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Brief Report

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 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

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

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Improvement,[3] 2) Hearing Handicap Inventory,[4] 3) Communication Profile for the Hearing Impaired,[5] 4) International Outcomes Inventory – HA,[6] and 5) Nijmegen CI Questionnaire.[7] 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 guide,[8] we replicated the qualitative methods used to create domains for a new Youth Quality of Life-DHH instrument.[9] 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 interviews.[10] 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 18–65) 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 min 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 2).

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

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