

Managing a Chronic Illness: An Exploratory Cross-sectional Study on the Association Between Contributing to an Online Self-help Platform and the Self-management, Illness Perception, and Chronic Care Assessment of Users Suffering From Chronic Tinnitus

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Abstract

Background. Chronic tinnitus is a bothersome condition that comes with a broad spectrum of symptoms and consequences to manage. Unfortunately, a lack of proper exhaustive research inhibits the development of sufficient treatment options and thus, patients often do not have access to the necessary resources. Oftentimes, patients then fall back on (online) self-help groups to get informational, social, and emotional support. Self-help platforms are beneficial for patients on various dimensions, by providing support, giving access to information, and offering a space to discuss.

Objective. This study aimed to discover to what extent the contribution to the tinnitus-specific self-help platform tinnitus talk is associated with three aspects important for dealing with a chronic illness: self-management, illness perception, and chronic care assessment. Specifically, it was assessed how different degrees of post contribution (current, previous, and no contribution) are associated with the three outcome variables. Three hypotheses were proposed. (1) Those who actively contribute to tinnitus talk have better self-management abilities. (2) Those who actively contribute to tinnitus talk have a less severe illness perception. (3) Those who actively contribute to tinnitus talk perceive chronic illness care to be insufficient.

Method. This was investigated by means of a cross-sectional study, sampling participants from tinnitus talk. The participants filled out a survey via Qualtrics consisting of demographic questions and pre-established questionnaires frequently used in psychology.

Results. Data analysis showed insignificant effects of post contribution for all three outcome variables. Hence, all three hypotheses were rejected.

Conclusion. This indicates that tinnitus talk is equally effective for active users versus previously active or inactive ones. It can be suggested that other mechanisms are more impactful in terms of how online self-help platforms work to benefit their users. This remains a subject of investigation for future research.

Keywords: chronic tinnitus, self-help platforms, self-management, illness perception, chronic illness care

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A commonly known but only scarcely researched condition is tinnitus (McFerran et al., 2019). Tinnitus can be defined as the “conscious perception of an auditory sensation in the absence of a corresponding stimulus” (Baguley et al., 2013, p. 1600). De Ridder and colleagues (2021) took it one step further with the proposal of two separate definitions, one for tinnitus and another for tinnitus disorder. Although the definition of the former resembles the one previously mentioned, the latter refers to the instances when tinnitus becomes “associated with emotional distress, cognitive dysfunction, and/or autonomic arousal, leading to behavioural changes and functional disability” (De Ridder et al., 2021, p.1). While it should be noted that the term ‘disorder’ might be questionable due to possible associated stigmas, the suggested definition does point out the psychological suffering that comes with the condition.

Tinnitus comes with a diverse spectrum of symptoms and characteristics. The most common auditory symptoms include the perception of hissing or ringing (Baguley et al., 2013). In more complex cases the affected can also perceive sounds that vaguely resemble voices or music. However, these sounds have to be distinguished from the clear and in some way meaningful auditory hallucinations that come with psychotic illnesses. An accompanying symptom of tinnitus can also be hyperacusis – a decreased sound tolerance. Additionally, the perceived severity can vary and is often influenced by other aspects such as stress or emotions. Furthermore, tinnitus can be localised differently, meaning that the sounds can be perceived as coming more from centrally within the head, unilaterally, or it can be perceived as originating from outside the head. Moreover, tinnitus can be classified as acute or chronic. It can be considered chronic when it persists for over three months (Trevis et al., 2018; Boecking et al., 2021). Another distinction can be made between subjective and objective tinnitus. While in subjective tinnitus only the patients themselves can hear the sounds, in some rare cases, the sounds can be heard by a third party as well because they are produced by the (muscle) structures of the ear and/or surrounding areas (Baguley et al., 2013; Salehi et al., 2019). In that case, it is objective tinnitus. A third distinction can be made between bothersome and non-bothersome tinnitus; some people are more severely affected by the condition than others (Esmaili & Renton, 2018). Out of all these classifications, clinically, chronic, subjective, and bothersome tinnitus is the most relevant, as there is, to this date, no universal cure and people suffering from this type of tinnitus require the most specific care (Esmaili & Renton, 2018).

Overall, prevalence rates for tinnitus range from 11.9% to 30.3% (McCormack et al., 2016, as cited by De Ridder et al., 2021). More specifically, the prevalence rates increase with age: 10% of young adults, 14% of middle-aged adults, and 24% of older adults (Jarach et al., 2022). Also, there appears to be no significant difference in prevalence between men and women (Baguley et al., 2013). Jarach and colleagues (2022) also reported an annual global incidence of approximately 1%, with 2% of adults being severely affected by it.

As tinnitus is a highly heterogeneous condition, numerous treatment options have been applied thus far to help patients cope (Baguley et al., 2013; Nagaraj & Prabhu, 2020; De Ridder et al., 2021). However, despite these options, not every patient can benefit from them. Unfortunately, the heterogeneity of the condition (i.e., the broad spectrum of symptoms and classifications) and major gaps in evidence-based practice complicate the diagnosis and subsequent treatment of tinnitus (Baguley et al., 2013; De Ridder et al., 2021; Jarach et al., 2022). Especially difficult is the development of treatment and care programs that are personalised. Additionally, important resources for effective treatment appear to be lacking, which “justifies a major investment in research in this area” (Jarach et al., 2022, p.889). Previous research has shown that the (healthcare) system fails to provide adequate resources and means to support them. In those cases, patients suffering from all kinds of chronic diseases often try to find help elsewhere, for example in the form of self-help groups and platforms (van Uden-Kraan et al., 2008a). Often established by people who suffer from tinnitus themselves, these can provide a means for emotional support, sharing of experiences, and a sense of belonging and being heard (Désfalvi, 2022). Subsequently, this facilitates education, coping, and mental well-being.

One non-profit initiative attempting to provide this is tinnitus hub (Tinnitus Hub, n.d.). The platform, established by people with tinnitus, aims to spread awareness, educate, connect affected individuals with research, and give them a voice. For instance, they actively supported and contributed to research on the process of and tools for diagnosing somatosensory tinnitus, conducting data collection by publishing surveys on tinnitus talk (Michiels et al., 2022a; Michiels et al., 2022b). Tinnitus talk is a self-help forum launched by tinnitus hub (Tinnitus Talk, n.d.). It provides a space for individuals with tinnitus to receive support from other affected people as well as to share experiences with a high probability of being understood. For example, Hall and colleagues (2021) used web-based discussions led via tinnitus talk which highlighted the importance of such platforms for gaining insights into tinnitus and treatments from the patients’ perspectives.

The Present Study

Despite the importance of self-help groups for people affected by (chronic) illnesses, there still is a lack of research about the ways through which these groups establish support (Nickel et al., 2019). Of particular interest for this research was therefore how tinnitus talk, as a self-help forum, works to establish the needed support for users – suffering from tinnitus – on three dimensions.

First, what is of special importance when dealing with a chronic condition is the ability to self-manage it (Udlis, 2011). Increased levels of self-management result not only in better clinical outcomes but also in reduced healthcare expenditures and improved quality of life. As tinnitus talk already embodies an attempt to self-manage, it could enhance users' ability to cope with their condition too. In addition, Nickel and colleagues (2019) discovered that benefits of self-help groups, as reported by participants suffering from – among other conditions – tinnitus, include learning about various ways to individually manage and deal with one's condition as well as being better able to cope. For both of these aspects agreement rates for tinnitus patients were above 80%. Therefore, it could be assumed that by participating in the group and thereby learning how to actively self-manage one's illness-related behaviour and subsequently applying these novel skills, self-management abilities are improved.

Second, an important (cognitive) basis for self-management and coping abilities is an accurate illness perception (Bonsaksen et al., 2013). Simultaneously, illness perceptions can impact self-management and coping. Hence, the two appear to be closely connected. Moreover, if accurate, the perceptions have been shown to enhance the quality of life, perceived health, self-management, or health-promoting behaviours, to name a few (Bonsaksen et al., 2013). This could also indicate that better self-management abilities often go hand in hand with a less severe illness perception, and vice versa. Related to self-help groups, it has been shown that participating in self-help groups provides support by facilitating a better understanding and knowledge of one's disease (Adamsen, 2002; Nickel et al., 2019). This might suggest that participating also facilitates a more accurate and positive illness perception.

Third, as mentioned before, in the case of chronic illnesses it seems that there is a lack of sufficient support on the part of the healthcare system and providers which is why patients fall back on self-organising this support. This is supported by Wagner and colleagues (2005), who also emphasise how improved health outcomes are, in part, dependent on the provision of effective treatment and care which should ideally be evidence-based and patient-centred. Considering this, it can be assumed that people who are looking for information and support via self-help platforms experience a lack of support from their healthcare professionals.

Therefore, it was explored how active contribution to tinnitus talk is associated with self-management, illness perception, and users' take on care provision. More specifically, this was done by comparing outcomes on different questionnaires – measuring mentioned aspects – of participants suffering from chronic tinnitus categorised into three groups. These three groups were: 1) those who have never contributed to tinnitus talk (with posts), 2) those who previously contributed but do not do so anymore, and 3) those who currently do contribute. Subsequently, insights gained through this might help to discover if that aspect of patient-organised self-help initiatives works well, and what could be improved so that eventually, these initiatives can provide the best possible support and care to those in need. Lastly, as previously mentioned, an important dichotomy that characterises tinnitus is that of acute versus chronic. For this research, the focus was narrowed down to those who suffer from chronic tinnitus because individuals with chronic tinnitus require more long-term and specific care and therapies (Esmaili & Renton, 2018). Hence, the related research question is: *To what extent is the contribution to the self-help platform tinnitus talk associated with self-management abilities, as well as illness perception and chronic care assessment of users with chronic tinnitus?*

This research question was investigated employing a cross-sectional study. Based on the findings suggesting that self-help platforms improve users' overall well-being, three hypotheses were developed. First, it was hypothesised that those who actively contribute to tinnitus talk (by posting) have better self-management abilities, meaning they score higher on self-management outcomes. The second hypothesis assumed that those who actively contribute to tinnitus talk have a less severe illness perception, which would be indicated by low scores on illness perception results. Lastly, it was hypothesised that those who contribute to tinnitus talk perceive chronic illness care to be rather insufficient, as indicated by low scores for chronic care assessment.

Methods

Study Design

The study was conducted with an exploratory cross-sectional approach. It consisted of a survey, with a total of 146 questions, that was designed and delivered via Qualtrics. The link for that Qualtrics survey was posted on tinnitus talk. Hence, participants were collected via convenience sampling. The survey itself was constituted of several parts, each part being dedicated to pre-established questionnaires frequently used in health and clinical psychology (see Appendix A). Informed consent, explaining the purpose, as well as the risks and benefits of participation and the participants' rights, was obtained via Qualtrics. Once posted, the study link was accessible for two weeks, from May 8 to May 22, 2023. Generally, all those who suffer

from tinnitus and visit the tinnitus talk platform were eligible for the study. However, as the research question focused on those who suffer from chronic tinnitus, only those who fit that category, which was assessed through a specific survey questionnaire item (illness duration > 3 months), were included in the data analysis. To collect a relatively representative sample it was aimed for at least 100 participants. All data were collected via the Qualtrics survey responses function and subsequently stored in the University of Twente's cloud service. Lastly, to facilitate a fairly structured and replicable approach to this paper, the STROBE guidelines (see Appendix B) for cross-sectional studies were used (STROBE, 2023).

Measurement Instruments

The survey consisted of six different questionnaires, five of which were of relevance to this study. The first questionnaire consisted of demographic questions about age, gender, country of origin, as well as education and employment status. Additionally, the Tinnitus Sample Case History Questionnaire (TSCHQ) was administered to assess the participants' history of and journey with tinnitus (Langguth et al., 2007). Secondly, questions about the participants' activity on tinnitus talk were asked to check for participation and active contribution on the platform. Next, the Brief Illness Perception Questionnaire (Brief IPQ) was used to measure illness perception (Broadbent et al., 2005). Following, the Patient Assessment of Chronic Illness Care (PACIC) was administered to assess patients' perspectives on patient-centred chronic illness care management (Schmittdiel et al., 2007). Lastly, the revised Partners in Health (PIH) scale was used to assess self-management abilities (Smith et al., 2017). The sixth questionnaire, irrelevant to this study, was the Empowerment Processes (EP) and Empowerment Outcomes (EO). Some of the questionnaires have been slightly adapted to better suit the research and to be in accordance with the feedback and ideas of the tinnitus hub collaborators. Lastly, some questions have been adapted or removed (due to irrelevancy or inapplicability) to reduce the burden on participants and increase understandability. These changes are discussed in detail below.

TSCHQ

The TSCHQ, as previously mentioned, was used to get an overview of the users' journey with tinnitus, including possible family history of tinnitus, the onset of illness, and how they experience different characteristics and symptoms of the condition. In its original form, the questionnaire consists of 35 items. For this research's purpose, four items have been excluded. As they did not provide valuable information for the study, items 13 ("Please describe in your own words what your tinnitus usually sounds like:") and 25 ("Does medication have an effect on your tinnitus?") were excluded. Moreover, to avoid overlap with items from other

questionnaires, items 16 ("What per cent of your total awake time, over the last month, have you been aware of your tinnitus?") and 17 ("What per cent of your total awake time, over the last month, have you been annoyed, distressed, or irritated of your tinnitus?") were cut.

In place of the removed items, four new items were added by the researchers. Three of these items were added to provide a better demographical picture. These items included the questions "In which country do you currently reside?", "Which statement best describes your current employment status?", and "What is the highest education level you have achieved?". Last but not least, the question "Do you currently receive any form of treatment for your tinnitus?" was included to investigate the patients' experience, or the lack thereof, with treatment(s).

Furthermore, of specific importance was the question "For how long do you live with tinnitus?". This question served to filter out which of the participants suffer from chronic tinnitus, meaning they have lived with the condition for at least three months.

Activity on Tinnitus Talk

Five questions were administered to assess the participants' activity on the self-help forum tinnitus talk. If the first question ("Are you currently using or have you used Tinnitus Talk?") was answered with "No", the follow-up questions were skipped. The follow-up questions were "How long have you been participating on Tinnitus Talk?", "How often do you visit Tinnitus Talk?", "Have you ever posted on Tinnitus Talk?", and "How often (on average) do you contribute to Tinnitus Talk with posts?". The activity questions were important to include as they assess the participants' degree of contribution to the platform.

Brief IPQ

The Brief IPQ was included to measure the participants' perception of tinnitus regarding cognitive and emotional illness perceptions, as well as illness comprehension. The questionnaire consists of nine items with an answer scale from zero to ten. Item nine ("Please list in rank-order the three most important factors that you believed caused your illness. The most important causes for me:") was removed as it was perceived to be too confusing and without added value. Moreover, as the Brief IPQ is an illness un-specific questionnaire, the questions were rephrased to specifically mention tinnitus. Generally, the Brief IPQ has good test-retest reliability and discriminant validity (Broadbent et al., 2005). For this sample, the questionnaire showed moderate reliability with Cronbach's alpha of .66.

PACIC

The PACIC is a 20-item scale that was included to measure patients' assessment of patient-centred and proactive care for chronically ill people. The 20 items were answered on a

Likert scale ranging from 1 ("Almost never") to 5 ("Almost always"). Moreover, the items are distributed over 5 subscales assessing patient activation, delivery system design/decision support, goal setting, problem-solving/contextual counselling, and follow-up/coordination (Glasgow et al., 2005). The subscales have good internal consistency. Overall, the PACIC has moderate test-retest reliability and provides "face, construct, and concurrent validity" (Glasgow et al., 2005, p. 436). For this sample specifically, the questionnaire had good reliability with $\alpha = .89$.

Furthermore, as the questionnaire focuses on healthcare encounters over the last six months, the filter question "Did you visit any healthcare provider (e.g., GP, ear-nose-throat doctor, neurologist, psychiatrist, audiologist, dentist, etc.) specifically for your tinnitus?" with four answer possibilities was added. The answer possibilities were "Yes, In the last 6 months", "Yes, Between 6 and 12 months", "Yes, Over 12 months ago", and "No, Never visited a healthcare provider". The second and third answer possibility specifically were added to enable a higher response rate, as with chronic conditions has often been a long time since a patient has last visited a healthcare provider. In case the participant replied with the "No, Never (...)" option the questionnaire was skipped.

PIH Scale

The revised version of the PIH scale consists of 12 items aimed at evaluating the ability to self-manage their chronic condition and accompanying aspects such as symptoms, treatments, and the effects on the person's emotional and social well-being. The items were answered on a scale of 0 ("Very little", "Never", or "Not very well") to 8 ("A lot", "Always", or "Very well"), with the numbers indicating different answer categories depending on the question at hand. The questionnaire has convergent and discriminant validity (Smith et al., 2017). For this sample, the scale showed good reliability with $\alpha = .8$.

Procedure

Firstly, before creating and conducting the survey, ethical approval was requested by the researchers and granted by the Ethics committee of the University of Twente (230236). The survey was then established in close collaboration with representatives of tinnitus hub to ensure active patient and public involvement in the process. After collecting an array of psychological and clinical questionnaires suitable for the research, the survey was created via Qualtrics. The link to the survey was posted on tinnitus talk. Upon opening the link, participants were asked to give informed consent by replying "Yes". This was required to continue in the survey. After giving consent, the participants filled in the questionnaires in the following order: TSCHQ, activity on tinnitus talk, Brief IPQ, PACIC, PIH scale, EP and EO.

Data Analysis

Data cleaning and analysis were done using R and RStudio (Version RStudio 2023.03.1+446), a software for statistical computation. This research focused on a between-subjects comparison, essentially comparing the scores of three different independent variables of three groups. The dependent variable, according to which the participants were distributed into groups, was *post contribution*, which was considered a three-factor variable with the factors Yes (2), Yes, but not anymore (1), and No, Never (0).

For the analysis of the demographic data, a table was created. Categorical variables were described with the number of participants per group and per variable category and the respective percentage. Numeric variables were described by the mean per group and the respective standard deviation.

For the analysis of the effects, the three independent variables were derived from the questionnaires in focus. The first independent variable was *self-management*, based on the PIH scale. In RStudio, the variable was coded as a numerical variable ranging from 0 to 8. For this scale, scores were concluded by calculating the total sum score as well as subscale scores for the four respective subscales. Higher scores signalled higher levels of self-management.

The second independent variable was *illness perception*, referring to the Brief IPQ. The variable was coded as numeric, ranging from 0 to 10. Items 3, 4, and 7 were coded reversely as instructed for the scoring (Machado et al., 2019). Scores of the Brief IPQ were computed by calculating the total sum, with higher scores indicating a more severe and threatening illness perception.

The third independent variable was *chronic care assessment*, which refers to the PACIC. In the analysis, the output was transformed into a numerical variable ranging from 1 to 5. For this questionnaire, scores were calculated by taking the average of all 20 items. Likewise, the five subscales scores were calculated by taking the average of the items within the respective scale. Higher scores reflected that the participants assessed chronic care provision as better.

Statistical Methods

The main specific statistical method applied to this data was a fitted linear model analysis. This was completed to check for main effects and correlations of post contribution on self-management abilities, illness perception, and chronic care assessment, according to the pre-established hypotheses. The “report” package in RStudio was used to retrieve important indicators of statistically significant outcomes (Makowski et al., 2020). Additionally, boxplots were integrated to visualise the results.

Results

Participants

In total, 96 participants responded to the survey. Six participants were excluded from the analysis due to missing values, making the final sample size $N = 90$. The three most mentioned countries of residence were the USA ($N = 27$), the UK ($N = 9$), and Sweden ($N = 8$). Information on other important demographic data can be found in Table 1.

Table 1.

Sociodemographic Characteristics of Participants According to Post Contribution

Characteristic	Never Posted, $N = 22$	Previously Posted, $N = 23$	Post Frequently, $N = 45$	Full sample, $N = 90$
Age (SD)	34.5 (10.7)	43.1 (13.4)	40.7 (11.5) ¹	40.1 (12.7) ²
Gender (%)				
Male	17 (77)	18 (78)	36 (80)	71 (78.9)
Female	4 (18)	4 (17)	8 (18)	16 (17.8)
Non-binary	1 (4.5)	1 (4.3)	1 (2.2)	3 (3.3)
Highest education level (%)				
Lower secondary (middle school)	0 (0)	0 (0)	2 (4.4)	2 (2.2)
Upper secondary (high school)	2 (9.1)	6 (26)	13 (29)	21 (23.3)
University (higher degree)	20 (91)	16 (70)	30 (67)	66 (73.3)
Other	0 (0)	1 (4.3)	0 (0)	1 (1.1)
Employment (%)				
Working (paid employee)	14 (64)	15 (65)	20 (44)	49 (54.4)
Working (self- employed)	3 (14)	2 (8.7)	5 (11)	10 (11.1)
Not working (temporary layoff from a job)	0 (0)	0 (0)	1 (2.2)	1 (1.1)

Not working (looking for work)	1 (4.5)	1 (4.3)	3 (6.7)	5 (5.6)
Not working (retired)	1 (4.5)	1 (4.3)	4 (8.9)	6 (6.7)
Not working (disabled)	2 (9.1)	3 (13)	5 (11)	10 (11.1)
Not working (other)	1 (4.5)	1 (4.3)	4 (8.9)	6 (6.7)
Prefer not to answer	0 (0)	0 (0)	3 (6.7)	3 (3.3)
Family history of tinnitus (%)				
Yes, parents	8 (36.4)	8 (34.8)	14 (31.1)	30 (33.3)
Yes, siblings	1 (4.6)	1 (4.4)	1 (2.2)	3 (3.3)
Yes, children	0 (0)	0 (0)	0 (0)	0 (0)
No	10 (45.5)	14 (60.9)	26 (57.8)	50 (55.6)
I don't know	3 (13.6)	0 (0)	4 (8.9)	7 (7.8)
Tinnitus chronicity (SD)	84.9 (101.8)	80.6 (84.1)	107.3 (109.1)	92.2 (99.8)
Tinnitus onset relation (%)				
Loud blast of sound	8 (36)	8 (35)	18 (40)	34 (37.8)
Whiplash	0 (0)	0 (0)	0 (0)	0 (0)
Change in hearing	1 (4.5)	1 (4.3)	5 (11)	7 (7.8)
Stress	2 (9.1)	5 (22)	1 (2.2)	8 (8.9)
Head trauma	0 (0)	0 (0)	0 (0)	0 (0)
Others	11 (50)	9 (39)	21 (47)	41 (45.6)
Tinnitus loudness degree (SD)	52.5 (22)	61.3 (23.7) ³	57.3 (26.3)	57.2 (24.8) ⁴
Treatment for tinnitus (%)				
Yes	6 (27)	5 (22)	10 (22)	21 (23.3)
No	16 (73)	18 (78)	35 (78)	69 (76.7)
Stress influence on tinnitus (%)				
Worsens tinnitus	16 (27)	18 (78)	27 (60)	61 (67.8)
Reduces tinnitus	0 (0)	0 (0)	0 (0)	0 (0)
No effect	6 (73)	5 (22)	18 (40)	29 (32.2)
Hearing problem (%)				
Yes	11 (50)	12 (52)	27 (60)	50 (55.6)

No	11 (50)	11 (48)	18 (40)	40 (44.4)
Hearing aids (%)				
Right ear	0 (0)	0 (0)	0 (0)	0 (0)
Left ear	0 (0)	0 (0)	1 (2.2)	1 (1.1)
Both ears	1 (4.5)	6 (26)	8 (18)	15 (16.7)
No	21 (95)	17 (74)	36 (80)	74 (82.2)
Sound toleration problem (%)				
Never	2 (9.1)	1 (4.3)	3 (6.7)	6 (6.7)
Rarely	6 (27)	3 (13)	1 (2.2)	10 (11.1)
Sometimes	6 (27)	5 (22)	9 (20)	20 (22.2)
Usually	2 (9.1)	8 (35)	18 (40)	28 (31.1)
Always	6 (27)	6 (26)	14 (31)	26 (28.9)
Pain caused by sounds (%)				
Yes	7 (31.8)	10 (43.5)	28 (62.2)	45 (50)
No	13 (59.1)	10 (43.5)	15 (33.3)	38 (42.2)
I don't know	2 (9.1)	3 (13)	2 (4.4)	7 (7.8)
Other pain syndromes (in the past month) (%)				
More than once a week	3 (14)	3 (13)	5 (11)	11 (12.2)
Once a week	0 (0)	1 (4.3)	3 (6.7)	4 (4.4)
A few times a month	4 (18)	4 (17)	5 (11)	13 (14.4)
No	15 (68)	15 (65)	32 (71)	62 (68.9)

¹ One missing value (NA) excluded

² One NA excluded

³ One NA excluded

⁴ One NA excluded

Note. $N = 90$. Age was measured in years. Tinnitus chronicity was measured in months. Tinnitus loudness degree was measured on a scale of 1-100.

Main Effects

Hypothesis 1

The first hypothesis stated that those who currently post on tinnitus talk have better self-management abilities and hence, score significantly higher on the PIH scale than those who do not use tinnitus talk.

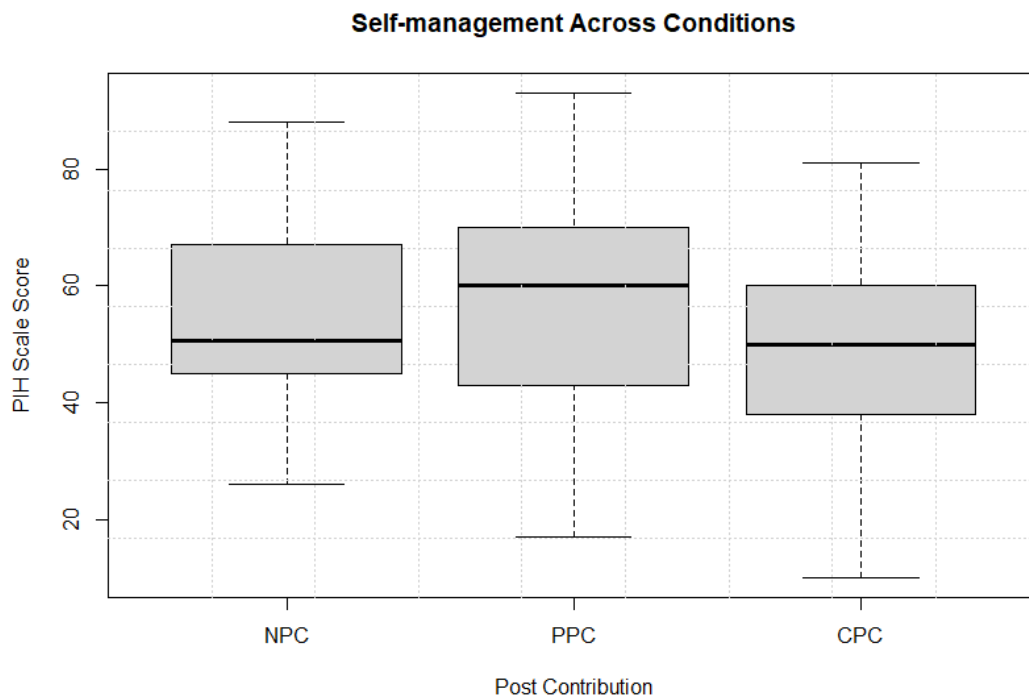
In this analysis, 15 observations were excluded due to missing values. Fitted linear model results indicated that neither having previously posted but not doing so anymore, nor currently posting, differ significantly from never having posted. Overall, the model explained a statistically insignificant and weak proportion of variance with $F(2, 78) = 1.39, p = .26$. Table 2 shows the linear model parameter estimates and their respective p-values. These results were further illustrated with a boxplot (see Figure 1). Considering these findings, the first hypothesis was rejected.

Table 2.

Parameter Estimates for the Effect of Post Contribution on Self-management

Effect	Estimate	SE	95% CI		p
			LL	UL	
Intercept	54.39	4.29	44.85	62.92	<.001
Previous post contribution	2.2	5.78	-9.31	13.71	.704
Current post contribution	-5.34	5.14	4.9	4.9	.302

Note. No post contribution is regarded as the intercept. *SE* = Standard error. *CI* = confidence interval; *LL* = lower limit; *UL* = upper limit.

Figure 1.*Self-management Scores for Post Contributors Versus Previous and Non-Contributors*

Note. Self-management is indicated by the participants' score on the PIH scale. Post Contribution indicates the participant group; NPC = no post contribution, PPC = previous post contribution, and CPC = current post contribution.

Hypothesis 2

The second hypothesis assumed that those who currently post on tinnitus talk have a less severe illness perception than those who do not post. Therefore, they would score significantly higher in the Brief IPQ than non-contributors.

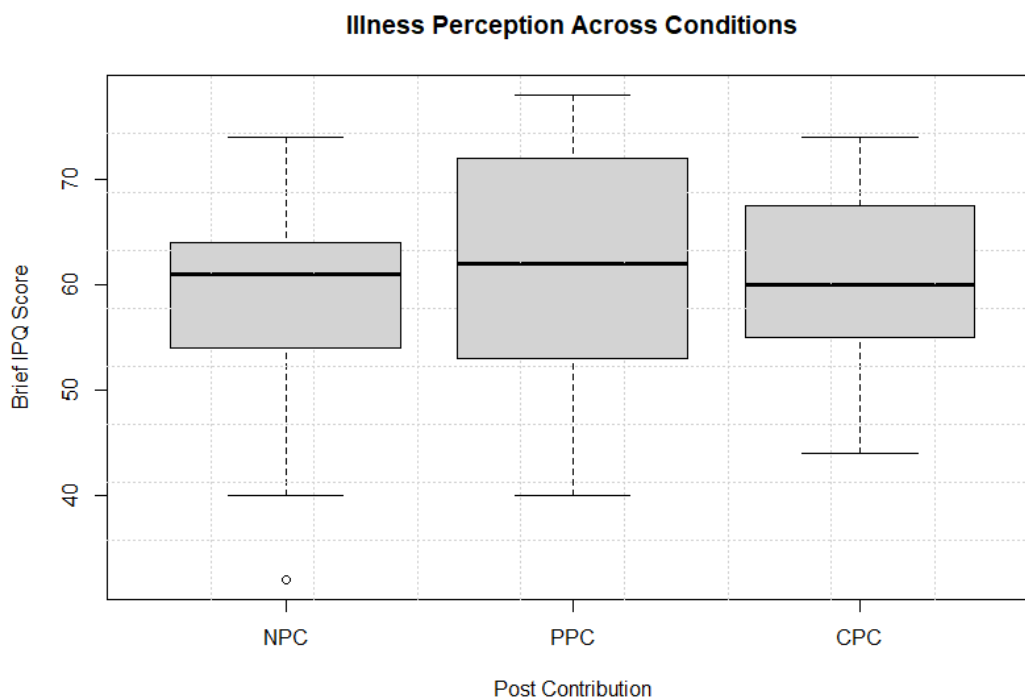
For this analysis, eight observations were deleted due to missing values. The fitted linear model output showed that a statistically insignificant and only weak proportion of variance is explained by post contribution with $F(2, 85)$, and $p = .37$. The linear model parameter estimates, and their p-values are depicted in Table 3. Additionally, Figure 2 shows these results in a boxplot. Due to the insignificant p-values the second hypothesis was rejected as well.

Table 3.

Parameter Estimates for the Effect of Post Contribution on Illness Perception

Effect	Estimate	SE	95% CI		p
			LL	UL	
Intercept	57.67	2.07	53.36	61.78	<.001
Previous post contribution	3.9	2.86	-1.79	9.59	.176
Current post contribution	2.83	2.51	-2.16	7.83	.263

Note. No post contribution is regarded as the intercept. *SE* = Standard error. *CI* = confidence interval; *LL* = lower limit; *UL* = upper limit.

Figure 2*Illness Perception Scores for Post Contributors Versus Previous and Non-Contributors*

Note. Illness Perception is indicated by the participants' score on the Brief IPQ. Post Contribution indicates the participant group; NPC = no post contribution, PPC = previous post contribution, and CPC = current post contribution.

Hypothesis 3

The final hypothesis proposed that those who post on tinnitus talk perceive chronic illness care to be worse than those who do not post, as would be indicated by significantly lower scores on the PACIC for users.

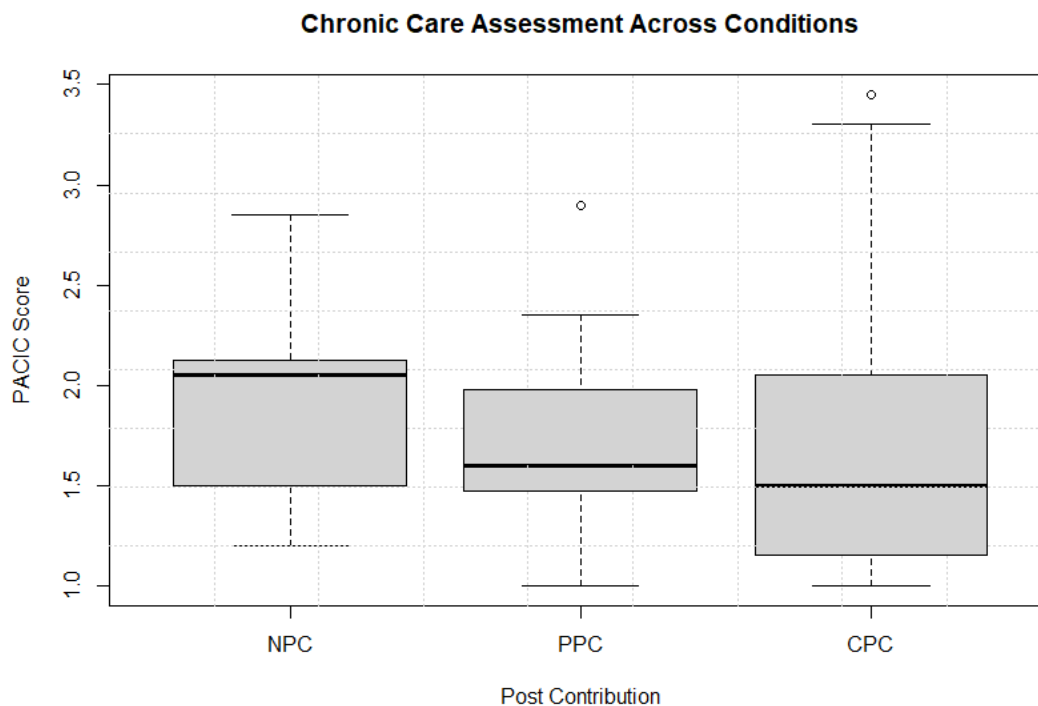
For this analysis, 23 observations were excluded as those participants indicated that they have never visited a healthcare provider for their tinnitus and hence, skipped the rest of the PACIC. A fitted linear model analysis output presented that an insignificant and weak proportion of variance was explained by post contribution, with $F(2, 70) = 0.64$ and $p = .53$. The linear model parameter estimates, and the respective p-values are shown in Table 4. Effects were insignificant. Consequently, the third hypothesis was rejected. These results are also shown as a boxplot in Figure 3.

Table 4.

Parameter Estimates for the Effect of Post Contribution on Chronic Care Assessment

Effect	Estimate	SE	95% CI		p
			LL	UL	
Intercept	1.9	0.13	1.63	2.17	<.001
Previous post contribution	-0.16	0.19	-0.54	0.22	.409
Current post contribution	-0.18	0.17	-0.52	0.15	.273

Note. No post contribution is regarded as the intercept. *SE* = Standard error. *CI* = confidence interval; *LL* = lower limit; *UL* = upper limit.

Figure 3*Chronic Care Assessment for Post Contributors Versus Previous and Non-Contributors*

Note. Chronic Care Assessment is indicated by the participants' score on the PACIC. Post Contribution indicates the participant group; NPC = no post contribution, PPC = previous post contribution, and CPC = current post contribution.

Discussion

This study investigated how the contribution to the self-help platform tinnitus talk (in the form of posts) is associated with self-management, illness perception, and chronic care assessment of people who suffer from chronic tinnitus. This was tested by focusing on three hypotheses.

The first hypothesis stated that those who contribute to tinnitus talk by posting have better self-management abilities than those who do not post, either having only done so previously or not at all. This hypothesis was rejected, as neither previous contributors nor current ones scored significantly higher on self-management than those who never contributed to the platform. The second hypothesis supposed that those who contribute to tinnitus talk by posting have a less severe illness perception. Due to insignificant effects, this hypothesis was rejected as well. The third hypothesis proposed that those who contribute to tinnitus talk

perceive chronic care to be less sufficient than those who do not contribute or have only done so previously. While a general trend that vaguely matches this assumption could be observed, effects remained insignificant. Hence, this hypothesis, too, was rejected.

To sum up, the data analysis presented results that were different from what was expected. Therefore, the research question was answered by stating that contribution to tinnitus talk is not associated with self-management, illness perception, and chronic care assessment. Therefore, it can be concluded that the self-help platform tinnitus talk is equally effective for post contributors versus non- or past contributors. Contrary to that and based on the previously analysed literature, it was assumed that the active contribution to a self-help platform would highly impact mentioned aspects as they are important for chronic illness patients. To mention a general example, an Australian study on the effects of self-help groups on chronic illness management illustrated numerous benefits such as better illness management, as well as better information access and illness understanding (Coppa & Boyle, 2003). Different to this study, however, they employed a qualitative study design by conducting interviews which grant other distinct insights. Further, they focused on in-person self-help groups while the present study focused specifically on online self-help groups which might influence results as well. Another frequently found benefit of online support groups is patient empowerment in terms of, for instance, feeling informed, being more confident in relationships with healthcare providers and the treatment, or increased perceived control over the condition (van Uden-Kraan et al., 2008a; van Uden-Kraan et al., 2008b). This, too, was discovered via qualitative research in the form of interviews. Moreover, participants in those studies were affected by conditions other than tinnitus, such as breast cancer, arthritis, or fibromyalgia. People with these conditions might benefit differently from online self-help platforms than those affected by chronic tinnitus.

However, specifically regarding the first hypothesis, similar results have been found in a study by Grosberg and colleagues (2016). Generally, they emphasise the (small) impact of participation in online groups or programs in terms of improved health behaviours and self-efficacy in users with chronic condition(s). They also point out that social health networks increase patient activation. Patient activation (as measured by the Patient Activation Measure) was indicated by different self-management abilities, such as collaboration with healthcare providers, illness management skills, or maintaining healthy behaviours. Thus, it is quite similar to the PIH scale used in this study. Interestingly, as in this study, Grosberg and colleagues (2016) had similar results in their research; there was no significant difference in the degree of patient activation between post contributors versus lurkers. As they suggest, a possible explanation for that could be that simply the knowledge and information acquired through

reading posts is sufficient to increase self-management abilities. This idea is in line with other research which showed that patient activation was supported and enhanced by feeling better informed about the chronic condition (Johansson et al., 2021). Therefore, it might be a plausible explanation for this study's outcomes regarding self-management.

For the second hypothesis, no similar previous studies have been identified. However, multiple other works support the importance of the role of illness perception for tinnitus patients. For example, it has been highlighted how negative or severe illness perceptions inhibited adjustment to and coping with tinnitus (Vollmann et al., 2012). In contrast, positive and less severe illness perceptions about tinnitus have been shown to increase patients' optimism and subsequently reduce depression (Vollmann et al., 2014). While there is – to the author's knowledge – no research on the impact of (online) self-help groups on the illness perception of users with chronic tinnitus specifically, an important aspect remains that being informed about and discussing tinnitus might be useful tools to combat negative and severe illness perceptions (Vollmann et al., 2012). As self-help platforms provide an environment to get information and discuss, participating in these groups might be of benefit to those with chronic tinnitus. These benefits could be considered in terms of self-help group participation leading to more positive and less severe tinnitus-specific illness perceptions. This suggestion might be subject to future research.

Moreover, related to the third hypothesis and chronic care assessment, crucial features are indicated by the Chronic Care Model (CCM), which is connected to one of this study's measurement tools, the PACIC (Glasgow et al., 2005). As there appears to be insufficient clinical practice within chronic illness care, the CCM proposes six dimensions critical for patient-centred and proactive care. These include, amongst others, healthcare organisation, decision and self-management support, as well as community resources (Glasgow et al., 2005). Connected to this, within the healthcare and health psychology sector, it should be an important goal to advocate for and empower tinnitus patients, whether it be via healthcare providers, psychologists, regulations, or self-help platforms. For instance, as Dineen-Griffin and colleagues (2019) emphasise, it could be highly beneficial if health professionals were actively involved in delivering support for (evidence-based) self-management for patients.

However, a previous study on the quality of audiology services in England points out how these lack proper implementation of self-management support (Barker et al., 2014). While audiologists are not the only healthcare provider for tinnitus patients, audiology is a common contact point for them. Furthermore, Convery and colleagues (2018) emphasise how adopting the CCM in hearing healthcare supports patient-centred care and facilitates a better relationship

between healthcare providers and their patients. Hence, a more active collaboration between healthcare providers and tinnitus patients as well as the implementation of the CCM in chronic illness care has the potential to improve the delivery and use of illness-related interventions. Additionally, it facilitates increasing awareness and patient empowerment. These aspects not only reiterate the importance of self-management and social support but also highlight the need for more active care and advocacy for patients by healthcare providers and the healthcare system in general.

Limitations

These study's results must be considered in light of some limitations. Regarding the study design, some things potentially require improvement. Firstly, the sample size was smaller than anticipated, and thus, it is difficult to draw generalisable conclusions and establish external validity. Related to this is also the observation of the participants' demographic data; the participants mostly came from Western, educated, industrialised, rich, and democratic backgrounds (Muthukrishna, 2020). This creates an extremely clustered representation of results. Moreover, the sampling method – convenience sampling via tinnitus talk – might also contribute to the limited representability of results. It can be assumed that perhaps only those who were extremely active on the platform and motivated to contribute participated. Subsequently, this might also explain the relatively small sample size. A third aspect concerns the independent variable, post contribution. The distribution among the three groups was not as equal and balanced as hoped. This makes the conclusion of valid inferences about results problematic. Lastly, it must be noted that the reliability of the Brief IPQ was only moderate ($\alpha = .66$) and thus below the commonly accepted reliability values equal to or above .7 (Gliem & Gliem, 2003). Therefore, the reliability of that questionnaire for this sample is questionable.

Future Recommendations

Considering the limitations, various recommendations can be made for future research. First, future studies conducted in a manner similar to this one should include a larger sample size to yield more representative and generalisable results. For this, it could be considered to use a power sample size calculation. Moreover, the study design and sampling method could be improved. A study design better able to address possible causal effects would be randomised controlled trials (Bhide et al., 2018). As post contribution did not appear to be significantly associated with any of the outcome measures, it might be interesting to look at other possible indicators to further investigate how tinnitus talk use is helping its users. For instance, instead of comparing tinnitus talk users to each other, it could be of value to investigate how tinnitus talk users differ from those who do not use it or any other self-help platform. To do that, the

sampling method would have to be adjusted to also reach those people who do not visit the tinnitus talk forum. Overall, as this study showed that tinnitus talk use is equally effective for different degrees of contribution, it is recommended to conduct more large-scale studies looking into the ways through which the self-help platform (or any self-help platform) is providing effective support.

Conclusion

Online self-help groups continue to be an important tool for establishing social and emotional support, as well as empowerment for people suffering from chronic tinnitus, ultimately aiming to benefit their psychological well-being. Therefore, the question of the effects of using self-help groups for tinnitus, and even other chronic conditions, remains an important one to be further investigated to discover what helps most, and what can be improved in order to establish the best support possible.

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Appendix

Appendix A

Qualtrics Survey Including Informed Consent Form (Export From Qualtrics)

Empowerment through Tinnitus Talk

Start of Block: Informed Consent

Q80 Dear participant,

First of all we would like to thank you for taking the time to participate in our study!

We, Alexandra Volckmer and Mia Terborg, are conducting this study in the context of our Bachelor Thesis in the fields of Health Psychology and Clinical Psychology.

Information about our research:

This research aims to assess the effects of self-management on tinnitus. We are investigating how platforms like Tinnitus Talk impact one's ability to deal with the condition. Specifically, we want to investigate the relation between using such a platform and self-management, empowerment, and health literacy.

This survey will take approximately 25 minutes.

Benefits and risks of participating:

By participating in this research you actively support patient and public involvement in tinnitus research.

There are no risks of participating in this study.

Only validated questionnaires (or specific items of questionnaires) frequently used in research and/or clinical practice will be used.

Further information:

You can withdraw from this study at any time without stating a reason.

All data will be collected anonymously, no personal information or tracking information (address, name, IP address, cookies, etc.) will be collected.

The anonymised data may be analysed and published in scientific projects like Bachelor, Master and Doctoral Thesis, as well as in scientific articles.

The data will be handled safely and with confidentiality, and will be stored in a secure server from the University of Twente.

This study was approved by the Ethics Commission of the University of Twente, the Netherlands (number 230236).

Contact information:

For questions and other matters, you can contact us at any time.

Alexandra Volckmer: a.volckmer@student.utwente.nl

Mia Terborg: m.m.terborg@student.utwente.nl

Jorge Piano Simoes, PhD (supervisor): j.pianosimoes@utwente.nl

Page Break

Understanding I have read and understood the study information, or it has been read to me. I have been able to ask questions about the study and my questions have been answered to my satisfaction.

Yes (1)

No (2)

Consent I consent voluntarily to be a participant in this study and understand that I can withdraw from the study at any time, without having to give a reason.

Yes (1)

No (2)

Skip To: End of Survey If I consent voluntarily to be a participant in this study and understand that I can withdraw from t... = No

End of Block: Informed Consent

Start of Block: Demographics / TSCHQ

Info In the following, you are asked to answer questions concerning your demographics, your tinnitus and your activity on Tinnitus Talk.

Gender Gender:

- Male (1)
- Female (2)
- Non-binary (3)
- Other (4)

Page Break



Age Age:

Page Break



Country In which country do you currently reside?

▼ Afghanistan (1) ... Zimbabwe (1357)



Page Break



Employment Which statement best describes your current employment status?

- Working (paid employee) (1)
- Working (self-employed) (2)
- Not working (temporary layoff from a job) (3)
- Not working (looking for work) (4)
- Not working (retired) (5)
- Not working (disabled) (6)
- Not working (other) (7) _____
- Prefer not to answer (8)

Page Break

Handedness Handedness

- Right (1)
- Left (2)
- Both Sides (3)

Page Break

Education What is the highest education level you have achieved?

- No school (1)
- Primary (elementary school) (2)
- Lower secondary (middle school) (3)
- Upper secondary (high school) (4)
- University (higher degree) (5)
- Other (6)

Page Break

Family Family history of tinnitus complaints:

- Yes, Parents (1)
- Yes, Siblings (2)
- Yes, Children (3)
- No (4)
- I do not know (5)

Page Break

Time_since_Diagnosis For how long do you live with tinnitus:

Months (1) _____

Years (2) _____

I do not know (3)

Page Break _____

Beginning How did you perceive the beginning of tinnitus?

- Gradually (1)
- Abruptly (2)

Page Break

Onset_relation Was the initial onset of your tinnitus related to:

- Loud blast of sound (1)
- Whiplash (2)
- Change in hearing (3)
- Stress (4)
- Head trauma (5)
- Others (6) _____

Page Break

Pulsate Does your tinnitus seem to **pulsate**?

- Yes with heart beat (1)
- Yes, different from heart beat (2)
- No (3)

Page Break

Location Where do you perceive your tinnitus?

- Right ear (1)
 - Left ear (2)
 - Both ears, worse in left (3)
 - Both ears, worse in right (4)
 - Both ears, equally (5)
 - Inside the head (6)
 - Elsewhere (7)
-

Page Break

Manifestation How does your tinnitus manifest itself over time?

- Intermittent (1)
 - Constant (2)
-

Page Break

Loudness1 Does the **loudness** of the tinnitus vary from day to day?

- Yes (1)
 - No (2)
-

Page Break

Loudness2 Describe the **loudness** of your tinnitus using a scale from 1-100.

0 10 20 30 40 50 60 70 80 90 100

1=Very Faint; 100=Very Loud ()



Page Break

Sound Does your tinnitus more sound like a tone or more like noise:

- Tone (1)
- Noise (2)
- Crickets (3)
- Other (4)

Page Break

Pitch Please describe the **pitch** of your tinnitus:

- Very high frequency (1)
- High frequency (2)
- Medium frequency (3)
- Low frequency (4)

Page Break

Treatment Do you currently receive any form of treatment for your tinnitus administered/prescribed by a healthcare provider?

- Yes (1)
 - No (2)
-

Page Break

Sound_reduction Is your tinnitus **reduced** by music or by certain types of environmental sounds such as the noise of a waterfall or the noise of running water when you are standing in the shower?

- Yes (1)
- No (2)
- Don't know (3)

Page Break

Loud_noise Does the presence of loud noise make your tinnitus worse?

- Yes (1)
- No (2)
- I don't know (3)

Page Break

Movement Does any head or neck movement (e.g., moving the jaw forward or clenching the teeth) or having your arms/hands touched, affect your tinnitus?

- Yes (1)
- No (2)

Page Break

Nap Does taking a nap during the day affect your tinnitus?

- Worsens my tinnitus (1)
 - Reduces my tinnitus (2)
 - Has no effect (3)
-

Page Break

Nightsleep Is there any relationship between sleep at night and your tinnitus during the day?

- Yes (1)
 - No (2)
 - I don't know (3)
-

Page Break

Stress Does stress influence your tinnitus?

- Worsens my tinnitus (1)
 - Reduces my tinnitus (2)
 - Has no effect (3)
-

Page Break

HearingProblem Do you think you have a hearing problem?

- Yes (1)
 - No (2)
-

Page Break

Hearing_Aids Do you wear hearing aids?

- Right ear (1)
 - Left ear (2)
 - Both ear (3)
 - No (4)
-

Page Break

Tolerating sounds Do you have a problem tolerating sounds because they often seem much too loud? That is, do you often find too loud or hurtful sounds which other people around you find quite comfortable?

- Never (1)
 - Rarely (2)
 - Sometimes (3)
 - Usually (4)
 - Always (5)
-

Page Break

Pain Do sounds cause you pain or physical discomfort?

- Yes (1)
 - No (2)
 - I don't know (3)
-

Page Break

Headache In the past month, how often did you suffer from headaches?

- More than once a week (1)
- Once a week (2)
- A few times a month (3)
- I did not suffer from headaches (4)

Page Break

Vertigo In the past month, how often did you suffer from vertigo or dizziness?

- More than once a week (1)
 - Once a week (2)
 - A few times a month (3)
 - I did not suffer from vertigo or dizziness (4)
-

Page Break

Disorder In the past month, how often did you suffer from temporomandibular disorder (pain in your jaw joint and in the muscles that control jaw movement)?

- More than once a week (1)
 - Once a week (2)
 - A few times a month (3)
 - I did not suffer from temporomandibular disorder (4)
-

Page Break

Neck_pain In the past month, how often did you suffer from neck pain?

- More than once a week (1)
 - Once a week (2)
 - A few times a month (3)
 - I did not suffer from neck pain (4)
-

Page Break

Syndromes In the past month, how often did you suffer from other pain syndromes?

- More than once a week (1)
- Once a week (2)
- A few times a month (3)
- I did not suffer from other pain syndromes (4)

End of Block: Demographics / TSCHQ

Start of Block: Activity

Q93 The following four questions concern your activity on Tinnitus Talk. If you do not currently use TinnitusTalk you will automatically be send to the next questionnaire.

Current_Activity Are you currently using or have you used Tinnitus Talk?

- Yes (1)
- No (2)

Skip To: End of Block If Are you currently using or have you used Tinnitus Talk? = No

Page Break

Timeframe How long have you been participating on Tinnitus Talk?

- Months (1) _____
- Years (2) _____
- I do not know (3)



Page Break



Frequency_of_Visits How often do you visit Tinnitus Talk?

- More than once a day (1)
- Once a day (2)
- More than once a week (3)
- Once a week (4)
- Once a month (5)
- Less than once a month (6)
- I do not use it (7)

Page Break

Contributing_Posts Have you ever posted on Tinnitus Talk?

- Yes, I am an active poster on Tinnitus Talk (1)
- Yes, but not anymore (2)
- No, I never posted on Tinnitus Talk (3)

Page Break

Number_of_Postings How often (on average) do you contribute to Tinnitus Talk with posts?

- More than once a day (1)
- Once a day (2)
- Once a week (3)
- Once a month (4)
- Less than once a month (6)

End of Block: Activity

Start of Block: Brief IPQ

Intro_IPQ The first questionnaire shortly assesses your perception of the effects of tinnitus on your life.

IPQ_Q1 How much does your tinnitus affect your life?

	0 - not at all (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 (6)	6 (7)	7 (8)	8 (9)	9 (10)	10 - severly (11)
Please indicate (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

IPQ_Q2 How long do you think your tinnitus will continue?

	0 - very shortly (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 (6)	6 (7)	7 (8)	8 (9)	9 (10)	10 - forever (11)
Please indicate (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

IPQ_Q3 How much control do you feel you have over your tinnitus?

	0 - no control (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 (6)	6 (7)	7 (8)	8 (9)	9 (10)	10 - extreme control (11)
Please indicate (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

IPQ_Q4 How much do you think your treatment can help your tinnitus?

	0 - not at all (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 (6)	6 (7)	7 (8)	8 (9)	9 (10)	10 - extremely helpful (11)
Please indicate (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

IPQ_Q5 How much do you experience symptoms from your tinnitus?

	0 - no symptoms at all (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 (6)	6 (7)	7 (8)	8 (9)	9 (10)	10 - many severe symptoms (11)
Please indicate (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

IPQ_Q6 How concerned are you about your tinnitus?

	0 - not at all (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 (6)	6 (7)	7 (8)	8 (9)	9 (10)	10 - extremely concerned (11)
Please indicate (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

IPQ_Q7 How well do you feel you understand your tinnitus?

	0 - don't understand at all (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 (6)	6 (7)	7 (8)	8 (9)	9 (10)	10 - understand very clearly (11)
Please indicate (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

IPQ_Q8 How much does your tinnitus affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)

	0 - not at all (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 (6)	6 (7)	7 (8)	8 (9)	9 (10)	10 - extremely (11)
Please indicate (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Brief IPQ

Start of Block: PACIC

PACIC_Info This questionnaire addresses healthcare encounters over the last 6 months and you only need to answer it if this applies. Therefore, the first question will ask for your last visit at a healthcare provider. If you never visited one you will automatically be send to the next questionnaire.

Healthcare_provider Did you visit any healthcare provider (e.g., GP, ear-nose-throat doctor, neurologist, psychiatrist, audiologist, dentist, etc.) **specifically for your tinnitus?**

- Yes, In the last 6 months (1)
- Yes, Between 6 and 12 months (2)
- Yes, Over 12 months ago (3)
- No, Never visited a healthcare provider (4)

Skip To: End of Block If Did you visit any healthcare provider (e.g., GP, ear-nose-throat doctor, neurologist, psychiatris... = No, Never visited a healthcare provider

Page Break

PACIC_Intro For the following statements, please indicate the frequency of encountering certain events when receiving health care for tinnitus. Think about the **most recent** health care you have received for tinnitus.

Page Break

PACIC_I1 When receiving medical care for my tinnitus, I was:

	Almost never (1)	Generally not (2)	Sometimes (3)	Most of the time (4)	Almost always (5)
Asked for my ideas when we made a treatment plan. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Given choices about treatment to think about. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asked to talk about any problems with my medicines or their effects. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

PACIC_I2 When receiving medical care for my tinnitus, I was:

	Almost never (1)	Generally not (2)	Sometimes (3)	Most of the time (4)	Almost always (5)
Given a written list of things I should do to improve my health. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Satisfied that my care was well organised. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Shown how what I did to take care of my illness influenced my condition. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Page Break

PACIC_I3 When receiving medical care for my tinnitus, I was:

	Almost never (1)	Generally not (2)	Sometimes (3)	Most of the time (4)	Almost always (5)
Asked to talk about my goals in caring for my illness. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helped to set specific goals to improve my eating or exercise. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Given a copy of my treatment plan. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Encouraged to go to a specific group or class to help me cope with my chronic illness. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asked questions, either directly or on a survey, about my health habits. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

PACIC_I4 When receiving medical care for my tinnitus, I was:

	Almost never (1)	Generally not (2)	Sometimes (3)	Most of the time (4)	Almost always (5)
Sure that my doctor or nurse thought about my values and my traditions when they recommended treatments to me. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helped to make a treatment plan that I could do in my daily life. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helped to plan ahead so I could take care of my illness even in hard times. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asked how my chronic illness affects my life. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

PACIC_I5 When receiving medical care for my tinnitus, I was:

	Almost never (1)	Generally not (2)	Sometimes (3)	Most of the time (4)	Almost always (5)
Contacted after a visit to see how things were going. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Encouraged to attend programs in the community that could help me. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Referred to a dietitian, health educator, or counselor. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Told how my visits with other types of doctors, like the eye doctor or surgeon, helped my treatment. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asked how my visits with other doctors were going. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: PACIC

Start of Block: PIH scale

PIH_Intro The following statements aim to assess one's knowledge and self-management of tinnitus.

Please note: You may find some of the next statements similar to those you have already answered. This is because we are using only already existing, tested questionnaires and adding them as they are, which unfortunately leads to some repetition.

 Page Break

PIH_I5 I am able to deal with health professionals to get the services I need that fit with my culture, values and beliefs

	0 - Never (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 (6)	6 (7)	7 (8)	8 - Always (9)
Please indicate (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

 Page Break

PIH_I6 I attend appointments as asked by my doctor or health worker

	0 - Never (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 (6)	6 (7)	7 (8)	8 - Always (9)
Please indicate (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

 Page Break

PIH_I7 I keep track of my symptoms and early warning signs (e.g., blood sugar levels, peak flow, weights, shortness of breath, pain, sleep problems, mood)

	0 - Never (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 (6)	6 (7)	7 (8)	8 - Always (9)
Please indicate (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

PIH_I8 I take action when my early warning signs and symptoms get worse

	0 - Never (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 (6)	6 (7)	7 (8)	8 - Always (9)
Please indicate (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

PIH_I9 I manage the effect of my tinnitus on my physical activity (i.e. walking, household tasks)

	0 - Not very well (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 (6)	6 (7)	7 (8)	8 - Very well (9)
Please indicate (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

PIH_I10 I manage the effect of my tinnitus on how I feel (i.e. my emotions and spiritual well-being)

	0 - Not very well (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 (6)	6 (7)	7 (8)	8 - Very well (9)
Please indicate (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

PIH_I11 I manage the effect of my tinnitus on my social life (i.e. how I mix with other people)

	0 - Not very well (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 (6)	6 (7)	7 (8)	8 - Very well (9)
Please indicate (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

PIH_I12 Overall, I manage to live a healthy life (e.g. no smoking, moderate alcohol, healthy food, regular physical activity, manage stress)

	0 - Not very well (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 (6)	6 (7)	7 (8)	8 - Very well (9)
Please indicate (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: PIH scale

Start of Block: Empowering Processes

Info_EP The following questionnaire concerns the empowering processes from using Tinnitus Talk and its consequences on your tinnitus.

Page Break

EP_Q1 The information and tips exchanged in this online support group are...

	Seldom to Never (1)	Sometimes (2)	Regularly (3)	Often (4)
...understandable (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...valuable (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...usable (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...new (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...applicable to my present situation (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...reliable (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...correct (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...of added value to the information I receive from my care providers (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...in line with the information I receive from my care providers (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

EP_Q2 Does it ever happen in this online support group that someone in this online support group...

	Seldom to Never (1)	Sometimes (2)	Regularly (3)	Often (4)
...invites you to have (personal) contact outside this online support group? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...starts a private conversation with you? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...is empathic? (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...consoles you? (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...pays you a compliment? (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...is interested in you? (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...pays particular attention to you in special cases, such as during illness or moving house? (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...reassures you? (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...offers you sound advice? (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...points out your strengths? (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...confides in you? (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...asks you for your help or advice? (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

EP_Q3 Does it ever happen in this online support group that...

	Seldom to Never (1)	Sometimes (2)	Regularly (3)	Often (4)
...you recognise yourself in the stories of other online support group members? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...you experience the sense of "not being the only one"? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...others are an example to you? (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...you realise that you are not so bad off after all? (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

 Page Break

EP_Q4 Does it ever happen in this online support group that...

	Seldom to Never (1)	Sometimes (2)	Regularly (3)	Often (4)
...you can be an example to other participants? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...you can offer advice and support others? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

 Page Break

EP_Q5 Does it ever happen in this online support group that you can share...

	Seldom to Never (1)	Sometimes (2)	Regularly (3)	Often (4)
...your experiences with your illness with others? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...your everyday experiences with others? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Empowering Processes

Start of Block: Empowering Outcomes

EO_Q1 Through my participation in this online support group...

	Completely disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Completely agree (5)
...I feel better informed as a patient. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I understand my illness better. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I have a clearer picture about my illness. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I feel like I have more (correct) knowledge at my disposal to deal better with my illness. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

EO_Q2 Through my participation in this online support group...

	Completely disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Completely agree (5)
...I feel better prepared for a doctor's appointment. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I am more knowledgeable about which questions to ask my physician. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I can explain my needs to my physician better. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I have more courage to raise matters with my physician. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I am more able to oppose my physician. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I understand the information provided by my physician better. (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...the relationship with my physician has improved. (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...the relationship with my physician has deteriorated. (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I am more able to judge when I really need the help of my physician. (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

...I feel less dependent on my physician.
(10)

...I am more able to think along with my physician about my treatment.
(11)

Page Break

EO_Q3 Through my participation in this online support group...

	Completely disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Completely agree (5)
...I am able to be more open about my own illness. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I can tell others more easily when I am no longer able to do something. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I can ask others for help more quickly. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I can give in to my illness better. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I can accept my illness better. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

EO_Q4 Through my participation in this online support group...

	Completely disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Completely agree (5)
...I can stick to my treatment regime better. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I am more able to follow the medical guidelines and advice of my physician. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I know where to go with questions about my illness. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I feel I am more skilled at dealing well with my illness. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I feel able to make the right decision with regard to my illness. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

EO_Q5 Through my participation in this online support group...

	Completely disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Completely agree (5)
...I feel more in charge of the course of my illness. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I feel I can influence my illness myself. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I feel more in control over what is happening to me. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...i feel less in control over what is happening to me. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I feel that what happens to me in the future is to a large degree dependent on myself. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I have learned to be more positive. (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I have more faith in the future. (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I have less faith in the future. (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

EO_Q6 Through my participation in this online support group...

	Completely disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Completely agree (5)
...I have a greater sense of worth. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I have a more positive attitude towards myself. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I am in general more content with myself. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

EO_Q7 Through my participation in this online support group...

	Completely disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Completely agree (5)
...I feel less lonely. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I have made new social contacts. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Empowering Outcomes

Appendix B

STROBE Checklist for Cross-sectional Studies

STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported
Objectives	3	State specific objectives, including any prespecified hypotheses
Methods		
Study design	4	Present key elements of study design early in the paper
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9	Describe any efforts to address potential sources of bias
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders

		(b) Indicate number of participants with missing data for each variable of interest
Outcome data	15*	Report numbers of outcome events or summary measures
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses
Discussion		
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

