

## **Positive experiences related to living with tinnitus: A cross-sectional survey**

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### **Key Words**

Tinnitus, Positive experiences, Self-management, Behavior modification, Acceptance

### **Abstract**

#### **Objective**

The aim of this study was to gain insights related to positive experiences reported by adults with tinnitus living in the UK.

#### **Design**

A cross-sectional survey design was used in a sample of adults with tinnitus who were interested in undertaking an Internet-based intervention for tinnitus.

#### **Setting**

The study was UK wide and data collection was online.

#### **Participants**

Participants consisted of 240 adults (137 males, 103 females), with an average age of 48.16 years and average tinnitus duration of 11.52 years (SD: 11.88).

#### **Main outcome measures**

Tinnitus severity was measured by means of the Tinnitus Functional Index. To evaluate the secondary effects of tinnitus, the Insomnia Severity Index, the Hearing Handicap Inventory for Adults-Screening Version and the Cognitive Failures Questionnaires were administered. Positive experiences related to tinnitus were explored using an open-ended question format.

## **Results**

Around a third of participants (32.5%) reported positive experiences associated with tinnitus. The number of positive responses ranged from one to eight responses per participant, although there were fewer participants with more than one positive response. The predominant themes concerned: (1) coping; (2) personal development; (3) support, and to a lesser extent (4) outlook. Younger participants, those with a lower hearing disability and those with fewer cognitive failures were more likely to report positive experiences associated with having tinnitus.

## **Conclusions**

This study has identified that personal development and a positive outlook is possible despite experiencing tinnitus. Ways to facilitate positive experiences related to tinnitus should be promoted, as this may reduce the negative consequences associated with tinnitus.

The most prevalent positive theme was the ability to cope with tinnitus. Positive experiences were also drawn from having clinical and other support networks. This highlights the importance of providing tinnitus interventions that can assist people in coping with tinnitus.

This may be particularly important to those less likely to relate tinnitus to any positive experiences. This may include those who are older with greater cognitive difficulties and more hearing disability.

## Introduction

Tinnitus is defined as the percept of sound in the absence of a corresponding external stimuli (1). It is highly prevalent, affecting an estimated 10-17% of the adult population across the globe (2-6). Despite its prevalence, a cure to permanently abolish tinnitus, is yet to be found (7). In addition, this chronic condition can be debilitating due to various secondary consequences, including insomnia, reduced concentration, anxiety, and depression (8). Understanding the impact of these effects on an individual's activity, participation and psychological consequences is important (9). The World Health Organisation has, therefore, developed an International Classification of Functioning framework (ICF) (10). This classification is based on the biopsychosocial perspective that suggests that any health condition can have both positive and negative consequences on functioning. The negative impact of health conditions is generally focused on. It is also important to understand aspects of human experiences that are positive and enriching (11). This has led to a branch of psychology, namely positive psychology that aims to understand the conditions and processes that contribute to the optimal functioning of people, despite the difficulties they face (12). Exploring this positive perspective is argued to provide additional understanding of the impact a condition as well as personal strengths and capabilities (13). Positive experiences have been explored for a range of health conditions, including cancer (14) and multiple sclerosis (15). Within auditory-related conditions, positive experiences have been reported by patients with hearing and balance disorders and by their significant others (11). There is, however, only one empirical study by Kentala and colleagues published regarding the positive experiences of those with tinnitus (16). In this study qualitative analysis of an open-ended question was used to identify positive experiences. There were 121 responders who attended a specialist Welsh tinnitus clinic, of which 50 (41.3%) reported at least one positive experience. Positive experiences fell into four main categories including treatment-related;

personal development; disease-specific; and other people. The literature regarding positive experiences associated with tinnitus is, therefore, limited.

Understanding how tinnitus is experienced and dealt with is also important from a rehabilitation perspective. Avoidance behaviors and catastrophic thinking about tinnitus has, for instance, been associated with greater tinnitus severity and emotional distress (17,18). If negative and catastrophic thinking results in greater emotional distress, positive thoughts may be one way of breaking this cycle. Thought and behaviour modification are important components of tinnitus management, and identifying how to promote these modifications is of value (19). As only one study has been published exploring the positive experiences with tinnitus, the aim of this present study was to expand our knowledge and gain further insights related to positive experiences in those experiencing tinnitus.

## **Method**

### *Ethical considerations*

Ethical approval was granted by the Faculty of Science and Technology Research Ethics Panel of Anglia Ruskin University (FST/FREP/14/478), Cambridge, United Kingdom and the study was registered with Clinical Trials.gov: NCT02370810, date 05/03/2015. The study was conducted in accordance with good clinical practice together with the ethical principles of the Declaration of Helsinki. A protocol complying with UK and European guidelines for data protection, electronic communication and confidentiality was established to ensure the security of participants' information on the web-portal holding personal data. This included encrypting information and the use of unique reference codes during data analysis to maintain confidentiality.

### ***Study design***

A cross-sectional survey design was used. The data for this study was collected during the recruitment of participants for a clinical trial investigating the feasibility and effectiveness of Internet-based CBT in the United Kingdom (20,21). Recruitment was UK wide for a period of two months and targeted people from various demographical backgrounds with significant levels of tinnitus distress. Study information was available in various formats including online (e.g., the NHS Choices and clinicaltrials.gov websites), Twitter (British Tinnitus Association), Facebook forums (e.g., Action on Hearing loss, Thyroid UK), newspapers, and magazines (e.g., Mature Times, People's Friend, Musicians Union bulletin, New Scientist, National Federation of Occupational Pensioners Magazine, Cambridge News), support groups (e.g., tinnitus, thyroid) and from healthcare professionals (GP surgeries, audiologists).

### ***Data collection***

Data collection was online and included background demographical information. Tinnitus severity was measured by means of the Tinnitus Functional Index, with a score range of 0-100 (9). As tinnitus can have an effect on sleep, the Insomnia Severity Index, with a maximum score of 28, was administered (10). The Hearing Handicap Inventory for Adults-Screening version (score range 0-40) was used to assess hearing handicap, often linked with having tinnitus (11). In addition the Cognitive Failures Questionnaire (12), with a maximum score of 100 was applied to evaluate the effect of tinnitus on concentration and other cognitive functions.

To use the same approach as that of Kentala et al. (16), an open-ended question regarding positive experiences was used and worded: *"Make a list of any positive experiences you have encountered due to tinnitus. Write down as many as you can think of."* To encourage

participants to consider this question, a response was required and this question could not be left blank. If no positive experiences could be identified they could explain this or type 'none'.

### ***Participants***

Adults, aged 18 years and over living in the UK and experiencing tinnitus for a minimum period of 3 months were invited to participate in the study. Recruitment was UK wide in various formats including online, twitter, facebook, newspapers, magazines and via support groups. Those interested in participating provided informed consent prior to participating.

In total, 240 participants completed the screening questionnaire. Of these 137 were men and 103 were women, with an average age of 48.16 years (SD: 22.70) and mean tinnitus duration of 11.52 years (SD: 11.88). The average tinnitus severity on the Tinnitus Functional Index (22) was 55.16 (SD: 21.86) indicating that this group were experiencing clinically significant tinnitus.

### ***Data analysis***

The responses to open-ended questions were analysed using the qualitative content analyses described by Graneheim and Lundman (23). The definition of positive experiences were any experience, belief, behaviour, event, or social structure considered to be a source of mental, physical, spiritual, social or emotional benefit (24). Positive experiences identified were analysed for 'meaning units' which are statements that relate to the same central meaning, and these meaning units formed the units of analysis for coding. The initial coding was done independently by two researchers. The coding was compared and where there were

inconsistencies a third researcher was asked to code the response. These units were amalgamated into ‘condensed meaning units’ and searched for repeated patterns to identify potential ‘themes’ and ‘sub-themes’ by one researcher. A second researcher further condensed the themes and sub-themes. The research team finalised the identified themes and subthemes.

The Statistical Package for Social Sciences version 23.0 was used for quantitative analysis. Analysis of Covariance (ANCOVA) and Chi-square testing was used to identify any group differences regarding baseline characteristics initially between those with and without positive experiences and then between those with one positive experience and those with more than one positive experience. For all analyses, a two-tailed significance level of  $<0.05$  was considered statistically significant.

## **Results**

### **Positive responses**

Of the 240 participants, the majority (n=162) reported no positive experiences in statements like “There is nothing positive I can say about tinnitus.” At least one positive experience was reported by 78 (32.5%) of the participants. Statistical analysis indicated that those describing positive experiences were significantly younger, had lower hearing disability and fewer cognitive failures, than those reporting no positive associations with tinnitus, as seen in Table 1.

No significant differences were found for tinnitus severity, level of insomnia, gender, tinnitus duration, level of education or employment status, between those reporting and not reporting positive experiences.



<Table 1 near here>

Of the 78 participants reporting positive experiences, 50 reported only one positive experience, whereas 28 recalled more than one positive occurrence, with a maximum of eight positive accounts. No significant differences were found for any demographical or clinical variables between those reporting one positive event and those reporting more than one positive occurrence.

The number of positive responses was compared between the present study and that of Kentala et al. (6). Figure 1 demonstrates that there were similar percentages of reported positive responses, except for more participants reporting they had no positive experiences in the present study.

<Figure 1 near here>

### **Themes**

A total of 126 positive responses were reported by participants. Each formed a 'meaning unit' which were amalgamated into 'condensed meaning units', 'sub-themes' and 'themes.' The responses fell into four main themes: (1) coping (n=41); (2) personal development (n=39); (3) support (n=35) and (4) outlook (n=11). Table 2 presents the themes, sub-themes and also examples of a meaning unit identified from the participants' responses using the qualitative content analysis.

<Table 2 near here>

### ***Coping theme***

The participants identified various positive aspects related to them being able to manage the tinnitus. *Being able to relieve the tinnitus, becoming more conscious of external factors affecting the tinnitus, and receiving help from professionals* were the main sub-themes. This theme suggests that, although there is often no cure for tinnitus, being able to find ways of coping with the tinnitus, can result in a number of positive changes. This theme had the most number of meaning units at 41 (32.5%).

### ***Personal development theme***

Many people with tinnitus reported that this chronic condition had contributed to their personal development. These included: *lifestyle changes; taking better care of their ears and hearing and having a greater understanding of tinnitus*. These reports indicated that lifestyle and mental adjustments made as a result of having tinnitus can result in positive outcomes. This theme had the second most meaning units at 39 (31.0%).

### ***Support theme***

The responses from people with tinnitus suggested positive experiences related to being able *to relate, empathise, help and support other sufferers*. Also, people with tinnitus recalled positive experiences due to *compassion and understanding from other people*. In addition, people with tinnitus reported *benefitting from support groups*, where they are able to make new relationships as a result of their condition. There were 35 (27.8%) meaning units attached to this theme.

### ***Outlook theme***

Positive experiences linked to a change in outlook included the *realisation that they were not the only ones with tinnitus* and considering their *symptoms could be worse*. A further positive effect was that tinnitus motivated them to *achieve goals and focus on what they considered the important aspects of life to be*. This theme suggests that having tinnitus could lead to a positive outlook and focus in life. This was the theme with the least meaning units at 11 (8.7%).

## **Discussion**

### **Synopsis of key findings**

The current study suggests that despite various adverse and distressing consequences, some people with tinnitus are able to identify various positive experiences related to experiencing tinnitus. It was found that those who were younger were more likely to report positive experiences. This may be connected to findings by Schlee et al. (25) demonstrating that those with an earlier onset of tinnitus have a lower tinnitus distress, compared with those having tinnitus onset at a higher age. Moreover, those with lower levels of hearing disability were more prone to describe positive experiences connected with tinnitus. This link deserves further attention as higher levels of tinnitus severity have been correlated with greater hearing loss (16). The combination of tinnitus and hearing disability may, therefore, have had an adverse influence on positive outlook. In addition, those with more cognitive failures were less likely to report positive experiences. This finding reflects the impact tinnitus can have on cognitive performances such as working memory and attention (17). Lower levels of attention and working memory may hamper identifying positive experiences.

It was of interest that differences in tinnitus severity, level of insomnia, tinnitus duration and gender were not found between those with and without positive experiences connected with

tinnitus. These effects should be monitored in further studies on positive experiences. There was also no difference found between those reporting one positive experience and those reporting more than one positive experience, indicating that identifying even one positive association with tinnitus may have a beneficial effect.

Therapeutic interventions should be available to those with distressing tinnitus. This may be important especially when these persons are older, have associated hearing loss and/or more cognitive failures. These interventions may lead to more positive experiences associated with tinnitus, which in turn may assist with thought and behavioral modifications required to adapt to tinnitus.

It should be noted that the majority of participants could not report any positive experiences. In addition, many of the positive experiences reported are cold comfort, meaning that they are small reassurances rather than the growth experiences (26). This is indicated by some responses for example: *'Met a lot of nice people along the way. Though I would have traded not meeting them for not getting tinnitus'* or *'I guess, experiencing tinnitus has forced me to stop and be less busy in my life which could be thought of as positive.'*

### **Comparison with other studies**

The demographical characteristic of the participants in the present study were similar to those in the study by Kentala et al. (16), except that the Kentala et al. study had a higher ratio of female participants. When comparing the positive experiences reported, a higher percentage (41.3%) of respondents in the Kentala et al. study reported positive experiences, compared with 32.5% in the current study. This may have been related to the difference in obtaining the information in a clinical setting versus online, as it may be easier to prompt and encourage a response in a clinical setting. The positive experiences reported in the present study were

similar to that found by Kentala et al., however, the frequency of responses correlated to the various themes and subthemes differed. There were 12 sub-themes for the present study, which were more than the 9 reported by Kentala et al. Although the themes found were similar between the two studies, the labels varied to reflect the content of the positive experiences in the present study. The theme *treatment-related* by Kentala et al., was labeled *coping*; the *disease-specific* theme, named *outlook*; and the *other people* theme, titled *support* in the present study. For the present study, there were roughly the same number of responses for the themes coping, personal development and support, with around a third of the responses for each category. The outlook theme had the least responses. The majority of responses found by Kentala et al. were treatment related at 59.8% (equivalent to the coping theme of the present paper) and the least for personal development at 7.6% of all responses. These differences may be indicative of greater availability of self-help tinnitus management strategies at present, than at the time of the previous study (19).

### **Clinical applicability of the study**

The findings confirm the importance of access to tinnitus treatment and support networks due to the positive effects this may have on not only tinnitus but also overall health. To promote the benefit of receiving support from others, treatment programs should ensure they include information directed at friends and family to help them understand tinnitus and how to support those with tinnitus. It also suggests that some individuals are able to draw personal growth as a result of this chronic condition. Mohr and Hedelund (26), in adopting a 'person-centered' psychotherapeutic approach to tinnitus, also found that experiences of tinnitus might lead to personal growth in some cases, citing increased maturity, resilience, and empathy as examples. The ability to associate positive experiences with tinnitus may, therefore, have some bearing towards thought and behavior modification, as well as reducing the negative effects such as anxiety often coupled with tinnitus.

It is suggested that positive experiences may be associated with acceptance, adjustment and coping with health-related conditions (27). In Ménière disease, positive experiences are linked with self-rated quality of life (28,29) and can also predict the impact of the condition (30,31). Studies exploring the relationship between positive experiences linked with tinnitus and other aspects such as acceptance, coping, and quality of life and treatment outcomes, are yet to be explored. Investigating whether it is possible to motivate people experiencing tinnitus to think more positively is of value. In addition, determining the relationship of positive thinking to that of thought and behavior modification is important, as this may have direct implications to self-management.

### **Study strengths and limitations**

A methodological advantage of this study was the utilisation of an open-ended question approach. This had the advantage of eliciting free responses from participants without imposing any pre-defined concepts. Furthermore, responses were collected via the Internet anonymously, where participants may be able to answer more honestly than they possibly may in a clinical situation. **An additional standardised measure of positive and negative thinking in tinnitus may have strengthened these results. Recently the Tinnitus Cognitions Questionnaire (32) has been indicated to have potential as such a measure (33).** The sample were volunteers for a tinnitus treatment study involving CBT techniques delivered via the Internet, and thus may not be representative of a wider clinical population. Potentially they experienced tinnitus of greater severity, their tinnitus had a greater impact, or they were socioeconomically disposed towards research trial participation. This effect has been noted in other studies with similar study populations (34).

### **Further research**

A greater number of positive responses are reported when using a structured questionnaire format. For example, studies on positive experiences of people with hearing loss and Ménière disease, show that nearly 90% of individuals would select 'often true' to at least a few questions when presented in a structured questionnaire format (29,35). The response themes identified in this study may be useful for developing such a structured questionnaire on positive aspects related to tinnitus. Responses obtained from a structured format can then be compared with those obtained when using an open-ended response. Investigating the association between identifying positive experiences and acceptance and coping with tinnitus, is required. Exploring ways clinicians can encourage positive thinking and the effects this may have, is needed. Research determining whether identifying positive experiences can be a predictor of treatment success is also important.

### **Table headings**

**Table 1:** Demographical information of participants

**Table 2.** Positive themes and sub-themes identified due to experiencing tinnitus

### **Figure heading**

**Figure 1:** Frequency of positive experiences comparison between the present study and those reported by Kentala et al. (2008)

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### **Authorship**

VM conceived this study and it was designed by VM, GA, DB, PA and EB. This manuscript was drafted by VM and EB. Data collection and analysis was done by EB. Thematic coding was done by TV and EB. All authors critically appraised and approved the manuscript.

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