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## Adverse Childhood Communication Experiences Associated With an Increased Risk of Chronic Diseases in Deaf Adults

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### Abstract

**Introduction:** The present study explores adverse childhood communication experiences and its relative risks for acquiring specific chronic diseases and mental health disorders in deaf and hard of hearing adults.

**Methods:** A cross-sectional design with snowball sampling was used to recruit deaf and hard of hearing adults who were born or became deaf in both ears prior to age 13 years. Patient-reported outcomes surveys in American Sign Language and English were disseminated to collect data about early life communication experiences with caregivers. Modified Poisson regression with robust SEs was used to calculate relative risk estimates and 95% CIs for all medical conditions with early life communication experiences as main predictors.

**Results:** Data collection occurred from May 2016 to July 2016, October 2016 to April 2018, and October 2018 to May 2019. The U.S. sample consisted of 1,524 adults who were born or became deaf early. After adjusting for parental hearing status and known correlates of medical conditions, poorer direct child–caregiver communication was significantly associated with an increased risk of being diagnosed with diabetes (RRR=1.12, 95% CI=1.01, 1.24), hypertension (RRR=1.10, 95% CI=1.03, 1.17), and heart disease (RRR=1.61, 95% CI=1.39, 1.87). Poor indirect family communication/inclusion increased risks for lung diseases (RRR=1.19, 95% CI=1.07, 1.33) and

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PK conceptualized and designed the study, translated the measures to American Sign Language, gathered and analyzed data, drafted the manuscript, and approved the final manuscript as submitted. CR gathered data, assembled the tables, drafted the manuscript, and approved the final manuscript as submitted. RP translated the measures to American Sign Language, drafted the manuscript, and approved the final manuscript as submitted. AS drafted the manuscript and approved the final manuscript as submitted. SG revised the manuscript and approved the final manuscript as submitted. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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depression and anxiety disorders (RRR=1.34, 95% CI=1.24, 1.44). The absolute risk increase and number needed to harm are also reported.

**Conclusions:** Deaf and hard of hearing patient-reported outcomes data demonstrated that poorer direct child–caregiver communication and ongoing exclusion from incidental family communication were associated with increased risks for multiple chronic health outcomes. Practices should consider developing and utilizing an adverse childhood communication screening measure to prevent or remediate language deprivation and communication neglect in deaf and hard of hearing pediatric patients.

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## INTRODUCTION

Until recently, medically underserved deaf and hard of hearing (DHH) individuals who use American Sign Language (ASL) have been excluded from health surveillance data and public health research. Current ASL-accessible population health research that collected self-reported health information from a large sample of DHH adults showed that certain social determinants of health are associated with a higher risk for medical and behavioral health conditions in this population<sup>1-4</sup>. As has been previously established in the literature, negative psychosocial experiences in early childhood can lead to poor health outcomes later in adulthood.<sup>5,6</sup> These experiences, known as adverse childhood experiences (ACEs), are a form of early life toxic stress, which can occur from prolonged activation of the body's stress response system and when the adverse experiences exceed the protective capacities of a child's environment.<sup>5,7,8</sup> Some DHH individuals may face unique stressors in addition to early life toxic stress experienced by those in the general population. Two forms of early life toxic stress that can potentially impact DHH individuals' health are language deprivation (insufficient access to direct child–caregiver communication during the critical period of language development) and communication neglect (ongoing or recurrent exclusion from indirect family communication and incidental learning).

Communication between DHH children and their caregivers can be disrupted in several ways. Most fundamentally, children who do not have full access to language through direct communication with caregivers during childhood and lack age-appropriate skills are at risk for delayed language and cognitive development.<sup>9</sup> Assistive hearing devices (e.g., hearing aids or cochlear implants) do not always provide adequate access to sound to acquire language fluently or pick up on incidental information.<sup>10,11</sup> Similarly, opportunities for adequate exposure to sign language for typical language development to occur are not always present.<sup>12-14</sup> Children who are severely deprived of language access show evidence of early life toxic stress exposure such as severe behavioral difficulties and poor emotional regulation.<sup>15</sup> Though one-to-one communication with a caregiver may be successful, DHH children face additional challenges with indirect family conversations, which provide opportunities for inclusion and incidental learning. The long-term impact of early life communication adversity (direct and indirect) on DHH adult health outcomes is not well understood.

Success in direct child–caregiver communication requires commitment and understanding from both child and caregivers. In some cases, a caregiver may have difficulties

understanding the DHH child regardless of the signed or spoken modality that the child uses. Poor direct child–caregiver communication risks language delays that impact psychosocial and cognitive health outcomes,<sup>9</sup> a growing public health concern for DHH children.

The extent to which the direct form of language-related stressor impacts health outcomes, concurrently or later in life, has been demonstrated empirically in several studies. Adjusting for age, parental hearing status, and language/communication modality used with parents, a youth cohort study found that DHH youths' perceived inability to understand what their caregivers said was significantly associated with lower quality of life and increased depressive symptomatology.<sup>16</sup> Adjusting for language preference and hearing level in a college sample of 143 DHH adults, poorer direct child–caregiver communication was also strongly associated with greater symptoms of depression.<sup>17</sup> Finally, in a retrospective study of 475 DHH adults, those who reported being unable to understand what their primary caregiver said during their formative years had significantly higher odds of experiencing food insecurity compared with deaf adults who understood some to all of what their caregivers said.<sup>2</sup> For all three studies, parental hearing status did not contribute significantly to health outcomes. As with other established forms of early childhood adversity, impaired direct child–caregiver communication may reflect a unique form of early life toxic stress for DHH individuals.

Even when caregivers are successful in isolated one-on-one conversations with their children, they may lack the communication abilities to fully include the child in all family and group interactions. This can be referred to as communication isolation, exclusion, or neglect, and forms another potential source of early life toxic stress for DHH children. The DHH child may attempt to remind family members to include them in conversations but may be told to wait or simply be ignored. Many DHH people recall family members' saying, "It wasn't important" or "I'll tell you later," where "later" is often forgotten. These concerns for DHH children remain regardless of parents' intention, awareness, or conscious efforts to ensure that their DHH child has full communication access in their immediate environment.

One 2013 survey included a question concerning DHH adults' retrospective perception of how well they understood family conversations.<sup>18</sup> In a sample of 211 adults who answered this question, 81% (141/175) of respondents with hearing parents and 18% (4/22) of respondents who had DHH parents reported lower levels of understanding indirect family conversations. Even when direct communication access is not obstructed (for example, if parents sign adequately to a signing DHH child), missing out on incidental family conversations can occur when a DHH child has trouble understanding conversations that caregivers have with other family members. A sense of belonging is essential for healthy child development; thus, feeling excluded or left out within the family may have an adverse impact on development. For DHH children, ongoing difficulty with participation in family conversations and missing out on incidental information is likely to result in psychological distress.<sup>16,19</sup> Again, this experience can happen regardless of parental hearing status.

The term "communication neglect" is used to indicate that a DHH child always or often feels ignored or excluded from family conversations. Even with the best caregiver intentions, communication neglect happens just like language deprivation happens. These phenomena

must be named and studied in order to be prevented and remediated. Given that a large majority of DHH children are born to parents with no experience using visual languages or assistive technologies to communicate,<sup>20</sup> the threat of adverse early life communication experiences and its impact on health outcomes are of great concern.

A better understanding of adverse childhood communication experiences as unique contributors to specific health outcomes is needed so that interventions and policy can be targeted to better support accessible, language-rich, and inclusive environments for developing DHH children and their families. The present study explores adverse childhood communication experiences and their relative risks for acquiring specific chronic diseases and mental health disorders later in life.

## METHODS

### Study Sample

Following approval by Gallaudet University's IRB, research staff recruited DHH adults who were born or became deaf in both ears prior to age 13 years (pre-puberty stage). Recruitment methods included snowball sampling through personal networks, distribution of flyers, and advertisements on Deaf-centered organizations' websites and e-newsletters. Data collection occurred from May 2016 to July 2016, October 2016 to April 2018, and October 2018 to May 2019. Those who provided consent completed the online survey in approximately 1 hour.

### Measures

Demographic information was collected on all participants. Self-reported health information was obtained by asking subjects if health providers had ever informed them of a diagnosis of any of the following: diabetes, heart disease, hypertension, lung disease, arthritis, depression/anxiety, or cancer. Given the national scope of this survey, chart review data from the survey participants to confirm self-reported diagnoses was not available. All survey items were fully accessible in ASL and English. Details of this translation procedure and administration of bilingual health survey online in ASL and English are discussed elsewhere.<sup>21</sup>

Adverse childhood communication experiences were assessed using the Patient-Reported Outcomes Measurement Information System (PROMIS) Deaf Profile\_ELCE measure, which has been validated in ASL.<sup>22,23</sup> Psychometric results revealed two separate but related constructs as follows:<sup>23</sup>

1. PROMIS-Deaf\_ELCE: Direct Child–Caregiver Communication. *Thinking about the person/caregiver/parent who took care of you the most when you were growing up, how much did this person understand you? (completely, mostly, moderately, a little, not at all).*

Thinking about the person/caregiver/parent who took care of you the most when you were growing up, how much did you understand this person? (completely, mostly, moderately, a little, not at all).

2. PROMIS-Deaf\_ELCE: Indirect Family Communication and Inclusion. *When you were growing up, how often did you feel included in family conversations or discussions? (always, often, sometimes, rarely, never; reverse scored).*

When you were growing up, how often did you feel ignored or left out by your family? (always, often, sometimes, rarely, never: reverse scored)

### Statistical Analysis

This study used SPSS, version 26.0 to examine the associations between adverse childhood communication experiences and prevalence of each medical condition. The main predictors were converted from T-scores to categorical predictors prior to analysis. T-scores that fell 1 SD below the mean were assigned to “inadequate access” group, with others assigned to “adequate access” group. The level of significance was set at  $p < 0.05$ .

Modified Poisson regression with robust SEs was used to calculate relative risk estimates and 95% CIs for all medical conditions with adverse childhood communication experiences as main predictors, adjusting for age, sex, race/ethnicity, education, parental hearing status, and health status. The modified Poisson approach was recommended for models with binomial outcomes, and the application of robust SEs helped rectify the overestimation for the relative risk of having a medical condition.<sup>24</sup> The RRRs were used to estimate the relative risks of having a medical condition among people who experienced adverse childhood communication compared with people who did not experience this (reference category). The absolute risk increase (ARI) and number needed to harm (NNH) were also calculated for the negative impact of adverse childhood communication experiences on each medical condition. ARI were determined based on severity of adverse childhood communication experiences (i.e., T-score  $< 1$  SD from the mean) and NNH was calculated for, on average, the number of patients that need to be exposed to a risk factor (e.g., language deprivation or communication neglect) for one patient to receive harm (e.g., a medical condition) relative to placebo. Therefore, an NNH close to 1 indicates a risk factor that frequently results in harm of having a medical condition, whereas larger NNH values indicate risk factors that rarely result in harm of having a medical condition.

## RESULTS

The current U.S. study sample consisted of 1,524 adults who were born deaf or became deaf prior to age 13 years (pre-puberty), with 27% having DHH parents and 73% having hearing parents. Among the hearing parent group, 49% used spoken language, 31% used sign language, and the remaining 20% used other modalities (e.g., gestures, writing, cued speech) to communicate with the DHH respondent. In the DHH parent group, 82% used sign language, 12% used spoken language, and the remaining 6% used other modalities (e.g., gestures, writing, cued speech) to communicate with the DHH respondent. The mean age for the DHH adult sample was 46 (SD=18) years, with 58% identifying as female and 66% identifying as white. The lifetime prevalence for medical conditions was 32% for diabetes, 8% for heart conditions, 32% for hypertension, 16% for lung condition, 27% for depression/anxiety disorders, and 10% for cancer. A majority (89%) of the sample perceived their health to be good (Table 1). Eleven percent of the DHH adult sample retrospectively

reported their direct communication with caregivers as difficult to understand (*a little* or *none at all*). For indirect family communication/inclusion, 39% reported *often* or *always* feeling excluded or left out from family conversations.

Here, only significant relationships between the main predictors and certain medical conditions are reported. Table 2 lists all significant and nonsignificant results.

Inadequate access to direct child–caregiver communication increased a person’s risks for being diagnosed with diabetes by 12% (95% CI=1%, 24%), hypertension by 10% (95% CI=3%, 17%), and heart disease by 61% (95% CI=39%, 87%) relative to people who have adequate access to direct child-caregiver communication.

If the person had inadequate access to direct child–caregiver communication, the ARI for acquiring each condition was as follows: 8% for diabetes (95% CI=5%, 8%), 13% for hypertension (95% CI=10%, 15%), and 7% for heart disease (95% CI=6%, 10%). The NNH for a person to be harmed by inadequate access was about one in 13 for diabetes (95% CI=10, 17), one in eight for hypertension (95% CI=7, 10), and one in 15 for heart disease (95% CI=12, 20).

Inadequate access to indirect family communication and inclusion significantly increased a person’s relative risk for depression and anxiety disorders by 34% (95% CI=25%, 44%) and lung disease by 19% (95% CI=7%, 33%) compared with people who had adequate access to indirect family communication/inclusion.

If a person had inadequate access to indirect family communication and inclusion while growing up, the ARI for acquiring each medical condition was as follows: 7% for depression/anxiety (95% CI=5%, 10%) and 4% for lung disease (95% CI=2%, 6%). The NNH for one person to be harmed by inadequate access was about one in 13 for depression/anxiety disorder (95% CI=10, 19) and one in 25 for lung disease (95% CI=17, 44).

## DISCUSSION

The current study is the first to gather and utilize patient-reported outcome data from a large U.S. DHH adult sample to explore the association of adverse childhood communication experiences, both direct and indirect, with adulthood health outcomes. Direct and indirect adverse communication experiences were differentially associated with increased risk for chronic health conditions.

After adjusting for demographics and health correlates, adverse direct child–caregiver communication was associated with significantly higher relative risk for being diagnosed with diabetes, hypertension, and heart disease compared with DHH adults who reported having adequate access to direct child–caregiver communication. The absolute risk estimates show that approximately one person in 13 who understood little to none of what their primary caregiver said and vice versa while growing up would be affected by diabetes, one in eight by hypertension, and one in 15 by heart disease.

Compared with adequate access to and inclusion in indirect family communication, ongoing exclusion from indirect family conversations was associated with an increased risk of lung disease and depression/ anxiety disorders. Among people who reported always or often experiencing exclusion from indirect family communication in childhood years, one in 13 would experience a depression or anxiety disorder and one in 25 would experience lung disease.

The current study is adequately powered to make the distinction between two types of adverse childhood communication experiences (direct and indirect) and their relationships with specific chronic health outcomes. The clinical significance for NNH for each type of adverse childhood communication experience is clear. A future direction for this research is to incorporate these constructs into standardized adverse childhood communication screening measures and targeted interventions to prevent or remediate the toxic stress exposure of language deprivation and communication neglect. In addition to creating and implementing evidence-based assessment and intervention, action must be taken to develop clinical practice, as well as early intervention and educational policies that emphasize direct and indirect communication access for DHH children. Language and communication, both direct and indirect, need to be made accessible to the DHH child, and the DHH child needs to feel included in family communication. This will in turn promote healthy child development and well-being, and ultimately may reduce the risk for developing chronic disease in adulthood.

Based on the current study results, adverse early life communication experiences such as language deprivation and communication neglect are in fact ACEs, which can potentially alter physiological (e.g., neuroendocrine activation and regulation) and psychological (e.g., coping) mechanisms during critical periods of development and consequently increase risk for adulthood chronic disease.<sup>25-28</sup> For these reasons, future studies that explore ACEs and developmental outcomes in DHH individuals should include history of early life communication adversity. Future studies might also elucidate the long-term impact of biological and psychological mechanisms associated with adverse childhood communication experiences on chronic diseases during adulthood, and whether this impact may potentially be moderated by resilience or other protective factors. As screening for ACEs is gradually becoming a standard practice in health care, adverse communication experiences should be included in regular ACEs screenings for DHH individuals. Interventions designed to target the underlying mechanisms of language-related stress may be a potential strategy to offset the impact of toxic stress associated with early life communication adversity on chronic health conditions.

## Limitations

Limitations of this study include the use of self-reported health information rather than medical record review. Study participants' family history of chronic medical conditions was also not evaluated as most participants reported that they did not know their family history. As a retrospective study, only correlation can be established between the exposure of early life toxic stress in the form of language deprivation and communication neglect and health outcomes. Designing a study aimed to establish causation, however, would be challenging

based on the ethical implications of purposefully subjecting children to a linguistically poor environment in a randomized manner.

## CONCLUSIONS

Concerningly high rates of poor direct and indirect child–caregiver communication were reported in the current U.S. study sample. Approximately 11% reported poor direct caregiver communication as a child while 39% reported feeling excluded from indirect family communication. Given the observed relationship between inadequate language and communication access during childhood and adverse health outcomes later in life, it is imperative for the medical and public health communities to implement interventions to improve DHH children’s early life communication experiences. Medical providers are critical in this process as they have frequent interactions with young DHH children and their families at preventative health visits and are in a position to screen for adverse childhood communication experiences. Ideally, efforts should be made to educate behavioral health and medical providers on language deprivation and communication neglect in DHH children and also develop tools for tracking language development and engagement in indirect family conversations.

The establishment of such evidence-based screeners and interventions is critical to improve access to language and engagement in family conversations by teaching caregivers how to create inclusive and accessible communication environments for their DHH child. Hopefully, by reducing the incidence of adverse early life communication experiences as a source of toxic stress, DHH children will have lower risk of developing chronic diseases and mental health disorders in adulthood.

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**Table 1.**

Unweighted Sociodemographic Characteristics of Respondents Who Answered Early Life Communication Experiences Items (n=1,524)

Variables	n (%) <sup>a</sup>
Age, mean (SD)	45.83 (18.12)
Age onset of hearing loss, mean (SD)	0.94 (1.94)
Sociodemographics	
Birth sex	
Male	613 (40)
Female	905 (59)
Race/Ethnicity	
White	999 (66)
Black	143 (9)
Asian	94 (6)
Latinx	209 (14)
Other	72 (5)
Education	
High school diploma or less	652 (43)
College degree (includes associates and bachelors)	871 (57)
Parents' hearing status	
Deaf	417 (27)
Hearing	1,101 (72)
Assistive hearing device	
Do not use	809 (56)
Hearing aids	484 (34)
Cochlear implants	135 (9)
Other types of listening devices	6 (<1)
Self-reported ability to understand speech in a quiet room (listening, speechreading, lipreading, or combined)	
Can understand everything	130 (7)
Can understand most	491 (26)
Can understand some to little	794 (41)
Cannot understand anything	512 (27)
Health status	
Very good/Excellent	830 (55)
Good	520 (34)
Poor/Fair	167 (11)

<sup>a</sup>Frequencies not summing to total reflect missing data.

**Table 2.**

RRR Estimates, Absolute Risk Reductions, Number Needed to Treat, for Each Medical Condition by PROMIS Deaf\_ELCE Domain

Medical condition	PROMIS-Deaf_ELCE					
	Direct child-caregiver communication			Indirect family communication/inclusion		
	RRR <sup>a</sup> (95% CI)	ARI (95% CI)	NNH (95% CI)	RRR <sup>a</sup> (95% CI)	ARI (95% CI)	NNH (95% CI)
Diabetes	<b>1.12 (1.01, 1.24)</b>	0.08 (0.06, 0.10)	13 (10, 17)	1.05 (0.95, 1.17)	0.04 (0.02, 0.06)	24 (16, 42)
Hypertension	<b>1.10 (1.03, 1.17)</b>	0.13 (0.10, 0.15)	8 (7, 10)	0.94 (0.88, 1.01)	0.04 (0.02, 0.06)	25 (16, 59)
Heart condition	<b>1.61 (1.39, 1.87)</b>	0.07 (0.05, 0.08)	15 (12, 20)	1.07 (0.92, 1.24)	0.02 (0.007, 0.04)	49 (29, 138)
Lung disease	1.04 (0.93, 1.16)	0.02 (0.001, 0.04)	52 (26, 797)	<b>1.19 (1.07, 1.33)</b>	0.04 (0.02, 0.06)	25 (17, 44)
Cancer	0.87 (0.75, 1.01)	0.02 (0.003, 0.03)	56 (29, 402)	1.11 (0.097, 1.26)	0.04 (0.02, 0.05)	26 (18, 44)
Arthritis	1.00 (0.92, 1.09)	0.09 (0.07, 0.11)	11 (9, 15)	0.99 (0.91, 1.08)	0.05 (0.03, 0.07)	19 (13, 30)
Depression/Anxiety disorder	0.92 (0.84, 1.01)	0.05 (0.03, 0.07)	20 (14, 35)	<b>1.34 (1.25, 1.44)</b>	0.07 (0.05, 0.10)	13 (10, 19)

Notes: Adequate access is the reference group. Values in bold indicate statistical significance at  $p=0.05$ .

<sup>a</sup> Adjusted for age, sex, race, education, parent hearing status, and health status.

PROMIS, Patient reported outcomes measurement information system; ELCE, early life communication experiences; ARI, absolute risk increase; NNH, number needed to harm.