Using Exploratory Focus Groups to Establish a Sampling Strategy to Investigate Disability Experienced by Adults Living with HIV

Running Title: Establishing a sampling strategy to investigate HIV-disability

Institutions where work was performed:

Centre for Research on Inner City Health,
St. Michael's Hospital
30 Bond Street
Toronto, Ontario M5B 1W8
Canada

Department of Health Policy, Management and Evaluation
University of Toronto
Health Sciences Building
155 College Street, Suite 425
Toronto, ON M5T 3M6
Canada

Kelly K. O'Brien*

Centre for Research on Inner City Health,
The Keenan Research Centre in the Li Ka Shing Knowledge Institute,
St. Michael's Hospital, Toronto, Ontario, Canada;

Department of Health Policy, Management and Evaluation,
University of Toronto, Toronto, Ontario, Canada;

Faculty of Health Sciences,
School of Rehabilitation Science,
McMaster University, Hamilton, Ontario, Canada

Ahmed M. Bayoumi

Departments of Medicine and Health Policy, Management, and Evaluation,
University of Toronto, Toronto, Ontario, Canada

Centre for Research on Inner City Health,
The Keenan Research Centre in the Li Ka Shing Knowledge Institute,
St. Michael's Hospital, Toronto, Ontario, Canada

Aileen M. Davis

Department of Health Policy, Management and Evaluation,
University of Toronto; Toronto, Ontario, Canada;

Health Care and Outcomes Research, Toronto Western Research Institute,
University Health Network, Toronto, Ontario, Canada

Nancy L. Young

School of Rural and Northern Health, Laurentian University; Sudbury, Ontario;

Department of Health Policy, Management and Evaluation,
University of Toronto, Toronto, Ontario, Canada

Carol Strike

Centre for Addiction and Mental Health, Toronto, Ontario, Canada;

Department of Psychiatry, University of Toronto, Toronto, Ontario, Canada

*Correspondent Footnote:

Kelly O'Brien

Faculty of Health Sciences

School of Rehabilitation Sciences

McMaster University

1400 Main Street West, Room 403

Hamilton, Ontario

L8S 1C7

kelly.obrien@utoronto.ca

Phone: 416-978-0565

Fax: 416-946-8562

Key Words: HIV/AIDS; disability; focus groups; sampling strategy; qualitative research

ABSTRACT

In HIV clinical research, participants are typically sampled based on demographic and/or disease characteristics. As little is known about HIV-specific disability, we did not know whether this purposive type of sampling would be helpful and what characteristics (if any) should guide our sampling strategy. We describe using exploratory focus groups to determine a sampling strategy to investigate disability from the perspective of adults living with HIV. We conducted 4 focus groups with 23 men and women and asked participants to describe their health-related challenges and impact on their overall health. We analyzed data to determine whether health-related challenges differed based on age, gender, ethnocultural background, length of time since HIV diagnosis and antiretroviral use and if these characteristics should be considered when sampling. Participants described seven health-related challenges that appeared not to vary based on demographic or disease characteristics. Variations emerged in the way health-related challenges manifested and the strategies participants used to deal with these challenges. Consequently, we decided upon a broad theoretical sampling strategy for the subsequent interview phase. Exploratory focus groups may be a useful technique to determine a sampling strategy when exploring a new phenomenon in HIV qualitative research.

INTRODUCTION

With improved longevity, individuals will likely face a variety of health-related consequences from HIV, including adverse effects of treatment, and social stigma [1-5]. Collectively, such health-related consequences may be termed, *disability* [6].

Little is known about the HIV-disability experience. Existing disablement frameworks exist, but none were developed specifically for, or from the perspective of adults living with HIV [7-12]. Hence, it is unclear whether these frameworks capture the complexity of this evolving illness as medications change and life expectancy increases. Consequently, we set out to develop a conceptual framework of disability from the perspective of adults living with HIV.

Conceptualizing HIV-related disability poses methodological challenges. Epidemiological studies often categorize people living with HIV according to demographic, risk, or disease characteristics but it is unclear whether, or to what extent, these characteristics influence the way in which disability is defined and experienced. For example, it is unclear whether stage of illness, length of time since HIV diagnosis, ethnocultural background, or gender result in varying perspectives on how disability is experienced. Perhaps individuals experience similar types of health-related challenges (disability), but the severity in which they are experienced vary based on personal characteristics.

Given our exploration of this new phenomenon in the HIV context, and the uncertainty of whether demographic or disease characteristics influence the conceptualization of disability, we were uncertain whether to adopt a diverse sampling approach, recruiting a range of adults with varying personal and experiential characteristics, or whether to focus on sampling a select subgroup of participants within the larger HIV population. Researchers examining other new phenomenon within the realm of HIV may face a similar dilemma.

Sampling in Qualitative Research

Sampling is a key element of qualitative research possessing importance for the trustworthiness (validity) and transferability (generalizability) of a study's analyses and interpretations [13]. Many different sampling strategies exist [14-17] but there are no clear guidelines for clinician researchers. Purposive (or purposeful) sampling is a common approach, defined as 'intentionally selecting specific cases that will provide the most information for the question under study' (pg. 279)[13]. This approach seeks to minimize sample size by selecting individuals who might best contribute to answering the research question. Theoretical sampling is a specific type of purposive sampling in which participants are recruited based on their ability to contribute to elements of an evolving theory [14]. An underlying assumption of many sampling strategies is that the researcher has a fairly good understanding of the phenomenon of interest. However, this assumption may be violated when researchers investigate an unexplored or new phenomenon, such as HIV-related disability. In such circumstances, it may be unclear whom should be sampled to answer the research question [18] and develop future theory or conceptual frameworks [14-17]. Recruiting individuals with varied backgrounds might lead to difficulties with saturating key thematic domains if experiences differ by sub-group. Alternatively, recruiting participants based on hypotheses about the relationship of disability to particular characteristics (such as sexual orientation) might lead researchers to miss factors that broadly influence disability.

Multimethod Study Design: Exploring an Unknown Phenomenon

Multimethod study design combines multiple data collection strategies within a single qualitative or quantitative study and provides an approach to refining sampling strategies for the

investigation of disability experienced by adults living with HIV [19, 20]. For example, a combination of focus groups and interviews can be used to identify areas of interest for further exploration, provide unique insights, or reexamine results from a different perspective. One method for such design is the use of exploratory focus groups. This method, a form of group interview that uses discussions and interactions to generate ideas and investigate a topic, can help determine the sampling strategy for subsequent interviews in qualitative research. Exploratory focus groups can be particularly helpful when investigating an unknown phenomenon with a new population [21].

We describe our experience using a multimethod study design to establish a sampling strategy for subsequent interviews. This article is organized as follows. In the methods section, we describe our use of exploratory focus groups. In the results section, we demonstrate how, using disease and demographic characteristics, we determined the optimal sampling strategy for subsequent study interviews. In the discussion section, we analyze the advantages and potential challenges associated with the exploratory focus group approach in HIV qualitative clinical research.

This research was needed to develop a conceptual framework of disability from the perspective of adults living with HIV. While the exploratory focus groups enabled us to collect initial data on the disability experience, our primary focus of this paper is on our process to determine a clear sampling strategy. We were particularly interested in how the relationship between participant characteristics and the array of disability experiences would inform the selection of either a selective purposive or broad theoretical sampling strategy.

MATERIALS AND METHODS - Using Exploratory Focus Groups

We recruited participants using maximum variation sampling [22] a strategy in which participants with variable characteristics are recruited to analyze differences across dimensions of interest. Maximum variation sampling enabled us to recruit a heterogeneous group of participants in order to explore potentially diverse themes and perspectives while gaining a preliminary understanding of disability. We initially sought equal representation from men and women.

We recruited adults over the age of 18 living with HIV who self-identified as having experienced at least one health-related consequence attributed to their illness from a hospital, a primary care clinic, and a number of local AIDS Service Organizations. A Community Advisory Committee representing people living with HIV, AIDS Service Organizations, and government, advised about all stages of this research project. The St. Michael's Hospital (Toronto, Ontario) and University of Toronto Research Ethics Boards approved the study protocol.

In the focus groups, we asked participants to describe their health related challenges and how these challenges affected their overall health. The term 'health related challenges' was used because we did not want to presume participants would define their experiences as disability. Participants also completed a personal demographic questionnaire and HIV Symptom Index to describe their personal characteristics and symptom presence and severity [23]. The HIV Symptom Index is a 20 item self-reported questionnaire that describes the presence of HIV symptoms and the degree to which present symptoms are bothersome [23]. Scoring of this index involves totaling the number of symptoms present (out of 20) and the number of symptoms which are bothersome. See previous publication for further detail [6].

All four focus group discussions were audiotaped, later transcribed verbatim and verified for accuracy. We used grounded theory analytic techniques [14] to analyze the exploratory focus group data. In this approach, we identified themes related to the phenomenon of disability and determined whether the experiences related to these themes differed based on particular participant characteristics which were self-reported by participants. We focused on five characteristics: gender, age, ethnocultural background, length of time since HIV diagnosis, and antiretroviral use. We selected these characteristics as they are commonly used to classify participants in quantitative HIV research or are hypothesized to be important predictors in the lived experiences of people living with HIV [24-26]. To assist with the analysis, we used a matrix displaying the five characteristics (each expressed as dichotomous variables) along one axis and themes of health-related challenges along the other to track the presence of data examples that illustrated whether a health-related challenge was experienced across participants with varying disease and demographic characteristics [27].

We used a constant comparative analysis and validity checks to enhance rigor [28]. With constant comparative analysis, we collected and analyzed data simultaneously, which ensured the discussion guide questions continually evolved to build on themes related to the health-related challenges of HIV and allowed us to check for differences in experiences between and within different sub-groups of participants. We conducted validity checking by independently assigning data codes with two focus group transcripts by two authors (KO, CS), followed by a face-to-face meeting to compare codes and discuss overall interpretations of the data. Authors and the Community Advisory Committee formally reviewed interim data and analytical interpretations on two occasions.

RESULTS

Twenty-three participants (12 men, 11 women) took part in one of four exploratory focus groups, each approximately 90 minutes in duration. Two groups consisted of men only, one consisted of women only, and one consisted of both men and women. More than two-thirds of participants were taking antiretroviral therapy (Table 1). Participants experienced a median of 13 of 20 HIV-related symptoms, 12 of which were considered bothersome. The most bothersome symptoms included fatigue or loss of energy, feeling sad, down or depressed, and feeling nervous or anxious.

Table 1: Participant characteristics (n=23)

Characteristic	Number (%)
<i>Gender</i>	
Male	12 (%)
Female	11 (%)
Age in years, mean (range)	42 (28-58)
Identified with a particular ethnic group	17 (74%)*
Nadir CD4 count <200 cells/mm3	13 (56%)
<i>Date of HIV Diagnosis</i>	
1980-1989	4 (17%)
1990-1995	5 (22%)
1996-1999	6 (26%)
2000-2005	8 (35%)
Currently Taking HIV Medications	16 (70%)
<i>Self Rated Health Status</i>	
Poor	0 (0%)
Fair	1 (4%)
Good	9 (41%)
Very Good	9 (41%)
Excellent	3 (14%)
<i>HIV Symptom Index</i>	
Median Number of Symptoms Present	13/20 (IQR: 6-18)

Median Number of Bothersome Symptoms	12/20 (IQR: 5-17)

*13 identified themselves as African / African Caribbean / Black / Black African; 2 Jewish; 1 French Italian; 1 not specified; IQR=interquartile range

Health-Related Challenges: Highlighting Similarities and Differences across Disease and Demographic Characteristics

Seven major themes emerged from the data that represented health-related challenges experienced by participants: fatigue, mental health challenges, stigma, work, getting through day-to-day activities, personal relationships, and self-esteem. We use quotations to describe each challenge, highlighting similarities and differences across different characteristics of participants. To maintain participant anonymity we include no more than two descriptive disease and demographic characteristics with each data excerpt [29].

Fatigue

Fatigue was commonly experienced by participants across characteristics. Participants described being “*tired*”, “*knocked down*”, “*whacked out*” or “*physically drained*”. Fatigue was experienced by participants taking antiretroviral therapy (ARVs) “*I think the fatigue is probably something that I struggle with the most...*” (F4-1) as well as those not taking ARVs: “*You’re always tired... Sometimes, some mornings you can’t get out of bed you’re so tired.*” (F4-8). While fatigue was experienced by both men and women, it had specific implications for mothers caring for their children:

“We were used to just going on, everyday without having to stop for any stretch of time for any length of time... I lived many years with it [HIV], working full time, taking care of 5 kids and doing everything that I have to do, and it was fine.... Now because of that [ARVs], you have to sit, and you can’t do extraneous work like you did before [ARVs],

and there are times when you're always sleepy and tired for no apparent reason..." (F4-4)

Fatigue was articulated among participants who identified with a particular ethnocultural group, such as this woman *"For me it just knocks me out; I just can't get out of bed. I feel like I have the flu, but I know it's not"* (F4-5) as well as those who did not identify with an ethnocultural group, such as this man *"like your energy level is nowhere..."* (F3-7).

Fatigue also was articulated by participants of all ages. Some living with HIV for many years were uncertain whether their fatigue was attributed to HIV, antiretroviral use, or aging:

"I also realize that... you can blame everything on energy but you also have to realize that you also get older..."(F3-7)

Mental Health Challenges

Stress, anxiety and depression were commonly experienced across all groups and were characterized by periods of alternating wellness and illness as illustrated by this woman who identified with a particular ethnocultural group:

"I have bouts of depression, where I just don't want to talk about it [HIV], or think about it or answer the phone, nothing... and I have to really force myself to get out of that."
(F4-1)

Individuals who were diagnosed with HIV infection over 20 years ago spoke of the stress that came from being diagnosed when little was known about the disease such as this man currently taking antiretroviral therapy, who identified with a different ethnocultural group from the woman above:

“I’ve been [HIV] positive since ’87, I didn’t get sick until ’98. The only way it affected me through that time before that was psychologically... because it was still new back then ...” (F3-6)

Participants who were diagnosed more recently similarly spoke of their struggle with receiving news of their diagnosis, their adjustment to living with the disease, and the challenging decisions they faced related to initiating antiretroviral therapy, as with this man who did not identify with an ethnocultural group:

“Right now I’m working on my mental state, because that’s what needs work on right now. I’m way behind every one of you in that area. I’ve been living with HIV for just a year, so I’m still getting over it, getting used to it. So that’s where I’m at and that’s the kind of medication, mental medication that I’m trying to find lots of hope to keep going...” (F3-2)

Coping strategies for dealing with stress, anxiety and depression varied. One participant living with HIV for 20 years adopted a positive outlook: *“Every day I have is a marvelous day.” (F3-6)* whereas a participant diagnosed more recently spoke of how he struggled to find a sense of optimism living with HIV: *“Every day I have are bad days.” (F3-4)*. This despair was also articulated by a long term survivor, who spoke of the ongoing struggle to gain a sense of hope living with HIV: *“One day I woke up and I had no life, that’s what it feels like right now” (F3-5)*

Stigma

Stigma was experienced at times from family, work colleagues, employers, and health care providers. Depending on the participant, stigma could arise from one’s HIV positive status, sexual orientation, ethnocultural background, employment status or gender. For some, this limited the ability to engage in personal relationships, work, school or other social role activities.

One male participant felt more stigmatized because of his ethnocultural background than because of his HIV status: *“being black was worse than having HIV. I have to agree...you can’t see my HIV.”* (F3-3) whereas another participant spoke of how her gender, ethnocultural background and employment status collectively exacerbated the stigma she experienced within her community:

“I feel when I’m around certain people or around certain ethnicities, I have to hide who I am ... We are who we are, but because of the stigma that comes with it... that’s what I’ve been struggling with...being able to overcome that stigma that lies within me, because a woman, a woman with no job, and then being infected...” (F4-7)

While ethnocultural background contributed to the stigma experienced by these participants, others who did not identify themselves with a particular ethnocultural group similarly reported challenges of stigma.

Stigma did not appear related to the length of time since the participants’ HIV diagnosis. For instance, one participant diagnosed more than 15 years ago felt stigma was less of a challenge compared to when the community was less educated about HIV: *“I think we’re over that. I don’t encounter that very much anymore, personally... it’s not like it was 20 years ago”* (F3-6), whereas another participant (also diagnosed with HIV more than 12 years ago) disagreed and reported how he struggled with the longstanding stigma he experienced from family: *“Really? Come to my sister’s house and she’ll tell you not to touch the serving tray.”* (F3-5)

While sources of stigma appeared attributed to some participant’s ethnocultural background, (in addition to HIV status), we could not uniformly classify the stigma experience based on a specific subgroup of participants.

Work

Work-related challenges were common across participants. Many had left the workforce years ago and continued to struggle with the physical and mental health challenges associated with HIV, such as this man in his 30's who stated:

"I can't [work] because of my depression, my problem. I can't function you know. I don't know where to go sometimes, I forget things..." (F2-4)

Others considered returning to work, but were unsure whether they could handle the physical and emotional demands of the workforce given the unpredictable nature of their illness, including this woman in her 40's:

"Maybe I'll feel good today, tomorrow and the next day, but Thursday, I can't go to work, and I have to call in and say I'm sick." (F4-1)

As a result, some spoke of the importance of flexibility in the work environment to accommodate for periodic episodes of illness, such as this woman who was diagnosed with HIV less than 5 years ago:

"I don't have to go out of home and go to the office and work there. So if I felt ok, I could get onto the computer in my pajamas ... and then do the work. But in the situation where the client ... wants to see you... it was just so frustrating and depressing." (F2-5)

Participants in the workforce spoke of the challenges trying to balance the demands of their workload while maintaining their health, including this participant who was diagnosed more than 15 years ago:

"Today I had a good day. Last Thursday I worked over time and it was a very bad day because by the time I got home, I was limping and people I swear, they think I'm drunk when I'm walking along the street because I'm in so much pain with my feet... and so now I realize that I can't work overtime." (F3-1)

Mothers specifically spoke of the challenges associated with paid employment as well as their roles as a parent:

“I was working... I was able to do long hours... I lived many years with it [HIV], working full time, taking care of 5 kids and doing everything that I have to do, and it was fine. I got up early, got to work at 7 o’clock got back home and did everything that I had to do, and now I’m on medication and I can’t get out of bed before 8 o’clock.” (F4-4)

Despite the challenges, many described their considerations of returning to work, which did not appear to vary based on age, length of time since HIV diagnosis, or length of time since leaving the workforce, as demonstrated by this participant in his late 50’s:

“I went on to a cocktail [combination of ARVs] and I have been, in relatively good health and I would think as far as my condition is concerned now, I’m in a position I think about possibly considering going back to work so that will be a big step as well.” (F2-2)

Getting Through Day-to-Day Activities

Despite fluctuations in health with HIV, some participants were challenged to forge ahead and carry out daily activities such as household chores, work and parenting. Mothers specifically articulated how living with HIV and the periods of illness influenced their ability to care for their children. Many shielded their children from the challenges they experienced to avoid having them worry about their mother’s health. For many mothers, carrying on with the daily activities such as caring for their children emerged as a priority over caring for their own health:

“What can you do? It still needs to get done right? ... not every day you’re going to feel 100%... Many of us have children... and sometimes they don’t even know what’s going on with us... we have to pretend that everything’s ok and it’s not, and these are the things

that you have to do, you have to cook for your kids, you have to do the laundry, you have to clean the house, and if you're single, it makes it worse...you have to do what you have to do.” (F4-6)

Personal Relationships

Some participants were reluctant to engage in new relationships, either casual or intimate in nature for fear of rejection after disclosure of their HIV status such as this woman:

“It’s very difficult, because sometimes you meet somebody nice, who’s interesting, who’s interested in you. There is an initial rapport, but then you have to, the missing thing now, when do I tell him? Do I tell him now? Or do I let this thing develop? So with me, the tendency has been just to cut it off before it goes any further because ... I don’t think I’m ready to say to somebody, look I’m HIV positive you know, can you handle this?” (F2-5)

This challenge similarly was experienced by men who also feared stigma and discrimination.

Some avoided new relationships all together to avoid feeling dishonest or guilty for not disclosing their HIV status immediately after meeting a new individual:

“I have a problem with finding, or not finding, or holding onto friends, because I’m not going to tell them, I’m not honest. So I always distance myself. Once I finish the business, whatever I have with them, I just distance, I disappear... instead of telling them... 7 years and I don’t have a friend...” (F2-4)

For those reluctant to disclose their HIV status, initiating relationships was difficult, particularly among mothers who wanted to protect their children from potential stigma and discrimination:

“I had to make huge decisions about disclosure and be a single mom at the same time... I was in a relationship where my partner didn’t know, and I thought it was too stressful to me... So I broke it off. Simply, I want to love myself...” (F4-7)

Self-Esteem

Self-esteem, similarly experienced across different types of participants, was influenced by a number of factors such as one's ability to work and changes in body composition. For example, this woman described her loss of self esteem as it related to her employment status:

"There are times where I feel because I'm not working... I'm a person that's been working all my life....So now that I haven't been, I don't feel of use. I feel that it's taken away a lot of my, not respect for myself... but just that financial responsibility has been taken away from me..." (F4-6)

Some participants felt body composition changes in relation to their antiretroviral use that could identify them as HIV positive, despite wanting to withhold their status for fear of stigma and discrimination:

"I have the lipodystrophy. The back of my neck is humped and my enlarged stomach. That has affected me a lot. When I'm wearing anything without a collar, I have to be very aware of it...So if someone is sitting behind me, I'm thinking it's going to affect me..." (F4-2)

Reduced self esteem sometimes transpired into a reluctance to socialize with others and affected the ability to engage in new personal relationships as with this woman in her 40s:

"Like with me, I just got in a new relationship with this guy, and I feel if I start showing some of the signs and symptoms, then I'm going to lose him. I mean, my self esteem can't be that good for me to think stuff like that." (F4-1)

Sampling Strategy for Interviews

The seven themes that emerged from these exploratory focus groups provided baseline information about experiences of disability from the perspective of adults living with HIV. We found data examples that suggested health-related challenges were experienced across a range of participants with each disease and demographic characteristic. Given the similarities of experiences between different groups of participants, and the variability of experiences within some groups, we were unable to classify health-related challenges based on specific demographic or disease characteristics. This inference was supported by a participant who stated: *“everyone’s body deals with the HIV differently, so we’re not all apples to apples comparisons.”* As a result we decided to pursue a broad theoretical sampling strategy for the subsequent interview phase where we recruited a range of participants with varying experiences and perspectives related to disability. However, since some women possessed unique parental roles, we decided to seek equal representation of women and men for the interviews.

DISCUSSION

We used exploratory focus groups to determine the sampling strategy for subsequent interviews to investigate a new phenomenon, disability from the perspective of adults living with HIV. While health-related challenges were similarly described across demographic and disease characteristics, a notable exception were the specific challenges described by mothers in their role as a parent. We are unable to say if these challenges were gender-specific as we did not have any self-identified fathers. We did not sample participants for these exploratory focus groups based on their parental status, nor is this category typically sought after in HIV clinical research, but these findings suggest the importance that parental roles may have on disability and the value of sampling based on parental status for future research.

Despite apparent similarities in the seven health-related challenges experienced among different types of participants, variations emerged in the way these challenges manifested (severity, duration and frequency of disablement) and the strategies participants used to deal with these challenges. However, these variations within and across different types of participants and could not be classified based on particular subgroups of personal or disease characteristics.

Advantages and Potential Challenges of Exploratory Focus Groups

The use of exploratory focus groups with maximal variation sampling as a preliminary phase of a multimethod design in HIV clinical research had some significant advantages that might be considered by other researchers exploring new issues in the context of HIV. First, the data contributed to the understanding of disability as well as informed the sampling strategy of subsequent interviews. Second, the sample heterogeneity facilitated exploration of similarities and differences among a range of participants living with HIV. Third, using focus groups offered a way to observe dynamic interactions between participants, drawing out complementary and conflicting points of discussion [30, 31]. This was illustrated when a participant left a focus group discussion early due to a difference in opinion about the way in which he dealt with living with HIV. Such dissonant views, termed ‘argumentative interactions’, enabled us to highlight key differences within a group [31]. Finally, our use of a combination of heterogeneous (men and women together) and homogeneous (men or women only) exploratory focus groups allowed us to compare responses across gender and maximize exploration of different perspectives and assumptions of how disability may relate to gender. For example, homogeneous groups may have enabled participants to express their views more comfortably and confidently in a gender-specific forum [32].

While our approach suited the needs of the study, it was not without its limitations that might be considered by others prior to embarking on a similar strategy. First, adopting focus groups as a preliminary component of a multimethod study design lengthened the project because we required additional participant recruitment and extra costs were introduced. Nevertheless, the extra time and expense were offset by identification of a sampling strategy suited to our study goal. Had we not undertaken this step, we might have incurred additional costs later when trying to confirm findings with additional participants. . Second, we adopted a particular and commonly used set of demographic and disease characteristics to guide recruitment and analyses at the expense of others such as socioeconomic status, exposure category, disease severity or geographical area of residence. When exploring an unknown phenomenon, it can be difficult to *a priori* identify important characteristics that explain differences in experiences. Third, the sample sizes may be too small to explore more nuanced differences. . For example, most of the women in our study were black and self-identified as African, African Caribbean, African Canadian, Black, or Black African. Fourth, despite apparent similarities in health-related challenges experienced among different participants, variations in the nature, severity, duration and frequency of these challenges between groups of participants may exist. For example, we were unable to determine whether specific types of mental health challenges differed across participants. Additionally, while stigma was experienced among participants with varying ethnocultural backgrounds and length of time living with HIV, the nature and strategies used to address stigma may differ between participants. Further research is needed to explore potential variations in the nature, severity, duration and strategies to address a given challenge across these areas of disablement. Fifth, we did not explore how combinations of demographic or disease characteristics affected

experiences. Nevertheless, our work may inform a quantitative, multivariate approach with a larger sample that is better suited to exploring multiple combinations of characteristics. Sixth, participation bias may exist if those who volunteered experienced these health related challenges differently from those who chose not to participate. For example, aboriginal Canadians, youth and persons from rural geographic regions were not represented in this sample.

Finally, we were not always able to differentiate between experiences and the willingness to discuss those experiences. For example, although women tended to speak more about relationships and challenges associated with intimacy, we cannot conclude that men never had these challenges. In our case, they may have been uncomfortable disclosing these challenges, particularly with a woman facilitator (KO). Similarly, the absence of diversity does not necessarily indicate consensus or similarity. Rather, this absence may be attributed to group dynamic if participants with differing experiences were reluctant to articulate their views in a group setting [33].

Considerations for Future HIV Qualitative Research

HIV researchers conducting qualitative research should carefully consider the sampling strategy of participants, specifically whether disease or demographic characteristics influence the way in which the phenomenon of interest is experienced or conceptualized. Exploratory focus groups with a range of participants may be used to help determine whether specific characteristics should be considered in sampling for subsequent focus groups or interviews. Finally, during the analysis researchers should remain open to characteristics not traditionally considered in HIV clinical research that may emerge as an important subgroup for exploring an unknown phenomenon in qualitative research (such as parental status in this example).

CONCLUSION

Exploratory focus groups were useful, as the preliminary step in a multimethod study design, to determine a sampling strategy for a qualitative HIV research project. Participants described seven health-related challenges that relate to disability including: fatigue, mental health challenges, stigma, work, getting through day-to-day activities, personal relationships, and self-esteem. These health-related challenges did not appear to differ in relation to specific demographic and disease characteristics such as gender, age, ethnocultural background, length of time since HIV diagnosis, and antiretroviral use. Consequently, we used a broad theoretical sampling strategy for the subsequent interview phase where participants were recruited based on their ability to contribute to the development of a conceptual framework of disability, rather than focused or limited to the above characteristics. Exploratory focus groups may be a useful technique to help determine sampling strategies when exploring a new phenomenon in qualitative HIV clinical research.

ACKNOWLEDGEMENTS

This research was supported by the Wellesley Institute. We gratefully acknowledge the members of the Community Advisory Committee including Winston Husbands (AIDS Committee of Toronto), Ken King (Canadian Working Group on HIV and Rehabilitation), Claudia Medina (Toronto People with AIDS Foundation) and James Murray (AIDS Bureau, Ontario Ministry of Health and Long Term Care).

Kelly O'Brien was supported by a Fellowship from the Canadian Institutes of Health Research (CIHR), HIV/AIDS Research Program. Salary and infrastructure support for

Carol Strike were provided by the Ontario Ministry of Health and Long Term Care. Nancy Young is supported by a Canada Research Chair from the CIHR. Ahmed Bayoumi was supported by a Career Scientist Award from the Ontario HIV Treatment Network. The Centre for Research on Inner City Health is supported in part by a grant from the Ontario Ministry of Health and Long-Term Care. The views expressed in this article are those of the authors, and no official endorsement by supporting agencies is intended or should be inferred.

REFERENCES

- [1] O'Dell MW, Hubert HB, Lubeck DP, O'Driscoll P. Pre-AIDS physical disability: data from the AIDS Time-Oriented Health Outcome Study. *Arch Phys Med Rehabil* 1998, **79**(10):1200-1205.
- [2] Rusch M, Nixon S, Schilder A, Braitstein P, Chan K, Hogg RS. Prevalence of activity limitation among persons living with HIV/AIDS in British Columbia. *Can J Public Health* 2004, **95**(6):437-440.
- [3] Alonzo AA, Reynolds NR. Stigma, HIV and AIDS: an exploration and elaboration of a stigma trajectory. *Soc Sci Med* 1995, **41**(3):303-315.
- [4] Blanch J, Rousaud A, Martinez E, et al. Impact of lipodystrophy on the quality of life of HIV-1-infected patients. *J Acquir Immune Defic Syndr* 2002, **31**(4):404-407.
- [5] Henderson M, Safa F, Easterbrook P, Hotopf M. Fatigue among HIV-infected patients in the era of highly active antiretroviral therapy. *HIV Med* 2005, **6**(5):347-352.
- [6] O'Brien KK, Bayoumi AM, Strike C, Young NL, Davis AM: Exploring disability from the perspective of adults living with HIV/AIDS: development of a conceptual framework. *Health Qual Life Outcomes* 2008, **6**:76.
- [7] Nagi S. Some conceptual issues in disability and rehabilitation. In: *Sociology and Rehabilitation*. Edited by Sussman M. Washington, DC: American Sociological Association; 1965: 100-113.
- [8] World Health Organization. International classification of impairments, disabilities and handicaps (ICIDH). Geneva: The World Health Organization; 1980.
- [9] Fougereyrollas P, St-Michel G, Bergeron N, Cloutier R. The handicap creation process: analysis of the consultation. *ICIDH International Network* 1991, **4**:8-37.

- [10] Nagi S. Disability concepts revisited: implications for prevention. In: Disability in America: Toward a National Agenda for Prevention. Edited by Pope A, Tarlov A. Washington, DC: National Academy Press; 1991: 309-327.
- [11] Verbrugge LM, Jette AM. The disablement process. Soc Sci Med 1994, 38(1):1-14.
- [12] World Health Organization. International classification of functioning, disability and health (ICF). Geneva: The World Health Organization; 2001.
- [13] Kemper EA, Stringfield S, Teddlie C. Mixed Methods Sampling Strategies in Social Science Research. In: Handbook of Mixed Methods in Social and Behavioral Research. Edited by Tashakkori A, Teddlie C. Thousand Oaks, California: Sage Publications, Inc; 2003: 273-296.
- [14] Strauss A, Corbin J. Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory, vol. 2nd edition. Thousand Oaks, California: Sage Publications; 1998.
- [15] Patton MQ. Qualitative Evaluation and Research Methods, vol. 2nd edition. Newbury Park, California: Sage Publications, Inc; 1990.
- [16] Morse JM. Strategies for Sampling. In: Qualitative Nursing Research. Edited by Morse JM. Newbury Park, California: Sage Publications, Inc; 1991: 127-145.
- [17] Sandelowski M. Sample size in qualitative research. Res Nurs Health 1995, 18(2):179-183.
- [18] Coyne IT. Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? J Adv Nurs 1997, 26(3):623-630.

- [19] Morse JM. Principles of Mixed Methods and Multimethod Research Design. In: Handbook of Mixed Methods in Social and Behavioral Research. Edited by Tashakkori A, Teddlie C. Thousand Oaks, California: Sage Publications, Inc; 2003: 189-208.
- [20] Creswell JW, Clark VPL. Designing and Conducting Mixed Methods Research. Thousand Oaks, California: Sage Publications, Inc.; 2007.
- [21] Morgan DL, Kreuger RA. The Focus Group Kit. Thousand Oaks, California: Sage Publications, Inc; 1998.
- [22] Patton MQ. Chapter 5: Designing Qualitative Studies. In: Qualitative Evaluation and Research Methods. vol. 2nd Edition. Newbury Park, California; 1990: 145-198.
- [23] Justice AC, Holmes W, Gifford AL, et al. Development and validation of a self-completed HIV symptom index. J Clin Epidemiol 2001, 54 Suppl 1:S77-90.
- [24] Cunningham WE, Hays RD, Duan N, et al. The effect of socioeconomic status on the survival of people receiving care for HIV infection in the United States. J Health Care Poor Underserved 2005, 16(4):655-676.
- [25] Liu C, Johnson L, Ostrow D, Silvestre A, Visscher B, Jacobson LP. Predictors for lower quality of life in the HAART era among HIV-infected men. J Acquir Immune Defic Syndr 2006, 42(4):470-477.
- [26] Liu C, Ostrow D, Detels R, et al. Impacts of HIV infection and HAART use on quality of life. Qual Life Res 2006, 15(6):941-949.
- [27] Miles MB, Huberman AM. Qualitative data analysis, 2nd edition. Thousand Oaks, CA: Sage Publications; 1994.

- [28] Eakin J, Mykhalovskiy E. Reframing the judgment of qualitative health research: reflections on a review of appraisal guidelines in the health sciences. *Journal for the Evaluation of Clinical Practice* 2003, 9(2):187-194.
- [29] Morse JM, Field PA. *Qualitative Research Methods for Health Professionals*, 2nd edition. Thousand Oaks, California: Sage Publications; 1995.
- [30] Morgan DL. *Focus Groups as Qualitative Research*. Thousand Oaks, California: Sage Publications, Inc; 1997.
- [31] Kitzinger J. The methodology of focus groups: the importance of interaction between research participants. *Sociology of health & illness* 1994, 16(1):103-121.
- [32] Stewart DW, Shamdasani PN. *Focus Groups: Theory and Practice*. Newbury Park, California: Sage Publications, Inc; 1990.
- [33] Sim J. Collecting and analyzing qualitative data: issues raised by the focus group. *Journal of Advanced Nursing* 1998, 28(2):345-352.