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## Participants' Perceptions of an HIV/AIDS Workshop Perceptions des participants à un atelier sur le VIH/SIDA

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### ABSTRACT

This brief report describes the perceptions of individuals who attended an educational program that targets HIV-positive people. Analysis of quotes from participants in a 90-minute focus group revealed three benefits of attending the workshop (empowerment, patient-physician relationship, and knowledge of medications). Four ways to improve the workshop were identified: peer support and support groups, additional information on medications, nutrition, and more information about the disease. The findings suggest that there may be an unmet need for counselling. Counselling practitioners could make further contributions to the systematic development, implementation, and evaluation of theory-based programs for people with a chronic disease.

### RÉSUMÉ

Ce bref compte rendu décrit les perceptions de participants à un programme d'éducation destiné aux personnes séropositives. L'analyse des propos tenus par les participants dans le cadre d'un groupe de consultation de 90 minutes révèle 3 avantages liés à la présence à l'atelier : habilitation, relation patient-médecin, et connaissance des médicaments. On identifie 4 façons d'améliorer l'atelier : soutien par les pairs, groupes de soutien, plus d'information sur la médication et l'alimentation, et plus de renseignements sur la maladie. Les résultats semblent indiquer la possibilité d'un besoin non comblé en matière de counseling. Les praticiens de counseling pourraient contribuer davantage et systématiquement au développement, à la mise en œuvre, et à l'évaluation des programmes théoriques destinés aux personnes atteintes de maladie chronique.

December 1, 2011 officially marked World AIDS Day ("How to get to zero," 2011). On this day, President Barack Obama renewed the commitment of the United States to ending human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) (Bohan & Selyukh, 2011). In Canada, the Minister of Health, The Honourable Leona Aglukkaq, marked the day by highlighting Canada's long-term approach to fighting HIV and AIDS and our government's investment of over \$17 million in new research programs (Aglukkaq, 2011).

These and other initiatives around the world are starting to improve outcomes for persons living with HIV/AIDS. Statistics published in a report released by the Joint United Nations Programme on HIV/AIDS (UNAIDS) indicate that new HIV infections have been reduced by 21% since 1997. In addition, deaths from AIDS-related illnesses have decreased by 21% since 2005 ("How to get to zero," 2011).

Although much has been achieved in the 30 years since HIV was identified as a virus that causes AIDS, there have been calls for yet more to be done (Centers for Disease Control and Prevention [CDC], 2011; Patel, 2011; Schwartlander et al., 2011). The CDC reported that only about 40% of people with HIV are getting HIV-fighting medications regularly and only one quarter of people with HIV have their disease under control (i.e., have low blood levels of the virus). CDC stated that World AIDS Day served as a call to action for the creation of universally accessible programs (CDC, 2011). In Canada, Christopher Bunting, the president and CEO of the Canadian Foundation for AIDS Research (CANFAR), has also stated that more needs to be done (Patel, 2011). There are more people today living with HIV/AIDS in Canada than there were 10 years ago. As of 2008, the prevalence was estimated to be 76,000 in Canada, and one quarter of those people do not know that they are infected. CANFAR has called for more HIV testing (Patel, 2011).

Much can be done now to further improve outcomes. Research has identified the challenges that people with HIV/AIDS face and the interventions that help people overcome the challenges. Due to the continuing improvement of treatments such as the highly active anti-retroviral therapy (HAART), HIV/AIDS is now considered to be a chronic rather than an acute and fatal disease (Psaros, Israel, O'Cleirigh, Bedoya, & Safren, 2011; Thompson et al., 2010). Similar to most chronic diseases, HIV/AIDS has a prolonged and uncertain course. The disease changes relationships and is often accompanied by anxiety and depression. HIV/AIDS requires daily self-management behaviours (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; de Bruin et al., 2010; Johnson et al., 2003; Kennedy, Rogers, & Crossley, 2007; Lai, Larson, Rockoff, & Bakken, 2008; Simoni, Pearson, Pantalone, Marks, & Crepaz, 2006).

One self-management behaviour of particular importance is adherence to HIV medications or HAART (Kelly & Kalichman, 2002; Morin et al., 2011). High levels of adherence to HAART are required for viral suppression and for the prevention of resistance, disease progression, and death (Kacanek et al., 2010). Yet HAART non-adherence ranges from 33% to 88%, depending on how adherence is evaluated (Mills et al., 2006). Because adherence to HAART is so essential, research on ways to improve adherence has burgeoned and has been summarized in the 2011 NIH Antiretroviral Guidelines (Panel of Antiretroviral Guidelines for Adults and Adolescents, 2011). The evidence supports the conclusion that adherence can be improved through patient support and educational workshops that deliver clear, simple, and direct information.

This article describes the perceptions of individuals who attended an educational program that targets HIV-positive people who want to learn more about the disease and its treatment. The head of this program, an HIV specialist, believes that the 20-minute doctor visit specified by government medicare is not sufficient time to provide the information that patients need to know about antiretroviral therapy. The core activity of the program is confidential workshops conducted by a physician, and held in small interactive groups that pro-

vide participants with up-to-date information on HAART and its side effects. Also present at the sessions is a dietician, who gives the participants the tools necessary to make healthy diet choices. The goal of the program is to empower newly HIV-diagnosed people with the necessary knowledge and information they require to make informed decisions regarding their treatment and to take responsibility for their own health care. This exploratory descriptive study was designed to determine, from the perspective of participants, what worked well and what could be improved with the workshop.

#### METHOD

A qualitative exploratory study was conducted. In a mini focus group, seven open-ended semi-structured questions were used in a round table format (see Appendix for focus group questions).

##### *Participants*

Seven individuals attended the HIV/AIDS workshop, and five participated in the focus group. Ethics approval was received from the HIV/AIDS clinic that ran the program. Verbal consent was received from all participants.

##### *Measures*

Participants shared their comments and ideas about anxiety, feelings of empowerment, attitudes toward medication, and willingness to cooperate with health care providers. The 90-minute discussion was recorded using two recording devices and transcribed verbatim. As well as the researcher, an assistant, who took verbatim content notes that were given to the transcriptionist, was also present.

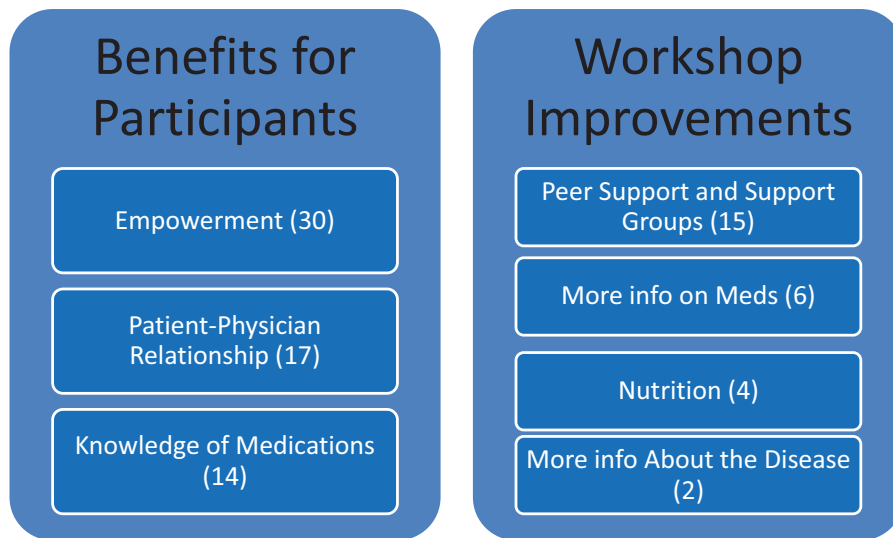
##### *Data Analysis*

The participants' quotes were recorded on 88 index cards. A multidisciplinary team of health care professionals analyzed the data using an affinity diagram. All professionals had previous experience with analyzing qualitative data, and none of the team members had any connection with the service providers of the workshop. Affinity diagrams are one of the innovative quality control tools used to visually organize large amounts of verbal data to help solve complex problems (Balanced Scorecard Institute, 2010). The professionals were told to silently read the quotes on the index cards and move the cards one by one, placing those that seem to be most closely related into groups. The professionals were told that the index cards could be moved between groups, and that the sorting would end when index card movement ceased. The professionals sorted cards silently for approximately two hours, and then together agreed on the common characteristics of each group of index cards. They put labels on each group and then displayed the relationships between the groups in an image referred to as an Affinity Diagram.

## RESULTS

The health care professionals assigned the 88 quotes from the participants to two headings: *Benefits* and *Workshop Improvements*. Under Benefits, the participants' quotes were arranged by the health care professionals into three groups of index cards: *Empowerment*, *Patient-Physician Relationship*, and *Knowledge of Medications*. Under Workshop Improvements, the index cards were arranged into four groups: *Peer Support and Support Groups*, *More Information on Medications*, *Nutrition*, and *More Information About the Disease*. The seven groups of index cards are visually displayed in the Affinity Diagram (see Figure 1).

Figure 1  
*Affinity Diagram*



### *Benefits*

Almost 70% of the quotes related to the benefits that participants believed they received during the 3-hour workshop. The professionals placed Empowerment, Patient-Physician Relationship, and Knowledge of Medications under Benefits.

#### EMPOWERMENT

Participants expressed the opinion that the information session empowered them. “The knowledge to get empowered, to take charge of own care.... just knowing that there are various types of resources out there to help and assist in that process.”

## PATIENT-PHYSICIAN RELATIONSHIP

Approximately one third of the quotes were assigned to the group labelled Patient-Physician Relationship. Individuals stated that they sometimes felt intimidated by their doctors, believing doctors were frequently too busy and that the 20-minute appointment time was insufficient. "I can see my doctor watching his watch.... so I say to myself, maybe I should just shut up and leave." One participant believed the workshop had boosted their confidence to challenge the doctor when appropriate, request additional information, or seek a second opinion about treatment.

## KNOWLEDGE OF MEDICATIONS

Individuals reflected on the value of their increased knowledge of medications. "It was important to hear about the pros and cons of medication, and also about the pros and cons of starting earlier versus later." An individual who had started a complex medication regimen commented, "I'd much rather have attended the workshop before I started the medication, because this would have answered my questions, addressed the anxiety I felt, and helped me to understand things better."

*Workshop Improvements*

About 30% of comments suggested some improvements to the workshop. More than half related to the need for organized peer and social support.

## PEER SUPPORT AND SUPPORT GROUPS

Participants remarked that they found the focus group helpful because they heard other people's experiences. However, they mentioned that they would have appreciated a more guided group discussion. As one participant indicated, "It's helpful to be around people who are alike, somebody who hasn't gone through the seroconversion or had that news dropped in their lap." An interest in learning about existing HIV/AIDS support groups was expressed.

## MORE INFORMATION ON MEDICATIONS

Several quotes from participants suggested that they wanted more written information on medications. "It would help to have an up-to-date chart of all available HIV drugs and their side effects, along with a website listing the current medication information."

## NUTRITION

There were few comments on nutrition. Of these, half were positive while others felt it was unimportant and could be provided in a different session. "I don't really care about the diet; it is not so important. Maybe the diet info could be in a different session."

## MORE INFORMATION ABOUT THE DISEASE

Some quotes suggested an interest in receiving more information on the virus and how it provokes AIDS. "Slow down on the explanation of the virus."

## DISCUSSION

This exploratory study examined the positive aspects of and suggested improvements to a workshop designed to promote self-management from the perspective of individuals living with HIV/AIDS. Analysis of quotes from participants revealed three benefits of attending the workshop: empowerment, patient-physician relationship, and knowledge of medications. Four ways to improve the workshop were identified: peer support and support groups, additional information on medications, nutrition, and more information about the disease. The findings suggest that there may be an unmet need for counselling. These results are consistent with those that have been reported elsewhere (Barlow et al., 2002; de Bruin et al., 2010; Johnson et al., 2003; Kennedy et al., 2007; Lai et al., 2008; Simoni et al., 2006).

The results of the present study provide partial support for a social ecological model of health promotion developed by McLeroy, Bibeau, Steckler, and Glanz (1988). The model postulates that health-related behaviours are determined by five categories of factors: intrapersonal factors, interpersonal processes and primary groups, institutional factors, community factors, and public policy. The model predicts that interventions focused exclusively on the individual, at the expense of other factors, are likely to fail. The social ecological model has been used previously to examine HIV medical care (Mugavero, Norton, & Saag, 2011). The model has not yet been fully applied in research and practice (Glanz & Bishop, 2010).

*Strengths*

This study has two strengths. First, the topic is important for counsellors and is a topic that has not been given much focus in the Canadian literature. The identification of the need for clear information and support groups for people with HIV/AIDS is not new. We know that education and counselling increase HAART adherence (Rueda et al., 2006). Experts accept that individuals with this chronic disease require teams of providers that integrate behavioural and biomedical approaches (American Psychological Association, 2010; Kolbasovsky & Reich, 2005). Yet evidence suggests that people with HIV/AIDS are not receiving integrated care (Psaros et al., 2011). As a result, many individuals may suffer unnecessarily from mental health problems. This brief report is a reminder to ensure that what does work is actually delivered (e.g., counselling).

The second strength of this study relates to the methods used to analyze the qualitative data. The affinity grouping methods have been successfully used by Lepley (1998, 1999) and Rao et al. (2000). It has also been used successfully by the author in the past (Beaty, Young, Slepko, Isaac, & Matthews, 2009; Young et al., 2004). Paddock, Phillips, and Chodoff (2001) commented that these methods are frequently used to monitor and improve the quality of self-management programs.

Using the affinity diagram can help researchers understand the difficulty of changing behaviours. Paddock et al. (2001) compare the affinity grouping method to the pile-sorting methods used by cognitive anthropologists across a wide range of topics. In a pile sort, individuals make a list of topics relevant to a particular

subject, and then they group these topics into related piles (Lincoln & Guba, 1985; Sayles, Ryan, Silver, Sarkisian, & Cunningham, 2007). Pile-sorting and affinity grouping methods have many advantages to alternative methods (Ryan & Bernard, 2003). Very little expertise is required to create the affinity diagram. The method is efficient as one 2-hour period is often enough to identify themes. In addition, subjectivity in identifying themes is addressed by having the group of individuals who create the affinity diagram continue to sort the data until consensus is reached. The affinity grouping methodology is therefore another resource to add to the qualitative toolbox available to researchers.

### *Limitations*

Weaknesses of this exploratory study include the small size of the group sample, selection bias, and the use of a convenience sample. Participants who go to this clinic may differ in important ways from other participants. The sample may be biased toward people with positive experiences in HIV clinics. We did not attempt to recruit a representative sample in this exploratory study.

### CONCLUSION AND IMPLICATIONS FOR COUNSELLING PRACTITIONERS

We conclude that counselling practitioners have an opportunity to make significant contributions on teams of practitioners by systematically developing, implementing, and evaluating programs for people with HIV/AIDS or other chronic diseases. Some counselling practitioners have the expertise to collect and analyze qualitative data that could be used as a basis for developing programs. The inclusion of additional training in qualitative methods into curriculum may need to be explored in order to increase the number of practitioners with this expertise. Once programs are developed, counselling practitioners could then participate in the implementation of the evidence-informed interventions and lead the collection of data to assess their effectiveness. Counselling practitioners could ultimately improve the quality of life with all individuals with a chronic disease, including those with HIV/AIDS.

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#### APPENDIX: FOCUS GROUP QUESTIONS

##### Preamble:

Hello, my name is XX. Thank you for participating in today's discussion about the Workshop. As you know, this focus group is one part of the evaluation of the program. Before we get started, I'd like to go over a few guidelines for our discussion. Let's respect one another's opinions and points of view. There are no right or wrong answers. In fact I am very interested in different points of view. Negative comments are just as interesting and valuable as positive ones. Say exactly what

you think, not what you think others want to hear. As a courtesy, let's try to type and speak one at a time.

1. To get started, I'd like each of you to take a moment and write down three things about the workshop that would help you to become an active partner in your care. Just the first three things that come to mind. Then write down at least one thing that could be improved in the workshop to help you access care. {Pause}
2. Let's think about some of these areas in more detail.
  - a. Tell me about how you think the information you received today on medication will help you.
  - b. What are your impressions of the information that you received on medication?
  - c. Tell me about the tools you have received to make a comfortable/good decision to take your medication.
  - d. Tell me how the information on side effects and access to care will help you.
3. Let's move on to thinking about how the Workshop could be improved.
  - a. How could the workshop be improved to assist you in being a partner in your care?
  - b. What other suggestions do you have for improving the Workshop?
4. Is there anything else that you would like to add?

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