

Well-being of Parents of Children Who Are Deaf or Hard of Hearing

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Abstract

Purpose: The purpose of this study was to explore factors influencing the well-being of parents who have children who are deaf or hard of hearing (DHH) and to compare their experiences to non-clinical samples.

Method: A cross-sectional online survey was used to collect data ($N = 296$).

Results: Data analyses revealed the majority of parents of children who are DHH were functioning similarly to or better than the non-clinical samples in our comparison and within the non-clinical range for the included measures. No relationship was found between factors related to child age or timing of services (age at diagnosis, time between diagnosis and amplification fitting, age fit with hearing technology, child's current age) and parent psychosocial functioning.

Conclusions: Although most parents are likely to be functioning well, knowing when a parent is experiencing challenges has important implications for clinical practice, including supporting parents in finding solutions when sub-optimal daily intervention practices are occurring. Audiologists can incorporate strategies to identify parents that may be experiencing challenges into their routine practice.

Keywords: counseling, pediatrics, psychosocial impact

Acronyms: DASS-21 = Depression, Anxiety, and Stress Scale; DHH = deaf or hard of hearing; GSES = Generalized Self-Efficacy Scale; MHC-SF = Mental Health Continuum Short Form; PCC = person-centered care; SF-36 = RAND 36-Item Health Survey; WSAS = Work and Social Adjustment Scale

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Hearing loss affects 34 million children worldwide (World Health Organization [WHO], 2018). In the United States, two to three out of every 1,000 children are born with permanent hearing loss (Centers for Disease Control and Prevention, 2018a). Parents are central to the intervention process and instrumental in supporting language development; however, parents can experience challenges incorporating intervention tasks (e.g., hearing aid care and use) for a variety of reasons, that can change over time. For example, initially many parents are unprepared for the news when their child is identified with hearing loss as most parents of children who are deaf or hard of hearing (DHH) have normal hearing (Mitchell & Karchmer, 2004). Furthermore, life variables can be unpredictable, interfering with parent engagement and how effectively they are able to manage intervention tasks. Understanding parental well-being can help audiologists consider the support parents may need as they implement person-centered care (PCC) within their clinical encounters with families. Well-being (emotions and functioning) is a concept that encompasses physical and mental health and provides insights into perceptions on how people feel their

lives are going (CDC, 2018b). When people have higher levels of well-being, they are better able to manage typical daily routines (Healthy People, 2020).

When children are identified with hearing loss, the demands of intervention represent a new layer in the daily lives of families and consideration of how parents are managing hearing care is an important part of the intervention process. The concept of family quality of life is used to discuss the degree to which the family members' needs are met as well as the extent to which family members enjoy their time together and are able to do things that are important to them (Poston et al., 2003). Research has highlighted the need to support parents of children who are DHH related to their emotional well-being and intervention management challenges (Hintermair, 2006; Lederberg & Golbach, 2002; Most & Zaidman-Zait, 2003; Muñoz et al., 2015; Jean et al., 2018). For example, parents of young children who are DHH have reported significantly higher levels of context-specific stress (e.g., language development, hearing devices, child behavior) compared to parents of children with typical hearing (Quittner et al., 2010). Studies have also found young

children inconsistently wear their hearing aids (Jones & Launer, 2010; Muñoz et al., 2014; Walker et al., 2013), which hinders spoken language development (Tomblin et al., 2015).

Parents are required to change their behaviors to add new elements to their daily routines to provide effective day-to-day hearing care management. Audiologists have an important role in helping parents adjust and gain new skills, and how audiologists communicate with parents is a critical consideration. For example, in a meta-analysis patient adherence was found to be highly correlated to physician communication (Zolnierek & DiMatteo, 2009). Communication plays an important role in behavior change and adherence in the treatment of chronic pediatric health conditions (DiMatteo, 2004). In addition to how audiologists communicate, they need to understand challenges parents are experiencing that may interfere with effective hearing care management, as having this information allows audiologists to better support parents. Therefore, the purpose of this study was to explore factors influencing the well-being of parents who have children who are DHH, and to compare their experiences to non-clinical samples.

Method

Participants and Procedures

This study met ethical approval by the Utah State University Institutional Review Board. Parents of children who are DHH were recruited to participate via flyers posted on social media, on parent organization websites, and in pediatric audiology facilities across the United States. Participants were eligible to participate if they were proficient in English and a parent of a child with hearing loss. Participants completed an online survey in Qualtrics from June to August 2018. As an incentive, participants were eligible to enter a drawing for one of ten \$50 Amazon gift cards by providing their contact information in a separate window after completion of the study, ensuring anonymity of survey responses.

The study was designed to reach participants broadly, therefore, it is not possible to calculate a response rate. Three hundred and eighteen survey submissions were started, and 296 were subsequently analyzed for demographic data. Responses from 22 participants were dropped entirely, as they appeared to have been opened by participants; however, no items in these 22 surveys were completed. Responses to individual survey questions were not forced, thus leaving a variable amount of responses for each item. For participant demographic information see Table 1. The majority of respondents were mothers (94%; 277/296), were White (83%; 248/296), had a college degree (75%; 222/296), and reported an annual income of more than \$81,000 (58%; 172/295).

Instruments

Demographic Questionnaire

The demographic questionnaire included 10 items related to the child, six items related to the parent, and two items

on the impact of the hearing loss. The first question on the impact of hearing loss asked participants to rate how their child was currently doing as a result of the treatment they have received/are receiving for their hearing loss on a seven-point scale of improvement/decline from *much improved* to *very much worse*, along with an option for *my child does not receive treatment for hearing loss*. The second question asked participants to indicate, in a *Yes/No* format, the areas that they or their child have received help in 11 categories (i.e., Friends/Social, Relationship/Family, Marriage/Intimate Relationship, Parenting, Financial, Academic/Education, Communication Confidence, Self-identity/Stigma, Recreation, Self Care, Bullying).

Depression, Anxiety, and Stress Scale (DASS-21)

The DASS-21 is a 21-item self-report questionnaire measuring psychological distress. It includes three subscales for depression, anxiety, and stress. Items are scored from 0 (*never*) to 3 (*always*) with higher scores indicating more distress. The questions for this measure are time-bound to the past week and include a four-point scale (i.e., *did not apply to me at all*, *applied to me some degree*, *applied to me a considerable degree*, *applied to me very much*). An example question is "I was intolerant of anything that kept me from getting on with what I was doing." The scale has high total reliability (Cronbach's $\alpha = .88$), high item reliability for depression (Cronbach's $\alpha = .82$), anxiety (Cronbach's $\alpha = .90$) and stress (Cronbach's $\alpha = .93$), and has adequate construct validity (Henry & Crawford, 2005). Internal consistency for the DASS-21 in the current study was good for depression (Cronbach's $\alpha = .89$), anxiety (Cronbach's $\alpha = .83$), and stress (Cronbach's $\alpha = .89$).

The Generalized Self-Efficacy Scale (GSES)

The GSES is a 10-item self-report questionnaire measuring an individual's perception of his or her ability to respond to new or challenging situations. The questions for this measure include a four-point scale (i.e., *not at all true*; *hardly true*; *moderately true*; *exactly true*). An example question is "I can always manage to solve difficult problems if I try hard enough." The measure has a maximum score of 40, with a higher score indicating more self-efficacy. The scale has high internal consistencies reported, ranging from Cronbach's $\alpha = .82-.93$ (Schwarzer & Jerusalem, 1995). Internal consistency for the GSES in the current study was good (Cronbach's $\alpha = .88$).

The RAND 36-Item Health Survey (SF-36)

The SF-36 is a 36-item scale that measures individual functioning based on eight elements which include: (a) physical functioning (Cronbach's $\alpha = .93$), (b) role limitations due to physical health (Cronbach's $\alpha = .84$), (c) role limitations due to emotional health (Cronbach's $\alpha = .83$), (d) energy and fatigue (Cronbach's $\alpha = .86$), (e) emotional well-being (Cronbach's $\alpha = .90$), (f) social functioning (Cronbach's $\alpha = .85$), (g) pain (Cronbach's $\alpha = .78$), and (h) general health (Cronbach's $\alpha = .78$). A higher score overall and in each subscale defines a more favorable health state. The SF-36 has been used to

Table 1*Participant Demographic Information*

Demographic Variables	% (n)	M (SD)	Median	Range
Parent				
Race (<i>N</i> = 296)				
White	83 (248)			
Latino/a	4 (14)			
Asian	4 (11)			
Black/African American	3 (9)			
Multiracial	3 (8)			
Other	2 (5)			
Native/Indigenous	1 (1)			
Age (<i>N</i> = 296)		39 (8)	38	45
Education Level (<i>N</i> = 296)				
Graduate degree	34 (101)			
College education	41 (121)			
Partial college	15 (44)			
High school diploma/GED	7 (20)			
Less than high school	3 (10)			
Annual Income (<i>N</i> = 295)				
More than \$81,000	58 (172)			
\$41–80,000	26 (78)			
\$21–40,000	10 (28)			
Less than \$20,000	6 (17)			
Relation to Child (<i>N</i> = 296)				
Mother	94 (277)			
Father	5 (14)			
Other caregiver	1 (5)			
Child				
Race (<i>N</i> = 288)				
White	80 (230)			
Multiracial	8 (24)			
Latino/a	5 (14)			
Asian	3 (9)			
Black/African American	2 (6)			
Other	2 (5)			
Current Age in years (<i>N</i> = 292)		7 (6)	6	30
Age Identified in months (<i>N</i> = 286)		20 (30)	3	168
Degree of Hearing Loss (<i>N</i> = 296)				
Mild-moderate	25 (74)			
Severe-profound	74 (219)			
Unsure	1 (3)			
Unilateral or Bilateral (<i>N</i> = 296)				
Unilateral	22 (64)			
Bilateral	78 (232)			
Age fit with technology in months (<i>N</i> = 239)		26 (31)	15	168
Technology Type (<i>N</i> = 296)				
Hearing aid (HA)	43 (127)			
Cochlear implant (CI)	32 (96)			
Bimodal (HA+CI)	8 (24)			
Other (did not write in response)	8 (24)			
Bone conduction hearing aid	5 (15)			
FM system only	2 (5)			
Does not use technology	2 (5)			
Parent-reported hours of device use (<i>N</i> = 169)		12 (3.5)	12	23
Other comorbidities (<i>N</i> = 296)	32 (95)			
Primary mode of communication (<i>N</i> = 286)				
Spoken language	87 (250)			
Sign language	13 (36)			
Language spoken in the home (<i>N</i> = 288)				
English only	85 (244)			
English plus another language	14 (40)			
Other	1 (4)			

measure functioning in a variety of individuals representing a wide range of health conditions. The questions for this measure are time-bound and have varying scales (e.g., *limited a lot, limited a little, not limited at all*). Example questions include “Does your health now limit you in climbing several flights of stairs?” (physical functioning), “During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health—accomplished less than you would like?” (role limitations due to physical functioning), and “During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems—cut down the amount of time you spent on work or other activities?” (role of emotional health). The scale has been validated to accurately distinguish impacts of health conditions on physical and mental health (Hays & Sherbourne, 1993; Hays & Stewart, 1990). Internal consistency for the SF-36 in the current study ranged from acceptable to excellent: (a) physical functioning (Cronbach’s $\alpha = .93$), (b) role limitations due to physical health (Cronbach’s $\alpha = .90$), (c) role limitations due to emotional health (Cronbach’s $\alpha = .85$), (d) energy and fatigue (Cronbach’s $\alpha = .77$), (e) emotional well-being (Cronbach’s $\alpha = .83$), (f) social functioning (Cronbach’s $\alpha = .86$), (g) pain (Cronbach’s $\alpha = .85$), and (h) general health (Cronbach’s $\alpha = .82$).

Mental Health Continuum Short Form (MHC-SF)

The MHC-SF is a 14-item self-report questionnaire measuring facets of emotional, psychological, and social well-being. It measures the frequency which respondents experience symptoms of positive mental health, providing clear standards for assessment and categorization of three levels of mental health (flourishing, languishing, and moderately mentally healthy). The questions for this measure are time-bound to the past month and include a six-point scale (i.e., *never, once or twice, about once a week, about 2 or 3 times a week, almost every day, every day*). An example question is “During the past month, how often did you feel good at managing the responsibilities of your daily life?” Total scores can range from 0–70 with a higher score indicating a higher level of emotional well-being. The MHC-SF has demonstrated excellent internal consistency ($> .80$) and validity (Cronbach’s $\alpha = .88$; Keyes et al., 2008; Westerhof & Keyes, 2009). Internal consistency for the MHC-SF in the current study was excellent (Cronbach’s $\alpha = .91$).

The Work and Social Adjustment Scale (WSAS)

The WSAS is a 5-item self-report questionnaire that assesses the impact of a person’s psychological difficulties on functioning in terms of work, home management, social leisure, private leisure, and personal/family relationships. It allows for comparisons of functional impairment across studies and disorders and was modified in this study by placing the carrier phrase “Because of my child’s hearing loss...” at the start of each item. The questions for this measure include an eight-point scale (e.g., *not at all impaired to very severely impaired*). An example question

is “Because of my child’s hearing loss, my ability to work is impaired.” Scoring is continuous up to a maximum score of 40. The higher the score, the more an individual sees their disability or disorder as an impairment to functioning. The scale has high internal consistencies reported (Cronbach’s $\alpha = .70-.94$; Mundt et al., 2002). Internal consistency for the WSAS in the current study was excellent (Cronbach’s $\alpha = .90$).

Analyses

The IBM Statistical Package SPSS v25 was used for data analyses (IBM SPSS Statistics for Macintosh, Version 25.0). Prior to analyses, data were checked for normality using measures of skewness and kurtosis (absolute values that fall within 1 suggest normality). Central tendency (i.e., means, medians) and variability were calculated to provide sample descriptives. One sample *t*-tests (for continuous independent variables) were used to compare the present sample to non-clinical score samples, defined as individuals who do not require psychological intervention based on normed scale scores, drawn from previous research studies. In addition, effect sizes (Cohen’s *d*) were calculated to provide an estimate of the magnitude of between-group differences. Regression analyses were conducted to examine the relationship among age of diagnosis, time between diagnosis, age fit with technology, and all outcomes of interest.

Results

Parents rated how their children have responded to the intervention they have received for hearing loss on a seven-point scale of improvement/decline (i.e., *very much improved, much improved, minimally improved, unchanged, minimally worse, much worse, very much worse*). Parent responses ($N = 296$) indicated 73% reported *very much* or *much improved* (see Figure 1), less than 1% ($n = 1$) reported *much worse*, and 5% ($n = 14$) reported their child had never received treatment for their hearing loss.

Parents also indicated types of support from a list of 11 services they have sought for themselves and/or their child (see Figure 2). Almost half (49%; 144/296) indicated they have attended a hearing loss support group. Over half of the respondents reported seeking two types of support services—Academic/Educational (63%; 186/296) and Social/Friends (52%; 155/296).

Outcomes of Interest

The scores for parents of children who are DHH were compared to non-clinical samples. The results of the comparisons are described below and can be found in Table 2.

Psychological Distress (DASS-21)

Compared to a non-clinical sample (Henry & Crawford, 2005), the current sample did not report higher levels of distress. The majority of the present sample fell within the normal range for clinical cut-offs (Depression: 77%, 188/243; Anxiety: 80%, 195/244; Stress: 77%, 185/241);

20 to 23% of parents reported experiencing depression, anxiety, and/or stress ranging from mild to extremely severe. All questions in each subscale required completion to obtain accurate scores. Scores and participant breakdowns can be found in Table 3.

Sense of Self-Efficacy (GSE)

There was a statistically significant difference between our sample and the non-clinical sample ($p < .0001$; $d = .94$; Schwarzer & Jerusalem, 1995). Parents of children who are DHH self-reported a greater sense of self-efficacy (belief that they have an innate ability to achieve goals) than the non-clinical sample. The authors of the scale recommended a dichotomous split for scoring, using the median as a cut-off point. Therefore, our sample was categorized into scores of 0–29 (moderate self-efficacy) and 30–40 (high self-efficacy). Eighty-nine percent (231/261) of the current sample reported high self-efficacy. Results of this measure can be found in Table 3.

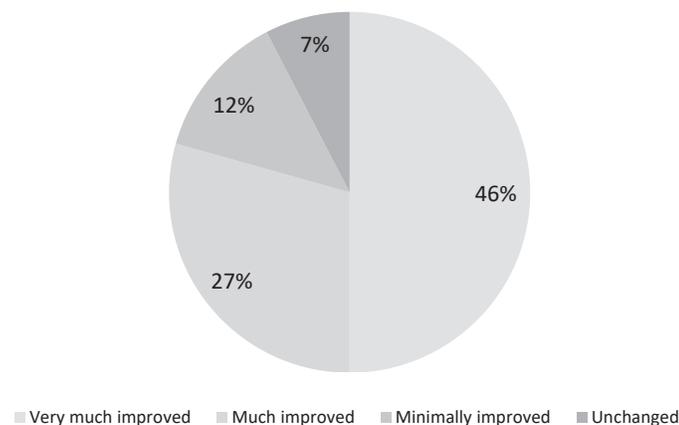
Quality of Life (SF-36)

Parents in our sample had statistically significantly better scores (see Table 2) than the non-clinical sample for measurements of physical functioning ($p \leq .0001$), the role limitations due to physical functioning ($p \leq .0001$), the role of emotional health ($p \leq .001$), pain ($p \leq .0001$), and general health ($p \leq .0001$). Some participants fell below the mean (see Table 4), in particular in the area of energy/fatigue, (21% 1–2 SD and 7% > 2 SD) and emotional health (8% 1–2 SD and 15% >2 SD).

Overall Well-Being (MHC-SF)

The majority of participants fell into the *flourishing* category (66%; 167/254) meaning they frequently (i.e., *every day or almost every day*) experience symptoms of positive mental health. Thirty-three percent (84/254) fell into the *moderate* group (categorized as neither *languishing* or *flourishing*) and 1% (3/254) were in the *languishing* group (i.e., *never or once or twice* during the past month have experienced positive mental health). Participant results can be found in Table 3.

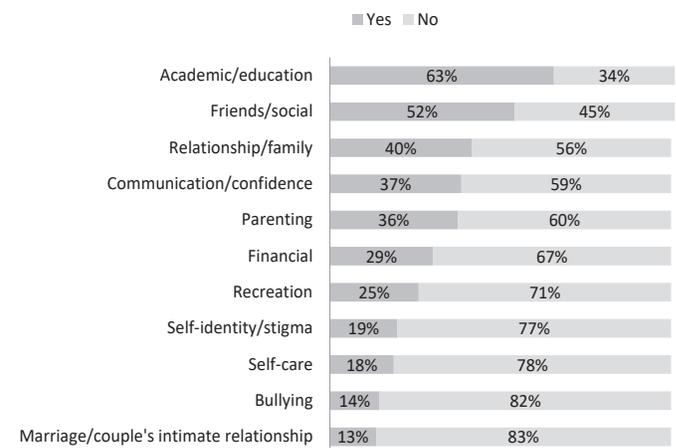
Figure 1
Parent Perceived Response to Intervention (N=296)



Functional Impairment (WSAS)

The majority of the current sample (70%; 171/246) reported subclinical scores (< 10 points) meaning they do not perceive their child's hearing loss as impeding their ability to work or socially interact with others in meaningful ways. Scores above 20 suggest moderately severe or worse psychopathology, scores between 10 and 20 have been associated with significant functional impairment but less severe clinical symptomatology, and scores below 10

Figure 2
Areas of Support Sought (N = 296)



reveal typical functioning (Mundt et al., 2002). Participant responses can be found in Table 3.

Regression Analysis

Preliminary regression analyses were completed to see if there was any relationship between degree of psychosocial functioning and age of diagnosis, time between diagnosis and amplification fitting, age fit with technology, and current age. There were no significant relationships between predictors tested (i.e., age of diagnosis, time between diagnosis, age fit with technology, current age) and outcomes (e.g., psychological distress, sense of self-efficacy, quality of life, overall well-being, functional impairment).

Discussion

The purpose of this study was to explore factors related to the well-being of parents who have children who are DHH, and to compare their experiences to non-clinical samples. The majority of parents in this study were functioning similarly to or better than the non-clinical samples in our comparison. Furthermore, there was no relationship between factors related to child age or timing of services (age at diagnosis, time between diagnosis and amplification fitting, age fit with hearing technology, child's current age) and parent psychosocial functioning. The finding that parents reported positive indicators for well-being is encouraging and may be influenced by multiple factors, such as the type of support and services they are receiving. Recruitment for our study included social media and parent support organizations, and this may

Table 2
Group Comparison of Means on Outcomes of Interest

	Non-clinical Sample	Study Sample		<i>d</i>
	<i>X</i> (<i>SD</i>)	<i>X</i> (<i>SD</i>)	<i>p</i>	
DASS-21 (<i>N</i> = 245)				
Total score	9.43 (9.66)	10.02 (9.67)	.37	
Anxiety (<i>N</i> = 244)		2.05 (3.07)		
Depression (<i>N</i> = 243)		2.76 (3.44)		
Stress (<i>N</i> = 241)		5.26 (4.3)		
GSES (<i>N</i> = 261)				
Total score	29.46 (5.33)	33.9 (4.07)	< .0001	.94
SF-36				
Physical functioning (<i>n</i> = 230)	70.61 (27.42)	88.35 (20.19)	< .0001	.74
Role limitations due to physical functioning (<i>n</i> = 232)	52.97 (40.78)	85.35 (30.61)	< .0001	.90
Role of emotional health (<i>n</i> = 232)	65.78 (40.71)	75.00 (37.45)	< .001	.24
Energy fatigue (<i>n</i> = 230)	52.15 (22.39)	49.98 (20.07)	.1564	
Emotional well-being (<i>n</i> = 230)	70.38 (21.97)	73.23 (18.05)	.0565	
Social functioning (<i>n</i> = 228)	78.77 (25.43)	81.30 (24.60)	.1496	
Pain (<i>n</i> = 232)	70.77 (25.46)	79.25 (21.75)	< .0001	.36
General health (<i>n</i> = 230)	56.99 (21.11)	69.54 (19.97)	< .0001	.61
MHC-SF (<i>N</i> = 254)				
Total score	3.98 (.85)	3.74 (.83)	< .0001	.29
WSAS (<i>N</i> = 246)				
Total score	10.8 (8.8)	6.89 (8.62)	< .0001	.45

Note. Normed Sample Populations differ per test. Depression, Anxiety and Stress Scale (DASS-21): 1,794 (Henry & Crawford, 2005); Generalized Self-efficacy Scale (GSES): 17,553 (Schwarzer & Jerusalem, 1995); RAND 36-Item Health Survey (SF-36): 2,471 (Hays & Sherbourne, 1993); Mental Health Continuum Short Form (MHC-SF): 1,662 (Lamers et al., 2011); Work and Social Adjustment Scale (WSAS): 365 (Mundt et al., 2002).

DASS-21: Higher score indicates more distress. GSES: Higher score indicates more self-efficacy. SF-36: Higher score indicates more favorable health state. MHC-SF: Higher score indicates a higher level of emotional well-being. WSAS: Higher score indicates more impairment to functioning.

have influenced the number of participants connected and supported by other parents. Parents have reported that an important source of support and information is other parents of children who are DHH (Jackson, 2011).

Although most parents are likely to be functioning well, knowing when a parent is experiencing challenges has important implications for clinical practice, including supporting parents in finding solutions when sub-optimal daily intervention practices are occurring (e.g., low hours of hearing aid use). It is important to keep in mind sample characteristics when interpreting comparisons to a non-clinical sample (e.g., non-clinical samples are obtained at a different time). The analysis does not represent a true comparison as our study had different population characteristics given the design of our study (e.g., cross-sectional design and measures not normed for a population related to hearing disorders), and caution should be taken to guard against over-interpretation.

Although our study looked at psychological functioning overall, our findings corroborate other research. For example, Dyson (1996) stated that families of children with learning disabilities are similar to families of normally achieving children in that they have a positive and cohesive family relationship and use rules for operating the family routine, despite experiencing higher levels of parenting stress in relation to their child's learning disability. Furthermore, Hayes & Watson (2013) found parents of children with autism spectrum disorder experience higher parenting stress than parents of typically developing children; however, research also shows positive parental characteristics and early intervention may reduce the impact that stress has on the family. These findings, in addition to research related to parents of children who are DHH (Hintermair, 2006; Jean et al., 2018; Quittner et al., 2010), reveal parents of children with chronic conditions may experience more challenges related to that particular condition. However, research

Table 3
Clinical Cut-off Statistics

	% (n)
DASS-21 (N = 245)	
Depression (N = 243)	
Normal (0–9)	77 (188)
Mild (10–13)	11 (26)
Moderate (14–20)	8 (19)
Severe (21–27)	2 (4)
Extremely severe (28+)	2 (6)
Anxiety (N = 244)	
Normal (0–7)	80 (195)
Mild (8–9)	5 (12)
Moderate (10–14)	8 (20)
Severe (15–19)	4 (9)
Extremely severe (20+)	3 (8)
Stress (N = 241)	
Normal (0–14)	77 (185)
Mild (15–18)	8 (20)
Moderate (19–25)	8 (18)
Severe (26–33)	6 (15)
Extremely severe (34+)	1 (3)
GSES (N = 261) *Dichotomous Split	
Moderate self-efficacy (0–29)	11 (30)
High self-efficacy (30–40)	89 (231)
MHC-SF (N = 254)	
Flourishing	66 (167)
Moderately mentally healthy	33 (84)
Languishing	1 (3)
WSAS (N = 246)	
Normal (< 10)	70 (171)
Significant functional impact (10–20)	20 (49)
Moderately severe psychopathology (> 20)	11 (26)

Note. DASS-21 = Depression, Anxiety and Stress Scale; GSES = Generalized Self-efficacy Scale; SF-36 = RAND 36-Item Health Survey; MHC-SF = Mental Health Continuum Short Form; WSAS = Work and Social Adjustment Scale.

*The author of this measure does not endorse clinical cut-offs but does state that a median split/dichotomous split can be used to show how many fall above or below a median score of 30.

also shows intervention helps reduce the level of negative psychosocial impact on the family unit.

Clinical Implications

The majority of parents in our study had a high level of well-being, underscoring the importance for audiologists to explore multiple life variables (e.g., other caregiver involvement, child factors) when challenges related to treatment adherence arise. When audiologists create a safe space to comprehensively understand parent concerns and respond to parent emotions, they are better able to determine underlying challenges. Furthermore, talking with parents about their struggles and their emotions is therapeutic and may reduce the power of negative emotions, opening the parent up to exploring solutions to problematic behaviors (e.g., not putting on their child's hearing aids).

Parents often will not initiate sharing their emotions. Having a prompt, such as use of a mental health screening tool from a caring professional, can be a welcome opportunity (Muñoz et al., 2017), and parents have reported it can help with recall, validating their concerns, reframing issues that may not have been seen as relevant, and in raising new questions (Fothergill et al., 2013). Additionally, Fothergill reported physicians felt that the screening tool helped open the conversation to sensitive issues while providing more comprehensive care. If significant emotional challenges are identified, for example on a screening tool such as the DASS-21, referral to a mental health professional can be facilitated.

Limitations and Future Research

The study was conducted exclusively online and that may have deterred responses from parents less comfortable with this format (e.g., several people opened the survey but did not complete it). The majority of our sample consisted of White mothers with a college education. This is not reflective of the multicultural population that makes up the United States. Additionally, the majority of parents reported their children had a severe-profound degree of hearing loss. The demographic composition of our sample is not inclusive of the heterogeneity of parents of children who are deaf or hard of hearing. Early Hearing Detection and Intervention programs have found that more than 50% of infants identified with hearing loss have a mild bilateral loss or a unilateral loss (White, 2018). Furthermore, the results of our study reflect parent perceptions at a single point in time; it is not possible to know the relationship between variables or the causes. Life variables change and can influence parent well-being in an unpredictable manner.

Further research is needed to explore experiences of a more diverse sample of parents, parents of younger children, as well as parents with children who have mild to moderate and unilateral hearing loss. Research is also needed to understand factors that may predict parents who are more likely to experience challenges, as well as supports that can mitigate problems to improve hearing management and child outcomes.

Table 4*Rand 36-Item Health Survey (SF-36) Analyses of Distribution*

Scale	> 2 SDs below mean % (n)	1–2 SDs below mean % (n)	0–1 SDs below mean % (n)	0–1 SDs above mean % (n)	1–2 SD above mean % (n)	> 2 SDs above mean % (n)
Physical functioning (n = 230)	7 (16)	5 (12)	12 (27)	76 (175)		
Role limitations due to physical functioning (n = 232)	9 (20)	6 (13)	10 (24)	75 (175)		
Role of emotional health (n = 232)	15 (35)	8 (19)	13 (31)	64 (147)		
Energy/fatigue (n = 230)	7 (16)	21 (49)	27 (60)	31 (72)	12 (28)	2 (5)
Emotional well-being (n = 230)	6 (14)	11 (25)	26 (61)	39 (89)	18 (41)	
Social functioning (n = 228)	6 (14)	9 (20)	24 (54)	61 (140)		
Pain (n = 232)	4 (10)	13 (31)	31 (71)	24 (56)	28 (64)	
General health (n = 230)	6 (14)	8 (19)	24 (55)	46 (106)	16 (36)	

Conclusion

This study sampled parents of children who are deaf or hard of hearing to explore how they were doing in various domains related to their well-being. The majority of parents in this study were functioning similarly to or better than the non-clinical samples in our comparison. Although most parents are likely to be functioning well, knowing when a parent is experiencing challenges has important implications for clinical practice, including supporting parents in finding solutions when sub-optimal daily intervention practices are occurring. Audiologists can incorporate strategies to identify parents that may be experiencing challenges in their routine practice.

References

- Center for Disease Control (2018a). Data and statistics about hearing loss in children. <https://www.cdc.gov/ncbddd/hearingloss/data.html>
- Center for Disease Control. (2018b). Well-being concepts. <https://www.cdc.gov/hrqol/wellbeing.htm>
- DiMatteo, M. R. (2004). The role of effective communication with children and their families in fostering adherence to pediatric regimens. *Patient Education and Counseling*, 55, 339–344. <https://doi.org/10.1016/j.pec.2003.04.003>
- Dyson, L. (1996). The experience of families of children with learning disabilities: Parental stress, family functioning and sibling self-concept. *Journal of Learning Disabilities*, 29(3), 280–286. <https://doi.org/10.1177/002221949602900306>
- Fothergill, K., Gadowski, A., Solomon, B., Olson, A., Gaffney, C., dosReis, S., & Wissow, L. (2013). Assessing the impact of a web-based

comprehensive somatic and mental health screening tool in pediatric primary care. *Academic Pediatrics*, 13(4), 340–347.

<https://doi.org/10.1016/j.acap.2013.04.005>

- Hayes, S., & Watson, S. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43, 629–642. <https://doi.org/10.1007/s10803-012-1604-y>
- Hays, R. D., & Sherbourne, C. D. (1993). The RAND 36-item health survey 1.0. *Health Economics*, 2, 217–227. <https://doi.org/10.1002/hec.4730020305>
- Hays, R. D., & Stewart, A. L. (1990). The structure of self-reported health in chronic disease patients. *Psychological Assessment: A Journal of Consulting and Clinical Psychology*, 2(1), 22–30. <https://doi.org/10.1037/1040-3590.2.1.22>
- Healthy People (2020). Health-related quality of life & well-being. <https://www.healthypeople.gov/2020/topics-objectives/topic/health-related-quality-of-life-well-being>
- Henry, J. D., & Crawford, J. R. (2005). The short-form version of the depression anxiety stress scales (DASS-21): Construct validity and normative data in a large non-clinical sample. *British Journal of Clinical Psychology*, 44, 227–239. <https://doi.org/10.1348/014466505X29657>
- Hintermair, M. (2006). Parental resources, parental stress, and socioemotional development of deaf and hard of hearing children. *Journal of Deaf Studies and Deaf*

- Education*, 11(4), 493–513.
<https://doi.org/10.1093/deafed/enl005>
- Jackson, C. W. (2011). Family supports and resources for parents of children who are deaf or hard of hearing. *American Annals of the Deaf*, 156(4), 343–362.
<https://doi.org/10.1353/aad.2011.0038>
- Jean, Y. Q., Mazlan, R., Ahmad, M., & Maamor, N. (2018). Parenting stress and maternal coherence: Mothers with deaf or hard-of-hearing children. *American Journal of Audiology*, 27(3), 260–271.
https://doi.org/10.1044/2018_AJA-17-0093
- Jones, C., & Launer, S. (2010). Pediatric fittings in 2010: The sound foundations cuper project. *American Journal of Audiology*, 10, 187–192.
- Keyes, C., Wissing, M., Potgieter, J., Temane, M., Kruger, A., & van Rooy, S. (2008). Evaluation of the mental health continuum-short form (MHC-SF) in Setswana-speaking South Africans. *Clinical Psychology & Psychotherapy*, 15(3), 181–192.
<https://doi.org/10.1002/cpp.572>
- Lamers, S., Westerhof, G., & Bohlmeijer, E. (2011). Evaluating the psychometric properties of the mental health continuum-short form (MHC-SF). *Journal of Clinical Psychology*, 67(1), 99–110.
<https://doi.org/10.1002/jclp.20741>
- Lederberg, A., & Golbach, T. (2002). Parenting stress and social support in hearing mothers of deaf and hearing children: A longitudinal study. *Journal of Deaf Studies and Deaf Education*, 7(4), 330–345.
<http://doi.org/10.1093/deafed/7.4.330>
- Mitchell, R. E., & Karchmer, M. A. (2004). Chasing the mythical ten percent: Parental hearing status of deaf and hard of hearing students in the United States. *Sign Language Studies*, 4(2), 138–163.
<https://doi.org/10.1353/sls.2004.0005>
- Most, T., & Zaidman-Zait, A. (2003). The needs of parents of children with cochlear implants. *Volta Review*, 103(2), 99–113.
- Mundt, J. C., Marks, I. M., Shear, M. K., & Greist, J. H. (2002). The work and social adjustment scale: A simple measure of impairment in functioning. *British Journal of Psychiatry*, 180, 461–464.
<https://doi.org/10.1192/bjp.180.5.461>
- Muñoz, K., McLeod, H., Pitt, C., Preston, E., Shelton, T., & Twohig, M. (2017). Recognizing emotional challenges of hearing loss. *Hearing Journal*, 70(1), 34–37.
<https://doi.org/10.1097/01.HJ.0000511730.71830.bf>
- Muñoz, K., Olson, W. A., Twohig, M. P., Preston, E., Blaiser, K., & White, K. R. (2015). Pediatric hearing aid use: Parent-reported challenges. *Ear and Hearing*, 36(2), 279–287.
<https://doi.org/10.1097/AUD.0000000000000111>
- Muñoz, K., Preston, E., & Hicken, S. (2014). Pediatric hearing aid use: How can audiologists support parents to increase consistency? *Journal of the American Academy of Audiology*, 25(4), 380–387.
<https://doi.org/10.3766/jaaa.25.4.9>
- Poston, D., Turnbull, A. P., Park, J., Mannan, H., Marquis, J., & Wang, M. (2003). Family quality of life outcomes: A qualitative inquiry launching a long-term research program. *Mental Retardation*, 41(5), 313–328.
[https://doi.org/10.1352/0047-6765\(2003\)41<313:FQOLAQ>2.0.CO;2](https://doi.org/10.1352/0047-6765(2003)41<313:FQOLAQ>2.0.CO;2)
- Quittner, A. L., Barker, D. H., Cruz, I., Snell, C., Grimley, M. E., Botteri, M., & Team, C. I. (2010). Parenting stress among parents of deaf and hearing children: Associations with language delays and behavior problems. *Parenting, Science and Practice*, 10(2), 136–155.
<http://doi.org/10.1080/15295190903212851>
- Schwarzer, R., & Jerusalem, M. (1995). Generalized self-efficacy scale. In *Measures in health psychology: A user's portfolio* (pp. 35–37). NFER-Nelson.
- Tomblin, J., Harrison, M., Ambrose, S., Walker, E., Oleson, J., & Moeller, M. (2015). Language outcomes in young children with mild to severe hearing loss. *Ear and Hearing*, 36(1), 76S–91S.
<http://doi.org/10.1097/AUD.0000000000000219>
- Walker, E. A., Sprattford, M., Moeller, M. P., Oleson, J., Ou, H., Roush, P., & Jacobs, S. (2013). Predictors of hearing aid use time in children with mild-to-severe hearing loss. *Language, Speech, and Hearing Services in Schools*, 44(1), 73–88.
[https://doi.org/10.1044/0161-1461\(2012/12-0005\)](https://doi.org/10.1044/0161-1461(2012/12-0005))
- Westerhof, G. J., & Keyes, C. L. (2009, August 26). Mental illness and mental health: The two continua model across the lifespan. *Journal of Adult Development*, 17(2), 110–119.
<https://doi.org/10.1007/s10804-009-9082-y>
- White, K. (2018). Demographic considerations in serving children who are hard of hearing or deaf. *Journal of Early Hearing Detection and Intervention*, 3(2), 14–17.
<https://doi.org/10.26077/k8j2-vp95>
- World Health Organization (2018). Deafness and hearing loss.
<https://www.who.int/news-room/fact-sheets/detail/deafness-and-hearing-loss>
- Zolnieriek, K. B., & Dimatteo, M. R. (2009). Physician communication and patient adherence to treatment. *Medical Care*, 47(8), 826–834.
<https://doi.org/10.1097/MLR.0b013e31819a5acc>