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Factors Associated with the Psychosocial Well-being Among Parents of Children who are Deaf or Hard of Hearing

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Abstract

Purpose: To identify factors associated with low psychosocial well-being among parents of children who are deaf or hard of hearing.

Method: A cross sectional survey that included instruments to measure psychological distress, functional impairment, and psychological inflexibility. Two hundred and ninety-six parents completed the survey.

Results: Analyses revealed that lower income, presence of additional disabilities, younger child age, and psychological inflexibility were factors associated with low parent psychosocial well-being.

Conclusions: Parents of younger children who are deaf or hard of hearing with low income, have children with additional disabilities, and higher psychological inflexibility may experience lower psychosocial well-being. Clinicians serving families may need to provide additional and/or different support for parents in adapting to and managing their child's hearing loss.

Key words: pediatric hearing loss, parent psychosocial

Acronyms: AAQ-MCHL = Acceptance and Action Questionnaire–Managing Child Hearing Loss; DASS-21 = Depression, Anxiety, and Stress Scale; DHH = deaf or hard of hearing

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The psychosocial well-being of parents of children with disabilities or chronic health conditions has been explored across multiple conditions and contexts for years (e.g., Barlow & Ellard, 2006; Gilson et al., 2018; Moody et al., 2019). For parents of children who are deaf or hard of hearing (DHH) specifically, research has explored a variety of psychosocial well-being factors, such as parents' satisfaction with life (Yiğit et al., 2018), anxiety and stress (Bilsin et al., 2015; Quittner et al., 2010), and the impact of pediatric deafness on the family dynamic (Dammeyer et al., 2019; Jackson & Turnbull, 2004). Identifying factors associated with low psychosocial well-being for parents of children who are DHH is an important step in helping providers and parents develop effective care plans, that include parent needs, during the intervention process.

After hearing loss is identified, parents are tasked with learning new skills and incorporating intervention recommendations into daily routines, and this can be challenging. For example, 10 or more hours of daily hearing aid use is recommended for optimizing spoken language development (Tomblin et al., 2015); however, studies have found low hours of hearing aid use for young children (Muñoz et al., 2016; Walker et al., 2013). This is not surprising, many parents are unfamiliar with hearing loss as 92% of children who are DHH have hearing parents (Mitchell & Karchmer, 2006). Individualized support is needed to address the range of barriers parents experience. They may experience difficult emotions and parental well-being can pose a barrier to how parents engage in hearing care. For example, Muñoz, Olson, and colleagues (2015) found in a sample of 40 parents of children who are DHH that 40% linked depression to their difficulty in managing consistent hearing aid use.

When parents experience difficult or uncomfortable thoughts and emotions about their child's hearing loss they may avoid these internal experiences (e.g., not put the hearing aids on their child). Experiential avoidance is the inability to handle private events (e.g., thoughts, emotions), and when this occurs, the individual's behaviors support avoidance of these private events (Hayes et al., 1996). Experiential avoidance can interfere with parents making critical health behavior changes (e.g., consistent hearing aid use; checking device function) to support their child's development. Psychological flexibility is a process important for behavioral change and has not been previously explored for parents of children who are DHH. Psychological flexibility can be measured by a recently developed instrument called the Acceptance and Action

Questionnaire–Managing Child Hearing Loss (AAQ-MCHL; Ong et al., 2019). This process describes how parents are influenced by their internal experiences (e.g., thoughts), that is, being in the present moment and taking actions that are consistent with their values, even while feeling uncomfortable with their internal experiences.

Of particular concern are parents who are struggling with the intervention process. Parent psychosocial well-being can be a barrier; however, it is often not explored or addressed as part of the intervention process for children who are DHH. Psychosocial well-being refers to outcomes for how people function (e.g., activities of daily living, social relationships, emotional health), which can play a role in how quality of life is perceived (Burns, 2016). In a recent study, Kasin and colleagues (2020) found that, among 296 parents of children who are DHH, approximately 15 to 34% reported clinical levels on a variety of psychosocial outcomes, including psychological distress, overall well-being, and functional impairment. Although many parents were doing well, the subset of parents who were experiencing distress suggests implications regarding audiology service delivery and the potential for hearing health at home to be compromised. Furthermore, it remains unclear when and/or which parents are at risk for psychosocial challenges, and how they can be identified to ensure appropriate supports are in place for optimal hearing health care.

The current study presents secondary analyses from Kasin et al. (2020) to identify factors that may be associated with low psychosocial well-being by investigating the influence of factors on two dependent variables: (a) psychological distress, and (b) functional impairment. The secondary aim was to investigate whether significant correlations existed between these two psychosocial outcomes and the reported daily amount of time spent using amplification technology.

Method

Participants and Recruitment

The data were collected over a three-month period from June to August 2018 using an online cross-sectional survey. Parents were notified of the opportunity to participate through multiple venues: (a) national organizations that provide technical and other supports to parents of children who are DHH, (b) pediatric audiology clinics, and (c) Facebook groups dedicated to parents of children who are DHH. Parents were eligible to participate if their child had a permanent hearing loss and if the parent was proficient in English; not all instruments were available in languages other than English. Due to the potential overlap of participant recruitment through the multiple venues, it was not possible to calculate the response rate. This study met ethical approval by the Utah State University Institutional Review Board.

Instruments

Demographic data were obtained to understand the make-up of the sample. All items were self-reported (e.g., age, race, relation to child) or reported to the best of parents' knowledge (e.g., child's degree of hearing loss, child has other disabilities). In addition to the demographic questions, three instruments were used to measure the outcomes of interest: The Depression, Anxiety, and Stress Scale (DASS-21; S. H. Lovibond & Lovibond, 1995); the Work and Social Adjustment Scale (WSAS; Mundt et al., 2002); and the Acceptance and Action Questionnaire–Management of Child Hearing Loss (AAQ-MCHL; Ong et al., 2019).

Psychological Distress

The Depression, Anxiety, and Stress Scale (DASS-21; S. H. Lovibond & Lovibond, 1995) is a self-report questionnaire with three 7-item scales to measure depression, anxiety, and stress, with the total score reliably indicating general psychological distress (Henry & Crawford, 2005). Since its development, it has been widely used to assess for depression, anxiety, and stress in adult populations with consistent results surrounding its validity and reliability (Crawford & Henry, 2003; Le et al., 2017; P. F. Lovibond & Lovibond, 1995, S. H. Lovibond & Lovibond, 1995).The scale has good total reliability (Cronbach's α = .88), and good to excellent item reliability for Depression (Cronbach's α = .82), Anxiety (Cronbach's α = .90) and Stress (Cronbach's α =.93); finally, the instrument reports good convergent and discriminant validity. For the present study, item reliability for the DASS-21 was measured as good for depression (Cronbach's α = .89), anxiety (Cronbach's α = .83), and stress (Cronbach's α = .89).

Functional Impairment

The Work and Social Adjustment Scale (WSAS; Mundt et al., 2002) is a 5-item self-report questionnaire which measures the impact of an individual's functional impairment in the context of employment, home management, social and private leisure, and personal/family relationships. The instrument may be used for comparisons of functional impairment across studies and disorders. For the purpose of this study, it was modified by placing the carrier phrase "Because of my child's hearing loss…" at the start of each item (e.g., "Because of my child's hearing loss, my ability to work is impaired" or "Because of my child's hearing loss, my ability to form and maintain close relationships with others, including those I live with, is impaired"). Scoring is continuous up to a maximum score of 40. The higher the score, the more an individual sees their child's deafness or hearing loss as an impairment to parents' functioning. The scale has acceptable to excellent internal consistencies reported, ranging from Cronbach's α = .70 to Cronbach's α = .94 (Mundt et al., 2002), with good convergent and known-groups validity. For the present study, reliability for the WSAS was excellent (Cronbach's α = .90).

Psychological Inflexibility

The Acceptance and Action Questionnaire–Management of Child Hearing Loss (AAQ-MCHL; Ong et al., 2019) is an 8-item questionnaire designed to measure psychological inflexibility. Psychological inflexibility refers to the extent to which parents of children who are DHH avoid difficult thoughts and feelings associated with the diagnosis and management of their children's hearing loss. Example questions include "My frustrations with my child's hearing loss have negatively affected my parenting" or "I worry what others think about my child's hearing loss." This questionnaire has shown good reliability (Cronbach's α = 0.85), and concurrent and discriminant validity (Ong et al., 2019).

Analysis

Backward elimination regression analyses were used to identify variables that independently predicted variance in psychological distress and functional impairment. First, all relevant independent variables (IVs) were included as factors in a regression model (IVs included demographic variables presented in Table 1, and psychological inflexibility). Second, IVs that did not significantly contribute to the model were excluded from subsequent models. Third, change in R^2 ($R^2\Delta$) was calculated for these nested regression models. If $R^2\Delta$ was non-significant, the more parsimonious model was retained. From this process, the following IVs were fit for the present multiple regression model:

(1) For psychological distress: Psychological inflexibility and income.

(2) For functional impairment: Psychological inflexibility, presence of other disabilities, and child age.

In addition, residual plots, Q-Q plots, and VIFs (cutoff was < 4) were examined to determine if regression models met statistical assumptions. Whether these assumptions are met reflects reliability of findings derived from these analyses. The plots and VIFs indicated homoscedasticity and no multicollinearity in all reported models. That is, variables had similar scatter and were not correlated so highly with each other as to adversely impact findings. A Spearman's correlation was calculated between each of the variables of interest. Finally, Pearson's correlation was calculated to determine whether significant correlations existed between parent-reported hours of device use and psychological distress and functional impairment.

Results

Data were analyzed for 296 parents (see Table 1). The sample represented primarily mothers who were White and college educated. Seventy-four percent of children had a severe to profound degree of hearing loss, and 78% of children had hearing loss in both ears.

Table 2 presents correlational data for each of the variables explored in this study. Greater psychological distress was weakly associated with lower income ($rho = -0.226$, $p < 0.001$) and greater psychological inflexibility ($rho = 0.345$, $p < 0.001$) and moderately associated with greater functional impairment ($rho = 0.468$, $p < 0.001$). More psychological inflexibility was weakly associated with lower income ($rho = -0.138$, $p < 0.05$) and moderately associated with greater functional impairment ($rho = 0.488$, $p < 0.001$). Higher income was weakly associated with less functional impairment ($rho = -0.242$, $p < 0.001$) and older child age ($rho = 0.138$, $p < 0.05$). More functional impairment was weakly associated with fewer co-occuring disabilities ($rho = -0.28$, $p < 0.001$) and younger child age ($rho = -0.166$, $p = 0.01$).

Factors Associated with Psychological Distress

Psychological inflexibility had the greatest influence on outcomes for psychological distress ($\beta = 0.30$, $SE = 0.05$, $p < .001$), followed by low income ($21,000–40,000; $\beta = 6.87$, $SE = 3.12$, $p < .05$). Whereas, participants with higher incomes (i.e., $41,000–80,000 and more than $81,000) did not show a significant influence ($\beta = 1.44$, $SE = 2.74$, $p > .05$; $\beta = -1.35$, $SE = 2.60$, $p > .05$, respectively). Psychological inflexibility and income were independently influential, given no significant interaction between the two variables was found ($\beta = 3.56$, $SE = 2.74$, $p > .05$). Thus, in this sample, parents with greater avoidance of difficult thoughts and feelings were more likely to experience greater levels of psychological distress when compared to parents with lesser avoidance. Parents with lower incomes were also more likely to experience greater levels of psychological distress than parents with higher incomes. See Table 3.

Factors Associated with Functional Impairment

All three independent variables in this model significantly influenced impairments to work, home, and social life. Specifically, parents of children who are DHH with no other disabilities showed they were less likely to experience impairment compared to parents of children with multiple disabilities ($\beta = -4.79$, $SE = 1.02$, $p < .001$); parents with high levels of psychological inflexibility were more likely to experience impairment compared to parents with lower levels of psychological inflexibility ($\beta = 0.36$, $SE = 0.04$, $p < .001$); and parents of younger children who are DHH were more likely to experience impairment compared to parents of older children who are DHH ($\beta = -0.32$, $SE = 0.09$, $p < .001$). Finally, a statistically significant relationship was found among the independent variables ($\beta = 5.18$, $SE = 1.50$, $p < .001$). See Table 4.

Correlation of Psychosocial Outcomes and Hearing Device Use

A negative correlation was found between parent-reported hearing device use and both psychological distress and functional impairment, meaning lower device use was correlated with higher levels of impaired well-being as measured by DASS-21 and WSAS. In both cases, however, the correlation was not significant ($r = -0.05$, $r = -0.02$ respectively).

Discussion

The purpose of this study was to identify factors that may be associated with low psychosocial well-being for parents of children who are DHH and to explore relationships with hours of hearing aid use. Four variables emerged as having higher risk for negatively impacting parents' psychosocial well-being: lower income, presence of other disabilities, younger child age, and psychological inflexibility.

Table 1
Demographics

Demographic Variables	% *(n)*	M *(SD)*	Median	Range
Parent				
Race: White	83 (248)			
Age		39 (8)	38	45
Education: college degree	75 (222)			
Annual Income				
More than $81,000	58 (172)			
$41,000–80,000	26 (78)			
Less than $ 41,000	16 (45)			
Relation to child: mother	94 (277)			
Child				
Race: White	80 (230)			
Current Age in years		7 (6)	6	30
Age Identified in months		20 (30)	3	168
Degree of Hearing Loss				
Mild-moderate	25 (74)			
Severe-profound	74 (219)			
Unsure	1 (3)			
Bilateral hearing loss	78 (232)			
Age fit with technology in months		26 (31)	15	168
Technology Type				
Hearing aid (HA)	43 (127)			
Cochlear implant (CI)	32 (96)			
Bimodal (HA+CI)	8 (24)			
Other	15 (44)			
Does not use technology	2 (5)			
Parent-reported hours of device use		12 (3.5)	12	23
Additional disabilities	32 (95)			

The findings are similar to other research as income has been shown to influence psychosocial well-being among parents of children with disabilities (e.g., Park et al., 2002; Shivers & Resor, 2019) and hearing loss. The presence of additional disabilities has also been shown to influence parent psychosocial well-being, and experiences specific to parents of children who are DHH with other disabilities (Whicker et al., 2019). Dammeyer and colleagues (2019) found that parents of children who are DHH with other disabilities were less engaged in activities and were more likely to report that the child was a burden for the family. There have been mixed findings in the literature for the relationship of parent or maternal stress and child age (e.g., Hintermair, 2004, 2006; Lederberg & Golbach, 2002; Pipp-Siegel et al., 2002). Pipp-Siegel and colleagues (2002) suggest this inconsistency may be linked to differing sample characteristics and instruments used to measure stress.

Psychological inflexibility for child hearing loss was found to significantly associate with both psychological distress and functional impairment. Higher levels of psychological inflexibility through avoiding thinking about and adapting to the situational demands of a diagnosis is common among chronic conditions (Ong et al., 2019). Outside of audiologic research, studies have shown psychological inflexibility to influence a variety of outcomes, including poor job performance and increased risk for psychopathology (Hayes et al., 2006). In audiology, this is the first research

Table 2
Correlations

	Psychological distress	Psychological inflexibility	Income	WSAS	Other disabilities
Psychological inflexibility	*rho* = 0.345 *p* = 0.000***	-			
Income	*rho* = -0.226 *p* = 0.000***	*rho* = -0.138 *p* = 0.024*	-		
WSAS	*rho* = 0.468 *p* = 0.000***	*rho* = 0.488 *p* =0.000***	*rho* = -0.242 *p* = 0.000***	-	
Other disabilities	*rho* =-0.114 *p* = 0.079	*rho* = -0.113 *p* = 0.065	*rho* = 0.021 *p* = 0.719	*rho* = -0.28 *p* = 0.000***	-
Child age	*rho = 0.002* *p* = 0.975	*rho* = -0.038 *p* = 0.541	*rho* = 0.138 *p* = 0.02*	*rho* = -0.166 *p* = 0.01**	*rho* = -0.084 *p* = 0.162

Note. WSAS = Work and Social Adjustment Scale.
$^{*}p < 0.05$; $^{**}p < 0.01$; $^{***}p < 0.001$

Table 3
Regression Results for Psychological Distress

	Depression, Anxiety, and Stress Scales (DASS-21)		
	β	SE	*p*
Independent variables			
Psychological flexibility (AAQ-MCHL)	0.30	0.02	< .001
Income[1]			
$21,000–40,000	6.87	3.12	< .05
$41,000–80,000	1.44	2.74	.60
> $81,000	-1.35	2.60	.60

Note. AAQ-MCHL = Acceptance and Action Questionnaire–Managing Child Hearing Loss.
[1] Reference level was < $20,000.

study to explore the effect of psychological inflexibility for parents of children who are DHH. The findings of this study have important clinical implications for understanding barriers that interfere with how parents take action to care for their child's hearing related needs. Early identification of hearing loss provides a developmental advantage for children when early intervention is effectively implemented. It is not surprising that this process can be difficult for parents and providing support for parents who are experiencing difficult thoughts or feelings is a neglected aspect of the overall intervention care plan. McCreery and Walker (2017) discuss the importance of addressing malleable factors within the intervention process in their model of cumulative auditory experience, and psychological flexibility is a factor that can be addressed.

The AAQ-MCHL can be used as a screening tool for psychological flexibility to help providers identify parents who are struggling. Other audiologic research has inferred a similar message regarding screening audiologic patients for cognitive decline (Shen et al., 2016; Sweetow, 2015) anxiety and depression (Muñoz, MacLeod, et al., 2015; Zöger et al., 2009), and even suicidality (Schwartzer and Parker, 2019; Zitelli & Palmer, 2018). Screening can help

Table 4
Regression Results for Functional Impairment

	Functional Impairment (WSAS)		
	β	SE	*p*
Independent variables			
Psychological flexibility (AAQ-MCHL)	0.36	0.04	< .001
Comorbid disability			
No[1]	-4.79	1.02	< .001
Child age	-0.32	0.09	< .001

Note. AAQ-MCHL = Acceptance and Action Questionnaire–Managing Child Hearing Loss; WSAS = Work and Social Adjustment Scale.
[1] Reference level was yes (comorbid disability was present).

providers as they partner with parents in determining education and support needs. The AAQ-MCHL is a brief questionnaire that can be administered during the hearing aid fitting process and periodically if there are concerns with engagement. The screening tool can serve as a bridge for audiologists to discuss problematic thoughts and perceptions parents are struggling with, and if indicated, a referral for counseling can be offered. Developing a therapeutic relationship through evidenced-based counseling strategies, such as Motivational Interviewing, can help parents to be open and honest about their challenges and may help audiologists understand when referrals to mental health professionals are necessary for parents. Furthermore, by understanding underlying challenges parents are experiencing, audiologists can target parent priorities and needs. For example, parent-to-parent support can be an important element in helping parents adjust (American Academy of Pediatrics, 2021) and support implementation of daily intervention tasks for hearing health care.

Study Limitations

The results of the correlations should be considered when interpreting these data. Spearman's correlations show each of the three measures used (psychological distress, psychological inflexibility, and functional impairment) to have weak to moderate significant correlations, indicating that these variables are not totally independent of one another, that is, to a certain extent they measured similar attributes. The non-statistically significant correlations found between use of technology and both psychological distress and functional impairment should be interpreted with caution. Prior research has found that self-reported device use is often overestimated by parents (Muñoz et al., 2014; Walker et al., 2013). Furthermore, the average age of the children represented by parents in this study is 7 years. Prior research has indicated that device use is typically lower for younger children (Walker et al., 2013). Thus, future research focused on a sample of parents of younger children (e.g., birth to 3 years) could provide further insights. Furthermore, the study design was cross-sectional and reflects only a moment in time. Future research to explore parent psychosocial well-being over time is needed. The sample primarily consisted of White, college-educated mothers, and does not reflect the multicultural demographics that make up the United States. Future research is needed to explore psychosocial well-being for a more diverse parent sample and a broader range for degree of hearing loss as 74% of the children had severe to profound degrees of hearing loss.

Conclusion

Parents of children who are DHH may experience psychosocial impacts related to the diagnosis and care of their children's hearing loss. This study found that psychological distress and functional impairment may be influenced by factors including psychological inflexibility, low income, the presence of other disabilities tangent to hearing loss, and younger child age. Clinicians serving families may need to provide additional and/or different support for parents in adapting to and managing their child's hearing loss. Screening tools can be used to identify when parents are experiencing psychosocial struggles so that underlying issues can be addressed through targeted support within the overall care plan. Parent well-being is important to the intervention process, as parent struggles can negatively influence daily hearing care habits, such as hours of hearing aid use, and this can negatively affect child outcomes.

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EHDInfo

[Click graphic to visit the Virtual Waiting Room.]

Think about how much you have learned by visiting with others and reading material while you waited for your appointment. The Virtual Waiting Room has been created by Hands & Voices to help people who are receiving virtual services to replicate some of the experiences and benefits of an in-person waiting room.