

# Ethics In Innovative Knowledge Dissemination: The Use Of Readers' Theatre On Issues With Vulnerable People **Living With HIV**

## I n t r o d u c t i o n

There is an increased interest in the use of arts-based methodologies for data collection and dissemination strategies in research related to HIV/AIDS. Photovoice, performance ethnography, participatory video-making are some of the newer approaches used in Canada (e.g., the Gendering Adolescent AIDS Prevention project). Still, discussion is needed to come to terms with the ethical issues presented by these innovative approaches.

Our study examined the care experiences of people living with HIV as well as that of their informal caregivers in Winnipeg, Manitoba and Regina, Saskatchewan, Canada. The study used Photovoice to collect data. To disseminate the findings we not only relied on the visual representations of the participants, but also explored the use of readers' theatre. In conjunction with the photographs, a readers' theatre presentation can bring an enhanced experience to participants involved in the play, and bring to life the issues to the wider audience.

## I s s u e s

The development of a readers' theatre piece presented a number of ethical concerns:

- *How do we develop a play based on the transcripts of the interviews while maintaining anonymity, confidentiality and privacy?*
  - **Removing identifying information from quotes**
  - **Combining interview passages with those of many participants to avoid anyone being singled out**
  - **Preventing one character/actor from being connected to a single participant**

Nonetheless, ethics in community-based research (CBR) is a moving target. The Research Ethics Board (REB) of our university believed that because this was a completely different approach to disseminating the information as initially anticipated (e.g., reports, papers, conference presentations) we needed additional full written consent from the study participants to write and disseminate the play. In addition, the REB believed that because there would be a possibility for participants to attend the play, further protections were needed.

Predicting the specific knowledge exchange products of a research project may not be possible at the onset of the study. This is particularly true when a project is conducted in partnership with community stakeholders.

Obtaining further written consent presented additional challenges:

- **Regaining access to participants when those involved are highly transient, with some inconsistently connected to care.**
- **Predicting all possible ways a readers' theatre could be used or performed. Actual audiences may be difficult to anticipate. Currently, we are dealing with another layer of consent regarding the audio-recording of the play to increase accessibility and availability (e.g., online) to larger audiences.**
- **Research participants and readers (i.e., community volunteers) believed that this was unnecessary. In fact, when we had the opportunity to consult with them, they clearly articulated that this approach of dissemination was more meaningful to them, and that they believed that others would be mobilized by the stories told in this format.**

## C o n c l u s i o n

Arguably, readers' theatre is a very different form of dealing with the dissemination of qualitative data (Donmoyer & Donmoyer 2008). Furthermore, it is an approach that was very appealing to research participants, in our case people living with HIV/AIDS. Nonetheless, it raised a number of ethical concerns that our study sought to address with the university's Ethics Board. The experience suggested that innovative dissemination strategies encounter difficulties in being understood by Ethics Boards versed in more traditional approaches. The increased interest in the use of arts across scientific disciplines requires that the ethics field study more carefully the implications for researchers and ethics boards. One recommendation is that REBs include some expertise in creative practices in research (Interagency Advisory Panel on Research Ethics 2008).

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