



Council on Crime and Justice

Participatory Approaches to Research: Understanding Sexual Violence in the Deaf Community

Researching Sexual Violence Project (RSVP)

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When doing research to broaden the understanding of sexual violence in diverse communities, it is critical to acknowledge the exploratory nature this inquiry requires. Undeveloped areas of study call for researchers to not only employ exploratory approaches using qualitative methods, they also require culturally competent approaches in conducting research activities. Participatory Action Research (PAR) is an approach that is effective in building community relationships and understanding social issues in a manner that is rich and full of depth. In a study of sexual violence in the deaf community in Minneapolis, Minnesota, a model of PAR was employed. The aim of this ongoing research is to understand the deaf community's perceptions of sexual violence and barriers that they experience in seeking help. A secondary aim of this study is to determine how effective PAR is in conducting this investigation.

What is Participatory Action Research (PAR)?

Participatory Action Research (PAR) was developed in contrast to conventional research approaches in which social scientists control the research agenda, design and implement research while treating participants purely as human subjects (Hall, 1993; Rose, 2001). The participatory component of the PAR model originates from developing countries in response to ethical concerns to the research process. North American and European researchers were characterized as being more concerned with describing the social world than with changing it (Krogh & Lindsey, 1999; Vander Stoep, Williams, Jones, Green, & Trupin, 1999). Conventional research was of little use to community stakeholders, attempted to achieve unrealistic goals, and exploited community participants (Rose, 2001). Kurt Lewin is generally cited as having introduced the action-oriented western component of PAR in 1946. His work is described as social research

involving the researcher as an agent of change while at the same time generating critical knowledge about it (Small, 1995).

PAR is often characterized by qualitative research methods (Krogh & Lindsay, 1999). However, PAR is distinguished by 3 primary facets: 1) an iterative process for conducting research that includes reflection and action; 2) having community members and stakeholders involved with the research process; and 3) using findings to promote positive community change (Hall, 1993; Rose, 2001). Though participatory action-oriented researchers frequently use qualitative methods, quantitative methods may also be used (Krogh & Lindsay, 1999; Miles & Huberman, 1994; Sommer & Sommer, 1991). PAR researchers must be prepared to use a range of methods as the social problems of interest tend to be more novel and understudied. PAR researchers need to design new instruments and techniques to gather data as well as make methodological choices about rigor. PAR researchers must also be sensitive to the needs and perspectives of their non-researcher counterparts by selecting measures that have a high degree of face validity and practical utility (Small, 1995).

PAR is not the most appropriate approach for all studies. Methods and approaches must match the type of research question, the stage of the field of inquiry and the purpose of the research. Studies that are designed to investigate the impact of treatment or services often involve an experimental design. Experimental studies are not as conducive to having participants guide the research process (Krogh & Lindsay, 1999). However, PAR is useful when studying social phenomena that has not received much previous attention. In these contexts, PAR utilizes community member's knowledge of both the political context and the community dynamics surrounding the issue. Community members are also poised to use the findings to make positive changes in their community.

When using PAR approaches the concepts of objectivity and validity are under scrutiny. Community researchers bring with them characteristics, attitudes, and feelings that can conflict with the neutrality of the research process. While the issues of objectivity and validity are present in any research approach, PAR makes explicit these challenges at the outset of the study. Acknowledging the challenges to objectivity that are inherent in using community members in the research process assists in maintaining the integrity of the work. Qualitative methods are often employed because methodological rigor can be assured through immersion in the setting (prolonged exposure), triangulation of data from several sources, and checks with persons familiar with the setting or issue (Krogh & Lindsay, 1999; Lincoln & Guba, 1985; Padgett, 1998).

PAR possesses epistemological assumptions that conflict with beliefs of more mainstream social science. Social science that is more positivist in nature assumes:

(a) the existence of a single, tangible reality that can be divided and reduced to independent parts, any of which can be studied, independently of others; (b) the belief that every action or effect can be explained as resulting from a cause that precedes it in time; (c) the view that research is a value-free endeavor and that the researcher is able to maintain objectivity and distance from the phenomenon under study; and (d) the belief that the goal of research is to develop a nomothetic body of knowledge that is highly generalizable across settings, people, and time (Small, 1995).

In contrast PAR has a more post-positivist epistemology and rejects positivism because of its perceived inadequacy for creating social change. PAR is concerned with creating social change that will benefit those in the impacted study communities and views research participants as collaborators in the identification and analysis of their own community's problems. PAR acknowledges that science cannot be neutral or completely objective in addressing social problems by emphasizing the context of the research rather than the universal laws of science (Small 1995).

PAR is effective in studying problems that originate from the community context and recognizes community issues, strengths and capacity for social change. Both researchers and community members are viewed as having knowledge critical to carrying out the PAR process (Small, 1995). PAR methods may involve people with specialized training and community members as researchers. The research process itself may be led by community members or by a collaborative team of insiders and outsiders of a given community (Hall, 1993; Krogh & Linsay, 1999). The PAR researcher brings to the research process theoretical knowledge, experience, and the skills of conducting social science research; community collaborators bring practical knowledge and experience about the topics of study (Small, 1995).

Minneapolis PAR Model: Researching Sexual Violence in the Deaf Community

This study is an exploratory examination into the deaf community's perceptions of sexual victimization. As an undeveloped area of research, this exploratory study employs qualitative methods and contributes to a theoretical framework for understanding help seeking patterns and behavior with the deaf victims of sexual violence. The aim of this study is to answer the empirical questions: 1) what are the perceptions of the deaf community around the of the scope of the problem of sexual assault in their community; 2) who do individuals in the deaf community tell about their experiences of sexual assault and why; and 3) what service gaps exist for the deaf community? The study focuses on collecting primary data from individuals who are deaf and key informants (also known as service providers) using qualitative methods. A secondary aim of this study is to determine how effective PAR is in conducting this investigation.

PAR is characterized by having 3 primary components: 1) an iterative process for conducting research that includes reflection and action; 2) having community members and

stakeholders involved with the research process; and 3) using findings to promote positive community change (Hall, 1993; Rose, 2001). Researchers conducting studies involving adults with disabilities tend to employ participatory qualitative methods exclusively and sometimes have a combination of qualitative and quantitative approaches (Krogh & Lindsay, 1999). Many PAR researchers have documented their research processes and the issues they have encountered. Such researchers recognize that collaborative relationships with community members are difficult to establish, maintain, and develop (Brydon-Miller, 1993; Krogh & Lindsey, 1999).

Involvement by Community Stakeholders

An advisory group of community stakeholders was recruited to provide direction to the research process from a community perspective. Advisory group members were, made up of law enforcement officials, hospital workers and deaf and hearing human service providers. This group helped shape the research questions, recruit participants and identify key informants as members of the community who are likely to be knowledgeable about the issues of abuse in the deaf community.

Early in the research process it was decided that some team members should be knowledgeable about deaf culture. A project coordinator was hired to oversee participant recruitment. The project coordinator for the interviews was someone who was deaf and well respected in the deaf community. Having a deaf interview coordinator was crucial and added to the credibility of the study. Also involved in the project team were consultants. Some consultants were Children of a Deaf Adults (CODA). CODAs are often bicultural in understanding the nuances of deaf culture and hearing culture. Having consultants with this experience greatly helped the researchers with being more culturally competent in their research

approach. The interview coordinator and consultants contacted many organizations to ask that they refer individuals to the study. Flyers were posted at organizations and on the Internet.

The methods used in this study include semi-structured key informant interviews and interviews with community participants. To determine what service gaps exist for deaf individuals key informant interviews were conducted. The key informant interview technique involves interaction with selected community leaders and agency representatives to estimate the needs of a particular community. Information was gathered via interviews with 15 service providers. Semi-structured interviews allowed the interview to have a conversational flow covering topics rather than focusing on specific questions. Interview protocols were developed with guidance from the advisory committee and pilot tested before implementation. Interviews with 50 deaf community participants were also conducted to help answer the research questions. These interviews used videotaped scenarios as a tool to ascertain perceptions about sexual victimization. Trained interviewers showed various scenarios to deaf community members and asked follow-up questions about the event described on the video. After the scenarios, interviewers asked participants if they are a survivor of sexual abuse and would they answer questions about their experience.

The community member interviews were intended to capture the needs of survivors and non-survivors alike. The rationale for including other community participants who may or may not be survivors in the study was to fully understand help seeking patterns. Though in this study some participants may not have been victimized or may have chosen not to disclose if they were victimized, in general, most people know someone who has been the victim of sexual violence. In fact victims and survivors tend to turn to friends as the most common source for social support following an assault. Ullman (1996), studied whether the type of positive and negative social

reactions by significant others had a significant effect on sexual assault victims' adjustment. He found that friends are the most common support source for sexual assault victims and that positive emotional support and neutral support from friends is associated with better recovery. Understanding the perceptions of both survivors and non-survivors of sexual assault in the deaf community is useful in understanding survivor needs as well as what course of action friends might influence victims towards.

This study recruited participants through a variety of approaches. It sponsored a forum at a Deaf SAFE workshop to explain the study and ask interested individuals to participate. The Deaf SAFE workshop is a community meeting where criminal justice issues related to the deaf community are discussed. Members of the deaf community were able to meet the interviewers, see who was involved in the project and also have immediate questions addressed. After the workshop, the project contacted area deaf organizations and asked them to make information available about the study and to refer interested individuals to the interview coordinator to get more information.

This study incorporated both deaf interviewers and hearing interviewers using interpreters. This allowed participants to have a choice of the type of interviewer. Some participants wanted an interviewer who was not a member of the deaf community since they perceived confidentiality to be compromised if they know the interviewer personally. However, others preferred having someone from their own culture in the interview setting.

Iterative Process

The advisory group and the research team met regularly to incorporate feedback and learnings back into the research design, the process and the data analysis. This process of constant integration of learnings is central to the iterative process. Advisory meetings discussed

what progress had been made to date, discussions that needed to occur at present and what steps were going to occur in the near future. Team meetings synthesized key learnings so that the research design or lines of inquiry could be modified.

In the beginning of the research project, there were bi-monthly meetings with the advisory group. The goal of the first meetings was to acquaint the group with each other and to discuss their role on the project. The working definition of “advisory” meant the group providing advice and guidance on the project for each step forward. The study requested that advisory members make a 1-year and 6 meeting commitment to this group. Project staff maintained communication with the advisory group via email and meetings were held in a community center in the city of St. Paul, Minnesota. The study coordinators also informed the advisors that their participation, roles and communication could be revisited and discussed at any point during the project.

One initial modification that the advisory board requested was that materials presented at meetings be done in a more visual format. Since the research design and questions were complex and the materials were written in English, the advisors believed that pictorial descriptions of discussion topics would be more helpful. The first decisional discussion that the research team assigned to the advisory group was to name the project. It seemed likely that project staff would refer to the project as the “deaf project” or the “sexual assault project.” It was imperative to quickly choose a name that would be attractive to community stakeholders. There was a brainstorming session that led to a vote and “Researching Sexual Violence Project” (RSVP) was born.

The second set of decision-making questions focused on the development of interview guides. Since the key informant interviews were to be semi-structured, topics that should be

covered were identified in a focused conversation format. As the project was preparing to recruit members of the community to be interviewers for the community member interviews, it was evident that the interviewers would not be qualitative researchers by training. At this time the advisory group needed to make important decisions about how structured the community member interviews should be. Finally, the advisory group discussed the topic of creative methods or media to conduct interviews. This discussion was useful as most participants would be using American Sign Language to communicate with interviewers and visual images had been highlighted as an important mode of communication. The advisory group's creativity produced the concept of videotaped scenarios.

Each video scenario depicted a story about someone who was first sexually assaulted and then raped. The interviewer then asked follow-up questions about what the character in the story should do, what barriers they might encounter, and what advice the interview participant would give the character. At the end of the scenarios, the interviewer would ask the participant if they were a sexual assault survivor and if they felt comfortable telling their story. The advisory group looked over the scenarios and the follow-up questions to provide the research team insight about how they might be revised to be most appropriate. The advisory group was also helpful in highlighting areas that should be addressed in the interviewer training.

Once the interviews began, the research team and interviewers would meet regularly to discuss what had been emerging as themes in the interviews. Though the interviews would be analyzed as a whole later, these meetings allowed the group to process the thoughts, ideas and issues emerging from the community. The information from the community interviews also helped to inform the key informant or service provider interviews that were conducted after the second round of community interviews. The key informant interviews were less structured and

issues identified in the community interviews were included so that key informants could provide insight into the community identified issues. For example, the issue of the availability of interpreters and the role of interpreters were emerging themes in many deaf community member interviews. It was clear that the issue of interpreters was a popular and controversial topic with the deaf community. After processing this information, the researchers, with the assistance of the advisory group, designed specific questions for key informants (service providers) to gain more perspective on the implications of this issue.

One tool that was used to facilitate some theme extraction meetings with the research team was Focused Conversation Facilitation developed by the Institute of Cultural Affairs (ICA). Since 1971 ICA has been teaching courses on building consensus, decision-making, ensuring full group participation, and clarifying direction. ICA methods are instrumental in helping individuals and groups create and define their identity, support and integrate diversity, and develop a strategy to attain goals (Stanfield, 2000). Using the Focused Conversation questioning formula which incorporates objective, reflective, interpretive, and decisional questions, the research team was able to stimulate the group's ability to think collectively, engage in meaningful dialogue, process the interviews and articulate clear ideas about the them.

Using Findings to Promote Social Change

Published examples of participatory research are not common in mainstream peer-review social science journals. However, written reports are available from research centers and institutions that sponsor such research (Small, 1995). One of the hopes the advisory group expressed is that written reports of this study will be used to help provide guidance for change in order to better assist deaf victims of sexual assault in accessing resources to cope with the aftermath of abuse.

As themes emerged in advisory group meetings, discussions about future action have also developed. One theme that emerged is the lack of culturally specific deaf sexual assault programming in the Twin Cities. A local hospital had a state-funded program for a period of time, but that program was de-funded. In interviews hearing service providers often state that they wish there was a deaf-specific program that they could refer clients to for assistance. Deaf community members think it is important to have a choice between seeking help in the deaf and hearing community. Advisory group members hope that findings from this study can be used to influence public policy and to secure additional resources for both deaf and hearing service providers. One advisory group member has been using the knowledge gained from participation in this study to refine the design of a deaf-specific non-profit entity. The information from this study regarding interpreter services emerged as such an important topic that this advisory member's design now includes training for service providers on the issues surrounding interpreting services.

Conclusion

The Researching Sexual Violence Project (RSVP) in the deaf community in Minneapolis appears to be a great success in PAR. This was primarily evidenced by having a hearing-dominated team of researchers collaborate with deaf individuals to connect with deaf persons and discuss sexual assault. Not only were participants recruited within the established time frame; participants had to be turned away at the end of the interview period.

Success is most likely due to having an advisory group with a diverse membership (law enforcement officials, hospital workers and deaf and hearing human service providers), having recruited deaf interviewers and a hearing interpreter, using a video taped consent form and scenario-based interviews that featured a notable member of the deaf community. The interview

stipend was also \$50 and that seemed to be a great incentive to participate. Having an advisory group also helped align the research with the tenets of PAR. The research questions more closely reflected the day-to-day worlds of people who are seeking solutions to the challenges in their communities. Problem solving around the challenges of the research process were addressed in a manner that was consistent to the realities of being deaf in this region.

Future replications of this study should include the active ingredients of establishing a well-rounded advisory group, employing deaf individuals and bi-cultural consultants as members of the research team and having a sizable stipend. Modifications to the design might include strategies to include members of the deaf community who are skeptical or distrustful of “hearing” activities and deaf community members with alternative or minimal languages skills. Replications are crucial to continue the accumulation of knowledge in this area. It is important to broaden the understanding of sexual violence in a community that is often overlooked. Replication is also important to understand if PAR is an effective approach that can be demonstrated in other geographical locations. Further exploration is warranted.

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