The lived experience of loneliness in older men living with HIV: A qualitative analysis to guide service development

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December 2019

A thesis submitted to McGill University in partial fulfillment of the requirements of the degree of Masters of Science

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ACKNOWLEDGEMENTS

I would like to express my extreme gratitude to all the **participants** of the Positive Brain Health Now study and especially those who agreed to participate in my study. Without their brave willingness to open up and share their emotional experiences, this project would have been impossible. I am very thankful for their sincerity and the time they spent to meet with me. I have learned an immense amount about the challenges of living with HIV; it is so much more than the virus itself.

I am also forever thankful to have been part of such an amazing and supportive team working on the Brain Health Now project. I am especially thankful for my supervisor **Marie-Josée Brouillette**, MD, Associate Professor, Department of Psychiatry, Faculty of Medicine, McGill University. Her consistent and endless support, encouragement and insight have been invaluable as well as her praise of my autonomous nature while teaching me to branch out and increase my networking. I also cannot express enough gratitude for **Nancy Mayo**, PhD, Professor, Department of Medicine, Faculty of Medicine, McGill University. She has given me countless learning experiences and exposed me to a multitude of projects outside of my own which has really broadened my knowledge; making me more well rounded. In addition, all of her students have been amazingly supportive and have assisted me and helped me adapt and excel as a graduate student. A big thank you as well to the final member of my committee, **Melissa Park**, PhD, Associate Faculty, Department of Family Medicine, McGill. She has been instrumental in guiding me through the complexities of qualitative research.

I would also like to thank **Kim Engler**, PhD, **David Lessard**, PhD and **Richard Montoro**, MD for their advice and encouragement. Last but certainly not least, thank you to the research assistants **Melissa Vu** and **Fernando Gonzales Aste** who have helped me through the complex logistics of my research project.

ABSTRACT

Background: Loneliness is a known predictor of poor health and early mortality in the general population and it is found at higher rates among older people living with HIV. While there are many services available to people living with HIV, the greatest area of unmet need for this population is access to services to help overcome loneliness. Loneliness is a multifaceted issue that is experienced differently across gender, cultural, and age groups. However, to develop focused and effective services, the experience of loneliness in older people living with HIV needs to be understood. For historical reasons, white men are a major component of the HIV community; therefore, this study aims to understand the lived experience of loneliness in older white men living with HIV in the Montreal area and to inform interventions to address the psychological and social difficulties involved.

Methods: Grounded theory, a qualitative research method was used to access and compare distinct lived experiences of loneliness among older men living with HIV. First, participants were selected using a theoretical sampling method, which aims to recruit individuals based on theoretical relevance, rather than representativeness of a given population. Thus, for comparison purposes, older white men who answered, 'quite often' (n=6) and 'almost never' (n=4) to the question "do you find yourself feeling lonely, quite often, sometimes or almost never?", from the Canadian Positive Brain Health Now study were recruited. Then, one-to-one, face-to-face, semi-structured, audio-recorded interviews with participants were conducted and analyzed until theoretical saturation was reached (total=10), meaning no novel information was being obtained.

Audio-recordings were transcribed verbatim and MaxQDA was used to facilitate data analysis. Three rounds of inductive thematic analysis were completed to identify major emerging themes.

***Results*:** The participants defined their loneliness as an overall lack of intimacy. Their experiences of contributors to loneliness were generally centered on three main interacting themes: 1) an immense amount of loss throughout their lives which severely impacted them and limited their social support; 2) ‘a deceiving search for intimacy’ whereby participants faced many barriers when trying to find friends or partners online or in person, but more often than not, found superficial contacts and/or ‘hook-ups’ which did not remedy their loneliness; and 3) participants spoke about ‘shielding themselves’, needing to protect themselves from further losses, stigma and rejection, leading to self-isolation and more loneliness. Their experiences of living with the loneliness involved keeping busy, having an animal companion, having a belief in something greater than themselves and use of drugs/alcohol. Finally, they described that current services are not addressing loneliness and suggested more social activities be offered in addition to services for dealing with traumas, overcoming fears and improving self-esteem.

***Conclusion*:** Our qualitative study identified three main themes indicating that participants are concerned about an absence of intimacy, as well as the difficulties they experience when trying to restore intimacy in their lives. In addition, it identified how participants are currently trying to minimize the negative impact of loneliness and that service development should focus interventions on the barriers and facilitators associated with creating meaningful relationships with partners and/or friends.

RÉSUMÉ

Contexte: La solitude est un facteur prédictif de mauvaise santé et de mortalité précoce dans la population générale et se produit plus fréquemment chez les personnes âgées vivant avec le VIH. Alors que de nombreux services sont disponibles pour les personnes vivant avec le VIH, des services pour vaincre la solitude constituent le principal domaine de besoins non satisfaits pour cette population. La solitude est un problème à multiples facettes qui est vécu différemment selon le sexe, la culture et l’âge. Cependant, pour développer des services ciblés et efficaces, il faut comprendre l’expérience de la solitude chez les personnes âgées vivant avec le VIH. Les hommes de race blanche constituent une composante majeure de la communauté du VIH; par conséquence, cette étude vise à comprendre l'expérience de solitude chez les hommes âgés de race blanche vivant avec le VIH dans la région de Montréal et à informer des interventions pour les difficultés psychologiques et sociales impliquées.

Méthodes: La théorie à base empirique, une méthode de recherche qualitative a été utilisée pour identifier et comparer différentes expériences de solitude, vécues parmi des hommes âgés vivant avec le VIH. Tout d'abord, les participants ont été sélectionnés à l'aide d'une méthode d'échantillonnage théorique, qui vise à recruter des personnes en fonction de leur pertinence théorique, plutôt que de la représentativité d'une population donnée. Ainsi, à des fins de comparaison, les hommes qui ont répondu « assez souvent » (n = 6) et « presque jamais » (n = 4) à la question « vous retrouvez-vous seul, assez souvent, parfois ou presque jamais »? de l’étude canadienne ‘Pour un Cerveau en Santé’ ont été recrutés. Des entrevues individuelles, en personne, semi-structurés, avec enregistrement audio ont ensuite été conduites et analysées jusqu'à ce que la saturation théorique soit atteinte (total = 10), ce qui signifie qu'aucune information nouvelle n'a été obtenue. Les enregistrements audios ont été transcrits intégralement et MaxQDA a été utilisé pour faciliter l'analyse des données. Trois séries d’analyses thématiques inductives ont été effectuées pour identifier les principaux thèmes émergents.

Résultats**:** Les participants ont défini leur solitude comme un manque général d'intimité. Leurs expériences de contributeurs à la solitude étaient généralement centrées sur trois thèmes principaux en interaction: 1) des pertes considérables tout au long de leur vie qui ont eu un impact significatif et ont limité leur soutien social; 2) "une recherche décevante d'intimité": les participants font face à de nombreux obstacles lorsqu'ils cherchent des amis ou des partenaires en ligne ou en personne, et souvent, ils trouvent des contacts superficiels et / ou des ‘hookup’ qui ne remédient pas à leur solitude; et 3) Les participants ont évoqué le besoin de se ‘faire une armure’, se protéger contre de nouvelles pertes, de la stigmatisation et du rejet, mais cela menait à l’isolement et à une solitude accrue. Leurs expériences de vivre avec la solitude impliquaient rester occupés, avoir un animal de compagnie, croire en quelque chose de plus grand qu'eux-mêmes et une consommation de drogue / d'alcool. Enfin, ils ont expliqué que les services actuels ne règlent pas le problème de la solitude et ont suggéré de proposer davantage d'activités sociales en plus des services visant à traiter des traumas, surmonter les peurs et améliorer l'estime de soi.

Conclusion: Notre étude qualitative a identifié trois thèmes principaux indiquant que les participants s'inquiètent de l'absence d'intimité, ainsi que des difficultés qu'ils éprouvent

lorsqu'ils tentent de rétablir l'intimité dans leur vie. En outre, elle identifiait comment les participants essayent de minimiser l’impact négative de la solitude et que le développement des services devrait concentrer les interventions sur les obstacles et les facilitateurs associés à la création de relations significatives avec des partenaires et / ou des amis.

CONTRIBUTION TO ORIGINAL KNOWLEDGE

Multiple studies have investigated various aspects associated with loneliness in many different samples of people living with HIV. There are many overlapping findings with the interrelations of loneliness, stigma, depressive symptoms, physical symptoms, social support and alcohol/tobacco use in people living with HIV. Importantly, the majority of these studies have been cross-sectional (Chambers et al., 2014). In addition, a scoping review on HIV and aging reported that quantitative studies dominated the research, leaving a knowledge gap with respect to the lived experience of older people living with HIV as well as their challenges (Chambers et al., 2014). This knowledge gap can be filled with qualitative research as it allows for the exploration of subjects' experiences as well as highly complex, multidimensional problems. Overall, this project contributes to original knowledge by presenting the experiences of loneliness in older men living with HIV, including the meaningful connections they make between loneliness and contributing factors, the ways in which they try to alleviate the negative impact of loneliness on their life, as well as raising some opportunities for service development.

CONTRIBUTION OF AUTHORS

Amanda Austin-Keiller, the M.Sc candidate, developed the project based on an area of priority identified by community groups-loneliness in older persons living with HIV. The candidate reviewed the literature to identify the knowledge gap and took courses on qualitative research in the departments of Psychiatry and Family Medicine in order to write the protocol for this qualitative project. The candidate wrote the consent forms and received ethics approval to conduct the study before proceeding to conduct the qualitative interviews with the participants, transcribe the audio-recordings from the interviews and complete the analysis of the data. The candidate interpreted the results and wrote the entirety of the thesis dissertation. All of the previous steps were supervised by **Marie-Josée Brouillette**, MD, Associate Professor, Department of Psychiatry, Faculty of Medicine, McGill University. The committee members also assisted with the supervision: **Nancy Mayo**, PhD, Professor, Department of Medicine, Faculty of Medicine, McGill University and **Melissa Park**, PhD, Associate Faculty, Department of Family Medicine, McGill University. All the citations in this thesis are based upon the works of others and the sources of this information are provided in the “References”.

INTRODUCTION

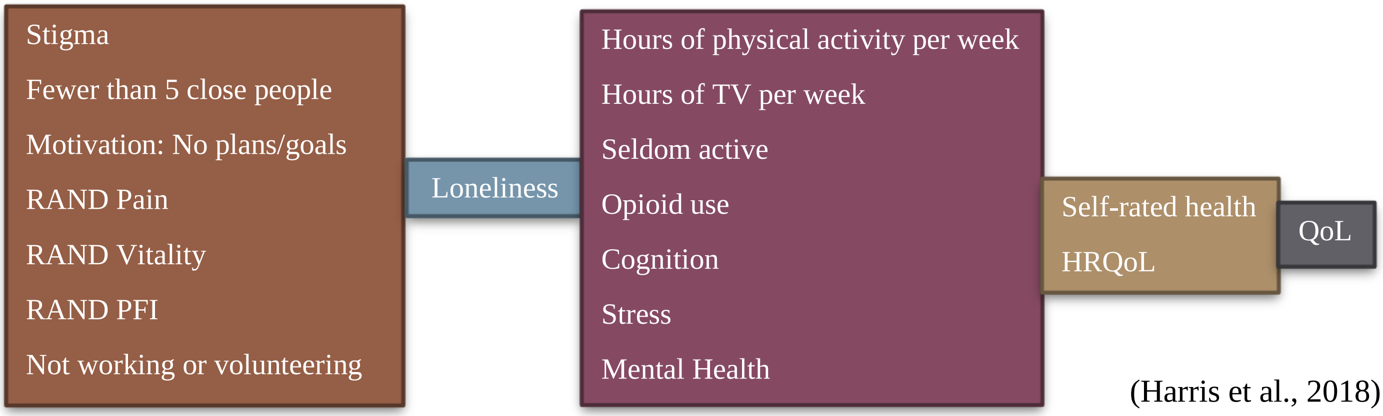
Background

Since the advent of effective antiretroviral therapy (**ART**) for the viral infection, HIV is no longer a death sentence (Greene et al., 2018; Hubach et al., 2015). In the United States and Canada, the life expectancy of a 20-year-old on ART approaches that of a person of the same age in the general population (Katz and Maughan-Brown, 2017; Samji et al., 2013). In addition, the gap in life expectancy that does exist may be attributable to demographic, clinical and behavioural characteristics rather than the HIV infection itself (Samji et al., 2013). Life expectancy of people living with HIV has increased dramatically due to ART, leading to an increased proportion of older people living with HIV (Chambers et al., 2014).

While we still do not have a cure for HIV, ART has made it more of a chronic infection rather than a fatal infection. Considering HIV as a chronic condition, means that the management and psychosocial aspects should be emphasized. Infection with HIV remains a heavy burden for individuals; specifically, in the Positive Brain Health Now longitudinal cohort study, cognitive and emotional problems are common (present in up to 50%). In particular, loneliness was identified as a frequent source of emotional distress among study participants. Loneliness is defined as a negative feeling in response to a low quantity or quality of social support compared to desired levels (Mannes et al., 2016; Stanton et al., 2015). This definition emphasizes three points: loneliness is unpleasant, it is a personal experience and it is due to a deficiency in the person's social relations (Perlman and Peplau, 1981). In the literature, the terms, 'social isolation' or 'social exclusion' are sometimes used as synonyms for loneliness. However, social isolation is defined as the "objective availability of social contacts or frequency with social network members" (Menec et al., 2019); therefore, this term does not take into consideration the person's experience which is one of the defining elements of loneliness. A person could have a large social network and thus, not be socially isolated, but may still feel lonely. Alternatively, a person could have a very limited social network but not feel lonely. Herein, 'loneliness', 'social isolation' and 'social exclusion' will not be used synonymously.

The reasons for investigating loneliness in this study are fourfold. First, a recent study of HIV-positive adults over the age of 50 in San Francisco, found that loneliness was reported in 57% of the sample (Greene et al., 2018). This is compared the Canadian Longitudinal Study on Aging data which reported loneliness in 10.2% of the sampled Canadian population between the ages of 45 and 85 (Menec et al., 2019). Therefore, there is a much higher prevalence of loneliness in older people living with HIV. Second, in the general population, loneliness has been shown to be a predictor of poor health and early mortality (Segrin and Passalacqua, 2010; Stanton et al., 2015), so understanding and addressing loneliness may improve the health and survival of those living with HIV. Third, while there are many services available to people living with HIV, the greatest unmet need reported by this population is the availability of services dedicated to helping them deal with loneliness and isolation (Kall, 2018). Fourth, it has been reported that loneliness in people living with HIV is associated with an increased risk of engaging in unprotected sex; therefore, potentially spreading the infection (Golub et al., 2010). Overall, the high prevalence of loneliness in people living with HIV, the lack of services to address it as well as the correlation between loneliness and early mortality as well as risky sexual behaviour, indicates a clinical problem worthy of further investigation. In order to develop interventions to decrease loneliness in this population, we need to better understand its contributors through the experiences lived by the individuals.

The Positive Brain Health Now longitudinal cohort study recently found that multiple factors are correlated with loneliness, as reported at the 9th International Workshop on HIV & Aging (Harris et al., 2018). The Wilson Cleary theoretical model that was used to link clinical variables to health-related quality of life (Wilson and Cleary, 1995) (included on the next page as **Figure 1** and in **Appendix 1** for convenience). However, due to the cross-sectional nature of the data, it was not possible to determine, among the mood and behavioural factors correlated with loneliness, which were causal and which were consequences. Determining which of the correlated factors are 'upstream' and contributing to the development of loneliness is important because these would represent ideal targets for interventions, as opposed to other correlated factors that are best understood as consequences of loneliness. Therefore, further investigation into loneliness was warranted, given the significant associations with poor cognition, stress, poor self-rated health and quality of life reported (Harris et al., 2018).



(Harris et al., 2018)

Figure 1: Psychosocial and behavioural factors associated with the presence of loneliness. The Wilson Cleary theoretical model was used to link clinical variables. From left to right, the presence of symptoms explaining loneliness; in turn explaining hypothesized consequences on function and health-related quality of life.

Research Aims

The aim of this project is to contribute to the literature regarding the lived experience of loneliness in older people living with HIV including the factors they experience as contributors as well as how they seek to minimize its negative impact on their life. In turn, the theoretical knowledge generated can help inform the development of interventions for loneliness or the factors that contribute to its development.

LITERATURE REVIEW

Before embarking on the project, the literature surrounding loneliness in people living with HIV was thoroughly reviewed. Multiple studies have investigated loneliness in people living with HIV and its association with stigma, depressive symptoms, physical symptoms, social support and alcohol/tobacco use. Major epidemiological findings and the research gaps that still exist are summarized herein.

Stigma and Loneliness

Goffman (1963) pioneered the work on stigma and defined it as an “attribute or characteristic that is profoundly discrediting to the individual possessing the attribute or characteristic” (Goffman, 1963). People living with HIV can be stigmatized for several reasons; drug use (prior or continued), sexual orientation and/or their seropositive status; in addition, stigma related to their socio-economic status, race/ethnicity or age should also be considered. Individuals with a greater number of minority burdens, such as, sexual orientation, socio-economic status, race/ethnicity and/or drug-related behaviour, experience greater HIV-related stigma and increased mental health challenges (Storholm et al., 2013). When individuals accept the stigmatizing beliefs that are present in the community, they experience what is called ‘internalized stigma’ (Turan et al., 2016). Internalized stigma is associated with higher levels of reported loneliness and, in turn, with more depressive symptoms and suboptimal ART adherence (Fekete et al., 2018; Grov et al., 2010; Turan et al., 2016). One study details a potential mechanism of the interaction between stigma and poor adherence; patients may avoid taking their medication when people are around, wishing to keep their seropositivity a secret for fear of stigma (Ware et al., 2006). Overall, HIV-related stigma is associated with loneliness and depressive symptoms thus, negatively impacting quality of life and disclosure (Nachega et al., 2012). Non-disclosure of one's seropositive status can potentially lead to risky sexual behaviour and in turn, potential infection of other individuals.

Depressive Symptoms and Loneliness

Depression is a mental disorder that is common in HIV infected individuals, with population-based prevalence of major depressive disorder estimated as high as 36% (Bing et al., 2001). A recent study found that older people living with HIV reporting loneliness were more likely to also report depressive symptoms (66%) than participants who did not report being lonely (39%) (Greene et al., 2018). Depression can also be associated with shame, defined as "a painful, self-conscious emotion in which one perceives the self to be defective" (Vincent et al., 2017). In older people living with HIV, shame associated with depression, was found to affect physical well-being (Vincent et al., 2017). Interestingly, the link between shame and depression might be overlapping with internalized stigma which, itself, has been associated with depression and loneliness, as was described in the previous section (Fekete et al., 2018; Grov et al., 2010). In addition, depressive symptoms are associated with poor viral suppression and other comorbidities, which is likely due to poor medication adherence (Nguyen et al., 2018). Overall, loneliness and depression in people living with HIV are tightly intertwined and can impact quality of life.

Physical Symptoms and Loneliness

People living with HIV can experience physical symptoms either from the infection itself, medication adverse effects or, from comorbidities; these also might be amplified by the natural aging process. These symptoms may contribute to loneliness by limiting people’s capacity to go out and in turn, increasing social isolation (O’Brien et al., 2014). Therefore, investigating whether physical symptoms are important contributors to loneliness in older people living with HIV is of interest. In addition, in the general population, loneliness has been reported as a risk factor for functional decline (Perissinotto et al., 2012). It is unclear whether physical symptoms and functional decline affect or are affected by loneliness in this population. In addition, a side effect of certain antiretrovirals is the development of HIV-associated lipodystrophy, an abnormal distribution of fat in the body that results in a typical appearance which can identify the affected person as someone who is HIV-positive (Casado et al., 2013). Lipodystrophy has been shown to be related to social isolation through discrimination and impaired self-esteem; social isolation could potentially lead to loneliness (Casado et al., 2013).

Social Support and Loneliness

Social support is correlated with better mental health and not surprisingly, having a smaller support network is associated with loneliness (Greene et al., 2018; Reich et al., 2010). Importantly, it has been shown that perceived social support is significantly more predictive of mental health than actual social support; thus, individuals with small social networks can still feel adequately supported (McDowell and Serovich, 2007). In addition, the source of social support was found to vary between gay men, bisexual men and women; specifically, gay men reported social support from friends over family while bisexual men and women reported equal support from each social group (McDowell and Serovich, 2007). Social support preferences might also vary between cultures; for instance, in China, family social support is a strong cultural norm and they tend to take responsibility for sick family members, generally, this includes those with HIV (Sun et al., 2009). A study conducted n China with men who have sex with men found that social support was negatively associated with internalized stigma which in turn was associated with fewer depressive symptoms (Li et al., 2017). In other words, stigma contributes to fear of disclosure which in turn limits social support and leaves the individual at risk for depressive symptoms. As there are differences between genders and cultures, specifically investigating one group would increase understanding of their experience and how it can be ameliorated.

Alcohol/Tobacco Use and Loneliness

A recent study found that lonely participants were more likely to be smokers and were more at risk for problems with alcohol and/or drug use (Greene et al., 2018). Importantly, cigarette smoking related diseases in people living with HIV have become a leading cause of death in this population (Stanton et al., 2015). A study that looked at gender differences in the association between loneliness and substance use found that loneliness was significantly associated with heavy drinking and illicit drug use in women but not in men (Mannes et al., 2016). Therefore, the experience of loneliness and the response to it might be different depending on gender or potentially the age of the individual and should be considered. Overall, loneliness and alcohol/tobacco use are associated and can have serious consequences in people living with HIV.

Research Gap

As described above, the Positive Brain Health Now study (Mayo et al., 2016) and multiple others, have looked at various mood and behavioural aspects associated with loneliness in many different populations of people living with HIV. With the above literature review, it is clear that there is an overlap between loneliness, stigma, depressive symptoms, physical symptoms, poor social support and alcohol/tobacco use in people living with HIV. Importantly, the majority of existing studies have been cross-sectional (Chambers et al., 2014). Therefore, while these studies provide evidence of association, they cannot untangle the highly complex interactions between these facets. In addition, a scoping review on HIV and aging reported that quantitative studies have dominated the research, leaving a knowledge gap with respect to the lived experience of older people living with HIV as well as their challenges (Chambers et al., 2014). This knowledge gap can be filled with qualitative research since it allows for the exploration of subjects' experiences and the meaningful connections they make with the highly complex, multivariable difficulties the face. In light of the difference between correlates of loneliness among different genders, cultures and age groups, the focus will be on one of the largest groups, older white men.

RESEARCH QUESTION AND OBJECTIVES

This study's research question is "what has been or is the experience of loneliness in older white men living with HIV in the Montreal area". The objectives of this study were (1) to generate a theory of the contributors and consequences of loneliness in older men living with HIV and (2) inform interventions to address psychological and social difficulties associated with loneliness in older men living with HIV.

METHODOLOGY

Measuring loneliness

The UCLA Loneliness Scale (Russell et al., 1980) is the most commonly used scale in the literature that has been reviewed for the purpose of this study. The other two measures that have been used are the de Jong Gierveld Loneliness Scale (de Jong Giervel and van Tilburg, 1999) as well as the Social and Emotional Loneliness Scale for Adults (SELSA) (DiTommaso and Spinner, 1993). Interestingly, one study looked at loneliness in different age groups using two measures of loneliness, the de Jong Gierveld Loneliness Scale and a single question directly asking if the participants if they are lonely, and both measures found a similar prevalence of loneliness (Nicolaisen and Thorsen, 2014). Therefore, multi-item scales might not be necessary in order to measure loneliness. In the Positive Brain Health Now study (Mayo et al., 2016), the prevalence of loneliness was estimated using a single item drawn from the Older Americans Resources and Services (OARS) Social Resource Scale: "Do you find yourself feeling lonely: quite often, sometimes or almost never" (Fillenbaum and Smyer, 1981). Therefore, data from that study can be taken as a valid estimate of the prevalence of loneliness in this population.

Qualitative Approach

This study uses grounded theory, a qualitative research method that underscores an inductive approach to generate theory. This methodology was developed by Glaser and Strauss (1967) and entails generating a theory as concepts emerge from the data rather than trying to fit the data into pre-existing theories or hypotheses. This is done through simultaneous collection and analysis of the data and ongoing comparisons through each stage of the analysis in order to continuously develop the theory (Glaser and Strauss, 1967). The purpose of this study is to develop a substantive theory, meaning one that is directly applicable to the situation at hand: the contributors and consequences to loneliness in older men living with HIV (Glaser and Strauss, 1967).

Study Design and Sampling

The Positive Brain Health Now prospective cohort study recruited patients from five HIV clinics across Canada including the Chronic Viral Illness Service at the McGill University Health Center (Brouillette and Fellows, 2014). The inclusion criteria for the study were: age ≥ 35; HIV+ for at least 1 year; able to communicate adequately in either French or English; and able to give written informed consent (Brouillette and Fellows, 2014). The exclusion criteria were: dementia, as defined by an MSK-rating stage of 3 or more- cognitive component only (**Appendix 2**); concern about capacity to consent; life expectancy of < 3 years or other personal factor limiting the ability to participate in follow-up; non-HIV-related neurological disorder likely to affect cognition; known active central nervous system opportunistic infection or hepatitis C requiring interferon treatment during the follow-up period; known psychotic disorder; and current substance dependence or abuse (as per DSM-IV criteria) within the past 12 months (Brouillette and Fellows, 2014).

A total of 856 participants, across 5 Canadian sites, were comprehensively characterized and followed longitudinally at 9-month intervals over a 27-month period for a total of 4 assessments as part of the parent study (Fellows et al., 2018). Data were collected from personal interviews, direct measurements, self-report questionnaires, and chart review. Permission to conduct this proposed study as a sub-study of Positive Brain Health Now was obtained from the McGill University Health Center Research Ethics Board. The participants of this study were all part of the parent study and were recruited from the Chronic Viral Illness Service at the McGill University Health Center. The participants were asked to sign a consent form (**Appendix 3**), if they agreed to participate in this proposed study and to be qualitatively interviewed.

This study uses theoretical sampling, as described by Glaser and Strauss (1967) in the grounded theory methodology. Accordingly, the study participants were selected for theoretical relevance to the research question rather than for representativeness of the population (Glaser and Strauss, 1967). Men who self-defined as white, were aged ≥50 years and who, in response to the question from the OARS Social Resource Scale (Fillenbaum and Smyer, 1981) selected, “quite often” and “almost never” were invited to participate. The objective was to compare and contrast their narratives in order to understand the contributors and consequences of loneliness, as they experience them. Participants were recruited and interviewed until theoretical saturation was reached, meaning the point at which no new information is provided through additional interviewing (Glaser and Strauss, 1967). Saturation occurred at a total of ten participants, six had responded “quite often” and fours had responded “almost never”.

Methods for collecting and analyzing data

A total of ten participants were audio-recorded as they were interviewed one-to-one, face-to-face with a semi-structured qualitative interview guide. The interviews were conducted by the candidate in either French of English based on the participant’s preference. Since loneliness is an individual experience and this study aims to elicit personal narratives, individual interviews are appropriate (Green and Thorogood, 2018). The questions not directly asking about the contributors or consequences of loneliness because they were meant to emerge during the interview as the participants talked about their experiences. Therefore, the questions were meant to elicit a narrative rather than eliciting the participants rationalization of some contributors and consequences. There were four main questions: Can you tell me about your day yesterday? Can you tell me about the last time you really enjoyed yourself? Can you tell me about a moment when something got in the way of you enjoying yourself? Can you tell me about a moment when you felt lonely? Active listening and prompts encouraged elaboration throughout the interview. The audio-recorded interviews were held in a room at the Centre for Integrated Medicine (CIM), MUHC and were a maximum of two hours long.

The first step towards data analysis is to transcribe the interviews verbatim. The candidate transcribed each of the interviews herself within a few days of the interview in order to incorporate any non-verbal cues that occurred. Completing this step without transcription software or a professional transcriber, also allowed for the familiarisation of the interview before coding. The complete transcripts were then transferred into MaxQDA in order to manage the data for analysis. The transcripts were analyzed in their original language so as not to lose any meaning in translation. First, the data was analyzed by initial coding which involves naming each segment of data with a code (Charmaz, 2006). The objective of this initial round of coding is to remain open to all possibilities; it is critical at this stage that the codes are named from the data and not derived from preconceived notions forced on the data (Charmaz, 2006). A second round of coding, called focused coding, was also performed. Focused coding entails using the most frequent codes established in the initial round in order to cluster them together into categories (Charmaz, 2006). From these broader categories, a hypothesis was formed, which is called theoretical coding (Charmaz, 2006). The hypothesis or theory generated was then further modified through each cycle of data collection and analysis. Member checking, that is, getting feedback from the respondents on the findings, adds credibility to the theory (Schwandt, 2015). All participants were invited to give feedback on the research findings in a group setting, however, some participants were not comfortable with the group setting or were too busy to participate (n=6). Four participants agreed to participate and two groups of two individuals were made based on their spoken language (English or French). Each of the groups discussed the findings for over three hours. Once again, the discussions were audio-recorded and then transcribed verbatim to be analyzed. The quotes from the individual interviews and the group discussions that were selected to be presented in the results were translated into English.

RESEARCH FINDINGS

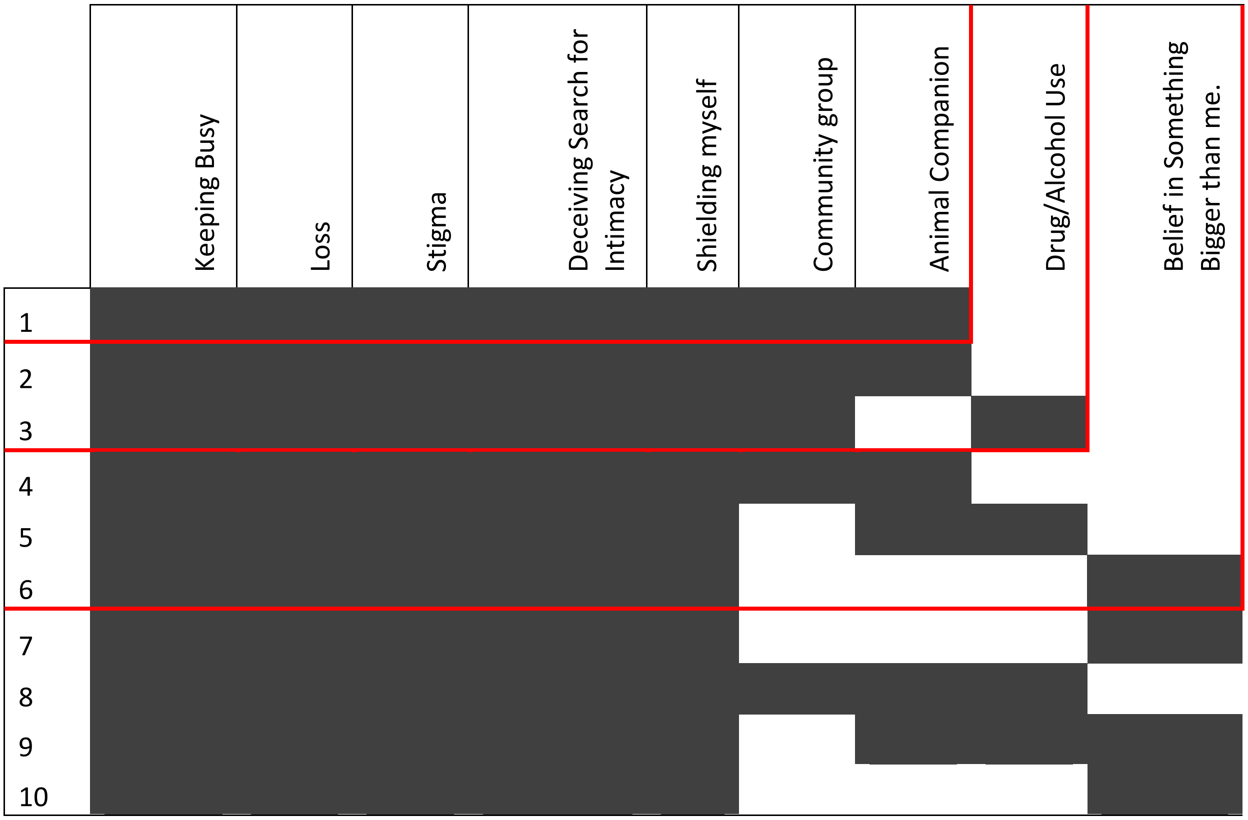
Participant Demographic Information

	Participants									
	1	2	3	4	5	6	7	8	9	10
Lonely		■			■	■		■	■	■
>60	■			■		■				■
Working		■						■	■	
Living with someone	■		■							

Table 1: Participant Demographic Information. The participants were asked “Do you find yourself feeling lonely: quite often, sometimes or almost never?” from the OARS (Fillenbaum and Smyer, 1981) in parent study. In the first row, the darkened squares represent the participants that responded, “quite often” (n=6) and the white squares represent the participants that responded “almost never” (n=4). All of the other information in the table was voluntarily offered by the participants during the course of the interviews, they were not asked specifically for this information. The ages of the participants ranged from 54 to 66; in the second row the darkened squares represent those that are over 60 years old (n=4) and the white squares represent those that were between 54 and 60 (n=6). The darkened squares in the third row represent participants that were working either part-time, full-time or self-employed and working from home with variable hours (n=3), while the white squares represent those not working (n=7). Lastly, the darkened squares in the last row represent the participants that were living with a roommate (n=2), while the white squares represent those living alone (n=8).

Data Saturation Grid

When considering data saturation, it can be difficult for a researcher to determine when this point has been reached; even more so for a junior researcher. In order to help this process, a data saturation grid can be made (Fusch and Ness, 2015). The grid for this study can be seen below.



	Keeping Busy	Loss	Stigma	Deceiving Search for Intimacy	Shielding myself	Community group	Animal Companion	Drug/Alcohol Use	Belief in Something Bigger than me.
1	■	■	■	■	■	■	■		
2	■	■	■	■	■	■	■		
3	■	■	■	■	■	■		■	
4	■	■	■	■	■	■	■		
5	■	■	■	■	■		■	■	
6	■	■	■	■	■				■
7	■	■	■	■	■				■
8	■	■	■	■	■	■	■	■	
9	■	■	■	■	■		■	■	■
10	■	■	■	■	■				■

In the first interview (first row), seven major themes were extracted (column headers). In the third interview, an additional major theme arose, as did in the sixth interview. Finally, in the seventh through tenth interviews, no new major themes arose, at which point data saturation can be argued. All participants had experienced loneliness at one point and therefore there were no major differences between the group that had responded “almost never” and the group that responded, “quite often”.

The three major themes that arose as contributors to loneliness were ‘loss’, ‘a deceiving search for intimacy’ and ‘shielding myself’. As can be seen in the data saturation grid, these three themes were discussed across all of the interviews. Stigma was also discussed in each interview, however, it was mainly discussed in conjunction with the other themes named above and therefore, it has been included in that way. In terms of consequences of loneliness, the participants rather described how they were living with their loneliness; therefore, the terms ‘living’, ‘dealing’ or ‘coping’ will be used instead of ‘consequences’ herein. In addition, there was quite a variability in how the participants described living with their loneliness. The major themes that arose were ‘keeping busy’, ‘believing in something bigger than me’, ‘having an animal companion’ and ‘using drugs and alcohol’.

Contributors to Loneliness

Loss

Loss of an intimate other

During the course of the interviews, all of the participants talked about loss. Most of them have lost a partner to HIV or other diseases. The loss of this intimate other left them without someone to share their life with. They revealed how lonely it is to live alone, eat alone, not have anyone waiting for you or greeting you when you get home. For instance, Participant 6, who's partner had to be placed in a nursing home explained:

"*Love. It's the contact, I am not talking about the sexual side. I am talking about talking to a person, touching a person, something like that. If there is something that is not working, well at least the other person is next to you. Its relieving a bit. Alone there is nobody. […] I miss the little things, its true that when you live alone, there are little things that you miss. Just a touch or I don't know, just another person there. Eating alone is really boring you know. I always eat standing up. In the kitchen. I have a small dining table but I prepare it in the kitchen and then just eat at the counter, standing.*"

On the other hand, Participant 8 spoke about the loss of a really close friend rather than a romantic partner, which also really affected him:

> "*I have a few friends but I have one really major friend. Best friend that I have known for many many years who I met through uh a support group from the AIDS community and he ended up going into liver failure like 3 years ago and he passed away. So for me that was a big. He was the one person that I could be around and be how I was. where. when you. when you. I am not a very good actor anymore. and I am not good at covering my emotions*."

Many other participants had similar stories of the loss of a partner or close friend for various reasons and so this was presented in the focus group as the loss of an intimate other. However, the participants corrected this because they explained that it is not about the loss of one person or even a few people. It goes way beyond that, often starting early on in their life.

Loss of familial support

From when they were young many were rejected by their families due to their homosexuality. Participant 7 said "*my mother, at the beginning she was not really accepting. of it. and uh. she loves all her kids but it took her several years and process and of course she was always involved in the church*". Participant 8 had a similar experience and he explained "*I am not a* *religious person but some of my family members are quite religious. […]. so I have always had a trouble with them being HIV and being gay. because you know it is something for some people*". Therefore, many are left without the social support of their family from the time when they first come out as gay, even before they are diagnosed with HIV.

Loss during HIV/AIDS epidemic

Throughout the height of the HIV/AIDS epidemic, they lost an incredible number of close friends and acquaintances. For instance, Participant 6 explained how difficult it was for him after his partner died but he also reflected on how many people he has lost besides his partner, he said:

> "*the 5 years after my partner died, I felt really alone. I was dealing with the fact that the person that I used to be able to talk to was no longer there. and um. Of course, that really mixes up your whole life. so just overtime adjusting with that. […] lots of people that I know have never seen anyone pass away yet. So I was like wow. I can't even count how many I have lost*"

Participant 8 echoed this experience: "*you get to know someone really well and they would die because this was the era that people would die, and many many people […] so it was difficult sometimes because you get close to somebody and then they would pass away".*

Moreover, Participant 10 said: "*In the years 80-85, I met people, I met couples. But when the disease came, 90% of the people disappeared. I lost more than 90% of my friends*." Participant 4 had unique insight because he volunteered for a community group that helped individuals with HIV and their families. Speaking of an exceptional client, he said:

> "*I really liked talking to him and his whole family on the phone when they called for appointments. they were very respectful […] and the guy you can tell he was very educated. very polite very gentle and the parents were the same way. […] The parents called me in the morning, they said he has to go to the hospital I have the car but I cannot take him alone because he has to have somebody to take care of him and I said let me see what I can do […] and he was all happy and thankful and all that and three days later he died. It broke my heart. I never saw the guy […] but I got attached to that whole family and I talk about and it's been years and years and its still getting me emotionally and uh I'm glad I did that. and then he died and when I closed the file, I gave my resignation. 137 files I closed there because of death*."

While he did not know these individuals in person, he made emotional connections with 137 individuals who died due to HIV. All of these individuals are really speaking to the magnitude of the loss felt by this population.

Moreover, there is also an element of survival guilt that comes into play here, as participants watched others die of HIV/AIDS while they are still living relatively healthy with the virus. For instance, Participant 7 said:

“*watching all of our friends die I think was the hardest because you're just wondering. you say okay. why am I still here and everyone else is gone? that was. I think the hardest part for me was accepting that okay you are still here so. you have got a second chance. that is the way that I looked at it. seeing all these people die at such an early age it was. it was. It was difficult.*”

Therefore, coming to terms with not only the loss of their friends but also their own survival can be very difficult and weigh on their mind.

Loss due to HIV stigma

The participants have also lost friends due to the stigma surrounding HIV. For instance, this is explained by Participant 3 who said:

“*One of my friend, she’s kind of like I was always thinking that she was open open and one day […] she was starting to get different about things and one day she called me and said oh you and your guys and girls from that group and that group and that group I don’t want to meet you anymore and eat at the same table I’m going to catch something. I said what? are you crazy lady?*”

These situations are hurtful on two levels, first there is the rejection due to the stigma and second they are left without the support of that friend.

Lastly, participants are also getting older, as are their friends so naturally their own death is also becoming more salient. For instance, Participants 3 and 7 discussed this during the member checking session:

> Participant 7: "*because we are aging. we see our parents, our friends, our family. going to big housing for seniors and Oh my God I don't want to live like that. […]*"
>
> Participant 3: "*we are preparing*"
>
> Participant 7: "*what am I going to do when I get to that stage? will I have friends around me to help me? how am I going to deal with it? that crosses my mind a lot. it is easier when you are in good health to continue living without thinking about that whole process. it is not easy to sit down and say okay I have to plan out what I am going to do if.. ya it comes up often but so far so good. […]*"
>
> Participant 3: "*especially if we don't have any children backing us. we don't have a family backing us. so we have to prepare ourselves for that. we have to plan for ourselves*."

Therefore, participants are also worrying about whether they will have the social support to deal with any illnesses they may in addition to their own death. As participant 3 mentioned these worries are especially prominent since many of them do not have children and are distant from their families so they really feel alone in dealing with all of these factors.

Overall, the participants described the loss of their partners and/or close friends which left them without an intimate other to share their lives with. However, during the member checking the participants also highlighted the fact that they have cumulated losses throughout their lives. As mentioned above, they experienced rejection from their families due to their homosexuality, even before they contracted HIV. Next, throughout the height of the HIV/AIDS epidemic, they watched countless friends or even acquaintances succumb to the disease. The deaths greatly impacted their social support and also caused survival guilt for some of the participants. In addition, many described losing friends after revealing their HIV status to them. Therefore, their social circles are constantly shrinking and as they age they also worry about the support they will need should they fall ill. This theme describes the immense loss they have been experiencing throughout their lives and how this leaves them feeling alone and lonely.

A Deceiving Search for Intimacy

The participants also discussed their experiences in trying to reinstate intimacy into their lives. There were a lot of difficulties and barriers while trying to do so. They discussed these difficulties in two contexts, online or in person encounters.

Online - Age as a barrier

They often talked about how deceiving their experiences were with the online dating sites or applications. Simply navigating these sites or apps posed problems since they often faced rejection due to their age. Participant 2 explains, “*its one thing to be online when you’re cute and 26 and its a totally different thing to be online with lots of photos when you are 58 and everybody is looking for cute guys who are 26*”. Participant 10 shares this sentiment and added:

> “*the sites for gay meetups. When you pass the age of 50-60. We forget about it. In their head when you pass 50 years old you need Viagra. Its no good. We forget about it. There are some young guys who are looking for sugar daddies. No no, I am not a sugar daddy so I forget about it.*”

Overall, they do not feel that these apps are conducive to meeting people due to their older age which is not what is generally sought by individuals on the apps.

Online – HIV as a barrier

The participants explained that they also face difficulties on these apps due to their HIV status. Some include that they are HIV+ on their profile, which prevents them from having to experience the rejection, since those who are not interested will not bother making any connection with them. However, others are more fearful of indicating their serostatus on the app since having it on public profiles could be risky should their insurance companies or employers find out. For instance, Participant 2 explained his reluctance:

“*uh part of the online dating experience […] I’ve always found that too dangerous to reveal online. You know, who knows where that information goes, who can use it, anybody can visit the site […] my first fear is actually insurability. […] employability. can employers check up on this? […] and there would be the level of if anybody can go to the website, anybody can find out that means anybody in Montreal that might be using that website, and then almost anybody like also sharing with friends oh you know this guy... this guy at bowling look... look at his site he says he is HIV positive.. I didn’t know,* did you know*?”*

Moreover, Participant 2 went on to explain that if it is not indicated that they are HIV+ on the site, then they must deal with the disclosure in person in which they could face rejection:

“*so the HIV disclosure I’ve tried over the years I’ve tried all sorts of methods […] it makes for a really lousy first date... and then the guy he. you can see him kind of going off in his head and he’s talking and he’s gone and he’s far away. okay... well... so I guess we’ll see if he ever phones again kind of thing*”.

Therefore, the participants described different ways of dealing with potential rejection due to their HIV status when using the apps.

Online – meetings often result in hook ups

The participants explained that if they are successful at planning to meet in person after connecting online, the development of intimacy beyond sexual interactions was rare. While the sexual interactions could help remedy the loneliness for a short period of time, participants explained that they are left feeling lonely again soon after. For example, Participant 3 said:

"*the cellphone [...] it's rapid sex it's a meat market oh he has a big dick. oh yes I'm home are you free. so you go over there and you don't want to connect you just want to have sex. so they just have sex and they leave and after you end up with yourself*."

In addition, Participant 2 explained:

"*I don't necessarily believe that the apps have made it easier to meet people. I think they have made it easier to immediately meet people like within the next 20 minutes. but beyond that I don't know if they are making long term or sustained or in depth, I don't believe that it really has facilitated that. It might be the opposite*."

This sentiment was echoed by Participant 5 who said:

“*often on the sites and applications, they complain so much. The discussions are never ending and finally it’s for the now. Or you plan to meet and finally it doesn’t work two days later. There can be a lot of frustration for people with these applications. And trying to deal with loneliness in that way*.”

Furthermore, Participant 9 also commented on this and he said “*but to break the loneliness, I had tried that. And I was doing well with it, but it was superficial.*” Therefore, if the participants overcame the challenges of using the online platforms previously described, the meetings that tended to result were not remedying their loneliness in a sustained fashion.

Online – not for making friends

With respect to the online platforms, the participants also mentioned trying to use them to make friends and not only to find romantic partners. Specifically, Participant 1 said:

“*well I tried being online and on those apps and just saying I’m only interested in friendships not partners. and.... I met someone in December and we had like a little lunch thing and we had a great conversation and we knew a lot of people but we um but I wouldn’t... I didn’t... we kind of have the same acquaintances but we had never met. and we were supposed to* *go again for lunch and […] then I sent him another message and he just didn't answer again, and I thought well I tried*."

Once again, the online contact allowed for a connection to be made but it did not necessarily help foster any long-term relationship. Participant 2 also discussed how the apps do not seem to encourage any lasting rapport, he said:

"[to make friends] you have to be meeting people that you don't already know, you can't do that at home and you can't do that just by walking and its hard to do that just by walking your dog or by going shopping or whatever or by going to a movie with a friend. Right. None of that is making you new friends. Its kind of like well where? and there is no app for let's be friends. […] does that make me new friends? they are online people, so there is that. So I think making friends is very difficult […] uh so if I had to say I would say its almost easier to do a hook up or some kind of meeting that way than the new friends thing I find it very difficult".

In general, the participants explained that the online platforms were not useful for finding friends since they did not foster intimate discussions or connections.

Online – not the same intimacy as talking to a person

Some participants explicitly said that they dislike the online sites due to the inability to really connect with a person online. Participant 2 discussed the generational aspect and he said:

"*because I didn't grow up with them I have always felt I didn't adapt to them and I didn't know quite how to do it. and what I say to well my friends my age, gay men my age we say well you don't get the same feedback, like sensory feedback, like you don't get the same picture of the person you may or may not be interested in from a series of photos on a screen as you do by having them in a room […]so I have always found it hard to adapt to that knew environment because it seems like that's where its going*".

In addition, Participant 7 said:

"*well I used to be on three of them. a long time ago. but I cut all that off. it was just so annoying. you are looking at a picture of someone and a few little words that they say and then you meet the person and it is totally different. and no it is not me. I grew up with the you socialize in clubs and out in the street and all the people that I know now that are on these apps. I find it totally funny. it is just like they are always complaining about this one and this one and this one. but ya that's the whole thing with that. you either have to take a chance and meet the* *person and deal with whatever reality is there or just go out and find a connection. in real life. or you know. applications are totally useless*."

This quote summarizes quite well the deception of using the apps overall; they allow for connections to be made but they may not be genuine or long-lasting.

In person – gay bars are not the same

Since, for many, the online platforms do not meet their needs, they also discussed trying to meet people in other ways. However, most of the time they told me they were perplexed as to where they could do so. They tried to go to the gay bars, where they were the most comfortable and used to meeting people when they were younger. Unfortunately, they still find this problematic because as Participant 8 explained:

> *"[my] generation doesn't go out very much anymore. there is no such gay bars. they kind of disappeared because of the internet. so there is no kind of gathering of my age group*".

Furthermore, they still experience their age as a barrier during their search, as they had described for the online platforms. For example, Participant 9 said:

"*also, for sure after my boyfriend died. Then I found myself in the community again. But I was 50 years old. Um. I don't fit with the young ones that are 20 years old*."

In addition, Participant 7 explained his displeasure and defeat when he said:

"*I have more or less given up on it. it is not easy. you know when we go out I mean you are always looking around but I mean. at my age it is the thing. I will be 56 in September*".

In addition, during the member checking, Participants 7 and 3 discussed how important age was, during their search for intimacy. They said:

Participant 7: "*you become invisible*"

Participant 3: "*that's right*"

Participant 7: "*through my mutual friends and going out to bars I have met many young guys and they are. you start talking with them and it's just the lack of communication but different ages all over the place so. It's nice but not everybody has that. but I mean as you get older I notice that. its like nobody is looking at me anymore. Okay. I am invisible. that is what it feels like. but you know. age is a factor for sure. straight or gay. we all want to be in a relationship. well not everybody but. age is a big thing for any person. to deal with and you just have to live with it. and find your place.*"

> Participant 3: “*the age is part of the invisible. but at the same time we are in a community that the beauty and the youth are very very important*.”
>
> Participant 7: “*perfect body*”
>
> Participant 3: “*its consumerism. its about money. the bars are for that. to make money on beers and meeting guys or girls. bars. but the same thing we are living in a community where. well the world. aging is kind of the left-overs.”*

Therefore, age emerged as a large barrier to making social connections both online and in person.

Participants also said that the environment has really changed in the bars and most people do not make many interactions unless they have already planned to meet through one of the online platforms, or they meet in person but will only follow up online. For instance, Participant 5 said:

“*I go to a bar Friday nights and it is a gay bar and often we are introduced to people and then later they go back and see you on Facebook or Instagram or online applications for sexual encounters. And its only there that they will talk to you. Because they saw you in a bar and if we are in a group with friends and stuff they are too shy or something. Relationships. You know relationships have really changed*”.

Therefore, the method of meeting people they were most used to using in the past, no longer seems to be an effective way of making friends so they expressed being perplexed as to where to go to do so.

In person – sex parties are just for sex

In terms of other ways of meeting new people, some participant mentioned attending sex parties but they were still not able to make long term connections because that was not the objective of the party, it was for sex. For instance, Participant 1 shared his experience and he said:

"*I've tried everything to socialize. I went to a sex party and there was lots and lots of men there and they were all having sex and I was having sex with these men as well and it was all known that we were all undetectable and had HIV and it was a very nice bond. there was a couple of people that I met but we didn't really... and they all kind of knew each other and they all kind of did the bar thing but I was kind of like they would be okay people to hang out with but when I talked to them the only reason they wanted to hang out was to go to more sex parties and I was like well I don't really want to have more casual sex. like this isn't really my whole goal in life is to have as much sex with as many people as possible*".

In addition, Participant 1 also expressed his opinion regarding the difficulties of meeting people and sustaining relationships. He said:

"*a lot of the problem with HIV people is that they are also sex addicts. and a lot of that is how we became HIV. I mean I absolutely know I am addicted to sex that is why I have to keep myself in check and its easy to fall into that pattern and so when you take the sex away from it, it's really hard to meet people that are going to... that's a real struggle in this community I find*".

These two quotes show that there is a desire for an intimacy beyond sex but it is hard to find because often intimacy and sex come hand in hand; in addition, the platforms most often used to meet people such as applications, bars and sex parties, inherently include the sexual aspect.

In person – community groups are not for friendship building

The participants also discussed trying to meet people at the LGBTQ and/or HIV community groups since they felt that it would be a safe place. However, they struggled to develop any long-term relationships. Participant 2 described his experience in a LGBTQ bowling group:

"*uh so if I had to say I would say it's almost easier to do a hook up or some kind of meeting that way than the new friends thing I find it very difficult. even within my social let's say my socializing at bowling umm... I don't know if I have made new friends, there's people that I have chatted with. when I am there. whatever. but to say like that we... outside that venue that we would actually get together and in my case its quite rare*."

In terms of HIV+ community support groups, the participants explained that while these groups did provide support, they felt that the connections they made were superficial and only held while at the group but did not foster into any friendships or romantic relationships. Participant 10 explains why he does not feel the groups are conducive to developing relationships:

“*Often, it’s the people that monologue. Its not dialogues. They talk about their little world, they don’t listen. To talk about their problems and do not to listen to the problems others have. Some people talk more than others, but others simply ignore. And in a group, they start to make insensitive jokes and when you don’t know that person you shouldn’t make jokes about the person*.”

Participant 8 had a similar opinion and he said:

“*It was different/ dynamics changed, the people changed, and I didn't really like the people that were in the group. at one point I just said I can't deal with this. I am here more for. for moral support. just friendship. not to complain not to. talk about stuff. I wasn't having any more issues anymore*”.

Therefore, while the participants did not deny the usefulness of the groups to express their difficulties, they did not feel that they provided an environment conducive to making intimate connections.

In person – HIV as a barrier

When making connections in person the participants also faced HIV stigma and misinformation. For instance, Participant 10 said:

> “*the last sexual encounter I had with a man my age. He wouldn’t dare touch my sperm. Because for him, in his head, it was a source of contamination. I told him no that is over. But it still hasn’t gotten into their heads. as soon as you say, in the gay community, like in the hetero community. There is a lack of information. As soon as you say seropositive undetectable it is well he is going to die soon. So finding a friend. Forget that*”.

This participant describes how HIV can be a barrier to a long-term relationship, first because the individual might not fully accept their status even if they accept to have a sexual encounter; second, because he explains that many feel they are dying even though their infection is under control so they do not envision a long-term relationship being a possibility.

Overall, there were many barriers to finding the intimacy they are lacking. First, with respect to the online applications, the participants explained that age and HIV were major barriers to meeting people online. The participants also indicated that the online applications often did not allow for the development of intimacy beyond meeting for brief sexual encounters which does not remedy the loneliness in the long term. Moreover, the participants described their inability to meet friends online or making any deep connections with individuals on these platforms.

Second, with respect to meeting in person, the individuals did not know where to go, to do so. They explained that the gay bars, which they often frequented in the past in order to socialize, no longer worked as effectively to meet people because many rely instead on the online applications. In addition, the community groups were described as useful for expressing difficulties and for problem-solving but not for the development of long-term relationships. Moreover, age and HIV also remained barriers to developing relationships with people they met in person.

Shielding Myself

For this third and final major contributor, the participants explained that due to previous negative experiences, they often shield themselves so as not to relive the pain. Unfortunately, this shielding leads to them isolating themselves from others and contributes to their loneliness.

Avoiding more loss

First, relating to the first theme, since participants have experienced an immense amount of loss, they do not want to get close to someone and go through another loss. For instance, Participant 8 discussed the recent death of his close friend, another friend moving away and the fact that losing his job left him without the social support he had there. He said:

“*its loss. a lot of loss. of people who were important in my life either physically by not being there or having to change. or something. so. ya. its true. I don't. it affects. my willingness to participate or contact or be more social. because I am not. I am not*”.

Therefore, all the loss he has experience has left him not wanting to participate and in turn has led to him isolating himself.

Prevailing homophobia

The participants often discussed a prevailing and societal homophobia which has affected their level of socializing. For instance, Participant 2 said:

“*there was a prevailing homophobia around so I was very aware of that from kids at school and name calling and things like that and whenever I observed bullying I thought oh it won't take much for me to be next... so that um you know, I really integrated that. you know I don’t really like that expression internalized homophobia but I recognize what it means but certainly I have it and had it. and it effects you just about everywhere and it affects your decisions. you know your actions and your decisions*.”

Participant 6 also expressed feeling this and he said:

“*I was raised in a Judeo-Christian area. My father was very religious. We went to church every Sunday. […] maybe the environment also caused in part this sort of isolation because in reality we feel different than how society is supposed to be. Automatically, I think it is internalized. […] even today I keep a distance from others. […] maybe I have a fear of rejection*”.

The participants described how they keep a distance from others in order to protect themselves from experiencing homophobia, however, this limits the social support they can receive and leaves them feeling lonely.

Prevailing HIV-related stigma

In addition to the prevailing homophobia, the participants also described a prevailing stigma towards HIV which they also feel they need to shield themselves from. For instance, Participant 6 was talking about the beginning of the HIV/AIDS epidemic and he said:

“*I remember at the beginning there were homosexuals, Haitians, a few groups. And I remember that everywhere in North America, when it was a Haitian driver, a taxi driver, people would refuse to get into their taxi. […] and one time it happened to me at school, I heard behind me a student. Because I was skinny, he said, he looks like he’s got AIDS or something. It hurt me so much*”.

Both the homophobia and HIV stigma are also very relevant in the professional sphere of their lives which has also limited their ability to make social contacts in that setting. Participant 9 explained:

“*there was stigma in the ‘90s. I think there still is, if they know that you are seropositive. The fact that you are gay, maybe less. But if I look back to how I reacted, I was not open open. I had a lack of confidence or acceptance. […] and if people knew at that time that I was seropositive, or even gay. I was a professional, an engineer. And what was running my life was fear. Fear of not being loved and especially fear of not being secure financially*”.

Therefore, participants described being afraid of experiencing stigma due to HIV which once again led them to isolate themselves; contributing to their loneliness.

Personal experiences of stigma and rejection

In addition to the societal homophobia and HIV stigma, some participants have personally experience stigma and rejection which is very hurtful and they do not want to experience that again. A strong example is the following experience from Participant 6:

“*the loneliness, I might have created it. Because I don’t open myself up to everyone. Because I have had a few bad experiences, so I have decided to take a distance. […] I became* *lonely. […] my lipodystrophy, the loss of fat with the medications. Well that, automatically. In that era. Today, I don't know, what they think but in that era they new automatically what you were. Its hurtful. […] I was at the YMCA. And one guy. A stranger, a person I didn't know at all, […] he came to me and said, I have never seen a person that is so skinny in my life. And a young lady that was coming in looked at me and it hurt me immensely*".

Participant 6 was also deeply insightful when he said:

"*Living with HIV and loneliness, I think it is common. Because whether you like it or not, your life is flipped upside down and you have to face everything that you had before. It's there, that the distances form, the barriers. And loneliness also. I think it comes with that. And I think it is a little bit like when you tell someone you have cancer. At one point the person withdraws and I think that is normal too. It is part of life. And with HIV it is even worse because it was badly digested by society so automatically there is a form or protecting yourself. Withdrawing. The least you appear, the least they can see you. That's what I saw. It is a little like the original sin. And once you have HIV, you have it for life. There is no medication yet that eliminates the virus. You are condemned for life*".

So for this participant there is the idea that he is protecting himself from others because of the bad experiences he has had regarding stigma; in addition, he feels others withdraw to protect themselves either from getting the virus or because they believe the person is dying.

Overall, participants explained that societal homophobia and HIV stigma that has existed for their entire lives, instilled a fear of personally experiencing such stigma and rejection. In turn, they described isolating themselves to shield from the stigma and negative experiences. However, they acknowledged that their reaction to these fears prevents them from socializing to the degree they feel they should. Moreover, many still personally experienced stigma due to their sexuality or their HIV status even with their efforts to shield themselves from it; these experiences reinforced their desire to avoid such situations, leading to further isolation and loneliness.

Living with Loneliness

Keeping Busy

Most of the participants explained that when they were feeling lonely, they would try and find something to keep them busy. For instance, as Participant 10 said, "*on Thursdays, its grocery day. I have a little routine established*"; so, it could be as simple as doing errands or housework which can pass the time and also leave them feeling accomplished. In addition, many had a set schedule that included working or volunteering. Participant 8 is working full-time and he said:

> "*I have really good moments at work with the people. where I can really make them laugh or they can really make me laugh or something. that I always. that always wakes me up and I always try to lighten the moment or say something silly or […] kind of witty*".

For those that are not working full time they discussed their volunteering such as Participant 10 who said, "*In the winter, Wednesdays, its Wednesdays that I […] give massages for relaxation at [the organization]*". Therefore, giving back to the community, through volunteering helped the participants keep busy, socialize and feel less lonely.

In addition to organized activities such as working or volunteering, the participants also spoke about hobbies that they do; Participant 1 said:

"*well for me to prevent loneliness I just keep myself really busy. like I am very active like I try to pursue some interests like you know vegetarian cooking and you know self-absorbed interests but who cares*".

Participant 8 also explained how he doesn't let himself dwell on the loneliness, he said:

"*I get bored. I draw I paint a little bit too. my hobbies. but. sitting around thinking okay. I am really depressed. it is easy to do but it is not me. it is just always something I can do but whether it is just in my 3 1/2 or going outside for half an hour walking around just to change my mind a little bit. but not sitting down and letting it go down. that is the worst thing that you can do. so. no no. I stay clear of that*".

As this participant described, many discussed keeping themselves busy with their personal interests instead of dwelling on their loneliness.

Moreover, many participants mentioned physical activity as a way to distract themselves; such as Participant 7, who said:

"*walking. I do a lot of walking. I love walking. […] a couple of weeks ago I walked 5 hours up the mountain, around the mountain down to the east end again and home. I have always loved that*".

Participant 2 also explained how he kept himself busy:

"*so the gardening it's actually a passion for me […] I don't know, what else do I like to do? […] I like to read. I'm kind of a news junkie that kind of thing. TV […] I enjoy walking. walking the dog, just walking I enjoy. depending on the weather like when I travel, I like to just explore neighbourhoods and walk around. I very much enjoy the walking part*".

On the other hand, Participant 5 preferred training at a gym:

"*For sure with the training. It changes everything. Sports change everything. Physical activity like 4-5 times a week. With that rigor. Also, it's another place where you can talk to people. […] doesn't mean we will become friends […] but maybe acquaintances*".

Alternatively, Participant 10 enjoyed an organized class:

"*In my neighbourhood, I found a group for Tai Chi […] I did it for three winters. It really helped me a lot. Tai Chi is good for the memory, equilibrium, stress, stretching, concentration and breathing*"; as well as individual activity: "*normally I do the big bicycle paths. […] And the other possibility is the South Shore, Longueuil. You can get to Varennes. […] I do routes of 4 hours. I have to stop at least half an hour, I take my nap, eat something, drink. And my routine when I do a big trail is to find a quiet corner and I do my exercises, I eat a granola bar, water and a little nap while listening to the birds. […] I have had good times because I make myself a little world of my own. To break the loneliness*".

Many participants described using physical activity, whether it was alone or in an organized class, as a way of feeling less lonely.

Furthermore, some of the participants also discussed their screen time. For instance, Participant 3 said:

“*going for a movie [...] sometimes I feel like okay I would like to have a movie that is going to touch me or even get a good cry, so I search the news and oh ya I want to see that movie. and not necessarily gay it can be straight it can be like they call it women's movies. I don’t care. it just gives the feeling. I like that*.”

In addition, Participant 8 described relying quite a bit on entertainment to keep himself from being lonely:

“*I can sit and watch YouTube videos for hours or I can play videogames or whatever and be distracted be kind of focused on something else that doesn't make me think about. and my partner says oh, you just do YouTube videos, but it has been a form of distraction when I have felt really bad. I think about something else, so I don't think about it. but I guess it has become my way of interacting. without having to be around people to interact*”.

These participants used more sedentary means such as movies, shows or games to distract themselves and not focus on feeling lonely.

Overall, the participants described keeping busy instead of dwelling on their loneliness. While some of the activities did involve some level of socializing, in general, the activities were used to pass the time in a way they could enjoy but they were not ways of solving the lack of intimacy they are facing.

Believing in Something Greater

The participants also discussed spirituality, or in their words ‘believing in something greater’. None of the participants mentioned following any specific religion; in fact, many discussed what they perceive as the hypocrisy of certain religious beliefs. For instance, Participant 7 said:

“*I am not very religious. we are Anglicans but um. I stopped going to Church quite young because of the hypocrisy that I was hearing all the time. and I am a person that has a lot of love and everybody needs love. everybody should be loved and the Church has been a huge problem for me. especially coming out gay. it is like why are you spreading all this hypocrisy. like everybody believes in something. whether you call it God or any other religion. something that we are all supposed to have this faith in something otherwise there is no purpose*”.

However, participants did discuss having a belief in a greater being and/or destiny; having these beliefs allowed them to come to terms with their HIV or anything else that was happening in their lives and never feel completely alone since there is some greater being or some greater plan. For instance, Participant 7, after explaining how he is not religious, spoke about his spirituality and how it has helped him cope with the losses:

“*I have my own spirituality. something higher than me. I don't know what it is but I know that it is there and that is my purpose to do the best I can. and I can't do more than that. […]*

well it has been a long process but I mean I have. seeing all the other people suffer and then leaving. um it has helped me in a way as. as. what I have always thought about the afterlife. what is going to happen. and for me it is seeing these people pass on. I almost become to believe. that you can actually see the person's spirit leaving their body. so it is. for me it is like and energy that. goes on. the body is gone but it is. there is energy that goes on. everything that we accumulate here. survives somehow. so I call it energy. I can't really explain it and never will but it is. helps in dealing with all that and to say well it has to be a purpose. just has to be".

On the other hand, Participant 9 explained that his beliefs gave him confidence:

"*If you believe in something bigger than you. It can be the chair. But. You stop beating yourself up. You have a confidence. It is to develop a confidence in something bigger than yourself that can change. When we aren't really changing but you stop beating yourself up and we come to accept and love ourselves. That is what happens*".

Participant 9 also went on to explain how it specifically helps with his loneliness, he said:

"*there is isolation and then there is feeling along. But when you have a deep conviction that you are loved by something bigger than you. By life. Anything. There is no loneliness*".

Overall, having these beliefs, whether they are grounded in religion or not, help the participants by giving meaning to their lives despite their illness, their losses and the stigma they faced; all of which helps them cope with the loneliness.

Animal Companion

A number of the participants had cats or dogs as pets, and they explained that the animals provided companionship. Specifically, the animals helped some participants deal with loss, for instance, Participant 9 explained:

"*my boyfriend passed away in 2015 and I wanted to keep our apartment because we have two young. Well. I have dogs. They are 7-8 years now. The 'kids' of my boyfriend who passed away. I am keeping them, I love them*".

Therefore, for this participant his dogs are a connection to his partner that he lost so they help keep memories alive and also keep the person company. In addition, Participant 4 had a similar experience after his boyfriend passed away and he said:

"*I have a cat I can't get rid of it because its only thing that helped me through that period. he's a lovely pet. […] he chose me and I chose him […] its like a link too, with my boyfriend*".

Moreover, Participant 1 also discussed getting a dog soon after he was diagnosed with HIV and he explained how helpful that was for his initial recovery since he would have otherwise been alone; he said:

“[the organization] helped me find a new doctor and they got me my first dog, my dog before this one. the woman there, who was my intake person actually she said my sister is getting rid of her dog and cause he barks when they are not there and they are not there during the day so I said while I am happy to take him so they brought him and it was great. especially when I was recovering, it was just what I needed in order to sort of get better.”

Therefore, the companionship the animals provide was described as helpful for coping with loss and with their illness.

Besides the companionship, participants that are dog-owners mentioned that the dogs gave them a reason to get out of the house. For instance, Participant 2 said:

“*uhh usually [we walk] about an hour, rain or shine, snow, sleet whatever uhhh and part of that was uhh also because I work at home that its a good motivator to make sure that I actually get out and walk because there was time like I’ve been self employed for 20 years and there was time especially during those early years where I was very sedentary and since I didn't* *have to go out to work downtown and I didn't realise until later that its like wow there was days I didn’t even go out*”.

In addition, the dog owners were more scheduled and had a routine for the day because of the dogs which could help prevent them from feeling lonely since they are occupied. For instance, Participant 5 said:

“*I have two dogs, two cocker spaniels. So the first step when I get up is to walk the dogs. So taking a 15-30 minutes to walk the dogs*”.

Participant 5 also added the importance of having the dogs in his life, he said:

“*I have the dogs for 9 years. And I would say they helped me get through all of this. If I didn’t get those animals there. There would be no reason to get out of bed. None at all*.”

For this participant, the dogs are giving him a purpose and adding meaning to his life.

Moreover, not only are the animals helping with their loneliness by keeping them company, they are also keeping them busy and breaking the ice to talk to others. Participant 5 explained:

> “*first, people find me good having dogs. Having the discipline of 4 walks a day. And by doing these walks, especially summer or spring, I walk in the village, I walk in the street, I say hi to people and people say hi to me. There can be people that don’t know me by we can have an exchange. We can talk maybe 10 minutes, thanks to the dogs. I won’t see these people again but I had an exchange with them. So, it comes and helps with the loneliness*”.

Therefore, the animals might allow for contacts that would not otherwise be made.

Overall, pets were described as being helpful by keeping the memory of lost loved ones alive, by keeping the individuals’ company, encouraging them to have a schedule, giving their lives more purpose and potentially even helping them socialize.

Drugs and Alcohol

Some of the participants also mentioned turning to drugs and/or alcohol when they felt lonely. Most of the time alcohol was mentioned during the grief process after a loss. For instance, Participant 9 said:

> “*I found out I was seropositive, I lost my job. I didn’t have a salary. I thought my life was over, my career was over. So that is how it developed. My partner was sick for 10 years, he had heart problems, he was at risk for sudden death. I was in survival mode. I was isolated but I*

was also isolated because of my own difficulties. Because I was drinking. It brought on more isolation. Not only the HIV but my own difficulties and by behaviour resulted in that. And it results in isolation because when you have weird behaviours, you have problems. You have traumas. You react in a certain way and the people that are doing fine… They go in the other direction".

Interestingly, this participant describes how he was isolated and lonely when he caring for his sick partner, then his drinking followed these traumas; however, the drinking also contributed to his isolation because people did not want to interact with him.

Drug use was mentioned in relation to social events, parties and sex parties; the drugs were used to help them loosen up, make contacts and enjoy themselves to a greater extent. For instance, Participant 8 said:

"*I do dabble with something on Sunday afternoon to make you a little more fun but not in any kind of abusive way. but. you know. if that is the only that when you feel like you can be social and happy*".

Participant 3 also described a similar situation that he watched a close friend go through:

> "*for him he was more about the libido than genital stuff so him it was more like 3-4 times a day so the sex is very very encored in himself so having HIV its kind of like umm stigma. stigma but at the same time its kind of a big attack on his own inside. his own soul. so if being refused by all the people around and having that connection was drugs with sex parties and drugs that makes more people because when they are on drugs they love everybody and everyone loves you so that connection help him to survive. […] he has to smoke and inject himself to have that sense of being part of a family and being loved. that's a sad part*".

Therefore, the drugs were described as being useful to disinhibit individuals and allow for more social interactions. However, dependence on drugs to socialize could become problematic in the long term.

Opportunities for Service Development

The participants also discussed the current psychosocial services that are available to them and where they fall short in terms of helping with the psychological and social difficulties related to loneliness. Importantly, many participants shared words of praise for the HIV community groups in the Montreal area. For instance, Participant 1 explained how a staff member for a community group was instrumental in helping him access care after his diagnosis:

"*I really liked the intake person […] and she was non-judgemental, she knew. I said this is why I am here, I have HIV. full blown AIDS and I want to be around people and hear their experience because I have no idea what's happening with me now, what state my life is in, what state my health is in, if I'm going to live, if I'm gong to die, if the meds are going to work, that was all new territory for me and she had been doing this for years so she was really good at explaining to me what was happening and I discussed the doctor I was with at the hospital I was with and uhh how much I didn't like him and I didn't feel like he was giving me any information and she said well there is a better one at the General and she gave me the card and set up the appointment and I went and met my new doctor and I loved him […] I went to support group and I really enjoyed the support, meeting the people and being with other people and it was the same people every week for twelve weeks*".

Many other participants had similar stories in terms of a deep appreciation for the support of the organizations immediately following their diagnosis. However, after they become more stable, the groups no longer provided the support they really needed. Participant 3 described this:

"*so the group was ya at one point they were helping me and we can say they helped me to express myself more I can say in that way. but at the same time, it is kind of a double effect because you meet so much people that are negative, so you say okay you are. you have HIV or Hep. C. or you are a drug addict or whatever, but you have life. continue living. but there are people that are so negative about it. I realized in life that you can be a victim or be part of the solution*."

Therefore, while the groups are important to provide support after the initial shock and help the individuals stabilize themselves, the discussions are centered on difficulties which, by nature, creates a negative environment. If the individuals are no longer facing these problems, then the groups are not really providing them with support.

In terms of service development, the participants described what they felt would be helpful to deal with the loneliness. For instance, they suggested organizing social activities away from the groups talking about difficulties or from the gay bars. For instance, Participant 3 said:

"*well I would say like us in the gay community downtown we don't have a lot of place to really socialize. our life has been based on bars. this is the only place where at that time in 1960-70-80 we could meet each other. […] you can meet and socialize. you don't have that very much in the gay community. well I know that a few. uh. a few guys that are part of the gay community […] they want to start that kind of group. meeting those once a month or 2 times a month. just go outside. it is not a bar and you can talk. because of the loneliness and we are all aging*".

Importantly, they suggested that these groups be advertised as events for HIV positive individuals but should also be open to anyone who would like to join, Participant 3 said:

“*why a closed group? you know you want to have an openness from everyone so it should be opened. but like an HIV event but everyone is welcome. kids can come. because one day they might face it. if we don't cure that virus. you don't want to keep yourself just me me me me*”.

Therefore, organizing social event involving activities could help create an environment for contacts to be made, outside of the bars and HIV community groups.

The participants also suggested peer programs in order to encourage close bonds, give newly diagnosed individuals access to information based on first-hand experience and give the supporter a sense of purpose. For instance, Participant 3 explained,

“*the new generation is coming for HIV and we should face them with the old generation so they can deal with them. all together. yes you have that and that and that and now there are people that have lived 20 years already with it. they will tell you all about it. [...] it is something that no doctor will tell you*.”

These types of programs could help individuals who are more reserved or have difficulties in socializing since the pairing would be done for them. In addition, in terms of helping with socializing, Participant 8 said:

“*I was the uh really shy guy. always. always. everybody would come to me because I wouldn't say a word. they always made the first move. and over the last few years I have been improving my personality and uh I took the self-esteem courses and that helped bring out things that I didn't process. and its easier when I go out now to be able to. someone next to you at the table will make a comment and you hear and you laugh and you add something to it and that is how you start talking. so I find it easier now but it is a big process to say you I'm going to talk to you. no. its hard*”.

Perhaps self-esteem classes could be useful to other individuals who have difficulties socializing as well.

Moreover, participants also suggested that education is important, not necessarily to help them, but rather to reduce stigma for future generations. For instance, Participants 6 and 4 discussed this during the member checking session:

> Participant 6: “*But for education, at school. Are we teaching these things?”*
>
> Participant 4: “*I have friend who worked and he did the tours of the schools to talk about it. Its not easy to do.”*
>
> Participant 6: “*the earliest we can, we need to give the information to the population”*
>
> Participant 4: “*and the person’s social network is important too. Because if the family is problematic…*”

Interviewer: “*what education specifically?*”

Participant 6: “*sexual education*”

Participant 4: “*there should be classes on socializing and sexuality*”

Participants felt that sexual education including, birth control, sexually transmitted infections, practicing safer sex should be included in school programs. The aim of the education would be to provide necessary information for prevention of sexually transmitted infections but also to decrease the stigma that comes with them. In addition, the participants suggested education on healthy relationships and socializing because they felt that children are most often using online means of communication and have difficulties expressing themselves in person.

Overall, the participants explained that the HIV community groups are instrumental for providing support to the newly diagnosed or to those that are having difficulties. What is lacking for them are groups for people seeking long term platonic and/or romantic relationships since they are doing well other than their loneliness. They also expressed wanting groups that are for HIV-positive individuals but not exclusive to this population. By advertising that they are for HIV-positive individuals, they hope that members of the general population who do not hold stigmatizing beliefs will participate and that anyone uncomfortable with this will simply not join. Moreover, they suggested that these groups be centered around activities such as arts, sports, cooking, etc. in order to avoid repeating the social circles in which problems are discussed and to allow for connections to be made based on similar interests. Finally, their desire is that future generations do not experience such difficulties when it comes to experiencing stigma related to homosexuality and HIV. They hope that the education system can inform young people and dispel stigmatizing beliefs to build and more inclusive society.

DISCUSSION

Overall, the results describe the lived experience of loneliness in older white men living with HIV in terms of contributors, consequences and opportunities for service development.

Contributors to Loneliness

With respect to contributors, three main themes emerged according to the participants: ‘loss’, ‘a deceiving search for intimacy’ and ‘shielding myself’. First, the immense amount of loss they have face throughout the entirety of their lives, from the loss of familial support when they were quite young and came out as gay, the loss of acquaintances, close friends and romantic partners during the HIV/AIDS epidemic and still; in addition to the loss of other friends or family to HIV stigma. Second, since their social support has been consistently shrinking for their entire lives, they explained trying to renew it and make intimate connections again. They discussed online platforms and in person opportunities; unfortunately, in both cases they faced barriers due to age and HIV-related stigma. Moreover, online platforms did not allow for sustainable platonic or romantic connections to be made since the intimacy of actually being face-to-face with a person is not recreated; when online platforms were used to initiate in person meetings, hookups often resulted. In person, the participants discussed that the environment of gay bars has changed since many are using online platforms to talk to people rather than communicate at the bars directly. They also discussed other venues such as sex parties and LGBTQ+ or HIV community groups, but none were useful in fostering long term relationships. Thirdly, the participants described shielding themselves from more loss or stigma because they did not want to experience more pain. However, this shielding results in self-isolation and in turn more loneliness. How these results can be situated in the existing literature is described herein.

Loss/Traumatic Experiences

All of the participants lived through the HIV/AIDS epidemic of the 1980's and 1990's. They discussed all the people they have lost throughout their lives. The loss of these individuals limited their social networks significantly, leaving them socially isolated and in turn, lonely. Moreover, the participants also described a lack of family support when grieving since they were estranged after coming out as gay. However, the impact of loss was also beyond that of the individuals physically not being there. Some studies have reported that traumatization can occur when individuals are unable to cope with the multitude of losses experienced during the HIV/AIDS epidemic (Machado, 2012). These individuals can face post-traumatic stress like symptoms such as numbing, flashbacks, nightmares, emotional outbursts and substance abuse (Machado, 2012). Living with these trauma symptoms are likely to greatly effect their lives and their ability to build new social connections (Oram et al., 2004). Moreover, the participants of our study discussed feelings of survivors' guilt for outliving their partners and friends. Survival guilt can be destructive since it can prevent individuals from accepting the loss and progressing (Machado, 2012).

Moreover, their own diagnosis of HIV might also add to their loss, the loss of their former self (Zeligman and Wood, 2017). Having to adapt to living with the virus comes with many challenges and has been investigated in terms of different disease models (O'Brien et al., 2009; Solomon et al., 2014a, b). The models highlight the uncertainty and episodic nature of the illness which on one hand encourages finding contacts since they require social support should they become ill; on the other hand, discourages social contact since their death is more salient.

Additionally, since HIV is negatively viewed by the population, their grief and challenges is often not acknowledged which leads to isolation, and potentially loneliness (Zeligman and Wood, 2017). Another qualitative study on aging men with HIV explained how the participants described their lives as “a shrinking kind of life” (Masten, 2015). Overall, the sheer magnitude of the loss this population has experienced, from family, lovers, friend and acquaintances, in addition to their own self, evidently has a huge impact on their psychological well-being.

Searching for Intimacy Online

All of the participants discussed using online dating websites or apps in order to find an intimate partner. This is not surprising since, in general, there is a growing use of online technologies for the purposes of establishing and maintaining social contacts (Brym and Lenton, 2001). A Canadian report on digital dating found that people mainly use online dating services because it is convenient, allows them to meet people they would not otherwise meet and offers privacy an confidentiality (Brym and Lenton, 2001). Another study reported that gay men are particularly likely to find their partners online, perhaps since there is a fewer number of potentially partners (Rosenfeld and Thomas, 2012). In addition, the privacy factor likely also plays a role in their choice of online dating over meeting in gay bars (Rosenfeld and Thomas, 2012). As participants of our study mentioned, they were also able to avoid facing direct rejection by putting their HIV-positive status on their profiles or through the chatting instead of having to disclose it during face-to-face meetings. This is in line with the results of another study which reported that individuals who are less confident in their face-to-face skills may prefer online interactions since they can control when and how they respond (Coduto et al., 2019). It has been suggested that lonely individuals tend to have other lonely individuals in their social networks (Cacioppo et al., 2009). Therefore, online applications allow for exploration of new social contacts anytime and anywhere (Coduto et al., 2019). However, the participants of our study explained that online dating was not, in fact, helping remedy their loneliness. They struggled to turn the online meetings into in person meetings due to age and HIV stigma. A study on Grindr, one such gay dating app, also reported that older individuals and those with HIV often faced stigma (Conner, 2019). For instance, on some profiles there were messages indicating that they would not respond to anyone over a certain age (Conner, 2019). In addition, they referred to people who did not have HIV as ‘clean’ and to those with HIV as ‘dirty’ (Conner, 2019). In our study, the participants also often described the applications as a ‘market’ and explained that more often than not they found hookups but nothing long-term. Other studies have reported similar findings, with individuals describing people on the apps as products for consumption (Barraket and Henry-Waring, 2008; Licoppe et al., 2015). Such applications have also been blamed for the decline in socializing in gay bars or other gay places (Conner, 2019). This decline in socializing was also mentioned by participants in our study; therefore, they do not know where to turn to make social contacts. Overall, it is not surprising that the participants mentioned turning to online dating as a way to make new social contacts. It is also logical that the intimacy they are searching for is not often satisfied by these means.

Stigma

The concept of stigma appears in all three of the major themes that emerged as contributors to loneliness in this study. Between homophobia, age-related stigma and HIV-related stigma, it is not surprising that this population is heavily effected (Masten, 2015). In the first theme, participants discussed losing friends or family due to negative reactions and stigmatization after disclosure of their diagnosis. Second, when looking for intimate relationships, the participants also spoke of experiences of rejection due to their HIV. Finally, in the third theme, the participants explained how they would shield themselves from experiencing more loss and rejection through avoidance and social isolation. The result is not surprising since stigma was already included as a contributor to loneliness in the theoretical model of loneliness generated by the Positive Brain Health Now study quantitative data (**Appendix 1**).

In the past, the early medications to treat HIV led to the development of lipodystrophy which caused a skeletal appearance that could identify a person as HIV-positive. With the advances in HIV treatments, there is no external evidence that can identify a person as someone who has HIV. Since it is not visible, HIV is considered a concealable stigma (Pachankis, 2007). People living with HIV have deal with the threat of potential discovery from individuals that they do not wish to share it with, in addition to any negative consequences of disclosure, all of which can have cognitive, affective and behavioural implications (Pachankis, 2007). Cognitively, the individuals are vigilant and suspicious of anyone who might recognize their condition leading to the development of negative affective states such as being anxious, unhappy or shamefulness (Pachankis, 2007). In terms of behavioural consequences, individuals with concealable stigmas are likely to avoid social situations and therefore isolate themselves (Pachankis, 2007). Our study supports the work on concealable stigma since participants did report isolating themselves in order to protect themselves from situations of inadvertent discovery of their status and from experiencing rejection which was described in the third theme. Other studies have also reported similar findings in terms of social withdrawal due to HIV stigma (Lawrence, 2013; Masten, 2015). With respect to individuals with lipodystrophy, their stigma is no longer concealed which can make them preoccupied with their appearance and also effect their social life. In this study, some participants did have lipodystrophy and reported negative interactions with individuals due to their appearance. Another study reported that individuals with lipodystrophy tended to limit their social life, especially in the gay milieu's where they felt that physical appearance is particularly important (Power et al., 2003). The importance of physical appearance was echoed by individuals in this study in terms of lipodystrophy but also in terms of aging. The participants of this described being rejected by younger individuals when searching for intimate relationships. Another study found similar results when investigating HIV and age related stigma; they reported that many individuals were rejected based on their age and experienced name calling (Emlet, 2006). As was mentioned above, this has also been found to be the case on dating apps (Conner, 2019).

Living with Loneliness

The results also show that the participants have found ways to live with their loneliness. First, they discussed the many ways they keep themselves busy to avoid feeling lonely, such as, working, volunteering, physical activity and watching television or playing computer games. Second, they talked about how having an animal companion helps by keeping them company, encouraging a routine and motivating them to get out of the house. Third, they discussed a belief in something greater to help them cope with their loss and other difficulties and to find purpose in their life. Fourth, the participants also described drug and alcohol which might be helpful to cope with loneliness in the short term but may become more problematic in the long term.

In general, these results align with the literature available on ways of dealing with loneliness. For instance, in the Brain Health Now theoretical model of loneliness, not working or volunteering was included as a potential contributor to loneliness and the participants reported that working or volunteering to keep busy helped them manage their loneliness (**Appendix 1**). For those that were not working or volunteering, many still discussed having a set routine with their errands and hobbies. This is in line with a study of widowed women that reported that these individuals developed new routines to keep busy and manage their loneliness (Davies et al., 2016). With respect to the effect of loneliness on physical activity, existing data is conflicting. In the Brain Health Now model of loneliness, physical activity was decreased as a consequence of loneliness as potential consequences (**Appendix 1**). Likewise, another study also found that older men with less social participation were more likely to be sedentary (Kikuchi et al., 2017).

Another study found no association between loneliness and physical activity (Schrempft et al., 2019). However, in our study the participants reported using physical activity as a way to keep busy and cope with their loneliness, which seems to be contradictory. Importantly, not all the participants in our study reported using physical activity to cope with loneliness and perhaps those that did discuss it, do not use it regularly.

Next, in terms screen usage such as television or computers, the Brain Health Now model of loneliness included an increase in such activity, and this was echoed by the participants of our study. Likewise, a study of older individuals found that loneliness levels decreased as internet usage increased, suggesting that this activity could help individuals feel less lonely (Şar et al., 2012). It could be hypothesized that the internet usage allows for social connections to be made; thus, helping to remedy the loneliness. However, the participants of our study reported that online applications were not helping them make long-term contacts that could make them feel less lonely. In addition, a study on social network usage found that older individuals that reported frequent use of such networks did not have any differences in terms loneliness (Aarts et al., 2015). Therefore, it seems that the individuals incorporate screen time as part of their routine which helps them cope with their loneliness rather than using the internet to make social contacts.

In terms of animal companions, a systematic review of loneliness and animal companions reported that while the included studies showed that companion animals were associated with less loneliness, the methodological quality of these studies was questionable (Gilbey and Tani, 2015). The participants of our study described how the animals provided them companionship but also encouraged them to have a routine; especially with dogs, walking them and feeding them on a consistent schedule gave some organization to their day. Therefore, while the current study provides qualitative data that suggests that animal companionship helps older people living with HIV cope with their loneliness; rigorous quantitative studies could add to the strength of the evidence.

With respect to 'a belief in something greater', some studies have reported on religiosity and loneliness in older adults. It has been described that religiosity may help reduce loneliness since there is opportunity for social interaction during religious services (Johnson and Mullins, 1989). However, in our study the individuals did not discuss attending any religious services, mainly due to their homosexuality. Besides increasing the opportunity for social interactions, religious beliefs can provide meaning to an individual's life (Johnson and Mullins, 1989). Moreover, the feeling of being in the presence of a greater being can also decrease feelings of social deprivation (Johnson and Mullins, 1989). Overall, it has been reported that higher religiosity is associated with lower loneliness in older individuals (Johnson and Mullins, 1989). In people living with HIV, spirituality has been reported to be one of the most common forms of emotional coping for general stressors and it has been shown to be a positive coping technique for HIV-related stigma (Porter et al., 2015; Rueda et al., 2014).

Some participants also mentioned using alcohol or drugs when discussing living with their loneliness. Most often, the participants spoke about alcohol use during the grief process after a loss. This is supported by the literature; a review on problematic alcohol and drug use in older adults reported that loss of close friends of family members or other stressful events are associated with alcohol use disorders among men (Satre, 2015). In terms of drugs, in the Brain Health Now model of loneliness (**Appendix 1**), opioid use was found to be a potential consequence. However, the participants of our study did not discuss opioid use but referred to smoking cannabis, taking ecstasy or methamphetamine use. In an American study, it was reported that internalized homophobia is associated with drug-related problems (Moody et al., 2018). In our study, drug use was often mentioned as a way for participants to reduce their stress and loosen up to enjoy themselves when they go out; therefore, perhaps there was an element of using the drugs to overcome internalized stigma. In addition, as was found in our study, motives of cannabis use in HIV-positive individuals has been reported to include alleviation of stress, relaxation and coping with the diagnosis (Bruce et al., 2013). In terms of ecstasy, it has been reported that the drug can effect emotional perceptions as well as the individual’s response to emotional stimuli; therefore, having a pro-social effect (Wardle and de Wit, 2014). This is again inline with what our study found, since the participants reported using ecstasy before going to social events in order to help them socialize. Finally, it has been reported that methamphetamine use in gay or bisexual men is meant to mask difficult emotions and enhance sexual pleasure (Halkitis et al., 2007). It is possible that loneliness or the fears related to HIV-stigma and rejection could be two of those difficult emotions, based on the findings of this study. Overall, many studies have investigated alcohol or drug-use in people living with HIV in the context of depression or medication adherence, but few studies have included loneliness in such investigations.

Some other research has been done on protective factors related to loneliness. For instance, studies investigating changes in the expression of genes reported that there is an expression profile that has been associated with loneliness (Cole et al., 2015). A study showed that eudaimonia, or a sense of meaning and purpose in life was correlated with a decrease in the expression the profile associated with loneliness (Cole et al., 2015). Another study also reported that having a lower purpose in life was an indicator of loneliness (Neville et al., 2018). Interestingly, participants in our study mentioned how a belief in something greater than them, gave them a sense of purpose. Other participants also described how volunteering and helping others was their purpose, and for others having an animal to take care of gave their life meaning. Therefore, these results align with the study that found that eudaimonia might help cope with loneliness. Another study looked at wisdom as a protective factor against loneliness in older adults. Wisdom was defined as a human trait involving emotional regulation, self-reflection, empathy, compassion, decisiveness, social advising, tolerance and spirituality (Lee et al.). Lee et al. reported that wisdom was associated with less loneliness in older adults (Lee et al.). The self-reflection and spirituality components of wisdom parallel the findings of our study in which participants expressed that having a belief in something bigger than them allowed them to reflect on their purpose and feel less lonely. Another study found that loneliness tended to increase nostalgia which in turn, increase perceived social support to restore some social connectiveness (Zhou et al., 2008). The results of our study did not specifically involve nostalgia, however, anecdotally, during the member checking participants did express the fact that they enjoyed being able to talk to others around the same age as them and reminisce about the past, and that they hoped that services for loneliness would allow them to do the same.

Of note, the techniques described by the participants to deal with their loneliness, coincide with resilience techniques that have been described to overcome stigma. For instance, faith and hobbies were reported by participants of a study on HIV-related stigma as protective factors, or characteristics that helped buffer the negative experiences (Block, 2009). Furthermore, as was described above, stigma was involved in all three of the major themes regarding the contributors to loneliness. Therefore, perhaps these activities are acting on two levels by helping to buffer stigma and loneliness.

Overall, encouraging the positive coping strategies mentioned above could be beneficial, however, all the responsibility cannot be placed on the individual and services should be developed to assist them.

Opportunities for Service Development

In terms of service development, ideally, the three main themes that arose as contributors to loneliness would be targeted. With respect to the first theme, loss, there is of course no way for anyone to bring back all the people they have lost throughout their lives. Luckily, with the new generations of antiretrovirals, HIV is quite manageable which will mean fewer deaths due to the virus in the future. However, people living with HIV are still aging and face other comorbidities. Therefore, services to help them deal with the grief and help them cope with the ongoing losses might be beneficial. Next, in terms of the second theme, ‘a deceiving search for intimacy’, the participants mentioned that they would like to see the creation of social activity groups which will allow them to make contacts and foster long term relationships, something is currently lacking online or with the community groups. The third theme, ‘shielding myself’, could perhaps be addressed through self-esteem classes as one participant suggested. Importantly, a meta-analysis of interventions to reduce loneliness reported that interventions that targeted maladaptive social cognition had larger effect sizes than ones that attempted to improve social support or those that increased opportunities for social support (Masi et al., 2011). Therefore, cognitive behavioural therapy to help individuals overcome fears might also be useful to address loneliness.

Importantly, the need for advocacy and anti-stigma campaigns cannot be understated. Lessons can be learned from mental illness, another concealable stigma that is well researched and understood. For instance, The Mental Health Commission of Canada is currently running the Open Minds Anti-Stigma Initiative which uses contact-based education of clearly defined target groups (Stuart et al., 2014). The contact-based education emphasizes stories of hope and recovery, as individuals who have experienced mental illness first-hand tell their stories (Stuart et al., 2014). The target groups for this anti-stigma initiative are youth, healthcare providers, workplaces and media/journalists (Stuart et al., 2014). The same target groups could be used for HIV-related anti-stigma campaigns. The participants of our study emphasized that educating the youth was important to them in order to prevent further HIV infections and for stigma reduction; in general, educating the youngest members of the population is logical. Participants also explained that they want to show the population that they are aging well with HIV. Healthcare providers are likely to have contact with HIV-positive individuals and should, therefore, also be targets of anti-stigma campaigns in order to provide sensitive care. Workplaces are also an ideal target since with the new antiretroviral therapies, HIV-positive individuals will likely be able to continue working and should not be discriminated against. For instance, some participants of our study mentioned losing their employment after their HIV status was wrongly disclosed to their employers. Another qualitative study in Quebec also found HIV-related workplace discrimination to be a problem (Wallach and Brotman, 2013). Finally, the media reaches a large audience and ensuring that the messages that they are sharing are not propagating HIV-related stigma is essential.

Currently, the Public Health Agency of Canada is funding POZitivity, a national HIV anti-stigma campaign which aims to challenge stigma, improve access to services, testing and prevention and educate people on pre-exposure prophylaxis, post-exposure prophylaxis and undetectable = untransmissible. It might be beneficial for this campaign to incorporate contact-based education in order to help complete their first aim of reducing stigma which, in turn, might help the issue of loneliness.

Limitations and Future Directions

Qualitative research methods allow for the meaningful connections that participants make to be understood, however, they do not provide evidence of causation, especially with a very small sample size (n=10) and no comparison group. Moreover, by design, the study participants were all older white men living in the Montreal area, but the perspectives of other women, other cultural groups or ages are likely to be different and should be examined in future research. In addition, the participants themselves even mentioned that individuals living outside of Montreal, in more suburban or rural areas are likely to have more pronounced experiences of isolation, stigma and loneliness. Therefore, the needs of these populations should also be considered and the topic of further research. Furthermore, with respect to research methods, while the themes were discussed and reviewed with many researchers, only one person completed the coding. A second coder would have increased the credibility of the results. However, member checking was performed, and the themes were refined and endorsed by the participants in order to increase the validity of the results.

SUMMARY AND CONCLUDING THOUGHTS

In sum, this project contributes to original knowledge by presenting the experiences of loneliness in people aging with HIV, including the meaningful connections they make between loneliness and contributors or consequence as well as some opportunities for service development.

Three main themes emerged as contributors: ‘loss’, ‘a deceiving search for intimacy’ and ‘shielding myself’. First, the immense amount of loss they have face throughout the entirety of their lives, from the loss of familial support when they were quite young and came out as gay, the loss of acquaintances, close friends and romantic partners during the HIV/AIDS epidemic and still; in addition to the loss of other friends or family to HIV stigma. Second, since their social support has been consistently shrinking for their entire lives, they explained trying to renew it and make intimate connections again. They discussed online platforms and in person opportunities; unfortunately, in both cases they faced barriers due to age and HIV-related stigma. Moreover, online platforms did not allow for sustainable platonic or romantic connections to be made since the intimacy of actually being face-to-face with a person is not recreated; when online platforms were used to initiate in person meetings, hook ups often resulted. In person, the participants discussed that the environment of gay bars has changed and that other venues such as sex parties and LGBTQ+ or HIV community groups, were not useful in fostering long term relationships. Thirdly, the participants described shielding themselves from more loss or stigma because they did not want to experience more pain. However, this shielding results in self-isolation and in turn more loneliness. Importantly, stigma was a common thread between all three themes of contributors and should be considered or upmost importance.

In terms of consequences, the participants discussed the many ways they keep themselves busy to avoid feeling lonely, such as, working, volunteering, physical activity and watching television or playing computer games. In addition, they described how having an animal companion helps by keeping them company, encouraging a routine and motivating them to get out of the house. Religiosity, or a ‘belief in something greater’ also help them cope with the loneliness, their losses and to find purpose in their life. Lastly, the participants also described drugs and alcohol which might be helpful to cope with loneliness in the short term but may become more problematic in the long term. Overall, these coping strategies have been reported as ways of coping with stigma; therefore, once again supporting that perhaps stigma is the underlying factor.

Finally, in terms of service development, the participants suggested a few services they would like to see. They mentioned the creation of social activity groups which will allow them to make contacts and foster long term relationships, something the current platforms lack. Self-esteem classes as were also suggested and research has suggested that targeting maladaptive social cognitions are more effective at reducing loneliness that increasing opportunities for social support. Therefore, self-esteem classes or cognitive behavioural therapy to overcome fear might be more suitable than creation of social activity groups. Finally, anti-stigma campaigns are crucial as stigma appeared to be an underlying theme throughout the contributing factors and play an enormous role in their loneliness. Participants also expressed a desire for education to reduce stigma be introduced at the primary-school level. Contact-based education is currently being used to reduces stigma surrounding mental illness and this approach may be applicable to anti-stigma campaigns for HIV/AIDS. The problem of loneliness in older men living with HIV is not really their problem, it is a societal problem.

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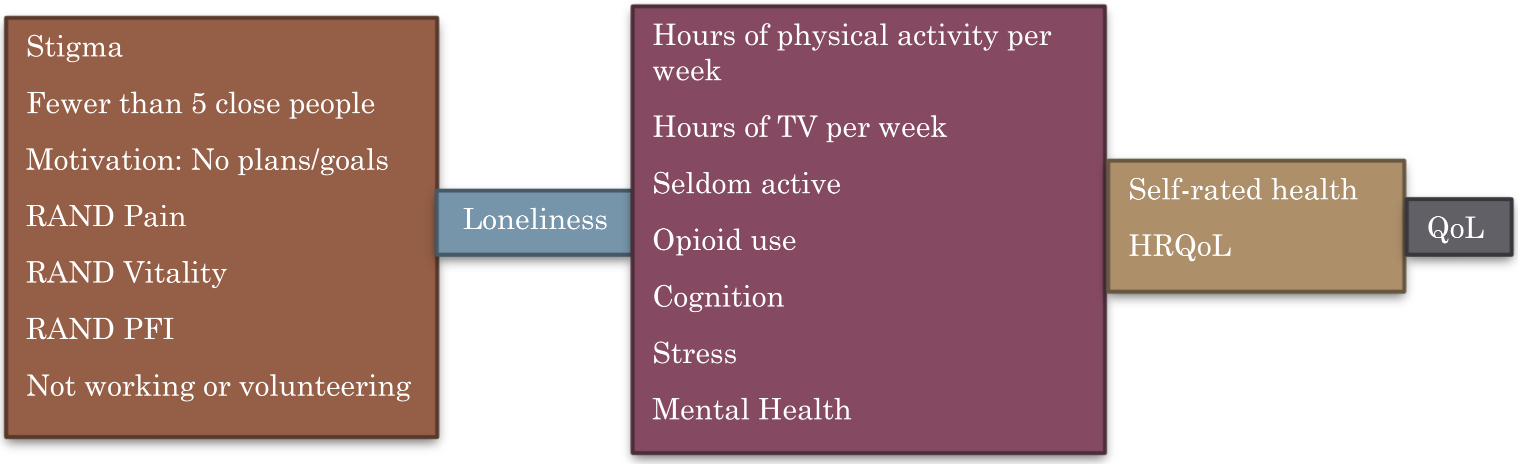
Zhou, X., Sedikides, C., Wildschut, T., Gao, D.-G., 2008. Counteracting Loneliness: On the Restorative Function of Nostalgia. Psychological Science 19 (10), 1023-1029.

APPENDICES

Appendix 1: Model of Loneliness (Harris et al., 2018)



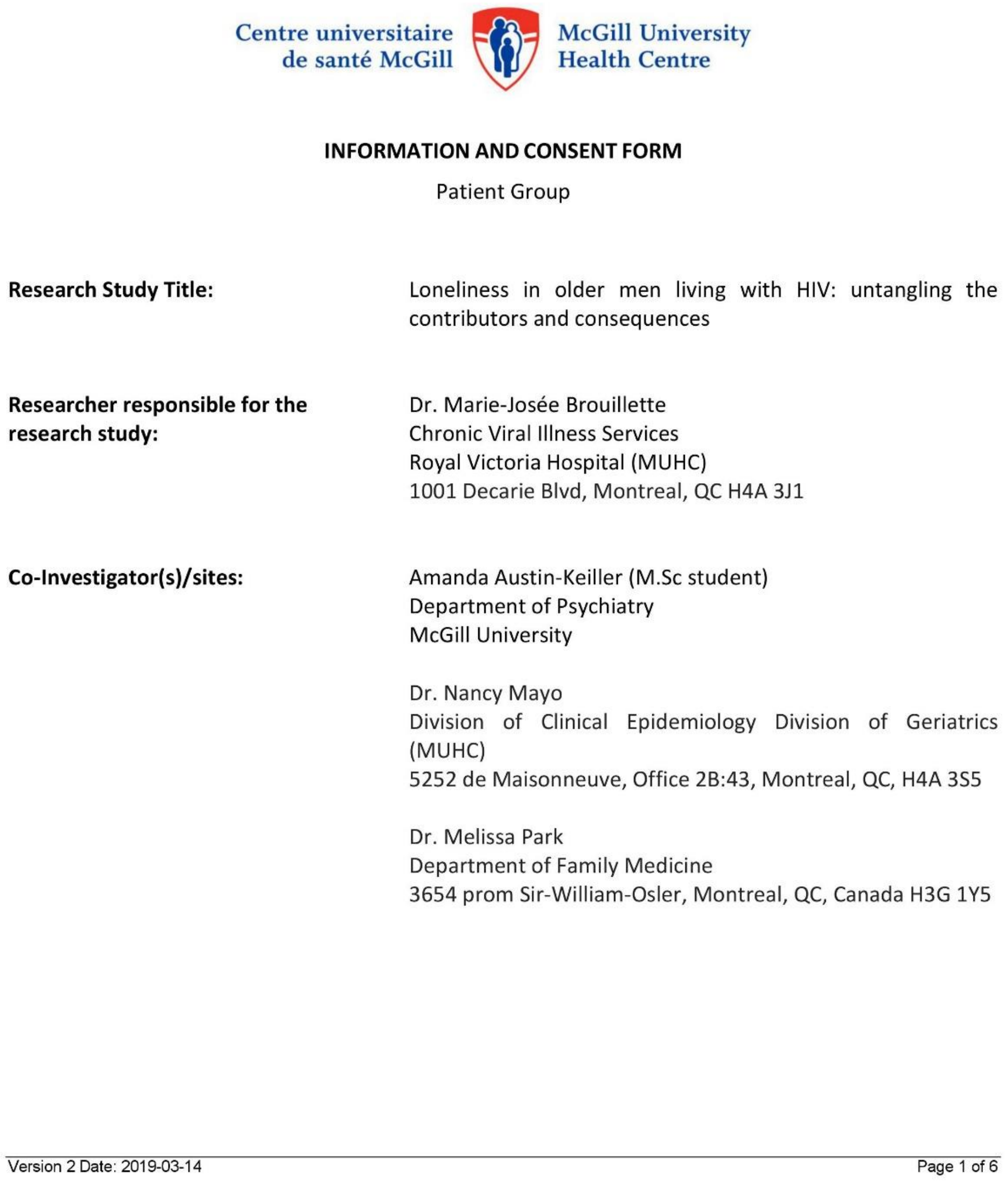
Psychosocial and behavioural factors associated with the presence of loneliness. The Wilson Cleary theoretical model was used to link clinical variables. From left to right, the presence of symptoms explaining loneliness; in turn explaining hypothesized consequences on function and health-related quality of life.

Appendix 2. MSK clinical staging system for the AIDS dementia complex-cognitive component

MSK clinical staging system for the AIDS dementia complex- cognitive component	
ADC stage	Characteristics
0 (normal)	Normal
0.5 (equivocal)	Absent, minimal, or equivocal symptoms, without impairment of work or capacity to perform activities of daily living (ADL)
1 (mild)	Able to perform all but the more demanding aspects of work and ADL, but with unequivocal evidence of intellectual or motor impairment, which may include impaired performance on neuropsychological testing
2 (moderate)	Able to perform basic activities of self-care but cannot work or maintain the more demanding ADL
3 (severe)	Major intellectual incapacity—cannot follow news or personal events, cannot sustain complex conversation, considerable slowing of all output
4 (end stage)	Nearly vegetative, intellectual and social comprehension and output are at a rudimentary level, nearly or absolutely mute

Adapted from Price and Brew, The AIDS dementia complex. *J Infect Dis* 1988;158:1079-1083. University of Chicago Press 1988.

Appendix 3: Informed Consent Forms (English and French)



Centre universitaire de santé McGill
McGill University Health Centre

INFORMATION AND CONSENT FORM

Patient Group

Research Study Title:	Loneliness in older men living with HIV: untangling the contributors and consequences
Researcher responsible for the research study:	Dr. Marie-Josée Brouillette Chronic Viral Illness Services Royal Victoria Hospital (MUHC) 1001 Decarie Blvd, Montreal, QC H4A 3J1
Co-Investigator(s)/sites:	Amanda Austin-Keiller (M.Sc student) Department of Psychiatry McGill University
	Dr. Nancy Mayo Division of Clinical Epidemiology Division of Geriatrics (MUHC) 5252 de Maisonneuve, Office 2B:43, Montreal, QC, H4A 3S5
	Dr. Melissa Park Department of Family Medicine 3654 prom Sir-William-Osler, Montreal, QC, Canada H3G 1Y5

INTRODUCTION

We are inviting you to take part in this research study because you were a participant in the Brain Health now study and you indicated that you could be contacted for any sub-studies. We would like to hear about your experience of loneliness as a person living with HIV.

However, before you accept to take part in this study and sign this information and consent form, please take the time to read, understand and carefully examine the following information. You may also want to discuss this study with your family doctor, a family member or a close friend.

We invite you to speak to the researcher responsible for this study ("the researcher") or to other members of the research team and ask them any questions you may have about this study. Please also ask a member of the research team about any parts of this consent form you do not understand.

PURPOSE OF THE RESEARCH STUDY

The purpose of this study is to better understand what causes loneliness in men aging with HIV and how it affects their health. We hope this will lay the groundwork for future studies to develop interventions which will help reduce loneliness.

DESCRIPTION OF THE RESEARCH PROCEDURES

This research study will take place at McGill University Health Center.

1. Duration and number of visits

Your participation in this research study will last up to 12 months and will include 1 individual interview. The visit for the individual interview will last 1-2 hours. In addition, you will be invited to an optional focus group in which the results will be presented in order for you to make any additional comments. The focus group will last 2-3 hours.

2. Overview of study participation

This study is of qualitative design, meaning we are not interested in numerical data but rather we are interested in hearing about your experience. This entails being interviewed by the researcher on the topic of loneliness. You will also be invited to participate in an optional focus group in order to discuss the results with the researcher and other participants.

3. Study Procedures

During your participation in this research study, you will participate in the following procedures:

- Audio-recorded individual interview

AND

- Audio-recorded focus group (optional)

PARTICIPANT'S RESPONSIBILITIES

- Keep everything shared during focus group confidential

BENEFITS ASSOCIATED WITH THE RESEARCH STUDY

There is no direct benefit to you for participating in this research. However, we hope that the study results will contribute to the advancement of scientific knowledge in the study field.

RISKS ASSOCIATED WITH THE RESEARCH STUDY

Due to the nature of focus groups, it is impossible to guarantee complete confidentiality as other members of the group will be aware of your identity. However, all participants are instructed to keep what is said in the focus group confidential, as mentioned in the "Participant's Responsibilities" section.

You may find the topics discussed in the interview upsetting or distressing. You can refuse to answer any of the questions and/or choose to stop participating in the study altogether at any time. You do not have to give any reason for refusing to answer a question or for stopping to participate. If you feel uncomfortable at any time, do not hesitate to tell the researcher(s) who will stop the interview and, if you agree, refer you to your treating team.

We do not foresee any other risks associated with this study.

VOLUNTARY PARTICIPATION AND THE RIGHT TO WITHDRAW

Your participation in this study is voluntary. Therefore, you may refuse to participate. You may also withdraw from the *ongoing* project at any time, without giving any reason, by informing a member of the study team. Your decision not to participate in the study, or to withdraw from it, will have no impact on the quality of care and services to which you are otherwise entitled. You will be informed in a timely manner if any information becomes available that may impact your willingness to continue participating in this study.

The researcher or the Research Ethics Board may put an end to your participation without your consent. This may happen if new findings or information indicate that participation is no longer in your interest, if you do not follow study instructions, or if there are administrative reasons to terminate the project.

If you withdraw or are withdrawn from the study, you may also request that the data already collected about you be removed from the study. If you request that your data be removed and the information already collected about you can be identified as yours it will be destroyed.

CONFIDENTIALITY

During your participation in this study, the researcher and his/her team will collect and record information about you. They will only collect information necessary for the study.

The following information will be collected: everything discussed during a one-to-one, face-to-face semi-structured interview in addition to everything discussed during a focus group.

All the information collected during the research project will remain confidential to the extent provided by law. You will only be identified by a code number. The key to the code linking your name to your study participant number will be kept by the researcher.

All audio-recordings will be transcribed (your words will be written down) in a de-identified fashion (i.e. your name will not appear in the transcripts). The audio-recordings will then be destroyed. It is possible that direct quotes of what you said will be presented in publications and/or conferences. However, precautions will be taken to ensure that it will not be possible to identify you.

The study data will be stored for 7 years by the researcher responsible for the study.

The data may be published or shared during scientific meetings; however, precautions will be taken to ensure that it will not be possible to identify you.

For auditing purposes, the research study files which could include documents that may identify you may be examined by a person mandated by the study sponsor, the institution, or the Research Ethics Board. All these individuals and organizations adhere to policies on confidentiality.

FUNDING OF THE RESEARCH PROJECT

The researcher and the institution have received funding from Canadian Institution of Health Research (CIHR) to conduct this research project.

CONFLICT OF INTERESTS

The researchers have no conflict of interest to declare.

COMPENSATION

You will receive an amount of 40$ per study visit for costs and inconveniences incurred during this research study. If you withdraw from the study, or are withdrawn before it is completed, you will receive compensation proportional to the number of visits you have completed.

SHARING STUDY RESULTS

If you wish you will receive a summary of research results by email.

Results from this study will be presented at conferences and published in journals.

SHOULD YOU SUFFER ANY HARM

Should you suffer harm of any kind following any procedure related to the research study, you will receive the appropriate care and services required by your state of health.

By agreeing to participate in this research project, you are not waiving any of your legal rights nor discharging the researcher, the sponsor or the institution, of their civil and professional responsibilities.

CONTACT INFORMATION

If you have questions or if you have a problem you think may be related to your participation in this research study, or if you would like to withdraw, you may communicate with the researcher or with someone on the research team at the following number: 514-934-1934 ext. 35502.

For any question concerning your rights as a research participant taking part in this study, or if you have comments, or wish to file a complaint, you may communicate with:

> The Patient Ombudsman of the Royal Victoria Hospital at the following phone number:
> 514-934-1934 ext. 35655

OVERVIEW OF ETHICAL ASPECTS OF THE RESEARCH

The McGill University Health Centre Research Ethics Board reviewed this research and is responsible for monitoring the study.

Research Study Title:	Loneliness in older men living with HIV: untangling the contributors and consequences.

SIGNATURES

Signature of the participant

I have reviewed the information and consent form. Both the research study and the information and consent form were explained to me. My questions were answered, and I was given sufficient time to make a decision. After reflection, I consent to participate in this research study in accordance with the conditions stated above.

1) I accept that my participation in the study be audio-recorded:

Yes ☐ No ☐

2) I wish to receive a copy of the study results by email.

Yes ☐ No ☐

Name of participant Signature Date

Signature of the person obtaining consent

I have explained the research study and the terms of this information and consent form to the research participant, and I answered all his/her questions.

Name of the person obtaining consent Signature Date

Centre universitaire de santé McGill
McGill University Health Centre

FORMULAIRE D’INFORMATION ET DE CONSENTEMENT

Titre du projet de recherche:	La solitude chez les hommes vieillissant avec le VIH : démêler les contributeurs et conséquences.
Chercheur responsable du projet de recherche:	Dre Marie-Josée Brouillette Service des maladies virales chroniques Hôpital Royal Victoria (CUSM) 1001 Decarie, Montréal, QC H4A 3J1
Co-chercheur(s)/sites:	Amanda Austin-Keiller (étudiante M.Sc) Département de psychiatrie Université de McGill Dre Nancy Mayo Division d’épidémiologie clinique (CUSM) 5252 de Maisonneuve, Bureau 2B:43, Montréal, QC, H4A 3S5 Dre Melissa Park Département de médecine familiale 3654 prom Sir-William-Osler, Montréal, QC, Canada H3G 1Y5

INTRODUCTION

Nous vous invitons à participer à ce projet de recherche parce que vous avez participé au projet de recherche Brain Health Now et vous avez indiqué la possibilité de vous contacter dans le cadre d'autres projets de recherche. Nous voulons connaitre vos expériences de solitude comme personne vivant avec le VIH.

Avant d'accepter de participer à ce projet et de signer ce formulaire d'information et de consentement, veuillez prendre le temps de lire, de comprendre et de considérer attentivement les renseignements qui suivent.

Nous vous invitons à poser toutes les questions que vous jugerez utiles au chercheur responsable de ce projet de recherche (le « médecin responsable ») ou à un membre de son équipe de recherche et à leur demander de vous expliquer tout mot ou renseignement qui n'est pas clair.

OBJECTIFS DU PROJET DE RECHERCHE

Le but de ce projet est de mieux comprendre les facteurs menant à la solitude chez les hommes vieillissant avec le VIH ainsi que comment la solitude impacte leur santé. Ceci peut inspirer des études subséquentes pour développer des interventions dans le but de réduire la solitude.

DÉROULEMENT DU PROJET DE RECHERCHE

Ce projet de recherche se déroula au Centre universitaire de santé de McGill.

1. Durée et nombre de visites

Votre participation à ce projet de recherche dura jusqu'à 12 mois at comprendra d'une entrevue individuelle. La visite pour l'entrevue individuelle dura entre 1 et 2 heures. Vous serez ainsi invité à participer à une discussion de groupe durant laquelle les résultats vont être présenter pour que vous puissiez ajouter vos commentaires. La discussion de groupe dura entre 2 et 3 heures.

2. Description générale de la participation

Ce projet de recherche est qualitatif, voulant dire qu'on ne s'intéresse pas des données numériques, plutôt, on veut connaitre vos expériences. Ceci implique une entrevue individuelle avec la chercheuse portant sur la solitude. Vous serez aussi invité à participer à une discussion de groupe optionnelle pour discuter des résultats avec la chercheuse et d'autres participants.

3. Procédures

Durant votre participation à ce projet de recherche, vous participerez aux procédures suivantes :

- Entrevue individuelle avec enregistrement audio

ET

- Discussion de groupe avec enregistrement audio (optionel)

RESPONSABILITÉ DU PARTICIPANT

- Conserver les informations partagées pendant toute discussion confidentielle.

AVANTAGES ASSOCIÉS AU PROJET DE RECHERCHE

Vous ne retirerez pas de bénéfices de votre participation à ce projet de recherche. Nous espérons que les résultats obtenus contribueront à l'avancement des connaissances scientifiques dans ce domaine.

RISQUES ASSOCIÉS AU PROJET DE RECHERCHE

La nature des groupes de discussion nous empêche de vous garantir une complète confidentialité quant à votre identité. Néanmoins, les autres participants et vous-même sont requis de garder l'information partagée pendant le groupe de discussion confidentiel tel que mentionné dans la section « Responsabilité du participant »

Il est possible que vous trouviez les sujets discutés durant l'entrevue stressants et bouleversants. Si c'est le cas, vous avez la possibilité de refuser de répondre à n'importe quelle question et ce à n'importe quel stade de l'entrevue. Vous avez aussi le droit de décider de vous retirer de l'étude sans devoir fournir une justification. Si vous vous sentez inconfortable ou troublé à n'importe quel moment durant l'interview, n'hésitez pas à le mentionner au chercheur(s) qui arrêtera l'interview et pourra vous référer à votre équipe de traitement.

Nous ne prévoyons pas d'autres risques reliés à cette étude.

PARTICIPATION VOLONTAIRE ET DROIT DE RETRAIT

Votre participation à ce projet de recherche est volontaire. Vous êtes donc libre de refuser d'y participer. Vous pouvez également vous retirer de ce projet à n'importe quel moment, sans avoir à donner de raisons, en informant l'équipe de recherche. Votre décision de ne pas participer à ce projet de recherche ou de vous en retirer n'aura aucune conséquence sur la qualité des soins et des services auxquels vous avez droit ou sur votre relation avec les équipes qui les dispensent. Toute nouvelle connaissance acquise durant le déroulement du projet qui pourrait affecter votre décision de continuer à participer à ce projet vous sera communiquée rapidement.

Le médecin responsable de ce projet de recherche, le comité d'éthique de la recherche, l'organisme subventionnaire ou le commanditaire peuvent mettre fin à votre participation, sans votre consentement. Cela peut se produire si de nouvelles découvertes ou informations indiquent que votre participation au projet n'est plus dans votre intérêt, si vous ne respectez pas les consignes du projet de recherche ou encore s'il existe des raisons administratives d'abandonner le projet.

SI vous décidez de vous retirer ou si vous êtes retiré de l'étude, vous avez le droit de demander à ce que les informations recueillis à votre sujet soient détruites.

CONFIDENTIALITÉ

Durant votre participation à ce projet de recherche, le médecin responsable de ce projet ainsi que les membres de son personnel de recherche recueilleront, dans un dossier de recherche, les renseignements vous concernant et nécessaires pour répondre aux objectifs scientifiques de ce projet de recherche.

À cet effet, les informations suivantes seront recueillies : l'entièreté de ce qui sera discuté pendant l'entrevue individuelle ainsi que ce qui sera discuté durant le groupe de discussion.

Tous les renseignements recueillis demeureront confidentiels dans les limites prévues par la loi. Vous ne serez identifié que par un numéro de code. La clé du code reliant votre nom à votre dossier de recherche sera conservée par le médecin responsable de ce projet de recherche.

Tous les enregistrements audios des entrevues seront retranscrits mots-pour-mots de manière à ne pas révéler votre identité (*i.e.* votre nom n'apparaitra pas sur le compte-rendu). Par la suite, l'enregistrement sera détruit de façon sécuritaire. Il est possible que des citations provenant des discussions soit utilisées dans les publications et/ou conférence auquel cas, des précautions seront prises de façon à conserver votre identité secrète.

Ces données de recherche seront conservées pendant 7 ans par la chercheuse responsable du projet de recherche.

Les données de recherche pourront être publiées ou faire l'objet de discussions scientifiques, mais il ne sera pas possible de vous identifier.

À des fins de surveillance votre dossier de recherche pourrait être consultés par une personne mandatée par des représentants du commanditaire, de l'établissement ou du comité d'éthique de la recherche. Ces personnes et ces organismes adhèrent à une politique de confidentialité.

FINANCEMENT DU PROJET DE RECHERCHE

La chercheuse responsable de ce projet de recherche ainsi que l'institution ont reçu un financement de l'Institut de recherche en santé du Canada (IRSC) pour mener à bien ce projet de recherche.

CONFLIT D’INTÉRÊT

Les membres de l’équipe de recherche ne déclarent aucun conflit d’intérêt.

COMPENSATION

En guise de compensation pour les frais encourus en raison de votre participation au projet de recherche vous recevrez un montant 40$ par visite prévue au protocole Si vous vous retirez du projet (ou s’il est mis fin à votre participation) avant qu’il ne soit complété, la compensation sera proportionnelle à la durée de votre participation.

PARTAGE DES RÉSULTATS D’ÉTUDE

Si vous le désirez, un résumé des résultats de la recherche pourra vous être acheminé par courriel.

Les résultats de cette étude seront présentés dans le cadre de conférence et publiés dans les journaux scientifiques.

DANS LE CAS OU VOUS SOUFFRIEZ DE QUELCONQUE TORT

Dans le cas où vous souffririez de quelconque tort suivant quelconque procédure relié à cette étude, vous recevrez les soins et supports nécessaires requis par votre état de santé.

En acceptant de participer à ce projet de recherche, vous ne renoncez à aucun de vos droits et vous ne libérez pas le médecin responsable de ce projet de recherche, le commanditaire et l'établissement de leur responsabilité civile et professionnelle.

IDENTIFICATION DES PERSONNES-RESSOURCES

Si vous avez des questions ou éprouvez des problèmes en lien avec le projet de recherche, ou si vous souhaitez vous en retirer, vous pouvez communiquer avec le médecin responsable ou avec une personne de l’équipe de recherche au numéro suivant: 514-934-1934 ext. 35502.

Pour toute question concernant vos droits en tant que participant à ce projet de recherche ou si vous avez des plaintes ou des commentaires à formuler, vous pouvez communiquer avec :

> Le Commissaire local aux plaintes et à la qualité des services de l’hopital Royal Victoria au numéro suivant : 514-934-1934 ext. 35655

SURVEILLANCE DES ASPECTS ÉTHIQUES DU PROJET DE RECHERCHE

Le comité d’éthique de la recherche du Centre Universitaire de santé McGill a approuvé le projet et en assurera le suivi.

Tire du projet de recherche :	La solitude chez les hommes vieillissant avec le VIH : démêler les contributeurs et conséquences.

SIGNATURES

Signature of the participant

J'ai pris connaissance du formulaire d'information et de consentement. On m'a expliqué le projet de recherche et le présent formulaire d'information et de consentement. On a répondu à mes questions et on m'a laissé le temps voulu pour prendre une décision. Après réflexion, je consens à participer à ce projet de recherche aux conditions qui y sont énoncées.

1) J'accepte que ma participation à cette étude et aux discussions y étant reliées soit enregistré (audio seulement)
   Oui ☐ Non ☐

2) J'aimerais recevoir un résumé des résultats de cette étude par courriel.

   Oui ☐ Non ☐

Nom du participant Signature Date

Signature de la personne qui obtient le consentement

J'ai expliqué au participant le projet de recherche et le présent formulaire d'information et de consentement et j'ai répondu aux questions qu'il m'a posées.

Nom de la personne qui obtient le consentement Signature Date