in isolation and difficulties associated with tinnitus in one area of a child's life may subsequently contribute to additional difficulties which may compound and have long-term consequences. For example, difficulties attending in class or concerns about experiencing tinnitus in certain settings may contribute to social withdrawal and reduced activity participation which may have negative ramifications for their education and later their employment and productivity (Maes et al., 2013; Mucci et al., 2014; Schaette & McAlpine 2011; Westin et al., 2008).

### *Impact of tinnitus*

Several statements generated during this study demonstrate how the experience of tinnitus may be a compounding one, where a difficulty experienced in one area of a child's life may contribute to difficulties in another aspect of their lives. For example, statement 33: *Sense of fear; weird fear of the tinnitus but don't know enough about it*, and statement 46: *Mental health – know that something is different and wrong or weird but can't say what is wrong*, show how the impact of perceiving tinnitus during childhood/adolescence may be compounded by not knowing or understanding what is being experienced. A lack of understanding and fear may contribute to children having difficulty controlling/regulating their emotions is evidenced by statement 85: *Control of emotions; much more emotional*, and statement 94: *Emotions and tolerance, become more of a struggle*. These difficulties, which may be expressed as irritability, moodiness and nervousness, concurred with the findings of earlier studies (Baguley et al., 2013; Sanchez & Stephens, 1997). Statements such as statement 6: *Relationship with school; if kept awake at night because of tinnitus, days*

*from school may be missed due to tiredness, if the school raises concerns the child may become more stressed* illustrate how the impact of tinnitus can cascade with the perception of tinnitus being associated with impact in multiple aspects of a child's life.

Other statements such as statement 84: *Tinnitus can cause anxiety and depression*, statement 43: *Tinnitus affects anxiety, anxiety makes tinnitus louder. Anxiety and tinnitus go hand in hand* and statement 19: *Exacerbates mental health issues; if having a breakdown the noise just exacerbates it*, demonstrate how the impact of tinnitus may be further compounded by other concomitant issues such as depression or anxiety. Statements 90: *Ability to concentrate at school*, 20: *One can be very distractible*, and 114: *Can't go to parties, family gatherings etc. as it gets too noisy and sets off the tinnitus*, illustrate how the impact of tinnitus may be exacerbated by or interact with other conditions, such as central auditory processing issues and sensory processing hearing loss and hyperacusis (Brunnberg et al., 2008; Holgers & Juul, 2006; Y. H. Kim et al., 2012; Rosing et al., 2016).

The diffuse nature of tinnitus impact during childhood was illustrated through the participants' statement groupings. Participants grouped statements associated with issues such as difficulty sleeping, difficulties with conversation and difficulties with attention and concentration, into three of the four clusters. These groupings further reinforce how the impact of tinnitus during childhood is not one of discrete problems, as is often indicated in the literature surrounding the experience of tinnitus in adults. Rather, the experience of tinnitus during childhood may be associated with pervasive implications and impacts that affect multiple aspects of a child's life.

### *Degree of impact*

Of note was the relatively low degree of impact and direction of impact reported by the participants. The mean ratings for the clusters were between 2.69 and 3.03 (Table 1), indicating the perceived impact was between somewhat more than slight but less than moderate. The mean ratings for the individual statements ranged from 2.00 (SD1.7) for statement 22 to 3.77 (SD1.7) for statement 87 (Appendix 1). However, the degree of impact ranged from 0 to 5 for all statements, showing that children experience tinnitus in various ways and that for some children, the impact is significant. This range of impact is reflected in the findings of Mills et al. (1986) and Mills and Cherry (1984) who suggested that the impact of tinnitus during childhood may be mild and Kentish et al. (2000) who found that tinnitus has a significant impact on some children. It was also noted that none of the individual statements reflected a positive impact associated with tinnitus. This is despite the fact that the descriptors of tinnitus can sometimes reflect a pleasant experience, such as *Happy sounds e.g. angel noises* or *Enjoyable 'friendly bees'* (Tegg-Quinn et al., 2020).

Statements generated during this study provided illustrations which supported the findings of earlier studies. For example, statements such as 72 and 81 raised *Deep-rooted fear* and being *On guard and alert all the time*, not only for the tinnitus but also for triggers and the sequelae of perceiving tinnitus, supported the findings Holgers and Juul (2006). They found that the association between the degree of impact ascribed to tinnitus and the relation to psychological factors is greater than the degree of impact ascribed to tinnitus in association with hearing loss. These were echoed by Y. H. Kim et al. (2012), S. Kim et al. (2016) and J. Y. Kim et al. (2018), who also found reported an association between tinnitus severity and stress. However, it is also important to consider that the ratings in this study were from

adults who reflected on their experience of tinnitus as a child or from the perspective of parents or clinicians. They were not from children currently experiencing tinnitus without the benefit of understanding what they are experiencing, hindsight or an adult's experience of life. Indeed, the individual rating data demonstrated a spread of impact results for each of the statements.

### *Clinical implications*

How tinnitus is experienced during childhood and the corresponding impact has important ramifications for assessing and managing tinnitus within a clinical setting. Clinically, it is difficult to assess the impact of tinnitus during childhood without understanding how it is experienced. Clinical assessment, management, and resources need to identify and cater to the areas of impact identified by stakeholders during this study and the emotion and experiences conveyed by the statements. While adults may be able to conceptualise tinnitus as a discrete percept of sound, such separation may be more difficult for children especially if they cannot voice what they are experiencing (Kentish et al., 2000). Several studies have looked at the impact of tinnitus during childhood using patient report measures (PRM) designed for adults. However, such measures may not adequately address the issues and concerns experienced by children. In a recent scoping review of the clinical management of tinnitus during childhood, Smith et al. (2020) found that the Tinnitus Handicap Inventory, Tinnitus Functional Index and Mini-Tinnitus Questionnaire were the most commonly used in clinical practice in the UK as measures of tinnitus for children. PRMs have also been used in research settings to study the impact of tinnitus during childhood (Y. H. Kim et al., 2012; J. Y. Kim et al., 2018; Szibor et al., 2017). J. Y. Kim et al. (2018) applied the Tinnitus Handicap Inventory to a group of adolescents and reported a general finding that children who

experience tinnitus have a greater propensity for higher trait anxiety scores than children and adolescents who do not. On the other hand, studies where children's experiences were investigated through interviews or case note reviews provided more in-depth insights and described more specific areas of impact. For example, Szibor et al. (2017) found that children who experience tinnitus may also experience difficulties with sleeping, concentration and social exclusion. Adegibiji et al. (2018) described difficulties with attention in association with the experience of tinnitus, and Kentish et al. (2000) described daily difficulties experienced by children who experience tinnitus. These differences suggest that how a child is questioned about their tinnitus and its associated impact can influence the information is obtained. Developing assessment and management tools tailored specifically to children is crucial, and the information contained within the statements generated during this study should be considered when developing such resources.

The statements generated during this study also highlighted the importance of identifying the factors contributing to tinnitus distress to inform the implementation of targeted management strategies. By understanding how a child experiences tinnitus, specific management strategies can be devised that better address each child's particular concerns. Six of the statements such as statement 86 *Breakdown in relationships at home if some family members do not understand chronic tinnitus* and statement 89 *Negatively impacting upon relationships with parents and siblings* highlighted the impact that a child experiencing tinnitus can have within a family. The statements illustrated how tinnitus might not only impact the child but also their relationships with immediate family members and potentially impact the relationships of their immediate family and extended family if they feel unable to attend family events due to the impact of the noise upon their tinnitus. Such statements highlight the importance of extending the scope of care beyond just the child experiencing

tinnitus to include their family using family-centred care and family-centred practice. These care models not only consider the needs of the child with tinnitus but also those of their family and regard them as central to decision making and implementation processes (Bennett et al., 2020; Johnson, 1990; King et al., 2004).

The Tinnitus in Children Practice Guidance (Kentish et al., 2015) and Kentish et al. (2000) recommend including tinnitus education in the management of tinnitus during childhood. Statements from the current study, such as statement 98: *Thinking that something is seriously wrong*, illustrates why tinnitus education for both children and their parents is important. Children may feel as if they are alone in experiencing tinnitus. However, if they are troubled by their tinnitus, and it impacts other aspects of their lives, members of their family may also be worried by what the child is experiencing and how best to help them. Ensuring that parents are well supported and educated about tinnitus is likely to help them support their child (Johnson, 1990; Kentish et al., 2000; King et al., 2004). It is foreseeable that when clinicians can identify how each child experiences tinnitus and how the impact manifests within their daily lives, they will be better able to tailor tinnitus education and management strategies. Clinicians need to ask about the presence of tinnitus and be mindful of the varying degrees of impact in the four key areas highlighted during this study. With this information, they will be better able to facilitate appropriate management strategies to ameliorate any associated negative impacts that the child is experiencing.

#### *Limitations and future research*

This study sought to recruit participants who were heterogenous in terms of their age at the time of the study, their age of tinnitus onset, and their country of origin to inform this study.

However, participants within this study may represent a section of the population for whom the experience of tinnitus was troublesome, either during childhood or as a parent or carer. Such a population would likely generate statements and ratings that indicate a greater degree of impact associated with the experience of tinnitus during childhood/adolescence than can be expected from those for whom tinnitus is less troublesome. However, the inclusion of a clinician participant group comprising clinicians with significant experience in tinnitus assessment and management during childhood balanced potential bias.

The qualitative nature of the brainstorming activity is highly suited to the exploratory nature of this study. However, given the nature of this data collection method it is highly likely that if the study were to be replicated using a different cohort, slightly different thoughts, ideas and experiences may be forthcoming. However, the study sought to mitigate potential concerns associated with reproducibility by including a large concept mapping sample of 34 participants representing three different informant groups to ensure that a variety of experiences, insights and opinions were generated, and that data saturation would be reached. Minimal sample sizes of between 10 and 20 participants are recommended to ensure that a variety of experiences and opinions are gathered, and saturation is often reached within the first 12 interviews (Guest et al., 2005; Trochim & Kane, 2006)

This study may also have been limited by the lack of a participant group representing children who were currently experiencing tinnitus. However, concerns existed over the possible participant burden of the concept mapping research method for children. As previous studies have demonstrated that adults can reliably recall with detail important autobiographical events and experiences from their childhood without influence from more recent experiences (Smith, 2009), this is likely to be a minor limitation.



This study may also have benefited from further exploration regarding the possible impact of co-morbidities on the participants' perceived tinnitus impacts. It is possible that the perceived impact of the tinnitus may have been influenced by other co-morbidities but this was beyond the scope of this study.

While it would have been interesting to analyse the grouping and rating results of adults who experienced tinnitus during childhood separately from parents and primary carers in the tinnitus group, the participant numbers were not large enough to do so.

## **CONCLUSION**

The experience of chronic tinnitus during childhood and adolescence is more than just the mere perception of sound. During this study, participants identified four principal areas of impact *Emotional Wellbeing; Academic Performances; Social/Relational* and *Auditory/Cognitive Processing* aspects of a child's life may be affected by tinnitus. This study also identified that the sequelae of the impact in one aspect of a child/adolescent's life might manifest in other aspects of their lives.

As indicated by the two groups' ratings, the degree of impact varied from "somewhat more than slight" for *Auditory/Cognitive Processing* to "less than moderate" for *Academic Performances*. Such responses suggest that often the impact of tinnitus may be mild.

However, the individual variation suggests that individual assessment should be undertaken to establish if and what care is required. Differences noted in the degree of impact associated with each of the statements' ratings by individual participants compared to the group cluster rating scores suggest that the lived experience and degree of impact perceived by each child may be highly individual.

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## REFERENCES

- Adegbiji, W. A., Olajide, G. T., Olubi, O., Aluko, A. A., Olajuyin, A. O., Eletta, P. A., & Yahya, A. I. (2018). Characteristics and management of childhood tinnitus in a developing country. *The International Tinnitus Journal*, *22*(1), 66–71.
- Andersson, G. (2002). Psychological aspects fo tinnitus and the application of cognitive-behavioral therapy. *Clinical Psychology Review*, *22*(7), 977–990.  
[https://doi.org/10.1016/S0272-7358\(01\)00124-6](https://doi.org/10.1016/S0272-7358(01)00124-6)
- Baguley, D., McFerran, D., & Hall, D. (2013). Tinnitus. *The Lancet*, *382*(9904), 1600–1607.  
[https://doi.org/10.1016/S0140-6736\(13\)60142-7](https://doi.org/10.1016/S0140-6736(13)60142-7)
- Baguley, D. M., Bartnik, G., Kleinjung, T., Savastano, M., & Hough, E. A. (2013). Troublesome tinnitus in childhood and adolescence: Data from expert centres. *International Journal of Pediatric Otorhinolaryngology*, *77*(2), 248–251.  
<https://doi.org/10.1016/j.ijporl.2012.11.009>
- Bartels, H., Middel, B., van der Laan, B., Staal, M., & Albers, F. (2008). The additive effect of co-occurring anxiety and depression on health status, quality of life and coping

strategies in help-seeking tinnitus sufferers. *Ear and Hearing*, 29(6), 947–956.

<https://doi.org/10.1097/AUD.0b013e3181888f83>

Bauer, P. J., & Larkina, M. (2016). Predicting remembering and forgetting of

autobiographical memories in children and adults: a 4-year prospective study.

*Memory*, 24(10), 1345–1368. <https://doi.org/10.1080/09658211.2015.1110595>

Bennett, R., Barr, C., Cortis, A., Eikelboom, R., Ferguson, M., Gerace, D., Heffernan, E.,

Hickson, L., Montano, J., Preminger, J., Pronk, M., Saunders, G., Singh, G., Timmer, B.,

Weinstein, B., & Bellekom, S. (2020). Audiological approaches to address the

psychosocial needs of adults with hearing loss: perceived benefit and likelihood of use. *International Journal of Audiology*.

<https://doi.org/10.1080/14992027.2020.1839680>

Bhatt, J. M., Bhattacharyya, N., & Lin, H. W. (2017). Relationships between tinnitus and the prevalence of anxiety and depression. *Laryngoscope*, 127(2), 466–469.

<https://doi.org/10.1002/lary.26107>

Brunnberg, E., Lindén-Boström, M., & Berglund, M. (2008). Tinnitus and hearing loss in 15–16-year-old students: Mental health symptoms, substance use, and exposure in school. *International Journal of Audiology*, 47(11), 688–694.

<https://doi.org/10.1080/14992020802233915>

Burke, J. G., O'Campo, P., Peak, G. L., Gielen, A. C., McDonnell, K. A., & Trochim, W. M.

(2005). An introduction to concept mapping as a participatory public health research method. *Qualitative Health Research*, 15(10), 1392–1410.

<https://doi.org/10.1177/1049732305278876>

- Coelho, C. B., Sanchez, T. G., & Tyler, R. S. (2007). Tinnitus in children and associated risk factors. *Tinnitus: Pathophysiology and Treatment, Progress in Brain Research*, 166, 179–191. [https://doi.org/10.1016/S0079-6123\(07\)66016-6](https://doi.org/10.1016/S0079-6123(07)66016-6)
- Dionne-Dostie, E., Paquette, N., Lassonde, M., & Gallagher, A. (2015). Multisensory integration and child neurodevelopment. *Brain Sciences*, 5(1), 32–57. <https://doi.org/10.3390/brainsci5010032>
- Gopinath, B., McMahon, C. M., Rochtchina, E., Karpa, M. J., & Mitchell, P. (2010). Risk factors and impacts of incident tinnitus in older adults. *Annals of Epidemiology*, 20(2), 129–135. <https://doi.org/10.1016/j.annepidem.2009.09.002>
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and reliability. *Field methods*, 18, 59–82. <https://doi.org/10.1177/1525822X05279903>
- Haas, S. A., & Bishop, N. J. (2010). What do retrospective subjective reports of childhood health capture? Evidence from the Wisconsin Longitudinal Study. *Research on Aging*, 32(6), 698–714. <https://doi.org/10.1177/0164027510379347>
- Hall, D. A., Lainez, M. J., Newman, C. W., Sanchez, T. G., Egler, M., Tennigkeit, F., & Langguth, B. (2011). Treatment options for subjective tinnitus: self reports from a sample of general practitioners and ENT physicians within Europe and the USA. *BMC Health Services Research*, 11(1), Article 302. <https://doi.org/10.1186/1472-6963-11-302>
- Hinkle, D. E., Wiersma, W., & Jurs, S. G. (1988). *Applied statistics for the behavioral sciences* (2nd ed.). Houghton Mifflin.

- Holgers, K.M., & Juul, J. (2006). The suffering of tinnitus in childhood and adolescence. *International Journal of Audiology*, 45(5), 267–272.  
<https://doi.org/10.1080/14992020500485668>
- Jackson, K. M., & Trochim, W. M. (2002). Concept mapping as an alternative approach for the analysis of open-ended survey responses. *Organizational Research Methods*, 5(4), 307–336. <https://doi.org/10.1177/109442802237114>
- Johnson, B. (1990). The changing role of families in health care. *Children's Health Care*, 19(4), 234–241. [https://doi.org/10.1207/s15326888chc1904\\_7](https://doi.org/10.1207/s15326888chc1904_7)
- Kane, M., & Trochim, W. M. (2007). *Concept mapping for planning and evaluation* (Vol. 50): Sage Publications.
- Kentish, R. C., Crocker, S. R., & McKenna, L. (2000). Children's experience of tinnitus: a preliminary survey of children presenting to a psychology department. *British Journal of Audiology*, 34(6), 335–340. <https://doi.org/10.3109/03005364000000149>
- Kentish, R., Benton, C., Kennedy, V., Munro, C., Philips, J., Rogers, C., Rosenberg, J., & Salvage, S. (2015). *Tinnitus in children. Practice guidance*. British Society of Audiology. <http://www.thebsa.org.uk/wp-content/uploads/2015/03/2015-Paed-Tin-Guidelines-FINAL.pdf>
- Kim, J. Y., Han, J. J., Sunwoo, W. S., Koo, J. W., Oh, S. H., Park, M. H., & Kim, Y. H. (2018). Sudden sensorineural hearing loss in children and adolescents: Clinical characteristics and age-related prognosis. *Auris Nasus Larynx*, 45(3), 447–455.  
<https://doi.org/10.1016/j.anl.2017.08.010>

- Kim, S., Jeon Y., Lee, J. Y., & Kim, Y. H. (2016). Characteristics of tinnitus in adolescents and association with psychoemotional facts. *Laryngoscope*, *127*(9), 2133–2119.  
<https://doi.org/10.1002/lary.26334>
- Kim, Y. H., Jung, H. J., Kang, S. I., Park, K. T., Choi, J. S., Oh, S. H., & Chang, S. O. (2012). Tinnitus in children: Association with stress and trait anxiety. *Laryngoscope*, *122*(10), 2279–2284. <https://doi.org/10.1002/lary.23482>
- King, S., Teplicky, R., King, G., & Rosenbaum, P. (2004). Family-centred service for children with cerebral palsy and their families: A review of the literature. *Seminars in Pediatric Neurology*, *11*(1), 78–86. <https://doi.org/10.1016/j.spen.2004.01.009>
- Kruskal, J. B. (1964). Multidimensional scaling by optimizing goodness of fit to a nonmetric hypothesis. *Psychometrika*, *29*(1), 1–27. <https://doi.org/10.1007/BF02289565>
- Langguth, B. (2011). A review of tinnitus symptoms beyond ‘ringing in the ears’: a call to action. *Current Medical Research & Opinion*, *27*(8), 1635–1643.  
<https://doi.org/10.1185/03007995.2011.595781>
- Maes, I., Cima, R., Vlaeyen, J., Anteunis, L., & Joore, M. (2013). Tinnitus : a cost study. *Ear and Hearing*, *34*(4), 508–514. <https://doi.org/10.1097/AUD.0b013e31827d113a>
- Mancini, P. C., Tyler, R. S., Perreau, A., Batterton, L. F., & Ji, H. (2018). Considerations for partners of our tinnitus patients. *The International Tinnitus Journal*, *22*(2), 113–122.  
<https://doi.org/10.5935/0946-5448.20180020>
- Martin, K., & Snashall, S. (1994). Children presenting with tinnitus: A retrospective study. *British Journal of Audiology*, *28*(2), 111–115.  
<https://doi.org/10.3109/03005369409077921>

- Mills, R. P., Albert, D. M., & Brain, C. E. (1986). Tinnitus in childhood. *Clinical Otolaryngology*, 11(6), 431–434. <https://doi.org/10.1111/j.1365-2273.1986.tb02033.x>
- Mills, R. P., & Cherry J. R. (1984). Subjective tinnitus in children with otological disorders. *International Journal of Paediatric Otorhinolaryngology*, 7, 21–27. [https://doi.org/10.1016/S0165-5876\(84\)80050-6](https://doi.org/10.1016/S0165-5876(84)80050-6)
- Moroe, N., & Khoza-Shangase, K. (2014). The impact of tinnitus on daily activities in adult tinnitus sufferers: A pilot study. *The South African Journal of Communication Disorders*, 61(1). <https://doi.org/10.4102/sajcd.v61i1.65>
- Mucci, S., Geoczé, L., Abranches, D., Antunez, A., & Penido, N. (2014). Systematic review of evidence on the association between personality and tinnitus. *Brazilian Journal of Otorhinolaryngology*, 80(5), 441–447. <https://doi.org/10.1016/j.bjorl.2014.05.031>
- Poost-Foroosh, L., Jennings, M. B., Shaw, L, Meston, C. N., & Cheesman, M. F. (2011). Factors in client–clinician interaction that influence hearing aid adoption. *Trends in Amplification*, 15(3), 127–139. <https://doi.org/10.1177/1084713811430217>
- Rosas, S. R., & Camphausen, L. C. (2007). The use of concept mapping for scale development and validation in evaluation. *Evaluation and Program Planning*, 30(2), 125–135. <https://doi.org/10.1016/j.evalprogplan.2007.01.003>
- Rosas, S. R., & Kane, M. (2012). Quality and rigor of the concept mapping methodology: a pooled study analysis. *Evaluation and Program Planning*, 35(2), 236–245. <https://doi.org/10.1016/j.evalprogplan.2011.10.003>

- Rosas, S. R., & Ridings, J. W. (2017). The use of concept mapping in measurement development and evaluation: application and future directions. *Evaluation and Program Planning, 60*, 265–276. <https://doi.org/10.1016/j.evalprogplan.2016.08.016>
- Rosing, S. N., Kapandais, A., Schmidt, J. H., & Baguley, D. M. (2016). Demographic data, referral patterns and interventions used for children and adolescents with tinnitus and hyperacusis in Denmark. *International Journal of Pediatric Otorhinolaryngology, 89*, 112–120. <https://doi.org/10.1016/j.ijporl.2016.07.036>
- Rosing, S. N., Schmidt, J. H., Wedderkopp, N., Baguley, D. M. (2016). Prevalence of tinnitus and hyperacusis in children and adolescents: A systematic review. *BMJ Open, 6*(6), Article e010596. <http://dx.doi.org/10.1136/bmjopen-2015-010596>
- Sanchez, L., & Stephens, D. (1997). A tinnitus problem questionnaire in a clinic population. *Ear and Hearing, 18*(3), 210–217. <https://doi.org/10.1097/00003446-199706000-00004>
- Schaette, R., & McAlpine, D. (2011). Tinnitus with a normal audiogram: physiological evidence for hidden hearing loss and computational model. *The Journal of Neuroscience, 31*(38), 13452–13457. <https://doi.org/10.1523/JNEUROSCI.2156-11.2011>
- Schiller, C., Winters, M., Hanson, H. M., & Ashe, M. C. (2013). A framework for stakeholder identification in concept mapping and health research: a novel process and its application to older adult mobility and the built environment. *BMC Public Health, 13*(1), Article 428. <https://doi.org/10.1186/1471-2458-13-428>
- Sindhusake, D., Mitchell, P., Newall, P., Golding, M., Rohtchina, E., & Rubin, G. (2003). Prevalence and characteristics of tinnitus in older adults: the Blue Mountains



Hearing Study. *International Journal of Audiology*, 42(5), 289–294.

<https://doi.org/10.3109/14992020309078348>

Smith, H., Fackrell, F., Kennedy, V., Barry, J., Broomhead, E., & Hoare, D. (2020). An evaluation of paediatric tinnitus services in UK National Health Service audiology departments. *BMC Health Services Research*, 20, Article 214.

<https://doi.org/10.1186/s12913-020-5040-y>

Smith, H., Fackrell, F., Kennedy, V., Barry, Partridge, L., & Hoare, D. (2019). A scoping review to catalogue tinnitus problems in children. *International Journal of Pediatric Otorhinolaryngology*, 122, 141–151. <https://doi.org/10.1016/j.ijporl.2019.04.006>

Smith, J. P. (2009). Reconstructing childhood health histories. *Demography*, 46(2), 387–403.

<https://doi.org/10.1353/dem.0.0058>

Szibor, A., Jutila, T., Mäkitie, A., Aarnisalo, A. (2017). Clinical characteristics of troublesome pediatric tinnitus. *Clinical Medicine Insights: Ear, Nose and Throat*, 10, Article 1179550617736521

Tegg-Quinn, S., Bennett, R., Brennan-Jones, C., Barabash, S., Mulders, WHAM., & Eikelboom, R. (2020). Reflections and perceptions of chronic tinnitus during childhood and adolescence. *International Journal of Pediatric Otorhinolaryngology*, 138, Article 110258. <https://doi.org/10.1016/j.ijporl.2020.110258>

Trochim, W. (1993, November 3). *The reliability of concept mapping*. [Paper presentation]. Annual Conference of the American Evaluation Association, Dallas, Texas.

Trochim, W. M. (1989). An introduction to concept mapping for planning and evaluation.

*Evaluation and Program Planning*, 12(1), 1–16. [https://doi.org/10.1016/0149-7189\(89\)90016-5](https://doi.org/10.1016/0149-7189(89)90016-5)

Trochim, W., & Kane, M. (2005). Concept mapping: an introduction to structured

conceptualization in health care. *International Journal for Quality in Health Care*, 17(3), 187–191. <https://doi.org/10.1093/intqhc/mzi038>

Viani, L. (1989). Tinnitus in children with hearing loss. *The Journal of Laryngology and*

*Otology*, 103(12), 1142–1145. <https://doi.org/10.1017/S0022215100111223>

Yetiser, S., Tosun, F., Satar, B., Arslanhan, M., Akcam, T., & Ozkaptan, Y. (2002). The role of

zinc in management of tinnitus. *Auris Nasus Larynx*, 29(4), 329–333.

[https://doi.org/10.1016/S0385-8146\(02\)00023-8](https://doi.org/10.1016/S0385-8146(02)00023-8)

**Appendix 1: Statements grouped according to cluster from highest to lowest mean ratings, and with standard deviation and median of the rating for each statement.**

Cluster	Statement	Mean rating	STDEV	Median rating
<b>1. EMOTIONAL WELL-BEING</b>				
87	Nights; lying in bed full of anxiety.	3.77	1.69	4.5
34	Lying awake at night; the tinnitus just rings and rings and rings to the point that it is frightening.	3.65	1.8	4
84	Tinnitus can cause anxiety and depression.	3.55	1.79	4
9	General happiness.	3.5	1.53	4
43	Tinnitus affects anxiety, anxiety makes tinnitus louder. Anxiety and tinnitus go hand in hand.	3.5	1.56	4
98	Thinking that something is seriously wrong.	3.5	1.85	4
107	Anxiety; definitely increases anxiety.	3.41	1.5	4
3	Emotional disturbance; instils fear.	3.39	1.59	4
51	Scared at night about what can't be heard, not worried about the tinnitus but scared about what it is covering; lying awake at night listening for the monster under the bed.	3.39	1.9	4
88	Affects mood; contributes to depression.	3.32	1.78	4
2	Focus and sense of well being; may feel annoyed, down and miserable and develop a headache when tinnitus flares up in response to classroom noise.	3.3	1.4	4
39	Worry about triggering the tinnitus is overwhelming.	3.26	1.57	4
19	Exacerbates mental health issues; if having a breakdown the noise just exacerbates it.	3.25	1.82	4
70	Increases stress.	3.23	1.8	4
92	The quiet times are not so quiet.	3.18	1.59	3.5
109	Mood; becoming more irritable and snappy when tinnitus is present.	3.14	1.67	4
117	It is harder to dismiss when tired, stressed or moody.	3.14	1.39	4

1	Confidence and well being; if unaware of what the sounds are, can create a fear of 'what's wrong' and it can be difficult to vocalise this.	3.13	1.36	3
49	Worrying that the tinnitus sound will have the same impact for the rest of their life and that nothing can be done about it.	3.13	1.71	4
53	Mood - may not know how to deal with frustration / annoyance.	3.13	1.74	4
60	Coping; ability to cope is compromised.	3.09	1.6	4
85	Control of emotions; much more emotional.	3.04	1.81	3.5
23	Can feel quite isolated if they think that they are the only one who experiences tinnitus amongst their peers.	3	1.51	3
69	Stress; worry that something worse might happen.	3	1.88	4
72	Deep-rooted fear that at anytime, in the unpredictable universe, the tinnitus condition can actually get worse.	3	1.83	3
73	Discomfort especially while relaxing.	3	1.51	3
93	Worry about the noises in ears: 'Why?', 'What does it mean?'.	3	1.66	4
94	Emotions and tolerance, become more of a struggle.	3	1.69	4
102	Anxiety before loud events that children usually go to such as music concerts and parties etc.	2.96	1.7	4
33	Sense of fear; weird fear of the tinnitus but don't know enough about it.	2.91	1.62	3
108	Thought processes.	2.91	1.69	3.5
46	Mental health -know that something is different and wrong or weird but can't say what is wrong	2.87	1.82	3
103	Nervousness.	2.86	1.89	4
52	Causes confusion.	2.83	1.61	3
80	Blocks the hearing in one ear; it is very distracting and distressing.	2.82	1.44	3
35	Might not be enough to effect life, but it can be hard to know because you never know what young people are thinking.	2.74	1.45	3
76	At the time one may think that it does not have much effect, but later when thinking back one may realise that it has a lot of effect.	2.73	1.35	3
81	Children can be on guard and alert all the time.	2.73	1.75	3
97	Health	2.64	1.71	3
18	Worrying about which soft sounds may not be heard because of the tinnitus.	2.61	1.5	3

48	Early life not tremendously affected because when younger may not know that the ringing is not normal	2.61	1.47	3
28	Negatively affecting ability to enjoy music.	2.43	1.44	3
45	Behaviour; become less vocal.	2.39	1.59	3
77	May lead to substance abuse.	2.32	2.03	3
17	Sense of self; some can feel that tinnitus is almost an extra part of them, for example - Jessica (with tinnitus) in a similar way to someone describing Jessica (the vegetarian). This can make it hard for them to manage the tinnitus.	2.3	1.58	3
30	Lots of things.	2.22	1.51	2
67	Clear lucid awareness of the mortality and permanent deterioration of the body.	2.18	1.92	2
22	Becoming aware of singular existence in the world. It can be a good thing, but sometimes it is too much for a young person.	2	1.73	2

<b>2. ACADEMIC PERFORMANCES</b>		<b>Mean rating</b>	<b>STDEV</b>	<b>Median rating</b>
100	When classroom is noisy, find it hard to focus, then buzzing noise begins, then become annoyed when can't continue work, then have tinnitus and a headache, can feel down and miserable	3.5	1.77	4
66	Labelled day dreamer, or getting in trouble because of not listening to the teacher, because they are listening to the tinnitus because it changes.	3.27	1.58	4
91	Concentration because of the noises.	3.27	1.67	4
11	Concentration during exams.	3.26	1.42	4
90	Ability to concentrate at school.	3.23	1.74	4
101	Adding to the stress of trying to listen in class.	3.23	1.63	4
6	Relationship with school; if kept awake at night because of tinnitus, days from school may be missed due to tiredness, if the school raises concerns the child may become more stressed.	3.22	1.78	3
14	Concentration during quiet work at school and on homework.	3.22	1.35	4
95	Concentration; can't concentrate when it is quiet or noisy.	3.14	1.58	4
12	Schooling.	3.13	1.49	3
57	Academic performance.	3.09	1.74	4

106	Attention; distracting during class, making it hard to hear and follow lessons.	3.09	1.54	3
59	Negatively affecting exam performance.	3.05	1.73	3.5
26	Hearing; the noise is distracting; can't hear when the noise is there i.e. in the classroom.	3.04	1.46	3
82	Academic performance associated with the anxiety due to the possibility of the tinnitus occurring in school and stopping them hearing.	3	1.75	3.5
10	Give up studying because of difficulty concentrating.	2.96	1.85	4
75	Listening in the classroom; children either miss what is being said or become more tired from the strain of listening over the tinnitus.	2.96	1.53	3
111	Ability to focus	2.95	1.62	3.5
8	Ability to study.	2.91	1.59	3
37	Presents distractions.	2.91	1.41	3
62	Lesson transitions at school become difficult to follow due to distractions from tinnitus.	2.91	1.6	3
79	Loosing concentration trying to keep up.	2.86	1.58	3
38	Attention.	2.74	1.45	3
20	One can be very distractible.	2.61	1.44	3
29	Trouble understanding.	2.61	1.75	3
24	Difficulty in echoey classes such as PE and art.	2.52	1.47	3

<b>3. SOCIAL/RELATIONAL</b>		<b>Mean rating</b>	<b>STDEV</b>	<b>Median rating</b>
99	Sleep; tinnitus is annoying when trying to sleep.	3.73	1.55	4
58	Sleep, lying awake at night listening to the tinnitus.	3.68	1.52	4
65	Struggling to get to sleep; a lack of sleep can impair ability to function well.	3.55	1.54	4
42	Sleep, as the tinnitus is associated with nightmares and scary thoughts.	3.52	1.68	4
56	Falling off to sleep is difficult.	3.46	1.5	4
7	Sleep because when waking up in the middle of the night, the tinnitus is all that can be heard.	3.37	1.55	4
5	Becoming socially withdrawn as avoid noisy places or become hypervigilant about noise, depending on which situations exacerbate their tinnitus.	3.3	1.74	4

86	Breakdown in relationships at home if some family members do not understand chronic tinnitus.	3.14	1.83	4
13	Socialising: go out less because of discomfort associated with loud noise.	3.13	1.6	3
89	Negatively impacting upon relationships with parents and siblings.	3.09	1.88	4
115	Sleep but could be associated with anxiety or middle ear discomfort.	3.09	1.6	4
25	Inability to talk to friends about tinnitus: fear of being laughed at.	2.96	1.36	3
104	May shut down, even withdraw from the family.	2.96	1.86	3
64	Sense of belonging; feeling isolated, different from friends.	2.91	1.72	3
55	Breakdown in family relationships if unable to confide in parents about what may have triggered the tinnitus.	2.86	1.94	4
41	Negatively impacting upon friendships.	2.83	1.7	3
114	Can't go to parties, family gatherings etc. as it gets too noisy and sets off the tinnitus.	2.77	1.88	3
47	Can't do the same things as friends.	2.7	1.82	3
68	Become less social.	2.68	1.73	3
113	Can't attend events with friends because sounds are too much.	2.68	1.73	3
50	Stop being able to do the things that one wants to do.	2.65	1.75	3
116	Impacts on family events.	2.5	1.66	2
54	Wanting to be with peers.	2.41	1.71	2.5
74	Once stable it rarely impacts upon day to day life	2.33	1.56	2
32	Complicates already altered movements when child has a disability.	2.3	1.74	2
4	Wanting to join in anything.	2.26	1.66	3
16	Physical activity.	2.26	1.54	3
44	Adversely affects eating.	2.13	1.79	2
<b>4. AUDITORY/COGNITIVE PROCESSING</b>		Mean rating	STDEV	Median
40	Difficulty in very quiet environments.	3.26	1.42	4
63	Conversations; struggle to pick up certain sounds out of the environment; seemingly not able to hear.	3.09	1.47	3

71	Difficulty listening to others, because instead of listening to what is happening, they listen to when the tinnitus changes. The focus is inwards rather than outwards.	3	1.69	3
96	Hearing soft sounds is difficult because of the tinnitus.	2.91	1.51	3
31	Hearing when tinnitus is present.	2.87	1.42	3
61	Conversations; one on one conversation is ok but conversations in groups are harder.	2.77	1.6	3
36	Interferes with hearing tests.	2.74	1.38	3
21	Difficulty in dinner hall at school; it is too noisy, so can't sit with friends.	2.7	1.55	3
83	Ability to play a musical instrument.	2.55	1.63	3
105	Slower to react, because hearing isn't great there is a need to catch up.	2.55	1.54	3
27	Speech because it takes a while to process.	2.52	1.41	3
118	Need to see people's faces.	2.41	1.47	3
78	Safety; can't cross the road.	2.36	1.84	2.5
110	Slower to react when others talk.	2.36	1.56	2.5
15	Physical reaction times are slower.	2.26	1.57	2