

CASE STUDY

Disclosure of intimate partner violence while studying positive mental health in wheelchair users: ethical dilemmas

SONU S BABU, RAVI PRASAD VARMA

Abstract

This case study discusses the ethical dilemmas faced by the researchers when a woman with disability voluntarily disclosed her experience of intimate partner violence during an in-depth interview on positive mental health and resilience in wheelchair users. The interviewer's role as a researcher and public health professional raised dilemmas relating to the tenets of privacy, confidentiality and non-maleficence. Professionals working with women with disability and similar vulnerable participants should anticipate such ethical challenges around violence and discrimination that such individuals face, and strive to resolve challenges based on basic ethical tenets within a context-informed approach.

Keywords: incidental findings, researcher obligation, privacy, non-maleficence, disability, domestic violence

Background

Ethical dilemmas can frequently arise unexpectedly during data collection in research studies. In this case study we share the moral conundrum that we faced in a study on positive mental health among wheelchair users. One participant chose to recount the specifics of her trauma related to intimate partner violence rather than answering our questions on her psychological state. We try to explore the ethical dimensions of the researcher's duties regarding commitment to the research objective while being a caring public health professional.

Intimate partner violence (IPV) is "a pattern of coercive and oppressive behaviour that is harmful to... emotional, social, or physical well-being". Women with disabilities are more likely to

remain in such violent relationships than non-disabled women [1]. A 2004 report from Orissa indicated that about half of the married women participants with disabilities had experienced IPV [2]. Another report from Mumbai found women with disability to be at significantly higher risk of physical, sexual and emotional violence as compared to women without disability, often overlapping with neglect [3]. Professionals encountering this phenomenon in research or practice may face several ethical dilemmas, the resolution of which may be challenging [4].

Against this background, we share our experience of a voluntary disclosure of IPV by a woman with disability while conducting a study on resilience and positive mental health in wheelchair users in Kerala, India.

We were conducting exploratory interviews for narratives to describe resilience and positive mental health among wheelchair users in Kerala. Questions focused on household routines, vocations, family and social interactions, and traveling. Participants were encouraged to describe what they enjoyed and how they coped with difficulties. Data were being collected by means of open-ended unstructured interviews. Both the authors have a professional background in public health. Interviews were conducted at the participants' home or at a place suggested by the participant, while ensuring their privacy and safety. The interviewer had a guide handy to help her keep the narrative on course, so as to get descriptions relevant to her research question. She also maintained a reflective field diary during the study. The protocol and tools had been reviewed and cleared by the Institutional Ethics Committee of the Sree Chitra Tirunal Institute for Medical Sciences and Technology (SCTISMT), Trivandrum.

The expression of IPV, the principal focus of this manuscript, was revealed when we were into the fifth of the 10 interviews of the study. Here, we discuss the immediate ethical questions raised by the disclosure and their resolutions.

The disclosure of IPV

Riya (name changed) was a 49-year-old woman from a poor household. The conversation began with the pandemic and the lockdown experience and moved on to Riya's education, vocation and daily routine; but soon the narrative shifted to the violence she had been experiencing at the hands of her husband.

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"Anyway, my life has turned out like this. But when (my son) Abhi intervenes, he will take a knife. And that terrifies me. What will I do, if something happens to Abhi?"

What followed was a conversation where Riya kept referring to the violence she was experiencing, often cutting short a question that was being asked. Riya recollected:

While they started looking for prospective matches for me, my father thought that we should tell the boy and his family about my problem. But, in the first prospective match, they rejected me because of it. I had ... younger sisters also. My father didn't have much money... Then my father decided that he won't tell anyone about my condition... Except that we went for an Ayurvedic treatment, nobody knew anything about my condition, nobody knew that I have <this disease> then. My father too didn't know (the exact nature of the diagnosis) ... Anyway, my now-husband came and we got married. After marriage, the condition aggravated. Then started the blaming. He started insulting me even in front of people while we are outside, with relatives or with strangers.

A doctor had an inadvertent role, at least partially, in activating the violence that was to scar Riya's life. She mentioned that:

...the doctor understood that it was <this disease> the moment he saw me. The doctor said that this would have started around when I was 20 years old. He said this in front of my husband and I became a culprit before him.

Riya's narrative also revealed in her lack of contraceptive choice, and possibly limited sexual autonomy, in addition to the physical and emotional violence.

In between, I had to go through many abortions... Before my <first child>, after him... even after my <second child>... two abortions... He didn't have any concern about such things...

Riya had actually sought police assistance for the problem and initiated action against her husband but she had later withdrawn her complaint:

My husband is a drunkard. He makes a lot of problems here and beats me too... We complained in the police station and they took a case against him. He was in jail for two months. Then I went and revoked the case and brought him back home. Somebody has to be there to take care of me ...

Ethical dilemmas faced by the researcher

Several dilemmas occurred during and after the interview. We have listed these based on the interviewer's position first as a researcher and second as a public health professional.

Challenges faced as a researcher

Integrity of the data collection processes needs to be ensured as also autonomy of the participant to share information.

1. Is it methodologically appropriate to continue with the interview if it departs from the objective and the

guidelines of the original study meant for exploring the potential for enjoyment and overcoming of challenges?

2. Even if the conversation could be linked to the study's objective and analytical categories, was it really an intended disclosure? Was the disclosure made with full understanding of autonomy or was it an unintended catharsis? If so, should the interview data be used for analysis or not?

Challenges faced as a public health professional

Intimate partner violence is a serious public health problem and a public health professional would feel obliged to take some action on encountering this. However, the tenets of privacy, confidentiality and nonmaleficence should be upheld as well. Hence, these issues arise:

3. Does a researcher have a right to intervene in the private life of a participant and her children?
4. If the researcher chooses to act, how will she safeguard the privacy and confidentiality of the participant or her family members?
5. Would taking action do more harm, given the rural, patriarchal society the participants reside in? How will she balance "do no harm" with the "social justice" aspect?

Choosing to act based on the self-disclosure of violence experienced by a person can be a potential slippery slope. The experience challenges the emotional boundaries and assumptions of the researcher. The complex relationships in the participant's environment also call for an ethics of care approach rather than one limited to a principle-based approach [5]. Our competence for handling the situation and the dilemma arising from trying to respect the participant's capacity for self-determination, while perceiving the vulnerability and limited autonomy such women have were also important concerns [4]. Several guidelines and recommendations advise the balancing of "do no harm" and "beneficence", particularly in research settings [6].

Attempted resolution

As the conversation progressed, the interviewer discerned ongoing efforts on Riya's part to address the problem. She had a safe place to go to when the situation worsened. She had a small network of people to support her, emotionally at the very least. She had already sought legal recourse once and was aware of the related procedures, and she had resumed her studies.

The interviewer attempted to provide validation to Riya's statements with empathy. The interviewer and the research supervisor (RPV) initiated discussions with experts in gender issues and ethics. A decision was taken to present the participant with options she could have access to and could

choose by exercising her own level of autonomy and agency. She was contacted again by the interviewer and presented with possible options like the Mitra information and emergency helpline for women which is run by the Kerala State Women's Development Corporation [7]. Additionally, a senior woman clinical psychologist was also identified – who consented to provide psychological support should the participant feel the need to call her on her own behalf or that of her children. Riya's permission was obtained before providing these suggestions. Toporek and Williams recommend such an approach where the relationship is a collaborating one rather than an imposed one – a social justice approach respecting the power differential between the researcher and the participant [8].

For the interviewer, the disclosure was connected with the past experience of overcoming a somewhat similar personal adversity. This caused some discomposure to the interviewer. Still, the interviewer perceived that given the choice of date and place and freedom to refuse, and the nature of interactions where the interviewer was always addressed as “daughter”, which the interviewer interpreted as expressing a palpable sense of intimacy without any indication of fear. Hence, it is unlikely the interview would trigger further distress for Riya. Also, Riya repeatedly assured the researcher that she had come to terms with the violence and it would not add to her trauma.

I would have started crying if this conversation happened two or three years ago. Now I have come to terms with it as I have support from (name of the organization) and my children are grown up.

The situation had not worsened a few days later, as verified through a follow up call, and the telephone helpline numbers were presented in a manner that Riya preferred.

Discussion

The researcher's immediate dilemma in the face of disclosure of IPV is whether to report it using available institutional and legal provisions, despite the ethical assurance to uphold the privacy and confidentiality of participants while initiating research interactions. The layers of individual and structurally imposed vulnerabilities complicate this situation. The moral position from which the researcher chooses to act also needs reflection to rule out the “saviour syndrome”. A saviour syndrome in the context of disability may be considered if the researcher idealises their understanding of the situation based on their body of knowledge and devalues actions already taken or assistance already in place for the participant [9]. The interviewer (SSB) was fully dependent on the participant to get directions to reach the participant's house. During the interview, she perceived herself to be in a daughter's position rather than that of a professional. Prior to the interview with the IPV disclosure, the study had been largely from an etic perspective but there were personal antecedents for the interviewer that placed this interview in more of an emic

perspective. Later, while choosing to act, we acknowledged the existing support that the participant had — her natal family, the peer group and local law enforcement. We offered more alternatives — psychological counselling and a gender specific helpline — the utilisation of which remained within the participant's agency.

Ethical dilemmas of this type in psychology and public health research and practice can arise at both the individual and proximate group level. Firstly, concerns regarding client safety, privacy and confidentiality and the handling of the paradoxical role of the caregiver also being a perpetrator of violence [10]. Then there is the risk of unauthorised disclosure or nonvoluntary disclosure [11]. A breach of privacy and confidentiality is possible as there are only a few thousand persons in wheelchairs in the region and accurate accounts of the context and experience may lead to identification [12]. Also, social networks may support the patriarchal order, and stakeholders who may otherwise be ready to support a person with disability, may feel discomfort around the topic of IPV or on holding the perpetrator accountable [13].

We conclude that researchers engaging with vulnerable participants, especially women living with disability may have to reckon with complex ethical dilemmas, often unanticipated, besides the usual ethical considerations followed at present. When confronted with such issues, there is a need for discussing those in real time, if researchers are to respond appropriately to dilemmas that emerge during the conduct of public health research involving human participants. Our account is indicative of the need for a broader discourse on gendering and interconnectedness of violence and discrimination experienced by women with disabilities.

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CASE STUDY

Adolescent assent in research: a relational ethics approach

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Abstract

Researchers often neglect adolescents' willingness to participate in research. The granting of permission by parents is sometimes not in accordance with the unwillingness of adolescents. Relational ethics is the right approach to overcome inconsistencies between legal and ethical agreements in granting parental permission and adolescent's assent. This is because relational ethics is based on building relationships among many parties. The focus of this case study is to improve understanding of the assent of adolescents through intensive study of research conflict, reinforced using existing research and to understand how relational ethics can be used as an approach in decision-making, especially in conflicts between parental permission and assent from adolescents.

Keywords: consent, assent, adolescents, parents, research, relational ethics

Case scenario

Daniel, aged 14, had a medical diagnosis of osteosarcoma. He underwent hospitalisation to undergo the induction phase of chemotherapy treatment. Daniel experienced some side effects of chemotherapy, including nausea, vomiting, fatigue, and mucositis. He said that due to this mucositis, he had difficulty chewing and swallowing food. Daniel's mother expressed concern about the condition experienced by her child. The mother always tried to provide him with suitable food, even in small portions, so that his nutritional needs were fulfilled.

Due to the side effects he experienced, Daniel was selected as one of the prospective participants in a study aiming to determine the effectiveness of gargling with honey to overcome mucositis. The incidence of mucositis is a symptom that is often experienced by patients undergoing chemotherapy. Researchers explained the study's objectives, procedures to be carried out, and side effects that might occur because of this intervention to Daniel's mother. She was very enthusiastic about this research, and gave her permission for Daniel to participate in the study. However, when asked, Daniel refused to participate, saying he could not withstand the pain of gargling according to the research procedure described. He worried that this research would increase his fear of the pain he was experiencing. Daniel's objection frustrated his mother. She then discussed this with Daniel's father, who insisted that Daniel participate in the research. This raises the ethical challenge for the researcher: "Do I have to follow the parents' decision, or do I have to grant Daniel's request not to participate in the research?"

Introduction

Consent of parents for adolescents to participate in treatment or research sometimes does not reflect the

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