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A Pilot Study of Deaf Trauma Survivors' Experiences: Early Traumas Unique to Being Deaf in a Hearing World

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Abstract

Conducting semi-structured American Sign Language interviews with 17 Deaf trauma survivors, this pilot study explored Deaf individuals' trauma experiences and whether these experiences generally align with trauma in the hearing population. Most commonly reported traumas were physical assault, sudden unexpected deaths, and "other" very stressful events. Although some "other" events overlap with traumas in the general population, many are unique to Deaf people (e.g., corporal punishment at oral/aural school if caught using sign language, utter lack of communication with hearing parents). These findings suggest that Deaf individuals may experience developmental traumas distinct to being raised in a hearing world. Such traumas are not captured by available trauma assessments, nor are they considered in evidence-based trauma treatments.

Keywords

Posttraumatic stress disorder; PTSD; Life Events Checklist; Deaf and hard-of-hearing community; Developmental trauma

Deaf¹ individuals report trauma at nearly twofold higher rates than hearing individuals, including experiences of child abuse, intimate partner violence, sexual assault, and crime victimization (Anderson and Leigh 2011; Francavillo 2009; Harrell 2011; Pollard et al.

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Compliance with Ethical Standards

Ethical Approval All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000.

Informed Consent Informed consent was obtained from all individual participants for being included in the study.

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¹The U.S. Deaf community is a sociolinguistic minority group of approximately 500,000 persons who communicate primarily using American Sign Language. Members of this community are unique from other individuals with hearing loss in their identification as a cultural – not disability – group and are delineated by use of the capital "D" in "Deaf."

2014; Sebald 2008). Factors believed to contribute to their increased vulnerability to trauma include, but are not limited to, deprivation of early language development, conflict in the family over education and communication methods, poor/inappropriate parental involvement, low self-esteem, and social isolation (Ridgeway 1993), as well as significant barriers to accessing services in American Sign Language (ASL), which severely limits Deaf individuals' options for escaping from abusive relationships or other unsafe situations (Nosek et al. 2001).

Most research on Deaf trauma disparities has focused primarily on one type of trauma (i.e., intimate partner violence only, sexual assault only), rather than the multiple types of trauma events that one may experience across their lifespan, with the exception of one study. Schild and Dalenberg (2012) found that Deaf adults experienced an average of six unique trauma types across their lifetimes, with the most commonly reported traumas being transportation accidents, unexpected deaths, physical assaults, and natural disasters. The researchers also found that 62 % of their sample endorsed "other" trauma events, but "detailed information about many of these events was not available" (Schild & Dalenberg, p. 123). Without this information, it is difficult to determine whether Deaf individuals' traumatic experiences align with what is generally considered as trauma in the hearing population, or if they are exposed to "other" traumas that are unique to the Deaf population. This gap in our basic understanding of Deaf individuals' trauma experiences prevents the effective design and utilization of clinical interventions for Deaf trauma survivors, as well as public health interventions to prevent initial trauma exposures.

To address this gap in the literature, we conducted semi-structured ASL interviews with Deaf individuals to explore their lifetime trauma experiences. This pilot investigation sought to ascertain prevalence rates of multiple types of trauma events commonly reported by the general population within a Deaf sample.

Methods

Study Population

We recruited 17 Deaf trauma survivors from across Massachusetts to the present pilot study. Participants were recruited via online advertisements posted on Craigslist and Deaf-related listservs, as well as distributed to agencies, clinicians, and case managers who serve Deaf clients. To increase accessibility, these advertisements were disseminated in two forms: written English flyers and ASL digital video. Recruitment materials directed interested individuals to contact the research team using videophone, the standard telecommunication device for the Deaf. During this videophone call, the Principal Investigator (a hearing ASL-fluent psychologist) briefly explained the purpose of the study, the procedures involved, and screened potential participants for the following pre-determined inclusion/exclusion criteria.

Inclusion criteria consisted of: (a) age 21 years and older; (b) Massachusetts residency; (c) self-identified hearing status of Deaf or hard-of-hearing²; (d) self-identified primary

²Data regarding age of hearing loss (i.e., congenital, acquired) was not collected as part of the current investigation. However, the majority of individuals who self-identify as Deaf or hard-of-hearing and claim American Sign Language as their primary communication mode are either born with hearing loss or experience hearing loss before the age of three years (Mitchell et al. 2006).

communication mode of ASL; and (e) history of trauma exposure. Trauma exposure was defined as “direct exposure to, witnessing of, learning about, or repeated indirect exposure to aversive details of... death, threatened death, actual or threatened serious injury, or actual or threatened sexual violence,” as outlined in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)* (American Psychiatric Association 2013). Exclusion criteria were minimal in order to recruit a diverse sample of Deaf trauma survivors, with only adults unable to consent and prisoners excluded from the present sample.

Interview Instrument

Eligible participants were scheduled for an in-person study session during which the Principal Investigator obtained informed consent and conducted a 45-min semi-structured interview in ASL. The individual interview format was selected over a focus group format due to the sensitive interview topic as well as concerns about anonymity and confidentiality that are often observed among members of the small, close-knit Deaf community (Barber et al. 2010). The interview collected basic sociodemographic information and was comprised of questions from the *Life Events Checklist* (Blake et al. 1995), the *PTSD Symptom Scale Interview* (Hembree et al. 2002), and original questions about Deaf individuals' help-seeking behaviors. We focused here on participants' lifetime experiences of trauma and, therefore, report on only our findings from the *Life Events Checklist*.

The *Life Events Checklist* (Blake et al. 1995) queries each participant's level of exposure (i.e., *happened to me, witnessed it, learned about it, not sure, doesn't apply*) to 16 events that commonly result in posttraumatic stress disorder (PTSD; e.g., natural disaster, physical assault, sexual assault). It also includes a final item about exposure to any “other very stressful event or experience” not represented in the previous 16 items. For the current investigation, we focused only on events that participants had directly experienced (i.e., *happened to me*). The *Life Events Checklist* has demonstrated acceptable psychometric properties as a stand-alone trauma assessment tool with hearing individuals, including adequate temporal stability and good convergent validity with other measures of trauma history (for detailed psychometric properties, see Gray et al. 2004).

Interview questions were adapted into ASL. Adaptation occurred in collaboration with the Deaf & Allied Clinicians Consult Group, a clinical and research consultation group comprised of professionals from the University of Massachusetts Medical School and the Massachusetts Department of Mental Health. At the time of this project, this multidisciplinary group included two Deaf and three hearing members with backgrounds in psychology, psychiatry, mental health counseling, mental health case management, and social work. Item adaptation focused on preserving linguistic equivalency and psychological conceptual equivalency between the English and ASL interview questions. A typical three-stage procedure was used (i.e., translation, back-translation, equivalence comparison), similar to the translation of other psychological measures into ASL (Brauer 1993).

Data Analysis

Interview responses were entered into a Research Electronic Data Capture (REDCap) database. Quantitative data were exported to SPSS Statistics Version 22 for analysis.

Since the aims of this study were exploratory rather than hypothesis-driven, power analyses were not conducted. Descriptive statistics were used to summarize the sample's lifetime experiences of trauma: (a) mean, median, and range of total number of trauma events reported by Deaf trauma survivors; (b) frequencies of each type of trauma event; and (c) frequencies of responses to "other very stressful event or experience."

Results

We enrolled a total of 13 female and four male participants between March and September 2014. Most identified as being culturally Deaf, White, middle-aged, and heterosexual (see Table 1).

Participants reported an average of six trauma types across their lifetimes ($M = 6.12$; $SD = 3.14$), ranging from 2 to 13 types per participant. Of note, none of the participants reported experiencing only one type of trauma during their lifetime.

Frequencies of each trauma type are listed in Table 2. The most frequently reported type was "physical assault," which was reported by 82 % of study respondents. This was closely followed by "sudden, unexpected death of someone close to you" and "other very stressful event or experience," which were each reported by 76.5 % of study participants.

Within the "other" category, participants reported 14 trauma experiences not captured by the items in the *Life Events Checklist* (see Fig. 1). Eight were experiences frequently reported by the general population, with the most common being emotional abuse and family poverty. Six types of "other" traumas, however, were those typically not experienced by hearing individuals. These experiences included physical or verbal punishment at oral/aural school if caught using American Sign Language instead of speaking, and experiences in which there was a severe lack of communication access at home, school, or in the medical system.

For example, when asked if they had experienced any traumatic events not queried on the *Life Events Checklist*, one participant described an early experience that she claimed so affected her ability to trust and relate to others that it continued to impair her social functioning throughout adulthood. She described, "My parents dropped me off at Deaf residential school when I was 3 years old. They didn't sign; I didn't speak. We had no shared communication, so I had no idea where I was. When they left, I was inconsolable. I was terrified that I would never see them again. I next saw them for winter break a few months later, but it was too late. For most of my life, I continued to blame my mother for that experience."

Another participant described experiences of bullying at an oral school for the Deaf, where her speech abilities were constantly criticized by teachers, staff, and peers. She reported that this ongoing criticism led to behavioral avoidance of school, low self-concept and self-blame, difficulty sleeping, difficulty concentrating, and severe avoidance and isolation from interacting with others. Other participants reported being hit with brushes or other objects by oral/aural school teachers if they were caught using American Sign Language instead of spoken English. Many reported that these punishments were continued at home, as their

parents had been incorrectly advised by medical and educational professionals that the use of sign language would inhibit their acquisition of spoken English.

Such developmental experiences might not typically be considered “trauma” as defined by Criterion A of the *DSM-5*: exposure to “death, threatened death, actual or threatened serious injury, or actual or threatened sexual violence” (American Psychiatric Association 2013). Yet, participants described their experiences as eliciting feelings of “intense fear, helplessness, or horror,” a previous requirement for *DSM-IV-TR* (4th ed., text rev.; American Psychiatric Association 2000) PTSD diagnosis. More importantly, participants in our study *perceived* that these early developmental experiences had caused them emotional injuries that lasted well into adulthood, and that perception resulted in long-term symptoms of posttraumatic stress. Recent research on the structural validity of *DSM-5* PTSD criteria suggests that symptoms arise regardless of *DSM-5*-defined trauma severity, with qualitative similarities between a trauma and a sub-threshold stressful life event: “...although patients experiencing a Criterion A trauma reported more PTSD symptoms than the sub-threshold stressor sample, our results suggest that the structural patterning of such symptoms is quite similar regardless of whether Criterion A is satisfied” (Zelazny and Simms 2015, p. 21). Therefore, the sub-threshold developmental stressors reported by our participants may have indeed had great impact on their psychological functioning, even if these experiences did not precisely fit the *DSM-5* definition of “trauma.”

Discussion

This pilot study explored the lifetime trauma experiences of 17 individuals from the Massachusetts Deaf community. In our study sample, participants reported having experienced an average of six different types of trauma. This frequency is similar to trauma-exposed individuals from hearing community samples in others areas of New England (Marshall-Berenz et al. 2010).

The Deaf trauma survivors in our study most commonly reported experiences of physical assault, sudden unexpected death of individuals close to them, and “other” very stressful events or experiences. These types of traumas were reported by more than three-fourths of the sample. In the 2012 Schild and Dalenberg study, more than two-thirds of their Deaf adult sample reported having experienced transportation accidents, unexpected deaths, physical assaults, and natural disasters. These results are largely similar to current findings, with the exception of the high rate of natural disasters in Schild and Dalenberg’s sample. It is likely that this elevation is due to the location from which their sample was recruited – southern and central California – and the relative frequency of earthquakes, floods, mudslides, and wildfires compared to New England.

In a relatively comparable sample of 81 trauma-exposed hearing individuals from New England, physical assault was the seventh most common type of trauma; sudden unexpected death was first, and “other” events were fifth (Marshall-Berenz et al. 2010). Sudden unexpected death was commonly reported by the hearing sample, Schild and Dalenberg’s (2012) Deaf sample, and our Deaf sample, suggesting that the frequency of this particular trauma is similar across Deaf and hearing populations. However, our findings, paired with

Schild and Dalenberg's findings, suggest that Deaf individuals may be particularly vulnerable to experiences of physical assault compared to the general hearing population. Our finding is corroborated by recent literature, which has demonstrated disparate rates of partner-perpetrated physical assault and crime victimization among Deaf individuals (Anderson and Leigh 2011; Harrell 2011; Pollard et al. 2014).

Especially noteworthy is the frequency with which "other" very stressful events or experiences were reported by our sample (77 %) and by the Schild and Dalenberg Deaf sample (62 %). Although some of our participants' experiences were similar to the general population (e.g., emotional abuse), many were unique to Deaf individuals. Such events included experiencing a complete lack of communication with one's hearing parents, experiencing severe attachment disruptions with caregivers, or undergoing corporal punishment at oral/aural school when caught using American Sign Language.

Our findings are consistent with the Deaf childhood development literature, which suggests that Deaf children born to hearing parents (approximately 90 % of Deaf people) are vulnerable to early attachment disruptions (e.g., obstructed communication with parents, isolation, parents' grief and attempts to cure child's deafness; Brice and Adams 2011). Additional traumas can occur within educational settings, especially those not designed to support Deaf children's communication needs. Adulthood traumas are, therefore, often superimposed on a variety of stressful or traumatic developmental experiences, potentially increasing Deaf people's risk for developing trauma-related behavioral health problems within their lifetimes.

Study Strengths and Limitations

This is one of the first known studies to explore the variety of traumatic experiences that Deaf individuals may encounter throughout their lifetimes. A key strength of our study was the use of Deaf-accessible methods (e.g., recruitment materials, informed consent, and interviews provided in American Sign Language; provision of Certified Deaf Interpreters as needed). This is largely attributable to collaboration with Deaf colleagues throughout each step of the research process, including when designing our methods, selecting and translating trauma instruments, interpreting study findings, and preparing this manuscript.

Our primary study limitation was the small sample size, which did not permit us to compare the trauma experiences of various sociodemographic subgroups in our Deaf population. Second, our sample was primarily White, middle-aged, and heterosexual. Inasmuch, the results of this small exploratory study should be generalized with caution to the U.S. Deaf community.

Third, the *Life Events Checklist* (Blake et al. 1995) assesses one's exposure to 16 different types of trauma. It does not assess the respondent's total number of lifetime trauma experiences. For example, an individual who reports two types of trauma may in fact have experienced many more trauma experiences across their lifetime (e.g., 10 instances of physical assault, five instances of sexual assault). This information is, therefore, not captured in the current data.

Fourth, due to the pilot nature of this study, we did not include control groups to whom we could compare our sample of Deaf trauma survivors. Our study results, therefore, cannot make a direct comparison of trauma experiences between Deaf survivors and hearing survivors. Nor can our results distinguish the experiences of Deaf survivors from the experiences of hearing survivors who likewise exhibit communication differences from the general population (e.g., individuals learning English as a second language, individuals with autism spectrum disorder). Indeed, the early traumas reported by our sample may be more attributable to the failure of the general population to make appropriate accommodations for individuals with communication differences, rather than just a failure to accommodate those with sensory disabilities.

Study Implications and Future Directions

Our findings suggest that Deaf trauma survivors frequently experience types of trauma that are distinct to being a Deaf child raised in a hearing world. These Deaf-specific traumas are not captured by available trauma assessments, nor considered in evidence-based trauma treatments developed for the general population. As such, Deaf clients' experiences of trauma may go undetected in typical screening procedures, be consistently underreported, and/or remain unaddressed via available therapy interventions.

Future research is therefore needed to develop and validate assessment tools and clinical interventions that account for the unique experiences of Deaf trauma survivors and better support Deaf people's recovery from lifetime trauma experiences. To increase the robustness of these findings, methodological improvements building upon the current study could include: comparison to hearing controls matched on factors associated with trauma vulnerability (e.g., age, gender); comparison to a control group of individuals who experience communication differences from the general population stemming from etiologies other than deafness; and larger samples drawn from a national population of Deaf trauma survivors.

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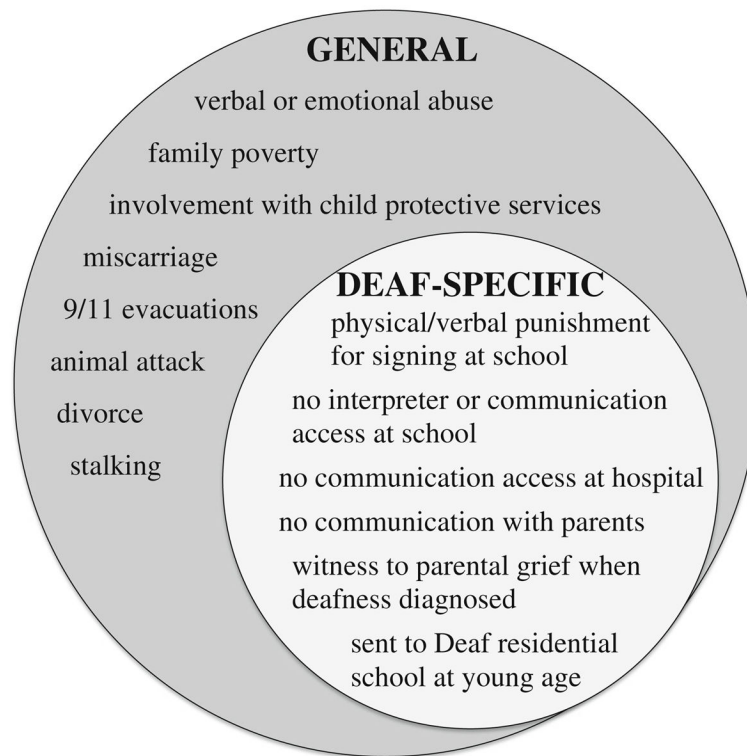


Fig. 1.
“Other” types of trauma reported by Deaf trauma survivors

Table 1

Study sample characteristics

Sociodemographic characteristic	%
Age (years)	
21–34	23.5
35–44	11.8
45–54	52.9
55+	11.8
Ethnicity	
Not Hispanic/Latino	82.4
Hispanic/Latino	17.6
Race (select all that apply)	
White	100.0
Black/African-American	5.9
American Indian/Alaska Native	5.9
Sexual orientation	
Straight	76.5
Gay/lesbian	17.6
Bisexual	5.9
Hearing status (self-identified)	
Deaf	88.2
Hard-of-Hearing	5.9
Not sure	5.9
Preferred language	
American Sign Language	88.2
Spoken English	5.9
Other	5.9
Use of assistive hearing device	
No device	47.1
Hearing aid	41.2
Cochlear implant	11.8
Parental hearing status	
Both hearing	82.4
Both Deaf	17.6
Parental communication method (select all that apply)	
Spoken English	52.9
American Sign Language	29.4
Home sign	11.8
Signed Exact English	5.9
Other	41.2
School type	
Deaf school only	52.9

Sociodemographic characteristic	%
Both Deaf and mainstream school	29.4
Mainstream school only	17.6
Education level	
Some high school	17.6
High school diploma	23.5
Some college	23.5
4-years college degree	29.4
Some graduate school and above	5.9
Employment status	
Collecting SSDI/SSI	47.1
Employed full-time	35.3
Employed part-time	17.6

Table 2

Most common experiences reported by deaf trauma survivors

Type of Trauma	%
Physical assault	82.4
Sudden, unexpected death of someone close to you	76.5
Other very stressful event of experience	76.5
Transportation accident	58.8
Assault with weapon	52.9
Sexual assault	52.9
Other unwanted or uncomfortable sexual experience	52.9
Sudden, violent death	41.2
Life-threatening illness or injury	29.4
Natural disaster	23.5
Fire or explosion	17.6
Serious accident at work or home	17.6
Witness to severe human suffering	11.8
Captivity	5.9
Exposure to toxins	5.9
Exposure to war zone	5.9