

# Evaluating Tinnitus Distress from the Perspective of Significant Others Using a Novel Questionnaire

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## ABSTRACT

**Background:** It is common for significant others to serve as a support unit for patients with chronic conditions. Tinnitus sufferers may benefit from incorporating their significant other in the management process. While numerous self-report measures are available for tinnitus sufferers, no subjective questionnaires currently exist to assess the significant other's perspective of the sufferer's tinnitus distress.

**Purpose:** The objective was to develop a preliminary questionnaire to assess the severity of sufferers' tinnitus distress from their significant other's perspective to involve the significant other in the counselling and rehabilitation process.

**Research design:** A prospective cross-sectional pilot study. Forty-four subjects with a mean age of  $57.1 \pm 7.6$  years old consented to participate in the study, including 22 patients and their respective significant other.

**Study sample:** Forty-four subjects with a mean age of  $57.1 \pm 7.6$  years old, including 22 patients and their respective significant other, were prospectively studied.

**Data collection and analysis:** Tinnitus distress reported by the sufferer was assessed using the tinnitus reaction questionnaire. Perceptions of the sufferer's tinnitus distress were assessed in the significant other using a novel subjective tool, the significant others tinnitus questionnaire. Preliminary responses from both study groups were analysed for differences in perception of tinnitus distress.

**Results:** No significant difference was observed in tinnitus distress for significant others versus tinnitus sufferers for work, sleep, concentration, relaxation or ability to work, indicating the impact of tinnitus was perceived similarly in the sufferers and their respective significant others. One difference observed was the significant others rated tinnitus to be more bothersome in social situations than the tinnitus sufferer ( $p < 0.01$ ).

**Conclusion:** Significant others have an appropriate understanding of the adverse effects of tinnitus on the sufferer. Clinicians providing tinnitus care should consider incorporating questionnaires such as the significant others tinnitus questionnaire as counselling tools when involving a significant other in the tinnitus sufferer's management process.

**Keywords:** Tinnitus, Significant other, Quality of life, Questionnaire, Self-report measure.

**Abbreviations:** SO: Significant Other; SOTQ: Significant Other Tinnitus Questionnaire; THI: Tinnitus Handicap Inventory; TRQ: Tinnitus Reaction Questionnaire

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## INTRODUCTION

Approximately 50 million Americans suffer from a phantom perception of sound called “tinnitus”<sup>1,2</sup>. Individuals who experience tinnitus frequently report negative impacts on their quality of life such as sleep disturbance<sup>3,4</sup>, impaired relaxation and concentration<sup>5</sup>, anxiety and depression<sup>4,9</sup> and withdrawal from social activity<sup>4</sup>.

Currently, there is no cure for tinnitus, though numerous coping and management strategies exist<sup>10</sup> to mitigate these deleterious effects of tinnitus. Cognitive behavioural therapy, sound therapy and tinnitus activities are examples of common management options utilized to facilitate a reduction of tinnitus perception in the sufferer<sup>11-13</sup>. The involvement of a Significant Other (SO) can play a crucial role in supporting maximum outcomes for a patient with tinnitus in several ways. The perception of tinnitus can be emotionally challenging for the patient therefore the presence of a supportive SO can provide emotional reassurance, encouragement and a sense of comfort during difficult times. Emotional support from the SO may help reduce stress, anxiety and feelings of isolation which are all common in individuals coping with tinnitus<sup>14,15</sup>. The SO can play a vital role in facilitating social engagement by supporting coping mechanisms (*i.e.*, use of earplugs in loud environments or identifying more comfortable listening environments<sup>15,16</sup>). A SO may also serve as an advocate for the patient, especially during healthcare appointments and interactions with healthcare providers. The support and encouragement of an SO can motivate the patient to actively engage in rehabilitation efforts and adhere to treatment recommendations<sup>17,18</sup>. Furthermore, involving the SO in the decision-making process regarding the patient’s tinnitus care allows for shared responsibility and fosters a sense of teamwork<sup>17,18</sup>.

While numerous self-report tools exist for the tinnitus sufferer, there are very few options available to assess the perceptions of the SO. Findings from a 2018 survey by Mancini et al. emphasized the importance of including outcome measures for not just the sufferer but the SO as well<sup>19</sup>. To address this gap in available outcome measures, the Significant Other Tinnitus Questionnaire (SOTQ) was created. This self-report questionnaire designed to assess tinnitus distress from the SO’s perspective was modeled after the TRQ as the TRQ has a high test-retest reliability, internal consistency and ease of clinic utility<sup>20</sup>. Further, the domains in the TRQ relate most to the reaction-type issues that the SOs would be able to readily observe as opposed

to measures related to the sufferer’s self-perceived handicap. The reaction to tinnitus is a key aspect of what differentiates one who suffers from tinnitus from those who just experience it and do not require clinical care<sup>20</sup>.

This study aimed to implement a new questionnaire to investigate the difference in perception between the SO and the tinnitus sufferer on the impact of tinnitus on the sufferer to involve the SO in the counseling and rehabilitation process.

## MATERIALS AND METHODS

University of Miami Institutional Review Board approval was obtained for a prospective study of all adult (>18) English-speaking patients undergoing a comprehensive tinnitus evaluation and their respective SO. Enrollment criteria included an otology consult, comprehensive audiometric evaluation and a tinnitus evaluation and counseling session. Subjects were excluded if they did not have an SO or had incomplete data for review before enrollment. In this study, the SO was defined as a spouse, partner or similar close companion living with the tinnitus sufferer.

The SOTQ was divided into two sections. A preliminary section (Part I) consisted of five questions addressing whether the SO themselves experience any degree of tinnitus or sound sensitivity. The main section (Part II) consisted of 10 questions focused on the SO perception of how they felt tinnitus affects the sufferer. SOs scored the SOTQ using the same forced scaling system as the TRQ with responses ranging between 0- not at all, 1) A little of the time; 2) Some of the time; 3) A good deal of the time and 4) Almost all of the time<sup>20</sup>. Among these questions, five focused on key issues associated with tinnitus distress commonly reported both in literature<sup>20</sup> as well as by patients at the University of Miami Tinnitus Clinic. These key issues (concentration, relaxation, work, social situations and sleep) have corresponding items in the TRQ that allow for direct comparison between the TRQ and the SOTQ (**Table 1**). The remaining questions pertained to SO perception of the sufferer’s current tinnitus awareness and disturbance (annoyance) level, whether the sufferer was pre, post or currently undergoing tinnitus management and to list any previous or current tinnitus management techniques used by the individual experiencing the tinnitus.

To ensure the validity of the SO and tinnitus sufferer’s responses, individuals completed the questionnaires

**Table 1:** Key items from the Tinnitus Reaction Questionnaire (TRQ) and Significant Others Tinnitus Questionnaire (SOTQ).

	Tinnitus Reaction Questionnaire (TRQ)	Significant Others Tinnitus Questionnaire (SOTQ)
Item 1-Concentration	My tinnitus has made it hard for me to concentrate	How often do you feel that the patient's tinnitus interferes with their ability to concentrate?
Item 2-Relaxation	My tinnitus has made it hard for me to relax	How often do you feel that the patient's tinnitus interferes with their ability to relax?
Item 3-Work	My tinnitus has interfered with my ability to work	How much impact does the patient's tinnitus have on their work life?
Item 4-Social situations	My tinnitus has lead me to avoid social situations	How much impact does the patient's tinnitus have on their social life?
Item 5-Sleep	My tinnitus has interfered with my sleep	How much impact does the patient's tinnitus have on their ability to sleep?

independently at the time of the tinnitus evaluation. Incomplete questionnaires were excluded from the data pool. Statistical analysis was performed using Sigma Plot software, version 13.0. A p-value <0.05 was considered statistically significant. For the purpose of this study, two-tailed t-tests were performed to assess the differences between the sufferer and their respective SO on the five key items.

## RESULTS

Forty-four subjects consented to participate in the study, including 22 patients and their respective SO. Among the tinnitus sufferers, 14 were male (64%) with a mean age of 57.1 ± 7.6 years old. 59% of the sufferers had bilateral tinnitus and the mean time since tinnitus' onset was 23.3 months ± 24.2 months. The tinnitus was persistent in 95%

of the cases. The mean score for TRQ was 48.4 ± 25.7 with <17 considered as no distress and 17-104 considered distress with severity increasing with a higher score. 77% of the sufferers were also experiencing hearing loss in at least the same ear as the perceived tinnitus.

The SOs were mostly women (68%) with a mean age of 56.8 ± 8.2 years old. All SOs were living daily with the tinnitus sufferer. Among them, 29% reported suffering from tinnitus themselves with no alteration of daily life, sleep or emotional state ≥ 3 (a good deal of the time) in any of the cases. 33% of the SOs indicated they suffered from sensitivity to loud sounds a good deal of the time. The demographics of enrolled patients are summarized in **Table 2**.

Regarding the key items, similar handicap levels were

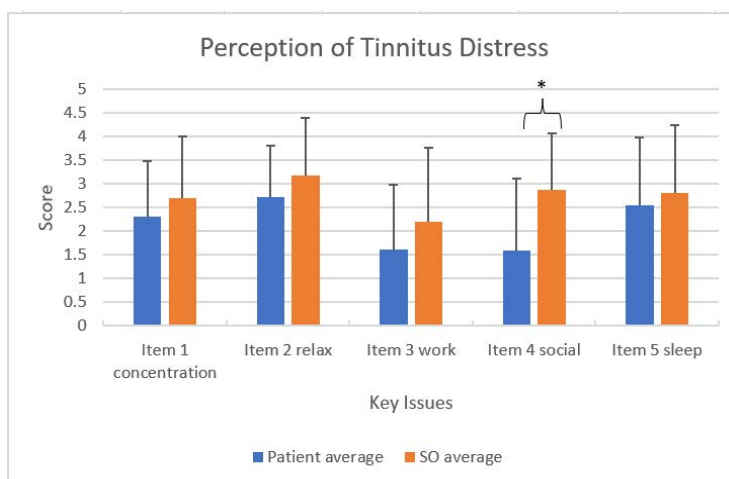
**Table 2:** Demographics of enrolled subjects (n=44).

Parameter	Tinnitus sufferer	Significant other
<b>Age, year</b>		
Mean	57.1 ± 7.6	56.8 ± 8.2
Range	43-74	42-77
<b>Sex, no.</b>		
Male	14	7
Female	8	15
<b>Tinnitus</b>		
Total	100%	29%
Bilateral	59%	ND <sup>1a</sup>
Persistent	95%	ND
Intermittent	5%	ND
Hearing loss	77%	ND

reported by the sufferer and SO as measured by the TRQ and SOTQ for 4 out of the 5 items: concentration (p=0.52), relaxation (p=0.29), work (p=0.17) and sleep (p=0.67). For social situations, the SO reported significantly greater

distress over the sufferer (p=0.01). The mean score reported by the sufferer was 1.59 versus 2.89 for the SOs (**Figure 1**).

Two subjects did not respond to key item #1



**Figure 1:** Average scores of tinnitus perception of the sufferer as reported by the Tinnitus Sufferer (TS) and the Significant Other (SO). Significant differences were found in item #4- social situation (p<0.01).

(concentration) and were excluded from the data pool. Similarly, five subjects did not respond and were excluded from the data pool for key item #3 (work).

## DISCUSSION

The integral role of SO as a support unit has been well-documented throughout the literature in other chronic conditions including chronic pain and hearing impairment. Tinnitus is commonly compared to chronic pain as symptoms of both conditions are thought to stem from both a peripheral and central cause<sup>21</sup>. Management is analogous as a variety of concomitant approaches are encouraged for both tinnitus and chronic pain sufferers<sup>22</sup>. Research in chronic pain management has supported the incorporation of SOs in pain management intervention due to the substantial amount of direct contact the SO has with the pain patient daily in addition to the level of trust established in the relationship<sup>23-28</sup>.

Similar to the tinnitus sufferer, individuals with a hearing impairment who fail to acknowledge and manage their symptoms habitually disengage from their routine activities and social events due to the emotional reaction, such as stress, frustration or even cognitive distortions associated with the activity<sup>29</sup>. As a result, strain is placed on interpersonal relationships with the SO and other family members<sup>30,31</sup>. Involving the SO in the management process allows an opportunity for both direct counseling of the SO as well as increased communication between the two parties.

Given this information, it is assumed that the SO of the tinnitus sufferer can serve an important support role in the tinnitus management process. To ensure the SO will be an effective support unit, their perspectives of the sufferer's distress levels associated with tinnitus should be assessed before engaging them within the support role. Doing so will establish if the SO has an appropriate understanding of what the sufferer is experiencing. Identifying consistencies and inconsistencies in perspectives can be utilized for counseling purposes for both the sufferer and the SO, however, no such measurement tool before the SOTQ existed for this purpose.

Results from this study demonstrated that the SO can accurately perceive the negative impact of tinnitus distress on the sufferer as seen with 4 of the 5 key items on the SOTQ. Our findings demonstrated a greater report of tinnitus distress on social activity by the SO. This difference might be explained by SOs noticing more objective changes in sufferers' social activity. The tinnitus sufferer may inadvertently engage in activity avoidance if they feel they will experience loud noise exposure and potential irritation to their tinnitus<sup>32</sup>. This result is consistent with studies assessing SO and individuals with hearing loss who are unmotivated to seek treatment. According to a 2001 study by Armero, the spouse of an individual with a hearing impairment is more likely to report a withdrawal from social activities than the individual themselves<sup>31</sup>. Often, individuals with a hearing impairment refrain from social activity using the excuse that the situation "is too loud" or that they are no longer interested in the particular activity<sup>31</sup>. SO of these individuals feel that the individual no longer enjoys the activity because they cannot participate in group conversations, become discouraged when they

have to have others repeat or do not hear music and theater dialogue as they once did with normal hearing<sup>31-33</sup>. Refraining from once favorable activities forces unwanted social withdrawal upon the SO and may lead to resentment or stress within the relationship<sup>31</sup>. These studies have found that individuals who pursue amplification not only improve their quality of life, such as returning to social activities but also benefit the SO. This could potentially be reflected after the completion of a tinnitus management program and the incorporation of coping techniques for loud environments as well.

Our findings indicated that 29% of SOs reported suffering from tinnitus themselves with no alteration of daily life, sleep or emotional state  $\geq 3$  (a good deal of the time) in any of the cases and 33% suffered from sensitivity to loud sounds a good deal of the time. Future studies will aim to investigate if there is a correlation between the severity of tinnitus perception and/or sensitivity to sounds in the SO and the accuracy of the SO's perception of the distress level of the tinnitus sufferer.

The SOTQ included five non-key questions focused on the frequency of the sufferer's spontaneous mention of tinnitus or sound sensitivity to the SO, the frequency of impact on emotional state and home life, as well as the sensation of the sufferer being bothered by their tinnitus. As these questions did not have a related TRQ response to directly compare the SO and sufferers' perspectives, the pilot data obtained was utilized for counseling purposes. For example, if a SO rated a score of  $>3$  (a good deal of the time) to the question inquiring "How often does the patient spontaneously mention their tinnitus to you?" the clinician addressed this with both the sufferer and the SO during the tinnitus session.

To foster a successful tinnitus management program, communication between the sufferer and their respective SO is imperative. Sullivan et al., reported that sufferers who choose to be effective communicators with their SO have a greater chance of achieving tinnitus habituation<sup>22</sup>. Similar to chronic pain management, if general communication between the sufferer and the SO is poor, communication about the condition will be impacted and the SO will not be able to serve as a strong support unit for the sufferer<sup>27</sup>. To open channels for communication, the SOTQ can be a useful tool to assess the perception of tinnitus disturbance from both the viewpoint of the sufferer as well as the SO. In the event the SO's perspective differs from that of the sufferer, the results can be used as a counseling opportunity during the associated visit with the tinnitus specialist.

Limitations of this study included some reluctance among SOs to participate as well as incomplete questionnaires which led to data exclusion. This study focused on the initial tinnitus evaluation and counseling session; further studies examining long-term sufferer and SO perception pre-, during and post-tinnitus management are warranted. Future studies should examine the actual amount of time the SO spends with the sufferer.

The results of this study indicate that the SOTQ can be used to assess the SO's perception of distress experienced by the tinnitus sufferer as well as provide valuable information for clinicians. It is a useful adjunct to a test battery including some of the other tinnitus

questionnaires available, such as the Consequences of Tinnitus on Significant Others Questionnaire (CTSOQ), a self-report measure to assess the impact of the sufferer's tinnitus on the SO themselves<sup>34</sup>. Our findings support the idea that the SOs included in this study had an appropriate understanding of the adverse effects of tinnitus on the sufferer. As such, the SO should be included as a support unit throughout the tinnitus management process. The SO can communicate to the clinician any changes they have seen in the sufferer since the time of tinnitus onset, encourage the sufferer to consider tinnitus management options and serve as a cheerleader by reinforcing subtle improvements made by the sufferer.

## CONCLUSION

In this study, the perceptions of tinnitus distress were examined in the tinnitus sufferer and SO. SOs appear to be in tune with the distress linked to the sufferers' bothersome tinnitus. The SOs can additionally detect negative changes that sufferers might unintentionally withhold, especially regarding social interactions.

The SOTQ was identified as a useful tool that can be utilized at the initial evaluation and serves to identify the need for counseling as well as encourage communication between parties. Clinicians should consider including the SO and SO-related outcome measures, such as the SOTQ, in the tinnitus management program from the initial evaluation onwards. Future studies will aid in the psychometric validation of this novel questionnaire.

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## REFERENCES

1. Jastreboff PJ. Phantom auditory perception (tinnitus): Mechanisms of generation and perception. *Neurosci Res.* 1990;8(4):221-54.
2. Tunkel DE, Bauer CA, Sun GH, Rosenfeld RM, Chandrasekhar SS, Cunningham Jr ER, et al. Clinical practice guideline: Tinnitus. *Otolaryngol Head Neck Surg.* 2014;151(2):1-40.
3. Folmer RL, Griest SE. Tinnitus and insomnia. *Am J Otolaryngol.* 2000;21(5):287-93.
4. Hiller W, Goebel G. Factors influencing tinnitus loudness and annoyance. *Arch Otolaryngol Head Neck Surg.* 2006;132(12):1323-30.
5. Andersson G, Stromgren T, Strom L, Lyttkens L. Randomized controlled trial of internet-based cognitive behavior therapy for distress associated with tinnitus. *Psychosomatic Med.* 2002;64(5):810-6.
6. Langguth B, Kleinjung T, Fischer B, Hajak G, Eichhammer PS, Sand PG. Tinnitus severity, depression and the big five personality traits. *Prog Brain Res.* 2007;166:221-5.
7. Kuk FK, Tyler RS, Russell D, Jordan H. The psychometric properties of a tinnitus handicap questionnaire. *Ear Hearing J.* 1990;11(6):434-45.
8. Folmer RL, Griest SE, Meikle MB, Martin WH. Tinnitus severity, loudness and depression. *Otolaryngol Head Neck*

- Surg.* 1999;121(1):48-51.
9. Kim YH. Seasonal affective disorder in patients with chronic tinnitus. *Laryngoscope.* 2016;126(2):447-51.
10. Yaz F, Buttner M, Tekin AM, Bahsi I, Topsakal V. A bibliometric analysis of publications on tinnitus: A study based on web of science data from 1980 to 2020. *J Int Adv Otol.* 2023;19(2):121.
11. Lourenco MP, Fuller TE, Ranson S, Vlaeyen JW, Cima RF. Better together. Group versus individual cognitive-behavioral therapy for tinnitus: A multiple-baseline single-case experimental design. *Ear Hearing.* 2023;44(1):167-78.
12. Grundfast KM, Jamil TL. Evaluation and management of tinnitus: Are there opportunities for improvement. *Otolaryngol Head Neck Surg.* 2023;168(1):45-58.
13. Perreau AE, Tyler RS. Tinnitus activities treatment. Cham: Springer International Publishing. In: *Textbook of Tinnitus*, 2024, pp. 631-43.
14. Bhatt JM, Lin HW, Bhattacharyya N. Prevalence, severity, exposures and treatment patterns of tinnitus in the United States. *Otolaryngol Head Neck Surg.* 2016;142(10):959-65.
15. Tyler RS, Baker LJ. Difficulties experienced by tinnitus sufferers. *J Speech Hear Disord.* 1983;48(2):150-4.
16. Barker F, Rolfe, H. The role of the spouse of a person with tinnitus. *Disabil Rehabil.* 2004;26(6):368-73.
17. Langguth B, Goodey R, Azevedo A, Bjerne A, Cacace A, Crocetti A, et al. Consensus for tinnitus patient assessment and treatment outcome measurement: Tinnitus Research Initiative meeting, Regensburg, July 2006. *Prog Brain Res.* 2007;166:525-36.
18. Kaldo V, Cars S, Rahnert M, Larsen HC, Andersson G. Use of a self-help book with weekly therapist contact to reduce tinnitus distress: A randomized controlled trial. *J Psychosom Res.* 2007;63(2):195-202.
19. Mancini PC, Tyler RS, Perreau A, Batterton LF, Ji H. Considerations for partners of our tinnitus patients. *Int Tinnitus J.* 2018;22(2):113-22.
20. Wilson PH, Henry J, Bowen M, Haralambous G. Tinnitus reaction questionnaire: Psychometric properties of a measure of distress associated with tinnitus. *J Speech Lang Hear Res.* 1991;34(1):197-201.
21. Moller AR. Similarities between chronic pain and tinnitus. *Am J Otol.* 1997;18(5):577-85.
22. Sullivan M, Katon W, Russo J, Dobie R, Sakai C. Coping and marital support as correlates of tinnitus disability. *Gen Hosp Psychiatry.* 1994;16(4):259-66.
23. Flor H, Turk DC, Rudy TE. Relationship of pain impact and significant other reinforcement of pain behaviors: The mediating role of gender, marital status and marital satisfaction. *Pain.* 1989;38(1):45-50.
24. Flor H, Turk DC, Rudy TE. Pain and families. II. Assessment and treatment. *Pain.* 1987;30(1):29-45.
25. Leonard MT, Cano A, Johansen AB. Chronic pain in a couples context: A review and integration of theoretical models and empirical evidence. *J Pain.* 2006;7(6):377-90.
26. Kerns RD, Haythornthwaite J, Southwick S, Giller Jr EL. The role of marital interaction in chronic pain and depressive symptom severity. *J Psychosom Res.* 1990;34(4):401-8.
27. Newton-John TR, de C Williams AC. Chronic pain couples: Perceived marital interactions and pain behaviours. *Pain.* 2006;123(1-2):53-63.

28. Turk DC, Flor H, Rudy TE. Pain and families. I. Etiology, maintenance and psychosocial impact. *Pain*. 1987;30(1):3-27.
29. Lotfi Y, Mehrkian S, Mousavi AE, Faghihzadeh S. Quality of life improvement in hearing-impaired elderly people after wearing a hearing aid.
30. Brooks DN, Hallam RS, Mellor PA. The effects on significant others of providing a hearing aid to the hearing-impaired partner. *Br J Audiol*. 2001;35(3):165-71.
31. Armero OE. Effects of denied hearing loss on the significant other. *Hearing J*. 2001;54(5):44-6.
32. Kleinstauber M, Jasper K, Schweda I, Hiller W, Andersson G, Weise C. The role of fear-avoidance cognitions and behaviors in patients with chronic tinnitus. *Cogn Behav Ther*. 2013;42(2):84-99.
33. Mick P, Kawachi I, Lin FR. The association between hearing loss and social isolation in older adults. *Otolaryngol Head Neck Surg*. 2014;150(3):378-84.
34. Beukes EW, Maidment DW, Andersson G, Fagleson MA, Heffernan E, Manchaiah V. Development and psychometric validation of a questionnaire assessing the impact of tinnitus on significant others. *J Commun Disord*. 2022;95:106159.