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Conceptual Model for Quality of Life among Adults With Congenital or Early Deafness

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Abstract

Background—A conceptual model of health-related quality of life (QoL) is needed to describe key themes that impact perceived QoL in adults with congenital or early deafness. Objective: To revise University of Washington Center for Disability Policy and Research's conceptual model of health promotion and QoL, with suggestions for applying the model to improving programs or services that target deaf adults with early deafness.

Methods—Purposive and theoretical sampling of 35 adults who were born or became deaf early was planned in a 1-year study. In-depth semi-structured interviews probed deaf adult participants' perceptions about quality of life as a deaf individual. Data saturation was reached at the 17th interview with 2 additional interviews for validation, resulting in a total sample of 19 deaf adults. Coding and thematic analysis were conducted to develop the conceptual model.

Results—Our conceptual model delineates the relationships between health status (self-acceptance, coping with limitations), intrinsic (functional communication skills, navigating barriers/self-advocacy, resilience) and extrinsic (acceptance by others, access to information, educating others) factors in their influence on deaf adult quality of life outcomes at home, college, work, and in the community.

Conclusions—Findings demonstrate the need for the programs and services to consider not only factors intrinsic to the deaf individual but also extrinsic factors in enhancing perceived quality of

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life outcomes among people with a range of functional hearing and language preferences, including American Sign Language.

Keywords

Quality of Life; Deaf or Hearing Loss; Sign Language; Hearing Aid; Cochlear Implant

BACKGROUND

A gold standard approach toward measuring QoL starts with the World Health Organization (WHO) general definition of QoL as people's perceptions of their position in life in the context of the culture and value systems in which they live, relation to their goals, expectations, standards, and concerns. This definition also requires that adults define the concept and items, that the measure uses subjective self-report whenever possible, and that the items be culturally appropriate^{1, 2}. Generic quality of life measures such as the Patient Generated Index (PGI) and WHOQoL global health measure do not adequately capture experiences unique to deaf adults, particularly those who became deaf early in life. Deaf individuals who became deaf early in life might share a number of similarities yet can differ widely in a variety of QoL domains compared to individuals who gradually lose hearing functions as an adult. For example, a person who was born deaf might experience early life stressors associated with not being able to understand family conversations and feeling left out.

In a review of QoL measures that tap deaf-related issues, we identified and evaluated five measures on their item generalizability to deaf adults with a range of hearing ability and language preferences: 1) Client Oriented Scale of Improvement³, 2) Hearing Handicap Inventory⁴, 3) Communication Profile for the Hearing Impaired⁵, 4) International Outcomes Inventory – HA⁶, and 5) Nijmegen CI Questionnaire⁷. One measure did not include any items that could be generalized to adults who became deaf early or late in life. Four measures had only a few items that were generalizable to all deaf adults. Additionally, all of these measures were developed from the practitioner's perspectives with some followed by validity check with assistive listening device users, and none of the questionnaires employed rigorous qualitative methods such as in-depth interviews with members of the target population and thematic analyses.

The study's goal was to establish content validity for a conceptual model through series of in-depth, semi-structured QoL interviews and member checks with adults who were born or became deaf early in life.

METHOD

Using the University of Washington Center for Disability Policy and Research's conceptual model for health promotion as a guide⁸, we replicated the qualitative methods used to create domains for a new Youth Quality of Life-DHH instrument⁹. The interview questions from the YQoL-DHH study were modified based on the literature that explored aspects of QoL among deaf adults and used in this study. A grounded theory approach guided the analysis of data collected from key informant interviews¹⁰. Grounded theory is used to model

phenomena about which little is known, such as the QoL of deaf adults. Human subjects approval was obtained from the first author's institution.

Sampling and Participants

Purposive and theoretical sampling of 35 deaf adults (ages 18 to 65) across the nation was planned to provide a range of language use (ASL or English), hearing level, functional speech communication ability, and communication preference (signed or spoken). We included participants who were deaf from birth or during childhood, and did not include adults who became deaf later in life. At time of the interview, approximately half of the sample was working in a hospitable environment where they had easy access to interpreting or captioning services. The other half was mainstreamed as the only or one of very few deaf employees at their workplaces.

Interviewees were recruited until what they reported became redundant to what previous interviewees had said with little new information gained (data saturation of concepts), resulting in a total of 19 deaf participants in the study sample. Constant comparison method was used to compare the data from one interview to subsequent interviews to determine how the data related to specific concepts that emerged from the analysis.

Hearing level was operationalized as self-reported hearing loss (moderate, moderate-severe, severe, profound). Functional speech communication ability was determined based on self-report of how well the deaf adult understood speech communication on a one-on-one basis without accommodations. Essential hearing and communication demographics are summarized in Table 1.

Interview setting and procedure

We conducted open-ended semi-structured interviews lasting approximately 50–60 minutes with adults on how being deaf affected their lives across various settings that are typically experienced by most people. Focused questions with probes were used to illuminate experiences of being deaf (Table II).

All interviews were conducted via video conferencing and recorded in this manner. Depending on the participant's communication preferences, interviews were conducted using ASL or English. Videophone software with built-in recording was used to capture both interviewer and participant's data for transcription.

A deaf research team member who is fluent in English and ASL transcribed all interviews conducted in ASL. Another deaf bilingual research member checked each transcript for accuracy prior to coding.

Coding Procedure

Selective coding method was used for identifying QoL themes in the transcripts. The thematic analysis involved assigning each QoL-related selected quotation to a domain and assigning these themes and facets to the coded text. The corresponding codes for these quotations were entered in a spreadsheet to monitor data saturation of the themes¹¹. A multirater Kappa measure (0.89 with 92% agreement) was used to calculate the overall

agreement between the three researchers for all of the themes¹². To further increase the trustworthiness and face validity of the study findings, the interviewees through member checks were asked to review the working conceptual model to confirm the relevancy of the themes to their experiences. A theory triangulation approach was used to establish the content validity of the working conceptual model¹³. Establishing content validity through this approach assures that the individuals from different disciplines (e.g. medicine, clinical psychology, health educator) interpret the information in the same way. Five external deaf professionals in health-related fields reviewed the codes and provided their interpretations of the emerging themes.

RESULTS

Recurrent themes and the literature conceptualize an AQoL-Deaf model (Figure 1). This figure includes both deaf-related extrinsic and intrinsic factors that might interact with the deaf individual's health status. Along with health, these factors are proposed to have positive or negative impact on individuals' health- and deaf-related QoL.

In the AQoL-Deaf model, an emphasis in self-care (i.e. health status) should be considered in the intrinsic context that serve to promote a healthy foundation for the deaf people to be willing to maximize their own functional communication skills, navigate through communication barriers to reduce fatigue and increase access to information, and persist through challenges/barriers. However, these factors are largely influenced by the attitudes that others hold toward deaf adults, access to information/social participation within the deaf person's environment (i.e. home, college, work, and community), and educating others to increase awareness and sensitivity about deaf adults' communication needs.

Health Status Theme: Self-Acceptance, Coping with Limitation

"If a deaf person has health issues, then this makes life more stressful for the person who also has to deal with communication issues with hearing people."

Asian, age 49, profound hearing loss, hearing aid user

In our study, participants reported that good physical health and mental health status is necessary to cope with communication fatigue and deal with societal oppression. These issues were present across all ages within the study, regardless of how well they could communicate with others and function in society. Given the evidence that the effects of general health perceptions and mental functioning on generic QoL are substantial⁸, it is not surprising that deaf people perceive their health status as an important component of deaf-specific QoL. Similarly to the general population, deaf people who report positive QoL are likely to perceive their health to be good. Analysis of the data in this study suggest that self-acceptance of hearing loss is an important part of the person's health status and QoL.

"I accepted myself a long time ago. This was helpful. So, as a hard-of-hearing person, you have to empower yourself to accept yourself regardless what happens in life. You have to use whatever makes you comfortable to communicate with others to have a good QoL." African- American, 44 year old, moderate hearing loss, does not wear hearing aid or cochlear implant

“I have learned that it is important to accept my limitations if you want to continue to work in this environment. Then I do what I need to do to advocate for myself in the workplace.” Biracial, age 57, profound hearing loss, hearing aid user

The self-acceptance served as the basis for the deaf participants’ willingness to recognize and accept limitations associated with current functional communication skills. Coping with limitations associated with being deaf is another factor that contributes to health status.

Intrinsic Theme: Functional Communication Skills, Navigating Barriers, Persistence/Resilience

Deaf people who speak fluently or can hear well with cochlear implants will have better chances of being promoted than someone like me who depends on sign language. I can speak on one-on-one basis, but I still need to communicate in sign language. Other deaf people who wear cochlear implants and can speak well tend to connect with hearing colleagues better in work places. Not completely, but they do. I work maybe 4 times harder than hearing people to get to the place where I want to be. Those deaf people who I am talking about probably have to work 2 times harder than hearing people to get to where they want to be. Asian, age 41, profound hearing loss, wears cochlear implant

Proficiency in both ASL and written English was frequently mentioned as being beneficial to a deaf person’s QoL. In addition, the ability to speak and understand spoken language served to be advantageous only at workplaces where hearing people make up the majority. Even so, deaf participants with high functional speech skills reported experiencing communication and listening fatigue in such environments, which had an impact on perceived QoL at the workplace.

Accepting limitations associated with being deaf influenced how well the participants navigated barriers to access information. Participants who were comfortable with their functional communication skills were more likely to self-advocate while navigating barriers and seek ways to gain greater access to information. They described using creative and different strategies to navigate barriers to access information and obtain accommodations or opportunities needed to succeed in their environments. Another participant, who was a college student, made a similar comment regarding the context of the classroom environment and he/she relied on the Internet for additional information beyond information provided by course materials. These strategies require expending more efforts than a typical student or employee who is hearing. Constantly putting in “extra effort” and “working harder” to gain better access to information risks mental and communication fatigue, which can place a toll on deaf people’s health status as well as their academic and/or work productivity.

“You can’t always hear everything. You need to find a way to ask people to repeat what they said and to search for information before you go in a meeting or appointment. This preparation will help you interact with hearing people better. It is important to research for information well in advance before going in any new situation. You also need to compromise or be flexible. Sometimes it feels like you have to do extra steps before going in such situations. So, yes, I think being hard of

hearing does have an impact on QoL. If I did not have access to information, then my quality of life is not optimal, you know.” African-American, age 31, moderate hearing loss, hearing aid user

The perception and reality of having to work harder were frequently mentioned by all participants. We found that the deaf person’s resilience, or the ability to adapt to these challenges, solve problems, and overcome barriers was an important contributor to perceived QoL. Interview data from some deaf individuals suggests that the resiliency stem from strong family support and modeling behaviors. For example, a college-aged participant stated that, while growing up, she watched how her deaf parents adapted to communication difficulties at public places and dealt with oppression in the community.

“[My parents] taught me a lot. By watching, I learned the ways that they used to encounter hearing people. I copied their behaviors. It’s important to keep a positive attitude and keep going.” Caucasian, age 26, profound hearing loss, does not wear hearing aid or cochlear implant

The ability to persist through environmental challenges and barriers was frequently mentioned in the context of having support within the participants’ social network. Deaf participants commented that getting support from those who share similar experiences was particularly helpful in persisting through difficult situations that impacted their deaf-related QoL.

Extrinsic Themes: Acceptance by Others, Accessibility, Social Participation, Educating Others

Regardless of whether the participant is a student in college or a working adult, the necessity of being recognized and accepted as a deaf member in their environment was a consistent theme. Many participants reported that acceptance by peers, colleagues, and/or professors or supervisors within their primary environment has a profound impact on having their accessibility needs met, which then allows them to fully participate in classroom or work activities.

Within health care environments, deaf participants value having providers who recognize them as being deaf and are willing to communicate through paper/pen writing, laptop typing and bringing in an interpreter on an as-needed basis. Participants who were satisfied with patient-provider communication typically reported higher health information access than participants who reported low satisfaction with communication accessibility with their providers. Those who seemed comfortable with health-related materials (i.e., indirect reflection of health literacy) obtained most of their information from the Internet. If the information appeared ambivalent or unclear, they would discuss this information with their providers through oral communication, paper-pen writing, computer typing, or interpreters if available. Participants with better functional speech and listening skills tend to arm themselves with pertinent background information prior to meeting with their providers. This background information provided the needed context to fill in missed information during oral conversation with the provider.

Consistent with a recent QoL study with deaf youth^{9, 14, 15}, social participation and feeling included in group conversations were identified as an important aspect of QoL among deaf adults in this study. All participants agreed that the shared language with their partners or close friends was a basic requirement for positive QoL. In situations that involve casual acquaintances or colleagues, participants felt they often had to initiate conversations to help other people to feel more comfortable around them. Participants also reported that they had to put in extra effort to be included such as reminding others to accommodate their communication needs (e.g. facing at them while speaking or taking turns to talk). Our data reveals a connection between the effort required to be understood by others and the participants' preference for a partner who shares the same language and experience as themselves.

Many participants reported the burden of constantly or frequently having to educate others about being deaf. There is a general agreement across participants that the willingness to educate others about being deaf is influenced by other people's attitudes and behaviors toward them.

"If that hearing person is open-minded and curious, you will feel comfortable explaining about deaf issues. If the person seems impatient, I feel like you shouldn't bother explaining. Just find someone else to talk to." Caucasian, age 21, Severe hearing loss in better ear, cochlear implant user

Discussion

This study aimed to describe the factors that influence perceived QoL among deaf adults and present a conceptual framework for understanding the impact of deaf-related issues on perceived QoL. Audiological intervention such as CIs and HAs might help reduce hearing difficulties that deaf adults experience, but modifiable lifestyle factors such as self-acceptance and health advocacy that interact with the deaf adult's functional communication skills are also particularly and perhaps even more important for an overall healthy QoL. For example, according to the health belief model¹⁶, the perceived severity and barrier of own condition may influence an individual's health behavior outcomes.

While auditory habilitation typically focus on hearing-specific treatment to reduce impairment, (i.e. speech training; cochlear implantation) our findings suggests that the emphasis in managing the deaf patient's treatment plan should be placed on intrinsic context to promote a healthy foundation for the deaf person to be willing to maximize his/her own functional communication skills, navigate through barriers, and persist through challenges while maintaining resilience. However, these factors are largely influenced by extrinsic context such as the attitudes that others hold toward deaf people, educating others to increase awareness and sensitivity toward deaf people, and the ease of access to information within the person's environment at home, college, work, and in the community. Our conceptual model delineates the relationships between health status (self-acceptance, coping with limitations), intrinsic (functional communication skills, navigating barriers, persistence/resilience) and extrinsic (acceptance by others, access to information, social participation, educating others) factors, all of which are based on deaf adults' self-perceptions of issues

that impact both generic- and deaf-specific QoL outcomes. With some exception of health status, these factors have not been captured in existing health-related QoL measures (HRQoL).

Although this study is an important stride forward in the field of deafness and functional communication differences, it is limited by a few concerns, in particular when applying these results to individuals with unilateral hearing loss, mild hearing loss and those with late onset hearing impairment. Furthermore, because most of our participants had postsecondary education and better accessibility in college or workplaces, these participants most likely have well-developed navigational strategies to obtain better access to information and participate in the society than those who might not have such levels of education and social exposure.

This study demonstrates the urgent need for programs and services to apply not only intrinsic factors (i.e., communication and navigating barriers/self-advocacy skills) but also extrinsic factors (i.e., people's attitudes toward disability and accessibility issues) to improve perceived QoL among people with a wide range of functional hearing and communication preferences, including sign language. Long term, higher perceived generic- and deaf-related QoL among deaf adults reduces health disparities and lowers the cost of associated health care.

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Figure 1. Conceptual Model* of QoL among Deaf Adults

*Adapted from model for health promotion in general population (University of Washington Center for Disability Policy and Research)

Table I**Demographics for Deaf Adult Participants**

Basic Demographics, Hearing History, & Language	Among 19 Adult Participants
Age onset of hearing loss:	Range: birth to 5 years; Mean=5 months
Gender:	
<i>Female</i>	12 (63%)
<i>Male</i>	6 (32%)
<i>Transgender</i>	1 (5%)
Race:	
<i>Caucasian</i>	7 (37%)
<i>Black/African American</i>	4 (21%)
<i>Asian/Pacific Islander</i>	7 (37%)
<i>Biracial</i>	1 (5%)
Education: <i>Undergraduate degree or higher</i>	13 (68%)
Primary language:	
<i>English</i>	10 (53%)
<i>American Sign Language</i>	9 (47%)
Self-rated functional spoken communication skills:	Range: 0 to 10
<i>(1=poor, cannot understand any speech ; 10=excellent, can understand everything)</i>	Mean: 6
	SD: 3
Preferred 1-on-1 communication with non-signers:	
<i>Spoken English</i>	8 (42%)
<i>Gestures, paper/pen writing, & lipreading</i>	7 (37%)
<i>Through an interpreter if available</i>	4 (21%)
Hearing loss in better ear:	
<i>Profound</i>	15 (79%)
<i>Moderate/Moderately-Severe</i>	4 (21%)
Device:	
<i>Hearing aid</i>	8 (42%)
<i>Cochlear implant</i>	5 (26%)
<i>None</i>	6 (32%)
Geographical Region:	
<i>Northeast (NY, NJ, MA)</i>	8 (42%)
<i>East (MD, VA, DE)</i>	3 (16%)
<i>South/Midwest (GA, MO)</i>	3 (16%)
<i>Southwest/West (TX, CA)</i>	5 (26%)

Table II

Sample open-ended interview questions (*adapted from YQoL-DHH interview script, Patrick et al. 2011*).

<i>Health Factor:</i> How does being [deaf or hard of hearing] affect or not affect your ability to communicate with other people?
<i>Extrinsic Factor:</i> Would you say people treat you differently because you are [deaf or hard of hearing], either positively or negatively?
<i>Extrinsic Factor:</i> How do you feel about the amount of accessibility you have? [Probe: Related to health information? At college or workplace? In health care setting?]
<i>Extrinsic Factor:</i> How do you think your college/workplace affects or not affect your quality of life as a person who is [deaf or hard of hearing]?
<i>Intrinsic Factor:</i> How would you describe a [deaf or hard of hearing] person with a “good” quality of life? “Poor quality of life?”
<i>Intrinsic Factor:</i> Does being [deaf or hard of hearing] make you feel different from others? [IF YES] Could you tell me more about that?