

1-20-2016

Symptom Patterns of Posttraumatic Stress Disorder among Deaf Trauma Survivors

Melissa L. Anderson

University of Massachusetts Medical School, Worcester, MA

Amanda Sortwell

Deaf Community Behavioral Health Services, San Diego, CA

Kelly S. Wolf Craig

Department of Developmental Services, East Hartford, CT

Douglas M. Ziedonis

University of Massachusetts Medical School, Worcester, MA

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Recommended Citation

Anderson, M. L., Sortwell, A., Wolf Craig, K. S., & Ziedonis, D. M. (2016). Symptom Patterns of Posttraumatic Stress Disorder among Deaf Trauma Survivors. *JADARA*, 50(1). Retrieved from <https://repository.wcsu.edu/jadara/vol50/iss1/3>

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Cover Page Footnote

We would like to acknowledge the members of the Deaf & Allied Clinicians Consult Group for their consultation and guidance on this project: Gloria Farr, LICSW; Susan Jones, LMHC; Lisa Mistler, MD; and Gregory Spera. We would also like to thank Robert Goldberg, PhD, for his feedback during the preparation of this manuscript. This work was partially supported by the National Center for Research Resources and the National Center for Advancing Translational Sciences, National Institutes of Health, through Grant KL2TR000160. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

Deaf¹ individuals report more lifetime trauma than the general population, including child maltreatment, intimate partner violence, sexual assault, and crime victimization (Anderson & Leigh, 2011; Francavillo, 2009; Harrell, 2011; Nosek, Foley, Hughes, & Howland, 2001; Pollard, Sutter, & Cerulli, 2014; Schenkel et al., 2014; Schild & Dalenberg, 2015). Consequently, recent findings suggest that posttraumatic stress disorder (PTSD) may be the most common diagnosis among Deaf psychiatric inpatients (Black & Glickman, 2006), and Deaf college students may exhibit higher rates of PTSD than matched hearing college students (Schenkel et al., 2014).

Despite early evidence of higher rates of trauma and PTSD among Deaf individuals, detailed information about the symptom presentation of PTSD remains relatively unknown due to the use of inaccessible recruitment, sampling, and data collection procedures in most epidemiological research regarding our nation's behavioral health (Barnett, McKee, Smith, & Pearson, 2011; Fellingner, Holzinger, & Pollard, 2012; Livermore, Whalen, Prenovitz, Aggarwal, & Bardos, 2011). Random-digit-dial surveys fail to sample Deaf ASL users, who generally use videophones for remote communication rather than standard telephone technology. In-person studies that collect detailed information about behavioral health disorders, including by the National Comorbidity Study Replication, sample only English-speaking individuals and do not document the provision of interpreters or other accommodations for individuals with hearing loss (Anderson, Ziedonis, & Najavits, 2014). These commonly-used procedures automatically exclude most members of the Deaf community (Livermore et al., 2011).

¹ The U.S. Deaf community is a sociolinguistic minority group of approximately 500,000 persons who communicate primarily using American Sign Language (Mitchell, Young, Bachleda, & Karchmer, 2006). 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” (Ladd, 2003; Lane, 1992).

With the exception of one study that documented potentially increased rates of dissociation among Deaf trauma survivors (Schild & Dalenberg, 2012a), relatively little is known about how symptoms of PTSD manifest among Deaf trauma survivors. To address this gap, semi-structured ASL interviews were conducted with trauma-exposed Deaf individuals to determine whether they met criteria for current PTSD diagnosis according to the DSM-IV-TR, and to explore how the symptoms of PTSD commonly present within this population.

Methods

Study Population

We recruited 17 Deaf individuals who had previously experienced trauma from across Massachusetts for the present study. They were recruited via online advertisements posted on Craigslist and Deaf-related listservs, and through agencies, clinicians, and case managers who served Deaf clients. To increase accessibility, these advertisements were disseminated in two forms: written English flyers and ASL digital videos. 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 criteria.

Inclusion criteria were: (1) age 21 years or older; (2) Massachusetts residency; (3) self-identified hearing status of Deaf or Hard of Hearing; (4) self-identified primary communication mode of ASL; and (5) 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” (American Psychiatric Association, 2013). Exclusion criteria were minimal in order to

recruit a diverse sample of Deaf trauma survivors, with only adults unable to provide informed 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-minute semi-structured interview in ASL. The individual interview format was selected over a focus group setting due to the sensitivity of the interview topic as well as concerns about anonymity and confidentiality that are often observed among members of the small, close-knit Deaf community (Barber, Wills, & Smith, 2010). The interview collected basic sociodemographic information, and was comprised of questions from the Life Events Checklist, the PTSD Symptom Scale Interview, and original questions about Deaf individuals' help-seeking behaviors.

The Life Events Checklist 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 (e.g., natural disaster, physical assault, sexual assault; Blake et al., 1995). 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 primarily on events that participants had directly experienced (i.e., *happened to me*), as direct exposure to potentially traumatic events is a better predictor of subsequent trauma symptoms than indirect exposure and "learning about or witnessing a number of the events assessed by the Life Events Checklist would not ordinarily be considered a DSM-IV Criterion A1 stressor for PTSD" (Gray, Litz, Hsu, & Lombardo, 2004, p. 337). 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 convergence validity with

other measures of trauma history (for detailed psychometric properties, see Gray et al., 2004).

The PTSD Symptom Scale Interview assesses the presence and severity of current PTSD symptoms (Foa, Riggs, Dancu, & Rothbaum, 1993). At the time of data collection, a validated measure of DSM-5 PTSD symptoms was not yet available. Therefore, the 17 semi-structured interview items represented the diagnostic criteria of PTSD as outlined in the DSM, Fourth Edition, Text Revision (DSM-IV-TR; American Psychiatric Association, 2000). Respondents were asked to report their symptoms during the past two weeks. For each item, the interviewer rated the frequency and severity of the symptom (from 0 = "not at all" to 3 = "5 or more times per week/very much"). This measure required approximately 20 minutes to administer. The PTSD Symptom Scale Interview has shown evidence of high internal consistency and high inter-rater reliability, and is strongly correlated with both the Clinician-Administered PTSD Scale and the Structured Clinical Interview for DSM-IV (Foa & Tolin, 2000).

Interview questions were translated, or 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. This multidisciplinary group included two Deaf and three hearing members from 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. We had incomplete data for one participant, bringing our total sample size to 16 participants.

Descriptive statistics were used to summarize the sample's lifetime experiences of trauma according to the Life Events Checklist: (1) mean, median, and range of total number of trauma events reported by Deaf trauma survivors; and, (2) frequencies of each type of trauma event. Summary scores for "PTSD severity" and "PTSD diagnosis" were calculated according to the instructions in the PTSD Symptom Scale Interview manual (Hembree, Foa, & Feeny, 2002). PTSD severity was determined by summing the frequency/severity ratings for all 17 interview items, using a possible range of 0 to 51. A diagnosis of PTSD was determined by counting the number of PTSD symptoms reported per symptom cluster (i.e., a frequency/severity rating of 1 or greater); one re-experiencing symptom, three avoidance symptoms, and two arousal symptoms were needed to meet diagnostic criteria for PTSD. Also required were duration of symptoms greater than one month and the presence of clinically significant distress or impairment (Hembree et al., 2002).

The prevalence rate of current PTSD in the study sample was determined in a standardized manner, i.e., descriptive statistics were conducted to calculate the percentage of participants with current PTSD based on the criteria outlined above. Characteristics of PTSD in this sample were analyzed using simple descriptive statistics of PTSD severity and frequency counts of each individual PTSD symptom.

Results

Complete data was collected from a total of 13 female and 3 male participants between March and September 2014. Most participants identified as being culturally Deaf, white, middle-aged, and heterosexual (Table 1). At the time of data collection, the majority of participants was over the age of 45, had attended at least some college, and was collecting Supplemental Security Income or Social Security Disability Insurance. Most participants reported that their preferred language was ASL, that they did not use an assistive hearing device, and that they were raised by hearing parents who communicated with them using spoken English—sample characteristics that align closely with the sociodemographics of most culturally Deaf individuals.

Table 1

Study Sample Characteristics

Sociodemographic characteristics		%
Age (years)	21 – 34	23.5
	35 – 44	11.8
	45 +	64.7
Ethnicity	Not Hispanic/Latino	82.4
	Hispanic/Latino	17.6
Race (select all that apply) ^a	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) ^a	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
	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-year college degree or above	35.3

Employment status	Collecting SSDI/SSI	47.1
	Employed full-time	35.3
	Employed part-time	17.6

^a For these items, participants were asked to “select all that apply” and could endorse more than one category. Therefore, total percentage across categories is greater than 100%.

In our sample of trauma-exposed Deaf individuals, 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. The most frequently reported type was “physical assault,” 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,” reported by more than 75% of study participants (e.g., 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 ASL).

Fifty percent of the participants met the criteria for current PTSD. PTSD severity ranged from 3 to 39, with a mean of 17 (maximum severity score = 51). See Table 2 for the prevalence of each PTSD symptom, organized by DSM-IV-TR PTSD symptom clusters. Analyzing the data on a cluster level, there were no significant differences in prevalence across symptom clusters. In other words, the participants reported similar rates of symptoms across cluster B (re-experiencing and intrusive recollection symptoms), cluster C (avoidance and numbing symptoms), and cluster D (hyperarousal symptoms). Analyzing the data on an individual symptom level, however, the most commonly reported PTSD symptoms were emotional distress in response to reminders of the trauma event, hypervigilance, and behavioral avoidance of trauma reminders. Least common were loss of interest in previously enjoyed activities and the

sense of a foreshortened future (i.e., the perception that there has been permanent damage or change to one's life that were directly attributable to the trauma event).

Table 2

Prevalence of PTSD Symptoms Reported by Trauma-Exposed Deaf and Hearing Individuals

PTSD Symptoms, Organized by DSM-IV-TR Symptom Cluster	Total % of Participants who Reported the Symptom
Cluster B: Re-experiencing and intrusive recollection symptoms	
1. Intrusive ideation	56.3
2. Nightmares	31.3
3. Flashbacks	43.8
4. Emotional reactivity	75.0
5. Physical reactivity	50.0
Cluster C: Avoidance and numbing symptoms	
1. Cognitive avoidance	56.3
2. Behavioral avoidance	62.5
3. Psychogenic amnesia	31.3
4. Loss of interest	25.0
5. Detachment from others	56.3
6. Emotional numbness	37.5
7. Foreshortened future	25.0
Cluster D: Hyperarousal symptoms	
1. Sleep difficulty	31.3

2. Irritability	50.0
3. Concentration problems	50.0
4. Hypervigilance	68.8
5. Exaggerated startle response	56.3

Note. The PTSD symptoms outlined above are according to criteria from the DSM-IV-TR (American Psychiatric Association, 2000).

Discussion

The findings are from interviews with 16 trauma-exposed Deaf individuals, including whether participants met criteria for current PTSD and their PTSD symptom patterns. In the study sample, participants reported having experienced an average of six different types of trauma, with more than three-fourths of participants reporting experiences of physical assault, sudden unexpected death of individuals close to them, and “other” very stressful events or experiences (e.g., 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 ASL). In a 2012 study of trauma among Deaf adults, more than two-thirds reported having experienced transportation accidents, unexpected deaths, physical assaults, and natural disasters (Schild & Dalenberg, 2012b). These results are largely similar to the current findings, with the exception of the high rate of natural disasters in Schild and Dalenberg’s Southern and Central California-based sample.

Half of this study’s sample met criteria for current PTSD, a rate higher than the general U.S. hearing population, for whom it is reported that 8% to 20% of trauma-exposed individuals develop PTSD (Breslau et al., 1998; Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995; Kilpatrick et al., 2013). These results are contrary to a recent study of Deaf outpatients, which

found that patterns of trauma and traumatization were similar to those in hearing clinical samples (Ohre, Uthus, von Tetzchner, & Falkum, 2015). The rate of PTSD in our sample was also higher than the 20% prevalence rate reported by a sample of 79 Deaf adults recruited from Southern and Central California (Schild & Dalenberg, 2012b). This is likely due to this study's focus on recruiting Deaf people with histories of trauma and the emphasis on trauma in our recruitment materials; conversely, Schild and Dalenberg aimed to recruit an unbiased population sample and did not disclose their study's trauma focus until after the recruitment phase. Therefore, our study may have been subject to selection bias, with Deaf individuals experiencing ongoing effects of trauma and current symptoms of PTSD more likely to enroll than those who had experienced trauma but are no longer experiencing PTSD symptoms.

One reason underlying the high rate of PTSD among Deaf individuals may be the increased frequency of trauma experienced by this population (Anderson & Leigh, 2011; Francavillo, 2009; Harrell, 2011; Nosek et al., 2001; Pollard et al., 2014; Schenkel et al., 2014; Schild & Dalenberg, 2015). Another possible reason is pre-existing characteristics of Deaf survivors—common characteristics possessed by many Deaf people that may make them more susceptible to developing PTSD in the aftermath of trauma. For example, research has identified limited education, language deficits, low levels of social support, and general childhood adversity as factors that may contribute to developing PTSD after trauma (Brewin, Andrews, & Valentine, 2000; Ozer, Best, Lipsey, & Weiss, 2008; Schild & Dalenberg, 2012b), issues that are unfortunately common to many Deaf people's developmental experiences.

With regard to PTSD symptom patterns reported in the general population, the participants were more likely to validate a number of PTSD symptoms. Compared to 103 hearing attendees at a PTSD clinic, the current Deaf sample reported a higher prevalence of

hypervigilance (69% vs. 53%), exaggerated startle response (53% vs. 45%), flashbacks (44% vs. 36%), and restricted affect (38% vs. 31%; Green, 2003). Given the physical nature of ASL and the importance of affect being conveyed in ASL grammar (Liddell, 2003), these symptoms of hypervigilance, exaggerated startle, and restricted affect may be particularly impairing to Deaf survivors' social functioning.

Yet, especially discrepant to the described hearing clinical sample were symptoms of psychogenic amnesia, with 31% of Deaf participants unable to remember key features of their trauma event; only 18% of hearing participants reported the same (Green, 2003). Although high rates of trauma and pre-existing characteristics of Deaf survivors may partially account for their high rates of PTSD, peritraumatic psychological processes have been shown to be stronger predictors of PTSD than pre-existing characteristics (Ozer et al., 2008), especially the individual's subjective response during the trauma event. These responses include the perceived threat to one's life during the trauma, one's emotional response during the trauma, and dissociation during the trauma (Ozer et al., 2008). Recent research indicates that Deaf people report more symptoms of dissociation than members of the general population (Schild & Dalenberg, 2012b), possibly related to the early language deprivation and social isolation experienced by many Deaf children.

The sample in this study showed early trauma experiences very similar to the early language deprivation and social isolation described by Schild and Dalenberg, including a complete lack of communication with hearing parents and severe attachment disruptions with caregivers. Such common developmental experiences among Deaf trauma survivors may partially account for increased rates of PTSD, as they potentially lead to increases in trauma-related dissociation and heightened rates of amnesia for the trauma event (Schild & Dalenberg,

2012b). In other words, the participants in the sample reported early traumatic experiences of language deprivation and isolation from family members; these early experiences could potentially increase their vulnerability to experiencing dissociation during later trauma events, resulting in high rates of PTSD symptoms compared to hearing populations and amnesia for the trauma event. This causal chain, however, was not investigated in the present study; therefore, further research is needed to explore this hypothesis directly.

Study Strengths and Limitations

A key strength of this study was the use of Deaf-accessible methods (e.g., recruitment materials, informed consent, and interviews provided in ASL, and provision of Certified Deaf Interpreters as needed). This is largely attributable to collaboration with Deaf psychologists, mental health counselors, social workers, and mental health case managers throughout each step of the research process. These individuals were involved in the design of this study and its methods, the selection and translation of trauma instruments, interpretation of study findings, and preparation of this manuscript.

A primary study limitation was small sample size, which did not permit the comparison of PTSD symptoms across sociodemographic subgroups, nor to compare symptom patterns based on type of trauma experienced, as had been done in previous research with the hearing population (Kelley, Weathers, McDevitt-Murphy, Eakin, & Flood, 2009). Second, the 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, data was collecting using a measure of DSM-IV-TR PTSD symptoms, as a measure for DSM-5 PTSD symptoms had not yet been validated. Fourth, primary data was not collected from a hearing comparison group in Massachusetts, which prohibited the conducting of inferential analyses to

directly compare the prevalence of PTSD diagnosis and PTSD symptoms across hearing and Deaf populations.

Study Implications and Future Directions

The findings suggest that Deaf trauma-exposed individuals may be more likely to develop PTSD than their hearing counterparts. This disparity could be due to increased rates of trauma in this population, as well as a number of vulnerability factors for PTSD that are common to Deaf children's developmental experience. However, one additional hypothesis for the disparity in rates of PTSD is the peritraumatic experience of Deaf survivors, including heightened rates of dissociation and psychogenic amnesia during the trauma event. Such experiences may result in an avoidant style of coping which delays processing the trauma and resolution of PTSD symptoms. Future epidemiological research with large samples of Deaf trauma survivors is needed to clarify these hypotheses, as well as to inform clinical interventions that more accurately target Deaf people's pattern of trauma symptoms.

Contact Information:

Melissa L. Anderson, Ph.D
Department of Psychiatry
University of Massachusetts Medical School
Systems & Psychosocial Advances Research Center
222 Maple Avenue
Chang Building
Shrewsbury, MA 01545
Phone: 508-856-8739; Fax: 508-856-8700
melissa.anderson@umassmed.edu

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