SHOW ME THE LOVE

Understanding Barriers to Sexual Intimacy among PHAs in Guelph and Wellington County

ONTARIO, CANADA

FINAL RESEARCH REPORT

MAY 2012

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The completion of a community-based research project is not possible without the contribution and commitment of a number of people. We thank the Ontario HIV Treatment Network for funding our project and for the direction provided in preparing our grant application. We would like to acknowledge the contribution of our advisory committee – Cythia Weijs, Linda Hunter, Iris Budd and Tashauna Devonshire – who provided their insight and expertise in the guidance of the research and our analysis. We thank Becky Verwolf for her diligence in note-taking and transcribing the interviews. We gratefully acknowledge the courageous contribution of the research participants themselves, who gave their time and shared experiences, and who inspired us throughout our work together.

Acknowledgements

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Overview of the Report

Sexual intimacy, an important part of emotional, mental and physical wellbeing, is instantly complicated by HIV diagnosis. The social – as well as physiological -effects of HIV carry burdens that may change, reduce, or even eliminate sexual contact with partners. Barriers to sexual relationships and activity present considerable impediments to quality of life, health and happiness. A better understanding of what these barriers are provides knowledge that organizations and communities can use to address these challenges. This report presents the key findings from a community-based research study conducted by the AIDS Committee of Guelph & Wellington County, designed to improve understanding of the barriers to sexual intimacy faced by people living with HIV and AIDS. It is hoped that this research will illuminate the impact that HIV has on sexual intimacy, while creating a springboard for further work that may address key challenges to our agency, community and beyond.

This report begins by introducing the Background and impetus for the project, as well as the values in which the research is situated. Secondly, the Research Questions & Objectives explain the goals and scope of the research, including the ways in which the research was anticipated to be used. Next, the Research Approach and Methods describe the methodology that was applied and why these methods were chosen. Following this is a description of the Research Participants, situating the findings in the demographics of the individuals who were interviewed. The analysis is then presented in Findings according to the research questions. An interpretation of the results is shared in the Discussion, followed by an overview of the Limitations of the research. Next is a description of the results that may have Implications, both for ACG as well as other organizations and providers in the field. Final thoughts are shared in the Conclusion.

Show Me the Love: Background

The need for the project

There are many reasons why people living with HIV and AIDS (PHAs) may experience challenges in sexual relationships, ranging from the physiological to the psychosocial. HIV disease as well as treatment may lead to decreased sex drive and other factors that lower one’s interest in having sex.\(^1\)\(^-\)\(^4\) Perhaps even more significant however, is the range of ways in which HIV creates social and psychological barriers, such as fear of rejection, fear of infecting others, and stigma leading to guilt, shame and isolation.\(^5\)\(^-\)\(^9\) The desire to better understand these barriers to sexual intimacy, specifically among ACG’s client population, grew out of the fact that many clients at the AIDS Committee of Guelph & Wellington County have anecdotally reported a lack of sexual intimacy as a result of issues stemming from their HIV-positive status. In the last 10 years, clients have expressed frustrations about these challenges, noting the following experiences:

› Decision to remain abstinent in response to fears around transmission, criminalization and rejection
› Repeated rejections following disclosure (online and in person)
› Decision to remain with an abusive partner because no one else will date an HIV+ person
› Fear and hurt around the partner who infected them, resulting in mistrust of future partners
Desire to sero-sort, but no knowledge of where or how to meet other HIV+ partners in the local area

HIV-negative partners have fear and a lack of correct information about the virus

Loneliness, sexual frustration, and isolation

The need for information and support for intimate relationships was also identified through a recent evaluation of programs offered to PHAs. Overall, ACG has 119 clients; it is estimated that as many as 90% of those who have accessed Support or Positive Prevention services have reported challenges with sexual intimacy.

The mission of ACG is to "provide exemplary multidisciplinary services, education and support in the area of HIV and AIDS through innovative health promotion strategies and community partnerships." The anecdotal evidence presented above suggests that the absence of sexual intimacy impairs the well-being of ACG clients. This recognition, and the desire to improve support to clients around this issue, provided the basis for this project.

**Previous literature**

At the request of ACG, the Ontario HIV Treatment Network (OHTN) completed a Rapid Response review of sexual abstinence among PHAs in North America (Appendix A). The results of the Rapid Response review of sexual abstinence among PHAs in North America yielded 12 research studies. In these studies, participants reported sexual abstinence or sexual dysfunction as a result of their serostatus. The factors that were reported to lead to sexual abstinence among PHAs included treatment, health status; alcohol consumption; stigma, guilt, shame and isolation; low sex drive; length of time since diagnosis, mental health and social connectedness; older age; fear of transmission and other feared outcomes.

1 Lambert, Keegan, Petrak, 2005

2 Bogart, et al., 2006

3 Relf, Bishop, Schiavone, Pawlowski, Bialko, et al, 2009

4 Palmer and Bor, 2001

5 Keegan et al., 2005

6 Siegel et al., 2003

7 Siegel et al., 2006

8 Siegel, 2005; Siegel 2003
However, while the Rapid Response revealed that research exists on this topic, there are limitations and gaps in this literature:

1. The majority of the research presented was conducted in large urban areas, and almost entirely in the United States (one study was from Montreal). The experiences of those living in Guelph & Wellington County may differ considerably, as its medium-sized city and rural area have unique cultures and attitudes towards HIV and sexuality that differ from metropolitan settings in which the other research was based.

2. The review identified a wide variation in factors that lead to sexual abstinence among PHAs. This suggests that particular demographic information impacts sexual intimacy and points to the need for community-driven interventions that are tailored to the needs of the population.

3. Existing research has not sufficiently explored factors and experiences that build resilience and support for enabling healthy sexual relationships.

Although not an extensive review, this literaturescan does reveal a lacking of information that could be relevant or useful to the local community. Using a community-based approach, Show Me the Love addresses issues around sexual intimacy in context that reflects local needs.

**Values and principles**

A number of values have informed the research questions and process. Understanding these values and principles helps to situate the research and its findings.

1. **Principles of Community-Based Research**

   Show Me the Love was informed by values and principles that guide community-based research. These values include: Community involvement and ownership of the project; Benefit from the research to the community which is being studied; and Translation and exchange of research findings to the participants and community. The Working Group Terms of Reference ([Appendix B](#)) provides a greater explanation of the community-based research principles which guided the research process from induction to completion.

2. **GIPA & MIPA**

   The Greater Involvement of People Living with HIV & AIDS (GIPA) and the More Meaningful Involvement of People Living with HIV & AIDS (MIPA) are principles that guide any and all work that is done at the AIDS Committee of Guelph & Wellington County, including service delivery and governance. (Also see the Ontario Accord, which elaborates on these principles, in Appendix C.) The principles of GIPA & MIPA are consistent with the community-based research approach, and make involving the target population a priority in all levels of the research process. The principles GIPA & MIPA also helped to inform the research objectives and questions, which are grounded in inclusiveness, equity, and promoting the health, dignity, and human rights of people living with HIV & AIDS.
3. **Sex Positivity**

In addition to other values, ACG operates with a sex-positive philosophy and approach. Likewise, this research is grounded in the assumption that sexual relationships, activity and pleasure are individual, healthy and positive components to life. This research project is grounded in the belief that HIV positive people have the right to experience and enjoy sexual contact and relationships. This right is listed in the Denver Principles (Appendix D) which states that people with AIDS have the right "to as full and satisfying sexual and emotional lives as anyone else."

These values have helped to shape the research process, reaffirming the importance of the subject matter, and helping to structure the research methodology and approach.

**Research Questions & Objectives**

**Objectives of the research**

The purpose of the research project was to understand the barriers to sexual intimacy among people living with HIV & AIDS. This research design had several goals. First of all, the research was intended to clarify the problem and illuminate client needs, so that ACG could address these issues through programming and service delivery. Secondly, it was anticipated that the research findings may be employed by other AIDS Service Organizations, Community-Based Organizations and other service providers in Guelph & Wellington County or cities with similar demographics, to utilize the knowledge in similar ways, helping to improve conditions for people with HIV.

Specifically, the findings of this project will be used to:

› Identify potential programs and service outcomes that will help ACG respond to the needs and challenges of clients experiencing a lack of sexual intimacy.

› Identify the tools and skills that ACG clients utilize when forming sexual relationships, which may be shared and strengthened through ACG programming.

› Engage other AIDS Service Organizations and community organizations with similar client populations to raise awareness and promote change in programs and services to better assist HIV-positive clients.

› Engage the PHA community and the wider community to address stigma and social barriers to sexual intimacy.

This study was funded by an OHTN Community Based Research Capacity Building grant. As such, one of the intentions with this study was for its contributing members to acquire skills and knowledge that build internal capacity to conduct community-based research. Community-based approaches have been shown to promote more responsive service design and delivery, promoting greater health and wellbeing among
Throughout this project, there was attention to the development of research skills and strategies that ACG could use for future needs assessments and exploration of issues that confront the community it serves.

**Research Questions**

The research questions for the study are as follows:

1. What are the barriers to sexual intimacy as experienced by individuals within ACG’s client community?
2. What are the impacts of these barriers and the lack of sexual intimacy on perceived quality of life?
3. What factors or supports lead to positive sexual relationships as experienced by individuals within AGC’s client community?
4. What services are needed to help meet community needs and priorities?

**Key terms**

Sexual intimacy and celibacy carry different meanings to different people, depending on their backgrounds and experiences. In this study, the term “sexual intimacy” is used to refer to any sexual activity that includes two or more people, and is not limited to, but may include, sexual intercourse. Sexual intimacy in this respect refers to sexual engagement, rather than emotional closeness, and is not limited to monogamous relationships, but may include consenting sexual activity of any kind. Although sexual intimacy may involve emotional closeness for some people, this definition is meant to be inclusive of all forms of sexual intimacy, including anonymous or casual sexual encounters. The term “celibacy” is used to refer to the complete absence of sexual intimacy, whether by choice or by default.

**Research Approach & Methods**

**Researchers**

A community-based research (CBR) approach requires the active involvement of community stakeholders as equal partners in all phases of the research. As mentioned previously, it is driven by a set of guiding principles that value diverse perspectives, lived experience, and mutually beneficial collaboration. To ensure that a diversity of perspectives was included throughout the project, *Show Me the Love* was designed and executed by a Working Group and Advisory Committee.

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9 Isreal et al.; Etowa, Bernard, Oyinsan&Clow, 2007; Schulz, Krieger & Galea, 2001
1. **Working Group** – The Working Group consisted of two co-Principle Investigators, a Research Consultant, a research assistant and a peer research assistant. The Working Group was responsible for the design and implementation of all phases of the research, including project management, data collection, analysis, reporting, and knowledge translation. Working Group members were selected for their complement of experience, and all were able to build their skills over the course of the project. Two working group members are people living with HIV. The Terms of Reference was created to guide the process for working together, which included responsibilities, shared values, and commitments to research ethics and knowledge sharing (Appendix B).

2. **Advisory Committee** – The Advisory Committee provided insight and guidance throughout the project and contribute by sharing the research findings through professional networks and community relationships. Advisory Committee members were identified based on their range of experiences and skills, and their position to both use and share research findings at an organizational and/or community level. One person living with HIV was a member of the Advisory Committee. Advisory Committee members provided input on the interview protocol, ethics applications, interpretation of findings and the development of key themes and messages.

**Interview Protocol**

Eighteen face-to-face qualitative, semi-structured interviews were conducted with clients of ACG by two members of the working group. The interview protocol aimed to understand experiences from the perspectives of the individuals involved. In accordance with the semi-structured interview technique, the protocol was
used to guide the discussion while participants were encouraged to speak about what was meaningful and important to them. Questions were directed at participants’ experiences and feelings around sexual intimacy, and how these may have changed or been affected by HIV. These, combined with further questions about challenges to sexual intimacy, led participants to discuss barriers to experiencing the kind of sexual intimacy they preferred. Participants were asked questions to do with sex, happiness, health, and idealized versions of sexual intimacy. The purpose of these questions was to better understand whether sex was considered to be an important part of life and whether a change or reduction in frequency of sex was interpreted as a significant loss. Participants who identified themselves as currently in relationships, or described previous relationships, were asked questions around successful factors in positive sexual relationships. Finally, participants were asked about services and resources from ACG and in the community, and what could be done to address the challenges they had named. (See Appendix E for the interview protocol).

Because of the sensitive and personal nature of the topic, the research assistants selected had been trained in conducting similar kinds of interviews. They were also provided with resources for referring clients to other services and supports as appropriate.

**Recruitment**

Participants were recruited from ACG’s client community using passive recruitment methods to ensure that no client felt obligated or pressured to participate. Posters and handouts advertising the study were available at ACG’s office and in the neighbouring Masai clinic (a specialist clinic for people living with HIV & AIDS). A digital advertisement ran on the television screen in the shared reception area for ACG and the Masai clinic. Announcements were made and handouts were given during ACG programs. The invitation to participate was also posted on ACG’s website, blog, and Facebook group. A $40 honorarium was given to participants, and participants were able to request an additional honorarium to cover childcare. Bus tickets were provided as needed.

Participation was voluntary and all participants were taken through an informed consent process. Participants had the opportunity to withdraw from the study at any time without any penalty. They were encouraged to contact ACG at any time following the interview if they wished to have any questions or concerns related to the research project. Interviewers provided referrals to the support worker when needed.

The research methods were reviewed and approved by the University of Toronto Research Ethics Board.

**Analysis**

Interviews were fully transcribed. All names and other potentially identifying information were excluded from the transcriptions. The excerpts used in the discussion below are identified by a confidential ID number.

A thematic analysis of the interviews was performed by the working group. This meant that the approach to data analysis was a systematic, iterative and reflective process. The working group met numerous times to develop and refine key themes based on close and repeated readings of the interview transcripts. Preliminary themes were identified, and interview excerpts were organized into broad categories. This involved creating
tables for each category and entering interview excerpts into each table. Tables and interview transcripts were reviewed, and excerpts were sometimes added or removed if they seemed unrelated upon further discussion. The working group then discussed each of the categories in more detail to further articulate and refine themes. Issues and questions for discussion with the advisory committee were noted and shared.

Once an initial summary was prepared, the working group and the advisory committee met to discuss themes and interpretations in detail. The product of this meeting was a more refined summary that focused on key messages.

Research participants were invited to a data validation session that would allow them the opportunity to respond to and provide their input on the analysis. Participants were asked to reflect on and discuss the extent to which the analysis captured and adequately represented experiences.

The discussions with the advisory committee and the participant group validated the initial data analysis overall while providing new perspectives and challenges to certain findings. The input of the advisory committee and participants was reviewed in detail until consensus on each revision was reached and the working group felt confident that the analysis captured the most relevant findings.

The data were richly detailed. Participants spoke openly and frankly about a variety of relationships and social interactions, including those with friends, family members, as well as those with acquaintances and with health care providers such as doctors and nurses. However, because this research project aims to examine barriers to sexual intimacy, the data gleaned on other kinds of relationships is not shared here. The following findings are thus focused on answering the research questions.

In the discussion that follows, the data is organized in key themes that relate to the original research questions.

**Research Participants**

In total, 18 clients of ACG participated in the research. The majority lived in Guelph. Demographics were consistent with ACG’s client population overall, and were as follows:

- **Age:** The average age of participants was 49 years old, ranging from 34 to 69.
- **Ethnic/Cultural Background:** 15 identified as white; 2 identified as North African; and 1 identified as Aboriginal.
- **Gender:** 13 men and 5 women.
- **Sexual Orientation:** 8 identified as gay; 6 identified as heterosexual; 3 identified as bisexual; 1 identified as uncertain.
- **Relationship Status:** 14 reported being single; 4 reported being in a current relationship.
Years Living with HIV: Participants on average had been living with HIV for 14 years, ranging from 1 year to 32 years. More specifically:

» 5 participants had been living with HIV more than 20 years
» 6 participants had been living with HIV 11 to 20 years
» 4 participants had been living with HIV 5 to 10 years
» 3 participants had been living with HIV less than 5 years

The following section presents a detailed discussion of the research findings. These emphasize the most dominant themes related to sexual intimacy, including barriers and implications for quality of life. Many of these themes intersect, building a web of factors and processes that influence participants’ perceptions, decisions and actions.

Findings

During the interviews, the participants expressed a number of barriers to sexual intimacy that significantly intruded upon their ability to experience sexual relationships and sexual encounters, sometimes leading to celibacy, as a choice or as a default. Across cohorts of gender, sexual orientation and relationship status, participants described a number of barriers that related to HIV status, often centring around stigma and fear, while other experiences such as trauma, aging, and lack of connectedness to a gay community further complicated matters.

In the following discussion, these barriers to sexual intimacy are presented. The outcomes of these barriers and the impact on participants’ lives are then discussed. Some of the participants shared positive experiences and the insights drawn from these experiences are presented as factors that support greater sexual intimacy. However, these factors are few and are outweighed by the number of barriers to sexual intimacy described. These factors are also overshadowed by the notable finding that each of the participants interviewed described celibacy or a loss of sex associated with HIV.

Barriers to Sexual Intimacy

There were a number of barriers to sexual intimacy that created significant tensions for the participants. These barriers were often interconnected and very much associated with the stigma of living with HIV. Many negative experiences emerged through the interviews. A number of participants related experiences of trauma that included childhood sexual abuse, intimate partner violence, housing instability, addiction, and other experiences of instability and exclusion. While these experiences and relationships were not the focus of the research, it was clear they influenced decisions about sexual intimacy and celibacy, as did participants’ approaches to managing disclosure and meeting new people. While it was not possible to isolate HIV from other experiences in the participants’ lives, it was clear that HIV added a distinct layer of complexity to sexual experiences that may have been already complicated from marginalization or trauma.
Barriers to sexual intimacy included: **Fear of transmission**, often associated with anticipatory guilt and sense of responsibility to protect others; **Fear of rejection** associated with disclosure; **Social isolation**, including “self-preservation” techniques relating to experiences of rejection, as well as challenges in meeting new people, often resulting from aging, a lack of a strong gay community in the area, and poverty; and **Negative self-perception**, including body image issues as a result of HIV, medications, and aging.

1. Participants expressed a deeply-rooted fear of transmission as well as the fear of hurting someone through exposing them to HIV. These fears were then in turn connected to feelings of anticipatory guilt and deep sense of responsibility to protect others.

There were a number of participants who expressed a deeply-rooted fear of infecting their partner. This fear appeared to be driven by the weight associated with the imagined consequences, even if transmission would be unlikely. Some participants conveyed an exaggerated sense of risk and appeared to have incorrect information about transmission risks. Others feared transmission even if they were aware the risk was low. The “what if” scenarios these participants described carried more weight than the actual likelihood of transmission. This fear led participants to dismiss reassurances from their doctors as well as from their partners. Often they reported that a partner’s reassurance and willingness to take the risk was not enough to overcome their fear. Imagining the potential harm and guilt they would feel if their partner acquired HIV outweighed everything else.

“[My doctor,] she says, ‘you can [have sex] now.’ I just don’t want to take a chance.... There are circumstances that could go wrong that could affect their life ...I felt ... suicidal when I first got it. ... I won’t have sex. I might pass it on. I won’t take that chance.” (P13)

“I’m scared to have sex now. ... Because I’m terrified of infecting my partner, and the funny thing is, my partner has said I know you have the virus, I’m perfectly willing to have sex with you, it’s not a problem for me. But ... I’m not willing to take that risk ... for me, it puts a damper on things, and I don’t want to have sex now.” (P01)

Other participants described similar distress when learning they were HIV positive. These feelings further contributed to their fear of transmission. For some, transmission was strongly associated with the feelings of betrayal, violence and victimization that they associated with acquiring HIV. Others characterized transmission as a “death sentence.” They emphasized that they would not be able to live with themselves if they infected someone else.

In the following excerpts, participants express their reactions to acquiring HIV. They also very negatively characterize the person who transmitted the virus to them. In one excerpt, the participant discredits the entire relationship he was in as a “betrayal”. These are powerful characterizations that appeared to entrench some participants’ determination not to have sex.

“When I was diagnosed HIV - and I know how I got it, from who - I just thought, ‘Well, you just murdered me. You wrecked my entire life.’” (P15)
“I am scared that, you know, what if I made him sick? ... Because of the fact that I would go off the wall, personally, because that’s one thing that used to be on my mind all the time, what if I get him infected.” (P06)

“To me it just comes down to that whole betrayal. You know, with the relationship that I was in when I was infected. To me that whole relationship was just straight up betrayal. So having that kind of feeling, and thinking about it in that sort of way, it’s like, I don’t even know if I could live with myself if I knew that I got somebody infected with HIV.” (P11)

“You have an incurable disease, and you don’t want to sleep with somebody and then end up giving it to them, because that’s going to be a guilty feeling. ... I don’t ever want to feel that ....thinking that I’ve hurt somebody in that way ... it’s almost like giving them a death sentence.” (P19)

Anticipatory guilt was connected to the fear of transmission. Anticipatory guilt also emerged in relation to the need to protect others from loss and grief. A few participants explained that they were avoiding an intimate relationship because they wanted to protect someone from having to go through what they saw as inevitable loss. They saw it as hurting someone and could only imagine how bad they would feel if another person had to watch them die.

“I don’t want to get into another relationship, because I don’t want to be getting hurt, or even hurting that person that I’m with in time. Say I get really, really sick and I’m on my deathbed. I don’t want them to have to go through that agony and pain of watching the person that they love die.” (P06)

The fear of transmission and the fear of hurting someone spoke very strongly to a need to protect others, which surfaced continually through the interviews. This need appeared again in identifying factors that supported sexual intimacy and positive relationships.

Disclosure was also an experience that appeared both as a barrier to sexual intimacy and as factor that supported positive relationships. As a barrier, struggles with disclosure were tied to fear of rejection.

2. Fear of rejection was associated with disclosure, including delaying disclosure or avoiding disclosure by avoiding intimacy.

Not all participants expressed challenges with disclosure. Many participants talked about needing to be up front about HIV, reporting that they told potential partners about their status right away. For some, this strategy was clearly associated with the desire to “weed out” anyone who would reject them. This strategy was used to prevent attachment in case of rejection. Participants characterized this strategy as “self-preservation”.

“I always disclose. I’m not interested in anybody that – if they don’t want to be around me because I’m HIV positive, that’s fine. ... I’d rather them not be in my life. It’s that simple. It’s really straightforward for me.” (P03)

“When you first meet and say, ‘By the way, I’m HIV positive. If that’s a problem with you, or if you just want to be friends, that’s fine.’ Because then you get feelings, you like the person, you want to have sex,
and then you divulge or disclose and ... if they say, ‘Well, I can’t handle that.’ Then it’s like a rejection, so maybe it’s better to do that right from the start and say ‘By the way, I’m HIV positive.’ I think that would work and be better for me and the other person, so we don’t get this bond or any attachments.” (P05)

When put forward as a matter of course, as in the first excerpt above, disclosure was not as frequently related to expressions of anxiety or fear. Waiting to disclose until one was sexually interested or intimate with a person, however, was associated with stronger experiences of anxiety and fear. Waiting to disclose was also more often associated with stories of rejection. Participants’ fear and struggles with disclosure were well-founded. Some participants shared rejection experiences, including having partners respond with anger or having partners turn away.

“One was a pretty definite rejection, ‘I don’t think we should see each other, I don’t want to see you anymore.’” (P10)

“There was one time when I met someone and we were getting all hot and heavy and I told him that I am HIV positive and he basically got up and left. Didn’t say anything. Just got up and left. And what do you do? I mean, you just got to let him go. They do what they want to do.”(P14)

As shown in the next excerpts, participants also expressed challenges in dealing with the ignorance and fear of potential partners.

“Now I’m scared to even approach people, I’m saying, oh god, will I be rejected, or will I be turned down? So really I’ve got my guards up ... and it’s like, I don’t want to deal with this crap. It just gets to me, I find it very, very difficult. Because if I like someone... then [disclosure’s] a hurdle that you have to cross, and some people are knowledgeable and willing to – will go on, but on my part it’s something that I have to deal with that I haven’t dealt with very well” (P05)

“I had known this guy for years ... the whole night I’d been trying to figure out how I was going to tell him that I was HIV positive. Ok, but I never could get it out until we were in bed, we hadn’t done anything yet, but - and then I told him and he got up and got dressed and left. Then I never talked to him after that. He did leave a few messages on my machine, apologizing, saying he’d like to get together again and start over, but - I never called him back ... I should have called him back.” (P04)

Captured in the following excerpt, one participant explained that when her partner admitted to being scared, she “cut him off.”

“He wanted to go further and ... I would back off ... And there was the last time, I had a couple drinks in me so I had the nerve to basically tell him ... I also tried to educate him at the same time, and he was fine, it was a great reaction initially. He had also been drinking though, and still wanted to pursue having sexual contact with me, and I refused it, because I wanted him to absorb the information. You know, wait ’til you’re sober. And so it was the following time I had seen him, he basically admitted to being scared, and I just ... didn’t want to deal with it so I just cut him off.” (P18)
Cutting others off was not unusual. A number of participants described not calling someone back or letting someone go. In some situations, participants reported pulling away completely rather than having to tell someone they were HIV positive.

“There is a fellow … I met once. We had coffee last year, he’s head over heels for me. He wondered why I pulled away – I tested positive – I never told him why. He’s given me his phone number and, you know, he’s just a super nice guy, and I’ve withdrawn … I think that he deserves a phone call explaining, but I just ... feel I’ll lose all contact, or I’ll gain pity or sympathy. I don’t want that. ... I’ve aborted some connections just because of this.” (P17)

In these excerpts, there are multiple sources of anxiety associated with disclosure. There is a strong fear of rejection, and there is also a sense that participants needed to avoid additional emotional burden. A number of participants reported not wanting to have to deal with others’ fear or reactions to learning one was HIV positive. They explained that they avoided or pre-emptively ended relationships as a way to protect themselves.

3. **Putting up barriers, while a way to protect one’s self from being rejected, was also related to isolation. Social isolation was a barrier to sexual intimacy.**

Avoiding relationships and sex was connected to experiences of isolation. The excerpts below show how participants described putting up their own barriers to avoid getting close to someone. These “self-preserving” barriers were intertwined with experiences of stigma and uncertainty. For these participants, isolation appeared to be easier to manage than rejection. These excerpts also suggest the ways in which participants internalized stigma.

“There’s actually been a few of them - people that have been interested in me and people that I’m interested in. And they just haven’t worked because I put it off. It’s something I can deal with and I think it’s something they can’t deal with, or I’m going to get rejected by them.” (P02)

“Yeah, I would love to have one [a relationship], but I can’t get past myself” (P04)

“Now I’m scared to even approach people. I’m saying, ‘Oh god, will I be rejected, or will I be turned down?’ So really I’ve got my guards up and it’s like, I don’t want to deal with this crap.” (P05)

“As soon as you tell that person, it’s gonna be like Roadrunner: beep beep, gone. You know what I mean? I know if somebody told me that, ‘Well, I got HIV, wanna have sex?’ I’d be like, ‘No way, you’re fucking crazy!'” (P13)

“There is a bit of shame, because you’re afraid to tell somebody, because you’re afraid of, will they still want to be your friend? And will they still be in your lives? ... It’s all the ‘what ifs.’” (P15)

Isolation was also connected to constraints in meeting new people; this was particularly true for the men – of all sexual orientations – in our sample. Most of the women in our sample were in relationships, and social isolation was not as predominant a barrier.
4. **Challenges in meeting new people/potential partners created barriers to sexual intimacy, especially for the male participants.**

The experiences of the gay/bisexual men in the sample show how living in a midsized city or rural area can be isolating. According to the participants, the city of Guelph and surrounding county, lacks the presence of a strong gay community. Many reported that it is not easy meeting new people, especially as one gets older. There was sense that one lives with the ‘triple jeopardy’ of being gay, living with HIV, and being middle-aged. Many questioned where one may even go to meet new people, as seen in the excerpts below.

“Where the hell do you go to meet someone? At my age, where do you go? ... Yeah, I don’t go out to bars, I’m not a bars person. Don’t go to the baths. ... What’s left?” (P3)

“Unfortunately [this town] doesn’t have a gay vehicle, apart from the [name of a local bar] on Thursday nights. By the time that gets going, I’m at home in bed. And most of the people in that crowd are, again, straight or just too young. There isn’t a place where men like myself can go.” (P14)

“[This city] sucks, you know? It’s a tough place to be when you’re gay and single and middle-aged... It just seems like there’s very little opportunity to meet people locally.” (P17)

These excerpts also emphasize the connection between age and meeting someone new in the gay community. The gay male participants frequently spoke of ageism in the gay community. Being older, or “middle-aged”, was another stigma on top of living with HIV. As the second excerpt below suggests, accepting the ideal of a “perfect young man” reinforces ageism and stigma. Confronting the experience of not being, or able to attract, the “perfect young man” seemed to be further connected to a sense of diminished self-esteem and body image.

“The minute you tell anyone over 40 that you’re poz, they’re out of there. That’s what I’ve found.” (P03)

“Now that I’m older, ageism is very much a component to this whole lack of sexual activity right now. ... It’s certainly more prominent in the gay community ... but I mean, even us older gay men pursue younger men because of that ideal, right? The perfect young man.” (P14)

The gay men in our sample who had difficulty meeting new people often noted that the bars and bathhouses were not their scene. Social media and online strategies did not meet their needs either. Dating sites targeted to HIV positive people were seen as not engaging or exciting. HIV positive dating sites also raised the issues of stigma and backlash.

“Call me old-fashioned, but I would rather meet someone accidentally, on the street. I would rather meet someone being introduced at a dinner, a party - something like that - rather than meeting someone online. There’s just a whole coldness to that that I don’t appreciate. And it does nothing to get my mojo going, so to speak.” (P14)

“I put my profile on two positive dating sites. It took me a while to do that. But three quarters of the profiles on there have no photograph, but I put my photograph on there. And I just thought, you know, what are we doing? ...Yes, there’s a small chance that someone we know who’s negative might come on,
might create a profile and come on just to see who’s positive, but ... I just felt that that was an example of perpetuating the stigma. Here on the HIV positive dating website, almost everybody doesn’t have their picture on, just a few courageous people.” (P17)

The straight men also described meeting new people as a challenge and barrier to sexual intimacy. These men reported not knowing how to approach women or how to tell a woman one is HIV positive. They recognized that telling a woman one was HIV positive would lead to rejection.

“I can’t speak sometimes. Shy to speak to her, ‘I have virus.’ ... I need to have a girlfriend. But, this virus make me feel like I’m in jail... I need it – but how? I’m scared sometimes, scared to find some woman and say ‘I have virus,’ and she go far away from me.” (P20)

Challenges to meeting new people were further connected to the financial constraints imposed by living with HIV. A few participants noted that having less income meant that they cannot afford the usual ways of meeting sexual partners by going to bars or being able to go out on dates. Limited income also meant that it can be difficult to maintain good self-presentations since going shopping for clothes or going to the gym was unaffordable. Far from insignificant, these constraints had a negative impact on how participants in these circumstances felt about themselves.

5. Another barrier to sexual intimacy was negative self-perception. In addition to the experiences of stigma and fear of being rejected, participants expressed concerns about physical changes and relayed a diminished sense of body image.

Participants described changes to their bodies that were related to living with HIV. These changes diminished their sense of body image, which further inhibited their desire to be sexually intimate. They expressed concerns about whether others would find them attractive. As seen the excerpts below, participants reported feeling uncomfortable when undressed. Feeling badly about one’s self and discomfort with one’s own body was connected to avoiding sexual intimacy. Participants expected others to not be attracted to them.

“I think the meds played a role in changing my body ... That’s a big factor actually, it’s hard ... to always feel good about yourself because you’re aware of those changes, and that’s probably another element that interferes into a relationship, because you want the person to like you, but you know what you look like now and you don’t look like you were [before HIV].” (P04)

“I won’t even take my shirt off ... there’s nothing really, it’s all in my own head, it’s only like an inch [of fat], but .. I just don’t like the way it looks. I had a nice hard six pack here, it was hard, but when I took the Kaletra I could slowly see it softened up, softened up.” (P15)

“When you look like shit and feel like shit, you’re not going to want to have sex.” (P12)

Physical changes were associated with HIV medications. The participant in the first excerpt above (P04) further explained that he had not been told about the side effects of the medication, and now he was left dealing with unexpected changes to his body. Both these excerpts reveal the self-consciousness that was
associated with the contrast between the before and after of living with HIV. This contrast was particularly discouraging for some participants.

In the excerpts below, participants note the effects of medication and how these interact with age. They also expressed their need to be seen as attractive, an important part of sexual intimacy.

“That [HIV medication] and my age has attributed contributed to it ... and I’ve noticed it especially in the past year, that I don’t feel handsome, good-looking, sexy. It’s not for lack of trying ... And that’s more from the medications than it is from anything else.”(P14)

Physical changes that diminished participants’ body image and feelings of attractiveness included lipodystrophy (irregular fat deposits), fluctuating weight, poor teeth, fatigue, insomnia, and lack of energy. One of the men mentioned erectile dysfunction and one of the women, lack of vaginal lubrication. While these changes were seen to be associated with HIV and medication, some were also seen to be in part related to age. As seen with the challenges to meeting new people, the effects of age again intersected with those of living with HIV.

All of the participants described barriers to sexual intimacy associated with their HIV status, and as seen throughout this discussion, these barriers were quite strong. Most predominant in these barriers was the fear of transmission. This fear was driven by anticipatory guilt and the need to protect others. This fear outweighed reassurances about risk and was tied to the experience of trauma associated with acquiring HIV. Rejection was also a predominant barrier to sexual intimacy, leading some to avoid sexual relationships altogether. For these participants, isolation was easier to manage than the hurt associated with being rejected after disclosure. Anticipated rejection and the stigma of living with HIV were then also associated with challenges in meeting new people. For the gay men in our sample, these barriers were further compounded by what they described as ageism in the gay community. Straight men also noted challenges in meeting and disclosing to women. Lastly, negative body image, particularly the self-consciousness of the change from before to after living with HIV, inhibited sexual intimacy.

**Impact on Quality of Life: Celibacy**

As a result of the barriers to sexual intimacy, all of the participants described a loss of sex due to HIV. For some participants, this meant fewer sexual encounters or infrequent sex with a partner. For others, this meant complete celibacy. The impact of celibacy often led to experiences of isolation characterized by a lack of relationships and other kinds of touch and connection, which seemed to be missed as much, or more, than sex itself.

1. **The most predominant impact on participants’ quality of life was celibacy.**

It was anticipated that the research would reveal a range of relationships and expressions of sexual intimacy. However, most participants reported being celibate. Some participants had determined they would remain celibate as a way to avoid the risk of rejection and the risk of transmission. Their anticipated feelings of hurt, guilt and grief were too great for anything else. Some were celibate because they were uncertain about themselves and finding sexual partners. For others, their partners ruled out sexual intimacy. For many
participants, living with HIV meant coping with not having sex. Celibacy was seen as the reality of living with HIV.

“I’ve remained celibate. And that sucks sometimes, you know. ... You just get used to it after a while and you just deal with it. ...Because I won’t do it, it’s not worth it. Some people will, but I’m not going to take that chance.”(P13)

“She was quite definite right from the beginning that there would be no more sex, period. We have stayed together, in what is a good platonic relationship. But that’s it. I have asked her a couple of times if she would consider sex, obviously protected sex, but no, she said she is not at all interested in that. And I live with that.”(P10)

The predominance of celibacy did not mean that sexual intimacy was unimportant. Indeed, in the first excerpt above, the participant points out how not having sex “sucks”. He was not alone in this feeling. Participants regularly noted the importance of sex to their happiness and wellbeing. Not having sex was connected to feelings of loss. Participants who were celibate reported that they missed having sex and that they missed being intimate. In each of the excerpts below, participants emphasize the connection between sex and happiness.

“I would expect I’d be a little bit happier if there was someone in my life and I had sex with them. It don’t think sex is the be all and end all...[but] other things branch off from there - into intimacy, sharing, you know.”(P03)

“I just avoid sex and thinking about it ...I think you if have a good sex life, it makes you happier, makes you more balanced. It should be part of your life. I know – it’s not part of mine, and it should be.”(P04)

“I think I would be a lot happier if I did have sex, in reality. Because it’s been so long, and I do miss it... If you do have a healthy sex life, you are a happier person – because that’s part of life. You need it to survive, in my opinion.”(P15)

“Sex is very important. ... I love sex. I love sex because with sex, you go happy. ... It’s very important. ... Sex is like honey – you know honey? Very sweet.”(P20)

Along with being happier, sexual intimacy was seen as a way to feel better about oneself.

“When I’m sexually active, I feel better about myself. And there’s that whole body chemistry thing where you have a release of certain chemicals in your body that makes you feel more positive about yourself, and gives you a more positive perspective and outlook on life in general.”(P14)

These excerpts suggest that participants were not as happy as they would be if they were having sex. They noted that they missed sex while at the same time suggesting they were resigned to celibacy. Participants explained that they were trying to learn to live without it, and just “deal with” the fact that sex is not a part of their lives.

“I miss it. I really, really do miss it. But I know I can’t have what I had.”(P01)
The next excerpt shows how some participants diminished the importance of sex, characterizing it as “not the be all and end all.” By comparing sex to chips or candy, the participant positions sexual intimacy as an indulgence rather than as a vital part of wellbeing. This comparison reveals a tension experienced by some participants. This tension, and the need to cope with it, arose from having to balance one’s awareness that sexual intimacy is important to happiness with the belief that one cannot have it.

“I don’t depend on any one thing to make me happy. Yeah, it feels great to have sex, of course it does. But it also feels great to eat a bag of potato chips or to eat a candy bar or some truffles or something. ... I don’t put a whole lot of bearing on sex, to be honest.” (P16)

Even if not all participants put a “lot of bearing on sex”, they did emphasize the importance of intimacy, of closeness and touch.

2. Celibacy and isolation also meant that there were fewer opportunities for participants to be close to a significant other, with or without sex. For some, just being close to someone was their ideal.

Though sex mattered, there was also a strong emphasis on physical contact and close, comfortable relationships. Some participants emphasized that being close to someone who mattered to them was very important to their happiness.

“I don’t want the one-night stands. I don’t want the casual. I could probably still do that, but I don’t want that. I want to actually settle down with somebody.” (P02)

“I’m by myself. I’m single. And like I said I’d rather cuddle than anything else.” (P12)

“I would have to say that for me, an ideal sex life would be having regular sex ... just having that physical contact with someone. And it doesn’t even have to be sex, per se. It could be something as intimate as sitting on the couch and cuddled up watching a movie, you know? Being able to walk down a street arm-in-arm, or hand-in-hand. Just having that physical contact.” (P14)

“One thing I’ll say is touch is as important as nutrition. It’s as important as sleep. So, if you’re not getting delightful, wonderful touch – it doesn’t have to be sexual – but ... you know, our skin is the largest organ of our body, and I think especially if you’re immune-depleted, you don’t need only great nutrition, you need touch.” (P17)

This last excerpt emphasizes how vital intimacy is to wellbeing. The participant further emphasizes that the need for touch is as important as nutrition to the health of someone living with HIV.

These findings clearly reveal the ways in which HIV add layers of complication to negotiating sexual intimacy. The following figure presents a view of how the barriers to sexual intimacy were connected. These barriers, including fears related to the risk of transmission, the risk of rejection, to diminished sense of esteem and body image, or to social isolation and opportunities to meet new people, were not isolated streams of influence. The result of these interconnections is that most participants are remaining celibate.
Factors or supports that lead to positive sexual relationships

The interview protocol was designed to ensure that participants had the opportunity to discuss ways that they had been able to achieve positive sexual relationships. It was anticipated that some participants would have experiences with positive sexual relationships, and that identifying factors or supports that contributed to these experiences could be shared with others. However, not all participants were able to offer ideas on what may contribute to positive sexual relationships. Suggestions were somewhat sporadic. The participants who were able to identify supportive factors in positive sexual relationships focused on disclosure and the need to protect others. When it came to agency or community supports, opportunities to build informal connections with PHAs and further opportunities for specialized counselling were identified as potentially beneficial.

1. A more positive, proactive approach to disclosure was believed to support stronger relationships. This approach is distinguished by feeling that one has the right to be open and honest.
A positive approach to disclosure was associated more with feeling entitled – like one has the right – to be open and honest rather than with feeling shame and stigma. Disclosure was seen as having the potential to support, or at least not to be a barrier to, sexual intimacy when it occurred early in the relationship. Early disclosure was important, but participants were also clear that it should come after having some chance to get to know each other. Participants believed that disclosing well before sexual intimacy would lead to better relationships.

“I find that everybody that I disclose to, especially if it’s been in an intimate kind of situation, they are more thankful that I’ve disclosed ... If I’m about to be intimate with somebody then don’t I deserve at least to be honest with this person?”(P11)

“Why beat around the bush? Eventually, everything comes out of the closet anyway, so you might as well be honest right off the bat. You know? And that’s just the way I have been with everybody. A lot of people admire me for being that direct – simply because, there’s no bullshit.”(P15)

“If I talk to a guy on the phone and on a chat site, I don’t tell them then... and then either through phone chat or second meeting, then tell them. ... The way I’m doing it is I want them first to just experience me as me, and let that resonate or not with them, and then throw them this curveball.... I’m strong enough to disclose, you know, psychologically and all that, so I’m not afraid of doing it.”(P17)

“If I get involved with anybody, with any man, any partner, I let them know right away. This is the way it is, I’m HIV positive. We can take it from here, or we don’t have to. I’ve given every man who has ever been involved with me the option of being protected or not protected. I leave that decision up to them.”(P19)

Disclosure in this sense was associated with feelings of strength and a more positive sense of self, as seen in the quotes below.

“Being honest increases our self-esteem. So that would be something I would say, is if you’re having self-esteem issues, then be honest with people and be honest with yourself, and keep your chin up.” (P17)

“I can’t let fear of something cage me in. I’m not going to let fear guide my life, I’m going to live my life. You know, my husband knew my status before we got married and he chose to be with me.” (P16)

In the following exchange between the interviewer and P14, the connection between disclosure and stigma is made explicit. The participant also emphasizes the importance of education.

Interviewer: “Some people mentioned having an idea who you can and can’t disclose to. Is that something you can relate to at all?”

P14: “No, in all honesty. Because that right there is where stigma - the negative stigma - comes from. That’s us perpetuating it. We have to talk to everyone, whether or not they – that other person – can handle it or not. We have to educate people, it’s up to us to do it. ... They cannot like what they’re hearing, that’s entirely up to them. But they have to know that we’re normal, functioning people, just like anyone else, for the most part.”
other’s health. HIV education, being open about risk and practicing safe sex were also part of protecting one’s sense of self and other’s health, and were seen as ways of supporting more positive sexual intimacy.

Participants were strongly motivated by their concern for and need to protect other’s health. Though for many participants, this concern was associated with an exaggerated fear of transmission, others described being comfortable with being the responsible one in the relationship. Positive experiences of sexual intimacy were associated with being safe, such as by insisting on using condoms. As demonstrated in the last excerpt below, being safe and responsible was connected to feeling more positive about oneself.

“I’m more concerned for the other person as well. I’ve had sex partners who have wanted to have unsafe or unprotected sex where I’ve had to say, ‘No, we can’t do that, I can’t take that responsibility.’” (P14)

“I’m concerned about my own health. Part of my relationship with another person is that I be concerned about that person’s health, too. So, that’s another aspect that’s important to me … these things have to be mutual, and so it can’t be all one-sided.” (P10)

“I have to think about my husband’s safety. And I won’t allow him to do anything without a condom, because I care too much.” (P16)

“I don’t believe that I have the right to engage in whatever behaviour I want because that’s what I want to do to make myself happy. … Who has that right? … I think that at the end of the day it’s better to be on the side of the people who are playing safe. I’m able to look into the mirror and like the person that I see because I know I’m playing safe.” (P11)

A few participants explained that when behaviour was risky, it was important to encourage a partner to get tested. A few others noted the importance of having a partner who was well-educated about HIV. Education, it was believed, helps one’s partner make an informed decision. These examples suggest that positive experiences of sexual intimacy are supported by sharing some of the responsibility for the risk of transmission.

“The only time I did something really risky was when I was with somebody else and a condom broke, and he was stoned at the time and he just didn’t care, but I cared. So I told him to go make coffee. … I made him get tested twice, three months later and six months later and he’s fine.” (P02)

“We’ve always had unprotected sex. … He knows the ins and the outs of it [HIV], I guess, and from what I’ve taught him and what he’s read, he used to study it all the time. … He tells me not to let it bother me.” (P06)

“By working with him, you know, telling him about [HIV] … making him more educated, I guess. … Yeah, communication made it better. Being honest, and not keeping things from [him].” (P19)

When asked about what supported sexual intimacy and sexual relationships, a number of participants offered encouraging advice. They emphasized the need to keep a positive perspective, not let fear dominate and not let HIV become the sum of one’s sense of self.
“I just don’t let it [HIV] become the definition of me. A lot of the time I don’t even address it through a day. The only time I think about it is when I have to take my goddamn medications. But that’s it. ... It’s a non-issue. It really is. I always, always, always tell people. And I’m not afraid of losing a job, or losing a friend, or something like that. I realize those realities are out there but it doesn’t affect me. ... I can’t live my life assuming that they will. Neither should anyone else.”(P14)

“You’ve got to be comfortable in your own skin. You have to. You’re all you have. Everywhere you go, there you are. You know you can’t run away from a disease, you can’t run away from whatever situations we put ourselves in. This is our bed, you have to sleep in it. ... I could very easily sit at home and be the most angriest person ... But what is that going to achieve? - Understand? What? Nothing. That’s not going to achieve anything.”(P11)

For some participants, the opportunity to convey a sense of hope and determination, and encourage others to be strong, was said to be one of the reasons why they participated in the research project. This motivation reflects the next theme, which describes participants’ emphasis on the need for both formal and informal support.

3. **Formal and informal systems of support were also thought to be way to help PHAs with relationships. Though not top of mind – few mentioned it without being asked – counselling and peer groups were recommended.**

When asked about the role of formal support, almost all participants strongly commended ACG and the contribution it makes to the PHA community. Many participants named ACG as the only community agency that they utilized, especially for counselling and support – an important finding in itself. Participants asked for more informal opportunities for getting together with other PHAs, as well as having these get-togethers outside the agency. They also asked for more one-on-one counselling, especially specialized forms of counselling.
Discussion

Untangling HIV from other experiences

HIV is only one factor among many that influences sexual intimacy. Risk, rejection, the concern for others, disclosure and stigma as well as age, physical wellbeing, appearance and body image do not exist as separate streams of influence or isolated variables. They intertwine in complicated systems that lead some participants to fear and struggle with a negative self-image. In the rich data presented here, it may be difficult to untangle what are pre-existing issues for participants and what emerged after being diagnosed with HIV. A number of participants experienced trauma earlier in their lives. These experiences have undoubtedly influenced their self-perception and their sexual relationships, and it is possible to see how these participants continue to carry the weight of these experiences with them. However, while recognizing that some of the barriers named here are bigger than HIV, it is also important to realize that living with HIV adds a distinct layer of meaning and significance to people’s perceptions and experiences. For the participants interviewed, HIV presented barriers and burdens that were difficult to overcome, in many cases leading to celibacy and isolation.

Shouldering the burden of risk and responsibility

The prospects of developing and maintaining sexual relationships while living with HIV are complicated by social and physiological realities, such as presence of stigma and the fact that that HIV transmission is harmful and potentially traumatizing. No one is more aware of the effects of HIV than people living with disease themselves, and the participants in this study were aptly aware of these risks. A strong sense of responsibility to protect other people from these risks appeared to be, for some, a source of self-esteem, but it also appeared to be a large burden to shoulder. Participants revealed themselves to be the primary decision-makers around risk management in relationships or sexual encounters. In addition, participants described having to manage disclosure, and manage partners’ reactions - especially fear. Carrying responsibility for other people’s health and emotions, as well as one’s own, were revealed to be extremely challenging - so challenging in fact, that many participants resorted to celibacy.

The impact of celibacy on quality of life

While celibacy may be a valid choice for some people living with HIV, it is important to recognize that the participants identified loss of sex as having a negative impact on their lives. While a few stated that they did not place a high value on sex, most participants identified sex as an important part of life, contributing to intimacy, happiness, self-esteem, or a “positive perspective and outlook”. As a result of celibacy and social isolation, participants also reported missing out on other physical but non-sexual components of relationships, such as cuddling or walking hand-in-hand, which were in some cases placed at a higher value than sex. While this research did not set out to carefully examine the impact that celibacy or social isolation has on health, it is clear that for these participants, celibacy or infrequent sex was experienced as a loss.
**Loss of sex, despite relationships**

It was anticipated that this research may reveal differences between the experiences of participants in long-term relationships and the experiences of participants who were single. Instead, there were many similarities in barriers and coping strategies across cohorts. Lack of sexual intimacy was a common experience, even among those in relationships, revealing that barriers presented by HIV did not disappear, even in committed, long-lasting relationships. HIV positive partners appeared to be the primary decision-makers when it came to managing risks in the relationship, and these decisions were complicated by fears of transmission and anticipated grief. Therefore, being in a relationship did not eliminate these barriers to sex.

**Internalized stigma**

The social meaning associated with HIV—however wrongly—is predominantly negative and reflective of intense stigma. While some participants described their efforts to construct a positive sense of self, experiences of stigma were a recurring theme in the interviews. Early disclosure techniques were seen as being a potential source of self-esteem or even being the precursor for sexual relationships, but fear of rejection provided a barrier to sexual intimacy, sometimes leading participants to curtail budding relationships. Fears or rejection were not unfounded, as most participants had experienced rejection due to their HIV status.

While the presence of stigma is not surprising, it is worth noting that the experiences of internalized stigma—especially though anticipated rejection—sometimes led participants to end what could potentially have been positive relationships. Examining internalized stigma and its outcomes, especially in new or developing relationships, may present an important consideration for service providers.

**Limitations**

This community-based research study was meant to gain an understanding of issues faced by clients of Guelph & Wellington County, which could help ACG respond to the needs identified through programming and service delivery. Therefore, the methodology employed was meant to provide rich qualitative data specific to the local community, and not necessarily be representative of the larger population. The experiences and perceptions uncovered by the research may not hold in other communities, contexts or cohorts. Nevertheless, because fear, stigma, disclosure and social isolation are common experiences among PHAs, it is likely that these findings will still resonate outside the walls of ACG. Furthermore, the population of Guelph, a midsized city, and its rural surrounding area, constitutes a geographic size that is shared by many other neighbouring cities, such as Kitchener, Waterloo and Cambridge, London, Windsor and Hamilton, as well as many cities north and east of Toronto. The challenges of living in a city that is not a major urban centre, especially for individuals identifying as gay or bisexual, are likely to be shared. Therefore it is anticipated that these findings will provide important considerations for other organizations and service providers working directly or indirectly with PHAs.

The older average age of our participant group may have set a particular context for understanding the findings of this research. A number of participants emphasized the importance of intimacy, with or without sex, and the desire for close, committed and monogamous relationships. As well, a few participants reported
disliking online dating sites. It is unclear if these findings would be similar for a younger group. A younger cohort may be more comfortable with online services for meeting people. They may also place less emphasis on the need for different types of physical closeness. It should be recognized that having captured an older age group, our research does not speak to the needs and barriers of experienced by younger PHAs, which may present a future opportunity for follow-up research.

While the findings confirm what ACG has heard from clients, it’s important to keep in mind that experiences and perceptions about sex may fluctuate over time; what one feels or thinks about oneself can change and relationships can change as well. What works in terms of disclosure or negotiating risk may be effective for some participants or in some circumstances, but not others. This variability is also true for integrating HIV positive status into one’s identity, which sometimes takes a central role and sometimes retracts into the background. Thus, one should be cautious when responding to the barriers listed here, as well as the factors that support sexual intimacy. What participants spoke about was both important and authentic, but may not be lasting. Furthermore, a number of participants had been living with HIV for more than 10 years. Examining how perceptions, experiences and needs change overtime may be another potential area for follow up research.

**Implications**

A number of implications have been identified from this research. Some of the implications are to do with programming at the AIDS Committee of Guelph & Wellington County, but many more are relevant to other service providers, activists, community members and PHAs.

**Beyond “prevention”: validating the need for sexual intimacy**

In the Background to this study, it was stated that GIPA & MIPA and sex-positivity are values of the AIDS Committee of Guelph & Wellington County, which are shared by many other providers and in this field. These values may help to guide the interpretation of the results, especially in terms of identifying implications. This research raises the question: What, as providers, can we do to support PHAs who experience challenges in sexual intimacy? With advances in treatment, HIV may be considered a chronic, manageable disease, leading HIV service providers to focus on supporting people to live well with the disease. It follows, then, that providers should consider sexual intimacy from a broad perspective that looks beyond the prevention lens. As this research suggests, sexual intimacy is seen to contribute to one’s quality of life, and is also seen as a necessary component or a precursor to other important dimensions in fulfilling relationships. If the value of sexual intimacy is to be taken seriously, providers in this field may ask what can be done to address these needs.

**Reconsidering the educational workshop format**

None or the participants mentioned barriers related to their own lack of understanding or awareness. All participants were clients of ACG, and all reported benefitting from the support, education and Positive Prevention workshops offered by the agency. However, while many had attended workshops on disclosure, HIV transmission, and other relevant topics, these education sessions did not appear to be completely
effective in helping the participants manage and negotiate fears around transmission, loss of sex, or criminalization risks. During the interviews, some participants conveyed misinformation about transmission or HIV non-disclosure and the law. This suggests that the factual information on these topics that has been presented during ACG educational workshops was not necessarily understood, absorbed or remembered. It may also be that fear and stigma overpower knowledge on these topics. Knowledge about HIV and the law does not necessarily translate to easier disclosure; knowledge about HIV and levels of risk does not necessarily soften fears around transmission. This finding has significant program implications for AGG and other ASOs in developing support strategies or delivering education for PHAs around transmission, sexual relationships, disclosure and similar topics. How to turn complex, frightening, and abstract issues into applicable skills that facilitate communication between partners poses an important new question for ACG and other organizations or providers who may be willing to reconsider the traditional educational format.

**Advocacy with PHAs around Criminalization of HIV non-disclosure**

What this research did not – surprisingly - identify, were complications to sexual intimacy related to the criminalization of HIV non-disclosure. None of the participants spontaneously mentioned criminalization; they only discussed it when asked directly. For the most part, they reported agreeing with what they had heard and understood about criminalization from the mass media, citing high-profile examples that were reported in the news. This seeming endorsement for criminalization was surprising. For some of the participants who supported criminalization, their endorsement was connected to feeling victimized and traumatized through acquiring HIV. Recognizing the importance of trauma on HIV acquisition may be important when attempting to engage PHAs in advocacy around the criminalization of HIV non-disclosure, since some PHAs may sympathize and identify with the “victim” rather than the “perpetrator” in court cases.

The advisory committee on this project was asked for input on this finding and the participants were asked for input during the datavalidation session. Asked why criminalization did not appear to be a barrier to sexual intimacy, both the participants and advisory committee members suggested this may reflect a public/private or external/internal distinction. Criminalization was seen as belonging to the public domain whereas sex and sexual intimacy were seen as belonging to the private domain. At the validation session, participants noted that criminalization is important but it was just not something that immediately came to mind when thinking about sex. Criminalization was seen to be an external factor, whereas participants believed the internal, personal issues are much more present. The internal sense of responsibility to avoid transmission was thought to be a much stronger consideration and motivation than criminalization. This finding may also have implications for community action and advocacy and may be a topic worthy of further study.

**Fighting stigma: inside and out**

Stigma continues to be a formidable foe in HIV prevention and support, and continues to affect the lives of people living with HIV in many serious ways. This research identified that while previous experiences of trauma or marginalization also affect people’s experiences with sexual intimacy, HIV stigma plays a considerable role in perpetuating fear and making disclosure a daunting task, often one that carries significant consequences. Stigma would sometimes lead PHAs to cease relationships before they begin. This was not without cause, and was often associated with previous experiences of rejection.

While not surprising, this research has reaffirmed that fighting stigma in the community is an important task that is related to all aspects of sexual intimacy and quality of life for people living with HIV.
This research has confirmed a lack in sexual intimacy among ACG clients, a finding which may be a shared experience among PHAs, especially in similar geographic regions. Celibacy or loss of sex is experienced as a detriment to happiness and wellbeing, and in some cases means that PHAs fail to experience the other kinds of physical or emotional closeness they desire. Fear of transmission, fear of rejection, social isolation, challenges in meeting new people and negative self-perception are key factors in perpetuating this loss. Experiences of trauma and marginalization surely affect sexual intimacy, as do other factors such as aging, ageism, and particular features of Guelph’s geography such as the lacking of a strong gay community. However, it is clear that HIV plays an important role in complicating sexual activity further. Partly this is a result of the physiological features of HIV and medication, but stigma – internalized, felt and enacted - looms heavily over issues such as transmission and disclosure. This finding serves to reiterate the importance of fighting stigma in the broader community, and also of working with clients to address their own internalized stigma.

ACG hopes to use this information to explore further opportunities for community-building among PHAs and reconsider its traditional educational format to ensure that workshops are reflecting the realities of how education on disclosure, transmission and sexual intimacy are interpreted. It is also anticipated that other organizations and providers in the field of HIV & AIDS are able to utilize this research to develop locally-appropriate strategies and support systems that validate and support the need for sexual intimacy among people living with HIV and AIDS. Building on the values and principles that have informed this research, such as the right of PHAs to satisfying emotional and sexual lives, this research provides motivation to move forward in responding to the barriers to – and needs for – sexual intimacy.
Appendix A

References and Complete Findings
from OHTN Rapid Review
Sexual abstinence among people living with HIV/AIDS

Question
What is the impact of sexual abstinence (lack of sexual intimacy or loss of sex) on people living with HIV/AIDS?

Key Take-Home Messages
- Diagnosis of HIV infection can have far-reaching implications for people’s sexual interest, the pleasure they derive from sex, their sense of attractiveness or appeal as a sexual partner may change considerably irrespective of their age, sex, race, sexual orientation, housing status, drug use, or underlying diseases such as hemophilia.
- Risk perception evolves with time and experience, and the fear of infecting partners. This lack of libido may continue to affect sexual relationship well after the initial “settling down” period (1,2)
- In many HIV-positive patients sexual desire decreases because of fatigue, generalized wasting, muscle aches, pain, paraesthesia, and depression. Medications such as protease inhibitors have been found to have an adverse effect on desire and arousal (3)
- Among older adults (aged 50 and more) celibacy is more prevalent following diagnosis with HIV. Women report celibacy more than men. In general, older adults may have difficulty resuming healthy sexual relationships following diagnosis with HIV/AIDS (4)
- Among HIV-positive adolescents with hemophilia, abstinence can be intentional and marked by a series of decisions and behaviors that are influenced by peer group norms and personal values (5)
- Among injecting drug users (IDUs), lower CD4 level (below 200), HIV-related medical symptoms, lower neuropsychological memory test scores are associated with more abstinence. In female IDUs, depressive mood has also been found to be associated with...
abstinence. (6)

- Although HAART use has been linked to sexual functioning of HIV-positive men, HIV-positive women describe highly similar experiences of diminished sexual activity, a loss of sexual interest, and decreased feelings of attractiveness both before and after the advent of HAART. (7)

The Issue and Why It's Important

Research exploring sexuality in people living with HIV/AIDS shows that a diagnosis of HIV/AIDS may result in a subsequent loss of libido and cessation or reduction of sexual activity. (7) Learning about the diagnosis may affect people's sexuality in other more subjective ways, such as altering sense of personal attractiveness or sexual desirability. In addition, the pleasure derived from even protected sex may be diminished greatly by anxiety related to the possibility of infecting others or becoming re-infected, as most recognize that condoms can break. When such changes occur, the pleasure of sexual intimacy is greatly diminished and, as a result, there may also be a substantial decline in one's interest in sex. (7) This summary outlines research exploring sexual abstinence (lack of sexual intimacy or loss of sex) due to HIV-positive status.

What We Found

Sexuality is an important part of being human and living a full life. The well-being of many individuals centers on affectionate intimate relationships that contribute to health and quality of life. A chronic illness such as HIV/AIDS can have far reaching implications on the lives of these individuals. (3, 7) Sexual abstinence (lack of sexual intimacy or loss of sex) is one of the most prevalent coping mechanisms (especially in newly diagnosed HIV-positive people) across various groups such as gay/bisexual men, heterosexual men and women, older people, adolescents, injecting drug users, homeless and unstably housed people and hemophilia patients. Although there are similarities across these groups, each of them has their unique characteristics, which are discussed in more detail below.

Men (gay/bisexual, heterosexual) and women

Bogart et al (2006) examined patterns and correlates of deliberate abstinence among men and women with HIV and found a substantial proportion of the participants in their HIV Cost and Services Utilization Study (HCSUS) chose abstinence (8). In addition, women and heterosexual men were more likely to deliberately abstain than were gay/bisexual men. Gay/bisexual men who deliberately abstained were more likely than women and heterosexual men to be motivated by a perceived responsibility to protect others.

The same study found that health factors were more strongly associated with deliberate abstinence among men and women with HIV and heterosexual men than gay/bisexual men. (8) Compared with gay/bisexual men, heterosexual men not taking HAART and with poorer emotional functioning were more likely to be deliberately abstinent. Health factors, including worse physical functioning and lower CD4 count, also predicted deliberate abstinence for women, although these effects were not significantly different from those for gay/bisexual men. Bogart et al. (2006) also found that gay/bisexual men who drink were less likely to deliberately abstain, although the effect for drug use was not significant.
addition, black gay/bisexual men were more likely than white gay/bisexual men to abstain, which was highlighted as potentially being the result of stigma within their own social networks and isolation from gay communities. Other potential explanations highlighted were that black gay/bisexual men may be more cautious about initiating sexual relations or have less information on lower-risk sexual practices.

Men

Many HIV-positive men experience some form of dissonance (such as guilt, shame, isolation, or avoidance when making decisions about selecting a partner, disclosing serostatus, and coping with the resulting sexual behaviors) associated with sexual intimacy and their HIV status. In managing these issues, HIV-positive men make choices and select different types of intimate relationships. A study by Relf et al. (2009) identified three types of intimate sexual relationships after HIV diagnosis—“avoiding sex,” “just sex,” and sex in a “going somewhere” relationship. For those study participants who chose to avoid sexual relationships entirely, the intense discomfort of disclosing HIV serostatus, and the subsequent fear of potential rejection was so great that complete avoidance of sexual intimacy with another person resulted.

A pilot study by Palmer and Bor (2002) exploring challenges to intimacy and sexual relationship for gay men in HIV serodiscordant relationships found that some seropositive study participants had little, if any, desire for sex after diagnosis. Furthermore, they found that this lack of libido continued to affect the sexual relationship with their partners well after an initial “settling down” period. In addition, even if concerned about this, participants did not access services for help with these sexual difficulties. The seronegative participant in these relationships typically negotiated permission with his HIV-infected partner to have a casual sexual relationship with other men and his partner’s lowered sexual interest (possibly because of antiretroviral treatment or advancing illness) made this more possible. The seropositive partner also perceived their reduced sexual interest as unalterable, as if it were an expected consequence of having become infected.

Physical experience of sexual activity may become a constant reminder of HIV. Rather than being an enjoyable, intimate experience, sex may reinforce the infectivity of the seropositive partner, the vulnerability of the seronegative partner to infection, and provide an opportunity for amplification of difference between the couple. All this may lead to further decrease of sexual intimacy or loss of sex.

Women

A loss of enjoyment of sex also affects seropositive women and appears to be related to women’s knowledge of their HIV status. From interviews with 21 seropositive heterosexual women, Keegan et al. (2005) highlight that any relationship between HIV and sex is likely complicated by other factors such as current health, length of time since diagnosis, mental health, and social circumstances. Fears around disclosure, in particular rejection upon revealing a positive HIV status were highly important for many study participants when considering or starting new relationships and formed a significant barrier for some. In addition, relationship avoidance and discouraging sexual contact appeared to be linked with the earlier stages of HIV adjustment. However, Keegan et al. note that despite these challenges, the sexual and relational
aspirations of HIV-positive women appeared to mirror those of women generally with many women living with HIV continuing to pursue sexual relationships.\(^{(1)}\)

The picture that emerges from another study (Siegel et al., 2006) is one of women who, due to the possibility of sexual transmission of their disease and/or reinfection by a partner, felt that sex had become too plagued with anxiety, worry, danger, and stress to still be pleasurable\(^{(1)}\). Most who were sexually inactive insisted that they had little or no desire for sex and did not miss it. Nevertheless, a few did express being open to seeking the friendship and companionship of a man that they could talk to, but insisted that they wanted the relationship to stop there. Most women who had previously suffered rejection still felt so hurt by those experiences that they were unwilling to risk putting themselves in a situation again where disclosure would be necessary. As a result, Siegel et al. note that some made a choice to become celibate, while others drifted into a “de facto” celibacy by their avoidance of any relationships that might eventually become sexual ones.

Siegel et al. (2005) further highlight that because sexual relationships can produce such feared outcomes (such as disease, death, emotional pain, pregnancy and infected children), many women felt it was best to suppress their sexual desires and remain sexually inactive.\(^{(7)}\) Lastly, this study found that HIV-positive women described highly similar experiences of diminished sexual activity, a loss of sexual interest, and decreased feelings of attractiveness both before and after the advent of HAART.\(^{(7)}\)

Lambert et al. (2005) also studied sexual activity among HIV-positive women and found that the majority of women in the study (72%) resumed sexual activity after becoming HIV positive.\(^{(10)}\) However, more than half indicated that their HIV status had impaired their enjoyment of sex or made it impossible. The study also suggests that HIV status alone may be insufficient to explain why some women do not resume sexual activity after HIV diagnosis because high rates of past sexual abuse were found and abstinence since diagnosis was significantly associated with a past history of sexual abuse.\(^{(10)}\)

**Older age**

Siegel et al (2003) suggest that sexual abstinence correlates strongly with age and sex and that many older adults may have difficulty resuming health sexual relationships following diagnosis with HIV/AIDS.\(^{(4)}\) Almost half of study population of older adults (aged more than 50) were currently celibate or had been celibate following diagnosis with HIV. Women reported celibacy (78%) more than men (36%). Both men and women reported that fear of infecting others and fear of becoming re-infected with another strain of HIV or with another STD were primary deterrents to any sexual involvement. A small number of men and women attributed at least some of the decline in the interest in sex to their age.

The same study highlighted that the choice to abstain from all sexual involvement was more emotionally driven for women than for men.\(^{(5)}\) Women usually felt hurt and violated by the men who infected them and very fearful of additional harm (both physical and emotional) that could come from further sexual contact with men. The men’s choice to be celibate was usually the outcome of a reasoned decision-making process.\(^{(4)}\)
Adolescents

HIV status is challenging for adolescents living with HIV since birth. Fernet et al. (2011) examined romantic relationships and sexual activities of the first generation of youth living in Montreal with perinatal acquired HIV (11). For these adolescents, risk is not just related to sexual transmission but more so to the emotional risk of getting rejected. They initiate their romantic and sexual lives but are filled with anxiety of being rejected by their partner. The study indicates that HIV-positive youth reported their sexual debut as comparable or slightly earlier than that of the general Canadian population. Of those reporting protected sex at first intercourse, over half mentioned taking risks (e.g., multiple partners, sexual relations with alcohol, drugs or during menstruation) in subsequent relationships. This suggests that risk perception evolves with time and experience. The fear of infecting the partners, which was found to be particularly salient at sexual debut, gradually dissipates when viral load is undetectable or when past experience suggests that partners might not become infected (11).

A study with HIV-positive adolescents with hemophilia, improvement and maintenance of safer sexual behavior were significantly associated with perceived peer support for abstinence, expected peer support for abstinence, and decreased general emotional distress (6). The study suggests that maintaining abstinence can be intentional and marked by a series of decisions and behaviors that are influenced by group norms and personal values (6).

Housing status

Abstinence has been observed among homeless and unstably housed persons living with HIV/AIDS (12). More than a quarter of participants in the Housing and Health Study in Baltimore MD, Washington DC and Los Angeles CA reported having no sex in the past 90 days and 20% reported that this was by choice (12). Reasons for having abstained from sex in the past 90 days selected by the most participants were that they were not interested, did not want to infect someone, and did not have a partner (12). A slightly lower percentage of heterosexual men were sexually abstinent compared to men who have sex with men (MSM) and women, but this trend was not found to be statistically significant. Those who had completed high school and who had no main partner or spouse were also found to be more likely to have abstained than others. Additional key findings from this study include the following:

- age and gender were not found to be significantly associated with sexual abstinence
- partner status (i.e., having a main partner or spouse) was associated with abstinence among all study participants
- abstinence among MSM was less likely among those with a detectable HIV viral load
- Among heterosexual men, abstinence was associated with higher education level and the experience of housing problems.
- Among homeless women, abstinence was less likely among those with a history of sexual abuse and those whose social network members were more aware of their HIV status.
Injecting Drug Users

Two longitudinal studies (Dolezel et al. 1999; Dolezel et al. 1998) concluded that intravenous drug users (IDUs) in New York City have modified their sexual behavior toward safer practices (7, 13). The studies found that for both HIV+ and HIV- IDUs there were increases in abstinence and monogamy, decrease in frequency of unprotected sex and a decrease in sexual risk index scores. It was also found that men were more likely to abstain from sex, to limit their sexual behavior to one partner, and to reduce the number of times they had unprotected sex (7). Among women who were abstinent there were higher levels of depression. As Dolizal et al. (1998) suggest, psychological status may be an important factor in sexual abstinence in this population as depressive mood is associated with less sexual activity in general. However, the strength of association is difficult to determine given that having unprotected sex is also associated with the loss or lack of a sexual partner and could therefore also result in psychological distress, loneliness, and depressive mood (7, 13).

Factors that May Impact Local Applicability

All studies explored sexual abstinence (lack of sexual intimacy or loss of sex) due to HIV positive status in developed countries (primarily in the USA). Cultural and demographic characteristics of the study populations are similar to those in Canada. For this reason the results of this rapid review are likely applicable to the Canadian context.

What We Did

We conducted a targeted search of PubMed in April 2011 using a combination of relevant search terms. Specifically, we conducted searches with two combinations of search terms: 1) HIV and (sexual abstinence OR sexualization OR intimacy) and 2) HIV and sexual intimacy.
Appendix B

Project Working Group Terms of Reference

These Terms of Reference (TOR) were used to guide the work of this project. Each member of working group was involved in the development of the TOR and commits to their practice.

1. Purpose

The purpose of this project is twofold:

A) to build the capacity of ACG for leading and conducting community-based research (CBR) and knowledge translation that will enhance both their services and contribute to the larger community; and

B) to complete a CBR project that examines the extent and impact of barriers to sexual intimacy among people living with HIV & AIDS in Guelph & Wellington County, and identify service outcomes to address these needs.

Objectives of this project are to:

i) Gain and in-depth understanding of barriers to sexual intimacy among PHAs in Guelph & Wellington County;

ii) Identify new programs and service outcomes that will help ACG address barriers to sexual relationships;

iii) Identify the strategies that ACG clients can utilize when forming sexual relationships, which may be shared and strengthened through ACG programming; and

iv) Share information and learnings with stakeholders including organizations and service providers (e.g. Public Health, CMHA, Guelph-Wellington Distress Centre, Women in Crisis, Student Services at The University of Guelph, The Homewood, Stonehenge, Rainbow Health Ontario), ACCKWA and other ASOs, and the community.

2. Guiding Principles

a) Community Ownership: This project will engage a set of principles that will foster community ownership and empowerment among team members, including power sharing, capacity building, and group participation in all appropriate phases of the research project.

b) Meaningful involvement of PHAs (GIPA & MIPA): This project will meaningfully involve PHAs as leaders and collaborators in all phases of the research and knowledge translation, incorporating principals of inclusion and engagement.

c) Transparency: This project will engage in an open and transparent process where a collective vision of research goals and objectives is shared, and where the roles and expectations of team members are clearly understood;
d) **Collaboration and Equity:** This project will be a collaborative and equitable research partnership where members draw upon individual skill sets to meaningfully and mutually work toward the team’s vision;

e) **Learning Opportunities:** This project will provide opportunities for building capacity and learning about research skills, community development, and community work;

f) **Respectful Research Processes:** This project will engage in data analysis and interpretation processes that honour the lived experiences/knowledge of community members;

g) **Benefit from Dissemination:** This project will employ dissemination strategies leading toward education, advocacy, community benefit, and social change;

h) **Supportive and Reflective Team Environment:** This project will foster a supportive team environment through critical reflection of our work and group process.

3. **Roles and Responsibilities of the Working Group**

The role of the working group is to collaboratively design and implement the research project. It will meet and communicate regularly about the project, and be guided by principles of equity, empowerment, capacity building, and collective ownership of the project. The working group is made up of the following members, each with different roles and responsibilities:

- **Co-Principal Investigators’ (Co-PIs) Responsibilities:** Co-Principal investigators will guide the research process, ensure that the research is conducted effectively, ethically and fulfills the commitment to the shared values of the working group and agency. The Co-PIs will ensure accountability, ongoing support and direction to the research assistants, and lead the transfer of research findings into new programs and resources. They will co-facilitate meetings and will take the lead in finding replacements if turnover occurs.

- **Research Consultant:** The Research Consultant will apply her skills and experience to all aspects of the project, and provide ongoing support to the Co-PIs, including for project management. She will co-facilitate meetings, provide methodological guidance, support the ethics review process, support data collection, analysis and validation. The consultant will share resources and templates for conducting research and knowledge translation. She will lead the evaluation components of the project and support the ongoing development of ACG’s capacity to lead and conduct CBR projects in the future.

- **Research Assistants:** Research assistants will be involved in the project development, including the research concept, purpose, questions, methods and partners. The Research Assistants will conduct the interviews, contribute to data analysis, and providing ongoing input into the project, including dissemination of results and drafting recommendations to the agency or other community members. The Research Assistants will maintain an audit trail during interviews.

4. **Decision-Making Process for the Project**

Our decision-making process in this project aims to:
encourage the participation and empowerment of all team members;

be transparent, open and clear, and respectful;

provide opportunities for exchanges of learning that draw on the various skills and areas of knowledge of different team members;

**Differing Responsibilities:**

› Working group decisions will include those related to the project’s overall goals and strategies;

› Co-PIs are responsible for decisions related to the management of the research and administration to the Project.

**Process for Working Group Decisions:**

› Decision-making at Working Group meetings will strive for consensus among those present (with consensus understood as feeling able to go along with a decision in order to move the project forward for the greater good). If those present at a meeting feel an issue is of serious concern that cannot be resolved by the working group, we will draw on the contribution of our partnership with an experienced facilitator who sits on the advisory committee.

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**5. Access to/Dissemination of Data**

Based upon the project’s guiding principles, the Working Group will collaboratively lead the project. ACG will have ownership of the research data and products, though members of the Working Group will be identified as authors on all reports, articles and presentations and can lead KT activities. Because of the sensitive and personal nature of the research topic, the small sample size and potential to identify individuals from transcripts of their conversation, the working group is committed to protecting the confidentiality of participants and of the research data. Data will be stored at ACG and will not be shared outside the working group. Following the completion of this project, decisions to pursue subsequent analysis of the data and responding to any future requests for access to data will be the responsibility of ACG’s Executive Director.

Usage of the data will be in accordance with the project goals. Data will be used for:

› advancement of knowledge;

› making recommendations for policy and service provision; and

› informing future research and work.

The data will not be used for:

› individual interests that are not related to the goals of the project.
Research findings will be disseminated in various ways including community forums, conference presentations, agency workshops, newsletters, web posting and journal articles. All members of the working group will share authorship on presentation and papers. Order of authorship and mechanisms for feedback on manuscript drafts will be decided up front by working group members. Working group members will also work together on the development of conference presentations, community forums, and other dissemination activities.

6. Process Evaluation

We will regularly chart our progress against our timeline submitted. We will also provide time within regular meetings to review our process. We may also choose to hold meetings specifically to debrief about our work. At these meetings we will both critically reflect on our process/outcome balance and make recommendations for adjusting our work accordingly.

7. Acknowledgement

In all publications, media strategies and other public activities related to the Project, the funder and all working group members will be acknowledged. The names and websites of respective organizations will appear with this acknowledgement as appropriate, including ACG, The O’Halloran Group, and OHTN.

8. List of Members

Co-PI’s

Tom Hammond, Executive Director, AIDS Committee of Guelph & Wellington County

Megan DePutter, Positive Prevention Coordinator, AIDS Committee of Guelph & Wellington County

Research Consultant

Tanya Darisi, Director, The O’Halloran Group

Research Assistants

Tim Walker, Peer Outreach worker, AIDS Committee of Guelph & Wellington County

Sarah Murray, Doctoral Candidate of the Department of Family Relations and Applied Nutrition at the University of Guelph.
Appendix C
The Ontario Accord

The Ontario Accord

“We, people living with HIV/AIDS and allies in the community:
Commit to the greater involvement and meaningful engagement of people living with HIV/AIDS (GIPA/MIPA).
GIPA/MIPA puts PHAs at the centre and is grounded in human rights and the dignity of the full human being.
Aim to transform all who live with, work in, and are affected by, HIV/AIDS in Ontario.
Commit to personal and social transformation.
Value community expertise in embracing the challenge for the betterment of society.
Value inclusion over exclusion, a quest for integrity at all times and the embodiment of self-determination.
Promote the evolution of thought, action and collaboration among us and with our allies.
Because GIPA/MIPA is about human struggles and aspirations, ethics, empowerment and accountability are its foundation.”

This Accord was created by HIV positive individuals and representatives of Ontario organizations at a Living and Serving 3 consultation meeting in Toronto Ontario in July 2011
Appendix D
The Denver Principles

We condemn attempts to label us as ‘victims,’ a term that implies defeat, and we are only occasionally ‘patients,’ a term that implies passivity, helplessness, and dependence upon the care of others. We are ‘People With AIDS.’

RECOMMENDATIONS FOR ALL PEOPLE.

1. Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us or separate us from our loved ones, our community or our peers, since available evidence does not support the view that AIDS can be spread by casual, social contact.

2. Not scapegoat people with AIDS, blame us for the epidemic or generalize about our lifestyles.

RECOMMENDATIONS FOR PEOPLE WITH AIDS.

1. Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda and to plan their own strategies.

2. Be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations.

3. Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.

4. Substitute low-risk sexual behaviors for those that could endanger themselves or their partners; we feel people with AIDS have an ethical responsibility to inform their potential sexual partners of their health status.

RIGHTS OF PEOPLE WITH AIDS.

1. To as full and satisfying sexual and emotional lives as anyone else.

2. To quality medical treatment and quality social service provision without discrimination of any form including sexual orientation, gender, diagnosis, economic status or race.

3. To full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives.

4. To privacy, to confidentiality of medical records, to human respect and to choose who their significant others are.

5. To die--and to LIVE--in dignity.

Denver, 1983
Hi, thanks for taking time to talk with me today. We are doing about 20 interviews with clients from ACG about sex and HIV. ACG has heard from clients that there can be challenges and barriers around relationships and sex. Some clients have asked for more support and ACG wants to be able to provide the kind of support that is needed. Our conversation today will help us better understand what the issues and challenges are, and how to better meet the needs of our clients.

I have a consent form that explains in more detail the purpose of the interviews and what participating in the research involves. We can go through it together ...

Before I begin, I just want to emphasize that there are no right or wrong answers. This is about you and your experiences. I have questions to guide our discussion, but please feel free to raise whatever issues are important to you about the topic. If there is a question you do not want to answer, please just let me know and we will move on.

The questions I have start generally, asking about your experience getting involved with ACG and about when you first got your HIV diagnosis. We then will talk a bit about what you think some of the barriers are to sexual intimacy and the effects of these barriers. The last part of our conversation will be about the kind of things that ACG could do for clients to help overcome barriers.

Do you have any questions before I begin?

**START RECORDING** (if they have agreed)

**Introduction**

How did you become involved with ACG?

Can you tell me about when you first got your HIV diagnosis?

Do you think that there is a lot of stigma about HIV?

    *Probe/Follow-up Question:* Do you think there is shame involved with being HIV positive?

**Barriers to sexual intimacy**

Has HIV changed the way you think about sex? In what ways?

    *Probe/Follow-up Question:* Has HIV has affected your feelings about sex? What has changed?

    *Probe/Follow-up Question:* Has HIV changed your body? In what ways has it changed?

    *Probe/Follow-up Question:* Do you think your sex drive has changed since you became HIV positive? Why do you think this is?

In what way do you think one’s sex life contributes to happiness?

In what way do you think one’s sex life contributes to health?

In an ideal world, what kind of sex life would you like to have?

How is this different from what your current situation is?
What would you describe as being a negative sexual experience?

*If participant has identified complaints with sex life:*

What do you think is getting in the way of having the kind of sex life you would like to have?

*Probe/Follow-up Question:* What are your biggest challenges in getting the kind of sex you want?

Are you looking right now to meet someone to date, have a relationship with, or have sex with?

*If yes*

Okay, so I know that some people, when they are looking to meet someone or hook up, they might try online dating, or go to parties, or visit parks or bath-houses or bars. What kinds of things to do you when you’re trying to meet someone?

*Follow-up Question:* When you’re (visiting a bath-house, going to a party, going to a bar, etc) do you drink alcohol or use recreational drugs?

Can you tell me about a time when you disclosed to a potential sexual partner (or someone you wanted to sleep with/have sex with/fuck/have a relationship with/ were interested in)?

Is that kind of response typical? What other kind of responses have you had?

Have you seen or heard about people living with HIV going to jail because of non-disclosure?

*If yes*

What was your response when you heard that?

*Probe/Follow-up Question:* Has that had an effect on how you disclose? If so, in what way?

**Impacts of barriers and the lack of sexual intimacy on perceived quality of life**

You mentioned some of the challenges that you faced were…. Are there any other challenges to having the kind of sex life that you want?

I’d just like to understand your experiences with these challenges a little more. How much do these challenges bother you?

*Probe/Follow-up Question:* In what way do these challenges affect your happiness?

*Probe/Follow-up Question:* In what ways to these challenges affect your health?

How would these things improve if you had the kind of sex life you wanted?

**Factors that support positive sexual relationships**

*If participant has identified positive aspects with sex life:*

Can you tell me why you think your relationship is so successful?

How were you able to (accomplish that/work that out)?

What has worked for you that you think might work for others?

**Service outcomes**

Now let’s turn to talking about services and resources.
What support networks do you access in the community?

*If participant has identified complaints with sex life:*

You mentioned that you have challenges with (named issue). What do you think might help you with this?

What would you like to see from ACG to help you deal with challenges like (named barriers)?

*Probe/Follow-up Question:* What do you think ACG could do to help PHAs in Guelph deal with this problem?

How do you think other PHAs could help each other with this?