VIHSIBILITÉ

SUPPORTING THE VOICE AND PUBLIC VIHSIBILITÉ OF PEOPLE LIVING WITH HIV/AIDS

RESULTS FROM AN ACTION-RESEARCH PROJECT ON ETHICAL APPROACHES TO CO-PRODUCING TESTIMONIALS IN QUEBEC.

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Information kit launch event, René Légaré, co-researcher.

Cultures du témoignage | Testimonial Cultures

COCQ-SIDA
COALITION DES ORGANISMES COMMUNAUTAIRES QUÉBÉCOIS DE LUTTE CONTRE LE SIDA
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BACKGROUND

People living with HIV/AIDS sometimes decide to share their personal experiences in contexts such as a media interview, research project, or community-based initiative. The ethical issues raised by such public testimonials, however, are rarely discussed. The few resources that deal with these issues are generally unknown to the organizations and individuals who help to co-produce testimonials in various contexts. To address this gap, the VIHSIBILITÉ research group implemented a knowledge transfer and exchange process focused on the social support required by HIV-positive people who give public testimonials.

METHODS

Bringing together university (UQAM) and community (COCQ-SIDA) partners, our research group used a number of collaborative methods:

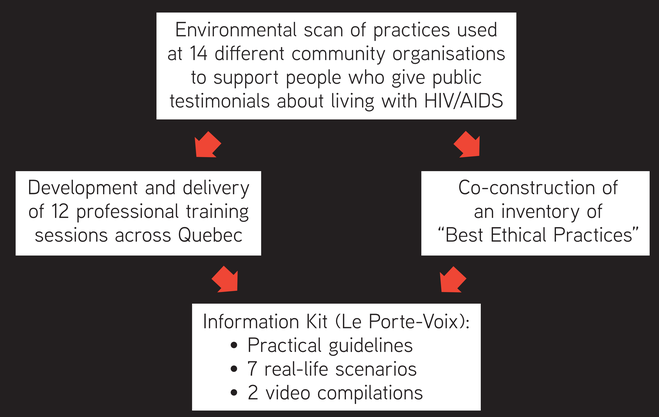

Figure 1: Collaborative Methods Used in the Context of a University-Community Partnership

Key information on existing social support and co-production practices was archived and collectively interpreted in consultation with community organizations in four regions of Quebec[5]. We also engaged participants in a critical and reflexive discussion of the ways in which first-person accounts are co-produced. The sites of co-production we investigated were primarily public education with social or community workers, participation in research and reports or interviews with media professionals.

"THIS TRAINING SESSION GAVE ME RELEVANT TOOLS FOR REFLECTING UPON MY ROLE. IT MADE ME AWARE OF THE IMPORTANCE OF PROVIDING SUPPORT TO OUR VOLUNTEERS WHEN THEY SPEAK IN PUBLIC, REGARDLESS OF THEIR HIV STATUS. IT ALSO HELPED ME TO THINK CRITICALLY ABOUT THE CULTURE OF TESTIMONIALS, TO ARTICULATE SOME OF OUR DAY-TO-DAY CHALLENGES AS SUPPORT PEOPLE, AND TO START LOOKING FOR SOLUTIONS." — Social worker, Trois-Rivières, Québec.

RESULTS

This action research project led to the publication of an information kit (*Le Porte-voix*) that includes practical guidelines, real-life scenarios, discussion questions, and a DVD compilation containing a range of key examples of video testimonials by HIV-positive people. Oriented by GIPA[6] Principles, the guidelines aim to facilitate the work of co-production before, during, and after a public testimonial is given:

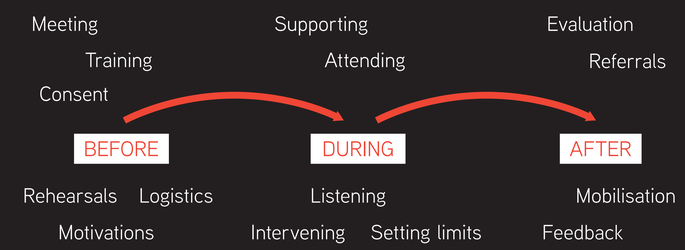

Figure 2: Ethical Co-production Practices: Before, During, and After a Public Testimonial

Organizations and individuals from across the province helped to identify, compile, and edit existing resource materials. The resulting information kit deals with the co-production and use of testimonials in various contexts (prevention, education, research, media, advocacy). The kit also includes written accounts, based on real-life situations, of seven scenarios that illustrate some of the ethical dilemmas social workers, researchers and media professionals can face as co-producers of testimonials by people living with HIV/AIDS.

CONCLUSION

This project has led to a broader understanding of the ethical challenges faced by co-producers when they solicit personal stories from HIV-positive people for public consumption, or when they accompany people through the process of giving a testimonial. We hope that the information kit will not only amplify the voice and visibility of people living with HIV/AIDS but also highlight the value of community input in developing social responses to the epidemic that have a sound ethical basis.

A key next step should be translation of the information kit to English. Adaptation of the approach and the materials developed through this project for use with other marginalized groups should also be considered.

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5 Province of Canada. population: 8.18 million
6 UNAIDS. 1999. From principle to practice: greater involvement of people living with or affected by HIV/AIDS (GIPA), Geneva: UNAIDS Best Practice Collection.