



SUFFOLK UNIVERSITY

CENTER FOR PUBLIC MANAGEMENT

THE IMPACT OF AGING ON THE QUALITY OF LIFE OF PEOPLE LIVING WITH HIV IN THE BOSTON EMA

*Understanding Aging and HIV Through
the Personal Experiences of Consumers*

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Introduction

Over the past 15 years, there has been an increased focus on older people living with HIV (PLWH). Advancements in therapeutic medicine for HIV and the implementation of supportive ancillary services have both contributed to an increase in the longevity and quality of life of PLWH. Nevertheless, a number of questions about this aging population remain unanswered. What are the characteristics of this population? What can be learned about their health and quality of life? What are the specific needs of older individuals living with HIV? What policies and programs can be developed that support a productive lifestyle and increase quality of life? In the interest of finding responses to these questions, the Boston Public Health Commission (BPHC) has funded this investigative exploration that will record and examine the experiences of several members of this population. By addressing these issues directly with PLWH who are 50 years old and older, the BPHC will be able to determine which elements of the service system can be modified or enhanced in order to improve the lives of people growing older with HIV.

Background

Federally funded by the Health Resources and Services Administration (HRSA) through Ryan White Part A, the Boston Eligible Metropolitan Area (EMA) service region includes seven counties in Massachusetts and three counties in New Hampshire.

Understanding the needs of older people living with HIV allows the Boston EMA to anticipate and respond to the emerging needs of this growing population. National studies have been conducted to understand the needs of this group. While collecting the data for this study, *Research on Older Adults with HIV* (ROAH) was published by the AIDS Community Research Initiative of America (ACRIA), a community-based HIV research and education agency in New York City attesting to the increasing attention to this issue.

An extensive literature review was conducted to inform the focus and methods of this exploratory study. A variety of studies have examined the psychosocial and medical implications of living longer with HIV, many of which documented a relationship between higher levels of depression, social isolation, decreased sexual activity, increased co-morbidity, and added stigma with both HIV and ageism. The research suggests that generalizations for this population should be limited. As we attempt to understand the needs of this population, effort should be made to contextualize their experiences rather than treating them homogeneously.

The Boston Public Health Commission implemented this particular study to explore these issues *locally* and understand the unique needs of PLWH who are 50 years of age and older in the Boston EMA. According to BPHC service utilization data, approximately 2,100 PLWH 50 years of age or older are being served under Ryan White Part A services in the Boston EMA. This group represents 25% of the Boston EMA clients. Nationally, about 19% of all people with HIV are 50 years and older.

Purpose

The purpose of this study is to understand the life experiences of individuals growing older with HIV in the Boston EMA and explore possible implications for program and policy development.

Methods

This study was conducted from March 2009 to February 2010. Qualitative research methods were utilized to elicit in-depth descriptions of the experiences of living older with HIV. The study used an inductive approach to data gathering, interpretation, and reporting. It is characterized by discovering the reality of participants through an understanding of their personal life experiences (McDavid, 2006). As an iterative process, in consultation with staff from the BPHC, focus group discussions and structured interviews were used to investigate and confirm findings whenever possible.

Focus Group Discussions

Focus group discussions were an important tool in the data collection for this study; this method is a medium for reflective discussions on life experiences because it provides the opportunity to build upon personal experiences. In turn, this creates high levels of interpretative validity.¹ Furthermore, focus groups foster broad dialogue, thus allowing the prospect of multiple issues that may be overlooked during a one-on-one interview.

Four focus groups were conducted in Boston. Three HIV service providers donated office space and helped with recruitment, considerably contributing to the successful participation rate. Using information and results from existing research, a facilitator's guide was developed in collaboration with BPHC program staff. The guide consisted of three open-ended, guiding questions and 12 probing questions that encouraged personal perspectives on living longer or older with HIV. The questions requested phenomenological insights on living with HIV and being older, changes in family and personal relationships, physical and medical experiences, perception of discrimination, and insights on quality of life improvements.

This study uses opportunistic sampling in the Boston EMA area. Therefore, the sample may include clients utilizing services provided through the Massachusetts Department of Public Health (MDPH) and/or those covered by private insurers since it was not limited to Part A service recipients only. Agencies under contract with BPHC's HIV/AIDS Services Division were contacted to aid in recruitment for the study. Flyers were developed and posted at provider agencies, emailed to community contacts, and handed out at a Boston EMA HIV Services Planning Council meeting. Staff from Suffolk University requested that clients call them directly to volunteer for participation. Suffolk followed a brief protocol to assess eligibility based on age and HIV status. If eligible, the clients were selected to participate in one of the four scheduled focus groups.

Focus groups were two hours in length and were held at three service locations in the Boston Area: AIDS Action, the Boston Living Center, and the Dorchester House Multi-Service Center. These particular agencies were chosen based on the fact that they are funded by Part A, centrally located, and highly-utilized programs with excellent reputations within the community. Furthermore, these agencies were willing and able to provide a comfortable and confidential space where focus group discussions could take place. In total, there were forty-eight (48) participants across the four groups. Figure 1 below details the number of participants at each location.

¹ The meaning of actions or behaviors from participants' perspectives equates to interpretive validity. Interpretive validity adds to the merits of qualitative research and cannot be captured in quantitative research.

Location	Date	# of Participants
AIDS Action	June 25, 2009	12
Boston Living Center	June 30, 2009 (AM)	13
Boston Living Center	June 30, 2009 (PM)	16
Dorchester House	June 30, 2009	7
Total		48

Figure 1. Focus Group Participants by Target Location.

All participants signed a consent form and groups were facilitated by co-investigators. Participants were also asked to complete a basic demographic survey (see page 6 for Demographic Profile or Appendix A-2 for the Demographic Survey tool). Three out of the four focus groups were tape recorded, due to time and budgetary restraints. For all focus groups, facilitators were assisted by a note-taker with stenographic skills. The tapes were transcribed and the full notes for the non-recorded group were typed; each focus group was coded individually and analyzed. The consent form (Appendix A-1), demographic survey (Appendix A-2), and interview tool (Appendix A-5) were all translated into Spanish and Haitian-Creole as these languages are preferred among many individuals in the service population.

To identify common themes and differences across groups, data was coded by the co-investigators for the first focus group and coding themes were developed with. Themes were identified for each group and a data display was prepared. Then, through group comparison and group to group validation, recurring patterns, range of variation, and nuances were captured.

Structured Interviews

In order to confirm the focus group findings with various sub-sets of the Boston EMA population, 26 additional face-to-face interviews were conducted. The interview tool was developed in partnership with staff from BPHC and based on the preliminary focus group findings. Researchers recorded all relevant insights on the interview tool, whether they were direct answers to the predetermined questions or additional information. In order to reach a more representative sample, Spanish-speakers, Hispanic individuals, and Haitian individuals were targeted. All PLWH in the Haitian target group were interviewed in Haitian-Creole. No Hispanic PLWH in Metro West (n = 5) requested an interview in Spanish. However, three of the interviews completed in New Hampshire were conducted in Spanish. Figure 2 below shows the number of completed interviews for each targeted population.

Target Population	Number of completed interviews
Manchester, NH	7
Southeastern, MA	8
Metro West, MA	6
Haitian Community (throughout EMA)	5
All Interview Participants	27

Figure 2. Interview Participants by Target Population

Demographic Profile

Three locations were selected for focus group discussions in an attempt to recruit clients from a diverse range of racial, ethnic, and socioeconomic backgrounds. Both female and Hispanic participants were oversampled for the interviews to compensate for under-representation in the focus groups. Participants have been living with HIV for between four and 30 years. The average participant has been living with HIV for 17 years. Figure 4 below shows key demographic indicators for the combined sample (focus groups and interviews). Participant demographics are compared to the demographic data for the Boston EMA. Based on the final demographic frequencies, the study sample was representative with regard to average age, gender, and race with the exception of the Caucasian group. (See Appendix B-1 for complete demographic data for focus groups and interviews).

Demographics	Study Sample	Boston EMA ²
Mean Age	57	56
GENDER		
Male	73%	67%
Female	26%	32%
Transgender	1%	1%
RACE		
African-American	32%	35%
Caucasian	16%	51%
Hispanic	38%	26%
Haitian	7%	6%
MODE OF EXPOSURE³		
MSM	31%	23%
IDU	34%	26%
MSM & IDU	0%	3%
Heterosexual	22%	30%
Sex with IDU	7%	Not available
Other ⁴	12%	18%

Figure 4. Study Sample Demographics vs. Boston EMA

² Based on FY 2008 Boston EMA service utilization profile.

³ Due to federal hierarchy, Boston EMA modes of exposure will amount to 100%. Since survey respondents were allowed multiple answers, survey responses will amount to greater than 100%.

⁴ Survey sample "Other" category includes self-reported blood transfusion, healthcare worker, sexual assault, and other category from the demographic survey. Boston EMA other category includes perinatal transmission, blood transfusion, other risk, and unknown/undetermined.

Results

Prominent themes found in focus group findings and confirmed in interview data are presented below, along with an interpretive discussion. (See Appendices B – 2 and B – 3 for complete focus group and interview data).

POOR PLANNING FOR THE ELDER AGE

Generally, participants did not anticipate that they would be living longer with HIV; early perceptions of HIV infection concluded that the disease was terminal as opposed to a manageable chronic disease. HIV infected clients and those diagnosed with AIDS were not prepared to live 10, 15, or 20 years with HIV. In the words of one of the participants:

“I thought I was going to die the following year. I let one year go. And after that I said maybe two years. So I didn’t plan ahead because I didn’t think there was a future.”

This absence of planning caused some participants to exhaust all resources that may have accumulated, as expressed in the following sentiments:

“I went through savings and my IRA and all of that stuff right off the bat because I was diagnosed in 1986...I figured that I wouldn't be here for like 5 or 10 years. Look at me now.”

“A lot of people who [were] diagnosed just thought they were going to be dead and [were] sort of reckless because they thought they would be gone.”

The knowledge of their HIV status affected participants’ sense of planning and purpose, which also changed their self-perception.

“It's like somebody opened a window and all my dreams flew out the window.”

It is clear that the participant’s lives dramatically changed once they learned they were living with HIV. The next prominent theme shows participants’ current perception of themselves and their experience after the passage of time.

INCREASED SELF-AWARENESS AND A RENEWED SENSE OF SELF

Participants expressed a sense of inner strength and an overall feeling of resilience from their experience with HIV. To the introductory question of “how do you feel to be older and living with HIV?”, many of the focus group participants did not express the general sense of despair one would expect from the published literature reviews, but rather they have acquired a level of wisdom and acceptance. They state the following perspectives:

“I feel much wiser with the info collected over the years.”

“[I feel] blessed and lucky, as I have younger friends who have passed.”

“I learned how to accept it and move on. As people with no legs or anything have moved on, I had to, too. I hated this disease, now I respect it and feel safe with it and have moved on with my life”.

“I have lived with HIV for 25 years and it is a whole lot different. Back then when I was drugging, I was miserable.”

"It took me a long time to accept the fact that I have Hepatitis and HIV and I was living with shame, guilt, and was horrified to be living with this disease."

Confronting the challenges of living with HIV has heightened participants' self-awareness. Many attribute this sense of wisdom to spiritual renewal; they feel it's a testament to their miraculous lives.

"I believe I'm a miracle as I'm still here, alive, and functioning within my lifestyle."

"I think about how that man upstairs has my back...I'm 70 years old and I'm bless[ed] you know...they wonder why I don't even think about it [HIV]."

"God heard my prayers and He intervened because I was ready to surrender...I wasn't born this way. For Him to get my attention, I returned to prison and served a seven year sentence. I grew a garden in prison and came across a book that brought tears to my eyes. I invested in more books while I was in prison."

This acquired wisdom helps participants focus on what they can change. They also expressed deliberate efforts to maintain proper health:

"Not worrying is key to survival."

"I feel better now. I'm more conscious of exercise, diet, and I take better care of [my]self."

"Taking care of myself (I exercise, eat right, and dress nice)...this makes me feel good."

COPING WITH PHYSICAL AND MEDICAL COMPLICATIONS

Despite acquired wisdom, growing older with HIV brings a series of complications such as difficulty dealing with daily chores and activities, medical issues, psychosocial issues, and morbidity factors amplified by their HIV status. Most participants in this study have maintained optimal HIV medical care: 96% of focus group participants reported having a CD4 count test in the last six months and 88% had been to see their doctor regarding their HIV/AIDS in the last 6 months.

However, participants still reported being burdened by physical and medical complications. For some, it is difficult to move around since their level of energy is not the same. Daily activities become a challenge; dealing with HIV becomes a full time job. When asked about physical ailments, participants shared these thoughts:

"My energy, not only exhausted energy, but my creative energy is just not there."

"Complications of aging compounded with HIV takes up more and more of the week... Being able to take care of myself. Everything that we deal with on a daily basis: eating, dressing, cleaning, making sure you have a clean house."

The medical complications from HIV and co-morbidities were the most prevalent issues shared by participants in both the focus group and individual interviews. The combination of HIV and aging makes managing routine medical care more difficult. Participants worried about cancer, osteoporosis, and other common health issues that may develop with age. As participants explain:

"It seems the progression of other things is much faster and stronger."

"You can get osteoporosis in your forties. You can get diabetes, which people don't usually get until they're 60 or 70, or at least the onset diabetes."

"I was diagnosed with osteoporosis at 41, and that's unheard of for a guy."

"My doctor says he used to just treat for HIV, now he treats for HIV and diabetes, HIV and high blood pressure—dual diagnosis goes for everyone."

It is essential to deal with the complications of older age in conjunction with HIV. In addition, there is the anxiety of finding the appropriate response to certain medical complications. Is it HIV or age-related? It often feels that there is not an answer.

"They are missing things. Is it HIV or age related, for example diabetes, osteoporosis?"

"There are a lot of things that I think is more a matter of primary care than HIV specialists, particularly as you get older."

There are many unknown answers regarding medical complications and participants felt that more research is needed regarding the implications of living older with HIV. The lack of knowledge regarding the interaction of HIV progression and aging is compounded by the fact that long-term side-effects of HIV medication are largely unknown and unstudied. This sentiment is shared in the perspectives below:

"What I'm concerned about is old age medications conflicting with my HIV medication... And whether or not they know its old age or HIV that's bringing me down."

"What are the long term effects from taking all these medicines?"

"It's new territory because we're living longer, and they don't really know."

"I know they've done studies on HIV [medications] but they haven't done studies on what happens when someone takes them for 30 years."

"Because we're aging and sometimes they have the wrong, how do you say it, research as necessary on people fifty and older... but they need to know that when you are older there are certain signs to look for from our medications."

"I've gone so long without hurting myself. I have to find what's good and best for me."

In the absence of tested knowledge and best practices, the participants believe it is their responsibility to inform their doctors of their needs as they age.

"It's unrealistic to us to look to doctors for the answers because we are the first generation aging with HIV."

"You have to basically tell them. I'm telling my doctor, 'I think it's time for my colonoscopy and my pulmonary thing'... I think it's up to us to really be able to tell them, until they get used to us aging."

For some it seems that their doctors are tired of dealing with their medical issues. Participants perceive that physicians no longer view HIV as the cutting edge issue that it once was compared to when they were first diagnosed.

“I think that one of the issues with people as they age is that most of the top primary care physicians who are HIV specialists are actually sort of getting bored with us because we are no longer the exciting HIV candidates.”

Participants reported several co-morbidities in the structured interviews. The most frequent responses are listed in Figure 5 below. (For a complete list of co-morbidities reported, see Appendix B-3).

Health Condition	Percentage of Participants (n = 26)
Arthritis	63%
Diabetes	38%
Hepatitis C	38%
High Blood Pressure	58%
Osteoporosis	33%

Figure 5. Reported Health Conditions

EXPERIENCED DISCRIMINATION AND STIGMATIZATION

When seeking care outside their HIV specialist, some participants experienced discrimination. This discrimination remains a serious barrier to getting necessary medical care. Some statements from participants are shared below:

“I think there is more of a stigma today than it was when I got diagnosed in 1993.”

“You can tell from body language if somebody wants to touch you or if they don’t want to touch you... You can feel when it happens.”

“Once your status is known, the treatment is very different.”

In dental clinics, dermatologist offices, and other specialized care facilities, participants stated that they were treated very poorly. Individual interviews recount experiences of discrimination below:

“I went to a dentist office that was a father-son practice. When I got there and they learned I have HIV...there was a lot of whispering....the father came and said he was going to see me instead of his son and then he put five pairs of gloves on...”

“The dental assistant was so cruel...I can’t remember exactly what she said but I left there crying...”

“My significant other’s dermatologist made him go to a hospital for a procedure that is normally done in the office...said they weren’t equipped to handle it.”

Gaining access to appropriate elderly services can also be difficult. For example, staff in nursing homes were perceived to have strong reservations about their capacity to deal with HIV patients:

"A person had HIV and they were not taking care of that guy."

"We are coming to the nursing homes and they don't understand this disease...They don't have the proper training...They don't care. They are understaffed. They are underpaid."

"He was neglected. He was not getting the proper care, the proper nutrition. They just let him be there [while] dying."

Unfortunately, participants also expressed that they've had serious discrimination issues within their communities and among family members. Stigma and discrimination often act as barriers to developing a support structure for emotional and social well-being, which negatively impacts PLWH. While some participants disclose their HIV status to family members and significant others, a number of participants face barriers in revealing their status to others. Fifty-four percent (54%) of the 26 individuals interviewed reported to have disclosed their status to family and friends. One participant declared:

"They do not need to know what I got. I don't need to tell the world."

Similarly, others said:

"I haven't informed my seven grandchildren because I don't know how they'd react towards me, as I see how they react towards others in similar situations".

"Regarding my family: my family is dysfunctional with their own issues and I do not need their approval."

Overall participants believe more could be done to inform the general public about HIV, and specifically about growing older with HIV. They were eager to offer ideas on how discrimination should be addressed:

"I think it is a lack of awareness among the general population...There [are] still people who are not educated about this disease. I think they need to be trained. A public campaign about HIV will help people who are aging with HIV."

SEVERE ISOLATION FROM FAMILY AND SIGNIFICANT OTHERS

Fear of rejection and discrimination can cause older PLWH to feel lonely and isolated. In the words of the study participants:

"I don't feel comfortable with people around me because I'm so used to being alone."

"Because I can't get to people... I don't go out to bars, I can't pick up people like I used to."

"There are so many things that you're dealing with that it's just one more rejection of having to tell someone you meet that you like them."

"Being older is a strike while dating, but because I'm older and HIV positive it's a double strike."

Almost all the participants expressed a sense of despair regarding loneliness. Dating is difficult due to the many changes brought on by aging and HIV, as well as a lack of confidence in approaching others.

"I'm single. And it's really hard to meet people because you know... do I want to meet somebody and am I going to tell them either way, or am I only going to date people with HIV, you know?"

"I don't want [to] be alone neither. I don't want to pass alone... a lot of people look at me and say, "well you look too old, that ain't my type."

"Am I going to die alone?"

COMMITMENT TO BE OF SERVICE AND GIVING BACK TO SOCIETY

Participants' experiences of discrimination and stigmatization did not affect their commitment to living a productive life. However, they notice a decrease in public funding for HIV services and note that the HIV community used to be more active in advocacy efforts. They shared ideas of how their wisdom could be of use to the community, such as educating the general public, running HIV support groups specifically for people over 50. This is an area that was explored and confirmed through individual interviews.

"Hire people with HIV that understand symptoms we go through... More equal opportunities because it is very unfair."

"I've always wanted to be part of a speaker's bureau...but I can't get anyone to support it."

"I work and my experience of dealing with other people's issues is so much easier than dealing with my own because I could voice my opinions through them."

DISCUSSION

This series of focus groups and interviews present a snapshot of the challenges faced by older people living with HIV in the Boston EMA. Participants shared an array of experiences from first being diagnosed to current medical conditions and discrimination. Many shared the perspective that they never expected to live this long with the disease and thus did not prepare financially, emotionally, or otherwise to meet the challenges they face today.

Medical complications were a very real concern in the daily lives of these participants. Sixty-three percent of participants across focus groups and interviews reported having arthritis, 58% had high blood pressure, and 33% had osteoporosis. As with most aging individuals, participants were often dealing with one or more of these common diseases that affect people over 50. For this special segment of aging adults, however, the physical and psychological impact of these more 'typical' illnesses tend to be greater and the age of onset is generally considerably younger.

The untold story behind the data seems to open up a whole new way of understanding the experiences of older PLWH. While the majority of participants (88%) reported feeling anxious, depressed, or confused within the past 30 days, they generally portrayed a more forward-thinking, longer-term view of life and their place in the world, and are not often restricted by the various daily challenges. A greater level of resilience from their individual struggles with HIV gives them the strength to continue the fight through anxiety and depression, remain actively engaged in society, and create living conditions that maintain and sustain their quality of life. For instance, participants often expressed an accrued sense of wisdom about how to deal with life's complications despite concurrently suffering from other health issues like diabetes, kidney disease, glaucoma, lipodistrophy, and

lipoatrophy. Apparently, this heightened awareness leads them to make positive, informed decisions about their health.

For example, in reference to the discrimination one participant experienced, he said, “worries only tear you down.” The adoption of such a stance, which was shared by many participants, actually serves as a coping mechanism for dealing with the stigma they’ve experienced. One of the worst forms is the discrimination associated with health care services. While the infectious disease unit that sees patients living with HIV over the course of many years remains the ideal place for services, other health issues, often related to aging, force patients to be referred outside of HIV specific care.

A shocking number of participants, mostly interviewed in New Hampshire, recalled experiences of discrimination in precisely this second level of care. *“You can feel when it happens”*, said one participant sadly when describing an incident with a phlebotomist who ‘stepped back’ during a routine lab exam. While experiences with discrimination varied by geography, with individuals in New Hampshire reporting the highest rates (Appendix B – 3), participants felt discriminated against in a range of other settings including the emergency room, at the work place, and among family and peers.

Aging introduces an additional set of issues for participants. For instance, many participants have difficulty getting from place to place, which turns a simple doctor’s appointment into a full day’s activity. In the absence of proper transportation services specifically geared to this population, aging PLWH are guaranteed to have more difficulty accessing quality services. Over half of the focus group participants cited support services as more important to medication adherence now than when they were first diagnosed.

Furthermore, since the connection with family is very weak for such participants, they are forced to rely on established support networks to deal with their isolation and be of service to the community. In fact, many expressed the hope that existing services would take advantage of their experiences and wisdom in order to develop new and improved programs and activities.

Although the participants in both focus groups and individual interviews were engaging in positive prevention, disclosure remains a serious issue. Twelve out of 26 focus group participants had chosen not to disclose their status to family and friends. Participants even requested help with disclosure since they find it so difficult to inform their support network. Though barriers to disclosure are informative, no further information is shared in this report in order to protect confidentiality.

LIMITATIONS

This report summarizes an exploratory study with the goal of better understanding the needs of older PLWH in the Boston EMA. Triangulation through multiple focus groups, individual interviews, and previous research reinforces the validity of findings. However, the findings represent the experiences of clients in the context of their individual circumstances which are not necessarily applicable to the entire population of older PLWH in the Boston EMA.

This study contains a limited sample of participants due to budgetary constraints. A larger sample would have included more perspectives and could have been expanded geographically and linguistically. Sampling for this study was also done through opportunistic sampling; individuals interested in participating in the focus groups

were accepted on a first-come, first-served basis. An effort was made during the individual interview recruitment to target agencies with ethnic and linguistic minorities in order to make the sample more representative. However, this led the Spanish-speaking group of participants to be limited to NH. Despite these limitations, the sample included in this study provides valuable life experiences and does include some geographic, ethnic, racial, and linguistic minorities.

The sample for this study was also derived from a population presumably already connected to HIV services. Recruitment for the study was only conducted through provider agency assistance. Therefore, this study does not contain the perspectives, needs, or recommendations from older PLWH who are outside the HIV service system.

Finally, this study captured the perspectives of long-term survivors of HIV who are over 50 years old. This could be due to the sampling technique, or the fact that there are more long-term survivors in the EMA than newly diagnosed individuals over the age of 50. Therefore, some of the themes which emerged from research may only be applicable to those who have been living with HIV for many years. More research should be conducted to look at the barriers, concerns, and challenges of individuals who are over 50 years of age and who have been recently diagnosed with HIV.

RECOMMENDATIONS

A specialized support network could be expanded to tap into the wisdom this group possesses and respond to the needs of PLWH 50 years of age and older. Sharing of these experiences could be an asset for the larger public health community. Health care providers should consider the array of challenges that come with aging and adjust their HIV services accordingly.

The level of isolation known by this group facilitates the need for programs with a focus on strengthening the connection between HIV clients and their family members. Participants expressed the need for help with disclosure to family and friends. Many of them desire a connection with others aged 50 and older, possibly through support groups exclusively dedicated to older HIV positive individuals. This would provide a forum to discuss age-specific issues related to health and quality of life.

While mental health services remain a need for this population, it is clear that the connection with some productive venture helps reduce the isolation and depression experienced by the participants. They confirmed that an active and productive lifestyle will improve their emotional and social well being.

Engaging PLWH aged 50 and older in public health ventures, education and outreach, substance abuse prevention, and other HIV services may help improve quality of life for this group. Participants expressed a desire to take part in an educational campaign about HIV for the general public. Learning from the experiences of participants and applying their knowledge to HIV prevention efforts would be beneficial to everyone.

Options for future analysis could include continuing a similar study with a larger sample size. Also, quantitative data exists that could be paired with this exploratory data. Demographic information, service utilization data, outcome measures, and quantitative data from a recent consumer needs assessment could be synthesized to create an even clearer picture of the needs of PLWH over 50 in the Boston EMA.

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Appendix A-1: Consent Form

Consent Form

Thank you for participating in today's focus group/interview. The Center for Public Management is working in partnership with the Boston Public Health Commission and the Planning Council to better understand the impact of aging on PLWH in the Boston EMA.

You have been chosen to participate today because you are at least 50 years of age, and are currently using HIV Services in the Boston EMA. Our purpose today is to talk openly about aging and living with HIV/AIDS. Whether you have been living with HIV/AIDS for a long time or have been recently diagnosed, we want to know how aging is affecting your quality of life.

There is no right or wrong answer. We only ask that you be as open and honest with us as possible. We are hoping to learn more about the challenges of being older and living with HIV.

Your response to the questions will be used to prepare a report for the Boston Public Health Commission and will help design interventions aimed at supporting and improving the quality of life for people 50 years and older who are living with HIV.

Your responses are confidential and will not be attributed directly to you or _____ in any of the reports that result from this focus group/interview.

You may decide not to participate now or at any point during the focus group/interview.

I _____ have verbally interpreted the information above to the person who is agreeing to be in the interview. **[Interviews only]**

Focus Group/Interview Site: _____

Do you agree to participate? _____ Yes _____ No

Signature _____

Appendix A-2: Demographic Survey



CENTER FOR PUBLIC MANAGEMENT SUFFOLK UNIVERSITY

THE IMPACT OF AGING ON THE QUALITY OF LIFE OF PLWH IN THE BOSTON EMA

DEMOGRAPHIC SURVEY (CONFIDENTIAL)

INSTRUCTIONS: Please answer the questions below (to the best of your ability). The survey is confidential and for research purposes only. The completed survey should be inserted into the attached envelope, sealed, and given to the group facilitator. Thank you!

1. What is your date of birth? _____ / _____
Month Year
2. What is your Zip Code? _____
3. What is your highest level of education? Grade school Some high school High School degree/GED Some college
College degree Some graduate school Graduate school degree
4. What is your sexual orientation? Gay Bisexual Straight Prefer not to Answer Other
5. Are you? Male Female Transgender Other _____
6. Do you consider yourself? African American American Indian Asian/Pacific Islander
Caucasian Hispanic/Latino Multi-Racial
Other _____
7. What is your primary language? English Spanish Haitian/Creole
French Portuguese Other _____
8. Are you HIV positive or has your HIV progressed to AIDS? HIV AIDS Don't Know
9. What Year were you diagnosed with HIV? _____ unknown
10. What Year were you diagnosed with AIDS? _____ unknown
11. When was the last time you saw a doctor to treat your HIV? _____ / _____
Month Year
12. When was the last time you had a CD-4 (T-cell) Count? _____ / _____
Month Year
13. Do you know how you may have acquired HIV/AIDS? (please check all that apply)

<input type="checkbox"/> Male sex w/male	<input type="checkbox"/> Injection Drug Use	<input type="checkbox"/> Health Care Worker
<input type="checkbox"/> Female sex w/female	<input type="checkbox"/> Sex with Drug User	<input type="checkbox"/> Mother w/HIV/AIDS
<input type="checkbox"/> Heterosexual sex	<input type="checkbox"/> Sexual Assault	<input type="checkbox"/> Unknown
<input type="checkbox"/> Prison	<input type="checkbox"/> Transfusion	<input type="checkbox"/> Other

Thank you for your time in completing this survey.

Appendix A-3: Focus Group Facilitator's Guide

Instructions for facilitators are in italics.

General Introduction:

The intent of this portion of the agenda is to welcome participants and make them as comfortable as possible by explaining the focus group and letting them know what to expect from the experience. Facilitators can also set ground rules for confidentiality, and explain how data will be dealt with (stored, transcribed, and analyzed). HANDOUT CONSENT FORMS

These remarks include thoughts about the following (SEE BELOW FOR EXACT STATEMENTS).

1. Ground rules
 - a. Respect all opinions (this does not mean you have to agree).
 - b. Contributions are voluntary; please feel free to express opinions and share ideas.
 - c. Confidentiality: we ask that you respect the private nature of what you might hear and not discuss it outside the meeting in any way that might identify the people you met here.
 - d. Talking one at a time: we want to be able to hear everyone's thoughts and opinions. Please try not to "talk over each other."
2. Purpose of the focus group
 - a. To better understand the experiences or challenges of being older and living with HIV
 - b. To learn about ways to improve current services or upgrade services to meet the needs of the older HIV clients
 - c. To learn about the things that "get in the way"
3. Audiotapes
 - a. The tapes are kept private and safe.
 - b. When the tapes are transcribed, participants will be identified by a code.
 - c. Anonymous quotations may go into reports or publications.

Format of Focus Group

Overall Design

Have participants help themselves to food.

- | | |
|-------------------------|--|
| 1. Welcome/Sign Consent | (10 minutes) |
| 2. Introductions | (10 minutes) |
| 3. Segment 1 | (30 minutes) |
| 4. Segment 2 | (30 minutes) |
| 5. Break | (5 minutes) |
| 6. Segment 3 | (30 minutes) |
| 7. Compensation | (5 minutes) |
| Total | 2 hours (<i>above times are estimates</i>) |

Opening

Welcome (~5 minutes)

Thank you for participating in this focus group. My name is _____ and I am from _____. I work at _____, as the _____. We appreciate your willingness to take the time to participate. A focus group is a group discussion. We want you to know that each of your opinions and perspectives are important to us. There is no right or wrong answer. We only ask that you be as open and honest with us as possible. You have been chosen to participate in this focus group because you are 50 years and older living with HIV.

My role is to be your guide by asking questions and keeping us on time; but this is really YOUR time to talk. You will notice that we are taping this group in order to accurately report all ideas. Your name will NOT be associated with anything you say. Also, the tapes will be kept private and safe. When the tapes are transcribed, participants will be identified by a code.

At this point please turn off your cell phones if you have not done so already.

In addition, guidelines for participating in focus groups should be clarified and expressed.

Focus group members should be told:

It is important to ‘be a good group member.’ This means that participants should be non-judgmental and not critical of others. Please speak when you have something to say, even if it is a different opinion than others might have. You are allowed to disagree; but please be sure not to interrupt other members.

Also, if you notice that I am not giving you eye contact, I am not trying to be rude; I just want you to speak to the other clients here, not to me.

In order to maintain confidentiality, please do not discuss what you hear in this group with people outside this group in any way that might identify the people you met here.

Finally, there is a lot of information that we would like to cover today, so there may be times that I need to stop you and move on to a new topic. We expect this will take about 2 hours.

Are there any questions before we get started?

Introductions (~ 5 minutes)

We are going to start with some introductions. We will not go in order around the room, please just jump in when you’d like to. (*Do not just have them go around the room introducing themselves; it should be more random – popcorn it!*) Please share with us:

1. Your first name (you do not have to use your own name)
2. What’s your favorite food?

To get the ball rolling, I will start. *Say your first name, and what’s your favorite food?*

Appendix A-4: Focus Group Tool

Discussion will occur in three 30 minute sessions.

1. Thinking about living with HIV now, compared to 10 years ago, how does it feel to be older and living with HIV?

Probing:

- *Does having HIV complicate your life as you are getting older, in what way?*
- *How much of your day to day health issues are due aging versus your HIV status?*
- *Are there specific health ailments that are more prevalent?*
- *In your community do you feel discriminated against because of your HIV status? Could you talk about specific cases?*

2. What does it mean to have a good quality of life as you age?

Probing:

- *How are your relationships when you are older with HIV?*
 - *Relationship with Family Members?*
 - *Relationship with Significant Others?*
 - *Finding/maintaining sexual partners?*
- *How is your support network as you age? Please Explain.*
- *Do you get the support you need? And where?*
- *What kind of support are you missing? Would like to have?*
- *What makes you feel active and productive?*

3. What would make your quality of life as you age even better?

Probing:

- *What additional supports or services would be helpful?*
- *What are the gaps that you think need to be addressed for this population?*
- *What should providers keep in mind/know as they work with older clients?*

Appendix A-5: Interview Tool



Interview Date of Interview Location:

Opening:
Again, thank you for agreeing to participate in today's interview. This interview should take approximately 20-30 minutes to complete. Before we begin, please take a few minutes to complete a one-page demographic survey. [Participant will be instructed to seal completed survey in the envelope provided].

Thank you for completing the survey. Let's begin the interview. Again, if you wish to stop at any time, please let me know.

Ok....let's start by talking about how you are currently managing your HIV.....

MANAGEMENT OF HIV

1. Where are you currently receiving HIV-related services? _____ (insert Town/City)

2. Have you been in contact with your case manager in the past 6 months? Yes No

If **NO**, do any of the following reasons describe why?

- I'm doing well on my own and/or with my other support systems and have had no need to contact my case manager
- I can't relate to my case manager because he/she is too young
- I haven't contacted my case manager because he/she doesn't seem to know the local service system well/have resources specific to my needs
- Other (please describe):

HEALTH

3. Have you developed any other health issues as you've aged? (Read list: PROBE for others)

- | | |
|--|--|
| <input type="checkbox"/> Arthritis | <input type="checkbox"/> Liver Disease |
| <input type="checkbox"/> Asthma | <input type="checkbox"/> Lung Disease |
| <input type="checkbox"/> Cancer | <input type="checkbox"/> Memory Problems |
| <input type="checkbox"/> Chronic obstructive pulmonary disease | <input type="checkbox"/> Neuropathy |
| <input type="checkbox"/> Diabetes | <input type="checkbox"/> Osteoporosis |
| <input type="checkbox"/> Heart Disease | |
| <input type="checkbox"/> Hemophilia/Blood Disorder | |
| <input type="checkbox"/> Hepatitis B | |
| <input type="checkbox"/> Hepatitis C | |
| <input type="checkbox"/> High Blood Pressure | |
| <input type="checkbox"/> High Cholesterol | |

Record
Others: _____

4. Have you seen medical specialists for any of the above health issues (other doctors, nurses, mental health, and medical providers) outside your HIV specialist? Yes No

4a. If **YES**, how is that going for you?

5. In the past 12 months, have you felt discriminated against because of your HIV status in any of the following places (*please choose all that apply*):

- Emergency Room Receiving medical services from a specialist outside the HIV Community Work Place Family or Peers None Other

5a. If **Selected any of the Above** or **Other**, please describe in detail what happened.

6. Has the experience of taking your HIV-related medications changed over the years?

- Yes No

6a. If **YES**, how so?

7. Overall, how has aging complicated the management of your HIV?

MENTAL HEALTH & EMOTIONAL STATUS

Now that we've talked about your physical health, let's talk about how you are feeling emotionally...

9. Thinking about the past **30 days**, have you experienced any changes in your mental health or emotional status? For example, in the past 30 days have you:

a) Felt anxious, depressed, or confused? Yes No

b) Felt sad or hopeless? Yes No

c) Worried so much that it has kept you from doing activities you would have liked to do? Yes No

d) Found it difficult to enjoy yourself when engaging in activities you have enjoyed in the past? Yes No

e) Had any significant difficulties sleeping? Yes No

f) Felt afraid that something bad is going to happen to you? Yes No

g) If **YES** to any of the above, do you think these feelings are...

- HIV-related Age-related Both Not sure

10. Have changes in your mental health or emotional status made it more difficult to manage your HIV? Yes No

10a. If **YES**, please explain?

SUPPORT

Thinking about managing your HIV, let's talk about the support you receive from others...

11. Are you receiving adequate support from...

a. Family Yes No

b. Significant other? Yes No No S.O.

c. From peers? Yes No

d. From other people living with HIV/AIDS? Yes No

12. Are your relationships (with family, friends, significant others) changing as you age? Yes No

12a. If **YES**, how so?

13. Have you chosen to disclose your HIV status with your family and friends? Yes No

13a. If **NO**, can you talk more about your choice?

(PROBE: Has this contributed to feelings of loneliness or isolation? How so?)

14. Considering everything we've discussed, what is your biggest concern as you grow older living with HIV?

Thinking about the Future.....

[This section should be tailored to the participant and questions should be asked based on the discussion. The goal is to identify the things that would help improve the participant's quality of life]

We've had a chance to talk about the things that are going well for you and the challenges that remain as you grow older. Now we would like to focus on the things that would help improve your quality of life. We would also like to explore what makes you feel active and productive, what kind of support you need, and what types of services would be helpful as your grow older living with HIV/AIDS.

Relationships

15. Would having the support of your family, friends, significant others, specifically around issues related to HIV/AIDS, contribute to your quality of life? In what ways?

16. Would you be interested in connecting with others over 50 living with HIV? In what ways?

Role in the Community

17. Would being connected to volunteer opportunities in the community (for example, helping out at a local community based organization or an AIDS service organization) contribute to your quality of life? In what ways?

18. Would employment opportunities (for example, working as a Peer Leader, going back to work in the field you have an interest, background, or degree in, working part-time in your community) contribute to your quality of life? In what ways?

19. Would educational opportunities (for example, classes at a local university, cooking classes, art classes, GED classes, etc.) contribute to your quality of life? In what ways?

20. Would being part of the service system/helping other PLWH/A contribute to your quality of life? In what ways?

20a. If **YES**, how would you like to help? How can the service system utilize your skills/wisdom?

Other Services [Interviewer should ask ALL of these questions]

21. Can you talk about your experiences with the HIV-related services you currently receive compared to when you were first diagnosed?

22. Compared to when you were first diagnosed, how important are support services (food, housing, peer support, transportation) in managing your medical care (getting to the doctor, remembering appointments)?

More important The same Less Important Not sure

23. Compared to when you were first diagnosed, how important are support services (food, housing, peer support, transportation) in adhering to your HIV medication?

More important The same Less Important Not sure

24. Which services do you need but cannot get?

Case Management Client Advocacy Dental Drug Reimbursement Food Services Housing Mental Health Peer Support Primary Care Substance Abuse Transportation

25. Which services can you get, but are not tailored to PLWH/A 50 years and older?

Case Management Client Advocacy Dental Drug Reimbursement Food Services Housing Mental Health Peer Support Primary Care Substance Abuse Transportation

26. What additional supports or services would be helpful?

The interview is complete. Thank you for taking the time to talk with us. (Interviewee will be given a thank you letter with \$25.00 CASH)

Appendix B: Data Tables

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Appendix B-1: Demographic Data, Focus Groups

	Location	Date	Number of Participants
Group 1	AIDS Action	June 25, 2009	12
Group 2	Boston Living Center	June 30, 2009 (AM)	13
Group 3	Boston Living Center	June 30, 2009 (PM)	16
Group 4	Dorchester House	June 30, 2009	7
Total			48

Figure 1. Participants by Focus Group Location

	Minimum Age	Maximum Age	Mean
Group 1 (n=12)	50	63	55
Group 2 (n=13)	44	73	58
Group 3 (n=16)	50	61	56
Group 4 (n=7)	52	60	57
All (n=48)	44	73	56
Boston EMA (n=2,010)	50	91	56

Figure 2. Age of Participants

	Male	Female	Transgender
Group 1 (n=12)	67%	25%	8%
Group 2 (n=13)	77%	23%	0%
Group 3 (n=16)	94%	6%	0%
Group 4 (n=7)	57 %	43%	0%
All (n=48)	77%	19%	2%
Boston EMA (n=2,010)	72%	27%	1%

Figure 3. Gender of Focus Group Participants

	African American	American Indian	Asian/Pacific Islander	Caucasian	Hispanic/Latino	Multi-Racial	Other	No Answer
Group 1 (n=12)	50%	8%	0%	42%	0%	0%	0%	0%
Group 2 (n=13)	31%	0%	0%	62%	8%	0%	0%	0%
Group 3 (n=16)	50%	0%	6.2%	31%	0%	0%	6%	6%
Group 4 (n=7)	71%	0%	0%	29%	0%	0%	0%	0%
All (n=48)	48%	2%	2%	42%	2%	2%	0%	2%
Boston EMA (n=2,010)	35%	3%	2%	51%	26%	N/A	N/A	N/A

Figure 4. Race of Focus Group Participants

	Grade School	Some High School	High School Diploma	Some College	College Degree	Some Graduate School	Graduate School Degree
Group 1 (n=12)	0%	8%	33%	42%	8%	8%	0%
Group 2 (n=13)	7%	0%	28%	7%	38%	15%	8%
Group 3 (n=16)	0%	6%	25%	25%	31%	6%	6%
Group 4 (n=7)	0%	43%	29%	0%	14%	0%	14%
All (n=48)	2%	10%	27%	21%	25%	6%	8%

Figure 5. Education Level of Focus Group Participants

	Gay	Bi-Sexual	Straight	Other
Group 1 (n=12)	18%	18%	55%	9%
Group 2 (n=13)	61%	8%	31%	0%
Group 3 (n=16)	63%	6%	31%	0%
Group 4 (n=7)	14%	14%	72%	0%
All (n=48)	44%	10%	42%	2%

Figure 6. Sexual Orientation of Focus Group Participants

	Minimum Years	Maximum Years	Mean	Median	Mode
Group 1 (n=12)	4	26	16	16	12
Group 2 (n=13)	5	30	19	18	18
Group 3 (n=16)	5	24	17	18	16
Group 4 (n=7)	10	25	19	20	10
All (n=48)	4	30	17	18	18

Figure 7. Number of Years Diagnosed with HIV

	Number Diagnosed	Minimum Years	Maximum Years	Mean	Median	Mode
Group 1 (n=12)	4	5	15	9	8	5
Group 2 (n=13)	4	10	17	14	14	10
Group 3 (n=16)	6	4	24	16	16	15
Group 4 (n=7)	2	16	16	16	16	16
All (n=48)	16	4	24	13	15	15

Figure 8. Number of Years Diagnosed with AIDS

Last T-Cell Count	0-6 Months	7-12 Months	13-18 Months	19-24 Months	More than 24 Months
Group 1 (n=12)	100%	0%	0%	0%	0%
Group 2 (n=13)	100%	0%	0%	0%	0%
Group 3 (n=16)	88%	0%	0%	0%	13%
Group 4 (n=7)	100%	0%	0%	0%	0%
All (n=48)	96%	0%	0%	0%	4%

Figure 9. Number of Months Since Last T-Cell Count for Participants

	0-6 Months	7-12 Months	13-18 Months	19-24 Months	More than 24 Months	No Answer
Group 1 (n=12)	92%	0%	0%	0%	8.3%	0%
Group 2 (n=13)	92%	0%	0%	0%	0%	7.7%
Group 3 (n=16)	86%	0%	0%	0%	7.1%	7.1%
Group 4 (n=7)	100%	0%	0%	0%	0%	0
All (n=48)	88%	0%	0%	0%	6.3%	6.3%

Figure 10. Number of Months Since Last Doctors Visit for Participants

	Male with Male	Heterosexual Sex	Injection Drug Use	Sex with Drug User	Transfusion	Health Care Worker	Other
Group 1 (n=12)	25%	33%	50%	0%	0%	0%	0%
Group 2 (n=13)	67%	25%	17%	8%	8%	0%	0%
Group 3 (n=16)	69%	6%	38%	13%	0%	6%	0%
Group 4 (n=7)	33%	0%	50%	0%	0%	0%	16.7%
All (n=48)	52%	17%	37%	6%	2%	2%	2%
Boston EMA (n=2,010)	21%	45%	25%	Not available	2%	Not available	2%

Figure 11. Mode of Transmission for Participants

Appendix B-2: Demographic Data, Interviews

Table One: Total Participants by Region and Date of Interviews

	Region	Date	Number of Participants
Group 1	Greater Manchester AIDS Project (NH)	11/9/09	7
Group 2	Plymouth (Southern MA)	12/2 & 12/16/09	8
Group 3	Haitian Community, Boston	11/8/09	5
Group 4	Western MA	12/17/09 & 1/13/10	6
Total			26

Table Two: Age of Participants

Participant Age	Minimum Age	Maximum Age	Mean
Group 1 (NH) (n=7)	40	63	54
Group 2 (Southern MA) (n=8)	51	77	62
Group 3 (Haitian) (n=5)	51	72	62
Group 4 (Western MA) (n=6)	50	60	54
All Interview Participants (N=26)	40	77	58

Table Three: Gender of Participants

Participant Gender	Male	Female
Group 1 (NH) (n=7)	57%	43%
Group 2 (So. MA) (n=8)	75%	25%
Group 3 (Haitian) (n=5)	40%	60%
Group 4 (Western MA) (n=6)	67%	33%
Interviewed Groups (N=26)	62% (n=16)	38% (n=10)

Note: No respondents identified as transgendered

Table Four: Race/Ethnicity of Participants

Race/Ethnicity	Caucasian	Hispanic/Latino	Multi-Racial	Other	Haitian/Creole
Group 1 (NH) (n=7)	43%	43%	0%	14%	0%
Group 2 (So. MA) (n=8)	88%	0%	12%	0%	0%
Group 3 (Haitian) (n=5)	0%	0%	0%	0%	100%
Group 4 (West) (n=6)	17%	83%	0%	0%	0%
All Participants (n=26)	42% (n=11)	31% (n=8)	4% (n=1)	4% (n=)	19% (n=5)

Table Five: Primary Language of Interview Participants

Primary Language	English	Spanish	Haitian/Creole
Group 1 (NH) (n=7)	71%	29%	0%
Group 2 (So. MA) (n=8)	100%	0%	0%
Group 3 (Haitian) (n=5)	0%	0%	100%
Group 4 (West MA) (n=6)	83%	17%	0%
Interviewed Groups (n=26)	69% (n=18)	11% (n=3)	19% (n=5)

Table Six: Highest Level of Education of Participants

Education	Grade School	Some High School	High School Diploma	Some College	Graduate School Degree
Group 1 (NH) (n=7)	43%	14%	29%	14%	0%
Group 2 (So. MA) (n=8)	0%	13%	25%	50%	12%
Group 3 (Haitian) (n=5)	20%	40%	40%	0%	0%
Group 4 (West MA) (n=6)	0%	17%	33%	50%	0%
Interview Group (n=26)	15% (n=4)	19% (n=5)	31% (n=8)	31% (n=8)	4% (n=1)

Note: No respondents selected either "College Degree" or "Some Graduate School"

Table Seven: Sexual Orientation of Participants

Sexual Orientation	Gay	Bisexual	Straight
Group 1 (NH) (n=7)	29%	0%	71%
Group 2 (So. MA) (n=8)	38%	12%	50%
Group 3 (Haitian) (n=5)	0%	0%	100%
Group 4 (West) (n=6)	0%	0%	100%
Interview Group (n=26)	19% (n=5)	4% (n=1)	77% (n=20)

Table Eight: HIV/AIDS Progression and Years Since Initial Diagnosis

	Diagnosed w/ HIV only	Diagnosed w/ AIDS	Don't Know Progression	Min. years since initial diagnosis	Max. years since initial diagnosis	Mean (years)	Median (years)
Group 1 (NH) (n=6)*	43%	29%	14%	6	27	13.5	11
Group 2 (So. MA) (n=8)	75%	25%	0%	0	25	8.1	6
Group 3 (Haitian) (n=5)	60%	40%	0%	2	20	12.6	17
Group 4 (West MA) (n=6)	67%	33%	0%	2	23	19.1	20
Interview Group (n=25)*	64% (n=16)	32% (n=8)	4% (n=1)	0	27	13.0	13.0

*One respondent did not complete this question

Table Nine: Mode of HIV Transmission

	Male with Male	Hetero Sex	Injection Drug Use	Sexual Assault	Sex w/ Drug User	Transfusion	Health Care Worker	Other or Unknown
Group 1 (NH) (n=7)	29%	14%	14%	14%	14%	14%	14%	0%
Group 2 (So. MA) (n=8)	50%	13%	12%	0%	0%	0%	0%	25%
Group 3 (Haitian) (n=5)	0%	80%	0%	0%	0%	20%	0%	0%
Group 4 (West MA) (n=6)	0%	33%	66%	0%	0%	0%	0%	0%
Interview Group (n=26)	23% (n=6)	31% (n=8)	27% (n=7)	4% (n=1)	8% (n=2)	8% (n=2)	4% (n=1)	8% (n=2)

Note: percentages may not equal 100% due to possible multiple means of transmission, as reported by participants.

Table Ten: Elapsed Time Since Last T-Cell Count or Doctor's Visit

	T-Cell Count: 0-6 Months	T-Cell Count: > 6 Months or Unknown	Doctor. Visit: 0-6 Months	Doctor Visit: > 6 Months or Unknown
Group 1 (NH) (n=7)	100%	0%	100%	0%
Group 2 (So. MA) (n=8)	88%	12%	100%	0%
Group 3 (Haitian) (n=5)	100%	0%	80%	20%
Group 4 (West MA) (n=6)	100%	0%	100%	0%
All Interview Group (n=26)	96%	4%	96%	4%

Appendix B-3: Interview Data

Table 1: Interview Length

Region	Interview Time, In Minutes (Average)
Southeastern	28
Western	37
Haitian	22
New Hampshire	50
All Timed Interviews	35.5

Table 2: Case Management

Q: Have you had contact with your Case Manager in the past 6 months?

Contact with Case Manager in the past 6 months	%Yes
Southeastern	100%
Western	100%
Haitian	100%
New Hampshire	100%
All =26	100%

Table 3: Age-Related Health Conditions

Q: Have you developed any other health issues as you've aged? (Multiple responses possible)

Health Conditions	Southeastern (n=8)	Western (n=6)	Haitian (n=8)	New Hampshire (n=7)	ALL (n=26)
Arthritis	43%	100%	40%	67%	63%
Asthma	29%	33%	0%	50%	29%
Cancer	0%	0%	0%	50%	13%
Chronic obstructive pulmonary disease	14%	0%	0%	17%	8%
Diabetes	29%	50%	20%	50%	38%
Heart disease	0%	0%	0%	17%	4%
Hemophilia/blood disorder	0%	0%	0%	16.7%	4%
Hepatitis B	14%	0%	0%	0%	4%
Hepatitis C	29%	83%	0%	33%	38%
High blood pressure	29%	50%	100%	67%	58%
High cholesterol	14%	17%	20%	17%	17%
Liver disease	14%	0%	0%	67%	21%
Lung disease	0%	0%	0%	0%	0%
Memory problems	0%	0%	20%	33%	12%
Neuropathy	29%	0%	0%	50%	21%
Osteoporosis	14%	67%	0%	50%	33%
Other	14%	17%	0%	67%	25%

Table 4: Non-HIV Medical Care

Q: Have you seen medical specialists for any of the above health issues outside your HIV specialist?

Medical Specialists	Southeastern	Western	Haitian	New Hampshire	All
Yes	88%	100%	40%	71%	77% (n=20)
No	12%	0%	60%	29%	23% (n=6)

Table 5: Change in HIV Treatment Experience

Q: Has the experience of taking your HIV-related medications changed over the years?

Change in Treatment Experience	Yes	No
Southeastern (n=8)	38%	62%
Western (n=6)	100%	0%
Haitian (n=5)	60%	40%
New Hampshire (n=7)	100%	0%
All (n=26)	73%	27%

Table 6: Experience of Discrimination

Q: In the past 12 months, have you felt discriminated against because of our HIV status in any of the following places? (multiple responses possible)

People or Places	Southeastern (n=8)	Western (n=6)	Haitian (n=5)	New Hampshire (n=7)	All Regions (n=26)
Emergency Room	0%	0%	0%	29%	8% (n=2)
Receiving medical services from a specialist outside the HIV community	0%	0%	0%	14%	4% (n=1)
Work Place	0%	17%	0%	14%	8% (n=2)
Family or Peers	0%	0%	40%	0%	8% (n=2)
None	37%	67%	60%	57%	54% (n=14)
Other	63%	16%	0%	0%	23% (n=6)

Table 7: HIV and Emotional/Mental Health

Q: Have you experienced any changes in your mental health or emotional status in the past 30 days? Have you:

Emotional and Mental Health	Southeastern		Western		Haitian		New Hampshire		All Regions	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Felt anxious, depressed, or confused?	88%	12%	100%	0%	75%	25%	86%	14%	88%	12%
Felt sad or hopeless?	88%	12%	100%	0%	100%	0%	57%	43%	84%	16%
Worried so much that it has kept you from doing activities you would have liked to do?	50%	50%	100%	0%	75%	25%	86%	14%	76%	24%
Found it difficult to enjoy yourself when engaging in activities you have enjoyed in the past?	38%	62%	38%	62%	50%	50%	57%	43%	60%	40%
Had any significant difficulties sleeping?	75%	25%	83%	17%	100%	0%	86%	14%	84%	16%
Felt afraid that something bad is going to happen to you?	63%	37%	50%	50%	50%	50%	29%	71%	48%	52%

Table 8: Emotional/Mental Changes Attributed to HIV or Age?

Q: If yes [to any of the above changes], are these changes a result of HIV, age-related changes, both, or not sure?

Attribution of Emotional/Mental Health Changes	HIV	Age	Both	Not Sure
Southeastern (n=8)	0%	0%		
Western (n=6)	0%	17%	66%	17%
Haitian (n=4)	20%	20%	40%	0%
New Hampshire (n=7)	0%	14%	57%	29%
All (n=25)	4%	12%	56%	28%

Note: One respondent did not answer this question.

Table 9: Emotional/Mental Health Impact on Treatment

Q: Have changes in your mental health or emotional status made it more difficult to manage your HIV?

Emotional/Mental Health Impact on Treatment	Yes	No
Southeastern (n=8)	37%	63%
Western (n=6)	17%	83%
Haitian (n=5)	20%	80%
New Hampshire (n=7)	57%	43%
All (n=26)	35%	65%

Table 10: Changes in Relationships

Q: Are your relationships (with family, friends, significant others) changing as you age?

Changes in Relationships	Yes	No
Southeastern (n=8)	75%	25%
Western (n=6)	100%	0%
Haitian (n=5)	20%	80%
New Hampshire (n=7)	86%	14%
All (n=26)	65%	35%

Table 11: Support Networks

Q: Are you receiving adequate support from:

Support Networks	Southeastern*		Western		Haitian		New Hampshire*		All Regions* (n=22)	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Family?	88%	12%	100%	0%	40%	60%	43%	57%	82%	18%
Significant other?	75%	25%	83%	17%	80%	20%	57%	43%	68%	32%
From peers?	88%	12%	100%	0%	60%	40%	43%	57%	86%	14%
From other people living with HIV/AIDS?	88%	12%	100%	0%	80%	20%	29%	71%	86%	14%

*Note: Not all participants answered this question, percentages based on responses.

Table 12: Disclosure of HIV

Q: Have you chosen to disclose your HIV status with family and friends

Disclosure of HIV Status	Yes	No
Southeastern (n=8)	37%	63%
Western (n=6)	100%	0%
Haitian (n=5)	60%	40%
New Hampshire (n=7)	29%	71%
All (n=26)	54%	46%

Table 13: Importance of Support Services Related to Managing Medical Care
Q: Compared to when you were first diagnosed, how important are support services (food, housing, peer support, transportation) in managing your medical care (getting to the doctor, remembering appointments)?

Support Services' Impact on Medical Care	More Important	The Same
Southeastern (n=8)	50%	50%
Western (n=6)	0%	100%
Haitian (n=5)	100%	0%
New Hampshire (n=7)	71%	29%
All (n=26)	54%	46%

Table 14: Importance of Support Services Related to HIV Medication Adherence
Q: Compared to when you were first diagnosed, how important are support services (food, housing, peer support, transportation) in adhering to your HIV medication?

Support Services' Impact on HIV Adherence	More Important	The Same	Less Important
Southeastern (n=8)	37%	63%	0%
Western (n=6)	83%	17%	0%
Haitian (n=5)	80%	0%	20%
New Hampshire (n=7)	43%	57%	0%
All (n=26)	58%	38%	4%

Table 15: Services Needed, Not Available
Q: Which services do you need but cannot get?

Needed Services Selected by Interview Respondents	Number of Responses	% of Participants
Dental	5	19%
Drug Reimbursement	4	15%
Food Services	2	8%
Housing	2	8%
Peer Support	3	12%
Transportation	2	8%

Table 16: Services Available; Not Tailored
Q: Which services can you get, but are not tailored to PLWH/A 50 years and older?

Needed Services Selected by Interview Respondents	Number of Responses	% of Participants
Dental	1	4%
Peer Support	1	4%
Transportation	4	15%