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Toward Ethical Research Practice With Deaf Participants

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Abstract

In recent years, scholars have been critical of what they consider unethical conduct by researchers whose studies focus on members of the Deaf or signing communities. This is the first empirical study that investigates ethical concerns and recommendations from the perspective of three stakeholder groups (Deaf research participants, researchers, and Deaf studies experts). We analyzed focus group discussions using strategies from *grounded theory* and *community-based participatory research*. The themes we identified highlight the need for the broader scientific research community to include linguistically and culturally sensitive research procedures that more adequately protect the rights of Deaf research participants, as well as other marginalized groups. We address the need to increase the number of Deaf scientists and reconsider collaboration practices between Deaf and hearing researchers.

Keywords

research ethics, community-engaged research, community-based participatory research, deaf participants, sign language research, deaf researchers, research in host communities

Historically, the study of Deaf people has been influenced by diverse perspectives, which are anchored within divergent disciplines, such as academic, medical, political, and social justice. Researchers bring to their investigations multiple agendas including the promotion of hearing and speech remediation, assistive technologies, deaf education reform, genetics of deafness, sign language linguistics, psycholinguistics, and the study of Deaf cultures and communities. Regardless of their viewpoint, researchers who involve Deaf participants in their research are nevertheless expected to conduct their investigations in an ethical manner, protecting the integrity of their research and the individual rights of the participants regardless of their age, ethnicity, and cultural and/or linguistic background.

In the past two decades, scholars have discussed ethical issues in deafness-related research and even criticized the conduct of some researchers who study Deaf people (Baker-Shenk & Kyle, 1990; Harris, Holmes, & Mertens, 2009; NIDCD, 1999; Pollard, 1992, 2002). A primary concern raised is that many investigators look at Deaf people through a disability lens, comparing them only with hearing groups, whom they call *normal*, and putting emphasis on clinical and behavioral interventions that address the purported negative ramifications of deafness. Furthermore, few researchers have gone beyond the consideration of individual rights, to consider the rights of the community as a whole (see Israel et al., 2008; Pollard, 2002, for a discussion). For example, there are cultural and linguistic affordances experienced by this population, such as the use of signed language for communication and social interaction with other members of the Deaf community. Some scholars, such as Pollard (1992) and Harris et al. (2009), argue that the continuing neglect of these important cultural and linguistic factors and the overly narrow description of individuals who are Deaf only according to their level of hearing loss perpetuate a negative and inaccurate interpretation of research findings as it pertains to Deaf participants. Drawing parallels to research involving other marginalized groups, these authors advocate that the broader research community should adopt culturally appropriate research guidelines, recognize the heterogeneity of the members of Deaf community, and ensure that research findings accurately represent the community of Deaf individuals. For a more detailed summary, please see Section A.2 in the supplementary material (available online at jre.sagepub.com/supplemental).

While the literature on ethical practices in research involving Deaf individuals has offered important suggestions to the research community, *to date, we do not have*

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empirical data relating to these issues. The present focus group study is situated within the American Deaf Community[1] context and directly engages various stakeholders in the research enterprise to ascertain *lived* examples of research experiences, ethical considerations, and host community perceptions. The focus groups, all conducted in American Sign Language (ASL), allowed us to obtain these perspectives by creating an opportunity for stakeholders to share their views and take ownership of the discussion through the use of their primary language (Balch & Mertens, 1999).

It is important to elaborate here why this research on ethical practice with Deaf research participants should be of interest to the broader research community. First, we know that the general public often holds incorrect beliefs or "myths" about Deaf people (Branson & Miller, 2002; Lane, Hoffmeister, & Bahan, 1996). For example, one might erroneously believe that if a Deaf person possesses good speech skills, they are smarter or more educated than an individual who only uses signed language to communicate. Despite one's credentials and qualifications to conduct or evaluate research, a researcher or Institutional Review Board (IRB) officer may be operating under a similar set of myths and would thus benefit from learning factual information about the Deaf community before they proceed with research that involves any Deaf participants.

Second, with the increased interest in social justice issues, disparities among populations in opportunities for research inclusion, and the principles and practices of a Community-Based Participatory Research approach (Wallerstein & Duran, 2008), the Deaf Community serves as an interesting and illustrative example of how its members may have been exploited by researchers or treated insensitively. Now, with more Deaf researchers entering the field, and documentation of the experiences of being researched, we can offer insights and guidance that may help to reduce the occurrence of future problems for the Deaf community or other similarly marginalized groups.

Method

Who Are We? And What Is Our Identity Within This Project?

We are members of an interdisciplinary research collaboration among Deaf and hearing researchers. We recognize that we each bring our own research experience and bias into this study. We provide in the supplementary material (Section B.1; jre.sagepub.com/supplemental) further detail about each of our backgrounds, including information about our sign language competence and Deaf Community experience. Very briefly, all three co-authors are fluent ASL/English bilinguals with lifelong personal and professional experience in the Deaf Community.

Participants

We conducted three focus groups involving 16 stakeholders in the research process: *Deaf college students* (who had been prior research participants), *researchers* (who were actively engaged in research involving Deaf participants), and *Deaf studies experts*. The participants were recruited through different means, but all were from the campus of Gallaudet University, a liberal arts college serving Deaf and Hard of Hearing students.[2] More detail regarding the participant groups (Section B.2), the room and video recording setup (Section B.3), the dynamics of the discussion sections (Section B.5), and special considerations for the use of video data (Section B.6) is provided in the supplement material.

Protection of Human Subjects

Human subjects review was obtained from University of Illinois, Georgia Institute of Technology, and Gallaudet University. As the research involves video recording, consent documents had to clearly explain the potential future uses of the data and the extent to which confidentiality could be assured. Gallaudet's IRB includes additional questions pertaining to communication accessibility of face-to-face and written communication between the researcher and the participant. The researcher must also provide information about their qualifications to use ASL. We provide further information about our informed consent procedure in the supplementary material (Section B.4).

Procedures

Participants were informed in advance that the focus groups would be conducted in ASL and video recorded. All focus groups were facilitated by one of the co-authors, Gabrielle Jones, who is Deaf and fluent in ASL. The informed consent explanation video in ASL was presented before the focus group discussion was initiated (see video in Section B.4 in the supplementary material**)**. The questions posed to each focus group are provided in the supplementary material (Section B.7).

Data Analyses

The focus group discussions were transcribed from ASL into written English by the three bilingual co-authors and cross-checked for accuracy by native ASL-signing research assistants. The three co-authors then approached the data by adopting a theme-generating process that was based on grounded theory methods (Bryant & Charmaz, 2007; Charmaz, 2001; Holton, 2007; Strauss & Corbin, 1998). Further detail, and an example of our coding procedure, is provided in the supplementary material (Section B.8).

In the next section, we present our results as key conceptual themes that emerged from each focus group. To support our results, we provide quotes from participants in the supplementary material (Section C.1). We then discuss some of the common themes that emerged based on our analysis of all three focus groups together.

Results

Student Focus Group

The *Student* focus group included undergraduate and graduate students with different levels of experience with the research process. All five students had prior experience as participants in experimental research, including psychological, linguistic, and medical studies (e.g., Magnetic Resonance Imaging [MRI] and genetic analyses) and cited financial interest or course credit requirement as a common motivation to volunteer as a research subject.

Disempowered participants. Several individuals in the Student focus group described what we consider to be rather troubling encounters with researchers. They expressed the feeling that they lacked the power to change uncomfortable situations or conveyed that they were unsure about how to handle cultural insensitivity or even potentially unethical conduct. For example, one student had encountered a researcher who had weak sign language skills, yet felt it would be disrespectful to question the researcher's competence because of her "high academic status." The student indicated he had to resort to "figuring out on his own what the researcher was trying to say." Another student reported that an interpreter was scheduled to translate the experimenter's explanation of the procedures and consent process; however, when the interpreter failed to show up, the non-signing researcher proceeded anyway, asking the student to just read and sign the forms. Furthermore, there was strong consensus in this college-age group that consent forms were often written in such a way that made it too difficult to fully understand[3] (Section C.1; jre.sagepub.com/supplemental).

On a positive note, the students commented that some hearing researchers have clear signed communication, and even those with limited sign fluency can demonstrate cultural competence in their interactions with Deaf individuals, especially with a sign language interpreter facilitating the exchange. At the beginning of our focus group, we played our *ASL Informed Consent Video* (see Section B.4 in the supplementary material), which subsequently elicited many positive comments from the students (Sections C.2, C.3) and suggested that perhaps they may not have fully understood their rights as a research participant in past studies.

Understanding the importance and broader impact of research. With the exception of the two students who had worked in a research environment, most students expressed that when they had participated in a study, they did not necessarily stick around to learn more about the purpose of the research or its potential broader impact on science, education, and innovation. Yet, two students spoke wistfully about their unfulfilled desire to receive educational information when they participated in past research studies (Sections C.4, C.5).

One research topic, genetics, however, elicited an interesting discussion. Some students were concerned about whether genetic research involving Deaf individuals sought to "cure deafness" and expressed their ambivalence toward that goal (Sections C.6, C.7). This is consistent with Lane's (2005) description that some members of the Deaf community fear that genetic research on deafness or widespread cochlear implants may lead to cultural genocide insofar as potentially eradicating their community. Interestingly, Boudreault et al. (2010) and Withrow, Burton, Arnos, Kalfoglou, and Pandya (2008) have explored some of the many reasons Deaf individuals pursue genetic testing, especially as a function of their cultural affiliation (i.e., strongly affiliated with the Deaf community, hearing community, or both).

Expert and Researcher Focus Groups

Our process of data analysis treated the Researcher ($n = 5$) and Expert ($n = 6$) focus groups separately; however, because we found so many of the core categories and conceptual themes overlapping between the groups, we report their findings together in the following section.[4] The interaction dynamics in these two focus groups revealed a sense of respect and trust and good individual participation rates (see Section B.5 in supplementary material for detail). The analysis of the core categories from these two groups revealed several key conceptual themes, and these are summarized next.

Distrust toward the researcher. Both experts and researchers expressed feelings of distrust toward any researcher who is unable to effectively communicate with a Deaf participant in his or her study. The group questioned a researcher's ability to run a study effectively and objectively if he or she possesses limited sign proficiency (Sections C.8, C.9) or used inaccessible consent procedures. Consistent with Pollard (2002), our participants stated that being told in advance who was on the research team would provide some measure of assurance or confidence in the researcher.

There was further discussion on data interpretation concerns. With the inability of a researcher to communicate in signs, the experts and researchers feared the potential for misinterpretation of data, which they felt could lead to a negative outcome, such as perpetuating pathological views toward individuals who are Deaf (Section C.10).

Distrust in the validity of standardized tests. Experts and researchers questioned the validity of adapted standardized tests used in research involving Deaf individuals and argued that they were likely to be culturally and/or linguistically inappropriate (Sections C.11, C.12). Several authors have discussed validity and translation issues in test development for signing populations (Graybill et al., 2010; Hanumantha, 2009; Haug & Mann, 2008; Herzig & Krumdick, 2011; Pollard, 2002; Singleton & Supalla, 2011) and the cultural equivalence of research tools (Trimble, 1988). Tests that are developed from scratch, taking a Deaf-centered or ASL-centered perspective, make important strides in the adoption of appropriate testing paradigms with the Deaf and sign language using populations.[5]

Deaf tokenism and ownership. The issue of Deaf tokenism arose in the discussion among the group's participants with a suggestion that many Deaf researchers harbor feelings of being exploited and felt that they had not received adequate credit or ownership for their contributions to the work being done. Both the experts and researchers believed that the presence of Deaf researchers in the research enterprise would ensure the cultural and linguistic accuracy of findings, as well as promote a respectful attitude within such cross-cultural interactions.

Bias in research funding and status. The Researcher focus group discussed how they experienced lack of funding opportunities for "Deaf-centric" research and proposed that this was due to disparities in allocation priorities of funding agencies and institutions. They argued that the majority of research-on-deafness funding is directed toward the medical field and significantly less so toward investigations into the socio-cultural aspects of Deafness and educational issues (Sections C.13, C.14).

Host community as gatekeepers. Following a discussion that focused on how the Deaf population is continually being overtested and how, historically, many researchers have lacked the cultural competence to study this community with accuracy, one participant, making a parallel with an Aboriginal community in Australia, raised the notion of establishing host community gatekeepers who would review a researcher's access request to protect Deaf citizens and children from unethical research practices (Section C.15).

Giving back to the Deaf community. Both focus groups emphasized the obligation for researchers to give back to the Deaf community after the research findings have been completed and published (Section C.16), bearing in mind that traditional pathways of research dissemination may not be accessible to the Deaf community (see Pollard, 1992, for a discussion). Furthermore, Baker-Shenk and Kyle (1990) suggested that the Deaf community has perhaps become disenfranchised from the research enterprise due to their continuing exclusion from the research decision-making process. Giving back to the Deaf community is clearly a *mind-set* and, more specifically, can be in the form of language-accessible materials, workshops on research findings, and media dissemination.

Confidentiality issues. Situations that compromise the confidentiality of Deaf participants were a concern to both experts and researchers. They expressed the struggle between the need for video recording participants to preserve their signed language production (including facial expressions for linguistic meaning) for data analysis and the inability to de-identify the video data (e.g., through blurring the face) to protect their identity. This issue can also be a problem for conference presentations of research findings (see Section B.6 in the supplementary material for further detail).

Discussion

This qualitative study brought together three separate stakeholder groups to discuss the process of research when Deaf individuals are involved. We included Deaf college *students* who had participated in research as subjects, *researchers* whose studies involved Deaf participants, and *experts* in the field of Deaf studies. Using an inductive process of data analysis, we identified and organized the themes that emerged within each of the three focus group discussions. Stepping back, looking across all three focus groups, we now discuss the broader conceptual themes that emerged. We organized the themes into three groups: the Research Process, the Deaf Researcher, and Negotiating Paradigms.

The Research Process

The process of conducting research with Deaf participants involves engaging with the host (Deaf) community, researching topics that may be culturally–linguistically laden, and interpreting the results in a culturally and linguistically appropriate manner. The core themes we identified across the three focus groups in this category were (a) lack of trust and (b) confidentiality.

Lack of trust. The participants expressed their mistrust toward researchers, toward the selection and rationale of the research question, and toward the interpretation and dissemination of research findings. All of our participants, whether directly or indirectly involved in research, cited hearing researchers' lack of sign language proficiency and cultural knowledge as the principal concern or source of their discomfort. A Deaf research participant cares about being understood, being put at ease, and being re-assured that their language and culture are valued (Harris et al., 2009). For some, this mistrust had ultimately generalized into a reluctance to participate in research altogether, whereas, others screened their involvement with prospective researchers, only engaging with those who have earned their trust.

Confidentiality issues. The second concern echoed by all three focus groups was the issue of *confidentiality*. It is difficult to conduct anonymous or de-identified research within such a tight-knit community where the possibility of someone knowing another member of that community is very high and almost unavoidable. Therefore, researchers whose studies involve Deaf participants are often unable to guarantee complete confidentiality, whether it is because of a pre-existing social relationship between the researcher (and members of their research team) and a participant, or the strong possibility that an audience member at a research conference may recognize an individual in a video clip or still image used to present examples of data. See Sections B.6 and D in the supplementary material for further discussion and suggestions on good practice around the use of video recorded data (jre.sagepub.com/supplemental).

The Deaf Researcher

The second major domain of conceptual themes cutting across the focus groups had to do with researchers who are Deaf.

Lack of Deaf researchers and tokenism. The Deaf experts and researchers in our focus groups conveyed continuing frustration with communication and professional socialization in their research careers. This includes a lack of Deaf mentors, or hearing researchers who are fluent in ASL, and a feeling that Deaf scholars are sometimes treated as tokens in research teams (see Sections C.17, C.18). Recognizing the historical disparity of educational opportunities for Deaf scientists and scholars, troubling barriers still remain as evidenced by the relatively few Deaf people involved in research and, especially, in the publishing of research and communication access in professional engagement (Sections C.19, C.20, C.21). Even in the case of collaborative research between Deaf and hearing researchers, Deaf scientists are often relegated to lower-status positions such as leaders or coordinators rather than the principal investigator, or equal co-author, of the project (Harris et al., 2009). Unfortunately, without a strong presence of Deaf scholars to engage in discussions and review of research protocols in studies involving Deaf people, hearing researchers may continue in their programs of research, securing funding and prestige, without concern for cultural and linguistic issues and the betterment of the Deaf community or quality of deaf education. See Woodcock, Rohan, and Campbell (2007) and Section D in the supplementary material for discussion regarding the mentorship of more Deaf scientists and the re-framing of collaboration models.

Some Deaf academic scholars have begun to form their own community (www.deafacademics.org) to provide mutual support, encourage up and coming Deaf scholars, and consider new frameworks for conducting science in signed language and proposing new constructs such as *Deaf-gain* —the transfer of interests, values benefits, and credit that has been given to hearing members to Deaf individuals (Bauman & Murray, 2009), *Deafhood*—an ecological view that considers deafness not as a deficiency but as a difference and source of pride (Ladd, 2003, 2008), and *Deaf epistemologies*—a *way of knowing* that is unique to Deaf individuals (Bahan, 2008; Hauser, O'Hearn, McKee, Steider, & Thew, 2010; Paul & Moores, 2010).

Negotiating Paradigms

A final major conceptual theme that emerged across the three focus groups was a recurring reference to navigating the normative professional and socialization practices among members of the scientific research community and a need for recognition of the unique cultural and linguistic practices of members of the Deaf community. It is more common that hearing individuals subscribe to an ideology that frames Deaf individuals as a vulnerable population in need of fixing. Thus, coming from a history of "being studied" and misinterpreted, it is reasonable that many Deaf people are skeptical of hearing researchers and shun the vulnerable identity. The researchers and experts expressed their frustration with the lack of a Deaf-centric perspective (Padden & Humphries, 1988) in the scientific community. From their perspective, the outsiders (the hearing scientists) are the voice of authority in the research enterprise, determining funding priorities, choice of problem and methodological approach, authorship credit, and publication outlets, and deciding how Deaf researchers are involved (from token to full collaborator). Jones (2004) also discusses the negotiations and potential for bias that Deaf scholars may experience when they research "the familiar."

Indeed, all members of the team must negotiate their relative contributions to a successful research project, how the professional credit will be attributed, and openly discuss their plan for engaging in ethical practice.

Best Practices

To uphold a "gold standard" of ethical practice, the broader scientific research community will have to increase its awareness and improve its practices with respect to the Deaf community, just as it should to other marginalized communities. With greater detail provided in the supplemental material (see Section D), we briefly summarize our recommendations for best practices in research involving Deaf participants:

Incorporate Cultural and Linguistic Awareness in Scientific Endeavors

As investigators frame research questions, it is important to ask how we, as members of a diverse scientific and educational community, recognize and address the cultural and linguistic issues that are embedded in studies that involve children and adults who are Deaf.

Create Accessible Research and Dissemination Practices

Researchers working with Deaf individuals must consider whether the recruitment, informed consent, and follow-up processes are culturally/linguistically accessible to their participants in both signed and written languages.

Make the Results of the Study Available to Any Participant Who Expresses Interest

Researchers need to communicate their findings with their individual subjects and the Deaf community using the most appropriate and desired method for *giving back*. For example, brief research reports could be created in ASL and shared through video clips offered on websites that are linguistically accessible to this community (e.g., the results of this study are summarized in ASL in the *Deaf Studies Digital Journal*: http://dsdj.gallaudet.edu).

Re-Frame Deaf and Hearing Collaboration Models

Transparency in the collaboration process and making the patterns of normative scientific practice explicit will benefit all members of the collaboration, whether Deaf or hearing. Community Advisory Boards may be a constructive venue for such discussions.

Research Agenda

Within the scope of this research project, we covered only three stakeholder groups in the research enterprise: *students* (research participants), *researchers*, and *experts* in Deaf studies. We recognize that this selected pool does not include other important stakeholders in the research community, such as Deaf community members, hearing scientists, educators/practitioners, parents of Deaf children who participate in research, national research funding organizations, and university and hospital IRBs. This initial study sets the stage for future work.

Educational Implications

Governmental funding streams designed to promote the higher education and professional development of underrepresented scientists tend to focus on individuals from racial/linguistic minority groups; Deafness is more likely placed within disability initiatives.[6] This categorization may be problematic, as many members of the Deaf community do not self-identify as disabled (Lane, 2005) and thus, may not pursue such funding. Moreover, the community of scholars engaged in research that involves studying Deaf people needs to become more active in the professional socialization of Deaf students and scientists, including collaborative research and publication mentoring. Cultural sensitivity to the Deaf community needs to be developed (see Epilogue [Section E] in supplementary material).

Authors' Note

Any opinions, findings, and conclusions or recommendations expressed are those of the authors and do not necessarily reflect the views of the National Science Foundation.

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Notes

1. It is important to note that there are different signed languages (e.g., Japanese Sign Language, British Sign Language, Swedish Sign Language) used all around the world and thus, Deaf communities are not to be thought of as one monolithic group with a universal language. American Sign Language (ASL) is used in the United States and parts of Canada by the American Deaf Community.
2. We reveal the name of the data collection site, because there is only one Liberal Arts College exclusively serving Deaf students. We purposely chose this site with the intention of gaining access to viewpoints that reflect the *Culturally Deaf* experience. Thus, we acknowledge that we may have entered our study with a positive bias, given that we might find an overrepresentation of exemplary practices regarding Deaf research ethics in our sample. Had we collected data in other

institutions, we may have encountered even more examples of ethical conduct violations. Even so, we benefit by collecting data from individuals with such relevant experiences, especially as their perspectives have not been empirically documented in prior studies. It is important to note that individual participants remain de-identified in the article and in all discussions of our findings.

3. To provide some context for this statement, according to the http://About.com website, Gallaudet University's average 2012 incoming Freshmen Scholastic Aptitude Test (SAT) Critical Reading subtest scores fall between 350 and 530, 25th and 75th percentiles respectively. These numbers translate to the 7th and 58th percentile scores among hearing high school students taking the SAT Test, nationally.
4. An individual from Deaf/American Sign Language (ASL) Studies could just as easily have attended the Researcher focus group. In the end, the distinction between these two groups was not really remarkable and for the purposes of analysis, we did combine their results.
5. For example, Pollard, Rediess, and DeMatteo (2005) and Pollard, DeMatteo, Lentz, and Rediess (2007) have developed instruments from an "ASL-center"; see also the National Science Foundation Science of Learning Center on Visual Language and Visual Learning's (VL2) ASL Toolkit for more examples (http://vl2.gallaudet.edu/document.php?id=14).
6. One nice example illustrating the promotion of Deaf scholars/scientists is this Task Force in the health care fields (http://www.rit.edu/ntid/hccd/about).

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