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Barriers and Facilitators to Deaf Trauma Survivors' Help-Seeking Behavior: Lessons for Behavioral Clinical Trials Research: A Master's Thesis

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BARRIERS AND FACILITATORS TO DEAF TRAUMA SURVIVORS'
HELP-SEEKING BEHAVIOR:
LESSONS FOR BEHAVIORAL CLINICAL TRIALS RESEARCH

A Master's Thesis Presented

By

MELISSA L. ANDERSON, PH.D.

Submitted to the Faculty of the
University of Massachusetts Graduate School of Biomedical Sciences, Worcester
in partial fulfillment of the requirements for the degree of

MASTER OF SCIENCE

MAY 10, 2016

CLINICAL INVESTIGATION

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This work was undertaken in the Graduate School of Biomedical Sciences

Master of Science in Clinical Investigation

Under the mentorship of

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May 10, 2016

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Abstract

Deaf individuals experience significant obstacles to participating in behavioral health research when careful consideration is not given to accessibility in the design of study methodology. To inform such considerations, we conducted a secondary analysis of a mixed-methods study that explored 16 Deaf trauma survivors' help-seeking experiences. Our objective was to identify key findings and qualitative themes from *consumers' own words* that can be applied to the design of behavioral clinical trials methodology. In many ways, the themes that emerged are what we would expect of any research participant, Deaf or hearing – a need for communication access, empathy, respect, strict confidentiality procedures, trust, and transparency of the research process. However, additional considerations must be made to better recruit, retain, and engage Deaf trauma survivors. We summarize our findings in a “Checklist for Designing Deaf Behavioral Clinical Trials” to operationalize the steps researchers should take to apply Deaf-friendly approaches in their empirical work.

Table of Contents

Acknowledgements.....	iii
Abstract.....	iv
List of Tables.....	vi
List of Figures.....	vii
CHAPTER I: INTRODUCTION.....	1
Deaf-Accessibility of Behavioral Health Treatment.....	2
Deaf-Accessibility of Behavioral Health Research.....	5
Research Objectives.....	6
CHAPTER II: METHODS.....	9
Study Population.....	9
Interview Instrument.....	11
Data Analysis.....	14
CHAPTER III: RESULTS.....	17
Recruitment.....	17
Enrollment.....	19
Assessment and Data Collection.....	22
Participant Retention and Satisfaction.....	23
CHAPTER IV: DISCUSSION.....	28
Study Strengths and Limitations.....	35
Study Implications and Future Directions.....	36
References.....	38

List of Tables

<i>Table 1.</i> Study Sample Characteristics	18
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List of Figures

<i>Figure 1. ASL and Written English Recruitment Materials</i>	10
<i>Figure 2. Qualitative Coding Structure.....</i>	16
<i>Figure 3. Checklist for Designing Deaf Behavioral Clinical Trials.....</i>	33

CHAPTER I: INTRODUCTION

The Deaf¹ community is one of the most underserved and understudied populations in behavioral health care, even though the frequency of behavioral health disorders is believed to be higher in the Deaf community than the general population (Fellinger, Holzinger, & Pollard, 2012; Kvam, Loeb, & Tambs, 2007). An American Sign Language (ASL) public health survey confirmed suspicions about these health disparities, with Deaf individuals more likely to be obese, to have attempted suicide in the past year, to have experienced physical abuse, and to have experienced forced sex than their hearing peers (Barnett, Klein, et al., 2011).

Indeed, recent research indicates that Deaf people experience twice the rate of trauma as compared to the general hearing population (Anderson & Leigh, 2011; Anderson, Leigh, & Samar, 2011; Berman, Streja, & Guthmann, 2010; Black & Glickman, 2006; Porter & Williams, 2011; Rendon, 1992; Schild & Dalenberg, 2012; Titus, Schiller, & Guthmann, 2008). The presence of such trauma often complicates behavioral health treatment and affects multiple domains of functioning (Najavits et al., 2008). Deaf people show even greater functional impairment, with poorer outcomes in socialization (Fellinger, Holzinger,

¹ The 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.”

Schoberberger, & Lenz, 2005), employment (Fellinger et al., 2005), and physical health (Barnett, Klein, et al., 2011) compared to their hearing peers.

One factor contributing to these disparities is lack of access to efficacious treatment. Hearing individuals seeking trauma treatment have many options – private practitioners and behavioral health agencies with access to dozens of evidence-based treatments that show efficacy in the hearing population (Najavits & Anderson, 2015). Conversely, there are no evidence-based behavioral health treatments that have been validated in the Deaf population (Glickman & Pollard, 2013; NASMHPD, 2012). Behavioral health intervention research with the Deaf population is non-existent, yet urgently needed. The National Association for State Mental Health Program Directors set 34 Deaf behavioral health research priorities in 2012, which emphasize the lack of intervention research in the Deaf population as compared to general and other minority populations– priorities calling for the development and evaluation of trauma treatment approaches, and the examination of methodologies to adapt evidence-based practices for Deaf people (NASMHPD, 2012).

Deaf-Accessibility of Behavioral Health Treatment

Deaf people's behavioral health disparities are, unfortunately, paralleled by disparities in their ability to access treatment. Similar to individuals from other sociolinguistic minority groups, Deaf individuals experience a number of obstacles to seeking help including, but not limited to: language barriers in the behavioral health system, limited health literacy, small community dynamics, and

stigma (Barnett, Klein, et al., 2011; Barnett, McKee, Smith, & Pearson, 2011; Glickman & Pollard, 2013; Pollard & Barnett, 2009; Sebald, 2008).

Especially salient for Deaf ASL users attempting to access the healthcare system are issues related to language access. For example, there is a severe lack of ASL-fluent clinicians and ASL interpreters trained in behavioral health or trauma-informed care – a concern frequently discussed in the Deaf behavioral health literature, but with no hard statistics to quantify the precise level of need (McKee, Barnett, Block, & Pearson, 2011).

Additionally, most Deaf individuals experience obstacles to understanding written health materials due to differences in language and development compared to hearing individuals (Glickman, 2013). Research suggests a fourth-grade median English reading level among Deaf high school graduates (Gallaudet Research Institute, 2003), significantly below the average seventh-to-eighth grade reading level among hearing high school graduates (Institute of Medicine, 2004). Yet, there are few health materials translated into ASL from written or spoken English (McKee, Barnett, Block, & Pearson, 2011; Pollard, Dean, O'Hearn, & Haynes, 2009), creating a major barrier to Deaf individuals' abilities to process and understand written education about important behavioral health topics.

In addition to these general English literacy concerns, low health literacy is also common due to limited language access during key developmental periods and “a lifetime of limited access to information that is often considered common

knowledge among hearing persons” (Barnett, McKee, et al., 2011): for example, limited communication with hearing family members; reductions in incidental learning from auditory information in their natural environment (e.g., information typically overheard in PSAs, news programs, television shows, public conversations); and lack of health education programs available in ASL (Pollard & Barnett, 2009; Pollard et al., 2009). Indeed, health-related vocabulary among Deaf sign language users parallels non-English-speaking U.S. immigrants (McEwen & Anton-Culver, 1988), and “many adults deaf since birth or early childhood do not know their own family medical history, having never overheard their hearing parents discussing this with their doctor” (Anderson & Kobek Pezzarossi, 2012; Barnett, McKee, et al., 2011).

When Deaf individuals *are* able to access behavioral health services, however, they often express confidentiality concerns common with persons living in small communities. These concerns include the high probability that ASL interpreters and Deaf-specialized clinicians belong to the same social circles, as well as the possibility that their private information will travel through the “Deaf grapevine” to those in the community that may judge or even harm them (Barber, Wills, & Smith, 2010).

Deaf individuals’ repeated encounters with such barriers fuel negative perceptions and avoidance of the behavioral healthcare system (Steinberg, Sullivan, & Loew, 1998). These real and/or perceived concerns unfortunately lead to a number of negative outcomes including misdiagnoses, inappropriate

and/or inadequate treatment, magnification of behavioral health related problems, and increased length of treatment with an increased risk of adverse effects (du Feu & Fergusson, 2003; Glickman & Pollard, 2013; Patterson & Baines, 2005; SAMHSA, 2011).

Deaf-Accessibility of Behavioral Health Research

Similar barriers are seen in the field of behavioral health research, including researchers' use of inaccessible recruitment, sampling, and data collection procedures (Barnett, McKee, et al., 2011; Fellingner et al., 2012; Livermore, Whalen, Prenovitz, Aggarwal, & Bardos, 2011). For example, random-digit-dial surveys fail to sample Deaf ASL users, who use videophones for remote communication rather than standard telephone technology. In-person studies that collect detailed information about behavioral health disorders, including the National Comorbidity Study Replication, sample only English-speaking individuals and make no documentation of provision of interpreters or other accommodations for Deaf individuals (Anderson, Ziedonis, & Najavits, 2014). Studies that rely on written English surveys or other written materials generally adhere to the sixth-to-eighth grade reading levels suggested by most institutional review boards (IRBs), which becomes an issue for the median Deaf high school graduate who reads at a fourth-grade level (Gallaudet Research Institute, 2003). These standard procedures, which are used across national epidemiological data collection efforts, automatically exclude most members of the Deaf community (Livermore et al., 2011) and contribute to the lack of further

research on Deaf behavioral health disparities and effective treatments for these disparities.

Access issues in the research world are further exacerbated by ongoing theoretical conflict between members of the Deaf community and the research community about the meaning of “deafness” (McKee, Schlehofer, & Thew, 2013). Researchers generally follow a “medical model,” focusing on how to “cure” or “fix” hearing loss (Bauman, 2004; Ladd, 2003; Lane, 1992). Most Deaf community members, however, follow a “cultural model” and do not believe they are disabled or need to be “fixed,” but that they are members of a minority group with rich culture, shared experience, history, art, and literature (Bauman, 2004; Ladd, 2003; Lane, 1992). This disconnect has fueled a long history of mistreatment against Deaf people in the research world. Common missteps include failure to provide ASL interpreters for participation in research studies, failure to explain research procedures and obtain informed consent in Deaf participants’ primary language, and an overwhelming focus on research questions meant to “solve the problem of deafness” (Lane, 2005; McKee et al., 2013). More egregious abuses include the use of eugenics and sterilization to prevent the expansion of the Deaf community (Lane, 2005; McKee et al., 2013), which underlie a communal feeling of mistrust toward researchers across disciplines (McKee et al., 2013).

Research Objectives

As described above, the barriers experienced by Deaf people in the behavioral healthcare system often carry over into the research world when

careful consideration is not given to Deaf individuals' ability to access various aspects of a study. To better inform such considerations, we conducted a secondary analysis of a recent mixed methods study that explored Deaf trauma survivors' experiences of help-seeking (Anderson, Wolf Craig, & Ziedonis, under review). Using semi-structured ASL interviews, the original study explored the types of help Deaf trauma survivors received, their barriers and facilitators to recovery, and their recommendations for improving Deaf trauma services within the behavioral healthcare system.

The objective of the current secondary analysis was to identify key findings and qualitative themes from these interviews that could be applied to the design of behavioral clinical trials methodology, with the ultimate goal of improving recruitment, retention, and community engagement with Deaf trauma survivors. Although we did not specifically interview participants about their experiences with or recommendations for clinical trials methodology, in this secondary analysis we extrapolate from participants' reported experiences in general behavioral health settings in an attempt to better inform researchers' design of Deaf-friendly clinical trials. In the approaches used to answer our research questions, our analyses inherently conflate the issues of treatment and clinical research – a key concern associated with the ethical issue of therapeutic misconception (Applebaum, Lidz, & Grisso, 2004); however, we would like to recognize here that clinical research *is not* analogous to treatment and that this

important distinction, therefore, influences any sort of generalization to the research environment.

CHAPTER II:

METHODS

Study Population

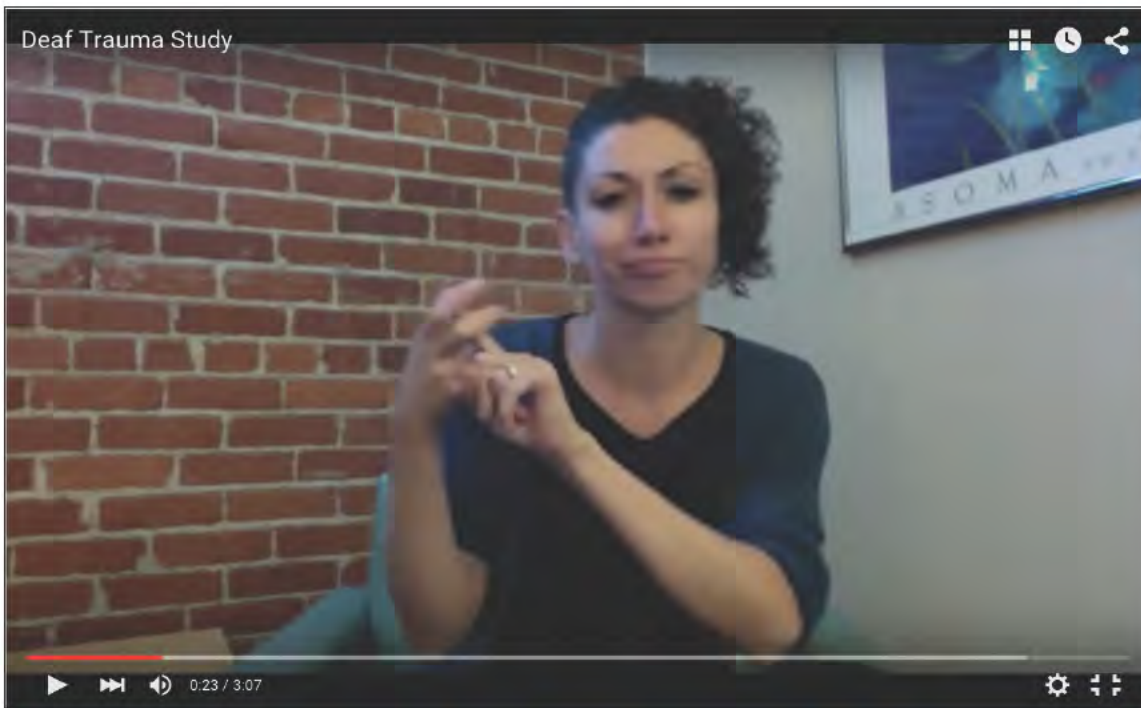
Between March and September 2014, we recruited from across Massachusetts 17 Deaf individuals who had previously experienced trauma. All study procedures were approved by the University of Massachusetts Medical School IRB. Participants were recruited via online advertisements posted on Craigslist and Deaf-related listservs, and through agencies, clinicians, and case managers who serve Deaf clients. To increase accessibility, these advertisements were disseminated in two forms: ASL digital video and written English flyers (see Figure 1).

Recruitment materials directed interested individuals to contact the research team, after which an appointment was scheduled for screening via 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 and the procedures involved, and screened potential participants for the following pre-determined inclusion and exclusion criteria.

Inclusion criteria consisted of: (1) age 21 years and 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,


Figure 1. ASL and Written English Recruitment Materials

Deaf Trauma Study



ARE YOU **DEAF** OR **HARD-OF-HEARING**?
HAVE YOU EXPERIENCED **SEVERE LIFE STRESSORS**?

**PARTICIPATE IN A RESEARCH STUDY ABOUT
TRAUMA SERVICES FOR THE DEAF COMMUNITY**



<p><u>WHO WE NEED:</u></p> <ul style="list-style-type: none"> ✓ DEAF OR HARD-OF-HEARING ✓ USE AMERICAN SIGN LANGUAGE (ASL) ✓ AGE 21+ ✓ CENTRAL MA RESIDENT ✓ HISTORY OF TRAUMA 	<p><u>WHAT YOU WILL DO:</u></p> <p>1-HOUR ASL INTERVIEW ABOUT:</p> <ul style="list-style-type: none"> - TRAUMA - HOW YOU GOT HELP AFTER TRAUMA - <u>YOUR SUGGESTIONS FOR BETTER TRAUMA SERVICES IN CENTRAL MA!</u> 	<p><u>WHERE IT WILL BE:</u></p> <p>UMASS MEDICAL SCHOOL, WORCESTER, MA</p> <p><u>WHAT YOU WILL GET:</u></p> <p>\$20 FOR YOUR TIME AND EFFORT</p>
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INTERESTED? CONTACT MELISSA.ANDERSON@UMASSMED.EDU

THIS STUDY HAS BEEN APPROVED BY THE UMass MEDICAL SCHOOL IRB!

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 provide informed consent and prisoners excluded from the 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. Individual interviews were selected over a focus group approach 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 et al., 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.

Life Events Checklist

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. We collected data primarily 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 convergence validity with other measures of trauma history (for detailed psychometric properties, see Gray, Litz, Hsu, & Lombardo, 2004).

PTSD Symptom Scale Interview

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*). The *PTSD Symptom Scale Interview* has shown evidence of high internal consistency, 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).

Help-Seeking Behaviors

Interview questions regarding help-seeking were developed by the Principal Investigator and 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 with backgrounds in psychology, psychiatry, mental health counseling, mental health case management, or social work. We created a series of 3 nested questions that explored participants' receipt of informal and formal support after trauma. These questions assessed from whom support was received, the type of support/treatment received, perceptions of helpfulness, recommendations for increasing helpfulness provided by support persons, barriers to help-seeking, and recommendations to resolve barriers to help-seeking.

Translation Process

Interview questions were adapted from written English into ASL, in collaboration with the Deaf & Allied Clinicians Consult Group. 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. We had incomplete data for one participant, bringing our final sample size to 16 participants.

Quantitative Analyses

Quantitative data were exported to *SPSS Statistics Version 22*. For this secondary analysis, descriptive statistics were used to summarize the rates of screening and recruitment; number and types of trauma events experienced; rates of full and partial PTSD; rates of formal help-seeking in the past; likelihood of seeking trauma treatment in the future; and length of administration time for each interview.

Rates of full PTSD were calculated according to instructions in the *PTSD Symptom Scale Interview* manual (Hembree, Foa, & Feeny, 2002). A diagnosis of full 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).

Rates of partial PTSD were calculated using the most common strategy in the PTSD literature, as outlined in *A Guide to the Literature on Partial PTSD* (Schnurr, 2014). A diagnosis of partial PTSD was assigned when the participant

met criteria for at least one re-experiencing symptom, one avoidance symptom, and one arousal symptom (Schnurr, 2014). Requirements for one-month duration and clinically significant impairment remained.

Qualitative Analyses

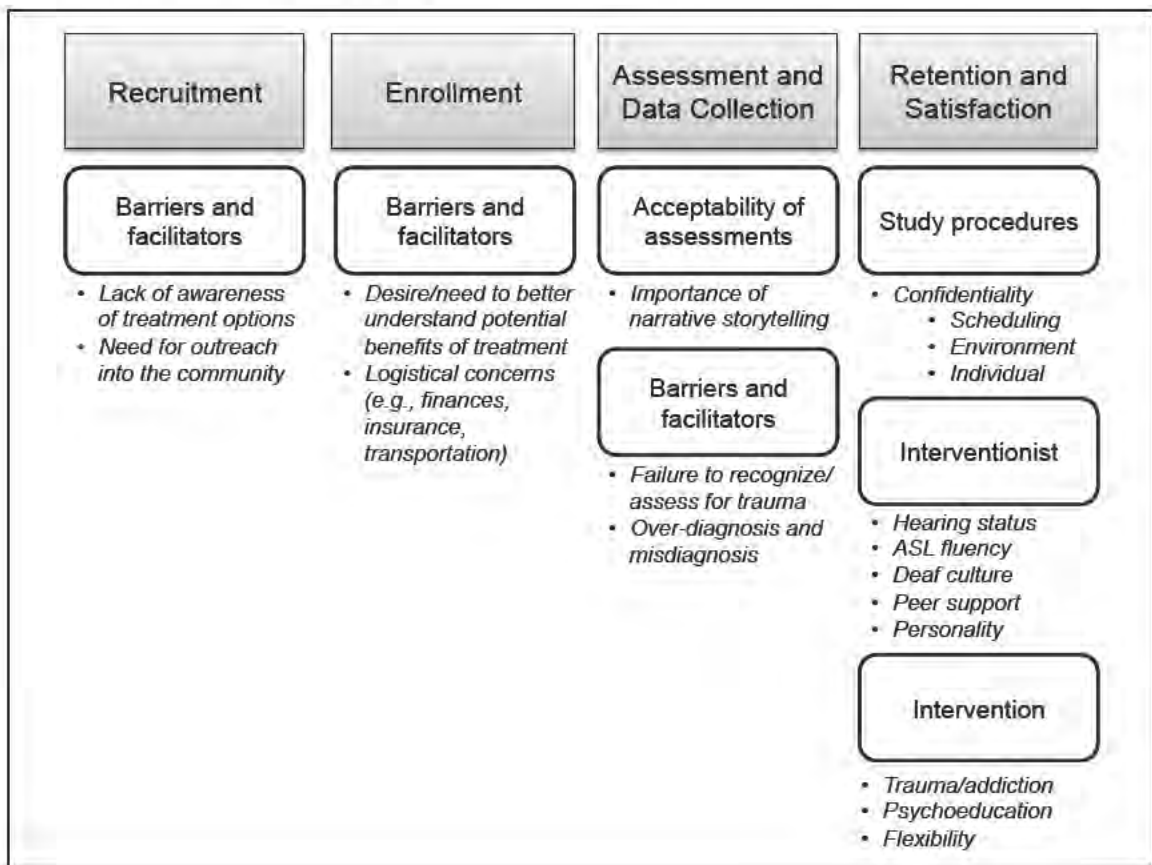
Qualitative data were exported to *ATLAS.ti*, where interview responses were analyzed for recurring themes and perspectives that are applicable to the design of behavioral clinical trial methodology. Again, it should be noted that, in the original study, we did not interview participants about their experiences with or recommendations for clinical trials methodology. Rather, we queried participants about their general experiences seeking behavioral health treatment and did not delineate between treatment provided in regular clinic settings and treatment provided as part of clinical research studies. From these qualitative data, we attempted to identify key themes that could better inform researchers' design of Deaf-friendly clinical trials.

To identify these themes, we used a grounded theory approach, which relied on two major techniques: (1) content analysis, where the number of similar responses to questions were tallied and described; and, (2) a summary of the answers to the questions outlined by Casey (Krueger, 1998). Such questions included: *What are the participants saying? What are they feeling? What is really important? What are the themes? Are there any comments said only once but deserve to be noted? Which quotes really give the essence of the conversation? What ideas will be especially useful for designing clinical interventions with this*

population?

Using these techniques, we defined a nested coding structure based on behavioral clinical trial feasibility outcomes; i.e., information that is relevant to recruitment, enrollment, assessment and data collection, and participant retention and satisfaction. To summarize our findings, we ran a code report for each parent code of interest and summarized the prevailing themes. See Figure 2 for a visual representation of our coding structure.

Figure 2. Qualitative Coding Structure



CHAPTER III:

RESULTS

We enrolled and obtained complete data from a total of 13 female and three male participants between March and September 2014. Most participants identified as being culturally Deaf, white, middle-aged, and heterosexual (Table 1). Most were middle-aged, had attended at least some college, and were employed full-time or collecting Supplemental Security Income/Social Security Disability Insurance at the time of data collection.

Findings are organized below according to behavioral clinical trial feasibility outcomes: recruitment; enrollment; assessment and data collection; and participant retention and satisfaction. Select participant quotes are included to elucidate our findings, and are represented here using ASL gloss as stated during the interview, rather than translated to exact English grammar and word order.

Recruitment

Rates of Participant Screening

Over a period of 30 weeks, a total of 18 interested individuals contacted our research team with hopes of participating in a study about “trauma services for the Deaf community.” If this rate of screening were applied to a one-year period of recruitment for a trauma treatment clinical trial, this could translate to a total of 30 participants potentially willing to participate. Rates of actual study enrollment ($n = 17$) are described below.

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)	White	100.0
	Black/African-American	5.9
	American Indian/Alaska Native	5.9
	Native	
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
	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

Qualitative Findings regarding Barriers and Facilitators to Recruitment

Participants reported that one of the primary barriers to seeking professional help for trauma was their general lack of awareness about treatment options, regardless of whether these treatment options were offered in general clinical settings or in research settings – *“I didn’t know about treatment because I was Deaf.”* They recommended that providers reach out into the community and have a community presence in order to attract Deaf individuals to their clinical practice. Similar recommendations could be used by clinical trials researchers to improve recruitment rates of Deaf research participants:

“Go to Deaf events, workshops, because many Deaf people don’t know about available services. Deaf people prefer to see you in person, hear about your experience, qualifications, etc. in person.”

“Go to events to meet people – someone there needs treatment or knows someone else who needs treatment. Visit group homes. Make yourself well known, get into the network. We trust what we see for ourselves.”

“If I know the therapist was Deaf or signed...how it is advertised. Should get exposure through health fairs, booths, with the therapist there. If I meet you, I might be more motivated to open up.”

“Should be involved in the community and socialize, but keep professional boundaries – not be so stiff.”

Enrollment

Rate of Enrollment

Of the 18 interested individuals who contacted the study team, 17 met our pre-defined inclusion criteria (i.e., Deaf or hard-of-hearing ASL-users at least 21-years-old, currently living in Massachusetts, with a self-reported history of trauma exposure). All 17 eligible individuals chose to enroll in the study. If this rate of

enrollment were applied to a one-year clinical trial with similar inclusion criteria, this could translate to approximately 29 enrolled participants. One enrolled participant provided incomplete data during the interview and was, therefore, excluded from further quantitative findings.

Rates of Full and Partial PTSD

For those researchers considering behavioral clinical trials that require a diagnosis of PTSD for study inclusion, eight (50%) of our 16 trauma-exposed participants met full criteria for current PTSD. When these criteria were expanded to include partial PTSD, 11 participants (69%) satisfied the criteria for either full or partial PTSD.

Interest in Behavioral Health Treatment

Approximately two-thirds of the sample (69%) reported that they sought help from a professional following their experiences of trauma. Regarding current interest in treatment, more than half (56%) reported that they were *extremely likely* or *likely* to seek professional treatment for trauma at the current time. Approximately one-fifth (19%) of study participants were neither interested nor disinterested in treatment, while one-quarter indicated that they were *unlikely* or *extremely unlikely* to seek treatment at the current time. Although these findings referred to participants' general interest in participating in trauma treatment, it is possible that they might show similar levels of interest in participating in a clinical research study about trauma.

Qualitative Findings regarding Barriers and Facilitators to Enrollment

Despite the general interest in professional treatment expressed by participants, they also reported that they needed to better understand the potential benefits of treatment to make a decision about whether to enroll in treatment or not – *“Realizing how treatment could help. Before, I thought, ‘For- for?’ (i.e., ‘What for?’).”* For clinical trials researchers, these findings highlight the importance of informed consent procedures that clearly outline the potential benefits and risks of each treatment arm. However, such comments also suggest the importance of making potential benefits known during outreach and recruitment efforts, as eligible individuals may not contact the research team without first having a good understanding of how the study might help them or help the Deaf community at large.

Participants also reported logistical barriers to enrollment in treatment, including financial concerns, insurance difficulties, and distance to clinicians – *“There are not enough services in the whole state, have to go too far for treatment.”* Clearly, participant finances and access to transportation are issues that all clinical trials researchers also need to consider; however, these issues may be more salient when recruiting from any small, highly-dispersed community, of which many of its members rely on fixed incomes.

Assessment and Data Collection

Qualitative Findings regarding the Comprehension and Acceptability of Assessment Instruments

During the conduct of 17 interviews, no participants reported difficulty understanding the current ASL translation of the *Life Events Checklist* or the *PTSD Symptom Scale Interview*. One participant, however, provided incomplete data due to a general inability or unwillingness to follow the question-and-answer structure of the interview. Rather, this participant preferred to tell the interviewer his/her detailed personal story from start to finish, emphasizing the importance of such a narrative approach in Deaf culture – “*Let them tell their story – don’t interrupt.*” Where possible, allowing such a narrative approach to the assessment process (as opposed to a highly-structured, standardized interview approach) might improve the level of disclosure among Deaf research participants. For example, the study assessor could alert the participant to the fact that there will be many short answer questions during the assessment process, but also allow time for the participant to tell their narrative in an open-ended way (e.g., “Tell me about yourself first.”).

Qualitative Findings regarding the Barriers and Facilitators to Assessment

Regarding their prior experiences with assessment, participants reported disappointment that some providers had failed to assess for trauma and had, therefore, overlooked the impact of trauma experiences on their care – “[*The therapist*] did not identify the emotional abuse. I almost admitted it, but I was

afraid.” While participants expressed a desire for increased assessment and identification of trauma experiences, they also expressed concerns about providers’ focus on pathology, both overdiagnosing and misdiagnosing them:

“With the newer therapist, she never explained diagnosis and wasn’t honest; there was no trust; she didn’t believe my story; she decided to diagnose me with Borderline; many wrong labels.”

“Diagnoses, labels, medications – lousy!”

Generalizing these findings to the design of behavioral clinical trials, this suggests that researchers must aim to achieve a delicate balance between conducting a sufficient amount of assessment to accurately identify major life events and behavioral health disorders, without flooding participants with assessment instruments that cause them to feel evaluated or judged. Possible approaches include allowing for open-ended responses in any questionnaires, asking participants, “Is there anything else you would like to comment on? Do you have any other concerns?”, and exercising care when sharing diagnoses or other health findings that might arise during the research study.

Participant Retention and Satisfaction

Qualitative Findings regarding Study Procedures

Participants overwhelmingly reported that procedures to protect their confidentiality were of utmost importance to their treatment satisfaction and likelihood of remaining in treatment, given the small, close-knit nature of the Deaf community:

“[I want] a professional therapist who knows confidentiality law and is not a rookie. I had a therapist once who violated confidentiality to my mom.”

“It’s a small Deaf community. I didn’t want people to gossip, I didn’t want my ex to find me.”

Given these concerns, participants made a number of suggestions about how best to protect their confidentiality, many of which could directly be applied to researchers conducting behavioral clinical trials with Deaf participants. First, participants recommended that providers *“be flexible with hours”* and avoid scheduling *“back-to-back appointments with other Deaf clients; they pass each other or see each others’ cars (breaks confidentiality).”*

Second, participants made recommendation regarding the treatment environment to protect their confidentiality and create a space where they could feel safe:

“The environment should feel safe and be hidden.”

“It should be homey, not cold and institutional.”

Third, many participants expressed a preference for individual treatment – *“If Deaf people know each other, they are ashamed to share.”* Even with these confidentiality concerns, some others noted a desire for group treatment – *“you feel validated, like a breast cancer support group”* – however, most participants indicated that they would ultimately not join such a group in order to protect their privacy, suggesting that recruitment and retention for group research interventions might be especially difficult within this particular population.

Qualitative Findings regarding Study Interventionists

Participants made conflicting reports about whether they preferred a Deaf or hearing behavioral healthcare provider. Those who stated a preference for a

hearing clinician primarily did so because of confidentiality concerns, as described above – *“I’m more comfortable with a hearing provider who knows sign because not see at Deaf events. Deaf may break confidentiality and spread your information.”*

Regardless of preferred hearing status, participants all stated a preference for a provider fluent in ASL who is able to provide treatment through direct communication, rather than through an interpreter:

“Sign...Can see the ‘real me,’ not through an interpreter.”

“I didn’t want to work with interpreters – no privacy.”

“I prefer direct communication, feels like home.”

Equally as important was the clinician’s awareness of Deaf culture, their ability to *“know Deaf culture through and through.”*

To ensure such in-depth understanding of Deaf culture and fluency in ASL, many participants expressly reported a preference for receiving peer support over professional support:

“If there is an authority in the room, the clients will reject them – peers are better.”

“You should ‘get’ Deaf, like peer support. Common bond, empathy. If not, will miss empathy.”

“Have similar experiences so you can empathize – same frustrations, same experiences of oppression.”

“She was open about herself. Shared her own experiences, felt like a peer.”

Those participants who preferred to seek professional support indicated

that they were most likely to be satisfied with highly experienced clinicians who delicately balanced bluntness, honest feedback, and confrontation with calm, compassion, and composure:

“She was soft, sweet like a mother. But it didn’t help.”

“Direct, blunt, told the truth. She knew how to confront me in the right way.”

“They have a good heart, make me feel comfortable.”

“Some staff have attitudes or bad facial expressions, not appropriate way; this triggers clients to blow up.”

For behavioral clinical trials researchers, these findings suggest that hiring a diverse group of study clinicians who have a common set of foundational skills may be the best approach to designing a trial. In other words, it may be preferable to employ both hearing and Deaf clinicians who have minimum qualifications of fluency in ASL, knowledge of Deaf culture and Deaf history, and who are compassionate yet direct in their clinical approach. Where possible, incorporating opportunities for peer support may also increase participant satisfaction and retention in behavioral clinical trials.

Qualitative Findings regarding Study Interventions

Participants reported that they would be most interested in engaging in treatments that target trauma, addiction, and provide psychoeducation:

“They should give more resources and education, so that Deaf people do not remain ignorant.”

“Some therapists never talked about domestic violence. I thought the abuse was my fault. I thought that I was not nice, that I was a bitch. I was angry, not innocent. I believed that ‘abuse only happens to innocent

people.”

“Bad programs deny trauma. They have no support for trauma programs. Good programs link trauma with addictive behavior.”

“It’s good to discuss about drugs and relapse. I like the support of therapy, talking.”

“We need dual diagnosis therapy for people who have trauma and substance problems.”

Participants expressed a preference for treatment that would be highly flexible. The ideal intervention would allow for frequent follow-ups and check-ins – *“keep in touch and check in to see how we’re doing (because we keep it to ourselves).”* It would also allow for assistance with case management, crisis sessions, and emergency contacts on an as-needed basis, intervention options that are not often available in structured, standardized research protocols.

CHAPTER IV: DISCUSSION

Between March and September 2014, we interviewed 16 Deaf individuals to explore the types of help they received after trauma, the barriers and facilitators to recovery from trauma, and recommendations for improving Deaf trauma services within the behavioral healthcare system (Anderson et al., under review). The objective of the current secondary analysis was to identify key findings and qualitative themes from these interviews that could be applied to the design of research methodology, with the ultimate goal of improving community engagement, recruitment, and retention with Deaf trauma survivors.

For clinical trials researchers planning to recruit Deaf individuals to trauma intervention studies, our findings suggest an estimated recruitment rate of 30 individuals per year per research site. Deaf individuals are similar to members of other communities whose primary language is not English, in that the absence of bilingual informational material about research studies becomes a significant barrier to research recruitment (George, Duran, & Norris, 2014). Therefore, researchers' recruitment efforts may be improved by creating advertisements in ASL and distributing these materials to Deaf-related listservs, Facebook groups, and agencies that serve Deaf individuals.

More important to recruitment, however, is the researcher's visual presence within the Deaf community – actually attending Deaf events and presenting at Deaf workshops – thereby allowing members of the community to

“hear about your experience, qualifications” and “trust what [they] see for [them]selves.” This emphasis on overcoming mistrust is not unique to recruiting Deaf research participants, but is a common thread that weaves through culturally-sensitive empirical work with any marginalized or oppressed group (George et al., 2014; Leung, Yen, & Minkler, 2004). Although it is important for researchers (especially hearing researchers) to create in-roads and visual presence within the Deaf community, it is perhaps more essential to create in-roads and presence of Deaf people within the research community:

Some of the hesitation to participate in research can be countered by having communities become full partners in the research process, beginning with community identification of an issue. CBPR [Community-Based Participatory Research] methods particularly lend themselves to research projects undertaken in populations that are ‘other’ to the researchers. (Leung et al., 2004, p. 503)

Regarding enrollment rates, nearly all the Deaf trauma survivors recruited to the original study chose to enroll in an interview-based study (the equivalent of approximately 29 enrollments per year). More than half reported that they were currently interested in receiving professional trauma treatment. Reported barriers that could interfere with enrollment in a behavioral clinical trial could include a lack of reliable transportation and limited finances, common concerns among many sociolinguistic minority groups (George et al., 2014).

Yet, one of the greatest barriers to enrollment reported by participants was

a general lack of understanding of the purpose of treatment. Indeed, a recent systematic review of the barriers and facilitators to minority group members' research participation found that two of the primary barriers shared across groups were mistrust (as discussed above) and lack of access to information about research opportunities (George et al., 2014). To better engage members of the Deaf community, or any sociolinguistic minority group, researchers need to provide clear, accessible information about the potential benefits and risks of experimental interventions when engaging in outreach, recruitment, and informed consent procedures.

Additionally, as noted in the Research Objectives section above, the distinction between treatment and clinical research is often easily misunderstood by research participants – a key concern associated with the ethical issue of therapeutic misconception (Applebaum et al., 2004). Therefore, in addition to describing potential benefits and risks of study interventions during outreach and recruitment efforts, researchers need to be extremely clear that research *is not* treatment and provide psychoeducation to the community about therapeutic misconception. This information should be carefully reiterated during informed consent procedures to ensure that participants do not believe that they will be provided access to the best treatment possible, which is not the case in a randomized clinical trial (where participants are randomly assigned to one of multiple treatment arms) or in any study with a placebo arm. Taking such care to clarify these issues on the front end of a study will help to avoid a significant

ethical misstep on the part of the research team.




Current themes from our analyses that can be applied to assessment and data collection include: conducting assessments in the participant's preferred language; being transparent about the diagnostic process, but avoiding an overemphasis on pathology; and allowing time and space for participants to "tell their story." Such a person-centered assessment approach has been previously recommended for general behavioral research (Bates, 2004); however, it appears that the role of the narrative among culturally Deaf individuals has deeper ties that may be rooted in the oral tradition of Deaf literature (Ladd, 2003). Therefore, interfering with this narrative approach during the research process would be culturally incongruent on the part of the researcher and could negatively impact the likelihood of participants remaining in a clinical research study, especially a longitudinal study with multiple assessment time points.

To further improve retention rates and satisfaction, participants reported that they preferred working with clinicians who are fluent in ASL and knowledgeable about Deaf culture, being treated in a direct but compassionate manner, and being provided accessible psychoeducation about topics that impact their community. Even more important to retention and satisfaction was the research team's role in protecting participants' confidentiality, a concern frequently expressed by other research participants from small, highly-connected communities (Damianakis & Woodford, 2012). Our participants strongly recommended that the research team have in-depth knowledge of and

commitment to adhere to procedures designed to protect confidentiality. Additionally, they recommended that research appointments be spaced appropriately so that Deaf participants do not cross paths in waiting rooms or parking lots. Although the research environment may be flexible enough to handle such a staggered scheduling procedure, translating this research finding into practice may present a challenge, as the funding for a typical treatment environment relies on insurance reimbursement of face-to-face time with therapy clients.

In many ways, the themes that emerged from the current analysis are what we would expect of any research participant that is a member of sociolinguistic minority group, Deaf or hearing – a need for communication access, empathy, respect, strict confidentiality procedures, trust, and transparency of the research process. However, how these themes are *applied* to the inclusion of Deaf research participants is distinct from any other sociolinguistic minority population, given Deaf people's unique sensory and linguistic characteristics (i.e., a *visual* community as opposed to an *auditory* community). To more clearly operationalize the steps researchers should take to apply Deaf-friendly approaches in their empirical work, at a minimum, we have summarized our findings in a preliminary "Checklist for Designing Deaf Behavioral Clinical Trials" (see Figure 3).

Figure 3. Checklist for Designing Deaf Behavioral Clinical Trials

			
GENERAL PROCEDURES	 Checklist for Designing Deaf Behavioral Clinical Trials		
	My research team includes both Deaf and hearing members.	<input type="checkbox"/>	<input type="checkbox"/>
	My research team includes at least one Deaf peer (i.e., non-clinician community member).	<input type="checkbox"/>	<input type="checkbox"/>
	My research team can be contacted directly via videophone, FaceTime, Skype, and email.	<input type="checkbox"/>	<input type="checkbox"/>
	I conduct research at multiple study locations across the state/region, or I provide funding for participants' transportation.	<input type="checkbox"/>	<input type="checkbox"/>
	The environment of my study locations is warm, safe, and homey.	<input type="checkbox"/>	<input type="checkbox"/>
	My research team is highly trained in procedures to protect participants' confidentiality, provides one-to-one study appointments, and adequately spaces appointments between Deaf participants.	<input type="checkbox"/>	<input type="checkbox"/>
RECRUITMENT	My recruitment materials are available in both American Sign Language (ASL) video and written English.	<input type="checkbox"/>	<input type="checkbox"/>
	I send my recruitment advertisements to Deaf-related listservs, Facebook groups, and agencies that serve Deaf individuals.	<input type="checkbox"/>	<input type="checkbox"/>
	I present at Deaf workshops, trainings, and health fairs about available treatment options and ongoing clinical research studies.	<input type="checkbox"/>	<input type="checkbox"/>
	I attend Deaf events to network with Deaf community members.	<input type="checkbox"/>	<input type="checkbox"/>
INFORMED CONSENT	My informed consent form is written in plain English, at or below a sixth grade equivalent.	<input type="checkbox"/>	<input type="checkbox"/>
	A member of my research team is capable of conducting informed consent procedures in the preferred language of the participant – ASL or English.	<input type="checkbox"/>	<input type="checkbox"/>
	During informed consent procedures, I make sure to emphasize both the potential benefits and the potential risks of the study intervention.	<input type="checkbox"/>	<input type="checkbox"/>
ASSESSMENT/ DATA ANALYSIS	My measures have been translated into ASL using a three-stage procedure: translation, back-translation, equivalence comparison.	<input type="checkbox"/>	<input type="checkbox"/>
	I allow extra assessment time for question clarification, technical difficulties, or to permit participants to "tell their story" if they so choose.	<input type="checkbox"/>	<input type="checkbox"/>
	If requested, I provide participants with their assessment results; however, I do not assign unsolicited or unsubstantiated diagnoses.	<input type="checkbox"/>	<input type="checkbox"/>
	Whenever possible, I collect data in its original ASL form via video recording, rather than transcribing responses into written English.	<input type="checkbox"/>	<input type="checkbox"/>
	I use qualitative data analysis software that can manage ASL video data.	<input type="checkbox"/>	<input type="checkbox"/>
INTER-VENTIONIST	I employ both Deaf and hearing ASL-fluent study interventionists.	<input type="checkbox"/>	<input type="checkbox"/>
	All study interventionists are highly trained in Deaf culture and Deaf history.	<input type="checkbox"/>	<input type="checkbox"/>
	I seek to hire highly experienced interventionists who are direct, blunt, and honest, but also calm, compassionate, and composed.	<input type="checkbox"/>	<input type="checkbox"/>
	At least part of my study intervention is peer-led or involves peer support.	<input type="checkbox"/>	<input type="checkbox"/>

INTERVENTION

My study intervention provides psychoeducation and resources for additional learning.

My study intervention addresses trauma and addiction.

My study intervention addresses participants' case management needs.

My study intervention is flexible and can adapt to participant needs.

My study intervention allows for frequent follow-ups and check-ins, including as-needed crisis sessions and between-session contacts.

Study Strengths and Limitations

The current secondary analysis is one of the first known studies to extrapolate from Deaf consumers' reported experiences in general behavioral health settings in an attempt to better inform researchers' design of Deaf-friendly clinical trials. Although previous literature has discussed the importance of cross-cultural ethics in the conduct of Deaf-related research (Glickman & Pollard, 2013; McKee et al., 2013; Pollard, 1992; Singleton, Jones, & Hanumantha, 2012), ours is the first known attempt to draw our empirical recommendations directly from Deaf trauma survivors *in their own words* (Stein & Mankowski, 2004).

Another key strength of our study was the use of Deaf-accessible methods (e.g., recruitment materials, informed consent, and interviews provided in ASL; 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 assessments, interpreting study findings, and preparing this manuscript.

Our primary study limitation was small sample size. Additionally, our sample was primarily white, middle-aged, and heterosexual. Inasmuch, the results of this small exploratory study should be generalized further with caution. Our second limitation was the use of measures with unknown psychometric properties in the Deaf population; however, we attempted to relatively reduce the impact of this limitation by administering all measures in ASL rather than written English.

A third limitation of the current analysis was that participants were not directly asked about their experiences with or recommendations for participating in behavioral clinical trials – rather, we drew from participants’ experiences with general behavioral health treatment to make assertions about receiving treatment in clinical research settings. As such, the current analyses may not have identified additional barriers and facilitators specific to the research process; for example, Deaf people’s communal feeling of mistrust toward researchers (Barnett, McKee, et al., 2011; McKee et al., 2013) and recommendations for how researchers might address this mistrust.

Study Implications and Future Directions

Despite these limitations, our results suggest that, as behavioral clinical trials researchers, we need to better listen to Deaf people in order to design methods that are more conducive to their meaningful participation in our research studies. This secondary analysis is a preliminary attempt to do just that. Ideally, however, we should collaborate with members of our target populations from the very beginning of a study’s inception – the essence of CBPR (Israel, Schulz, Parker, & Becker, 1998). Such early collaboration ensures that our research questions are relevant and the study design accessible and engaging to members of the Deaf community (Barnett, McKee, et al., 2011; Pollard, 1992). To improve and build upon current findings, future methodological research involving the Deaf community should engage Deaf individuals at the early planning stages, apply CBPR principles throughout the research process, and aim to recruit a

larger, national sample of Deaf individuals who better represent the U.S. Deaf community at large.

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