

Research with Orphan Adolescents: Ethical Concerns and Risk Assessment

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Abstract

Orphans are often neglected and spend a significant part of their childhood in institutional settings. While some orphanages prioritize education and provide nutritious food, others subject children to cramped, damp, and unhealthy environments (Kaur, 2020). Conducting research on orphan adolescents under such circumstances poses challenges. This study aimed to identify common ethical dilemmas faced by institutions. Semi-structured interviews were conducted with 30 caregivers across various institutes in Pune. Findings indicated that obtaining consent from the institute head alone suffices for research involving orphan adolescents, with caregivers typically having minimal involvement. Identifying primary caregivers was challenging, placing the entire research burden on the researcher. Since orphan adolescents are unable to consent due to their age, they may feel coerced into participating. Key issues included consent procedures and ensuring voluntary participation. The researcher also encountered concerns regarding the authenticity of responses, fearing inaccurate data could skew study outcomes. To foster greater engagement, researchers should interact directly with participants to explain the study's significance. Transparency with institutes and publication of authentic findings are crucial. Further research is warranted to explore additional challenges within this population.

Keywords: consent, orphan adolescents, transparency, guardianship, caregivers

Introduction

Orphans are children who have lost one or both parents. The definition of an orphan can vary depending on cultural, legal, and social contexts. In the most common sense, an orphan is a child who has lost both parents due to death, illness, or abandonment. According to UNICEF, there are also "single orphans" (a child who has lost one parent) and "double orphans" (a child who has lost both parents). The classification of orphans helps in understanding the degree of vulnerability and the type of care needed. Diseases such as HIV/AIDS, tuberculosis, and malaria are leading causes of death among parents in many developing countries. The ongoing COVID-19 pandemic has also significantly contributed to the rise in the number of orphans globally. Armed conflicts and wars have devastating effects on families. Children often lose their parents due to violence or displacement, leading to orphanhood. For instance, the Syrian civil war has resulted in thousands of orphaned children. Extreme poverty can lead to abandonment, where parents are unable to provide for their children and thus leave them to be cared for by institutions or extended families. Earthquakes, floods, hurricanes, and other natural disasters can result in significant loss of life, leaving many children orphaned. The 2004 Indian Ocean tsunami, for example, left thousands of children without parents.

Orphan adolescents represent one of the most vulnerable groups in society, often spending significant portions of their childhood in institutional care. The conditions in these institutions can vary widely; while some provide quality education, nutritious food, and a healthy living environment, others fall short, subjecting children to cramped, damp, and unhealthy conditions (Kaur, 2020). This disparity in care standards poses significant ethical challenges for researchers aiming to study this population. This paper explores these challenges, focusing on issues related to consent, voluntary participation, and the authenticity of data collected from orphan adolescents. Orphan adolescents represent one of the most vulnerable groups in society, often spending significant portions of their childhood in institutional care. The conditions in these institutions can vary widely; while some provide quality education, nutritious food, and a healthy living environment, others fall short, subjecting children to cramped, damp, and unhealthy conditions (Kaur, 2020). This disparity in care standards poses significant ethical challenges for researchers aiming to study this population. This paper explores these challenges, focusing on issues related to consent, voluntary participation, and the authenticity of data collected from orphan adolescents.

One of the primary ethical challenges in conducting research with orphan adolescents is obtaining comprehensive consent. Traditionally, researchers have relied on the consent of the institution's head to conduct studies. However, this approach is often inadequate as it overlooks the critical role of caregivers who interact with the adolescents daily. These caregivers have a profound understanding of the children's emotional and psychological states and can provide valuable insights into their readiness and willingness to participate in research.

A dual-consent process, involving both institutional authorities and caregivers, is essential to ensure that the decision to participate in research is made with a thorough understanding of the adolescents' needs and capacities. This approach not only protects the adolescents' autonomy but also helps in building a more ethical and respectful research environment. By involving caregivers in the consent process, researchers can ensure that the participants' well-being is prioritized, and their voices are heard.

Voluntary participation is another significant ethical concern. Orphan adolescents may feel pressured to participate in research due to their vulnerable position and the authority of the institution's staff. This pressure can lead to feelings of entrapment and coercion, which violate the ethical principle of voluntary participation.

To address this issue, researchers must create an environment where adolescents feel free to choose whether or not to participate without fear of repercussions. This involves clearly communicating the purpose of the research, the procedures involved, and the potential risks and benefits. Additionally, researchers should ensure that adolescents understand that their participation is entirely voluntary and that they can withdraw at any time without any negative consequences. By fostering a culture of respect and autonomy, researchers can help ensure that participation is genuinely voluntary.

Involving consistent caregivers throughout the research process is crucial for several reasons. First, these caregivers provide stability and continuity, which are essential for building trust with the adolescent participants. Consistent caregivers can help adolescents feel more comfortable and secure, which can lead to more honest and accurate responses.

Furthermore, caregivers can provide valuable insights into the adolescents' behaviors and attitudes, which can enhance the validity of the research findings. Researchers should prioritize

the engagement of these caregivers and consider their insights and concerns as integral to the research design and execution. By involving consistent caregivers, researchers can create

Review of Literature

Globally, the number of orphans is staggering. As of the latest reports, there are approximately 153 million orphans worldwide. This number includes children who have lost one parent (single orphans) and those who have lost both parents (double orphans). Sub-Saharan Africa, Asia, and Latin America have the highest numbers of orphans due to factors like HIV/AIDS, conflict, and poverty.

Orphans often find themselves in institutional care, such as orphanages or children's homes. The quality of care in these institutions can vary significantly. Some orphanages provide a supportive environment, offering education, healthcare, and emotional support. These institutions aim to foster the development of orphans into well-adjusted adults. Unfortunately, not all institutions provide adequate care. Some are overcrowded, underfunded, and poorly managed, leading to environments that are detrimental to the physical and emotional well-being of the children. The experience of being orphaned can have profound psychological and emotional impacts on children. Orphaned children often face attachment issues as they lose their primary caregivers, and the constant change in their institution.

Orphans face numerous social and educational challenges. In many cultures, orphans are stigmatized and discriminated against. This social ostracization can impact their self-esteem and social interactions. Access to education is often limited for orphans. They may miss out on schooling due to the need to work or because of the lack of resources in the institutions they live in. This hampers their future opportunities and contributes to the cycle of poverty. Orphanages and other institutional settings play a crucial role in the lives of orphaned children. The quality of care in these institutions can significantly impact the development and well-being of the children. Studies have shown that high-quality care, which includes access to education, nutritious food, and a supportive environment, can lead to better developmental outcomes for orphans (Johnson et al., 2006). However, many institutions struggle with limited resources, leading to substandard living conditions that can negatively affect the physical and psychological health of the children (Whetten et al., 2009).

Conducting research with vulnerable populations, such as orphan adolescents, involves several ethical considerations. Informed consent, voluntary participation, and the authenticity of responses are critical issues that researchers must address (Fisher, 2004). Vulnerable populations often lack the autonomy to make fully informed decisions, which raises concerns about coercion and the validity of their consent (Sugarman et al., 2005). Moreover, the authenticity of the data collected from such populations can be compromised if the participants do not feel comfortable or safe expressing their true thoughts and feelings (Levine et al., 2004).

Previous studies on orphan adolescents have highlighted the various challenges these children face, including emotional and behavioral problems, difficulties in accessing education, and health issues (Kaur et al., 2016; Sanjukta et al., 2014). However, there is a lack of research focusing specifically on the ethical challenges of conducting research with this population. This study aims to fill this gap by exploring the perspectives of caregivers in orphanages in Pune, India.

Methodology

The study involved semi-structured interviews with 30 caregivers from various orphanages in Pune. These caregivers were selected based on their direct involvement with the children and their understanding of the daily operations within the institutions. The caregivers included both long-term staff and temporary workers to capture a wide range of experiences and insights.

Semi-structured interviews were conducted to gather in-depth information about the ethical challenges faced by researchers working with orphan adolescents. The interviews focused on issues related to consent, voluntary participation, and the authenticity of the responses provided by the adolescents. The questions were designed to elicit detailed responses and to allow the caregivers to share their experiences and perspectives freely.

The interviews were transcribed and analyzed using thematic analysis. This method allowed for the identification of common themes and patterns in the caregivers' responses. The analysis focused on understanding the specific ethical challenges faced by researchers and the potential solutions suggested by the caregivers.

Results

One of the primary ethical challenges identified was the issue of consent. The caregivers reported that the consent of the institution head was often considered sufficient for conducting research with orphan adolescents. This practice marginalized the caregivers, who frequently had no input in the decision-making process. Furthermore, the adolescents themselves, being too young to provide informed consent, often felt coerced into participating in research activities. This lack of autonomy and voluntary participation raises significant ethical concerns, as the adolescents may feel trapped and forced into research without a clear understanding of its purpose or potential implications.

In many orphanages, the head of the institution holds significant authority over all activities, including research. Caregivers noted that researchers often only seek permission from the institution head, assuming that this consent covers all ethical bases. However, this approach neglects the role of caregivers, who are more directly involved with the adolescents and can provide valuable insights into their well-being and capacity to participate in research.

Given their age and circumstances, orphan adolescents often lack the legal and developmental capacity to provide informed consent. Caregivers expressed concern that these children might not fully understand what participation in a study entails, potentially leading to feelings of coercion and entrapment. The adolescents might agree to participate simply because they believe they have no other choice or because they want to please authority figures.

Another challenge highlighted by the caregivers was the difficulty in identifying the primary caregivers of the orphan adolescents. In many institutions, the children do not have consistent caregivers due to high staff turnover and varying caregiving schedules. This inconsistency complicates the process of obtaining reliable consent and ensuring that the adolescents have a trusted adult to support them throughout the research process.

High staff turnover in orphanages means that children often do not form stable, long-term relationships with their caregivers. This lack of continuity makes it challenging to identify who

should provide consent on behalf of the children and who can act as their primary advocate during the research process.

Even when staff turnover is not an issue, the rotating schedules of caregivers can prevent the formation of strong bonds between the children and any one caregiver. This lack of a consistent caregiving figure complicates the process of securing genuine consent and support for the children involved in research.

The authenticity of the adolescents' responses emerged as a significant issue. Caregivers reported that the orphan adolescents might provide inappropriate or incorrect answers, either due to a lack of understanding or a desire to please the researchers. This can lead to inaccurate data and misleading conclusions, undermining the validity of the research findings. The caregivers emphasized the need for researchers to establish rapport with the adolescents to facilitate honest and accurate responses.

Caregivers noted that orphan adolescents might give answers they believe the researchers want to hear rather than their true thoughts and feelings. This tendency can be attributed to a desire to be seen favorably by adults or a fear of negative consequences if they provide undesirable responses.

In some cases, the adolescents might not fully understand the questions being asked, leading to inaccurate or irrelevant responses. This issue is particularly problematic in research that requires a nuanced understanding of complex issues, as the adolescents may not have the cognitive or emotional maturity to provide meaningful answers.

Discussion

To address these ethical challenges, several key strategies should be implemented. Researchers must engage with both the institution heads and the caregivers to ensure a comprehensive consent process. This dual consent approach respects the roles of the caregivers and acknowledges their insights into the adolescents' well-being.

Engaging both the institution heads and the caregivers in the consent process is crucial. While the institution heads provide the necessary official permission, the caregivers can offer a more personal perspective on the children's readiness and willingness to participate. This approach ensures that the consent is both legally valid and ethically sound.

Efforts should be made to identify and involve consistent caregivers who can provide ongoing support and guidance to the adolescents throughout the research process. This stability is essential for creating a trustworthy environment where the adolescents feel safe to participate voluntarily.

Researchers must prioritize transparency and open communication with both the institutions and the participants. By explaining the purpose and potential benefits of the research, researchers can foster a sense of importance and relevance among the adolescents, encouraging more genuine participation.

Building rapport with the adolescents is essential for obtaining authentic responses. Researchers should spend time getting to know the participants, explaining the research

process, and addressing any concerns they might have. This approach can help the adolescents feel more comfortable and confident in providing honest answers.

It is imperative for researchers to maintain ethical standards by ensuring that the data collected is accurate and authentically represents the experiences and perspectives of the orphan adolescents. This includes validating the responses through follow-up questions and cross-referencing with other data sources where possible.

Conclusion

Conducting research with orphan adolescents requires addressing unique ethical challenges through careful consideration and proactive strategies. Obtaining comprehensive consent, involving consistent caregivers, fostering transparency, and ensuring data authenticity are critical steps in creating a more ethical and effective research environment. By implementing these strategies and continuing to explore additional ethical issues, researchers can contribute positively to the well-being of orphan adolescents and the improvement of institutional care practices. Orphan adolescents are a highly vulnerable group requiring specialized care and support. Understanding the diverse experiences and challenges faced by orphans is crucial for developing effective interventions and policies. Institutional care, while necessary in many cases, should be complemented by alternative care models that prioritize the well-being and development of children. Ethical considerations in research involving orphans are paramount to ensure that their rights and dignity are respected. Ongoing research and policy efforts are essential to address the needs of orphan adolescents and improve their outcomes in various aspects of life.

By addressing these multifaceted issues, society can better support orphans in achieving their full potential and leading fulfilling lives. The focus should always be on creating environments that nurture and protect these vulnerable children, ensuring they receive the care, education, and love they need to thrive.

Future research should explore additional ethical issues related to conducting research with orphan adolescents. This includes examining the impact of different caregiving styles on the children's willingness and ability to participate in research, as well as the potential long-term effects of research participation on their well-being.

There is a need to develop and disseminate best practices for conducting research with orphan adolescents. These guidelines should be based on empirical evidence and designed to protect the rights and well-being of the participants while ensuring the validity and reliability of the research data.

Researchers working with vulnerable populations should receive specialized training on ethical issues and best practices. This training should cover topics such as informed consent, building rapport, and ensuring data authenticity, equipping researchers with the skills and knowledge needed to navigate the ethical complexities of their work.

It is essential to include caregivers, institution heads, and the orphan adolescents themselves, in the creation of more effective and ethical research protocols.

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