TINNITUS TREATMENT OUTCOMES:
A PATIENT'S PERSPECTIVE

Malvina Levy, Au.D., Tracy Peck, Au.D., Rupa Balachandran, Ph.D.
Hearing and Speech Center of Northern California
San Francisco, California
ABSTRACT

Tinnitus treatment literature has typically addressed one treatment or comparison of a few treatments for a select group of participants.

This study attempts to assess the choices, duration and effectiveness of various treatment options from the perspective of a larger tinnitus community.

By gathering this information we hope to educate audiologists and health care professionals by providing data on the progression of treatments people use and their effectiveness.
PURPOSE

By analyzing outcomes from the patient's perspective, we hope to provide professionals with evidence to convince people to skip many of the treatments that have shown no benefit and move directly to treatments that have proved beneficial.

By looking at the progression and amount of time the various treatments were tried, we evaluated the migration from relief of symptoms to management of tinnitus.
Methods

Survey: 25 questions + comments
Participants: Patients of Hearing and Speech Center
Hearing and Speech Center website and Face Book
San Francisco Tinnitus/Education Group
Link on ATA website, ATA Face Book

Survey addressed: Basic demographics
  Cause of tinnitus and whether it had changed over time.
  A 9 point rating scale was created to quantify the effects of tinnitus on:
  Everyday life
  Work
  Sleep
  Concentration
  Hearing
  Social life.

Questions were also asked about:
  Professional involved in tinnitus treatment
  Different types and numbers of treatments sought
  Perceived benefit of treatments tried

By using an online survey we were able to reach out to a greater and more diverse number of people and get a quicker response. We received over 600 responses worldwide; 215 people added comments in the last question and we tried to include the most relevant and interesting ones that would give some guidance to professionals working with tinnitus patients.
Length of time you have had tinnitus

<table>
<thead>
<tr>
<th>Time Period</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-3 mo.</td>
<td>27</td>
</tr>
<tr>
<td>3-6 mo.</td>
<td>13</td>
</tr>
<tr>
<td>6 mo.-1 yr.</td>
<td>35</td>
</tr>
<tr>
<td>1-3 yrs.</td>
<td>68</td>
</tr>
<tr>
<td>3-5 yrs.</td>
<td>31</td>
</tr>
<tr>
<td>5-10 yrs.</td>
<td>43</td>
</tr>
<tr>
<td>over 10 yrs.</td>
<td>182</td>
</tr>
</tbody>
</table>

Location of tinnitus

- Both ears: 182
- Head: 68
- Right ear: 35
- Left ear: 27

Where do you hear your tinnitus?
Is your tinnitus the same as it was initially or has it changed?

- A little worse: 30%
- Significantly worse: 40%
- Same: 20%
- A little better: 5%
- Significantly better: 5%
Do you know what causes your tinnitus to change?

- Yes
- No

If yes, is it:

- Noise
- Anxiety
- Allergies
- Insomnia
- Other

- Foods
- Stress
- Illness/fatigue
- Drugs/medications
- Atmospheric changes
- Jaw & head movements
- Awakening from a nap
- Exercise
- Radiation
What caused your tinnitus?

- Meniere's disease
- Ear infection
- Labyrinthitis
- Otosclerosis
- Eustachian tube dysfunction
- Cochlear implant

Other (please specify):
- Major stress
- Sinus problems
- Lyme disease
- Corneal abrasion
- Rickets
- Ipod
- MS
Do you have a hearing loss?

- No: 37.80%
- Yes: 62.20%

Do you have hyperacusis (sound sensitivity)?

- No: 61.30%
- Yes: 38.70%
How much Does Tinnitus affect your everyday life?

Number of respondents

- Quite a lot: 120 respondents
- A moderate amount: 130 respondents
- Some: 90 respondents
- A little bit: 40 respondents
- Hardly at all: 30 respondents
How much Does Tinnitus affect your sleep?

<table>
<thead>
<tr>
<th>Ratings</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quite a lot</td>
<td>120</td>
</tr>
<tr>
<td>A moderate amount</td>
<td>100</td>
</tr>
<tr>
<td>Some</td>
<td>80</td>
</tr>
<tr>
<td>A little bit</td>
<td>60</td>
</tr>
<tr>
<td>Hardly at all</td>
<td>40</td>
</tr>
</tbody>
</table>
How much Does Tinnitus affect your concentration?

Ratings

Number of respondents

- Quite a lot
- A moderate amount
- Some
- A little bit
- Hardly at all
How much Does Tinnitus affect your Hearing?

Number of respondents

0 20 40 60 80 100 120 140

Ratings

Quite a lot
A moderate amount
Some
A little bit
Hardly at all
How much Does Tinnitus affect your Social Life?

Number of respondents

Ratings

- Quite a lot
- A moderate amount
- Some
- A little bit
- Hardly at all
How long did you research tinnitus before you went to a professional for help?

- Less than a month: 80 respondents
- 1-3 months: 50 respondents
- 3-6 months: 20 respondents
- 6-12 months: 10 respondents
- 1-3 years: 3 respondents
- 3+ years: 50 respondents
- Not at all: 60 respondents
Which professional(s) did you consult for help with your tinnitus? Check all that apply.

- ENT/Head Neck doctor (Ear, Nose, Throat) 62.8%
- Audiologist 52.6%
- Internist (PCP-primary care physician) 43.9%
- I did not consult any professional(s) 14.7%
- Acupuncturist 13.0%
- Neurologist 11.5%
- Dentist 10.4%
- Other (please specify) 10.4%
- Chiropractor 9.8%
- Psychologist 8.7%
- All Other Responses 3.6%

Massage therapist
Craniosacral therapist
Physical therapist
Hypnotherapist
Allergist
Oncologist
Endocrinologist
What type of treatment(s) have you tried for your tinnitus?
Time Period Treatment Tried
Where did you learn about this survey?

- 66%: ATA website
- 13%: ATA Facebook
- 9%: Hearing and Speech Center website
- 8%: Hearing and Speech Center Facebook
- 3%: Direct mailing
- 1%: Support group
“Like others I am waiting for someone to be able to make this go away. I won’t waste precious resources and $$ to chase cures.”

“I found that depression was a fairly large part of the tinnitus. Medications such as antidepressant have been very helpful. I also trained myself to think of other things in my life to focus away from the tinnitus. This took time but was quite successful.”

“No doc cares the way I feel.”

“Doctors need more information on tinnitus. Every M.D. I’ve asked about it responds – Oh there is nothing you can do about it.”

“Thank you for letting me talk about this for a moment.”

“If I were asked if I could experience any one thing, even briefly, I would reply, Silence.”

“I’m in Australia but get most help from the ATA.”

“If I have not tried any treatments because everything I read make it sound like none of them work. I would like to try PROVEN TREATMENTS. There are too many fake treatments on the market.”

“I’m in Australia but get most help from the ATA.”

“I’m in Australia but get most help from the ATA.”

“No doc cares the way I feel.”

“Doctors need more information on tinnitus. Every M.D. I’ve asked about it responds – Oh there is nothing you can do about it.”

“Help please – losing my mind, going nuts. I hate this condition – it’s terribly annoying. Where to get help with the nightmare.”

“The medical community needs improved education on this matter. I live in a town that has a “communication disorders department at a major teaching hospital, yet information seems lacking.”

“Just live with it.”

“Insurance should cover this horrible condition that not only takes its toll on you physically, but emotionally and mentally.”

“Tinnitus is a fairly large part of the condition. Medications such as antidepressant have been very helpful. I also trained myself to think of other things in my life to focus away from the tinnitus. This took time but was quite successful.”

“Doctors need more information on tinnitus. Every M.D. I’ve asked about it responds – Oh there is nothing you can do about it.”

“Thank you for letting me talk about this for a moment.”

“If I were asked if I could experience any one thing, even briefly, I would reply, Silence.”

“I’m in Australia but get most help from the ATA.”

“If I have not tried any treatments because everything I read make it sound like none of them work. I would like to try PROVEN TREATMENTS. There are too many fake treatments on the market.”

“I’m in Australia but get most help from the ATA.”

“No doc cares the way I feel.”

“Doctors need more information on tinnitus. Every M.D. I’ve asked about it responds – Oh there is nothing you can do about it.”

“Help please – losing my mind, going nuts. I hate this condition – it’s terribly annoying. Where to get help with the nightmare.”

“The medical community needs improved education on this matter. I live in a town that has a “communication disorders department at a major teaching hospital, yet information seems lacking.”

“Just live with it.”

“Insurance should cover this horrible condition that not only takes its toll on you physically, but emotionally and mentally.”

“Tinnitus is a fairly large part of the condition. Medications such as antidepressant have been very helpful. I also trained myself to think of other things in my life to focus away from the tinnitus. This took time but was quite successful.”

“Doctors need more information on tinnitus. Every M.D. I’ve asked about it responds – Oh there is nothing you can do about it.”

“Thank you for letting me talk about this for a moment.”

“If I were asked if I could experience any one thing, even briefly, I would reply, Silence.”

“I’m in Australia but get most help from the ATA.”

“If I have not tried any treatments because everything I read make it sound like none of them work. I would like to try PROVEN TREATMENTS. There are too many fake treatments on the market.”

“I’m in Australia but get most help from the ATA.”

“No doc cares the way I feel.”

“Doctors need more information on tinnitus. Every M.D. I’ve asked about it responds – Oh there is nothing you can do about it.”

“Help please – losing my mind, going nuts. I hate this condition – it’s terribly annoying. Where to get help with the nightmare.”

“The medical community needs improved education on this matter. I live in a town that has a “communication disorders department at a major teaching hospital, yet information seems lacking.”
Discussion

We clearly understand that people who participate in a survey like this are those who continue to be bothered by their tinnitus and are searching for information. However, it was surprising to see that the greatest number of respondents have had tinnitus for over 10 years. We’ve been telling people that the brain habituates to the tinnitus and, after time, one is no longer bothered by it. However, that does not seem to apply for a large number of people with tinnitus who, even after 10 years, have not habituated to their tinnitus enough to stop searching for help and a “cure”.

Similar to the recent ATA survey our age range showed that most people searching for tinnitus help were between the ages of 40 and 70 but unlike their data our male female ratio is now very close whereas years ago it was mostly males who reported tinnitus. Of course, these numbers do not reflect the numbers of young veterans, mostly male, who are returning home with tinnitus. The Dept. of Veterans Affairs cites tinnitus as the most common hearing problem among veterans returning from the wars in Iraq and Afghanistan and as the number one service connected disability from the global war on terror.
Noise continues to be the major culprit but anxiety and stress contribute significantly to questions about what caused your tinnitus and what makes it change. This is somewhat different from the causes that have been listed in the literature which mainly cite damage to the ear from noise, other conditions causing hearing loss, medications and abnormalities in the central auditory nervous system. Almost half of all respondents believed anxiety and stress played a major role in their tinnitus.

Almost two-thirds admitted to having a hearing loss but only 11.6% used hearing aids. Findings reported by Kochin and Tyler in 2008 found that more than 9 million adult Americans indicated they had not sought help for their hearing loss specifically because they concurrently had tinnitus. Yet hearing aids were one of the few treatments that showed the most perceived benefit over time along with home sound therapy. On our 9 point scale more people indicated that their hearing was affected “a moderate amount” by tinnitus than those who said “some”, “a little bit” or “hardly at all”.

Although most people indicated that the tinnitus affects their sleep quite a lot, almost 30% indicated hardly at all or only a little bit. This is consistent with the findings in our practice in which 70-80% report sleep problems most of whom relate it to their tinnitus. The people with sleep problems seem to be more distressed by their tinnitus than those who are able to have a good night’s sleep. “Around 9-12 percent of the American population report chronic insomnia”* and referral to a sleep center can be very helpful in working with these patients.

It was nice to see that most people sought professional help from ENT/Head Neck physicians, Audiologists or PCPs for advice when they first notice their tinnitus and most did not research it more than three months. Many professionals have been concerned about the information people are getting on the internet from chat groups and from unproven treatment advertisements. This concern was voiced in the survey comments. It is important that we provide our patients with valid and reliable information and websites that may help answer their questions. The ATA and most of the Universities with Tinnitus Clinics have wonderful websites to fill this need.
The questions about what treatments tried, how long, and perceived benefit provide insight into the progression of treatments people try in order to manage their tinnitus. Most people start out with either a prescription from their physician or a home “treatment” such as an OTC/ herbal remedy or sound therapy hoping that their tinnitus will disappear. Despite the comment that people don’t want to spend money on “unproven treatments” many are willing to take herbal remedies, try acupuncture, cranio-sacral or chiropractic manipulation in their hope for a cure. After some time people realize that these treatments are not helpful as seen in the benefit over time graph. By providing this information we could prevent people from wasting their resources on treatments that have shown no benefit and guide them toward ones that have proven to be beneficial for those with tinnitus.
References

Kochin and Tyler, “Tinnitus Treatment and the Effectiveness of Hearing Aids: Hearing Care Professional Perceptions”  

https://www.umn.edu/adult_sleep_dis

https://www.ata.org/survey_results

Department of Veterans Affairs, National Center for Rehabilitative Auditory Research, www.ncrar.org
About the Authors

Malvina C. Levy, Au.D., FAAA

Dr. Levy is Director of the Tinnitus Program. She is a California licensed Audiologist and Hearing Aid Dispenser. Dr. Levy earned her Bachelors in Speech Pathology and her Masters in Audiology at the University of Illinois and her Doctor of Audiology from the Arizona School of Health Sciences. Her clinical interests include digital hearing aid technology, assistive devices, hearing conservation, and Dr. Levy specializes in the evaluation, treatment, and management of tinnitus and hyperacusis. Dr. Levy has given statewide presentations on Tinnitus and facilitates the monthly Tinnitus Support/Education group at the Hearing and Speech Center.

Contact Info: mlevy@hearingspeech.org

Tracy S. Peck, Au.D., FAAA

Dr. Peck received her Bachelors in Communicative Disorders and Sciences with a minor in Psychology, her Masters in Audiology, and her Doctor of Audiology from the State University of New York at Buffalo. Her clinical interests include pediatric and adult diagnostics and amplification, assistive listening technologies, hearing conservation, and community outreach, with a special interest in the evaluation, treatment, and management of tinnitus and hyperacusis. In addition to her clinical work, Dr. Peck is a lecturer in the Rehabilitative Counseling Department/Deaf and Hard of Hearing program at San Francisco State University.

Contact Info: tpeck@hearingspeech.org
Acknowledgement

We would like to thank Geraldine Kim, student volunteer, for her help in inputting and gathering all the data from survey monkey.

We’d also like to thank June McCullough, Ph.D. for her comments and assistance in developing some of the questions.

Thank you to Katie Fuller from the ATA for placing the link for the survey on the ATA website and Face Book page.

Thank you to the Hearing and Speech Center of Northern California for their support of this research.