

# Defining the Lived Experience of Older Adults With Voice Disorders

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**Summary: Objectives.** The purpose of this qualitative phenomenological study was to gather rich thick descriptive data regarding the lived experiences of older adults seeking treatment for a voice disorder.

**Design.** Using qualitative methodologies, participants completed semi-structured interviews with trained investigators to detail their thoughts, beliefs, feelings, and experiences of living with a voice disorder. Using a process of horizontalization, themes were identified that described the experiences of older adults with voice disorders.

**Setting.** Research was conducted at four clinical voice centers in Kentucky, Wisconsin, and Ohio. Data were analyzed in the Laryngeal and Speech Dynamics Lab at the University of Kentucky.

**Participants.** A total of 28 adults (aged 65–90 years) with voice disorders were recruited for this study.

**Results and Conclusions.** Aging adults demonstrated a strong urge to communicate; however, they tended to describe their voice quality in negative terms and were emotionally impacted by these associations. They admitted to withdrawing from some activity or social event because their voice did not meet their expectations or voice needs; thought their voice quality was part of normal aging; and had resigned to accept their current voice.

**Key Words:** Quality of life–Aging–Voice–Presbylaryngeus–Lived experience.

## INTRODUCTION

Speech is the primary means of human communication and is vital throughout the life span. It is used to communicate basic needs as well as a means for social enjoyment, engagement, and interaction. Voice is the primary auditory component of speech. Unfortunately, for many older adults, the ability to use their voice for the above purposes declines with age.<sup>1–3</sup> Significant literature supports a deterioration and/or alteration of voice as part of the normal aging process.<sup>4–9</sup> The aged voice is often recognized by altered pitch, reduced loudness, hoarseness, breathiness, and tremor.<sup>10–14</sup> Changes in voice in older adults are readily identified by listeners and often lead to negative perceptions of the older speaker.<sup>15–19</sup>

Although the exact prevalence of voice disorders in the older adult is unknown, recent work suggests that between 19% and 29% of individuals older than 64 years may suffer from a current voice disorder.<sup>2,20–22</sup> This percentage is of note, as only 6.6% of individuals in the working age population (<65 years) report such a disorder.<sup>23</sup> Research suggests that voice disorders may have a significant impact on one's daily function and satisfaction with life. Furthermore, studies of treatment-seeking populations indicate that individuals older than 65 years account for approximately a quarter of those seeking specialty care for a voice disorder.<sup>24</sup> The impact of voice disorders has been shown to cut across a number of quality-of-life domains, affecting social interaction, general and emotional health, and psychological well-being.<sup>25–28</sup> These findings suggest a possible

increase in voice concerns in the aging population and highlight the need for continued research.

The World Health Organization (WHO) defines health-related quality of life as a “multidimensional concept that encompasses physical, mental, and social states of being.”<sup>25</sup> Because of the subjective nature of “quality of life,” a number of tools have been developed to consider the quality of life impact of voice disorders. Currently available instruments focus on the working-age population, the pediatric population, and/or a specific diagnostic classification (eg, vocal fold paralysis and head and neck cancer).<sup>29–33</sup> At present, there are no validated instruments for assessing the quality of life impact of voice disorders in the aging population, resulting in a lack of a critical resource for the comprehensive assessment of voice disorders in older individuals.

Studies have considered the quality of life impact of voice disorders in the older population.<sup>27,28</sup> Verdonck-de Leeuw and Mahieu collected longitudinal data from 11 healthy men aged between 50 and 81 years over a 5-year period. Investigators reported a gradual change in voice with aging, such as vocal fatigue, hoarseness, and a rough quality of voice. Participants noted that the gradual change in voice had a significant impact on daily life.<sup>28</sup> Investigations suggest that dysphonia can lead to quality-of-life changes in social, functional, physical, and emotional domains.<sup>27,28</sup>

There is a growing interest in the field of speech-language pathology in the quality of life of older individuals with voice disorders. In a recent position article, Branski et al<sup>34</sup> made a call for valid and reliable quality-of-life tools that use participant input and clinician expertise as well as completing psychometric testing to ensure clinical usability. Currently available quality-of-life instruments relied heavily on expert clinician opinion. Some scales used patient interviews, but the methods used to complete the interviews and develop the questions were unclear.

Therefore, this study reports the results of the first step in the development of a voice quality-of-life scale for the aging population. Using qualitative phenomenological methodologies,

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participants completed semi-structured interviews with trained investigators to detail their thoughts, beliefs, feelings, and experiences of living with a voice disorder. This information offers the speech-language pathologist greater insight into the impact of voice disorders on older patients and assists voice clinicians in developing treatment programs directed at the specific needs of this age group.

## METHODS

The design of the present study was modeled after Connor et al<sup>35</sup> who collected qualitative data and developed a valid voice-related quality-of-life scale for the pediatric population. A qualitative design was used to explore the lived experience of older adults with voice disorders. In this phenomenologically based study, researchers used a strategy of inquiry to understand the thoughts, experiences, and beliefs of a group of participants with a particular phenomenon, in this case, voice disorders.<sup>36,37</sup> The goal of the chosen qualitative design was to define and describe individuals' experiences using rich thick data gathered through their words. The experiences of older adults with voice problems guided the understanding of their perceptions of living with a voice disorder. As the primary concern was to learn more about the subjective perceptions of the participants, a qualitative design was chosen.

The grand tour question for this study was, "What is the lived experience of individuals with voice disorder?" Sub-questions were developed to further address the grand tour question. The sub-questions were, "What areas are most important to individuals with voice disorders?" "What parts of daily life are most affected by the voice disorder?" and "How has the voice disorder affected these areas?" In phenomenological research, data are collected through semi-structured interviews of participants who have experienced the phenomena of interest.

## Participants

Twenty-eight adults (15 men and 13 women) older than 65 years and seeking treatment for a voice disorder were recruited for this multicenter study. Trained interviewers at each of the four sites helped recruit participants who (1) had at least a mild dysphonia as judged perceptually by a speech-language pathologist for a minimum of 6 months, (2) lived independently or in an independent living facility, (3) were free of dementia as determined by a score of  $\geq 3$  on the Mini-Cog,<sup>38</sup> (4) had hearing sufficient to permit engagement in the interview process, and (5) were competent in English. Participant ages ranged from 65 to 90 years, with an average of 72.3 years. On enrollment, participants were identified by a code based on the initials of the trained interviewer and number within that site.

## Procedures

The University of Kentucky's Office of Research Integrity gave approval for this study, and informed consent was taken before data collection. Before starting the interviews, seven interviewers were trained in qualitative interviewing skills by the primary investigator and given specific tips and methods for encouraging the participants to share their experiences without

guiding or biasing them in a direction. Interviewers were asked to keep field notes during all interviews to later assist the primary researcher in coding and analyzing the data. Most participants were interviewed by their primary speech-language pathologist in the clinic they typically attended, so they already had a rapport and increased comfort level with their interviewer. The primary investigator conducted the remaining interviews. Most interviews were conducted at the participants' initial evaluation or treatment session. If participants were enrolled in the study after the onset of therapy, they were asked to think back and reflect on their voice before the start of therapy.

Participants were asked to respond to 16 open-ended questions designed by experts in voice care or qualitative methodologies (Appendix). The semi-structured format was used to permit interviewers the flexibility to ask follow-up questions after ambiguous comments by the participants, adjusting the sequence and flow of questions as indicated. Follow-up probe suggestions were given; however, interviewers were trained to approach the interviews as a conversation and ask clarifying questions, as needed, that would not lead or bias the participant. For example, if a participant answered a question with "yes," it was suggested the interviewer follow-up with "tell me more about that" or "can you give me an example?"

Questions focused on the impact of their voice disorder on daily function, family interactions, social activities, and physical and emotional well-being. Interviews lasted between 15 and 20 minutes and were audio recorded for transcription by the principle investigator and trained study assistants. In qualitative research, "saturation" is the point in data collection where no new themes or ideas are presented during the interviews.<sup>39</sup> Data collection continued until saturation was reached.

## Data analysis

The principal investigator and two trained assistants transcribed all audio-recorded data verbatim. The principal investigator reviewed all interviews transcribed by the trained assistants to check for accuracy and take notes regarding intonation and stress patterns. None of the trained interviewers were involved in the data analysis process. Using an approach stemming from Colaizzi<sup>39</sup> and Moustakas,<sup>40</sup> the primary researcher addressed personal experiences and set aside biases to ensure the information gathered in this study was from interaction with the participants. Using qualitative coding software to organize the data,<sup>41</sup> a list of nodes, single units of meaning, were identified. Nodes were identified by examining each line of transcription and highlighting significant statements, creating a list of meaningful comments. These statements were found in one or more interviews concerning the experience of the participants with their voice disorder. At this stage, each statement carried an equal amount of worth. In the next stage of analysis, the common or related nodes were grouped into categories in a manner so as not to be repetitive or overlapping but not so much as to alter or attempt to interpret the participants' intended meaning; this is called horizontalization of the data. The primary investigator returned to the full transcription if unclear on the meaning of the node. If at any time a judgment regarding the intended meaning of the node was made, a "memo" was added within

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