

Researching sensitive topics in healthcare.

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This document is the Accepted Version [AM]

Citation:

PINTO, Alexandra, RODRIGUEZ, Alison and SMITH, Joanna (2022). Researching sensitive topics in healthcare. Evidence-based nursing, 25 (2), 41-43. [Article]

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Title: Researching sensitive topics in healthcare

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Introduction

Research about sensitive topics in healthcare is crucial because it is essential to give voice to the underrepresented in research..¹ If research is not undertaken on sensitive topics or with marginalised populations our evidence base will be limited, lack significant knowledge or understanding of the individuals and community groups we support, with the potential for some areas and systems of care/interventions to lack an evidence based, ineffective, or not inclusive. In this article we will consider examples of research that could be deemed as sensitive before outlining key considerations when undertaking research within sensitive topic areas.

Sensitive topics in healthcare

The healthcare literature identifies a negative discourse when describing sensitive research topics or the participants of such studies, including words such as 'difficult', 'emotive' and 'vulnerable'. The vulnerability narrative further involves the adjectives 'fragile', 'emotional', 'controversial', 'delicate', 'weak' 'defenceless' and 'helpless'. Consequently, researchers exploring topics deemed as sensitive appear to be faced with a range of barriers and challenges when embarking on these types of studies. Researchers may encounter comments from peers such as: should we really be doing these types of studies; it is inappropriate to contact specific participant groups or you will not be able to recruit participants; the benefit of involvement does not outweigh the risk of involvement; and we need to protect these people from harm because the research is too sensitive. The assumption that we need to protect these people from harm reflects a paternalistic approach to healthcare and by association healthcare research, positioning the participants as requiring protection at the expense of inclusivity: this is particularly contentious for the researcher who is passionate about pursuing certain topics or for the participant who wants

to share their experiences and perceive others may benefit from their experiences, and may not consider themselves as vulnerable.

Sensitive topics often intersect with cultural taboos for example:

- Exploring experiences of receiving bad news, death and dying in a contemporary but death denying culture;²
- Involving children and young people in research where society deems by proxy consent and opinion for most areas of their lives, especially where the child is sick or disabled;³
- Involving people with mental decline – stigma of mental illness and compromised capacity;⁴
- Involving hard to reach populations – unveiling the political, illuminating issues of poverty and societal decline over advancement;⁵
- Offenders;⁶
- Sexuality or sex.⁷

The research process

Research into sensitive topics has implications for individuals and the wider society, and can be controversial or distressing for not only the participants but also the researcher. Therefore, as with all studies, there must be an explicitly outlined research protocol and robust processes when considering researching sensitive topics. Consideration needs to be given to the design, sampling and participant recruitment, data collection and storage, data analysis and finally dissemination of the results.⁸ Researchers need to be transparent not only when obtaining ethical approval but also with participants from the inception of the research. Participants need to feel comfortable to share their perspectives, therefore it is essential to understand the nuances of the topic and where possible engage with service providers and users to ensure the proposed research has meaning and value. It is important to understand the implications that talking openly about experiences may have for participants.

Patient and Public Involvement

It is good practice when researching sensitive topics to involve members of the public in order to understand any challenges or the issue that may arise from the group being researched and the use of their unique expertise when creating protocols and processes. The benefits of including PPI are:

- Creating participant materials such as information sheets and consent forms that are clear and are written in appropriate language;
- Ensuring research questions are developed in a way that is sensitive and relevant not only to meet the study aims but to the participants;
- The research will have been developed with people that have experience of the topic under investigation;
- Ensuring the research is developed and undertaken in a way that is sensitive and in a way that is sensitive and acceptable to the needs of participants;^{9,10}
- Ensuring involvement is not being seen as tokenistic and including users and ambassadors as co-researchers.^{9,10}

Ethical considerations

In addition to outlining the expectations of both researcher and participant, along with ensuring anonymity and confidentiality of participants and the data, consideration needs to be given to:

- The risk to the researcher such as lone working and emotional toll;
- The risk to the participant such as the emotional/psychological impact of discussing a sensitive topic e.g., reliving a traumatic event;
- Developing a rapport with participants to enable them to share their stories in a safe and sensitive environment.

Support for the researcher is essential, for example by implementing in advance of the study research supervision with an independent councillor. Similarly, the researcher should be prepared to offer support to participants if they become emotional or upset during data collection, and referring to professional support / support services if appropriate. The researcher must develop a rapport with participants that is culturally and developmentally appropriate taking into account gender, socioeconomic, culture and religious contexts. Rapport and trust can be developed by moving from descriptive to more emotive topics as the data collection progresses.¹¹ Engaging with participants when discussing sensitive topics will require flexibility, offering breaks and giving opportunity for participants to take the required time to sharing their experiences, and being prepared to stop data collection if participants become distressed. Consider training courses, or drawing on experiences from being in other roles to improve interview techniques.

Location of study

Research must be conducted in a safe environment, with sensitivity and in an ethical manner; the researcher should have the relevant training and experience to undertake the research and ensure no harm comes to the participants involved. Minimising any detrimental impact to individuals or groups involves:

- Identifying potential risks that may arise from the research;
- Identifying how the risks can be either be best managed, removed or reduced;
- Recognising ethical obligation to uphold respect for all individuals who participate in sensitive research;
- Understanding if the research requires any special procedures to ensure that all the participants are protected against exploitation, discrimination or any undue harm.

Locations for the data collection can have an impact on the participant;

- Asking participants to attend research labs may make them feel uncomfortable and are unlikely to provide a setting that is conducive to developing a therapeutic conversation. Consider alternatives, but ensure the participant is in a safe and secure environment, free from interruptions and not overheard by any third party at all times. Participants are more likely share their experiences if they have been made to feel comfortable and welcomed.
- If possible, give participants the choice of venue - hard to reach populations may want to meet the researcher in a café and just be asked a few conversational questions.
- Consider that if a child might want to draw and play as you sit alongside them and talk, or they might want you to join in play.

Participants' wellbeing

Building a rapport with your participants is crucial when researching sensitive topics as they may well be divulging very sensitive and personal issues with you. Building a good rapport with your participants will allow them to feel comfortable and facilitate them to be an active participant. Before you start the session clarify the consent form to them, make sure they are fully aware that you are there to hear about their experiences and they do not need to answer any questions they do not wish to. For some participants they may find talking about their experiences can be cathartic, but for others the discussion could be difficult and you may have to end the session. If you do need to end the session, make sure you have

planned how to do this without causing further distress. If you end the session too quickly, it could upset the participant further and may perceive their contribution is not valued.

Be prepared to be flexible particularly when following a topic guide and allow the conversation to flow, gently moving back to the focus of the study, if need be, as this will allow the participants time to process what they are telling you. Facilitate the participant to direct the conversation as this is their story to tell. Being comfortable with silence is a skill that requires developing.

A distress protocol should be created prior to the start of research as this will help guide you through the session. A distress protocol should outline the steps and measures to be taken if you perceive the participant is becoming distressed during the session. It should include forms of support, detail the participant cues that might indicate they need to stop, regroup or terminate the session¹². If a participant becomes distressed it is tempting to give them advice or try to help them in some way. As a researcher you should not give them advice, your role is to understand their experience. Consideration must also be given to participants who are incapacitated or young as their distress might mean that you need to bring in family support. You can guide the participants / family members to places where they could go to for help and information for support following the session. However, this is not possible for quantitative research so consideration must be given to the readability of the tools, appropriateness, description and the time expectations to complete a survey.

Researcher wellbeing

Consideration needs to be given to you as the researcher of sensitive topics. Listening to participant's traumatic experiences could be distressful, especially if you are listening to a number of participants on the same topic. In addition to listening to traumatic experiences, the topic may resonate with you for example if you are researching death and dying and have recently had a death in your family. This could cause emotional upset that you may need to come to terms with.

It may be tempting to gather all your data in a very short period of time, but it would be beneficial to unwind and take time between each session. This will give you time to process your own emotions and responses to the topic. Peer support sessions, and/or keep a journal reflecting on your own feelings and reactions are essential to maintain emotional well-being. You need to acknowledge that some sessions are likely to be particularly difficult therefore taking breaks from data collection will enable you to process the information and enables you time to reflect on what you have heard and make sure that you are ready for the next session.¹³

Conclusion

Researching sensitive topics is important as it gives a voice to many unheard groups and individuals. However there needs to be detailed and robust protocols and processes in place to allow the participants to feel they can discuss openly their lived experience with you, in a safe and comfortable environment and with sensitivity and care from you, the researcher. Involvement in sensitive topic studies can engage the researcher in a learning process, can induce emotional responses not fully appreciated from the outset and can open new avenues of thinking to develop the evidence base.

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