

Abstract

The initial idea to gather together sero-discordant couples (i.e., when one partner is HIV-positive and the other is HIV-negative) to learn about their experience of living with HIV was generated from conversations that I had with couples at the Southern Alberta HIV Clinic. Beyond the world of HIV medical care, many sero-discordant couples are unable to share personal experiences that might range from travelling and taking their medications, separation due to HIV and exposure, welcoming a child with negative HIV status, and the many other aspects of couples' lived experiences. My observation was that many sero-discordant couples felt invisible or silenced due to HIV's social stigma, and perceived that they fell outside of the North American society's dominant, socially-constructed couple narrative.

Multiple services – Alberta Health Services, the Conjoint Ethics Committee, HIV Community Link, the Taos Institute and other community professionals – were engaged to create a community space that would allow sero-discordant couples to come together to share their experience of living with HIV. The aim of this collaborative practice of community engagement was to develop an inclusive, collaborative agenda that would protect and provide a safe space for sero-discordant couples to gather and dialogue.

This study was conducted as a participatory action research process that included an initial process of community gathering for sero-discordant couples. The aim was to foster dialogic processes that could be woven together to empower couples to break through the stigma that has kept them marginalized through and after the AIDS epidemics of the 1970s and 1980s. The gatherings were intended to be a first step towards understanding the experience of these couples, which is often invisible, by lifting the veil of marginalization and isolation that has socially permeated their lives since being diagnosed with HIV.

This study was conducted over six years. The research phases included the initial gatherings and dialogues, the development of an action-oriented agenda by the sero-discordant community, an engagement of the action phase, and finally the creation of a fully funded, peer-support model that provides individual and group support to the sero-discordant community. This peer support model, as initiated by the action-oriented research process, is now provincially, nationally and internationally recognized as a working model for other oppressed groups of people living with chronic disease (Miller, 2017).