

Should We Interview Bereaved Parents?

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Category: Participant Recruitment

Case:

An investigator is working on a proposal to interview parents of children who had died within one month of a cancer diagnosis. At six-month post-mortem, the investigator hopes to speak with parents to determine the causes and events leading up to the precipitous death. A substantial number of children die within one month of the cancer diagnosis, but it remains unclear why this happens. One hypothesis is that the premature death is due to delayed start of treatment because the disease initially presents with no symptoms or because there is limited patient healthcare access resulting in late contact with a care team. Before the investigator continued with the protocol development, he was told by his institution to obtain a research ethics consult to ensure the recruitment methods and interview protocol were ethically sound. While the researcher's plan to interview parents to get more information on how to prevent these deaths in the future is commendable, the major concern is how to access and interview bereaved parents without causing undue harm.

Expert Opinion:

Background:

This case raises the question of how to appropriately recruit participants for and conduct interviews about sensitive topics with participants who are in vulnerable states. Topics considered sensitive include bereavement, especially of parents of young children, criminal activity, or serious illness¹. Conducting research interviews about sensitive topics has the potential to cause participant harm, which may compromise the ethical imperative of nonmaleficence². To ensure these research topics receive adequate attention without inciting participant discomfort or harm, it is essential the proposed interview protocol is thoroughly examined for ethical integrity.

As conducting research on sensitive topics can be uncomfortable for participants, experts have also explored different channels through which sensitive topics can be discussed, such as phone interviews³. Phone calls can help reduce participant discomfort, which may allow them to feel more open to discussing potentially upsetting topics. In a study exploring parent preferences about interview formats to discuss their experiences following a child's burn injury, most people preferred phone interviews, followed by email, skype, and then face-to-face interviews⁴. The authors also noted that several factors contributed to the parents' willingness to participate in the various formats, which the investigator should consider in the development of their recruitment strategy. These factors include the personal convenience of the interview, participant belief in their ability to be open with the researcher despite the potential to be upset about the topic, ability to connect with the researcher, and whether or not they felt as though they could give adequate answers to the researchers.

Further, there may even be some benefits to interviews on sensitive topics. Even if temporarily distressed by some of the interview questions about a sensitive topic, participants are grateful for the chance to participate in such research and would do so again in the future^{1,5}. The interviews can even be therapeutic—if conducted appropriately—and offer participants the space to share their feelings¹. There are also guidelines that specifically address post-mortem interviews. In guidelines published by the

Consensus Panel on Research with the Recently Dead, the authors proposed criteria for evaluating research with the recently dead and how to do so in a way that respects both the needs of the family members and newly deceased individual. The latter point is stressed: the interview must be carefully constructed so that it shows respect for the deceased individual. The guidelines also stress the importance of ensuring the benefits of conducting the research outweigh the risks to family members⁶. Additionally, they emphasize the importance of having an interdisciplinary ethics review board examine the research, allowing them to weigh in on the unique ethical concerns that may arise. With the careful oversight of ethics review boards, several studies have been conducted with families of children who recently died from cancer^{2,7,8}. While they require a rigorous review to mitigate risk to participants and the risk benefit ratio should substantially favor the benefit to the participant, they have the potential to provide insight into important research questions.

Recommendations:

We recommend some revisions to the proposed protocol to ensure the well-being of the grieving family is prioritized. First, we recommend designing a comprehensive chart review at several hospitals to see if the investigator can get the necessary information about the events leading up to the child's death without interviewing the family. This would allow the investigator to make headway on their commendable research project without burdening the families unnecessarily. If more information is needed, and the future benefits of the research significantly outweigh any potential harm to the parents, then we recommend the investigator works closely with patient advocates and/or social workers to develop a plan on how best to recruit and interview family members. Several methods can be considered, such as leveraging individuals or organizations trusted by the families to explain the study or utilizing relevant social media platforms to begin building trust early on in the research process^{4,9}.

As the investigators develop their interview protocol, we suggest the investigators consult the following framework for conducting interviews on sensitive subject matter⁹. First, the interviews should be piloted with patient advocates to ensure the questions are well-received. The research team should be flexible about the location and timing of the interviews to allow the parents to choose an environment that is comfortable for them, which can help with establishing rapport during the potentially sensitive discussion. We would also recommend the research team is trained on how best to manage an upset participant to provide the support they need. If the investigator—after conducting the comprehensive chart review—must conduct the parent interviews, and does so in a way that minimizes any risk and maximizes the benefits to the parents, we consider the research proposal to be ethically sound.

Summary:

The interview protocol must withstand a rigorous review to ensure no harm is inflicted on the family who has already endured the tremendous hardship losing a child to cancer. If all other sources of information about the events leading up to the premature death are exhausted, and if recruitment and interview protocols are carefully designed and executed using the steps outlined above to uphold the ethical imperative of non-maleficence, we do not believe this protocol will cause undue harm to participants.

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