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The role of significant others in the process of internet-delivered intervention for tinnitus: a qualitative study

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Abstract

Internet-delivered interventions for tinnitus have been found to be efficacious in reducing tinnitus distress. Additionally, various client, therapist, and intervention factors related to good outcomes in internet-delivered interventions have been studied. However, the role that other people play in the processes of internet-delivered treatments has received less attention. The aim of this study was to investigate how participants receiving an internet-delivered psychological treatment for tinnitus perceived the role of significant others in the process of their treatment. In total, 14 participants of an internet-delivered CBT and mindfulness-based psychological interventions for tinnitus were interviewed using a semi-structured interview after the completion of treatment. They were asked a series of questions, including if they told anyone about their participation in the intervention. Interviews were recorded, transcribed, and then coded using the method of thematic analysis. Two main themes with three and four sub-themes for each main theme were derived from the data. A) Other people know: 1. Support; 2. Neutrality; 3. Autonomy; 4. Misunderstood. B) Other people do not know: 1. Underappreciated; 2. Hiding; 3. Stigma. Results show that other people played various roles in the participants' efforts to complete the internet-delivered intervention. Some themes were found to be closely related to tinnitus, whereas others were more general. Other people may play a significant role in the treatment process when engaging in internet-delivered interventions, whether actively or passively, as reported by the participants. Stigma and previous negative experiences of not being understood after sharing information about tinnitus were among the few of the reasons for not involving others. In contrast, participants also talked about the positive impact of surrounding people who encouraged and supported their participation in the intervention. Further studies should examine how significant others may impact the engagement with the intervention and possibly the overall effects on treatment outcome. Social support has been shown to be an important factor in treatment success in previous studies. The present study demonstrated participants'

experiences with involving significant others with their tinnitus treatment. Strategies for how to meaningfully include surrounding people in internet-delivered treatments need to be investigated as this could increase treatment efficacy. _____

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1. Background

Very little is known about how other people impact the efficacy of internet-delivered psychological interventions for somatic and mental health conditions. Psychological treatments were traditionally delivered in a live format in the room of a psychologist where other people could not participate. However, with internet-delivered interventions gaining even more popularity in recent years [1], the question of how surrounding people influence the process of participating in internet-delivered interventions warrants investigation. A non-synchronous delivery of the intervention, including the support of a psychologist, allows participants to take the intervention at their own pace, at their desired time, and in a location of their choosing. Although these factors could be beneficial, certain risks also occur. For example, participants may decide to engage with the intervention when other people are around or, on the contrary, be restrained by time and instead look for opportunities to connect to the interventions when no one else is around.

Some problems requiring psychological treatment may be more evident to other people than others. Tinnitus is a condition when a person hears a ringing or buzzing sound(s) when there is no external sound [2]. This makes it impossible for others to observe subjective tinnitus. The estimated prevalence of tinnitus in an adult population is 10 to 15% [2]. Usually, individuals experiencing tinnitus adapt to living with it. However, a substantial minority of people experience tinnitus as debilitating (around 20%). This means that in the adult general population, 1 to 3% experience chronic tinnitus, which can disturb everyday life and cause emotional difficulties and sleep problems [3]. Hearing problems, which are very common in the tinnitus population, have been shown to be associated with stigma [4], and by definition, stigma is associated with isolation from others. Therefore, we could expect that some individuals experiencing tinnitus will be withdrawn from others or will not want to communicate with others regarding anything related to their tinnitus. However, not sharing your tinnitus-related difficulties also means not being able to receive social support.

Previous studies have demonstrated that social support could help clients engage better with psychotherapy. Engagement with the intervention has been operationalized variously across different studies, from ‘the more, the better’ to specific thresholds being proposed [5,6]. Engagement with the intervention was found to be directly related to better treatment outcomes [5,7]. It is, therefore, crucial to understand if and how other people (usually significant others) might influence the participant’s ability to engage with the intervention and to adhere to treatment protocol.

An extensive review of engagement measurement literature on digital behavior change interventions demonstrated that social support previously was usually studied within the intervention by exploiting participant forums and the like [5]. Although some studies have previously studied the impact of tinnitus on significant others [8–10], no studies seem to have examined how other people in participant’s everyday life could affect their engagement with internet-delivered interventions. This is a major gap in internet-delivered intervention literature. In traditional face-to-face therapy, we know that the client is alone in a session. This is not necessarily the case in internet-delivered asynchronous treatments. Some clients might decide to work through intervention materials at home or at work, or, with most interventions being mobile-accessible, even in public spaces like cafés or parks. Clients also have the ability to engage with the intervention at their chosen time. Do they wait for their cohabitants to fall asleep, or do they need to wait until the computer is free to use? Finally, do they tell others about their

participation in the treatment, or do they keep it to themselves? Although previous studies have investigated some of these questions, relatively little is known about how other people interact with them.

In sum, not enough is known about the role other significant persons play in the process of completing internet-delivered therapist-guided treatment. The aim of this study was to interview individuals who had taken part in an internet-delivered therapist-guided treatment program for tinnitus distress in order to gain a better understanding of how they viewed the role of significant others when engaging in the treatment.

2. Methods

To address the aim of the study, we conducted a qualitative study with participants of an internet-delivered intervention for bothersome tinnitus [11]. A semi-structured interview was designed to explore participants' experiences concerning the role of significant others in the treatment process/engagement.

Participants were selected from a study of a therapist-guided internet-delivered treatment for individuals with bothersome tinnitus to reflect various levels of adherence and engagement. In total, 12 women and 2 men participated in the interview. The mean age was 50.0 years ($SD = 16.86$, range: 22-77). All participants reported high scores (28+) on the Tinnitus Handicap Inventory [12] ($M = 53.0$; $SD = 14.34$).

Table 1. Participant's characteristics.

Code	Participant* male(m)/female(f)	THI pre-treatment score
P001	Olivia (f)	74
P002	Emma (f)	68
P003	Charlotte (f)	70
P004	Amelia (f)	58
P005	Sophia (f)	40
P006	Isabella (f)	40
P007	Ava (f)	58
P008	John (m)	52
P009	Evelyn (f)	40
P010	Martin (m)	72
P011	Mia (f)	74
P012	Evelyn (f)	76
P013	Luna (f)	50
P014	Harper (f)	78

Note: *- Participant name changed from original to maintain confidentiality.

The questions for the semi-structured interview were formulated in an open-ended manner and are presented in Table 2.

Table 2. Questions for the semi-structured interview

No	Question
1	Tell us what motivated you to get involved in the program.
2	What was it that prevented you from getting involved in the program?

- 3 What do you think was missing from the program? (CLARIFYING QUESTION: What other suggestions would you have for improving this program?)
 - 4 Please tell me how many people in your environment - relatives, friends, colleagues, other people - were aware of your participation in the program. (CLARIFYING QUESTION: How did you choose to share/not to share the fact that you are participating in a program for tinnitus?)
 - 5 Please tell me how others around you, including family members, influenced your participation and involvement in the program. (CLARIFYING QUESTION: How have the actions/presence of relatives/bystanders helped or hindered your participation in the program?)
 - 6 Finally, we would like to ask how you found out about the Tinnitus Support Program.
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The interview was done by phone and audio recorded. The interviewers (LA and JE) also served as psychologists in the trial but only interviewed participants that they had not managed. The interviews were transcribed (LA) and later analyzed using the thematic analysis approach [13]. Two independent researchers (DL, GAM) listened to the interviews and analysed the data. First, the text was searched for meaningful units, which were then grouped into codes. The codes were summarised and themes were derived from them. Later, both researchers discussed and resolved any differences in themes through discussion. A third researcher (JE) was consulted if disagreements could not be resolved. The trial was approved by the Vilnius University Psychology Research Ethics Committee, 22-01-2021 No. 57.

3. Results

The thematic analysis resulted in two themes comprised of three and four codes (Table 2). First, some participants shared that they had shared information about their participation with significant others and that they received support, neutral reactions or their own perspective that this is an individual matter and they were autonomous in the treatment process. Second, other participants reported that they did not share about their participation with other significant people and explained their reasons: fear of being underappreciated or even stigmatized. Additionally, some participants shared that they actively hid their participation from other people in their lives.

Table 3. Themes and codes

Theme	Code	Example Quote
Other people know	Support	"My husband knew about my participation. Of course, this is our relationship, so he was very supportive and even reminded me." (P002) "My granddaughter helped, tried to help me sign up and everything." (P009)
	Neutrality	"It's my business here, I suppose. They do not help. I decided to participate, I really wanted to and I participated. They had no effect. I just stated the fact that I am participating and that's it" (P011)
	Autonomy	"It wasn't that they were there to encourage or discourage. They knew I was involved and that was it, and more than that it was my personal business." (P014)
	Misunderstood	"My husband is very skeptical about all psychologists. He said to me, "Don't you have anything to do?" (P001)
Other people do not know	Underappreciated	"If you talk to professionals or people close to you who don't have tinnitus, nobody seems to understand" (P010)
	Hiding	"No, I didn't. <...> It was my personal business, but they didn't interfere." (P006)

	"It seems like a very boring and depressing subject, so it doesn't pay to talk about it." (P010)
Stigma	"<...> as my mother says, this is my shame, my misery. And maybe not that I consider it my shame, but it's still a thing that you don't talk about out loud to anybody and it's an internal thing that you're trying to deal with somehow." (P014)
	"My family, really, because I don't boast and tell about my illness to friends and colleagues." (P004)

4. Discussion

Our study showed that significant others played various direct and indirect roles in the process of participating in an internet-delivered intervention for bothersome tinnitus. Participants either shared or did not share information about their participation in the intervention with people in their lives.

Many participants talked about the support they had received from their family, colleagues, physicians and psychologists before and during the intervention. Social support has been found to be directly related to good mental health and treatment outcomes [14,15]. Neutrality emerged as another important topic – sometimes other people reacted just neutrally to the participation in the treatment – they were not supportive, but also not critical. However, at other times, the participants felt misunderstood after sharing information with their significant others. None of them, however, related these reactions to their level of engagement with the intervention. Finally, some participants shared about their participation but were determined to be autonomous and go through treatment on their own. Depending on the available social support, this strategy could be productive or counterproductive. On one hand, sharing your goals with others could help with treatment adherence if they are supportive. On the other hand, if surrounding people are critical and share their negative attitudes towards psychological interventions or interventions delivered over the internet, it could hinder adherence to treatment.

Surprisingly, some participants shared that significant others did some intervention exercises together with them. This is something that usually does not happen in individual therapy and could be considered as a form of social support. However, we do not know how performing treatment exercises with others may have influenced our participants. This experience might have been supportive or, alternatively, it could have caused participants to feel uneasy and self-conscious about potential judgment. This finding is something future internet-delivered interventions could use to guide their participants through the intervention. For example, it might not be enough to instruct participants to find a quiet and private place but also to specifically state that they need to be doing this exercise on their own. Moreover, it should be weighed if missing an exercise because of lack of private space would be better for treatment efficacy than allowing the individuals to do the exercises together with someone else.

Previous experiences of feeling underappreciated had led some participants to withhold and hide information about participation in the treatment. While another important finding was related to tinnitus itself. Apparently, some participants perceived tinnitus as a stigmatized condition. This finding was not surprising and has been discussed in the literature before [4]. However, this experience led some of the participants to hide not only that they had tinnitus but also that they were receiving treatment. Having to hide the fact that one is in a treatment could directly impact one's ability to engage with it successfully. Even in an asynchronous treatment such as the current one, participants could have had difficulties finding time and space to work on their treatment. If withholding information negatively impacts a participant's ability to engage with the intervention fully, then strategies to share the intervention with others and explain tinnitus to others could be implemented in treatments to, in turn, facilitate better engagement.

Not sharing information about participation in the intervention might not be a bad thing per se for the clients and could be a way to maintain autonomy. However, it could become an obstacle if individuals live or work with other people and have to adjust to their schedules in order to not give away that they are enrolled in an internet-delivered treatment.

Moreover, it appears that in order to understand the role other people play in internet-delivered psychological treatment uptake, it is not enough to study participant's perceptions. We observed a contradiction in participants' views about significant others not having any effect on their participation in the intervention and their statements about how others suggested the intervention to them or how they had to adjust to the schedule of other people in order to participate in the intervention in peace. Therefore, other methods might need to be deployed to capture the specific influence other people have on clients' participation in internet-delivered interventions. Future studies could consider collecting data about where and when the intervention was used and how that was affected by other people being around at the time of engaging with the intervention. Therefore, the relationship between the data on the engagement with treatment, adherence to intervention procedures, and the role of other people should be examined in further studies. Further

This study had some limitations. The heterogeneity of participants in this study in terms of their engagement with the treatment level was not considered before interviewing. Therefore, it might be that more themes could have emerged and that saturation has not been reached in this study. Moreover, most of our interviewees were women and, therefore, some caution should be exercised when generalizing the results to men. However, this study provided a glimpse into the mostly overlooked aspect of how other people influence client's participation in internet-delivered psychological treatments, and these findings could help guide the development of future internet-delivered interventions and help plan future studies examining the effects of other people in the engagement with the intervention process.

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