Research Article

Findings and Ethical Considerations From a Thematic Analysis of Threads Within Tinnitus Online Support Groups

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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 such as tinnitus. Patients find that communicating with each other, providing encouragement, and sharing information in the absence of physical and temporal boundaries are invaluable ways 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 4 public online support group websites. All threads were initiated between February and April 2016. Texts from these threads were coded by 3 separate analysts using both inductive and deductive thematic analysis, until data saturation was reached.

Results: Analysis of 75 threads (641 individual posts) found 9 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 everyday 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 1st research into discussion forums in tinnitus online support groups. A nonintrusive (passive) analysis method was used, whereby messages comprising the dataset 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, for example, they discover they are not alone, and they find new coping strategies. However, for those who are particularly vulnerable or prone to psychological stress, accessing these groups could be detrimental.

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 nonsteroidal anti-inflammatories and aminoglycosides (Meehan & Nogueira, 2014). Patients are increasingly predisposed to tinnitus with increasing age and with comorbidities such as thyroid dysfunction and hypertension, and factors such as stress, fatigue, and smoking are found to exacerbate its impact (E. F. Evans, 1981). As a largely subjective complaint, clinical presentation and tolerance vary from patient to patient. However, for many, quality of life is reduced (Henry, Dennis, & Schechter, 2005). Problems typically reported by patients include fear, emotional

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upset, difficulties in sleeping, and difficulties in concentrating (Watts et al., 2017). Indeed, Davis and 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 counseling 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, Strömgren, 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 that 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 (McEvoy, 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-hr 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 that connecting with people facing similar issues (Coulson et al., 2016) and the feeling "I am not alone" (Stommel, 2009, p. 21) contribute 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 (Coulson et al., 2016; Mo & Coulson, 2014; van Uden-Kraan et al., 2008). For example, within an online support group developed for "problem drinkers," Cunningham, van Mierlo, and 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 and 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, chitchat, 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 interest 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 and 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. First, are the data considered to be in the public domain or is informed consent required? In addition, if data are 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 that 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 being used for research purposes (British Psychological Society, 2017). Also, 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, and Fleming (2012) asked 132 young adult Facebook users how they 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, and 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 thus, “arguably no users could legitimately expect to consider their participation in the discussions as ‘private’” (p. 161). As such, the authors considered that 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 panel's 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, for example, by showing fewer positive posts, to test whether this would increase user expressions of sadness (Kramer, Guillory, & Hancock, 2014). This study involved hundreds of thousands of uninformed Facebook users and led to fierce debates 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, p. 36).

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, Schifano, Corazza, Deluca, & Psychonaut Web Mapping Group, 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, and 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 anonymized for publication.

In what appears something of a minefield, Eysenbach and 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 (a) be taken from a forum where registration or subscription is not required to secure access, (b) have an abundant number of members, and (c) consist of a group whose individual and social norms suggest it is a public domain. If not meeting these criteria, Eysenbach and 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 and 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 dataset 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. Texts 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 predefined 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 reread 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 to 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 an 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 regrouping 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 and 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 pseudonyms 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 to 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 sociodemographic 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 one to 81 messages. At the time when the threads were accessed and downloaded as the dataset (October 2016), they had not received additional messages for at least 1 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 dataset (see Table 1). Themes 1–6 reflect potential positive consequences, and Themes 7–9 reflect potential negative consequences, both from participation in online support groups.

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 manifested in messages where members empathized, reassured, and positively encouraged one another. The feeling of belonging, compounded by

Table 1. Potential experiences 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, for example, 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, health care, and coping strategies and compare their experiences of tinnitus with those of others.	Describing how they cope “here and now” Comparing own tinnitus with others
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
Gratitude	Users post positive messages expressing gratitude and affirming that the group has helped them. Users benefit from the knowledge they have helped others.	Expressing worries 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 online support group.	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

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 among 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” were 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 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. Multifaceted 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 (Attard & Coulson, 2012; Perron, 2002; van Uden-Kraan et al., 2008).

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 and 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, and 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” (M. 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 and 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 and 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 subcategories, 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 and Moyer (2012) hypothesized that emotional expression provides a healthy outlet for thoughts and feelings. This is based on Gilat, Tobin, and 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 subtheme “creative expression” has been mentioned steadily in the literature as a positive aspect of online support group use (Han et al., 2008; Perron, 2002). 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 (Chen, Chen, & Tsai, 2012; McCullough, Emmons, & Tsang, 2002). 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. Fredrickson (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 and Coulson (2010), authors have not commonly reported everyday conversation or “chitchat”; 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 everyday conversations between members were commonplace, providing a “normalizing experience” (Finn, 1999, p. 228), the popularity of which suggests that chitchat provides a welcomed distraction from the burden of tinnitus. Furthermore, what was coded as “direct conversation” was a finding consistent with Guo and 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 that 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 judgment. Fear was also observed by van Uden-Kraan et al. (2008). In the current study, some members were afraid that participating would negatively impact themselves or others, an observation that Breuer and 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 and 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. Whereas Coulson and Greenwood (2012) advised the benefits (users can reflect upon their interactions and allow adequate time to write measured responses), Attard and 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 health care 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 harmful advice (Hardey, 1999). Yet, people with tinnitus appeared likely to highlight nonmedical material and encouraged other users to triangulate any given information.

Loane and D’Anessandro (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 health care providers. Coulson and 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 with 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 nonintrusive, “passive” analysis method was used (Eysenbach & Wyatt, 2002), whereby messages comprising the dataset 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 pseudonyms 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, although 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, for example, 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 Hussein, 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 naive to the literature, second coders (SS, DH) were much less familiar with the themes they 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 3-month window (from February to 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 with summer months. Moreover, although 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 dataset. 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.

Conclusion

Online support groups offer members a unique facility in which to share experiences and express emotions and 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, that is, 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.

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