AJA | AMERICAN JOURNAL OF AUDIOLOGY

Findings and ethical considerations from a thematic analysis of threads within tinnitus online support groups

SCHOLARONE™
Manuscripts

Findings and ethical considerations from a thematic analysis of threads within tinnitus online support groups

Eve Ainscough[1], Sandra N. Smith[2], Kate Greenwell[3], Derek J. Hoare[2]

[1] School of Medicine, University of Nottingham, UK, NG7 2RD

[2] NIHR Nottingham Biomedical Research Centre, Otology and Hearing group, Division of Clinical Neuroscience, School of Medicine, University of Nottingham, UK, NG7 2RD

[3] Centre for Clinical and Community Applications of Health Psychology, University of Southampton, Southampton, UK, SO17 1BJ

Address correspondence to: Derek J. Hoare

Address: NIHR Nottingham Biomedical Research Centre, Ropewalk House, 113 The Ropewalk, Nottingham, UK, NG1 5DU.

Email: derek.hoare@nottingham.ac.uk

Running title: Online support groups for tinnitus

Abstract

Purpose

Tinnitus is the perception of noise without a corresponding external stimulus. Current management typically aims to moderate associated psychosocial stressors and allow sufferers to retain an adequate quality of life. With the increasing recognition of the internet as a repository for health advice, information, and support, the online support group has become a popular coping strategy for those living with chronic conditions like tinnitus. Patients find that communicating with each other, providing encouragement, and sharing information in the absence of physical and temporal boundaries, is an invaluable way of managing their condition. The purpose of this study was to explore the potential positive and negative consequences of participating in online support groups for tinnitus.

Method

Discussion forum threads were collated from across four public online support group websites. All threads were initiated between February and April 2016. Text from these threads were coded by three separate analysts using both inductive and deductive thematic analysis, until data saturation was reached.

Results

Analysis of 75 threads (641 individual posts) found nine independent themes pertaining to aspects of participation in tinnitus online support groups. The results revealed that using the forums allowed users to exchange knowledge and experiences, express complex emotions, profit from a network of support, and engage in every-day conversation away from the burden of their tinnitus. However, some experiences appeared to be compromised by negative messages, limited communication, and informational issues such as conflicting advice or information overload.

Conclusions

This study represents the first research into discussion forums in tinnitus online support groups. A non-intrusive (passive) analysis method was used, whereby messages comprising the data set

were retrieved without direct interaction with the discussion forum. Individuals and the community of tinnitus online support groups are deemed to be at low risk from potential harm in this study. Most tinnitus patients likely benefit from accessing online support groups, e.g. they discover they are not alone, they find new coping strategies. However, for those who are particularly vulnerable or prone to psychological stress accessing these groups could be detrimental.

Keywords: Tinnitus; support groups; social support; Internet; communication

Introduction

Tinnitus is the perception of sounds within the ears or the head in the absence of any external stimulus. These 'phantom' sounds vary in quality, can be fluctuating, constant or intermittent, and present in the ears bilaterally or unilaterally (Levine & Oron, 2015). Tinnitus may be the result of disturbances within the peripheral auditory system, including hearing loss and Ménière's disease (Selby, 2010). Other physical causes include tympanic membrane perforation, whiplash injury and exposure to prolonged and excessive noise. It is also thought to occur secondary to complications with certain types of ototoxic medications including non-steroidal anti-inflammatories and aminoglycosides (Meehan & Nogueria, 2014). Patients are increasingly predisposed to tinnitus with increasing age and with co-morbidities such as thyroid dysfunction and hypertension, and factors such as stress, fatigue and smoking are found to exacerbate its impact (Evans, 1981). As a largely subjective complaint, clinical presentation and tolerance varies from patient to patient. However, for many, quality of life is reduced (Henry, Dennis, & Schechter, 2005). Problems typically reported by patients include fear, emotional upset, difficulties sleeping, and difficulties concentrating (Watts et al. 2017). Indeed, Davis & El Refaie (2000), found that some 20% of those with tinnitus deem their condition detrimental enough to warrant medical counsel. In rare cases a causative pathology is identified and treated. In most cases tinnitus is idiopathic with no effective surgical or drug treatment, and so management involves addressing the emotional consequences and other comorbid problems (Department of Health, 2009, Tunkel et al., 2014). Typically, clinical guidelines recommend the provision of information and education, sound therapy, management of comorbid hearing loss, and the provision of counselling or psychological therapies (Fuller et al., 2017). As tinnitus is a chronic condition patient self-management is also advocated as the first stage in an effective treatment pathway.

Self-management reflects a patient's active involvement in the control of their condition, moving

away from their more passive 'professional delivered' health care models (Barlow, Wright,

Sheasby, Turner, & Hainsworth, 2002). A key feature of self-management is patients dealing with

the day-to-day consequences of their condition and maintaining an adequate quality of life;

patients are encouraged to take increased responsibility for their own health and participate in

'shared' decision making with clinicians (Trappenburg et al., 2013). Previous authors noted that

the limitations of traditional clinic approaches, including travel, time restrictions and expenses

(Malouff, Noble, Schutte, & Bhullar, 2010), may be avoided by patient self-management

interventions. Such interventions include the use of printed self-help books (bibliotherapy)

containing information about coping strategies, use of online self-help materials (Andersson,

Stroömgren, Ström, & Lyttkens, 2002, Beukes, Manchaiah, Allen, Baguley, & Andersson, 2015,

Greenwell, Featherstone, & Hoare, 2015), or participation in face-to-face or online peer support

groups where members can share practical and social support with others who understand life

with their illness (Goffman, 1963, Greenwell, Sereda, Coulson, El Refaie, & Hoare, 2016). It is

generally accepted that communicating with peers helps to establish cohesiveness, trust, and a

sense of community (Yopp & Rosenstein, 2013), leading to empowerment, a boosted morale, and

a higher quality of life (Skea, MacLennan, Entwistle, & N'Dow, 2011). For tinnitus, online self-

help programs have also been noted as relatively low-cost interventions which improve access to

psychological support (Greenwell et al., 2016) and overcome difficulties related to access

(Beukes et al., 2016).

Those who have certain chronic illnesses such as depression, anxiety, or stroke, have been

identified as significantly more likely to engage with online support (Owen et al., 2010). This in

part is due to the challenges of chronic circumstance; chronic disease is progressive, debilitating,

socially stigmatizing, and isolating (Mc Evoy, 2014). These characteristics, compounded by a

lack of access to, or willingness to access face-to-face interventions, result in sufferers seeking

other coping strategies. Consequently, many find solace in online support groups; which offer 24-

hour access, bear no geographical constraints (White & Dorman, 2001) and offer the potential for

emotional and informational support in a virtual and somewhat anonymous environment.

Moreover, studies affirm connecting with people facing similar issues (Coulson et al., 2016) and

the feeling *"I am not alone"* (Stommel, 2009, p21) contributes to the community aspect of online

groups, and is thus a positive effect of online communications.

Similar in philosophy and intervention techniques to face-to-face support groups (Finn, 1999),

online support groups are well established as a medium through which users share their

experiences and exchange relevant information (van Uden-Kraan et al., 2008, Mo & Coulson,

2014, Coulson et al., 2016). For example, within an online support group developed for 'problem

drinkers', Cunningham, van Mierlo, & Fournier (2008) found considerable demand for

information and advice. Similarly, in a study of women with metastatic breast cancer; Vilhauer

(2009) found that women expressed greatly benefiting from group participation, stating that this

had a powerful impact on their life. Malik & Coulson (2010) noted further consistencies in their

study conducted on online support groups for infertility; sharing information and advice in

addition to sharing personal experiences, friendship and empathy were all found to be beneficial.

Less often reported benefits include opportunities for creative expression, chit-chat, and gratitude

(Perron, 2002, Springer, Reck, Huber, & Horcher, 2011). Conversely, reports of negative and

damaging messages (Guo & Goh, 2014), inappropriate behavior, lack of replies (being

overlooked, or members not knowing how to help), or having members unwilling to share

personal information that was of interested to others (Attard & Coulson, 2012) have been

reported as negative aspects of online support group participation. In a study of women with

polycystic ovary syndrome Holbrey & Coulson (2013) also found that 'feeling like an outsider'

and reading about the negative experiences of other participants within the groups were aspects that disempowered some members.

Ethical considerations

The potential positive and negative consequences of participation in online support groups for people with tinnitus have yet to be studied but would be of value for many reasons. For example, it may help identify barriers to use in order to maximize user engagement with forums. It may also allow us to see whether online support groups are acceptable and of value to people with tinnitus, and for whom they are not. To do so however, key ethical questions common to online research first need to be considered. Firstly, are the data considered to be in the public domain or is informed consent required? And if data is considered public, how should the study and reporting be conducted to protect the data and ensure adequate confidentiality and anonymity? Some authors have argued that there is an indistinct definition of what is 'public' in an online environment, and formal online research guidelines such as those of the British Educational Research Association (2011) and Association of Internet Researchers (2002, 2012) are open to some level of interpretation. McKee (2013) discusses the ethical challenges of defining 'online privacy' when so many people routinely and freely share images and detailed information about themselves online, concluding the resolve between public and private can only really be defined by the subjects themselves *"..as they are the authors of their own words"*. It is necessary to consider whether individuals would be happy with their online posts to be used for research purposes (British Psychological Society, 2013), and where access to an online support group discussion is publicly available, do members perceive the content to be public? (Association of Internet Researchers, 2012). There are some dated reports in the literature to suggest not, and that research on online support group posts has been viewed as compromising or an intrusion by members (King, 1996, Sharf, 1999). A more recent study suggests this is still an issue. Moreno, Grant, Kacvinsky, Moreno, & Fleming (2012) asked 132 young adult Facebook users how they

7

would feel about their online profile being used for research purposes such as recruitment. Eighty-five percent of participants considered it acceptable or were indifferent, but 15% were uneasy (describing it as 'weird' or 'creepy') or overtly concerned about security and privacy.

Stevens, O'Donnell, & Williams (2015) also discuss the ethical issues and conflicting opinions faced in designing their study to examine, through social media, the role of learning in people's self-reported experience of chronic illness. They resolved to avoid use of "private, copyrighted" sources of online discussions and collected data exclusively from Facebook. As Facebook membership is available to anyone they judged posts and discussion threads to be firmly in the public domain and that *"arguably no users could legitimately expect to consider their participation in the discussions as "private"*. As such the authors considered their study did not require ethical approval, but in line with similar research approval from their institutional review board was sought. Ironically, their application for ethical approval was initially rejected, because of the panels' uncertainty whether informed consent from members was required, providing a stark example of the uncertainty in this field. A high profile example of this issue is the Facebook emotional contagion experiment, in which researchers manipulated Facebook's newsfeeds, e.g. by showing fewer positive posts, to test whether this would increase user expressions of sadness (Kramer et al., 2014). This study involved hundreds of thousands of uninformed Facebook users and led to fierce debate with some ethicists branding the study a "violation of the rights of research subjects" or proclaiming that "the way the study was conducted was unethical" (Selinger & Hartzog 2016).

In terms of reporting analyses of online materials and discourse there are further ethical issues to consider, not least of which is the use of direct quotes from online participants, with many recommendations calling for caution in doing so (Dawson, 2014). The main issue here is the potential traceability of lengthy verbatim (or even modified) quotes in search engines (Davey et al., 2012). This could constitute a breach of confidentiality. Even if members are actively seeking

publicity they may consider the quote their intellectual property. Williams, Burnap, & Sloan (2017) investigated Twitter users' concerns and expectations about their posts being included in research, consent, and anonymity in publishing. Interestingly, few concerns were raised but 80% of respondents expected to be asked for their consent ahead of their Twitter content being published, and over 90% stated they expected their content to be anonymised for publication.

In what appears something of a minefield Eisenbach & Till (2001) provide a useful summary of criteria against which online support group discussion posts might be considered public or private materials. To be considered public, they should (1) be taken from a forum where registration or subscription is not required to secure access, (2) have an abundant number of members, and (3) consist of a group whose individual and social norms suggest it is a public domain. If not meeting these criteria Eisenbach & Till (2001) consider the data private, and so requiring informed consent from members before it can be used for research purposes. How one determines whether an online community constitutes a public or private space continues to be debated (Roberts, 2015).

Purpose

The purpose of the current study was to explore and report, in a sensitive and ethically considerate manner, the potential positive and negative consequences of participation in tinnitus online discussion forums.

Method

Sample

Online support groups were identified by searching Google, Yahoo!, and Ask using the terms 'tinnitus', 'online', 'support group', 'forum' and 'discussion'. Eleven distinct groups were identified and assessed for inclusion. Exclusion criteria followed Lamerichs (2003), van Uden-

Kraan et al. (2008), and Attard & Coulson (2012), whereby groups that were not currently active (had received fewer than 50 posts per month) or were not publicly accessible, were immediately excluded. This left four online support groups suitable for inclusion. All four were relatively large, freely accessible, and did not require registration to access archived posts; this data set was therefore deemed to be within the public domain (Eysenbach & Till, 2001, Seale, Charteris-Black, MacFarlane, & McPherson, 2010) and so informed consent from members to analyze discussion threads was not considered necessary.

Data extraction

All discussion threads initiated during February-April 2016 were selected for extraction. Text from the threads were manually copied and pasted into Microsoft Word documents. Each thread was then assigned a number and a random number generator was used to randomly order threads from the different groups.

Analysis

The semantic content of messages in threads was analyzed using a thematic analysis approach that was both inductive (themes emerging from the data informed a coding manual) and deductive (these themes were organized according to pre-defined criteria - 'negative' or 'positive'). An initial random sample of five threads was selected to pilot the analysis procedure (piloting undertaken by EA, SS, and DH). Thereafter, threads were analyzed in groups of 10 threads until data saturation was reached. Analysis commenced with data familiarization, whereby each coder (EA, SS, DH) independently read and re-read posts to conceptualize the data. Next, elements of the data relevant to the study purpose were highlighted and corresponding initial codes were noted. All coding was conducted simultaneously and independently by at least two coders (EA and either SS or DH), who then met to review coding and agree a final set of codes for the data.

Codes then informed the creation of a preliminary coding manual (Joffe & Yardley, 2004). The manual reflected an exhaustive list of initial codes, with a description of the code and an example verbatim quote from the data. The coding manual was then used as a framework to code against further data in groups of 10 threads. New codes were added to the manual as they emerged. Data saturation was reached when no new codes were yielded from analysis of a new set of 10 threads, at which point no further threads were analyzed. All authors then reviewed codes and considered potential themes in an iterative process of grouping and re-grouping codes together. The initial themes were reviewed and discussed at length; they were examined to ensure all codes had been appropriately placed. This continued until a consensus was reached, when every code and theme was deemed appropriate, applicable, and true to the data. Finally, each theme was assessed against the research question and evaluated accordingly as a 'negative' or 'positive' facet. They were then defined; assigned a title, a concise description, and recorded with example codes. For the purposes of anonymity, verbatim quotes were removed at this point. To maximize confidentiality, text from threads selected for analysis was only seen by analysts (EA, SS, DH), and the names of the support groups, and members' actual names and pseudo-names were omitted from the report.

Results

Sample

The four online support groups selected for analysis were founded between 2001 and 2011. The number of registered members ranged from ~ 250-15,000 people, with the most popular group receiving close to 40,000 messages every year. One group was specifically reserved for users with tinnitus, whereas the other three offered discussion forums covering tinnitus and other conditions. All four groups had discussion forum moderators who answered questions and supervised content of message posts. Basic socio-demographic and relevant medical information

was available on three of the groups, albeit restricted to what members elected to share. It was, however, possible to conclude that all four groups comprised male and female members and had international memberships.

The primary dataset contained 1,012 conversation threads and 9,089 individual messages. The number of messages in single threads ranged from 1-81 messages. At the time when the threads were accessed and downloaded as the data set (October 2016) they had not received additional messages for at least one month, so it was likely they had ended.

Codes and themes emerging

Data saturation was reached at a point where the full text from 75 threads (a total of 641 messages) were analyzed, identifying 65 independent codes in total. Nine independent themes were identified from the data set (Table 1). Themes 1-6 reflect potential positive consequences, and themes 7-9 reflect potential negative consequences, of participation in online support groups.

INSERT TABLE 1 ABOUT HERE

Potential positive consequences of participation

Exchange of information and advice appeared to be a central function of the online support groups. The groups offered a wealth of information on tinnitus causes, medication options, and holistic management. Members often signposted links to published studies or other conversation threads. There was a definite demand for members to share information and advice with the group, and many of their specific questions and requests were answered.

Members appeared to appreciate *Sharing experiences and social comparison*. Many took the opportunity to narrate their story, directing readers through their tinnitus journey, and sharing

many of their everyday experiences relating to tinnitus management and medication. Generally, such posts were reciprocated by other members, often disclosing their story in response to a question. Members urged others to share their stories, as they expressly valued their contribution to the forum and wanted to know more about the people they were talking to online. Comparing their experiences to those of others and highlighting the similarities and differences of their struggles appeared to help some members to accept their condition, and find peace and reassurance that they were not alone.

For many individuals, the feeling of belonging to a *Network of support* was paramount to them reconciling and coping with their tinnitus. Those who felt alone in the real world, who had difficulty turning to family and friends, were able to connect to others who appreciated their situation, alleviating feelings of social isolation. This reciprocal understanding was manifest in messages where members empathized, reassured, and positively encouraged one another. The feeling of belonging, compounded by circumstantial similarities between members, allowed for friendships to develop. Members wished each other 'well', hoping they would 'feel better' and 'stay strong'. They acknowledged each other as 'friends', stating how they missed their presence and were delighted to speak again. They also initiated friendly conversation on subjects unrelated to tinnitus.

The most obvious grievance amongst users was that tinnitus is presently incurable. Users often used the group as an *Emotional outlet* and sounding board to express their innermost worries and desperations. For the most part, members did not feel obliged to reply to these messages, as venting was considered an effective form of self-therapy and was commonplace. However, during emotionally stressful periods where members toyed with destructive and suicidal thoughts, they appeared to benefit greatly from other members stepping in to provide a rational viewpoint. In

some cases, when words were not enough, and members struggled to articulate complex thoughts and feelings, they shared forms of poetry or prose.

Typically, reciprocal messages of *Gratitude* followed posts containing information, advice, and words of support provided by other members, affirming to others the benefit of participation. Members appeared to be overtly grateful for replies to their requests and specific questions. Many posts also evidenced appreciation to the groups themselves, with reference to it being a 'lifeline' in time of need, and allowing members to maintain a quality of life.

Elements of *Everyday conversation* featured highly across the groups. Certain threads were completely off-topic, such as pets or favorite musicians. Others that remained mainly 'on-topic' had elements of everyday conversation littered throughout. Everyday conversation was judged to be a positive consequence as these threads were widely engaged with, and received many messages, suggesting members valued being able to connect in this way.

Potential negative consequences of participation

Negative messages were occasionally exchanged between members. Some were sarcastic and damaging in nature, so much so that some members expressed feelings of distress. There appeared to be a certain element of intimidation, wherein particular members took it upon themselves to condescend and negate the input of others. This led to some members stating they were reticent to offer their advice and share experiences for fear of being judged.

The *Limitations of online communication* were judged to be problematic. Most posts focused on sharing information relating to the causes and treatment of tinnitus. However, for those who had been members for a long time, there was a dearth of new and relevant information. Members expressed frustration at seeing the same 'stale' information repeated and a current lack of interaction with their once popular group. Other observations likely to have negative

14

consequences included the time delay between messages being posted and answered, and messages being posted and not receiving any responses at all; this happened when messages were unnoticed or were perhaps too difficult to answer. Multi-faceted conversations also naturally digressed over time, resulting in several topics being addressed within one long and confusing thread.

Members also complained about *Informational issues*. The enthusiasm of members to provide an abundance of advice and information led to disagreement when conflicting information and opinions were given. Some threads also attracted a significant number of replies, resulting in a glut of information that appeared confusing and difficult to navigate. One of the biggest concerns with the anonymous nature of posts was that there was no way to validate the information provided. In some cases, opinions were branded 'facts' and incorrect information was mistaken as accurate. Some members drew attention to the reality that although helpful, the online support groups do not represent or replace medical advice, yet some messages began to supersede and discredit what at face value appeared to be legitimate medical knowledge. Consequently, members were unable to discern which information was indeed accurate.

Discussion

Support groups, including those online with discussion forums, are a common approach to self-management for those with chronic health conditions such as tinnitus. This study was the first to investigate the potential positive and negative consequences of participation in tinnitus online support groups. Nine independent themes were identified, all of which have been observed across the literature for other conditions and populations (Perron, 2002, van Uden-Kraan et al., 2008, Attard & Coulson, 2012).

Positive consequences of participation in online support

Exchanging knowledge in online discussion forums is well documented as a benefit (Huber et al., 2011, Mo & Coulson, 2014), so its observation here was to be expected. The provision of information encouraged discussions between members, especially debate about symptoms, causes and proposed treatments. Bartlett & Coulson (2011) found that conversations of this nature led to improved confidence in treatment and allowing members to feel more informed about their condition. Furthermore, Idriss, Kvedar, & Watson (2009) reported that the availability of good advice was a main advantage of group participation; in the current study members appeared to value such advice, especially from members considered as "peer experts" (Evans, Donelle, & Hume-Loveland, 2012). Some members hence voiced that they would consider or had already acted on advice received. 'Signposting' is yet to be acknowledged within the literature, yet in the current study many instances were observed where members shared links to articles, websites, and other forums.

Sharing experiences has been noted as beneficial in studies by Helgeson & Gottlieb (2000) and Coulson (2013), though the latter recognized it as a minor corollary of seeking others in a similar situation. Nonetheless, in the current study when people with tinnitus realized they were not alone it appeared to aid them in rationalizing their condition.

The online support group as a 'support' is one of the more commonly cited advantages of participation (Gleason, 1995, Sharf, 1997). Cutrona & Suhr (1992) developed the social support behavior code which has been exercised widely and successfully as a coding system in previous research (Coulson, Buchanan, & Aubeeluck, 2007, Perrone, Carmody, Philipson, & Greeley, 2015, Smedley, Coulson, Gavin, Rodham, & Watts, 2015). Of their proposed sub-categories, many were analogous to ideas coded for within our study's theme *Network of support*. Consistent with this, messages of sympathy, encouragement and empathy were commonplace.

The online support group as an emotional outlet was an unexpected finding as it has not been recognized as an independent theme in any previous study of online support groups. Considered in a small study sample, Haberstroh & Moyer (2012) hypothesized that emotional expression provides a healthy outlet for thoughts and feelings. This is based on Gilat, Tobin, & Shahar (2011), who found that suicidal patients sought to interact with online support groups to alleviate their emotional pain. Tinnitus members often posted such thoughts; worry and desperation were common. Being able to vent was an important mechanism for channeling frustrations about symptoms, psychosocial stressors, and the future, in a healthy way. The sub-theme *'Creative expression'* has been mentioned steadily in the literature as a positive aspect of online support group use (Perron, 2002, Han et al., 2008). Bolton (2008) suggested that creative writing may help patients reflect on experiences and find meaning in them, although individuals within our study appeared to use creative means mainly to convey abstract emotion they could not otherwise articulate.

The identification of *Gratitude* as a main theme in the current study was also unexpected as it has rarely featured in previous studies (Malik & Coulson, 2010), although widely acknowledged in a more general context to have therapeutic value (McCullough, Emmons, & Tsang, 2002, Chen, Chen, & Tsai, 2012). People with tinnitus expressed gratitude readily to those who had provided information and advice; it was particularly important for those who saw the group as a lifeline. A pioneering study by McCullough et al. (2002) hypothesized that grateful individuals have better self-esteem and are more likely to be healthy. Frederickson (2004) expanded on this idea, proposing that gratitude encourages reciprocal altruism and establishes lasting social bonds. Users with tinnitus who were thankful to others encouraged an environment of esteem, which encouraged more information to be shared.

Except for van-Uden Kraan et al. (2008) and Malik & Coulson (2010), authors have not commonly reported *everyday conversation* or 'chit-chat', therefore its prominence in the current

study was striking. In other online support group studies, posts and threads have almost exclusively concerned the condition, particularly demanding tangible assistance, information, and advice (Buchanan & Coulson, 2007). However, our study found that every-day conversations between members were commonplace, providing a *"normalizing experience"* (Finn, 1999, p228); the popularity of which suggests that chit-chat provides a welcomed distraction from the burden of tinnitus. Furthermore, what was coded as *'direct conversation'*, was a finding consistent with Guo & Goh (2014) who implied that members participate to connect with their online friends, and van Uden-Kraan et al. (2008), who rationalized that off-topic conversations build trust and concern for other members.

Negative consequences

The most common negatives found in the current study related to the exchange of *Negative messages* between individuals. Strongly evidenced in this theme was 'negative encouragement' and 'general negativity', posts which had sarcastic and damaging content. Our study found negative messages to be more apparent than previously accounted for (Perron, 2002, van Uden-Kraan et al., 2008); this may be in part due to the level of frustration at the lack of control of tinnitus. More explicitly, individuals in the current study expressed feeling negative emotions as an outcome of participation, including worry and fear of judgement. Fear was also observed by van Uden-Kraan et al. (2008). In the current study, some members were afraid that participating would negatively impact on themselves or others, an observation which Breuer & Barker (2015) considered a main barrier to participation.

Limited communication has been mentioned in research with other populations, although it is not frequently identified as a theme. Attard & Coulson (2012) provided the largest body of evidence, identifying analogies to the codes *'digression of thread'* and *'death of forum'* found in our study.

The matter of asynchronous online communication has been widely contested by previous authors. Whilst Coulson & Greenwood (2012) advised the benefits (users can reflect upon their interactions and allow adequate time to write measured responses), Attard & Coulson (2012) and the current study found a lack of replies to be a negative factor.

Informational issues are more frequently reported within research, so much so that Coulson and Knibb (2007) commented on the significant degree of cynicism toward online support groups for healthcare information among professionals. Our study emphasized that members post opinions and imprecise facts under the guise of legitimate medical information. Thus, there is always the danger that users may struggle to differentiate between potentially useful and potentially harmful advice (Hardey, 1999). Yet, people with tinnitus appeared likely to highlight non-medical material and encouraged other users to triangulate any given information. Loane (2014) commented that groups enable participants to develop a level of expertise in their condition, the likes of which may lead to negative encounters in a clinical setting when knowledge rivals that of healthcare providers. Coulson & Knibb (2007) formerly remarked that such empowered patients were often not 'well received' by professionals, especially when their information had come from online. This was particularly pertinent in the current study and reflects previous concerns regarding the understanding of tinnitus among some family doctors (Fackrell, Hoare, Smith, McCormack, & Hall, 2012).

Study Strengths and Limitations

Compared to other published studies, including those discussing the basis for online support in HIV/AIDS sufferers (Mo & Coulson, 2014) and those with depression and anxiety (Dean, 2013), the relative vulnerability of tinnitus sufferers can be regarded as low. Additionally, a non-intrusive "passive" analysis method was used (Eysenbach & Wyatt, 2002), whereby messages comprising the data set were retrieved without direct interaction with the support group or

discussion forum. With both factors considered, subjects as individuals and the community were deemed to be at low risk from potential harm in our study. To maximize confidentiality the threads selected for analysis were only seen by those directly involved in the study. Furthermore, anonymity was maintained as the names of the support groups were omitted; members' actual names and pseudo-names were also excluded from the study report. Adhering to the strict ethical standards acknowledged by Felzmann (2013), distinguishable personal and clinical information was equally removed. This does of course present a limitation insofar as it limits transparency and does not allow the reader to judge whether the interpretation provided is credible and adequately supported by the data (Yardley, 2007).

The involvement of three analysts reinforces the quality of the analytical process. This was demonstrated in the pilot coding phase, which proved beneficial in ensuring that all coding was of the same standard.

A number of limitations are noted. First, whilst thematic analysis allows the exploration of member experiences, this study did not actually *ask* members for their opinions. Thus, the potential positive and negative consequences interpreted from the data may differ to the actual views of the members. It would be interesting to conduct a prospective study, e.g. an online questionnaire, to explore users' views and experiences of online support groups, and test the credibility of the themes derived here. Furthermore, prior knowledge of the wider literature on forums may have influenced the eventual themes selected (El Hussain, Kennedy & Oliver, 2017). In planning the current study one author (EA) reviewed the wider literature on online forums and so was familiar with the themes therein. Although not truly naïve to the literature, second coders (SS, DH) were much less familiar with the themes arrived at in previous research and so were considered not subject to this potential influence.

The dataset may also represent a limitation. Although messages were taken randomly from across

four separate groups, opting to only study messages taken from a three-month window (from

February-April) may not be wholly transferable. Tinnitus symptoms may be seasonally affected

(Kim, 2016), so there may be bias associated with studying winter months compared to summer

months. Moreover, whilst the sample of 641 messages analyzed might be considered large and in

line with other studies, this only constituted a small fraction (7%) of the total available data set. In

any case, in this study transferability is limited as the descriptive data that would be required (e.g.

local context, sampling) is anonymous and these details are not available. Due to these factors,

and despite data saturation having been reached in a systematic fashion, other relevant themes

may exist.

Conclusions

Online support groups offer members a unique facility in which to share experiences, express

emotions, and to express empathy. They appear to be an undisputedly useful source of support;

people discover they are not alone, and potentially get exposed to new information and coping

strategies. Face-to-face tinnitus support groups already have an established basis in primary care

referral and are shown to have similar benefits to online support groups, so it is reasonable to

conclude that clinician referral to online support groups may prove an appropriate and practical

step in tinnitus management. Clinicians therefore have a responsibility to inform patients about

online support groups, and to discuss this form of support as part of shared decision making. That

discussion should be sufficient to inform patients of the nature of online peer-to-peer support, i.e.

information is shared somewhat haphazardly, and is typically based on personal experience. At

the same time information shared in online tinnitus support groups may be more practical and

tailored than that generally available online. For those patients who are particularly vulnerable

and prone to psychological stress clinicians should advise caution about participation, at the risk

of suffering further anxiety because of the negative themes identified. Future research can look to

confirm our findings by exploring participants' perspectives and experiences of online support

groups directly, via questionnaire or interview, or use a more quantitative approach such as

content analysis to examine the distribution of themes within support group discussions. It will

also be useful to investigate the specific information and types of support requested and

exchanged within tinnitus support group forums, and how this relates to engagement.

Acknowledgements

References

Andersson, G., Stroömgren, T., Ström, L. & Lyttkens, L. (2002). Randomized controlled trial of Internet-based cognitive behavior therapy for distress associated with tinnitus. *Psychosomatic Medicine*, *64,* 810-816.

Association of Internet Researchers. (2002). Ethical decision-making and internet research: Recommendations from the AoIR ethics working committee. Retrieved from http://aoir.org/ reports/ethics.pdf

Association of Internet Researchers. (2012). Ethical decision-making and internet research. Recommendations from the AoIR ethics working committee (Version 2.0). Retrieved from http://aoir.org/reports/ethics2.pdf

Attard, A. & Coulson, N. S. (2012). A thematic analysis of patient communication in Parkinson's disease online support group discussion forums. *Computers in Human Behavior, 28,* 500-506.

Barlow, J., Wright, C., Sheasby, J., Turner, A. & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling, 48,* 177-187.

Bartlett, Y. K. & Coulson, N. S. (2011). An investigation into the empowerment effects of using online support groups and how this affects health professional/patient communication. *Patient Education and Counseling, 83,* 113-119.

Beukes, E. W., Manchaiah, V., Allen, P. M., Baguley, D. M. & Andersson, G. (2015). Internet-based cognitive behavioural therapy for adults with tinnitus in the UK: study protocol for a randomised controlled trial. *BMJ Open,* 5.

Beukes, E. W., Vlaescu, G., Manchaiah, V., Baguley, D. M., Allen, P. M., Kalso, V. & Andersson, G. (2016). Development and technical functionality of an Internet-based intervention for tinnitus in the UK. *Internet Interventions, 6,* 6-15.

Bolton, G. (2008). "Writing is a way of saying things I can't say"—therapeutic creative writing: a qualitative study of its value to people with cancer cared for in cancer and palliative healthcare. *Medical humanities*, *34*, 40-46.

Breuer, L., & Barker, C. (2015). Online support groups for depression: benefits and barriers. *Sage Open, 5*, 2158244015574936.

British Educational Research Association. (2011). Ethical guidelines for educational research. London, UK: Author. Retrieved from http://content.yudu.com/Library/A2xnp5/Bera/resources/index.htm?referrerUrl=http://free.yudu.com/item/details/2023387/Bera

British Psychological Society. (2013). Ethics Guidelines for Internet-mediated Research. INF206/1.2013. Leicester: Author. Available from: www.bps.org.uk/publications/policy-andguidelines/research-guidelines-policydocuments/research-guidelines-poli

Buchanan, H., & Coulson, N. S. (2007). Accessing dental anxiety online support groups: An exploratory qualitative study of motives and experiences. *Patient Education and Counseling, 66*, 263-269.

Chen, L. H., Chen, M. Y., & Tsai, Y. M. (2012). Does gratitude always work? Ambivalence over emotional expression inhibits the beneficial effect of gratitude on well-being. *International Journal of Psychology, 47,* 381-392.

Coulson, N. S., & Knibb, R. C. (2007). Coping with food allergy: exploring the role of the online support group. *CyberPsychology & Behavior, 10,* 145-148.

Coulson, N. S., Buchanan, H., & Aubeeluck, A. (2007). Social support in cyberspace: a content analysis of communication within a Huntington's disease online support group. *Patient education and counseling, 68,* 173-178.

Coulson, N. S., & Greenwood, N. (2012). Families affected by childhood cancer: An analysis of the provision of social support within online support groups. *Child: care, health and development, 38,* 870-877.

Coulson, N. S. (2013). How do online patient support communities affect the experience of inflammatory bowel disease? An online survey. *JRSM short reports, 4,* 2042533313478004.

Coulson, N. S., Smedley, R., Bostock, S., Kyle, S. D., Gollancz, R., Luik, A. I., ... & Espie, C. A. (2016). The pros and cons of getting engaged in an online social community embedded within digital cognitive behavioral therapy for insomnia: survey among users. *Journal of medical Internet research, 18*.

Cunningham, J. A., van Mierlo, T., & Fournier, R. (2008). An online support group for problem drinkers: AlcoholHelpCenter. net. *Patient education and counseling, 70,* 193-198.

Cutrona, C. E., & Suhr, J. A. (1992). Controllability of stressful events and satisfaction with spouse support behaviors. *Communication Research, 19,* 154-174.

Davey, Z., Schifano, F., Corazza, O., Deluca, P., & Psychonaut Web Mapping Group. (2012). e-Psychonauts: conducting research in online drug forum communities. *Journal of Mental Health, 21,* 386-394.

Davis, A. & El Refaie, A. (2000). Epidemiology of tinnitus. *In:* TYLER, R. (ed.) *Tinnitus handbook.* San Diego: Singular.

Dawson, P. (2014). Our Anonymous Online Research Participants Are Not Always Anonymous: Is This a Problem? *British Journal of Educational Technology, 45,* 428-437.

Dean, J. (2013). *Online Support Groups for Depression and Anxiety: Outcome and Process.* Doctor of Philosophy, UCL (University College London).

Department of Health. (2009). *Provision of Services for Adults with Tinnitus: A Good Practice Guide.* London: Central Office of Information.

El Hussein, M. T., Kennedy, A., & Oliver, B. (2017). Grounded Theory and the Conundrum of Literature Review: Framework for Novice Researchers. *The Qualitative Report, 22,* 1198-1210.

Evans, E. F. (1981). Chairman's Introduction. *In:* Evered, D. & Lawrenson, G. (eds.) *Ciba Foundation Symposium 85 - Tinnitus.* London: Pitman Books Ltd.

Evans, M., Donelle, L., & Hume-Loveland, L. (2012). Social support and online postpartum depression discussion groups: A content analysis. *Patient education and counseling, 87,* 405-410.

Eysenbach, G. & Till, J. E. (2001). Ethical issues in qualitative research on internet communities. *BMJ, 323,* 1103.

Eysenbach, G. & Wyatt, J. C. (2002). Facilitating research via the internet. *In:* McKenzie, B. (ed.) *Internet and medicine.* Oxford, England: Oxford University Press.

Fackrell, K., Hoare, D. J., Smith, S., McCormack, A., & Hall, D. A. (2012). An evaluation of the content and quality of tinnitus information on websites preferred by General Practitioners. *BMC Medical Informatics and Decision Making, 12,* 70.

Felzmann, H. (2013). Ethical Issues in Internet Research: International Good Practice and Irish Research Ethics Documents. *In:* Fowley, C., English, C., Thouesny, S. (ed.) *Internet Research, Theory, and Practice: Perspectives from Ireland.* Dublin, Ireland: Research-publishing.net.

Finn, J. (1999). An exploration of helping processes in an online self-help group focusing on issues of disability. *Health and Social Work, 24,* 220-231.

Fredrickson, B. L. (2004). Gratitude, like other positive emotions, broadens and builds. *The psychology of gratitude*, *145*, 166.

Fuller, T. E., Haider, H. F., Kikidis, D., Lapira, A., Mazurek, B., Norena, A., ... & Brueggemann, P. G. (2017). Different teams, same conclusions? A systematic review of existing clinical guidelines for the assessment and treatment of tinnitus in adults. *Frontiers in psychology*, *8*.

Gilat, I., Tobin, Y., & Shahar, G. (2011). Offering support to suicidal individuals in an online support group. *Archives of Suicide Research*, *15*, 195-206.

Gleason, N. A. (1995). A new approach to disordered eating: Using an electronic bulletin board to confront social pressure on body image. *Journal of American College Health, 44,* 78-80.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity,* London, UK, Penguin.

Greenwell, K., Featherstone, D., & Hoare, D. J. (2015). The application of intervention coding methodology to describe the tinnitus e-programme, an internet-delivered self-help intervention for tinnitus. *American journal of audiology*, *24*, 311-315.

Greenwell, K., Sereda, M., Coulson, N., El Refaie, A., & Hoare, D. J. (2016). A systematic review of techniques and effects of self-help interventions for tinnitus: Application of taxonomies from health psychology. *International Journal of Audiology, 55*(sup3), S79-S89.

Guo, Y. & Goh, D. H.-L. (2014). "I Have AIDS": Content analysis of postings in HIV/AIDS support group on a Chinese microblog. *Computers in Human Behavior, 34,* 219-226.

Haberstroh, S., & Moyer, M. (2012). Exploring an online self-injury support group: Perspectives from group members. *The Journal for Specialists in Group Work*, *37*, 113-132.

Han, J. Y., Shaw, B. R., Hawkins, R. P., Pingree, S., McTavish, F., & Gustafson, D. H. (2008). Expressing positive emotions within online support groups by women with breast cancer. *Journal of Health Psychology, 13*, 1002-1007.

Hardey, M. (1999). Doctor in the house: the internet as a source of lay health knowledge and the challenge to expertise. *Sociology of Health & Illness, 21,* 820-835.

Helgeson, V. S. & Gottlieb, B. H. (2000). Support groups. *In:* Cohen, S., Underwood, L. G. & Gottlieb, B. H. (eds.) *Social support measurement and intervention.* Oxford: Oxford: University Press.

Henry, J. A., Dennis, K. C. & Schechter, M. A. (2005). General review of tinnitus: prevalence, mechanisms, effects, and management. *Journal of speech, language, and hearing research : JSLHR, 48,* 1204-35.

Holbrey, S. & Coulson, N. S. (2013). A qualitative investigation of the impact of peer to peer online support for women living with Polycystic Ovary Syndrome. *BMC Women's Health, 13,* 51.

Huber, J., Ihrig, A., Peters, T., Huber, C. G., Kessler, A., Hadaschik, B., ... & Hohenfellner, M. (2011). Decision-making in localized prostate cancer: lessons learned from an online support group. *BJU international, 107,* 1570-1575.

Idriss, S. Z., Kvedar, J. C., & Watson, A. J. (2009). The role of online support communities: benefits of expanded social networks to patients with psoriasis. *Archives of Dermatology, 145,* 46-51.

Joffe, H., & Yardley, L. (2004). Content and thematic analysis. *Research methods for clinical and health psychology*, *56*, 68.

Kim, Y. H. (2016). Seasonal affective disorder in patients with chronic tinnitus. *The Laryngoscope, 126***,** 447.

King, S. A. (1996). Researching Internet communities: Proposed ethical guidelines for the reporting of results. *The Information Society*, *12*, 119-128.

Kramer, A. D., Guillory, J. E., & Hancock, J. T. (2014). Experimental evidence of massive-scale emotional contagion through social networks. *Proceedings of the National Academy of Sciences, 111*, 8788-8790.

Lamerichs, J. (2003). Discourse of support: exploring online discussion on depression. Wageningen: Wageningen Universiteit.

Levine, R. A. & Oron, Y. (2015). Tinnitus. *Handbook of Clinical Neurology, 129***,** 409-431.

Loane, S. & D'Anessandro, S. (2014). Empowered and knowledgeable health consumers: The impact of online support groups on the doctor-patient relationship. *Australasian Marketing Journal, 22***,** 238-245.

Malik, S. H. & Coulson, N. S. (2010). Coping with infertility online: An examination of self-help mechanisms in an online infertility support group. *Patient Education and Counseling, 81***,** 315-318.

Malouff, J. M., Noble, W., Schutte, N. S., & Bhullar, N. (2010). The effectiveness of bibliotherapy in alleviating tinnitus-related distress. *Journal of Psychosomatic Research, 68*, 245-251.

McCullough, M. E., Emmons, R. A., & Tsang, J. A. (2002). The grateful disposition: a conceptual and empirical topography. *Journal of Personality and Social Psychology, 82,* 112.

McEvoy, P. (2014). *Chronic disease management: a new paradigm for care*. Radcliffe Publishing.

McKee, R. (2013). Ethical issues in using social media for health and health care research. *Health Policy*, *110*, 298-301.

Meehan, T. & Nogueira, C. (2014). Tinnitus. *The BMJ, 348,* 216.

Mo, P. K. H. & Coulson, N. S. (2014). Are online support groups always beneficial? A qualitative exploration of the empowering and disempowering processes of participation within HIV/AIDS-related online support groups. *International Journal of Nursing Studies, 51,* 983-993.

Moreno, M. A., Grant, A., Kacvinsky, L., Moreno, P. & Fleming, M. (2012). 'Older adolescents' views regarding participation in Facebook research'. *Journal of Adolescent Health, 51,* 439-444.

Owen, J. E., Boxley, L., Goldstein, M. S., Lee, J. H., Breen, N., & Rowland, J. H. (2010). Use of health-related online support groups: population data from the California health interview survey complementary and alternative medicine study. *Journal of Computer-Mediated Communication, 15,* 427-446.

Perron, B. (2002). Online support for caregivers of people with a mental illness. *Psychiatric Rehabilitation Journal, 26,* 70.

Perrone, M. E., Carmody, D., Philipson, L. H., & Greeley, S. A. W. (2015). An online monogenic diabetes discussion group: supporting families and fueling new research. *Translational Research, 166,* 425-431.

Roberts, L. D. (2015). Ethical issues in conducting qualitative research in online communities. *Qualitative Research in Psychology, 12,* 314-325.

Seale, C., Charteris-Black, J., MacFarlane, A., & McPherson, A. (2010). Interviews and internet forums: a comparison of two sources of qualitative data. *Qualitative Health Research, 20,* 595-606.

Selby, M. (2010). Ear Disorders. *In:* Roberts, A. (ed.) *The Complete Human Body The Definitive Visual Guide.* London, Great Britain: Dorling Kindersley Ltd.

Selinger, E., & Hartzog, W. (2016). Facebook's emotional contagion study and the ethical problem of co-opted identity in mediated environments where users lack control. *Research Ethics, 12,* 35-43.

Sharf, B. F. (1997). Communicating breast cancer on-line: Support and empowerment on the Internet. *Women & Health,* 26, 65-84.

Sharf, B. F. (1999). Beyond netiquette. The ethics of doing naturalistic discourse research on the internet. In: Jones S, ed. Doing internet research. London: Sage.

Skea, Z. C., MacLennan, S. J., Entwistle, V. A., & N'Dow, J. (2011). Enabling mutual helping? Examining variable needs for facilitated peer support. *Patient Education and Counseling, 85,* e120-e125.

Smedley, R., Coulson, N., Gavin, J., Rodham, K., & Watts, L. (2015). Online social support for complex regional pain syndrome: a content analysis of support exchanges within a newly launched discussion forum. *Computers in Human Behavior, 51,* 53-63.

Springer, A., Reck, C. A., Huber, C., & Horcher, E. (2011). Online hypospadias support group data analysis. *Journal of Pediatric Surgery, 46,* 520-524.

Stevens, G., O'Donnell, V. L., & Williams, L. (2015). Public domain or private data? developing an ethical approach to social media research in an inter-disciplinary project. *Educational Research and Evaluation*, *21*, 154-167.

Stommel, W. (2009). *Entering an online support group on eating disorders. A discourse analysis,* Amsterdam, Rodopi.

Trappenburg, J., Jonkman, N., Jaarsma, T., van Os-Medendorp, H., Kort, H., de Wit, N., ... & Schuurmans, M. (2013). Self-management: one size does not fit all. *Patient Education and Counseling, 92,* 134-137.

Tunkel, D. E., Bauer, C. A., Sun, G. H., Rosenfeld, R. M., Chandrasekhar, S. S., Cunningham Jr, E. R., ... & Henry, J. A. (2014). Clinical practice guideline: tinnitus. *Otolaryngology–Head and Neck Surgery*, *151*(2_suppl), S1-S40.

van Uden-Kraan, C. F., Drossaert, C. H. C., Taal, E., Lebrun, C. E. I., Drossaers-Bakker, K. W., Smit, W. M., ... & van de Laar, M. A. (2008). Coping with somatic illnesses in online support groups: do the feared disadvantages actually occur?. *Computers in Human Behavior, 24,* 309-324.

Vilhauer, R. (2009). Perceived Benefits of Online Support Groups for Women with Metastatic Breast Cancer. *Women & Health, 49*, 381-404.

Watts, E. J., Fackrell, K., Smith, S., Sheldrake, J., Haider, H., & Hoare, D. J. (2017). Why is Tinnitus a Problem? A Qualitative Analysis of Problems Reported by Tinnitus Patients. *Journal of Hearing Science*, *7, 2.

White, M. & Dorman, S. M. (2001). Receiving social support online: implications for health education. *Health Education Research, 16,* 693-707.

Williams, M. L., Burnap, P., & Sloan, L. (2017). Towards an Ethical Framework for Publishing Twitter Data in Social Research: Taking into Account Users' Views, Online Context and Algorithmic Estimation. *Sociology,* 0038038517708140.

Yardley, L. (2007) Demonstrating validity in qualitative psychology In, Smith, Jonathan A. (eds.) Qualitative Psychology: A Practical Guide to Research Methods. SAGE Ltd pp. 235-251.

Yopp, J. M. & Rosenstein, D. L. (2013). A support group for fathers whose partners died from cancer. *Clinical Journal of Oncology Nursing, 17,* 169.

Table 1: Potential expereinces of participation in tinnitus online support group discussion forums

Theme	Description of Theme (consequence)	Example Codes
Positive		
Exchange of information and advice	Users can readily share information e.g. links to relevant articles and events, and can give/receive advice.	Endorsing a treatment Acknowledging advice Product endorsement
Sharing experiences and social comparison	Users have a platform to share stories about their tinnitus, healthcare, and coping strategies and compare their experiences of tinnitus with those of others.	Describing how they cope 'here and now' Comparing own tinnitus with other
Network of support	Users acknowledge the group as a community, offering words of encouragement, sympathy, and reassurance to one another.	Well wishing Expression of sympathy Expression of empathy Seeking reassurance
Emotional outlet	Users have a platform to freely express complex and abstract thoughts, feelings, and emotions.	Use of metaphor to self-express Venting Expressing worries
Gratitude	Users post positive messages expressing gratitude and affirming the group has helped them. Users benefit from the knowledge they have helped others.	Forum appreciation Thanking other members Affirming benefit to others
Everyday conversation	Users engage in and enjoy everyday conversations that are not related to tinnitus.	Off-topic conversation Direct conversation
Negative		
Negative messages	Users may be exposed to, or the subject of, messages that are negative, damaging, or sarcastic, being offended or hurt by other members.	Experience general negativity Message engenders worry Negative encouragement
Limitations of online communication	Users may experience difficulties or frustrations because of the limitations of communicating within the OSG.	Digression of thread Lack of replies to a question
Informational issues	Users may be exposed to conflicting or medically incorrect information.	Conflicting advice Information overload

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60