Motives for meaningful involvement in rural AIDS service organizations

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The research described herein was a three-year exploratory descriptive study to examine how meaningful involvement (MIPA) is conceptualized and experienced in rural regions of the Maritime provinces of Canada. The focus of this paper is one aspect of the research; i.e., what motivates the clients of AIDS Service Organizations (ASOs) in rural Canada to become meaningfully involved? We interviewed 34 people who were past or current clients of ASOs in Maritime Canada and who self-reported as engaging in at-risk behaviors for HIV or living with HIV. The interviews explored participants' perspectives about their motives for becoming meaningfully involved in an ASO. Three themes regarding motives for MIPA were revealed: (1) meeting personal needs; (2) making a difference to others; and (3) recognizing a fit between their skills, goals, needs and the opportunities and experiences within the ASO and with other ASO clients. Participants generally cited more than one motive. This research study contributed to the field of knowledge about the motives for MIPA in which it reveals (1) that MIPA was conceptualized by the rural ASO clients as whatever participation provided them personal meaning (i.e., by fulfilling a personal need, by making a difference, and by recognizing a fit) and (2) the important role that ASO staff and volunteers have in fostering and sustaining MIPA. The study also highlighted a trajectory of involvements that support the need for ASOs to entertain a wide range of roles that are assumed as MIPA.

Keywords: HIV/AIDS; meaningful involvement; motivations; qualitative research; rural regions

In 1994, the Canadian Government signed the Paris Declaration affirming what is known as the “Greater Involvement of Persons Living with HIV/AIDS” (GIPA) principle (Roy & Cain, 2001). The aim of GIPA is to realize the right of people living with HIV to participate in making decisions that affect their lives. The recognition that such involvement must be meaningful to the individual, not merely tokenism, gave rise to the concept of meaningful involvement (MIPA) (Collins et al., 2007; Fischer, Jenkins, Bloor, Neale, & Berney, 2007; Fischer & Neale, 2008; Young, Kalibala, Neema, Lukwago, & Weiss, 2012).

In the following paper, we will present one component (i.e., motives for MIPA) of a research study funded by the Canadian Institutes of Health Research intended to explore and describe how MIPA is understood and experienced in rural regions within AIDS Service Organizations (ASOs) in rural Maritime Canada. The Maritime provinces are New Brunswick (NB), Prince Edward Island (PEI), and Nova Scotia (NS). The smallest is PEI with a population under 150,000; the largest is NS with a population of less than one million (Statistics Canada, 2006). Approximately 60% of each Maritime province is defined as rural (PHAC, 2006). The incidence of HIV is low in these provinces in comparison to the rest of Canada. One report documented that from 1985 to 2002,

there were less than 1000 confirmed HIV-positive people in the Maritime provinces compared to 51,479 in Canada (PHAC, 2003).

The researchers include six academics with expertise in HIV/AIDS and/or service user involvement. Six community researchers represent the partner organizations (ASOs in Maritime Canada, Canadian Aboriginal AIDS Network, Canadian AIDS Legal Network, and Atlantic Aboriginal AIDS Network). Two of the community researchers (Jürgens and Elliot) are authors of the 2008 seminal report, “Nothing about Us without Us” regarding MIPA for people with HIV/AIDS who use drugs.

The need for this research arose in discussions with staff of several ASOs within Maritime Canada. They reported that they experienced difficulty in enacting MIPA because the strategies used in the cities do not meet the unique needs of the people living in rural regions, nor do they adequately address the experience, context, and capacity of ASOs in rural regions. For example, although urban ASO clients are typically HIV-positive, in rural regions, ASO clients in the Maritime provinces are more often people who are at risk for HIV; this population may never intend to be meaningfully engaged in the organization because they perceive their engagement as limited to the exchange of needles or

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obtaining supplies that are not available in other local community agencies. The staff reported that they find it challenging to structure MIPA to meet the needs of both those at risk for HIV and those with confirmed HIV because of the different needs of both populations. In addition, ASOs in Maritime Canada rarely have the funding or staffing resources to market the opportunities available to promote the benefits of MIPA. Consequently, ASO clients often do not appreciate how their involvement could influence policy, practice, and programming decisions (Mawar, Sahay, Pandit, & Mahajan, 2005).

Review of the literature

Two fields of research inform this paper: (1) volunteerism and (2) user involvement. Research on volunteerism has focused on why people volunteer based on personal motives, perceived benefits or gains, and the fit of volunteering with the person's philosophy, role identity and values (Allison, Okun, & Dutridge, 2002; MacNeela, 2008). Research has demonstrated that the main reasons for choosing to volunteer in nonprofit disease-related organizations are (1) to improve human capital by participating in the activities carried out in the association; (2) for the social recognition associated with being a volunteer; and (3) to increase one's social network (Antoni, 2009; Batson, Ahmad, & Tsang, 2002). The motives for volunteering are similar across studies (Ramirez-Valles, 2002), but differences exist in what researchers report as the most salient motives. For example, Omoto and Snyder (1995) determined that personal needs were stronger motives for volunteering in an ASO than concern for the community.

Most authors present motives for volunteering as a static phenomenon. Luping (2011), however, found that the 27 participants in his study of volunteerism in an ASO identified both initial and sustained participation motives. Initial participation motives were often self-serving (e.g., to receive recognition), but became more altruistic as the person learned the benefits of volunteer activity to others. MacNeela (2008) determined that many individuals chose to become involved with disease-related organizations because they had a preexisting relationship with the organization that fostered positive perceptions of both the organization and the benefits of volunteering.

Another relevant field of research pertains to user involvement in health care. The importance of the users of health-care services being involved in policy and program decisions was advocated by the World Health Organization as early as 1978; this was the beginning of an ever-increasing trend in disease-related nonprofit organizations across all nations. Reviews of user involvement have identified the outcomes of this movement as improved health and well-being, as well as

better quality of life, for those living with disease (Grogan, Coughlan, O' Mahony, & McKee, 2012; The Irish Society for Quality and Safety in Healthcare, 2009).

The movement to encourage those living with HIV/AIDS to become actively involved in policy and program decisions was shaped by a number of forces (Kielmann & Cataldo, 2010). In the 1980s and early 1990s, the focus was on people with HIV to be "good citizens" and thereby to protect themselves and others from the risks of the disease (Parker & Aggleton, 2003). This individualistic focus was followed in the mid-1990s by the emergence of rights-based and community development approaches in population health. This paradigm was the impetus for the development of many ASOs (Roy & Cain, 2001) and is reflected in the GIPA principle.

Research about user involvement in ASOs has been limited to investigations of the benefits of and barriers to MIPA; motives for involvement have been implied but not clearly addressed. Factors and situations that prompt people to become meaningfully involved in ASOs are largely overlooked to date and the little that exists refers to ASOs in large cities.

Research design

The research had an exploratory descriptive qualitative design.

Sample

A purposive sample of 35 participants (26 males and 9 females) was recruited for the study. We selected to recruit people at risk, as well as those who were HIV-positive, because both populations are the clientele of ASOs in the Maritime provinces. Most participants (26/35) identified as HIV-positive and 21 described themselves as "straight." Eleven participants indicated they were "gay" and three as "bisexual." The age of the sample ranged from 22 to 67 years (mean = 41 years). Over three quarters indicated they were educated at a high school or above.

Recruitment of participants occurred in posters and flyers distributed to ASOs and to relevant community organizations. Volunteers for the study were given pocket-sized recruitment cards to provide to those whom they believed met the inclusion criteria. The posters/flyers and recruitment cards briefly described the study and requested that the readers contact the project coordinator (PC) if they were interested in participating. The PC screened all potential participants according to the inclusion criteria (i.e., a person at risk for or living with HIV; is currently or was at some time in the past meaningfully involved with a Maritime ASO; over the age of 18 years; able to speak and write English

and/or French; lives in NB, PEI, or NS; able and willing to participate in interviews).

The research received ethical approval from four universities (Thompson Rivers, New Brunswick, Saint Thomas, and Dalhousie). Participants signed an informed consent before in-person interviews; however, if a participant elected to be interviewed by telephone, the interviewer read the consent at the beginning of the interview and asked if the participant wished to continue in the interview.

Data collection

The data were collected in an individual interview, 90–120 minutes in length. All interviews were tape recorded and transcribed verbatim. The majority of participants (27/35) chose to be interviewed by telephone because of the challenges, such as lack of transportation; the remainder of the participants chose to be interviewed in a location of their choice. Because one of the sub-goals of the research was to explore how MIPA was conceptualized by the participants, we chose not to define it and instead, explored what they thought it meant.

Interviews began by participants discussing their perspectives and experience regarding MIPA (e.g., “How do you understand what it is to be meaningfully involved in an ASO?”) and then to questions specific to the research objectives (e.g., “What motivated you to become meaningfully involved?”). Prompts and probes were used to encourage the participants to extend their responses (e.g., “Can you say some more about that?”).

Data analysis

Data generated in interviews were analyzed by thematic content analysis, entailing identification of core meanings using a coding scheme to index, search, summarize, and analyze the data (Patton, 2002). Coding schemes emerged through both inductive and deductive approaches and are based on a thorough reading of all transcripts and discussion among the research team. Analysis of data included searches of data within and across subgroups (e.g., HIV status, gender, location). Two members of the research team developed an initial coding tree that was expanded and refined in further analysis.

Results

Three themes regarding motives for MIPA were revealed: (1) meeting personal needs; (2) making a difference; and (3) recognizing a fit. Participants generally cited more than one motive. There were no differences between the motives of people living with and those at risk for HIV except that the at-risk population indicated that

becoming meaningfully involved enabled them to avoid risky behaviors.

Meeting personal needs

Several participants indicated that their initial motive for becoming meaningfully involved was to address a personal need. Four of them described becoming involved in the ASO because they were newly diagnosed as HIV-positive and needed information about the disease and/or its treatment. Six others stated that they had initially become involved to obtain resources or services, such as income support. Some began their involvement with ASOs because they wanted to expand their social network, particularly among other people at risk for or living with HIV “and to also see what services we are seeking regarding health and wellness, you know, (such as) the men who have sex with men study.”

Two women and two straight men said they became involved with an ASO because they wanted to alleviate the isolation of being HIV-positive and “being different from the drug users and the gay men.” As well, these participants indicated that MIPA provided an opportunity to inform the ASO staff and clients about their unique needs.

Eight participants, all people who self-identified as at risk for HIV, acknowledged their motive for MIPA as helping them to avoid risk behaviors, particularly illicit drug use. They indicated that MIPA helped to distract them from drug cravings, and strengthened their resolve to avoid risk behaviors. “I volunteer at X (ASO) because it helps me get my life on track and stay away from drugs and crime.”

Participants, who indicated they had initially become involved in the ASO “at a basic level” such as “licking envelopes” to meet a personal need, often decided to become increasingly involved when they developed relationships with ASO staff or volunteers and when they became aware of the benefits of MIPA and the organization’s need for clients to be meaningfully involved. “At first, I was there (the ASO) because I needed the help. But after a while, I started to see that I could make a contribution.”

Making a difference

All but one participant identified a central motive as the need to make a difference to others like themselves. Making a difference entailed advocacy efforts such as lobbying the government for increased funding and bringing clients’ needs to the attention of the ASO board. It also entailed correcting a perceived wrong (e.g., when all ASO board members were gay men, one participant who was a user of drugs decided to become a ASO board member to represent the needs of his

peers), and providing publicity about the work of the ASO and the needs of ASO clients. Six participants believed that only people at risk for or living with HIV could truly advocate for ASO clients; this was their impetus to become ASO board members.

Eight participants emphasized that making a difference did not always entail “important tasks” such as functioning as an ASO board member or being a media spokesperson. They indicated that some activities generally perceived as menial made “huge differences” to how the ASO clients and volunteers experienced the ASO. “You know, shoveling the path when it snows so people can get in there because some people got canes and stuff like that. More or less caring about the place that you’re participating in.”

Making a difference was often linked to participants’ previous positive experiences, or that of a loved one. Most often, this was phrased in terms of “giving back” to the ASO that had provided support and acceptance in previous years. “I’ve been clean for almost six months now and I just want to give back. You know, like so many people helped me along the way. It’s only right that I do the same.”

Recognizing a fit

All participants referred to having to realize “a fit between you and the ASO” that was integral to becoming meaningfully involved. “Fit” referred to whether the person’s skills or ideas were recognized as making a contribution to the ASO; how inclusive the staff, volunteers, and other clients were; and how well the ASO’s programs and services met the participant’s needs. Several participants stressed that in contrast to urban centers, people in rural areas draw on the stories of community members to determine the fit of the ASO. “My girlfriend’s experience as a volunteer made me want to volunteer.” Two participants stated that often people recognize their fit with an ASO when they attend events with ASO staff or volunteers and “get to see firsthand how the ASO is a fit.”

Feeling accepted and being affirmed for making a contribution was identified by the majority of participants as contributing to a perception of “fit” with the ASO. One woman who used the ASO’s needle exchange services indicated that she began to be meaningfully involved when she received positive support from the ASO staff and was made to feel as if she “could make a difference” to others like herself.

Discussion

The conceptualization of MIPA revealed in the research findings resonates with research regarding voluntarism in that what provides meaning in volunteering or MIPA is

personally constructed. Similarly to the research by Akintola (2011), the participants of this study identified a variety of motives ranging from the need to meet personal needs to altruistic desires (making a difference). As well, the research findings support the notion that positive experiences foster one’s willingness to engage more fully in the organization. Factors such as being recognized for one’s contribution, being received well by the staff and other volunteers, and recognizing a fit with the ASO and/or its clients enhanced participants’ motives to be increasingly involved in the organization.

Some research findings were not located in the voluntarism or user involvement literature. For example, motives for MIPA were influenced by a number of factors, including interactions within the organization and the stories told by others. Motives for MIPA were not static and changed over time. It was striking how many people began their involvement in the ASO in what seemed to be minor ways, such as cleaning toilets in the ASO building, but often became increasingly committed to being meaningfully involved in the ASO and willing to assume higher level responsibilities. Another finding contrary to that of the body of volunteer or user involvement research was that some participants had become motivated to be meaningfully involved with the ASO because of the experience of others. The role of volunteers and staff of ASOs as potential advocates for MIPA in their interactions personally and professionally was highlighted in these findings. These findings suggest that ASOs who wish to foster MIPA should (1) inform people newly engaged with ASOs about the possible trajectory of MIPA, (2) welcome and facilitate involvement at all levels of complexity and sophistication, (3) encourage people who are meaningfully involved to tell their story of how involvement changed over time to others at risk for or living with HIV, and (4) be intentional about letting people know about available opportunities for increased involvement.

A limitation of the study is that it does not answer how the motives for MIPA differ between rural and urban populations. Nor does it offer rationale for differences that may occur. Directions for future research should include comparative studies of motives for MIPA between rural and urban ASOs.

There are attributes of people at risk for or infected with HIV/AIDS that were not a primary focus in this research; e.g., stigmatization because of sexual orientation and poverty (Herek, 1999). Future research should explore the impact of such attributes on motives for MIPA. In addition, the field of study may benefit from research that documents the changes in people’s motives over time, including the contexts and personal/organizational outcomes of these changes (Ramirez-Valles, 2002).

Conclusion

This research study contributed to the field of knowledge about the motives for MIPA in that it reveals (1) that MIPA was conceptualized by the rural ASO clients as whatever participation provided them a personal meaning (i.e., by fulfilling a personal need, by making a difference, and by recognizing a fit) and (2) the important role that ASO staff and volunteers have in fostering and sustaining MIPA. It has demonstrated congruence with much of the literature on volunteerism and user involvement generally; however, other motives, such as avoiding risk behaviors, appear to be unique to MIPA. The study also highlighted a trajectory of involvement that supports the need for ASOs to entertain a wide range of roles that are assumed as MIPAs.

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