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Ethical considerations in conducting research with students on HIV/AIDS: Implications for academics

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Presentation by Professor Jace Pillay
University of Johannesburg
South Africa



Introduction



- Educational psychologists/academics by virtue of being child support personnel need to be mindful of the impact research could have on the lives of children/students, especially those infected/affected by HIV/AIDS
- This entails being active agents in protecting the rights of children/students who participate in research.
- They have a role of being custodians of children's rights which have been enshrined in the United Nations Convention on the Rights of the Child (UNCRC) and also the African Charter on the Welfare and Rights of Children (ACWRC).
- However, violation of children's rights still remains a contentious issue in most parts of Africa, even though the UNCRC and ACWRC are legally binding.
- The emphasis placed on children's rights through the UNCRC and ACWRC necessitates the strict adherence to ethical measures that should be taken into consideration when research involves children irrespective if it is direct or indirect.
- According to Graham, Powell, Taylor, Anderson, and Fitzgerald, "ethics is not just about procedural compliance, but more about the application of rules and conduct" especially in the research context.



- This is evident in the Code of Ethics and Conduct (British Psychological Society, 2009), Ethical Principles of Psychologists and Code of Conduct (American Psychological Association, 2002) and the South African Code of Ethics for Psychologists (Department of Health, 2006) as well as the documents produced by Schenk and Williamson and Graham et al (2005).
- Educational psychologists/academics might assist children and families identify the contradictions between valuing the contributions made by children in research about their own lives, and the ethical frameworks used that actually limit their chances to participate.
- They also can act to create a safe and inclusive research context for children/students, and especially those with vulnerability such as HIV/AIDS.
- There is need from a social justice theoretical framework to promote the human rights and dignity of all children/students, treat them with respect, and provide them with fair and equal opportunities to develop and function optimally in society.
- Educational psychologists/academics should be instrumental in promoting social justice in their line of work and in their respective communities. The social justice theoretical framework compels researchers to view children from a rights-based paradigm rather than a needs-based one.
- A social justice approach is for children/students to participate in research activities geared to enhance the quality of their lives.



Goal of the study



This study aimed to explore ethical considerations in conducting research with children/students infected and/or affected by HIV/AIDS and the implications for academics

The main research question was:

What ethical issues should educational psychologists/academics consider when conducting research with children/students who are infected/affected by HIV/AIDS?



Method



Setting and participants

- Ten practicing South African educational psychologist/academics were purposively recruited for the study.
- All the participants are active researchers fully familiar with human research ethics protocols.
- Virtually all the participants had exposure to research ethics in various international contexts, including the African Continent.
- Consequently, their participation in this study added both an international and an African dimension.



Data collection

- Data on their perceptions of ethical issues concerning research with children/students infected/affected by HIV/AIDS were collected either through:
 1. *individual interviews (n = 4 participants) or*
 2. *a questionnaire (n = 6 participants).*
- Credibility and dependability of data was achieved by extended contact with the participants of over 6 months and with discussion of the research focus issues.
- Verbatim responses from the participants were used to confirm the authenticity of the data collected.
- In order to promote dependability, an educational psychologist/academic not involved in the study served as an independent external coder.



Ethical procedures

- Ethical clearance was obtained from the Faculty Ethics Committee at the University of Johannesburg
- Participants individually consented, and were still reminded that their involvement was voluntary and that they could withdraw at any point without penalty.
- In order to maintain confidentiality and anonymity no names of participants are mentioned in the study, even though some of them voluntarily indicated that they had no problem with their identities being revealed.

Data analysis

- Data were thematically analysed using the approach proposed by Merriam.
- The analysis approach sought to identify the main themes and patterns that emerged from the data.
- Repetitive words and thoughts of participants were coded and identified as the main themes reflecting the four major research ethical principles that emerged during the literature review process.



Results



The *findings* are presented in the actual words of participants according to the four major research ethical principles identified through the document analysis process, namely;

1. *harms and benefits,*
2. *informed consent,*
3. *privacy and confidentiality, and*
4. *payment and compensation.*



Harms and Benefits



HARMS

- The first concern risk for harm identified by the participants was related to the researcher himself/herself imposing own values on the children about HIV/AIDS.
- Researchers might “believe that their perspective of being prudent or helpful or uplifting is shared by the sample/community”
- The objectivity of psychologists/academics who conduct research was also questioned in relation to their dual roles: “there can be a lack of objectivity as a result of being both a therapist and a researcher”
- More importantly, it was noted that in an African context role confusion might arise from “a researcher may be viewed as a healer according to the participants or community’s understanding and expectations”.



- All participants perceived harm resulting from the lack of cultural sensitivity or imposition of Western cultural values on children/students. In the words of one participant: “some research, especially, dealing with culturally sensitive matters (such as mourning; rituals, abuse, etc.), take on Western practices, which fails to resonate with the beliefs and practices of different cultures within South Africa”
- “psychologists/academics should be sensitive to different traditions. They should note that there are many cultures and traditions in Africa”. So, as researchers they should learn more about the specific community before they do the study”
- Another participant wanted researchers: “to be very aware of the potential harm that can result from children talking about matters that should have remained hidden due to cultural norms”
- In order to safeguard children/students the participant suggested that community members should be included in research: “as ethics advisors to a project or even to be present in certain parts of the data-offering exercise”



- Most of the participants (80%) were critical of ineffective sustainability of interventions, care and support programs that are implemented once research is completed.
- This concern was clearly evident in the following statement: “post the research/intervention, the sustainability of support cannot be guaranteed leaving participants on their own, without the support provided during the research”
- Linked to this issue is: “the lack of access to counselling and psychosocial support to participants”
- Virtually all the participants emphasised that researchers have to be more vigilant to harm when working with children/students infected/affected by HIV/AIDS
- Children/students infected/affected by HIV/AIDS demand a different take on ethics.
- The no-harm principle should be extra carefully applied because of the intersectional levels of vulnerability and agency such as gender, age, trauma, grief, poverty, means-making, lawfulness of economic activities, unlawfulness of economic activities, discipline styles, independence, dependence and race”.



Benefits

- Participants noted likely benefits for the children/students and the researchers
- Some of the benefits for children/students infected/affected by HIV/AIDS identified by the educational psychologists/academics were:
 1. *knowledge management and acquisition of relevant data that can improve lives and increase care and support in communities;*
 2. *empowerment and capacity building with regard to skills, knowledge, resource linkages; and*
 3. *service networks in the sample/community; and access to services/support/resources which were otherwise inaccessible to children/students particularly those in rural and previously disadvantaged communities*



4. “information and program interventions assist in harm reduction and enables systems of care and support to be established in the local settings. It creates access to health, social welfare and livelihood networking of assets in the community of the research sample”.
5. “research creates awareness and ‘buy in’ of key stakeholders to shift attitudes and enable community dialogues to commence”. Also it was pointed out that research, “allows for the mobilisation of the sample and communities to lobby for care and support programs to effect policy changes”
6. Lastly, but probably one of the most significant benefits to participants in an African context was the possibility that research could be a good way of “debunking myths and folklore paving the way for therapy and healing.
 - For example, HIV can be cured by having sex with a virgin



- “Through interaction with researchers students can become aware of ways to alleviate their situation through, e.g. network-building; joining communities-of-practice; becoming aware of economic participation opportunities; claiming statutory rights like grants and other state assistance; decreasing, eliminating or avoiding exploitation where it occurs or can occur”
- The benefits of research to participants were summed up in the words of participant 2: “good research can be a catalyst to positively change the lives of affected communities”.

Benefits to educational psychologists/academics engaged in research.

- They have the opportunity to gain, “first-hand experience of delving into personal spaces, that is, individual’s thoughts, feelings and experiences; homes; families; and communities, which provide a contextually and culturally relevant research experience”
- As a result of research: “they are able to add to the current body of knowledge thereby providing greater insight into lived experiences with due consideration to the diverse cultural and social practice”
- “have the potential to provide accessible, non-stigmatising, culturally appropriate psychological support”



Informed consent

- “It’s critically important that participants and key stakeholders are given full disclosure of the process, benefits and risks as well as briefed on voluntary participation and withdrawal”.
- Most participants (90%) considered it mandatory that permission to conduct research is obtained from the relevant education/university department, if the sample is recruited from schools/universities.
- It was also pointed out that this process does not always occur: “school support services are only contacted when a crisis occurs”
- Participants noted a need for all documents safeguarding children involved in research to be completed by educational psychologists/academics so that “all [child] participants fully understand the requirements of the research project”, including audio and visual recordings, and for cultural-language translators to avoid harm from poorly implemented consent procedures due to language barriers.



- The participants reported that it is critical in an African context for: “customs, protocols and language issues to be accommodated, that is, meeting with the chief of the community and the use of translators”
- It was also suggested that if parents were not available “extended family/grandparents act in loco parentis”
- Complexities with meeting cultural consent were noted “when working with/conducting research with marginalised or vulnerable children or groups” who might not understand their rights to consent.
- Participant 8 provided a possible solution to the power dynamics by stating: “that, a statutory guardian or state-mandated official, the child/student in charge of OVC should co-sign informed consent agreements as recognition of the shared adult responsibilities”.
- However, he was well aware that his suggestion is not acceptable in terms of the current legislations.



Privacy and confidentiality

- All the participants in this study emphasised the point that educational psychologists/academics should assist in monitoring the privacy and confidentiality ethical requirements. For instance, Participant 6 observed: “child participants have a right to know that their information is safe and secure and that they will not be identified or exposed in any way”.
- Participant 2 noted that: “all raw data should be destroyed after two years of publication and five years if no publications emanate from the study”.
- Furthermore, it was noted that “participants have a right to see the final research document before it is published” as one way of ensuring privacy and confidentiality.
- Serious concern was raised about privacy and confidentiality issues with regard to HIV/AIDS cases amongst OVC “because OVC may not have any adult supervision there is a tendency by researchers to do with them as they please without respecting the children’s right to privacy and confidentiality”



Payment and compensation

- Most participants (80%) were in support of incentivising research participation by children/students as follows: “research studies may pay youth facilitators or mentors a stipend for their basic expenses and to retain their services for program support”
- However, it was pointed out that: “payment must not be seen as a bribe or compensation to affect the research outcomes”, although some kind of payment or compensation is necessary in that: “African culture may require some gifts when meeting the chief or possibly a celebration party at the end of the research for the participants and stakeholders” .
- Appropriate incentives noted by the participants included lunch and a transportation fare. However, participant 5 raised concerns about what happens if support is still needed after the research is completed: “do the psychologists now refer the participant to a ‘free services’ agency for additional support or start requesting payment for future support sessions?”
- Costs for OVC infected/affected by HIV/AIDS from receiving incentives included becoming “targets of not only their fellow classmates but also community members – they are often attacked for their supplies obtained at school.”
- The attention paid to them by external programmes/initiatives often makes them the envy of fellow learners. This negatively impacts on their relationships”



Table 1. Summary of themes and Sub-themes

Themes	Sub Themes
Harms	Imposition of educational psychologists/researchers own values on participants Objectivity of educational psychologist/researcher Educational psychologist/researcher viewed as healer Mismatch between Western and African cultures and traditions Ineffective sustainability of support interventions More harm to especially vulnerable children, such as OVC & HIV/AIDS infected
Benefits	Knowledge management and acquisition of relevant data Improvement of lives of children/students Empowerment and capacity building of children, families and communities Increase students/children's access to community facilities Challenge myths and folklores in African communities
Informed Consent	Participants should get clear and detailed information about the research right from the start Permission should be obtained from relevant stakeholders Completion of documents safeguarding children's rights in research participation Use language of participants Be aware of power dynamics
Privacy and Confidentiality	Information should be kept safe and secure Participants should see the findings Extra care for HIV/AIDS infected/affected students who are open to exploitation
Payment and Compensation	Support for payment and compensation of research participants, especially OVC No bribes In African culture payment and compensation may be seen as an act of goodwill Can be a safety risk for OVC



***Implications for educational
psychologists/academics practising in Africa***



The ethical principle on harms and benefits raises several implications for educational psychologists/academics.

1. Need to be aware of not confusing their roles as researcher and therapist.

One way of doing this would be for them to refrain from playing the therapist role by securing the services of other psychologists to support participants during the research process.

2. *must ensure that power dynamics are not visible in their research.*

3. should be aware of the differences between Western and African cultures, as well as how these differences could impact on the research process and findings.

4. Inevitably, this means that they should be careful of not imposing their own cultural values and beliefs on child/student participants. One way of ensuring this is to include significant community members as ethical and cultural advisers in the research project.

5. Permission from child participants should also be considered based on their age and stage of development.

6. the importance of someone being available to safeguard the rights and interests of participants and if this is not possible then the study should not be conducted.



CONCLUSION

This study explored perceptions of educational psychologists/academics on their role in promoting ethical research involving children/students infected/affected by HIV/AIDS.

- Participants were 10 South African educational psychologists/academics (females = 60%; males = 40%) .
- Data on their perceived roles in research ethics monitoring and implementation were collected through individual interviews and a brief questionnaire.
- The data were thematically analysed.
- Findings suggest that educational psychologists/academics have a role in protecting children/students infected/affected by HIV/AIDS from harm during research participation while also monitoring benefits due to them.
- A social justice perspective appears to explain the role of educational psychologists/academics in protecting children/students.



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Thank You😊
Professor Jace Pillay
jacep@uj.ac.za

