

Self-help Platforms for Users with Chronic Tinnitus

Alexandra Volckmer

Department of Psychology, University of Twente
202000381 - Positive Clinical Psychology and Technology (PCPT)

Dr Jorge Piano Simoes

Gerko Schaap, MSc.

June 28th, 2023

Word count: 4912

APA 7th Edition

**UNIVERSITY
OF TWENTE.**

Abstract

Around 9.8% of adults experience chronic tinnitus but nevertheless, there is currently no treatment that works which leaves people with tinnitus needing to self-manage their illness. For this, online self-help platforms provide support and can empower users to self-manage their illness. Due to the huge role of self-help platforms, further research into the empowering effects on users with tinnitus is necessary. Therefore, the current study aims to investigate the empowering effects of the self-help platform Tinnitus Talk on users. Further, the activity level on the platform will be analysed to investigate the effect of activity on empowerment.

A cross-sectional quantitative study was conducted. The questionnaires investigated the demographics, platform activity, illness perception, self-management abilities and empowering processes and outcomes. The sample consisted of 85 participants (76.5% male, 20% female, 3.5% non-binary) of which most of them were frequently active (30.6% more than once a day, 26% more than once a week). All data were analysed by means of regression analyses, Wilcoxon rank-sum comparisons, and correlation analyses. The different analyses were done to test the relationships between all variables and the different influences empowerment has on illness perception and self-management.

The results found the empowering processes and outcomes to be present in varying degrees. It can be said that users of the platform Tinnitus Talk experience the feeling of empowerment through interaction with other users (β between 0.04 and 0.13). This happens independently of the frequency with which the users participate on the platform and independently from the timespan of participation. Furthermore, different empowerment outcomes seem to have an influence on the illness perception (r between -.22 and -.29) and self-management abilities of the users ($r = .29$). Thus, all results suggest the existence of patient empowerment through Tinnitus Talk.

Contents

Introduction	5
Methods	7
Study design	7
Instruments	7
TSCHQ	8
Activity	8
Brief IPQ	9
PIH Scale	9
Empowerment Questionnaire	9
Procedure	10
Data analysis	10
Results	11
Participants	11
Main Results	14
Discussion	26
Strengths	27
Limitations	27
Future Directions	28
Conclusion	28
References	30
Appendix A	
Informed Consent	33
Appendix B	
TSCHQ	35
Appendix C	
User Activity	40
Appendix D	
Brief IPQ	41

Appendix E

PIH Scale	43
------------------	-----------

Appendix F

Empowering Processes and Outcomes	45
--	-----------

Empowering Processes	45
----------------------	----

Exchanging information	45
------------------------	----

Exchanging social support	45
---------------------------	----

The comparison with other online support group members	46
--	----

Helping others	46
----------------	----

Sharing experiences	46
---------------------	----

Empowering Outcomes	46
---------------------	----

Feeling better informed	46
-------------------------	----

Feeling more confident in the relationship with their physician	46
---	----

Improved acceptance of the illness	47
------------------------------------	----

Increased confidence in their treatment	47
---	----

Increased optimism and control over the future	47
--	----

Enhanced self-esteem	47
----------------------	----

Enhanced social well-being	48
----------------------------	----

Appendix G	49
-------------------	-----------

Introduction

Tinnitus is commonly defined as the perception of ringing sounds without a related external source which could explain the sensation (Kreuzer et al., 2013). Tinnitus can be acute or become chronic when the sensations last for more than six months (*Tinnitus: Ringing in the Ears and What to Do about It*, 2022). The onset in both cases can be sudden and can have different causes. The aetiology of tinnitus remains unclear but it can manifest after exposure to loud noise, like an explosion or music, hearing loss, or emotional distress (Baguley et al., 2013; Piccirillo et al., 2020). Due to the different experiences of tinnitus and unknown aetiology, prevalence estimates are hard to pinpoint. Nevertheless, a meta-analysis by Jarach et al. (2022) resulted in a prevalence of approximately 14% of the world population that experienced tinnitus regardless of gender in their lifetime. Additionally, the prevalence of tinnitus increases with increasing age. Further specifying chronic and severe cases of tinnitus among adults show prevalence values of 9.8% for chronic tinnitus and 2.3% for severe tinnitus while 6.8% present as being bothered by their tinnitus (Jarach et al., 2022).

Although tinnitus is a prevalent disease affecting a considerable proportion of the population, there is no cure for chronic tinnitus. Overall, there are many treatment approaches but not one that definitely provides a cure which can be seen as a consequence of the diversity of tinnitus. For many approaches, no evidence of effectiveness can be found, e.g., drug treatment or sound therapy (Mazurek et al., 2022). Those treatments are often used to alleviate symptoms or comorbidities of tinnitus, for example, depression. Nevertheless, no treatment can cure the sensation of hearing sounds without origin (Kreuzer et al., 2013; Mazurek et al., 2022). Therefore, there is no solution for many people suffering from chronic tinnitus. This scarcity of medical treatment leads to a high demand for coping options and to the patients engaging more in self-management. They use different self-help options in order to improve their knowledge, find support from fellow patients and manage their illness (S.N. Smith et al., 2018).

Especially important for self-managing a chronic illness is that the patient feels empowered to do so. There are many definitions of empowerment available from which Eskildsen et al. (2017) concluded one definition consisting of four components. According to them, patient empowerment means that the patient perceives themselves as “capable of influencing the context/situation” and as knowing “how the healthcare system works” in order to achieve desired outcomes (Eskildsen et al., 2017, p.157). Moreover, the patient actively engages in specific behaviours to influence their situation. Lastly, Eskildsen et al. (2017) also acknowledge that patient empowerment is facilitated by professionals, meaning that they must thoroughly inform their patients about their chronic illness and involve them in the treatment

processes. Professionals but also self-help options can provide support to the patients in taking power over their illness. With all these components fulfilled, self-management can be influenced by a feeling of empowerment (Eskildsen et al., 2017).

One option for self-management is engaging on self-help platforms where the users can exchange knowledge and support, and encourage each other to become active participants in their treatment journey (Foster, 2016; Nickel et al., 2019). They empower each other by discussing how to best deal with their illness or how to talk to medical specialists so that they are taken seriously. Longer-diagnosed patients can support newly diagnosed patients, for example, by providing more knowledge, suggesting treatment options, or discussing the regulation of emotions. With those resources, individuals learn more about the healthcare available and the possibilities to influence their situation but also psychological support, e.g. through normalising illnesses and exchanging emotions, is given. All these components strengthen patient empowerment (Foster, 2016; Petersson et al., 2022).

This is also proven in a study by Nickel et al. (2019) which shows that patients engaging in self-help groups have higher confidence in themselves to interact with medical staff and self-manage their chronic illness. With special regard to tinnitus patients, the study's results indicate that individuals who engage in self-help groups have a higher knowledge of their disease and treatment possibilities. Adding to that, another study suggests that tinnitus patients living with the illness for a long time engage more in self-help. It is hypothesised that this is probably because they either learned effective coping strategies or experienced too many ineffective treatments (Probst et al., 2017).

Overall, self-help platforms can provide support in many aspects and are therefore highly valuable for chronic illnesses. Especially tinnitus patients are dealing with a situation where many treatments are ineffective but self-help platforms can assist them in finding other coping strategies and support. Due to the scarcity of tinnitus research into the role of self-help platforms, it is necessary to investigate the influence of empowerment on people with chronic tinnitus. Current tinnitus research is mainly focused on finding new treatment options but an added focus on the influence of self-help platforms on patient empowerment could provide useful insights into the level of empowerment. Those insights can be utilised to incorporate empowerment through self-help platforms as support options for tinnitus patients. One organisation, named "TinnitusHub", supports tinnitus patients to empower and help patients but also to contribute to new knowledge gained through research (*Our Mission*, n.d.). The corresponding platform on which users and researchers can exchange knowledge and experiences is called "Tinnitus Talk" (*Tinnitus Talk Support Forum*, n.d.).

Because of the necessity of further research, this study aimed to answer the research question “To what extent do people with chronic tinnitus feel empowered by Tinnitus Talk?”. To support the answer process, two other questions needed to be answered first. Those are: “What influence does the frequency of platform activity have on users’ feeling of empowerment?” and “What influence does the timespan users already spent on the self-help platform have on their feeling of empowerment?”. For those research questions, it was hypothesised that (1) the frequency of platform activity has a positive influence on the feeling of empowerment, (2) a longer participation timespan on the platform positively influences the feeling of empowerment, and (3) users feel empowered through participating on Tinnitus Talk.

Methods

Study design

To answer the research questions a cross-sectional quantitative study in the form of an online survey was used. The survey was designed using Qualtrics and distributed via the online platform Tinnitus Talk. It was available for two weeks between May 8th to May 22nd, 2023. Participants eligible for the study were people suffering from chronic tinnitus and were selected via convenience sampling by posting a link to the study on the “Research News” thread. All collected data were stored on the secured MS OneDrive service provided by the University. To increase the transparency and structure of the current study, the report was oriented on the STROBE checklist (STROBE Checklist_V4 Cross-Sectional Study, n.d.).

Instruments

Next to the informed consent (Appendix A), the survey consisted of six components in the form of different questionnaires. The first two questionnaires addressed the demographics and the activity on the platform. Next, two questionnaires addressed the participant's illness perception and recent healthcare encounters. The last two questionnaires investigated the participant's ability to self-manage and the processes on the platform that influence that.

For this study, only five of the six questionnaires were important to analyse. Those were the Tinnitus Sample Case History Questionnaire (TSCHQ), the user activity, and the Brief Illness Perception Questionnaire (Brief IPQ) to gain an overview of the demographics and tinnitus profile of the participant. Further, the Partners in Health (PIH) scale and the empowerment questionnaire were important to investigate the users’ self-management skills and feelings of empowerment. The Patient Assessment of Chronic Illness Care (PACIC) was part of the survey but irrelevant to the current study since there was no further focus on external healthcare aspects of tinnitus.

TSCHQ

The TSCHQ (Appendix B) is a questionnaire by the Tinnitus Research Initiative (TRI) which collects demographic information and information about the participant's tinnitus history (*Tinnitus Sample Case History Questionnaire (TSCHQ)*, n.d.). It consists of 35 items with open and closed answer possibilities. In this survey, the questionnaire served to collect the demographics but also to indicate whether the participant has a chronic form of tinnitus if the answer to the question "For how long do you live with Tinnitus:" was over six months. The TSCHQ was slightly adjusted to fit the study's needs. Four original items were excluded, but equally four items were added by the researchers.

The original item 13 "Please describe in your own words what your tinnitus usually sounds like:" and item 25 "Does medication have an effect on your tinnitus?" were excluded because they do not provide an added value for the current study. Furthermore, item 16 "What percent of your total awake time, over the last month, have you been aware of your tinnitus?" and item 17 "What percent of your total awake time, over the last month, have you been annoyed, distressed, or irritated of your tinnitus?" were excluded to prevent duplication.

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?" were added to get a more detailed picture of the participant's demographics. Finally, the question "Do you currently receive any form of treatment for your tinnitus?" was added to ensure that the following answers concerning treatment can be put into perspective in later analysis.

Activity

This component measured the activity of the participant on the platform Tinnitus Talk (Appendix C). It served to identify the users' participation timespan with the question "How long have you been participating on this platform?" to which answer possibilities of month and years, or "I do not know" were given. Additionally, the frequency of platform activity was identified with the question "How often do you visit TinnitusTalk?". Participants could choose from seven answer levels, namely: "I do not use it", "Less than once a month", "Once a month", "Once a week", "More than once a week", "Once a day", and "More than once a day". Lastly, this questionnaire enabled the researchers to determine the posting activity on the platform by asking: "Do you contribute to the platform by posting?" and "How often (on average) do you contribute to the platform?" to which participants could choose between five levels ranging from "Less than once a month" to "More than once a day".

Brief IPQ

In this survey, the Brief IPQ (Appendix D) measured the perception participants have of their illness. In its original form, the Brief IPQ is a nine-item scale where answers are given on a scale from 0-10, except for the last item where three open answer possibilities are given (Broadbent et al., 2006). For this survey, the last item "Please list in rank-order the three most important factors that you believe caused your illness. The most important causes for me:" was deleted since the open answer possibilities and the ranking were not necessary for this study. Although the questionnaire is a highly simplified version of the IPQ, it has great test-retest reliability and the discriminant validity is given, meaning that each item represents the original subscale satisfactorily (Broadbent et al., 2006).

PIH Scale

The PIH Scale (Appendix E) measured the participant's ability to self-manage their chronic conditions and assessed their illness-related knowledge (D. Smith et al., 2017). The questionnaire consists of 12 items with response categories ranging from 0 to 8 with categories depending on the items. For items 1 and 2 the categories range from "0 - very little" to "8 - A lot", for items 3 to item 8 the categories are "0 - Never" to "8 - Always", and for items 9 to 12 the categories range from "0 - Not very well" to "8 - Very well". For this study, the questionnaire served to investigate the level of self-management ability which was used to further indicate the level of empowerment in the participants. This questionnaire's reliability was tested which resulted in good reliability ($\alpha = .82$).

Empowerment Questionnaire

The questionnaire by Van Uden-Kraan et al. (2008) measured the empowerment processes and empowerment outcomes happening on the platform (Appendix F). The scale of empowering processes consists of 29 items distributed over five subscales. The items are measured on a 4-point scale ranging from "seldom to never" to "often". The empowering outcomes scale consists of 38 items distributed over seven subscales and is measured on a 5-point scale ranging from "completely disagree" to "completely agree". The questionnaire provided insights into the empowering processes and outcomes on the platform which were used in further analysis. Here, the reliability proved to be good with $\alpha = .96$.

Procedure

Ethical approval for this study was obtained by the ethics committee of the faculty of Behavioral, Management and Social Sciences (BMS) at the University of Twente (request number 230236).

Participants were provided with written informed consent to which they could agree by means of clicking “Yes” or “No”. If “No” was selected the survey would automatically close for them. After the informed consent, the participants were asked to provide demographic as well as tinnitus-specific information by answering the adapted TSCHQ. The questions regarding their activity on the platform were only provided if they are currently using or have used “Tinnitus Talk”. If not, they were automatically sent to the IPQ to assess their current illness perception and severity. Next, the PACIC was also only displayed if they indicated that they had healthcare encounters over the last 12 months. The PIH Scale and the empowerment questionnaire were displayed to all participants. After that, the survey ended and there was no compensation for participating.

Data analysis

The data were analysed using the software R with the R Studio interface. Descriptive statistics from the TSCHQ and the activity questionnaire were used to analyse the participant group. Furthermore, participants that were eligible for the study were filtered using the item “For how long do you live with tinnitus” from the TSCHQ. Non-eligible participants were removed from the data set. Next, sum values for the Brief IPQ and the PIH Scale were calculated, and the subscales of the empowerment processes and outcomes were calculated for further analysis. The PACIC results were deleted from the dataset.

To investigate the different hypotheses, multiple analyses were performed. The first hypothesis was analysed by means of simple linear regression analyses with the factor “activity frequency” as the independent variable and the different empowerment outcomes individually as dependent variables. This tested whether the frequency with which people are active influences the empowering outcomes. Next, an exploratory analysis was performed to investigate whether engaging more frequently on the platform would make a difference in empowering outcomes. This was done by comparing “Power Users”, meaning users who answered “Once a day” or “More than once a day” to the question “How often do you visit Tinnitus Talk?” in the activity questionnaire, to standard users who use the platform once a week or less. Since an analysis of variance for the two user groups resulted in unequal variance, a Wilcoxon rank-sum test was used for comparison.

Secondly, to analyse the influence participation timespan has on the empowering outcomes, regression analyses were performed with the covariate “participation timespan” as the independent variable and the different empowerment outcomes individually as dependent variables. Following that, an exploratory analysis was conducted to test the difference between users who engage on the platform for a longer timespan and users who engage for a shorter

timespan. Here, a longer timespan meant every data from the mean activity timespan upwards whereas a shorter timespan was every data below the mean activity timespan. For those two participant groups the size and variance were unequal, so a Wilcoxon rank-sum test was used to compare the groups.

To assess the third hypothesis, multiple regression analyses were performed with the empowering processes as the independent variables and the different empowerment outcomes individually as the dependent variable to investigate to what extent the empowering processes on the platform influence the empowering outcomes. Next, the influence of the platforms' empowering processes and outcomes on illness perception and self-management abilities were analysed because empowerment should positively influence both constructs. This was done by means of Pearson correlation analyses. The influence on illness perception was analysed by calculating Pearson correlation coefficients between the IPQ and the empowerment processes and between the IPQ and the empowerment outcomes. The influence on self-management abilities was tested by computing Pearson correlation coefficients between the PIH and empowerment processes and between the PIH and empowerment outcomes. In all analyses, the significance level was set at $p < .05$ meaning that values greater than that indicate a missing effect and all possible missing values were excluded.

Results

Participants

After two weeks, 96 participants answered the study. 11 participants had to be excluded since they did not fulfil the inclusion criteria which left 85 final participants. Of those participants, the majority were male with 65 participants, 17 were female and 3 were non-binary. The time span of the participants having chronic tinnitus varies majorly ranging from 6 months to 32 years (384 months) with a mean of 8.7 years (103.9 months). Only 5 of the participants indicated that they are currently not active on "Tinnitus Talk". The mean of the participation timespan is 3.8 years (45.2 months). All participant-related descriptive variables are summarised in Table 1.

Table 1*Demographics and Platform Activity of Participants*

Variable	Participants (N = 85)
Gender	
Male	65 (76.5%)
Female	17 (20%)
Non-binary	3 (3.5%)
Age (in years)	
Mean (SD)	40.6 (12.9)
Minimum / Maximum	18 / 75
Country of Residency	
United States of America	26 (31%)
United Kingdom	9 (11%)
Sweden	7 (8.2%)
Spain	7 (8.2%)
Canada	5 (5.9%)
Other	31 (35.7%)
Family History of Tinnitus	
Parents	26 (34%)
Siblings	3 (3.9%)
No Family History	47 (62%)
Unknown	9 (0.1%)

Variable	Participants (N = 85)
Years with Chronic Tinnitus	
Mean (SD)	8.7 (8.4)
Minimum / Maximum	0.5 / 32
Tinnitus Onset Relation	
Loud Blast of Sound	29 (34%)
Change in Hearing	7 (8.2%)
Stress	8 (9.4%)
Other	41 (48%)
Timespan Platform Activity (in years)	
Mean (SD)	3.876 (4.03)
Minimum / Maximum	0.08 / 25
Platform Activity Frequency	
More than once a day	26 (30.6%)
Once a day	9 (10.6%)
More than once a week	22 (26%)
Once a week	15 (17.6%)
Once a month	5 (5.8%)
Less than once a month	2 (2.4%)
Not using the platform	1 (1.2%)
Unknown	5 (5.8%)

Variable	Participants (N = 85)
IPQ Sum Value	
Mean (SD)	60.42 (9.845)
Minimum / Maximum	32 / 78
PIH Sum Value	
Mean (SD)	51.765 (18.84)
Minimum / Maximum	10 / 93

Main Results

To analyse H1 “The frequency of platform activity has a positive influence on the feeling of empowerment” the relationship between frequency of platform activity and empowerment outcomes were measured by means of regression analyses. All analyses resulted without exception in insignificant *p*-values, indicating that there is no statistically significant relationship between the variables. Corresponding values can be found in Appendix G. The exploratory analysis to compare the empowering outcomes of “Power Users” with those of the standard users was done by means of a Wilcoxon rank-sum test since the group variances were unequal. This analysis resulted in thoroughly insignificant *p*-values indicating that there is no difference in empowerment between more frequent users and standard users. Table 2 displays the differences between the “Power Users” and standard users with the according *p*-values.

Table 2*Differences in Empowering Outcomes between Power Users and Standard Users*

	Standard Users		Power Users		<i>W</i>	<i>p</i> -value
	<i>M</i> (SD)	95 % CI	<i>M</i> (SD)	95 % CI		
Feeling better informed	4.1 (0.5)	3.9; 4.3	4.2 (0.8)	3.9; 4.5	646.5	.353
Increased confidence in Physician	3.6 (0.7)	3.3; 3.8	3.7 (0.6)	3.4; 3.9	546.5	.278
Improved illness acceptance	3.6 (0.6)	3.4; 3.8	3.3 (0.9)	3.0; 3.6	758	.539
Increased confidence in treatment	3.4 (0.8)	3.1; 3.6	3.3 (0.8)	3.0; 3.6	726.5	.615
Increased optimism and future control	3.0 (0.7)	2.8; 3.3	2.8 (0.6)	2.6; 3.0	800	.391
Enhanced self-esteem	3.1 (0.8)	2.9; 3.4	3.0 (0.8)	2.7; 3.3	797	.509
Enhanced social wellbeing	3.1 (0.8)	2.9; 3.4	3.1 (0.9)	2.7; 3.4	716.5	.983

Notes. A Wilcoxon rank-sum test was used for analysis. Number of Power Users = 45; Number of Standard Users = 35; total *N* = 80. Abbreviations: *M* = Mean; SD = Standard Deviation; CI = Confidence Interval; *W* = test statistic.

H2 “A longer participation timespan on the platform positively influences the feeling of empowerment” was analysed by investigating the relationship between time spent on the platform and empowerment outcomes. The analyses resulted in thoroughly insignificant *p*-values (significance at $p < .05$), indicating that there is no statistically significant relationship

between the variables (Appendix G). The data was further explored by comparing the users participating for a longer timespan to users participating for a shorter timespan. Since the participant groups showed to have unequal variances, a Wilcoxon rank-sum test was performed which resulted without exception in insignificant p -values. This indicated that there is no difference in empowerment between users who participate for a longer time and those who participate for a shorter time. Table 3 presents the differences between users with a longer participation time and users with a shorter participation time with the according p -values.

Table 3*Differences in Empowering Outcomes between Users with Longer Activity and Shorter Activity*

	Shorter Activity		Longer Activity		<i>W</i>	<i>p</i> -value
	<i>M (SD)</i>	95 % CI	<i>M (SD)</i>	95 % CI		
Feeling better informed	4.1 (0.57)	4.0; 4.3	4.1 (0.8)	3.8; 4.4	747.5	.676
Increased confidence in Physician	3.7 (0.51)	3.5; 3.8	3.5 (0.8)	3.2; 3.8	743.5	.882
Improved illness acceptance	3.5 (0.65)	3.3; 3.7	3.3 (0.9)	3.0; 3.7	795.5	.653
Increased confidence in treatment	3.4 (0.67)	3.2; 3.6	3.2 (0.9)	2.8; 3.5	807.5	.464
Increased optimism and future control	3.0 (0.54)	2.8; 3.1	2.8 (0.8)	2.5; 3.1	870	.407
Enhanced self-esteem	3.1 (0.71)	2.9; 3.3	3.0 (0.9)	2.7; 3.3	846.5	.647
Enhanced social wellbeing	3.1 (0.85)	2.8; 3.3	3.1 (0.8)	2.8; 3.4	751.5	.752

Notes. A Wilcoxon rank-sum test was used for analysis. Number of users with Shorter Activity = 52; Number of users with Longer Activity = 33; total $N = 85$. Abbreviations: M = Mean; SD = Standard Deviation; CI = Confidence Interval; W = test statistic.

The last hypothesis “Users feel empowered through participating on Tinnitus Talk” was investigated by means of multiple regression analysis as well as Pearson correlation analyses between the IPQ and PIH scores and the empowering processes and outcomes.

The multiple regression analysis resulted in significant as well as insignificant outcomes. The outcome of “Feeling better informed” was influenced by the process of “Exchanging information” but other processes showed no significant influence. The corresponding values can be seen in Table 4.

Table 4

Influence of the Empowering Processes on the Outcome “Feeling better informed”

Process	Beta	95% CI	SE	p-value
Intercept	2.00	1.37, 2.63	0.32	<.001
Exchanging information	0.06	0.04, 0.09	0.01	<.001
Exchanging social support	0.01	-0.01, 0.04	0.01	.263
Comparison with other members	0.04	-0.01, 0.10	0.03	.114
Helping others	-0.01	-0.12, 0.09	0.05	.781
Sharing experiences	-0.03	-0.11, 0.06	0.04	.512

Notes. Abbreviations: CI = Confidence Interval; SE = Standard Error.

Additionally, the process of “Exchanging information” had a significant influence on the outcome of “Increased confidence in physician” whereas other processes showed no significant influence (Table 5). This indicates that an increase in confidence in the physician is given when an exchange of information happens.

Table 5*Influence of the Empowering Processes on the Outcome “Increased confidence in physician”*

Process	Beta	95% CI	SE	p-value
Intercept	1.79	1.21, 2.37	0.29	<.001
Exchanging information	0.05	0.03, 0.08	0.01	<.001
Exchanging social support	0.01	-0.01, 0.04	0.01	.278
Comparison with other members	0.01	-0.04, 0.06	0.03	.699
Helping others	0.06	-0.04, 0.15	0.05	.243
Sharing experiences	-0.02	-0.10, 0.06	0.04	.630

Notes. Abbreviations: CI = Confidence Interval; SE = Standard Error.

The process of “Exchanging social support” resulted in a statistically significant influence on the outcome of “Improved Illness Acceptance”. Other processes showed to be non-significant (Table 6).

Table 6*Influence of the Empowering Processes on the Outcome “Improved acceptance of the illness”*

Process	Beta	95% CI	SE	p-value
Intercept	1.64	0.84, 2.43	0.39	<.001
Exchanging information	0.02	-0.01, 0.05	0.02	.231
Exchanging social support	0.04	0.01, 0.07	0.02	.021
Comparison with other members	0.05	-0.01, 0.12	0.03	.119
Helping others	0.00	-0.14, 0.13	0.07	.958
Sharing experiences	-0.03	-0.13, 0.08	0.05	.597

Notes. Abbreviations: CI = Confidence Interval; SE = Standard Error.

The empowering outcome of “Increased confidence in their treatment” showed to be significantly influenced by the processes of “Exchanging information” and “Helping others” (Table 7).

Table 7

Influence of the Empowering Processes on the Outcome “Increased confidence in their treatment”

Process	Beta	95% CI	SE	p-value
Intercept	1.44	0.70, 2.17	0.37	<.001
Exchanging information	0.05	0.02, 0.08	0.02	.003
Exchanging social support	0.02	-0.01, 0.05	0.01	.207
Comparison with other members	0.01	-0.05, 0.07	0.03	.754
Helping others	0.13	0.00, 0.25	0.06	.046
Sharing experiences	-0.06	-0.16, 0.04	0.05	.247

Notes. Abbreviations: CI = Confidence Interval; SE = Standard Error.

All empowering processes resulted in insignificant *p*-values for the outcomes of “Increased optimism and control over the future” (Table 8) and “Enhanced self-esteem” (Table 9). This indicates that both outcomes were not influenced by any empowering processes on the platform.

Table 8

Influence of the Empowering Processes on the Outcome “Increased optimism and control over the future”

Process	Beta	95% CI	SE	p-value
Intercept	1.63	0.84, 2.43	0.39	<.001
Exchanging information	0.02	-0.02, 0.05	0.02	.363
Exchanging social support	0.02	-0.01, 0.05	0.02	.246
Comparison with other members	0.06	-0.01, 0.12	0.03	.100
Helping others	0.06	-0.07, 0.19	0.07	.360
Sharing experiences	-0.08	-0.19, 0.02	0.05	.120

Notes. Abbreviations: *CI* = Confidence Interval; *SE* = Standard Error.

Table 9

Influence of the Empowering Processes on the Outcome “Enhanced self-esteem”

Process	Beta	95% CI	SE	p-value
Intercept	1.30	0.43, 2.17	0.44	.004
Exchanging information	0.03	-0.01, 0.06	0.02	.149
Exchanging social support	0.03	-0.01, 0.06	0.02	.103
Comparison with other members	0.04	-0.04, 0.11	0.04	.34
Helping others	0.03	-0.12, 0.17	0.07	.732
Sharing experiences	-0.01	-0.13, 0.11	0.06	.852

Notes. Abbreviations: *CI* = Confidence Interval; *SE* = Standard Error.

Finally, the analysis for the outcome “Enhanced social well-being” resulted in a significant p -value for the process of “Exchanging social support” indicating that the exchange positively influences social well-being (Table 10).

Table 10

Influence of the Empowering Processes on the Outcome “Enhanced social well-being”

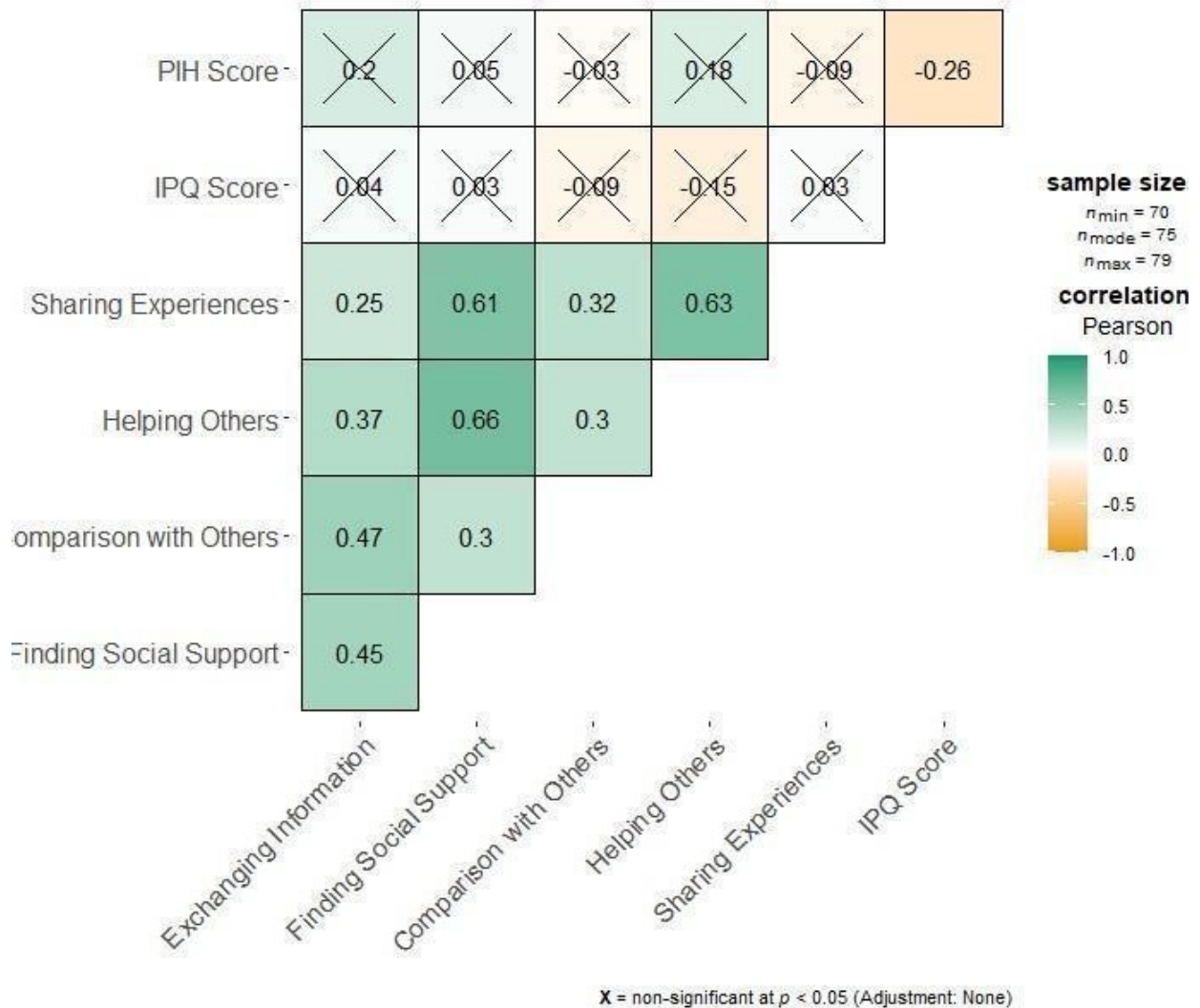
Process	Beta	95% CI	SE	p-value
Intercept	1.07	0.18, 1.97	0.45	.020
Exchanging information	0.04	0.00, 0.08	0.02	.057
Exchanging social support	0.06	0.02, 0.10	0.02	.001
Comparison with other members	0.01	-0.07, 0.09	0.04	.797
Helping others	-0.07	-0.23, 0.09	0.08	.393
Sharing experiences	-0.01	-0.13, 0.12	0.06	.891

Notes. Abbreviations: CI = Confidence Interval; SE = Standard Error.

The correlation analyses for the IPQ Score and the empowering processes as well as the correlation analyses for the PIH Score and the empowering processes resulted in thoroughly non-significant p -values indicating no significant correlation between the variables. The correlation coefficients are displayed in Figure 1. All non-significant p -values ($> .05$) are indicated by a cross. Missing values were excluded from the analyses.

Figure 1

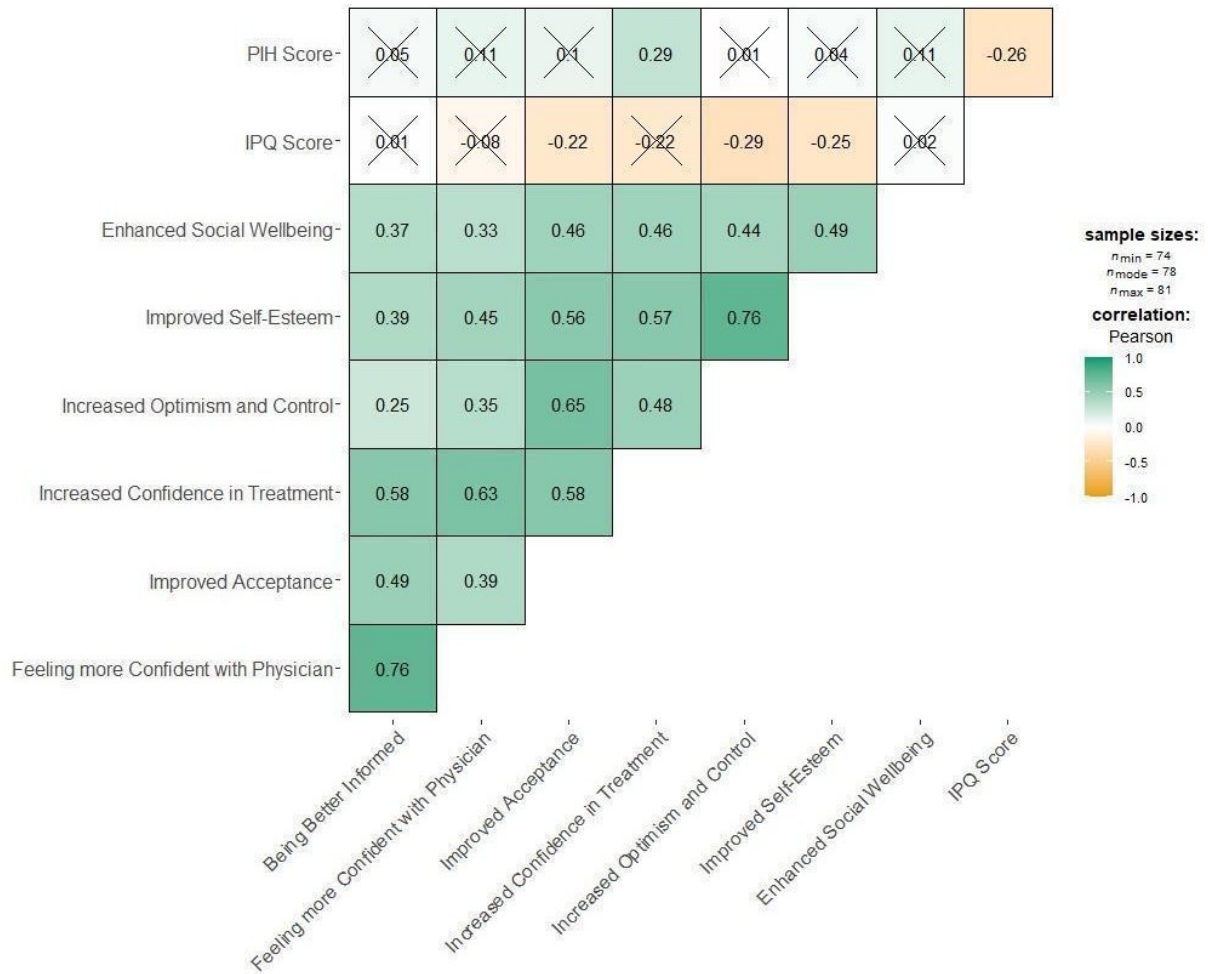
Correlation Coefficients for IPQ and PIH Scores and Empowering Processes



The IPQ score and the empowering outcomes were found to be moderately correlated with the outcomes of “Improved Acceptance” ($r(76) = -.22, p = .05$), “Increased Optimism and Future Control” ($r(77) = -.29, p = .009$) and “Improved Self-esteem” ($r(78) = -.25, p = .025$). This indicates that a significant correlation is at hand. For all other empowering outcomes, the correlation analyses remained insignificant. The PIH score and empowering outcomes analyses resulted in non-significant p -values except for the outcome “Increased Confidence in Treatment”. Here the variables were found to be moderately correlated ($r(73) = .29, p = .011$) which suggests that only for this outcome a significant correlation is existent. The corresponding correlation coefficients are displayed in Figure 2 with all insignificant p -values ($> .05$) marked by a cross. Missing values were excluded from the analyses.

Figure 2

Correlation Coefficients for IPQ and PIH Scores and Empowering Outcomes



Discussion

This study investigated the extent to which users feel empowered by the platform Tinnitus Talk. The results from the regression analyses and the Wilcoxon rank-sum test led to the conclusion that the first hypothesis “The frequency of platform activity has a positive influence on the feeling of empowerment” and the second hypothesis “A longer participation timespan on the platform positively influences the feeling of empowerment” can be rejected. The regression analyses showed that there is no significant relationship between the activity time nor the activity frequency and the empowering outcomes. This means that the frequency and timespan with which a user is active on Tinnitus Talk has no further influence on their feeling of empowerment. Furthermore, the comparison between user groups based on activity timespan and frequency showed that the time a user invests on the platform has no influence on the empowering outcomes.

The third hypothesis “Users feel empowered through participating on Tinnitus Talk” must be accepted. The results indicate that empowering processes happening on Tinnitus Talk have a significant influence on some empowering outcomes. This is suggested by the relationship that “exchanging information” and “helping others” have with several aspects of empowerment like being better informed about the illness or being more confident with their treatment and the physician. Furthermore, “exchanging social support” influences the acceptance of the illness and the social well-being of the user. Those results suggest that the processes happening on Tinnitus Talk increase the empowering outcomes and so the empowerment of the user. Adding to that, the results derived from the correlation analyses can be used to support the positive association between empowerment and illness perception and self-management (Foster, 2016; Nickel et al., 2019). In the current study, the correlation analyses indicate that some empowering outcomes moderately influence the self-management abilities of the users while also moderately influencing their illness perception. This can be explained by looking at the specific outcomes which are “increased acceptance”, “increased optimism and future control”, “increased self-esteem” and “increased confidence in treatment”. Those results suggest that self-management abilities and illness perception can be positively influenced to some extent by the empowering outcomes on the platform. Nevertheless, the empowering processes seem to influence self-management abilities or illness perception not directly in this analysis, indicating that only the “final” empowering outcomes are of importance in this context.

All those outcomes indicate a change in the user's perspective to a more accepting thinking about their illness and an indication of being supported in their self-management

through Tinnitus Talk. It can be said that simply joining the platform and participating in empowering processes like exchanging with others or finding support is enough to feel more empowered. The results of that study suggest that finding empowering outcomes is independent of the frequency or timespan of the users' activity and therefore, users of Tinnitus Talk experience empowerment.

Those findings are generally in line with previous research on the empowering effects of online self-help platforms. Two previous studies already indicated that users of self-help platforms experience an improvement in empowerment as well as an increase in their self-management abilities. Hereby, the studies also found that those outcomes are independent of the activity frequency or intensity of the users, meaning that consuming the content alone is sufficient to experience empowering outcomes (Smit et al., 2022; Van Uden-Kraan et al., 2008). Furthermore, a study by Hughes et al. (2021) indicated that participation in an online self-help platform could support users in feeling empowered. This happened by means of experiencing social support, finding advice regarding medication or different treatments or being encouraged by other users. Hughes et al.'s study also investigated part of the mental health aspects of self-help platforms and could indicate a positive influence of participation on mental health.

Strengths

To my knowledge all previous studies focused on a variety of illnesses, sometimes even combined, but not solely on tinnitus. Furthermore, there is no previous study in connection to Tinnitus Talk regarding the empowerment of the platform. Those studies mainly focus on treatment options and platform-specific processes like discontinuation of usage. Therefore, this current study is the first to investigate empowerment processes and outcomes specifically on Tinnitus Talk.

Limitations

First, it needs to be mentioned that there were fewer participants than expected since the distribution happened over a posting in a forum on the platform Tinnitus Talk itself. This form of distribution led to a self-selection bias meaning that it is probable that more frequently active users decided to participate than standard or less frequent users. Additionally, it was not possible to compare users with non-users since the survey was not published for the general public.

Secondly, publishing the survey only on one tinnitus platform does not allow for a larger variety of people with tinnitus to participate in the study. When publishing on an international platform the survey should account for different healthcare systems or cultures which might influence results. This was not given in the current study.

Lastly, it has to be noted that, although the results of this study can be said to be replicable, those results cannot be said to be representative of the whole tinnitus population. This is due to the named self-selection bias and because the sample was derived from only one self-help platform in a specific forum.

Future Directions

Because of the named limitations, this study cannot be titled generalisable but nevertheless, it serves as a basis for future research possibilities. Since there is still much to research in regard to tinnitus this could serve as a starting point for investigating the influence of mental support and empowerment through self-help platforms on tinnitus.

It is advisable to distribute the survey on multiple self-help platforms specialised in tinnitus to reach a greater number and variety of participants. Furthermore, the aspect of mental health should be investigated by adding a fitting questionnaire to the survey since there is evidence in this study as well as in the study by Hughes et al. (2021) that psychological processes like “social support” or “acceptance of illness” are taking a role in empowerment. The addition of a mental health aspect could provide the possibility to further investigate the processes happening and the outcomes resulting from the interactions, which can help in understanding the influence of self-help platforms on the users.

Furthermore, using a non-cross-sectional design in future research could assist in providing clearer directions of found relationships and gaining more insights into the processes. Additionally, future research should investigate differences between users and non-users of self-help platforms to gain a clearer picture of the actual influence of self-help platforms. Those improvements to the study could provide a better overview of the actual influence that empowerment through self-help platforms has on patients.

Finally, the use of self-help platforms should be supported in general healthcare. As Eskildsen et al. (2017) already discussed, doctors need to be supportive in the process of patient empowerment so they could include suggestions for self-help platforms for patients. Those suggestions and the provision of ideas could help tinnitus patients to gain more knowledge and learn possibilities to cope with the illness to influence their situation for the better.

Conclusion

Concluding it can be said that users of the platform Tinnitus Talk experience the feeling of empowerment through interaction with other users. This happens independently of the frequency with which the users participate on the platform and also independently from the timespan of participation. Furthermore, people that feel empowered should also be able to self-manage their illness better and perceive their illness as more manageable (Foster, 2016; Nickel

et al., 2019). In this study, it can be seen that different empowerment outcomes do have an influence on the self-management ability and the illness perception of the users. Therefore, all results suggest the existence of patient empowerment through Tinnitus Talk.

References

- Baguley, D., McFerran, D., & Hall, D. (2013). Tinnitus. *The Lancet*, 382(9904), 1600–1607. [https://doi.org/10.1016/S0140-6736\(13\)60142-7](https://doi.org/10.1016/S0140-6736(13)60142-7)
- Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The Brief Illness Perception Questionnaire. *Journal of Psychosomatic Research*, 60(6), 631–637. <https://doi.org/10.1016/J.JPSYCHORES.2005.10.020>
- Eskildsen, N. B., Joergensen, C. R., Thomsen, T. G., Ross, L., Dietz, S. M., Groenvold, M., & Johnsen, A. T. (2017). Patient empowerment: a systematic review of questionnaires measuring empowerment in cancer patients. *Acta Oncologica*, 56(2), 156–165. <https://doi.org/10.1080/0284186X.2016.1267402>
- Foster, D. (2016). ‘Keep complaining til someone listens’: Exchanges of tacit healthcare knowledge in online illness communities. *Social Science & Medicine*, 166, 25–32. <https://doi.org/10.1016/J.SOCSCIMED.2016.08.007>
- Hughes, A., Heydarian, N., Gerardo, D., Solis, I., & Morera, O. (2021). Seeking Health Information and Social Support in the Diabetes Online Community. *Frontiers in Clinical Diabetes and Healthcare*, 2. <https://doi.org/10.3389/fcdhc.2021.708405>
- Jarach, C. M., Lugo, A., Scala, M., Van Den Brandt, P. A., Cederroth, C. R., Odone, A., Garavello, W., Schlee, W., Langguth, B., & Gallus, S. (2022). Global Prevalence and Incidence of Tinnitus: A Systematic Review and Meta-analysis. *JAMA Neurology*, 79(9), 888–900. <https://doi.org/10.1001/JAMANEUROL.2022.2189>
- Kreuzer, P. M., Vielsmeier, V., & Langguth, B. (2013). Chronic Tinnitus: an Interdisciplinary Challenge. *Deutsches Ärzteblatt International*, 110(16), 284. <https://doi.org/10.3238/ARZTEBL.2013.0278>
- Mazurek, B., Hesse, G., Dobel, C., Kratzsch, V., Lahmann, C., & Sattel, H. (2022). Chronic Tinnitus: Diagnosis and Treatment. *Deutsches Ärzteblatt International*, 119(13), 225. <https://doi.org/10.3238/ARZTEBL.M2022.0135>
- Nickel, S., Haack, M., von dem Knesebeck, O., Dierks, M. L., Seidel, G., Werner, S., & Kofahl, C. (2019). Participation in self-help groups: impact on self-management and knowledge.

- Bundesgesundheitsblatt - Gesundheitsforschung - Gesundheitsschutz*, 62(1), 10–16.
<https://doi.org/10.1007/S00103-018-2850-8/FIGURES/1>
- Our Mission*. (n.d.). TinnitusHub. Retrieved March 7, 2023, from
<https://www.tinnitushub.com/about/our-mission/>
- Petersson, C., Nygårdh, A., & Hedberg, B. (2022). To support self-management for people with long-term conditions – The effect on shared decision-making, empowerment and coping after participating in group-learning sessions. *Nursing Open*, 9(5), 2444–2453.
<https://doi.org/10.1002/NOP2.1261>
- Piccirillo, J. F., Rodebaugh, T. L., & Lenze, E. J. (2020). Tinnitus. *JAMA*, 323(15), 1497–1498.
<https://doi.org/10.1001/JAMA.2020.0697>
- Probst, T., Pryss, R. C., Langguth, B., Spiliopoulou, M., Landgrebe, M., Vesala, M., Harrison, S., Schobel, J., Reichert, M., Stach, M., & Schlee, W. (2017). Outpatient Tinnitus clinic, self-help web platform, or mobile application to recruit tinnitus study samples? *Frontiers in Aging Neuroscience*, 9(APR), 113.
<https://doi.org/10.3389/FNAGI.2017.00113/BIBTEX>
- Smit, D., Vrijzen, J. N., Broekman, T., Groeneweg, B., & Spijker, J. (2022). User Engagement Within an Online Peer Support Community (Depression Connect) and Recovery-Related Changes in Empowerment: Longitudinal User Survey. *JMIR Formative Research*, 6(11).
<https://doi.org/10.2196/39912>
- Smith, D., Harvey, P., Lawn, S., Harris, M., & Battersby, M. (2017). Measuring chronic condition self-management in an Australian community: factor structure of the revised Partners in Health (PIH) scale. *Quality of Life Research*, 26(1), 149–159.
<https://doi.org/10.1007/S11136-016-1368-5/TABLES/4>
- Smith, S. N., Broomhead, E., Greenwell, K., Watts, E., Stockdale, D., & Hoare, D. J. (2018). Promotion and views on tinnitus self-help within United Kingdom national health service audiology departments. *International Journal of Audiology*, 57(12), 900–907.
https://doi.org/10.1080/14992027.2018.1512013/SUPPL_FILE/IJA_A_1512013_SM8893.DOCX

STROBE Checklist_V4 Cross-sectional study. (n.d.). Retrieved May 18, 2023, from <https://www.strobe-statement.org/checklists/>

Tinnitus: Ringing in the ears and what to do about it. (2022, August 15). Harvard Health Publishing. https://www.health.harvard.edu/newsletter_article/tinnitus-ringing-in-the-ears-and-what-to-do-about-it

Tinnitus Sample Case History Questionnaire (TSCHQ). (n.d.). Tinnitus Research Initiative. Retrieved April 13, 2023, from https://www.tinnitusresearch.net/images/files/migrated/consensusdocuments/en/TINNITUS_SAMPLE_CASE_HISTORY_QUESTIONNAIRE.pdf

Tinnitus Talk Support Forum. (n.d.). Retrieved May 19, 2023, from <https://www.tinnitustalk.com/>

Van Uden-Kraan, C. F., Drossaert, C. H. C., Taal, E., Seydel, E. R., & Van De Laar, M. A. F. J. (2008). Self-Reported Differences in Empowerment Between Lurkers and Posters in Online Patient Support Groups. *Journal of Medical Internet Research*, 10(2). <https://doi.org/10.2196/JMIR.992>

Appendix A

Informed Consent

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:

Mia Terborg:

Jorge Piano Simoes, PhD (supervisor):

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

No

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

No

Appendix B

TSCHQ

Gender

- Male
- Female
- Non-binary
- Other

Age

In which country do you reside?

Which statement best describes your current employment status?

- Working (paid employee)
- Working (self-employed)
- Not working (temporary layoff from a job)
- Not working (looking for work)
- Not working (retired)
- Not working (disabled)
- Not working (other)
- Prefer not to answer

Handedness

- Right
- Left
- Both sides

What is the highest education level you have achieved?

- No school
- Primary (elementary school)
- Lower secondary (middle school)
- Upper secondary (high school)
- University (higher degree)
- Other

Family history of tinnitus complaints:

- Yes, Parents
- Yes, Siblings
- Yes, Children
- No
- I do not know

For how long do you live with tinnitus:

- Months _____
- Years _____
- I do not know

How did you perceive the beginning of tinnitus?

- Gradually
- Abruptly

Was the initial onset of your tinnitus related to:

- Loud blast of sound
- Whiplash
- Change in hearing
- Stress
- Head trauma
- Other

Does your tinnitus seem to pulsate?

- Yes, with heart beat
- Yes, different from heart beat
- No

Where do you perceive your tinnitus?

- Right ear
- Left ear
- Both ears, worse in left
- Both ears, worse in right
- Both ears, equally
- Inside the head
- Elsewhere

How does your tinnitus manifest itself over time?

- Intermittent
- Constant

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

- Yes
- No

Describe the loudness of your tinnitus using a scale from 1-100
(1=Very Faint; 100=Very Loud)

Does your tinnitus more sound like a tone or more like noise?

- Tone
- Noise
- Crickets
- Other

Please describe the pitch of your tinnitus:

- Very high frequency
- High frequency
- Medium frequency
- Low frequency

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

- Yes
- No

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
- No
- I don't know

Does the presence of loud noise make your tinnitus worse?

- Yes
- No
- I don't know

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
- No

Does taking a nap during the day affect your tinnitus?

- Worsens my tinnitus
- Reduces my tinnitus
- Has no effect

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

- Yes
- No
- I don't know

Does stress influence your tinnitus?

- Worsens my tinnitus
- Reduces my tinnitus
- Has no effect

Do you think you have a hearing problem?

- Yes
- No

Do you wear hearing aids?

- Right ear
- Left ear
- Both ears
- No

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
- Rarely
- Sometimes
- Usually
- Always

Do sounds cause you pain or physical discomfort?

- Yes
- No
- I don't know

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

- More than once a week
- Once a week
- A few times a month
- I did not suffer from headaches

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

- More than once a week
- Once a week
- A few times a month
- I did not suffer from vertigo or dizziness

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
- Once a week
- A few times a month
- I did not suffer from temporomandibular disorder

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

- More than once a week
- Once a week
- A few times a month
- I did not suffer from neck pain

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

- More than once a week
- Once a week
- A few times a month
- I did not suffer from other pain syndromes

Appendix C

User Activity

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

Are you currently using or have you used Tinnitus Talk?

- Yes
- No

How long have you been participating on Tinnitus Talk?

- Months _____
- Years _____
- I do not know

How often do you visit Tinnitus Talk?

- Once a day
- More than once a week
- Once a week
- Once a month
- Less than once a month
- I do not use it

Have you ever posted on Tinnitus Talk?

- Yes, I am an active poster on Tinnitus Talk
- Yes, but not anymore
- No, I never posted on Tinnitus Talk

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

- More than once a day
- Once a day
- Once a week
- Once a month
- Less than once a month

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

0 1 2 3 4 5 6 7 8

Never

Always

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

0 1 2 3 4 5 6 7 8

Not

Very well

very well

I manage the effect of my tinnitus on how I feel (i.e. my emotions and spiritual wellbeing)

0 1 2 3 4 5 6 7 8

Not

Very well

very well

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

0 1 2 3 4 5 6 7 8

Not

Very well

very well

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

0 1 2 3 4 5 6 7 8

Not

Very well

very well

Appendix F

Empowering Processes and Outcomes

Empowering Processes

Answer categories: “Seldom to never”, “Sometimes”, “Regularly”, “Often”

Exchanging information

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

...understandable

...valuable

...usable

...new

...applicable to my present situation

...reliable

...correct

...of added value to the information I receive from my care providers

...in line with the information I receive from my care providers

Exchanging social support

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

...invites you to have (personal) contact outside this online support group?

...starts a private conversation with you?

...is empathic?

...consoles you?

...pays you a compliment?

...is interested in you?

...pays particular attention to you in special cases, such as during illness or moving house?

...reassures you?

...offers you sound advice?

...points out your strengths?

...confides in you?

...asks you for your help or advice?

The comparison with other online support group members

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

...you recognize yourself in the stories of other online support group members?

...you experience the sense of ‘not being the only one’?

...others are an example to you?

...you realise that you are not so bad off after all?

Helping others

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

...you can be an example to other participants?

...you can offer advice and support to others?

Sharing experiences

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

...your experiences with your illness with others?

...your everyday experiences with others?

Empowering Outcomes

Answer categories: “completely disagree”, “disagree”, “neither agree nor disagree”, “agree”, “strongly agree”

Feeling better informed

Through my participation in this online support group...

...I feel better informed as a patient.

...I understand my illness better.

...I have a clearer picture about my illness.

...I feel like I have more (correct) knowledge at my disposal to deal better with my illness.

Feeling more confident in the relationship with their physician

Through my participation in this online support group...

...I feel better prepared for a doctor’s appointment.

...I am more knowledgeable about which questions to ask my physician.

...I can explain my needs to my physician better.

...I have more courage to raise matters with my physician.

...I am more able to oppose my physician.

...I understand the information provided by my physician better.

...the relationship with my physician has improved.

...the relationship with my physician has deteriorated.

...I am more able to judge when I really need the help of my physician.

...I feel less dependent on my physician.

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

Improved acceptance of the illness

Through my participation in this online support group...

...I am able to be more open about my own illness.

...I can tell others more easily when I am no longer able to do something.

...I can ask others for help more quickly.

...I can give in to my illness better.

...I can accept my illness better.

Increased confidence in their treatment

Through my participation in this online support group...

...I can stick to my treatment regime better.

...I am more able to follow the medical guidelines and advice of my physician.

...I know where to go with questions about my illness.

...I feel I am more skilled at dealing well with my illness.

...I feel able to make the right decisions with regard to my illness.

Increased optimism and control over the future

Through my participation in this online support group...

...I feel more in charge of the course of my illness.

...I feel I can influence my illness myself.

...I feel more in control over what is happening to me.

...I feel less in control over what is happening to me.

...I feel that what happens to me in the future is to a large degree dependent on myself.

...I have learned to be more positive.

...I have more faith in the future.

...I have less faith in the future.

Enhanced self-esteem

Through my participation in this online support group...

...I have a greater sense of worth.

...I have a more positive attitude towards myself.

...I am in general more content with myself.

Enhanced social well-being

Through my participation in this online support group...

...I feel less lonely.

...I have made new social contacts.

Appendix G

Table 11

p-Values corresponding to Platform Activity, Timespan on Platform, and Empowering Outcomes

	Feeling Better Informed	Increased Confidence with Physician	Improved Illness Acceptance	Increased Confidence in Treatment	Increased Optimism and Future Control	Enhanced Self-esteem	Enhanced Social Wellbeing
Activity							
More than once a day	$p = .627$	$p = .299$	$p = .612$	$p = .620$	$p = .536$	$p = .780$	$p = .821$
Once a day	$p = .780$	$p = .621$	$p = .315$	$p = .352$	$p = .513$	$p = .463$	$p = .715$
More than once a week	$p = .775$	$p = .291$	$p = .646$	$p = .565$	$p = .783$	$p = .827$	$p > .999$
Once a week	$p = .801$	$p = .592$	$p = .928$	$p = .708$	$p = .924$	$p = .921$	$p = .782$
Once a month	$p = .534$	$p = .470$	$p = .814$	$p = .712$	$p = .464$	$p = .708$	$p = .599$
Less than once a month	$p > .999$	$p = .190$	$p = .855$	$p = .125$	$p = .298$	$p = .503$	$p = .814$
Timespan of Activity	$p = .453$	$p = .469$	$p = .626$	$p = .424$	$p = .857$	$p = .856$	$p = .610$