



Third party disability for significant others of individuals with tinnitus: A cross-sectional survey design

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Abstract: There is more awareness of third party disability, defined as the disability and functioning of a significant other (SO) due to a health condition of their family members. The effects of third party disability on SOs of individuals with tinnitus has received little attention. To address this knowledge gap, this study investigated third party disability in significant others (SOs) of individuals with tinnitus. A cross-sectional survey design including 194 pairs of individuals from the USA, with tinnitus and their significant others. The SO sample completed the Consequences of Tinnitus on Significant Others Questionnaire (CTSOQ). Individuals with tinnitus completed standardized self-reported outcome measures for tinnitus severity, anxiety, depression, insomnia, hearing related quality of life, tinnitus cognitions, hearing disability and hyperacusis. The CTSOQ showed that 34 (18%) of SOs had mild impact, 59 (30%) had significant impact, and 101 (52%) had severe impact. The clinical variables of tinnitus severity, anxiety and hyperacusis in individuals with tinnitus were the best predictors of the impact of tinnitus on SOs. These results show that SOs of individuals with tinnitus may experience third party disability. The effect of the individual's tinnitus on SOs may be greater when the individual with tinnitus has higher levels of tinnitus severity, anxiety, and hyperacusis.

Keywords: Significant others; Third party disability; Tinnitus; Tinnitus effects; Tinnitus treatment; Life effects; family members

1. Introduction

Tinnitus, defined as the perception of sound without a corresponding external sound source, has been associated with a range of physiological and psychological complaints including insomnia, difficulty concentrating, depression, and anxiety [1]. Tinnitus can hence impact not only the individual but also those living with them [2]. As the difficulties caused by tinnitus are not seen as with physical difficulties, those with tinnitus often describe feeling nobody understands the effects of tinnitus [3]. These effects include finding it difficult to maintain involvement in activities that they feel may exacerbate the tinnitus such as attending certain social situations. Raising awareness of these difficulties associated with tinnitus is important in both the general public and those with tinnitus.

To increase understanding of the impact of health-related problems on functioning and disability, the World Health Organization developed an International Classification of Functioning, Disability and Health (ICF) framework [4]. Using the ICF has provided increased awareness about the wider negative impact disability can have on the individuals with the disability. The ICF relates disability to body functions and structure,

Citation: To be added by editorial staff during production.

Academic Editor: Firstname Last-name

Received: date

Accepted: date

Published: date

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activities, participation and the environmental factors. An individual's level of functioning is viewed as a dynamic interaction between their health conditions, environmental factors, and personal factors on the ICF. According to the ICF, tinnitus is considered an aspect of body function (i.e. b2400- ringing in ears or tinnitus). The ICF was used to demonstrate that tinnitus affected body function including emotional functions, sleep functions, hearing functions, sustaining attention, and energy levels [5]. Those severely affected by tinnitus reported changing aspects of their daily life to reduce exposure to sounds they thought may aggravate the tinnitus [6]. Some reduced participation in household tasks, family gatherings, or socializing in fear of negatively affecting the tinnitus. These life-style changes may thus have a direct impact on the significant others (SOs) of those with tinnitus.

Recognition that health condition, including hearing loss affects SOs has led to the concept of third-party disability in the ICF framework [7]. Third party disability refers to the difficulties faced by SOs due to their family member's health condition [4]. SOs are often spouse or partners, but could also be family members or other individuals who have a close relationship to the individual with the disability. Due to most traditional rehabilitation efforts focusing solely on the person with the overt disability, many SOs may be "hidden victims" in including those with communication disorders [8-12].

Few studies have explored of the impact of tinnitus on SOs. Studies have generally examined the role of the spouse in moderating tinnitus experiences [13-15]. Another study reported that after those with tinnitus saw a professional it was identified that family members generally had a greater understanding of tinnitus, felt tinnitus had less of an effect on the individual with tinnitus and that those with tinnitus restricted their activities less often [16]. More recently a qualitative study identified that the impact on SOs include increased responsibility of household duties and childcare and a reduction in attending social events, music concerts, and functions [17]. In some cases this has had an emotional toll on SOs due to the increase stress and frustration they experienced. This in turn can also negatively affect the relationship between significant others and the individuals with tinnitus [11]. Despite this detrimental impact on SOs, quantifying the resulting third party disability for tinnitus SOs has not previously been studied in a structured manner. This may be partially due to no tool being available to quantify the impact of tinnitus on SOs, although such measures exist for hearing loss, such as the Significant Other Scale for Hearing Disability (SOS-HEAR) [18]. To enable measuring third-party disability for tinnitus, the Consequences of Tinnitus on Significant Others Questionnaire (CTSOQ) was developed and validated as a self-reported measure for SOs with tinnitus [19]. The aim of the present study was to identify the impact of tinnitus on SOs using the CTSOQ and to examine if there are any predictors of this impact based on the disease characteristics of individuals with tinnitus.

2. Materials and Methods

2.1 Study Design

A cross-sectional survey design was used for data collection using dyads (i.e., individuals with tinnitus and their SOs). To ensure that best practice was followed, the Transparent Reporting of

Evaluations with Nonrandomized Designs guidelines were used. Ethical approval was obtained prior to starting the study from Lamar University (IRB-FY20-200).

2.2 Participants

Participants consisted of pairs of individuals living in the USA, with tinnitus and their self-selected SOs. Individuals with bothersome tinnitus were those who participated in trials of Internet-based cognitive behavioral therapy (ICBT) for tinnitus [20–22]. To be included those with tinnitus needed a score of 25 or greater on the Tinnitus Functional Index [23] indicating significant difficulties with their tinnitus and the need for a tinnitus intervention. The participants thus represent those finding their tinnitus bothersome. Their task was to complete a series of outcome measures and consent to their SOs being involved in the study. Those who provided informed online consent, could self-select SOs to pass on the questionnaire link to. SOs, in this context were defined broadly to include those who have a close relationship with the individuals with tinnitus (e.g., spouse, partner, parent, child, sibling, other family members, house mate or a close friend). The SOs had the opportunity to consider their involvement in the study. If they wished to participate, they had to provide informed online consent before completing the questionnaire (see supplementary materials).

2.3 Data Collection

Data collection consisted of self-reported questionnaires provided electronically. Demographical information regarding each pair of participants was obtained, including gender, age, relation of the SO to the person with tinnitus, if the SO had tinnitus themselves, and if they lived with the person with tinnitus. After this, the following self-reported outcome measures were completed.

2.3.1 Outcome Measures for Individuals with Tinnitus

Clinical constructs measured included: tinnitus severity as measured by the Tinnitus Functional Index (TFI) [23], anxiety symptoms measured by the Generalized Anxiety Disorder–7 (GAD-7) [24]; depression symptoms measured by the Patient Health Questionnaire-9 (PHQ-9) [25]; insomnia measured by the Insomnia Severity Index (ISI) [26]; general health-related quality of life (HRQoL) [27] measured using the EQ-5D-5L, tinnitus cognition measured using the Tinnitus Cognitions Questionnaire (TCQ) [28], and hearing disability and sound tolerance measured using the Tinnitus and Hearing Survey (THS) [29]. The authors sought permission to use questionnaires that were not freely available.

2.3.2 Significant Others Outcome Measures

SOs completed only one questionnaire, the Consequences of Tinnitus on Significant Others Questionnaire (CTSOQ; Cronbach's α 0.93). The CTSOQ is a structured questionnaire that was developed and validated previously [19] and consists of 25 questions which focus on four subscales: (a) observations about the individual with tinnitus (10 questions); (b) personal impact (4 questions); (c) relationship impact (5 questions); and (d) providing support (6 questions) [19]. Each item is scored on a 5-point Likert scale, ranging from strongly disagree (0), disagree (1), sometimes (2), agree (3) and strongly agree (4). The scores are added to range between 0 to 100,

with higher scores indicating substantial effects of tinnitus on SOs and their relationship. Scores between 0-25 indicate a mild impact, scores between 26-40 a significant impact, and scores of 41-100 a significant impact [19].

2.4 Data Analysis

The Statistical Package for Social Sciences [30] was used for statistical analyses. Descriptive statistics including age, gender, and the relationship between the SO and the individual with tinnitus were used to describe the sample characteristics for each group. Continuous variables were summarized with means and standard deviations. Categorical variables were described using frequencies and percentages. Where ordinal data (the individual Likert scale questions) were present, the median was reported. When the scores from questions were combined (total scores) the mean scores were reported.

A p -value of .05 was used for significance interpretation, and .001, adjusted for multiple comparisons was used where applicable. Correlations between CTSOQ score and each clinical variable were explored. Pearson's product-moment correlation coefficients or Spearman's rank order correlation coefficients were used to estimate the strength of association between tinnitus severity and each variable. Correlation strength was categorized as very weak (.00 to .19), weak (.20 to .39), moderate (.40 to .59), strong (.60 to .79), and very strong (.80 to 1.0). Hierarchical linear multiple regression models were performed with the impact of tinnitus on SOs (i.e., CTSOQ scores) as the dependent variable and the tinnitus-related clinical variables (clinical variables of tinnitus severity, anxiety, depression and tinnitus cognitions) as predictor variables. The data met the assumptions of homogeneity of variance and the residuals were approximately normally distributed. There was no risk of multicollinearity, as indicated by the tolerances above 0.2 and variance inflation factor values below 10. Analysis of Variance (ANOVA) and Chi square testing was used to identify any group differences regarding baseline characteristics between those with different CTSOQ scores.

3. Results

There were 194 eligible pairs of participants (SOs and individuals with tinnitus). The age range was similar at a mean of 55 (SD: 14) years for the SOs and 56 (SD: 12) years for the individual with tinnitus as seen in Table 1. The majority were living together (87%) and were partners (84%). When SOs were asked if they experienced tinnitus, 18% reported having tinnitus themselves. The effect of tinnitus on individuals with tinnitus is seen in Table 1, indicating significant levels of tinnitus distress (55 out of 100).

Table 1. Demographic profile of the pairs of significant others and individuals with tinnitus

	Significant Others (SO)	Individuals with tinnitus
Demographics N (%) / Mean (SD) [Range]		
Mean age (Standard deviation) [Range]	55 (14) [18-84]	56 (12) [21-81]
Gender		
<i>Male</i>	100 (52%)	77 (40%)
<i>Female</i>	94 (48%)	117 (60%)
<i>Non-binary or other</i>	0	0
Relationship		
<i>Partner</i>	163 (84%)	
<i>Parent</i>	3 (2%)	
<i>Child</i>	13 (7%)	
<i>Relative</i>	9 (4%)	
<i>Friend</i>	6 (3%)	
Living together n (%)		
<i>Yes</i>	168 (87%)	
<i>No</i>	26 (13%)	
Presence of self-reported tinnitus by the SO		
<i>Yes</i>	34 (18%)	
<i>No</i>	160 (83%)	
Clinical variables Mean (SD) [Range]		
Impact of tinnitus on SOs (CTSOQ) [range 0-100]	43 (16) [3 to 82]	
Tinnitus severity (TFI) [range 0-100]		55 (20) [7-96]
Anxiety (GAD-7) [range 0-21]		7 (5) [0-21]
Depression (PHQ-9) [range 0-27]		7 (5) [0-26]
Insomnia (ISI) [range 0-28]		11 (6) [0-27]
Health-related quality of life (EQ-5D-5L) [range 0-15]		8 (2) [5-18]
Health-related quality of life VAS (EQ-5D-5L VAS) [range 0-100]		76 (15) [20-100]
Tinnitus cognitions [range 0-104]		43 (16) [2-89]
Hearing disability (THS) [range 0-16]		7 (5) [0-16]
Sound tolerance (THS) [range 0-8]		1 (1) [0-4]

Acronyms: SOs = Significant others; GAD-7 = Generalized Anxiety Disorder-7; PHQ-9 = Patient Health Questionnaire-9; ISI = Insomnia Severity Index; EQ-5D-5L = General health-related quality of life; VAS = Visual Analogue Scale; TCCQ: Tinnitus Cognitions Questionnaire; THS = Tinnitus and Hearing Survey.

3.1 Impact of Tinnitus on the Significant Others

Total scores for the CTSOQ ranged widely from 3 to 82 with a mean of 43 (SD: 16). The distribution of scores is shown in Figure 1 with the majority scoring between 21-60 on the CTSOQ. This indicated a mild impact for 34 (18%), moderate impact for 59 (30%), significant impact for 101 (52%) the SOs. The median responses for each of the Likert Scale questions is shown in Table 2. These results indicated that the SOs were generally aware of the difficulties the individual with tinnitus but indicated that they did not know how to provide support to those with tinnitus. Although there was an impact on SOs, they were not always unduly affected in one area, but rather across all subscales (observations, personal and relationship impact and providing support).

Table 2. Median responses to Consequences of Tinnitus on Significant Others Questionnaire (CTSOQ)

Question	Median	Subscale median
Subscale: Observations about the individual with tinnitus		1.9
Often worry about their tinnitus	2	
Have a poor quality of life	1	
Have difficulty concentrating or focusing their attention on what they are doing	2	
Have a low mood	2	
Are often anxious	2	
Have difficulty sleeping	2	
Have difficulty adjusting to experiencing tinnitus	2	
Are sensitive to certain sounds	3	
Participate in few activities or tasks	1	
Socialize less than before developing tinnitus	1	
Subscale: Personal impact		1.3
I experience a lot of stress	2	
My quality of life is poor	1	

There are more pressures on me due to the other person's tinnitus	1	
I get annoyed with them	1	
Subscale: Impact on the relationship		1.1
We have difficulty communicating	2	
We do not socialize with other people as much as before tinnitus	1	
Our relationship has worsened	1	
We have been unable to focus on what is important in life	1	
Subscale: Providing support (finding the following hard):		1.7
Showing sympathy	1	
Know how to help	2	
Encourage the person with tinnitus	2	
Understand what the effects of tinnitus are	2	
Understanding what tinnitus is	1	
Understand why tinnitus is hard to live with	1.5	

Table Scoring:

The scores from the subscales are added together and the total score reported as a range between 0 to 100, with higher scores indicating substantial effects of tinnitus on SOs and their relationship. Scores between 0-25 indicate a mild impact, scores between 26-40 a significant impact, and scores of 41-100 a significant impact [19].

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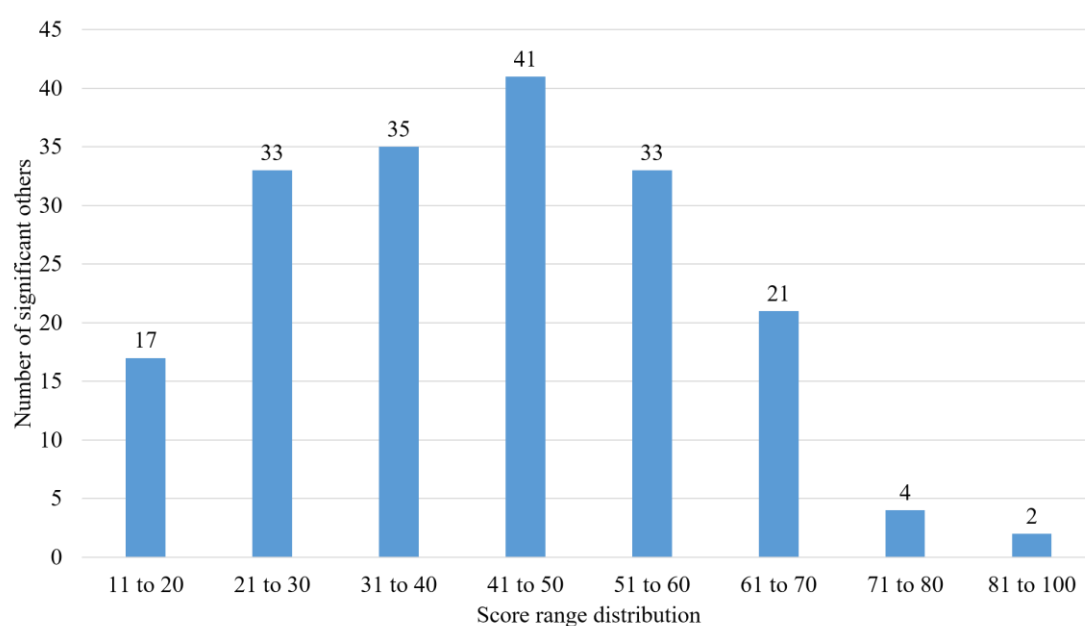


Figure 1. Score distribution regarding the impact of tinnitus on significant others

3.2 Associations Between Tinnitus Severity and the Consequences on Significant Others

There was a moderate positive correlation between the consequences of tinnitus on SOs and the clinical variables of tinnitus severity, anxiety, depression, and tinnitus cognitions (see Table 3). There was a weak positive relationship between the consequences of tinnitus on SOs and clinical variables insomnia, health-related quality of life, hearing disability and sound tolerance (see Table 3). All these variables were thus included in a multiple regression model (see Table 3). The hierarchical linear multiple regression model indicated that the clinical variables from the individuals with tinnitus were able to predict the CTSOQ score of the SOs [$F(10, 183) = 11.49, p < 0.001$] and explained 39% of the variability of the CTSOQ score. The most significant predictors regarding the impact on the SOs were tinnitus severity ($\beta = .26, p = 0.02$), anxiety ($\beta = .26, p = 0.02$) and reduced sound tolerance ($\beta = .18, p = 0.02$).

Table 3. Correlations and hierarchical linear multiple regression model with impact of tinnitus on significant others (CTSOQ) as the dependent variable and tinnitus-related variables as predictor variables. Significant results are indicated by a * representing $p < 0.05$.

Clinical variables in individual with tinnitus	Pearson's or Spearman rho correlation between the significant other score and tinnitus-related variables	Unstandardized Coefficient b (the individual contribution of each predictor to the model), CI	Coefficient standard error indicating the extent these values vary across each sample SE b	Standardized coefficients β	Whether the predictor is making a significant contribution to the model t-value (p-value significance)
Constant		18.6 [-5.29 to 42.58]			$t = 1.54, p = 0.13$
Tinnitus severity (TFI)	$r = .52, p < .001^*$.21 [.04 to .38]	.09	.26	$t = 2.4, p = 0.02^*$
Anxiety (GAD-7)	$r = .48, p < .001^*$.82 [.15 to 1.48]	.34	.26	$t = 2.4, p = 0.02^*$
Depression (PHQ-9)	$r = .49, p < .001^*$	-.21 [-1.0 to 0.60]	.41	-.07	$t = -0.52, p = 0.61$
Insomnia (ISI)	$r = .40, p < .001^*$	-.08 [-.60 to .44]	.27	-.03	$t = -0.30, p = 0.77$
Health-related quality of life (EQ-5Q-5L)	$r = .38, p < .001^*$	0.03 [-1.42 to 1.5]	.73	.003	$t = 0.04, p = 0.97$
Health-related quality of life VAS (EQ-5Q-5L VAS)	$r = .33, p = .008^*$	-0.03 [-0.25 to .18]	.11	-.03	$t = -0.30, p = 0.76$
Tinnitus cognitions (TCQ)	$r = .45, p < .001^*$	0.13 [-.07 to 0.33]	.10	.12	$t = 1.27, p = 0.21$
Hearing disability (THS)	$r = .23, p < .003^*$.19 [-.38 to .76]	.29	.05	$t = 0.66, p = 0.51$
Sound tolerance (THS)	$r = .39, p < .001^*$	2.4 [0.46 to 4.35]	.98	.18	$t = 2.45, p = 0.02^*$

Third-party disability for SOs of individuals with tinnitus has not previously been studied using a structured approach. To address this knowledge gap, the CTSOQ was designed and validated to determine the effects of tinnitus on SOs [19]. The study was the first to quantify third-party disability for 194 SOs of individuals with tinnitus. The key findings are discussed below.

4.1 The Consequences of Tinnitus on Significant Others

The impact of tinnitus was mild for 34 (18%), moderate for 59 (30%), significant for 101 (52%) of the SOs. Although participants attributed these difficulties fully on their tinnitus, it is possible that hearing difficulties contributed. Hearing tinnitus and having a hearing loss could have both contributed to the communication difficulties. Future studies need to establish the contribution of both. From many of the responses it appeared as though both tinnitus and hearing-related difficulties contributed to this impact. The majority of scores were between 30-60 out of 100, although the score range varied widely between 2-89. These findings suggest significant third party disability for the majority of SOs of individuals with tinnitus. These findings are comparable to third party disability noticed by SOs of individuals with hearing loss and vestibular problems [9-12]. It should however be considered that this may not be the proportions that would be found in the general tinnitus population where not everyone with tinnitus finds it bothersome. This sample only included those with bothersome tinnitus who were seeking online psychological interventions [20-22]. It would be helpful to compare these findings on a more representative tinnitus population. It was encouraging that significant others do notice the impact tinnitus has on individuals with tinnitus, as indicated from the high scores from this subscale of the CTSOQ. The impact on relationships had the lowest score overall.

4.2 Associations between Tinnitus Severity and the Consequences on Significant Others

The clinical variables of tinnitus severity, anxiety and hyperacusis were the best predictors of the impact of tinnitus on SOs. It is that expected that SOs of those with greater tinnitus severity, will have more third party disability. This helps triaging, due to the heterogeneous nature of tinnitus, where not everyone is equally affected by having tinnitus [31-32]. Health professionals should be mindful that SOs of individuals with higher levels of tinnitus severity, anxiety and the presence of hyperacusis, may experience third party disability. Where identified these SO should be invited to attend the tinnitus therapy sessions to help increase their knowledge and understanding of tinnitus. The SO should be monitored to determine whether attending these joint sessions decreases the third party disability, or whether further input is required. Furthermore, many other factors not investigated may impact on these results. The impact of marital satisfaction may be a confounding variable. It has previously been identified that poor marital cohesion was significantly associated with greater tinnitus severity, anxiety, depression and mediated maladaptive coping [14-15].

4.3 Clinical Implications

These findings are important in identifying that third party disability is present in SOs of individuals with tinnitus. This has direct implication for clinical practice. Following models focusing on the wider context of the individual is needed. It is possible that the third party disability of the SO is an additional burden on the individual with tinnitus. Thus, measuring third-party disability routinely for SOs of individuals with tinnitus would be prudent. Where third party disability is identified, these SOs may benefit from involvement in the rehabilitation process [13]. Internet-based interventions can be one way to offering accessible and affordable management options for SOs as they have been found to be effective for individuals with tinnitus [33-34]. There are examples of internet-based CBT for SOs in other areas [35-37], although none exist in the area of tinnitus. Nevertheless, this joint approach could benefit both the SO and those with tinnitus. More research should be done to identify effective joint care models as not such intervention presently exists. The approach can be tailored depending on the individual needs. Encouraging SOs to attend appointments, support groups meetings, group sessions, and support therapeutic approaches may help increase their knowledge about tinnitus and also help their partners feel supported. Informational counselling provided about the tinnitus mechanisms and causes can help both those with tinnitus and their significant others have a shared understanding. Individual sessions as well as group therapy approaches have been used in auditory rehabilitation program including SOs [38]. When SO were included in the rehabilitation program, there was more hearing handicap reduction for individuals who had SOs that attended group classes with them [39].

4.4 Limitations and Future Directions

Although this study provided us with some insights, these need to be considered with the context of this study. The participants represent SOs of those with bothersome tinnitus who felt they required an intervention to help them. They may thus not represent all individuals with tinnitus. Individuals who have more severe tinnitus are more likely to have passed on the questionnaire to their SOs. Further, SOs selecting to participate may be the ones noticing effect causing a self-selection bias in the study sample. Although self-reported questionnaires were administered to those with tinnitus, they were not administered to SOs to determine their levels of anxiety and depression. Further studies should include SOs for this data collections. This study did not explore the dynamics of the relationship between individuals with tinnitus and their SOs. It may be that those who felt support by their SO were more likely to involve their SO. Further bias may be introduced in some carers already being caring and supportive prior receiving the guidelines from this study. Future studies should make an effort to include more representative sample of SOs. In addition, further studies should be done to identify the effects of undertaking tinnitus intervention on SOs.

Supplementary Materials: The following supporting information can be downloaded at: <http://doi.org/10.6084/m9.figshare.15062691>

Author Contributions: Conceptualization, EB, GA, VM.; methodology, EB, GA, VM.; software, GA.; validation, EB; formal analysis, EB.; investigation, EB.; resources, GA.; data curation, VM, EB.; writing—original draft preparation, EB.; writing—review and editing, EB, GA, VM.; visualization, EB; funding acquisition, VM. All authors have read and agreed to the published version of the manuscript

Funding: This research was funded by This work was funded by the National Institute on Deafness and Other Communication Disorders (NIDCD) of the National Institute of Health (NIH) under the award number R21DC017214. The funding body was not involved in the design of the study, data collection, data analysis, interpretation of data, or in writing the manuscript.

Institutional Review Board Statement: Ethical approval was obtained prior to starting the study from Lamar University (IRB-FY20-200). The study was conducted in accordance with the Declaration of Helsinki and approved by the Institutional Review Board of Lamar University, IRB-FY20-200, on 16 July 2019.

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study. Written informed consent has been obtained from the patient(s) to publish this paper.

Data Availability Statement: The dataset is obtainable at <http://doi.org/10.6084/m9.figshare.15062691>

Acknowledgments: Our thanks are extended to all the participants who partook in this study.

Conflicts of Interest: The authors declare no conflict of interest.

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