THE WISDOM OF EXPERIENCE:
A REPORT ON HOW TO IMPROVE CONSUMER-PROVIDER RELATIONSHIPS AND KEEP CONSUMERS ENGAGED IN HIV CARE FROM THE PERSPECTIVE OF PEOPLE LIVING WITH HIV/AIDS IN NEW YORK CITY AND THE TRI-COUNTY REGION

HIV Health & Human Services Planning Council of New York
Consumers Committee and the
Tri-County Living Together Psychosocial Support Group
June 2018
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### List of terms and acronyms

<table>
<thead>
<tr>
<th>CC</th>
<th>Consumers Committee of the Planning Council</th>
</tr>
</thead>
<tbody>
<tr>
<td>CBPR</td>
<td>Community-based participatory research</td>
</tr>
<tr>
<td>Consumers</td>
<td>Consumers are people living with HIV/AIDS</td>
</tr>
<tr>
<td>DOHMH</td>
<td>Department of Health and Mental Hygiene</td>
</tr>
<tr>
<td>QI</td>
<td>Quality improvement</td>
</tr>
<tr>
<td>LTSG</td>
<td>Living Together Psychosocial Support Group of Tri-County region</td>
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<tr>
<td>NYC</td>
<td>New York City</td>
</tr>
<tr>
<td>Planning Council</td>
<td>The HIV Health &amp; Human Services Planning Council of New York that sets priorities for NYC Ryan White Part A funding</td>
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<tr>
<td>PLWHA</td>
<td>People living with HIV/AIDS</td>
</tr>
<tr>
<td>TC</td>
<td>Tri-County region consisting of Putnam, Rockland, and Westchester Counties</td>
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</table>
I. Executive summary

This evaluation was developed in response to an invitation for consumers to deliver a workshop to Ryan White Part A service providers of the New York City (NYC) and Tri-County (TC) region at the NYC Department of Health and Mental Hygiene (DOHMH) Power of Quality Improvement Conference on November 16, 2017. In order to develop the content for this workshop, the HIV Health & Human Services Planning Council of New York Consumer Committee (CC) and the Tri-County Living Together Support Group (LTSG) decided to focus their efforts on evaluating what makes for positive consumer-provider relationships and how such relationships do or do not support people living with HIV/AIDS (PLWHA) to move through the HIV Care Continuum to achieve viral suppression.

The CC, LTSG, and several DOHMH employees formed a quality improvement (QI) workgroup to carry out a qualitative evaluation using community-based participatory research approaches. After developing the evaluation goals, objectives and discussion questions, a facilitated discussion was carried out with consumers who participate in the CC in NYC and the LTSG in TC. Using a participatory analysis process, facilitated discussion participants and DOHMH staff analyzed the facilitated discussion transcripts, identified themes from the transcripts, and discussed these as a group in order to come to a consensus as to the most important themes. DOHMH staff wrote up evaluation findings in this report with input from the facilitated discussion participants.

The most common themes to come from the facilitated discussions were the topics of mental health, the characteristics of positive relationships with health providers, as well as the importance of support from family and PLWHA peers. The findings have resulted in recommendations for HIV providers as well as HIV planning bodies that are responsible for setting priorities and developing service directives and standards of care for the delivery of HIV care in the NYC and TC region.

These recommendations are:

1. At the time of diagnosis, provide emotional support, address the trauma of diagnosis, and begin educating the consumer on HIV as this visit impacts willingness to engage in future HIV care.
2. During medical visits, take the time to talk to consumers about a comprehensive set of concerns as this fosters trust, a will to survive, and positive outlook towards health care.
3. Comorbidities are common requiring better integration of care and adherence support for multiple types of medication. Plans need to be in place for when consumers switch providers to provide continuity of care.
4. Consumers with mental health illness or substance use addictions often experience difficulty remaining adherent to HIV medications. These consumers need intensive and integrated services with providers experienced in both HIV care and their comorbidity of mental health illness or substance use addiction.

5. Expanded mental health support is needed for all consumers and should be explicitly addressed at diagnosis and care visits as part of a mental health “universal precautions” approach.

6. Facilitate access to the support of family and peers as they are critical for consumers’ emotional health and their outlook on the importance of treatment and adherence.

7. Disclosure may not happen if consumers fear stigma. Although whether to disclose is ultimately the consumer’s decision, providers should start the conversation on disclosure in order to facilitate consumer’s access to more support from family and peers.

8. Providers should connect consumers to support groups and self-advocacy activities as these directly contribute to consumer empowerment and a greater desire to take care of oneself and other consumers.

9. Involve consumers in QI initiatives in a manner that is client-centered and meaningful. Provider-centric perspectives or client satisfaction surveys as QI initiatives may be inadequate without the substantive input of consumers.
II. Introduction

Background

In 1991 the Mayor of New York City established the HIV Health and Human Services Planning Council of New York (Planning Council). The Planning Council is charged with developing spending priorities and allocating funds for the Ryan White CARE Act Part A based on the needs of the HIV/AIDS epidemic. The Planning Council is a Mayorally-appointed body of people living with HIV/AIDS (PLWHA), HIV/AIDS service providers, governmental representatives, academic and research partners, and community members. In 2015-2016, the Planning Council added the Tri-County region, consisting of Westchester, Rockland, and Putnam Counties, to its portfolio as part of the NY Eligible Metropolitan Area (EMA).

The vision of the Planning Council is that PLWHA in the New York EMA will have access to appropriate, quality services across the continuum of HIV care, resulting in the best possible health and quality of life. As part of accomplishing this vision, the Planning Council includes a Consumers Committee (CC), composed of PLWHA from the NY EMA, that is central to the work of the Planning Council. As part of its activities, the CC works to improve HIV health services by advocating for quality improvement (QI) initiatives that center the needs of PLWHA in planning and service delivery/implementation processes. At the heart of such initiatives is the concept of client-centered care.

Client-centered care, sometimes called patient-centered care or person-centered care, is an approach to health care that considers clients and their families to be integral components of the health care decision making and delivery processes. A core tenet of client-centered care is that clients, not providers, have control over health care decisions and therefore it requires a reconfiguring of traditional client-provider relationships. Many quality improvement initiatives have client-centered care as one of their primary goals and yet achieving this is often difficult due to a number of factors including that such initiatives have long focused on provider’s experiences with the clients they serve. With clients as active participants in their own care, notable success has been achieved in the delivery of client-centric models of HIV care that are respectful of and responsive to individuals’ preferences, needs, and values. Less commonly, however, are services directly informed by the clients’ lived experiences as PLWHA and often PLWHA are not leaders of discussions on what quality improvement consists of.

In order to address this gap, the Planning Council’s CC participated in the Department of Health and Mental Hygiene’s (DOHMH) Power of Quality Improvement Conference on November 16, 2017. The Power of Quality Improvement Conference is an annual conference that gathers Ryan White Part A HIV/AIDS providers from throughout the NY EMA to present on their quality improvement work, demonstrate collaborative partnerships with clients, and share lessons learned through workshops and posters. At the 2017 conference, the CC delivered a workshop on quality improvement from the perspective of PLWHA and they chose to focus on
consumer-provider relationships. They did so because they felt that strong consumer-provider relationships are central to remaining engaged in care and yet many had had negative experiences with providers at some point since being diagnosed with HIV.

Data from PLWHA in NYC and TC more broadly supports this concern. In a 2007 report on satisfaction and dissatisfaction with medical providers among PLWHA in NYC and TC, most reported being satisfied with their primary medical provider, but among those dissatisfied, dissatisfaction with the patient-provider relationship was one of the most common reasons for their dissatisfaction. This finding has not disappeared with time. A similar 2017 report found that 25% of respondents from NYC and 12% from TC had dropped out of care for at least six months or more since being diagnosed. The reasons respondents gave fordropping out included dissatisfaction with doctor, organization, or care. Surprisingly, dropping out of care was no less a problem among recently-diagnosed PLWHA. In that same study, PLWHA diagnosed in the past five years were no less likely to drop out compared to those diagnosed longer ago. Given the concerns of the CC, the findings from data among PLWHA in the NY EMA, and advocacy across the US calling for collaborative and power-sharing relationships between providers and clients, more information is needed to clarify how consumer-provider relationships can be improved.

Theoretical and Methodological Framework

A participatory research framework guided the methods used to make this report and such a framework aligns with client-centered care. Participatory research is an umbrella term for methods that have as their basic principle that affected community members must be involved in decision-making regarding the research, and the extent to which control over the process is shared and knowledge is co-created between researchers and community members determines the extent to which it is participatory. Using this approach, it is insufficient to consult the community only during early phases of research, such as a meeting for community members to inform researchers of their concerns or educate them about the topic under study, and to call this participatory research.

In a move to make participatory research methods even more democratic, methodologies have developed that give greater power to affected communities over the research process and empower them to be potential catalysts for change. These approaches, such as community-based participatory research (CBPR), photovoice, and decolonizing methodologies, seek to challenge the traditional roles of researcher and participant, putting an emphasis on acknowledging and disrupting the typical power imbalance between the two through meaningful relationship building and collaboration. One example is photovoice, which is a participatory method where participants take pictures of their communities regarding an issue of concern and discuss the themes that emerge with researchers. It explicitly borrows Paulo Freire’s educational approach of having community members identify common
themes through dialogue, a method that is accessible to communities of all literacy levels. Decolonizing methods, as another example, acknowledge that Western research practices are often extensions of colonialism and seek to address this by making participants partners in research that is desired by the community and benefits them. Decolonizing approaches may be especially appropriate within marginalized communities, such as communities of color or other communities experiencing stigma.

In this evaluation, the Consumer Committee sought to utilize a variety of CBPR strategies common to participatory research methods, but to take them a step further. In CBPR, community members are often engaged in design, data collection, and dissemination phases of research, but typically not in the analysis phase. Often analysis steps are delegated to academics, who are assumed to be the experts. However, in this community-based evaluation project, the Consumer Committee adapted the participatory analysis steps described in Suzanne F. Jackson’s article “A participatory group process to analyze qualitative data.” In her article, community members divided up focus group findings amongst themselves, discussed them in small groups, and conducted qualitative coding first as small groups and then as a larger group. A researcher with qualitative research experience advised the process but did not manage it. An evaluation of this novel process found that is enabled the participation of individuals with a mixture of education levels and familiarity with analysis; it gave community members control over interpretation; and it could handle large volumes of data quickly and without great cost.

In the case of HIV health and social services, one could view the researcher/participant binary discussed in participatory research methods as instead a provider/consumer dichotomy. Although HIV health services delivery and research has a much stronger history of participatory activities than is the case for many other reportable diseases, there can still play out entrenched power dynamics that result in the privileging of provider and government representative voices over that of PLWHA voices. Integrating participatory research approaches into quality improvement activities by government agencies and providers has the potential to make HIV services more client-centered.
III. Evaluation Methods

Goals
The Planning Council’s Consumer Committee (CC), in collaboration with the Living Together Support Group (LTSG) from the TC region, engaged in an evaluation project identifying and assessing what makes for positive consumer-provider relationships. The goals of the project were: 1, to ensure that discussions on quality improvement of Ryan White Part A services include the lived experience of PLWHA themselves; 2, to make recommendations on how to improve consumer-provider relationships within the context of the delivery of HIV-related services; and 3, to improve the overall health of NYC and TC PLWHA by making each step of the HIV Care Continuum more client-centered. Central to this evaluation project was the commitment to a consumer-driven process that highlighted the desires and needs of PLWHA.

Objectives
In order to evaluate how to establish positive consumer-provider relationships, the two objectives of this evaluation were to assess:

1. Barriers and enablers to receiving HIV care among PLWHA at their HIV health provider
2. How the consumer-provider relationship either supports or hinders adherence to HIV medications and maintenance of viral suppression

Planning process
The CC formed a quality improvement (QI) sub-committee of CC members who wished to be closely involved with carrying out the evaluation project. Meeting at least twice a month from July to mid-November 2017, a chair for the QI sub-committee was appointed by leadership of the Planning Council. This chair worked closely with a DOHMH Planning Council staff member and a DOHMH staff person with research experience. The DOHMH staff person with research experience advised the group on qualitative methods but did not drive decision-making, which was instead conducted in an open, collaborative process involving all stakeholders as a group. The QI sub-committee developed the project goals, objectives, and methodological approach, deciding to carry out one facilitated discussion, similar in structure to a focus group, for the NYC-based CC and one for the TC-based LTSG in order to capture the perspectives of PLWHA living and receiving services in both areas. Based on a pilot-tested version of the HIV cascade developed by the New York State Department of Health AIDS Institute called the Living Cascade,11 the QI sub-committee developed the questions for the facilitated discussions and an anonymous questionnaire for each participant in order to understand the socio-demographic characteristics of those who attended. The DOHMH staff recruited a facilitator that was a DOHMH employee with experience in leading focus groups but
who was unknown to the CC and LTSG in order to increase comfort to discuss potentially sensitive topics.

**Data Collection/Facilitated Discussions**

All members of the CC (approximately 20) and the LTSG (approximately 15) were invited to participate and plans for the evaluation were discussed at several public meetings of these two groups. Participants were compensated for travel to the discussions, which is a standard incentive given to CC and LTSG members for attendance at meetings, and meals were provided. Before beginning the discussions, participants were asked to complete a brief questionnaire to collect socio-demographic characteristics of participants that were relevant to the discussion objectives (see Appendix A: Anonymous survey of QI discussion participant characteristics). Because CC and LTSG meetings are open to the community, the facilitated discussions were also public. They were audio taped and transcribed for analysis. At the close of each discussion, which were four hours in length, the group engaged in a brief guided meditation because the personal nature of the discussions had stirred up strong emotions within some consumers. Anyone who participated in the facilitated discussions was also invited to participate in the analysis of these discussions at a future meeting.

**Facilitated discussion questions:**

1. Can you describe your first HIV health care visit after you were diagnosed? When was that?
   a. Does anything stand out in your memory about the conversations you had, things you saw in the clinic, or how you felt?

2. How did this experience impact your willingness to go for continued HIV care?

3. Now thinking to the present, what motivates you to go to your HIV appointments?

4. If you’ve ever gone for more than 6 months without a medical appointment with your HIV care provider, what made you miss it?

5. What has been the hardest part about staying on your HIV meds?

6. What specifically does your HIV provider do that helps you take your HIV meds?

**Analysis**

Participatory analysis

The QI sub-committee reviewed the participatory analysis process in the article by Suzanne F. Jackson and modified it. One four-hour participatory analysis meeting was held in NYC to focus on the transcripts from the CC facilitated discussion and another meeting was held
in TC to focus on the transcripts from the TC facilitated discussion. Transcripts were divided by question and at each participatory meeting individuals split up into teams of at least two individuals and were given the transcript pages from one question per team. Teams could structure their time as they wished and were advised about general qualitative analysis principles by DOHMH staff who also themselves participated in the analysis teams (see Appendix B: Analysis meeting schedule and tips for analysis). DOHMH staff provided supplies, such as markers, post-its, and large pieces of paper. In the CC analysis meeting, members had the opportunity to read their section of the transcript in advance so they were asked to put the results of their team discussion on a poster paper along with quotes they cut from the transcript that exemplified themes they felt were important. After two to three hours of discussion in teams, the teams presented their findings to the entire participatory analysis group in order to have everyone’s input.

Four individuals, including DOHM staff, that participated in the NYC analysis meeting traveled to TC to assist the LTSG members with their analysis meeting. Due to time constraints, the LTSG members were not able to receive a copy of the transcript from their facilitated discussion prior to the analysis meeting, so they were asked to take notes on the themes of importance they found in their small teams and if there was time to put this on poster paper. As with the NYC participatory analysis meeting, the LTSG small teams presented their qualitative findings to the entire group and reflected on how they felt about the process. For both analysis meetings, the whole-group discussions were audio recorded to facilitate the writing of a final report. The DOHMH staff used the poster papers, notes from the two analysis meetings, and transcripts to write the report and shared this with the CC for feedback. In writing this report, it is also our goal to make the inclusive and client-centered approach detailed in this report accessible to other PLWHA consumer groups who may be interested in carrying out a similar process (see Appendix C: Budget for evaluation project).

Pictures in this report come from the analysis meetings and conference workshop, and have been included with the permission of the consumers.
IV. Evaluation Findings

Participant characteristics

Overall, 27 consumers participated in the facilitated discussions, approximately evenly split between NYC and TC. The mean age was 59 with a range of 37-69. About two-thirds were male, although in the TC discussion only 46% were male. About two-thirds were black, 22% Latino, and 15% white. In the NYC discussion 57% identified as gay/homosexual while 69% identified as heterosexual in the TC discussion. The average year of diagnosis was 1995 and the average year of initiating HIV medication was 1997. Everyone was currently on HIV medication, but about half had stopped their medication for some length of time. The demographics of participants closely resembled that of the characteristics of PLWHA in NYC and TC overall.

Table 1. Socio-demographic and HIV-related characteristics of discussion participants.

<table>
<thead>
<tr>
<th>Participant Characteristics</th>
<th>Total</th>
<th>NYC</th>
<th>Tri-County</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Total</td>
<td>27</td>
<td>100.0</td>
<td>14</td>
</tr>
<tr>
<td>Age Mean (Range)</td>
<td>59</td>
<td>100.0</td>
<td>56</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>17</td>
<td>63.0</td>
<td>11</td>
</tr>
<tr>
<td>Female</td>
<td>10</td>
<td>37.0</td>
<td>3</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>17</td>
<td>63.0</td>
<td>7</td>
</tr>
<tr>
<td>Latino</td>
<td>6</td>
<td>22.2</td>
<td>3</td>
</tr>
<tr>
<td>White</td>
<td>4</td>
<td>14.8</td>
<td>4</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>0.0</td>
<td>0</td>
</tr>
<tr>
<td>Sexual Orientation</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Heterosexual</td>
<td>13</td>
<td>48.2</td>
<td>4</td>
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<tr>
<td>Gay/Homosexual</td>
<td>10</td>
<td>37.0</td>
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<td>Bisexual</td>
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<td>7.4</td>
<td>2</td>
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<td>Area of Residence</td>
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<tr>
<td>New York City</td>
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<td>44.4</td>
<td>12</td>
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<td>Tri-County Region</td>
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<td>55.6</td>
<td>2</td>
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<tr>
<td>Year of Diagnoses</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>1995</td>
<td>1995</td>
<td></td>
<td>1997</td>
</tr>
<tr>
<td>Median (Range)</td>
<td>1992</td>
<td></td>
<td>1992</td>
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<td>Area Where HIV Services Are Obtained</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>New York City</td>
<td>Tri-County Region</td>
<td>Year Initiated Taking HIV Medications</td>
</tr>
<tr>
<td>--------------------------</td>
<td>---------------</td>
<td>-------------------</td>
<td>--------------------------------------</td>
</tr>
<tr>
<td></td>
<td>15</td>
<td>12</td>
<td>1997</td>
</tr>
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<td></td>
<td>55.6</td>
<td>44.4</td>
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<td></td>
<td>7.7</td>
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<td>92.3</td>
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<table>
<thead>
<tr>
<th>Currently Taking HIV Medication</th>
<th>No</th>
<th>Yes</th>
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<tr>
<td></td>
<td>0</td>
<td>27</td>
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<table>
<thead>
<tr>
<th>Has Stopped Taking HIV Medications</th>
<th>No</th>
<th>Yes, but for less than 6 months</th>
<th>Yes and it was at least for 6 months</th>
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<td></td>
<td>13</td>
<td>8</td>
<td>6</td>
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<td></td>
<td>48.2</td>
<td>29.6</td>
<td>22.2</td>
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<td>42.9</td>
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<td>7</td>
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<tr>
<td></td>
<td>53.9</td>
<td>30.8</td>
<td>15.4</td>
</tr>
</tbody>
</table>

For the Tri-County sample, there were missing answers for: 2 for sexual orientation, 2 for year of diagnosis, 2 for year initiated taking HIV medications.
Thematic findings

There were a number of cross-cutting themes and contextual factors that emerged from the two facilitated discussions. Table 2 shows the most common themes that emerged by discussion question. Mental health was the most common theme, followed by provider characteristics, peer support, family support, and substance use. Overall, it is notable that themes frequently clustered within a socio-psychological domain, highlighting the considerable importance of psychological aspects of HIV diagnosis and care as well as interpersonal relationships. In the following section we describe common themes and use quotes to illustrate each theme. Each quote is identified by the region of residence, gender, and diagnosis year (if disclosed) of the speaker.

Table 2. Common facilitated discussion themes by discussion question

<table>
<thead>
<tr>
<th>Theme</th>
<th>Facilitated Discussion Question</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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<tr>
<td>Individual Level</td>
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<td>Psychological</td>
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<tr>
<td>Emotional state at diagnosis</td>
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<tr>
<td>Mental health</td>
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<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<td></td>
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<tr>
<td>Will to survive/positive outlook</td>
<td>X</td>
<td>X</td>
<td></td>
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<tr>
<td>Health literacy and empowerment</td>
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<td></td>
<td>X</td>
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<tr>
<td>Treatment fatigue</td>
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<td></td>
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<td>X</td>
<td>X</td>
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<td>Non-Psychological</td>
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<td>Substance use</td>
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<td>Aging and co-morbidities</td>
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<td>Interpersonal Level</td>
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<td>Peer support</td>
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<td>Stigma and disclosure</td>
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Individual level themes- Psychological themes

Emotional state at diagnosis

Although participants were not asked about their diagnosis visit, for many they could not talk about the early days of HIV care without this bringing to mind that impactful moment of diagnosis and the feelings it caused within them. Most participants were diagnosed many years ago and yet they remembered that visit vividly. Their HIV diagnosis visit and first HIV health care visits following diagnosis made a lasting impression on them that impacted whether they established a long-term relationship with the health provider and/or whether they instead delayed care. These experiences had durable impacts on their mental health.

“But it’s that first experience that I got when I first was diagnosed...is what dictated and that’s why I waited so long to come into care. Because I mean, I -- I was in shock that she would just throw down a box of tissues and I mean literally run out of the office”
(TC, male, diagnosed 1986)

For many, the diagnosis experience was traumatic and yet participants did not feel that providers explicitly addressed this trauma.

“It didn’t address the trauma. And I think it was later when I understood that there was trauma involved”
(NYC, male, diagnosed 2001)

Common feelings at the time of diagnosis were feelings of depression, numbness, denial, anger and some felt suicidal.

“I kind of went into a depression and I really did not do anything for two years”
(NYC, male, diagnosed 1997)

“And I remember leaving and being near a highway and sitting on a guardrail watching the trucks go by because I felt like I wanted to walk in front of one”
(TC, female, diagnosed 2006)

While most began HIV care soon after diagnosis, some participants were not mentally prepared to do this.

“I kind of wore my body down in those two years, because I coped by using a lot of drugs and partying as a coping mechanism”
(NYC, male, diagnosed 1997)
Some participants felt a great deal of confusion because they knew very little about HIV at the time of diagnosis.

“And that's why I can't come into care until '92 [6 years after diagnosis] because I just didn't know, you know, what was going on”
(TC, male, diagnosed 1986)

**Mental health**

Mental health responses were common to all facilitated discussion questions, making it the most frequent theme to arise. Some participants spoke of mental health in terms of previously-diagnosed mental health illness and others spoke in terms of their emotions or state of mind. For some, mental health illness was described as their first battle before HIV.

“It was my other issue that was my issue that took time for the doctors to stop focusing on medication and being undetectable to thinking about the other stuff that was affecting me...And but I was lying there for months and months and months, and it was only until I got help for my mental health. Like you said, it becomes the first issue. Because without it, you know, no matter how faithful you are to your medication, no matter how much you, you know, you have -- you -- you are emphatic --emphatic to going to the doctor, all those things; when you're depressed, you just lie there no matter what”
(NYC, male, diagnosed 2001)

“Then when I'm up, the world is a happy place. You know, everything is good, you know. And I can adhere to my medication when I'm there, but when I'm down, sometimes I can't” (TC, male, diagnosis year unknown)

“Sometimes you don't even recognize a mental disorder. For instance, I'm -- I think I have mild depression, but that mild depression, I've noticed now -- I can recognize it now, but it comes and goes and it comes and goes. And again, it's mild, but it -- it does affect me. It does affect me and it does affect whether I go to my doctor's appointments or whether I take my medication or not”
(NYC, male, diagnosed 1991)

“So it was easier for me to lay there, and like I used to do with my psyche meds, look at the bottle sitting at the coffee table next to me and not have the will to open it up to swallow the damn pill. Like I was in a straight jacket. I couldn't reach over and pick up the bottle to put a pill in my mouth”
(TC, female, diagnosed 2006)
Even though a number of participants were not struggling with a diagnosed mental health illness, many still experienced difficulty dealing emotionally with their mental health surrounding their HIV infection. One participant spoke about how doing HIV advocacy work made her feel proud, and yet despite this she still has difficult days:

“Don’t get me wrong, I have days when, you know, I’m just -- you know, the – the virus, you know, it -- it -- it does things to you, so sometimes you’re just tired, you’re just really tired. You know, how do you -- I -- I say that honestly nine times out of ten, I -- nine times out often during the day, I can go through five different mood swings just because I know, you know, what I got to do. I’m only -- I’m only, how you say, I’m living with this”  
(TC, female, diagnosed 1992)

Good mental health and a mindset to remain in care helped consumers remain adherent even when they previously did not want to.

“One of the most important things that you have to realize with this, that you have to really have a mindset to do this. Without the mindset not to do this, you’re going to have a very difficult time, in which I did… My results come back great. And it’s a good thing to know. And it gives you the encouragement to go on, you know, on that right track even though sometimes it gets hard”  
(TC, male, diagnosis year unknown)

Will to survive/positive outlook

Many consumers described having or developing a strong will to survive and a positive outlook on life that motivated them to stay engaged in HIV care and take their medications. For some, having friends or family with HIV die strengthened their will to persevere. Having seen friends die of HIV also appeared to strengthen the determination of some consumers to adhere to their medications.

“If I’ve made it through all that hell, this right here is a cake walk. I get mad at myself, I fight with myself. I fight with my disease. Even though I don’t want to get up, I make myself do it. When you’re dealing with HIV, it’s like carrying an unseen passenger…you’ve got to find out if the seat belt is secure, you’ve got to make sure that it’s not falling out of the car. And who’s driving, you or the passenger? So, I’m in the driver’s seat”  
(TC, female, diagnosed 1992)
“I thank the Lord that I’m still here for my daughter. Regardless of whatever I’ve gone through, I’m a fighter. So you see, I don’t say, I’m dying because I have AIDS or HIV. I’m living with it”
(TC, female, diagnosed 1991)

“Later on I realized that I can still handle this on my own. I just took it as a challenge and I’ve just got to do what I’ve got to do, period. I didn’t do anybody a favor. I just want to live, period”
(NYC, male, diagnosed 2002)

“After a while of not being adherent, I was running out of options. So I think it was also just, you know, the -- probably the -- I had seen so many people die and the more will of wanting to live and not to get sick and die and go that way. So that was really more of what really kind of turned me around to become -- to get healthy”
(NYC, male, diagnosed 1997)

“I mean some of us may outlive those that don’t have it, and that’s a good thing. But for ever -- however long we’re here, we’re going to leave a mark in society that we -- we are human, and we make mistakes, too. All right”
(TC, female, diagnosis year unknown)

**Health literacy and empowerment**

Consumers really valued being educated on the clinical aspects of their HIV care, such as learning to understand their labs, medications and potential side effects, and on other HIV knowledge. Sources of this information were often their provider (if they had a good relationship with their provider) as well as learning this information through support groups and their involvement with HIV activism. Being educated on HIV motivated them to learn more and to get more involved in HIV advocacy work. In turn, becoming involved in HIV advocacy work increased their knowledge and motivated them to take better care of their health. Therefore, education was a tool of empowerment for these consumers.

“I took a self-management leadership training, you know, knowing, being your own healthcare advocate. What I learned from that was so much more than I ever would have learned from a doctor.
(TC, female, diagnosed 2006)

“I wanted to know as much as I could about this virus, and so I educated myself. I went to places that educated consumers”
(NYC, male, diagnosed 1987)

“And with him, I learned a lot, because he used to go to conferences all over the world and he used to break down the medical terminology for me. He would stay sitting with me for an hour. And he did this with all his patients. He took everything to heart. He made sure we all understood what was going on with our bodies, with our medications. He even showed me what was going on with my labs. And this encouraged me to go on to learn more”

(NYC, male, diagnosed 1991)

“I got a call to be a part of a mentoring, they’re mentoring to be a mentor to other people that took the class that I did. And I think one of the things that I know about myself is I will always help and advocate for someone else before I will for myself. And when I had somebody that I had to check in with and encourage, that it kept me on track. Because in order for them to stay on track, I had to stay up on top of information. I had to stay up on top of my own healthcare. I had to be responsible for someone else, which made me more responsible for myself”

(TC, female, diagnosed 2006)

Treatment fatigue

Participants described taking breaks from HIV medication because they felt tired of taking it. They also described a desire to feel “normal,” not having to plan a day’s activities around whether they would have their medication on hand, such as being able to stay over someone’s house without having to worry that they didn’t have their medication with them. Others spoke about feeling fatigue with engaging in HIV care especially if they did not have a good relationship with their doctor. Positive relationships with providers were helpful in overcoming feelings of treatment fatigue and encouraging them to return to care.

“I have actually gone over six months a couple of times. I just get tired of it, you know. I just want to feel like a normal human being again without having doctors probing or sticking me all the time and pulling out 12 vials of blood. I’m just tired of it. I’m coming in twice a year and I’m done. If I have a problem, I’ll come to you. I’m tired of feeling like a human experiment. I just got off an eight month stint without seeing a doctor because she wasn’t listening to me. She was not participating with me as part of it. And I said, thank you, but I’m not coming back”

(NYC, male, diagnosed 1997)
“You know, we all get sick of it. And you know, I got sick of it. I really got sick of just taking medicine. I would throw it in the garbage, go back and get it. You know, forget about it a couple days, leave it in the drawer somewhere, can’t find it, right?” 
(TC, female, diagnosed 1992)

“Most of us here are caregivers and we have children. And the stresses that arise every once in a while or the point that I’ve got nothing, not too long ago I didn’t want to take the meds. I’m just tired. You get to that point where you just, you’re sick of just taking pills...So that’s the hardest thing for me is the stresses, period, of life” 
(TC, female, diagnosis year unknown)

“So I went about a year, and I felt just like a normal person. I’m like, you know, I’m like, I don’t have to take medication. I can go. I can take a trip or hang out or go over to friends and just, you know, spend the night or whatever; but then from doing that my T cells dropped...I needed a mental health break. I needed that break. I needed something to say, I’m normal again, you know. And -- and I didn’t feel that way being -- beholding to medication to sustain life. So that was -- that was a whole mental issue, in itself” 
(NYC, male, diagnosed 1987)
Individual level themes - Non-Psychological themes

Substance use

A number of participants spoke about the powerful effect drug addiction had on their lives, making engaging with HIV care and adhering to HIV medications very difficult. They struggled with substance use for years, and often described the supportive relationships with HIV providers, family, and peers as being instrumental for motivating them to come back to care after periods of being out of care due to substance use.

“I was getting high and I just stopped. Just stopped. And I didn’t go see a doctor. I didn’t do anything. I don’t know how long it went on. You know, I lost track of time. But I know when I did go back [to the doctor] I went from HIV positive to AIDS. Drugs have a way of just taking your memory away. It’s been a whole chunk of my life that I just don’t remember”
(TC, male, diagnosis year unknown)

“When it turns into AIDS in 2000 -- I want to say 2001, it was because the lack of, like I said, selling drugs, doing drugs...And living there, I came across a good doctor at a health clinic -- at a health clinic. And she got to talking with me and so forth and telling me that it had switched over into being, instead of HIV positive, you are AIDS positive. That was a rude awakening for me. It was kind of like, I had to make a decision, did I want to live, I had kids, you know, did I want to live or did I want to die. But I got to say, she was phenomenal. She was phenomenal with getting me on medications, explaining stuff to me, which made me want to start learning more. It made me want to start examining myself and my healthcare”
(TC, female, diagnosed 1992)

“In the beginning, I didn’t -- I really didn’t care, you know. I kept getting high. And through the pills in the garbage, you know. And then when I did start taking them, I took them all at one time...before I --I got clean, I started going to groups, you know, trying to get some knowledge of -- of my condition, you know...And right now I thank God for my groups. You know, it keeps me holding on. And that’s where I’m at today. You know, I learn something in the process every day, you know”
(TC, female, diagnosed 1989)

“I stopped using drugs in 2009. And drugs and these medications don’t mix very well. I was hanging on by a thin thread. You know, I was taking them, but sometimes I’d forget. Sometimes I’d be so high I didn’t know if I took them or not, you know...And I started this
when I was 15 years old, and I'm 62 now, and I just stopped seven years ago...And once I started getting clean, I didn't expect them to embrace me like they did, but they just kept saying, dad, we were just waiting for you to come out of it, you know. It was like, they was -- they was -- they was on hold. I kept my whole family hostage”
(TC, male, diagnosis year unknown)

Side effects

Many participants were infected some years ago when HIV medications could be especially toxic and had stronger side effects. Participants spoke about this when reflecting on the course of their illness and in speaking about their relationship with their provider. AZT in particular was often mentioned as harmful to their health and consumers were appreciative of providers who were responsive to their concerns about medication.

“AZT made me so sick. I said, Dr. [name removed], what are you doing to me? You're giving me something that’s making me sick when I don’t feel sick. And he said, this is probably doing you more damage, so stop.”
(TC, female, diagnosed 1987)

“I took it for a whole year and the medicine worked, it worked; but the side effects what really got me. I mean – I mean, it’s -- I went through some -- through some side effects. But I hung in there and -- and then she was going to take me off of it because the side effects was -- was really taking a toll, but she wouldn't give up...she said she brought the medicine down because it was too high, and so the medicine worked”
(TC, female, diagnosed 1998)

“AZT was out at that time, and I refused to take it because I had more friends that had the virus, too, and they were dropping like flies. I didn't know why though. Because of AZT”
(TC, male, diagnosed 1992)

“I did miss like six months from going to see a doctor. Now, that's like years back. And it was basically because at that time the medication, the cocktail that I was on was making me sick. It was making me throw up, rashes, whatever. It was -- and to the point whereas I just didn't want to, I just decided, I'm not going into see a doctor”
(TC, female, diagnosed 1992)

Aging and co-morbidities
Participants frequently mentioned co-morbidities that impacted their life in addition to HIV. A number of participants were first tested for HIV as a result of entering care for another illness that then led to a provider ordering HIV testing for them. As participants aged, many have now gotten their HIV under control through medication but may need more primary care surrounding their co-morbidities and to be able to receive as much of this care from the HIV provider if possible. Some expressed concerns about the long-term use of HIV medications on their health.

“So you know, I take my medication. At 7 o’clock those pills are in my mouth. Now that I’ve got to take more pills because of the heart, it’s -- it’s even harder, but I still do it” (TC, female, diagnosed 1991)

“As I get older, I -- I find I need more specialists each day” (NYC, male, diagnosed 1987)

“She’s very on top of everything, you know. She makes sure that I keep my appointment. My -- you know, I’m a diabetic, so I have to make sure that I take care of that. I have high blood pressure, you know, the works. Every -- a lot of stuff. So she’s on top of everything. She’s the main -- like, she’s my primary. Everything that I need, I go to her, besides the pain management, that’s somewhere else” (TC, female, diagnosis year unknown)

“And not only that I have HIV. I have heart disease, I have hepatitis B, hepatitis C, I have diabetes, and I was just diagnosed with bone cancer. So I got a full plate. With all that being said, it’s okay, you know, because I’m in good hands, and I appreciate that” (TC, male, diagnosed 1986)

“I’m fortunate enough, I’m not dealing with multiple diagnosis like some of my -- my colleagues here. You know, I’m not dealing with multiple diagnosis. I’m grateful for that, you know, but at the same time, I see their pain, too. You know what I’m saying? Because if it -- it’s not the virus that will kill you, it’s everything else” (TC, female, diagnosed 1992)

“Under the new guidelines, if you’re doing well and maintaining, you only see your doctor every six months...So and I’m really not okay with that, because, you know, as we get older, there’s more things to -- because HIV is not the biggest thing for us to worry about anymore, there’s so many other things” (TC, male, diagnosis year unknown)
Interpersonal level themes

Positive provider characteristics

Most participants described positive experiences with at least one HIV provider and had a clear sense of what made for a good relationship. Such positive relationships often resulted in the participant being a client of their provider for many years, lasting to the present or until their provider retired or discontinued their practice. The attributes of a good provider included one who is: supportive, welcoming, caring, gentle, thoughtful, encouraging, honest, and who communicates well. Another aspect of positive consumer-provider relationships was that these providers were very responsive to consumer concerns, including concerns with medication side effects, medication adherence, and financial barriers.

“My doctor is the same doctor, [name removed]. That’s my friend. She is my friend. There’s nothing I can’t say to her. There’s nothing she won’t do for me, and she’s on top of everything”
(TC, male, diagnosis year unknown)

“I have changed a few doctors, you know. And the one I have now is actually a nurse practitioner, and she’s really the best and takes care of me. There’s nothing that we can’t talk about, you know, even with the struggles of raising the five kids on my own and stuff -- she’s there, she understands whatever I tell her. So I have a good relationship with my -- the nurse practitioner. She’s awesome”
(TC, female, diagnosis year unknown)

“What’s kept me coming is the relationship I have with my doctor. That he was able to be honest with me and tell me that he can’t cure me, but that he would do everything to keep me alive”
(TC, male, diagnosed 1986)

“She’s the kind of doctor that if she sees you’re not trying to help yourself...you’re not helping yourself and doing stuff that’s -- that’s not helping your health she, you know, she gets very upset about it and she will tell you about it”
(TC, female, diagnosed 1998)

Participants appreciated providers who were proactive, up-to-date on the latest information regarding HIV, and ones who shared HIV information with them.
“She’s on top of everything. And she’s been my only doctor since I’ve had HIV and I’m glad I have her. Every time I go in there, she has a list of things she wants to talk to me about. She tests for everything. Anything you can imagine, she takes a test for it and she wants to know exactly what’s going on inside my body and I appreciate it very much”
(TC, male, diagnosis year unknown)

Positive consumer-provider relationships were ones that did not just focus on clinical aspects of care. These providers helped instill courage, self-management skills, and self-esteem within the consumer and they motivated them to remain hopeful. These providers did not rush appointments and even took the time to have discussions about not-HIV issues, such as family and politics.

“My healthcare provider, if it weren’t for him, I probably wouldn’t be here today because he gave me the courage and the outlook that I need to live”
(NYC, male, diagnosed 1991)

Negative provider characteristics

Participants also described negative interactions with providers at the time of diagnosis or later when seeking HIV care. For some this delayed seeking care. Others described “firing” their provider. Providers who exhibited the following characteristics were not highly-regarded by their patients: impersonal, expressionless, abrupt, not a people person, lacking empathy, having a poor bedside manner, rarely available, judgmental, and does not make suggestions, inform or educate the client. Negative client-provider interactions were ones that left the client feeling uninformed, not listened to and they resulted in a lack of trust.

“I got tested in 91 and they call me in and they tell me I am HIV positive. And I said ‘How can I be HIV positive?’ But the thing I did not like the most was the doctor who tested me, she asked me ‘How many times did you use drugs? I’ve never been a drug user, but my husband was a drug user and he infected me”
(TC, female, diagnosed 1991)

“The doctor, I can tell you something, this guy, well, he’s not one of my favorite people to tell you the truth, because he -- there was no emotion in -- in the -- in the way he expressed it other – it was very clinical and so forth. And when I walked out of there, I tell you the truth, I had to sit in my car for quite sometime because I was afraid to get on the -- on the highway to go home because I had so much going on, you know, in -- in my
life at that particular time that I had to really calm myself down and take note of where I was“
(NYC, male, diagnosed 1987)

“Doctors will speak five minutes and they'll, you know, they'll see a problem and never mind, we'll wait until next time. And I'm like, no, let's talk about it now. And they were, you know, they were dismissing. I fired them. I said, we're done. And then they get all pissed off because – I mean, this is a recent, they're like what do you mean you're not coming here anymore? I was like, you -- you talk at me. You don't, you know, you -- you don't talk to me, and you don't allow me to engage”
(NYC, male, diagnosed 1997)

“Back then it was like, you know, you have HIV, here's the medication, take it. Come see me or -- in a month or so, whatever, that was it. It was very cold, very cold, you know, uncaring. So that led me to not want to go back”
(TC, female, diagnosed 1992)

One participant who did not begin HIV medication for three years after being diagnosed said about an HIV provider:

“The things that he said that stuck with me in -- in not a good way is, just take your medicines. If you don't take your medicines, you're going to die. And that's -- that's what I remember”
(TC, female, diagnosed 2006)

Peer support
Participants spoke about the vital role that peers living with HIV/AIDS served in educating them, teaching them the right questions to ask, how to advocate for themselves, and for sharing a safe space for laughter and emotional support. This was especially apparent in TC where the facilitated discussion was with a long-standing support group for individuals living with HIV/AIDS.

“Everything that I've learned from being in this group Living Together, it's become my family. My family knows about this family. My family knows I call this family before I call them. The facilitator of the group brought us so close together, because he made it personal for each and every one of us to be together and share our stories”
(TC, female, diagnosis year unknown)
“And because of their stories and because of the being able to ask questions I didn’t know how to ask made me reluctantly go back to the doctor that didn’t have a good desk-side manner, didn’t know how to talk to people, wouldn’t explain anything. So no, if -- if -- if I had to rely on the doctor, I probably may not be here right now”
(TC, female, diagnosed 2006)

“I came here to the group 20 years ago. And I think if I hadn’t came here, I would have been still out there lost and nowhere to go, nobody to talk to. I’m still -- it’s still kind of hard for me to talk to people because I’ve lost a whole lot, you know. But when I come here, I’m a different person, and it’s just nothing but caring and loving”
(TC, female, diagnosed 1990)

“If it wasn’t for the facilitator of Living Together...I wouldn’t know half of the shit that I know now. Because honestly what he taught us from the beginning of day one in coming to Living Together, how to read your -- your labs, how to determine, you know, your CD4 count from your viral load count”
(TC, female, diagnosis year unknown)

“I’d hear them in the background, take your meds after hanging up the phone, yeah, because they were disturbing me. That’s what I used to always think, but they were actually trying to save my life”
(TC, male, diagnosed 1992)

**Family support**

Although a few consumers described negative experiences with their family, most described families and partners who were very supportive. Family members and partners accompanied them to HIV care appointments, checked in on them, called them to make sure they were taking their medication, and gave them a reason to continue living. Being a parent with HIV was described as an especially difficult role, but children were also a major source of motivation to remain in good health.

“Great grandma, grandkids. I love them with all my heart. I’d do anything for them and that’s what’s keeping me here. Sometimes when I get depressed, I call my youngest and she says, Mom, we need you, you can’t leave us. You have to keep going on”
(TC, female, diagnosed 1990)
“He [the provider] said if I didn’t do it for myself, do it for my kids”
(TC, female, diagnosed in 1987)

“I really spiraled downhill. And he [the provider] knew. He knew enough about me to
tell me that if I didn’t do it for myself, that the drugs were going to kill me before the
virus did and I needed to set my priorities straight – he knew my kids. He said, Don’t you
want to see your kids graduate high school? I didn’t think that was possible”
(NYC, male, diagnosed 1991)

“If I’m drinking something, they come over and grab it. They drink out of my cup and eat
off of my fork. They treat me as if nothing is wrong with me. When you’re family, you’re
family. You’re supposed to hold each other up no matter what. I am so thankful”
(TC, female, diagnosed 1990)

“What motivates me? Because I want to live. I got a purpose of living today. I have seven
grandchildren and one -- one great-grand, okay? And through my drugging years, I never
thought it would be possible for me to see -- to see this”
(TC, female, diagnosis year unknown)

“And then the phone rings. And it’s like, what? Ma, did you take your medicine? No. Get
up”
(TC, female, diagnosed 1992)

**Stigma and disclosure**

Some participants described experiencing HIV-related stigma from family members or
providers. Issues of stigma and disclosure went hand in hand. Stigma generally came up when
discussing the difficulty of disclosing their HIV status to family members or other individuals.

“I had to face my people. I had to face the world. My family was the worst. My kids, they
was the worst. And -- and their father, two of my girls' father, he – he threw it in my face
every day that I was HIV positive. I gave this to him, I gave that to him. I never gave him
nothing”
(TC, female, diagnosed 1990)

“I couldn’t disclose it because I was scared that I would be alienated and so I kept it with
me until I -- until I got released from prison and then I told some family members. And
they treated me okay at first, but after time went on, they -- they got a little shady, too”
(TC, male, diagnosed 1992)
“I had to break my silence. But I -- I -- I'm getting better now with the -- I -- I have a hard time with the disclosure. You know, I don't like to be telling no one”
(TC, female, diagnosed 1998)

“The first thing of a newly diagnosed person is, is terrified. And some people still have, how do you say, not comfortable talking about it. They're not comfortable expressing themselves about it or whatever or afraid of rejection”
(TC, female, diagnosis year unknown)

“But you know, the experience throughout the years, it's tremendous. There's a lot of ups and downs. There's a lot of stigma”
(TC, female, diagnosis year unknown)

“Me disclosing my HIV to -- it's too -- sometimes I have seen people how they act and they don't know that I have it and I seen how they carry on with somebody else and I'm sitting there watching and I say, wow. If I had to tell them, you know...the first thing that come out of their mouth and I seen them have it, too, it be, oh, my God. Or I'm so sorry. You -- you know, well, when did you get it?... and then I be start feeling all low”
(TC, female, diagnosed 1998)
Societal level themes

Consumers also spoke of societal-level or more systemic factors that influenced their progression through the HIV Care Continuum from diagnosis to viral suppression. These were spoken of less frequently than the previous themes, but remain important to note in this report. Many consumers had experienced some financial difficulty at some point during their time living with HIV/AIDS. At times this meant that the cost of HIV medication or private health insurance was too high, impacting their access to high quality care. Consumers who had positive relationships with their providers often remained patients of these providers for many years. When these providers retired or left their practice consumers were at risk of falling out of care, and therefore continuity of HIV care was especially compromised at such times. Consumers sometimes noted a disparity in quality of care comparing doctors to other types of providers (e.g. nurses), and comparing publically-funded care to privately-insured health care. These differences impacted their willingness to return for HIV care. Consumers also spoke about the need for holistic team-based approaches for their care, and to be treated as a whole person, rather than simply as someone with HIV. Such an approach may include therapists, other social services providers, individuals important in the consumers’ lives, alternative medicine, mindfulness practice, and religious practice. Below are a number of quotes exemplifying societal-level factors.

Financial difficulty affording HIV care and medications

“Honestly, I -- and -- and I actually just fired -- I -- when I moved down here, it was still the same care. And then, you know, I had financial troubles. I had to go on -- on public assistance, and it was a nightmare. I mean, the public, it -- it’s good, but nothing compared to private healthcare”
(NYC, male, diagnosed 1997)

“You know, I don’t even have a Medicaid card. So you know, if it wasn’t for the VA Hospital, I don’t know what I’d do, you know, because I’d really be out of luck”
(TC, male, diagnosis year unknown)

“A week and a half after entering the hospital, I was sent a bill for $29,000 and harassed three times a week by the hospital. This continued until I mentioned it to the doctors and then it stopped”
(NYC, male, diagnosed 2002)

Continuity of care
“The only time I’ve ever gone without seeing my provider for six months is when my doctor, who I’ve known from the time I got sick in the hospital, left. I didn’t know where to go to find a doctor. I didn’t want to walk into a doctor’s office and say, I need a doctor, can you be my doctor? When my doctor left, someone took over his practice who I did not like at all and she knew it. I said I don’t like the way you deal with me. She said Okay, but she continued to give me my medication even though I didn’t see her anymore. She continued to give me my medication even though I didn’t see her”
(NYC, male, diagnosed 1988)

**Doctors vs nurses/physician assistants**

“With a PA, it's better than a doctor. I mean, some doctors really don't have any business being --treating people. And maybe -- you know, it’s like they've lost their bedside manner or their compassion and maybe they should stay behind doors – behind closed doors. I mean, really that's what my experience has been. And it doesn't mean that there aren't good doctors out there. I'm not saying that. But nurses are -- are -- and PAs are willing to like establish a relationship with you...it's a totally different teaching mentality between nursing school and medical school”
(NYC, male, diagnosed 1997)

**Public vs. private health care**

“Private care was not difficult because somehow it aligned in a system I understood. It was public care that became cumbersome. And the challenge for me was to understand that system”
(NYC, male, diagnosed 2001)

**Holistic/team approach**

“And it takes a team. Social services are quite important as well. It’s teamwork and an efficient composition of people that did the job. That’s what it’s all about – It’s a whole team that was around me and allowed me to actually focus on my health rather than paying my hospital bill”
(NYC, male, diagnosed 2002)

**Therapists**

“So I look at things and stuff like that with a whole new perspective, that anything is possible if you really want it. And I'm in therapy -- I'm in therapy and I go to my groups and everything and I feel a little bit better and stuff”
(TC, male, diagnosed 1994)
“It wasn't just the medical doctor, but I also enrolled in therapy, so that helped me. And everybody was very kind”
(NYC, male, diagnosed 1991)
V. Limitations

This evaluation has a number of limitations that should be kept in mind when assessing how to apply these findings. The participants came from two groups generally made up of older PLWHA who had been living with HIV/AIDS for many years, many of whom had begun treatment before the advent of highly active anti-retroviral therapy. The early experiences of a number of participants were during the time when HIV medications had more severe side effects and providers knew less about effective management of HIV disease and these early experiences left lasting impressions on them. Even though HIV disease management has improved greatly, providers may still want to be aware of early experiences and attitudes formed by their patients. The perspective of long-term survivors of HIV remains relevant and may become more so as the population of PLWHA age. In 2016, the DOHMH found that 55% of people diagnosed with HIV/AIDS in NYC were 50 years or older. Therefore, the findings in this report may help providers better understand how to provide HIV care to a PLWHA population that is aging.

Another potential limitation is that one group (CC) consisted of consumer members of an HIV planning council and the other (LTSG) was a support group of which a number of consumers had also engaged in HIV advocacy work. Their views may represent those of PLWHA with higher levels of education on HIV and who are more engaged in the HIV service delivery system than the average PLWHA. Nonetheless, over half of participants had at some point stopped taking HIV medication. They were able to speak to the difficulties of remaining engaged with HIV care from their own personal experiences and thus the evaluation findings shed light on how to better ensure adherence to HIV medication among PLWHA.

Lastly, there were 27 consumers in total who participated, therefore their experiences may not be generalizable to all PLWHA in the NYC and TC region and to other parts of the country. Future evaluations would greatly benefit from the inclusion of a greater number of consumers and including consumers who are younger and more recently diagnosed.
VI. Conclusions and recommendations

Strong consumer-provider relationships were at the heart of consumer stories of becoming mentally and physically healthy individuals living with HIV/AIDS. Such relationships often lasted many years, and consisted of an exchange that was respectful, empathetic, and trusting. Consumers came to trust providers that took the time to educate them on HIV infection and its management, and who also treated them in a holistic manner as individuals deserving the best of care before viewing them as individuals living with an illness. Such education helped many consumers to become partners in the process of maintaining their health, and empowered many to go do HIV advocacy work on behalf of PLWHA. It also enabled them to be more supportive of other consumers in the sense that they not only provided emotional support but were also a resource on how to take care of oneself when living with HIV. For a number of consumers this produced a positive feedback loop, where helping other consumers then motivated them to take better care of themselves, to be an example to others.

The themes of mental health and family and peer support came up frequently when discussing what impacted their engagement in HIV care and adherence to HIV medications. This was somewhat surprising given that mental health, family, and peers were not the focus of this evaluation. This finding speaks to the considerable importance of these three factors on the lives of these PLWHA. We believe that a more holistic approach, consisting of improving consumer-providers relationships, addressing mental health, and facilitating the support that family and peers can give, has the potential to improve the proportion of consumers who are virally suppressed and healthy overall in the NYC and TC region.

Although the fundamental importance of client-centered care is now a well-established pillar of what is considered quality health care in the US, a continuous quality improvement approach aiming to achieve what the Institute of Medicine defined as patient-centered care, as “respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions,”¹ is warranted. Quality care has long been measured through the use of satisfaction surveys, and while this practice continues to be used widely, utilizing this method alone has been discredited in recent years. (AIDS Institute Measuring Patient Experience Brief, unpublished) This evaluation went beyond merely assessing quality through a satisfaction survey. It utilized the inherent wisdom of experience of consumers that already work hand in hand with NYC and TC HIV organizations and planning bodies. They articulated eloquently what helps them and what hinders them from remaining engaged in HIV care and adherent to HIV medications from the time they were diagnosed until the present. We hope that this report will be taken seriously and will be utilized to provide higher-quality, client-centered HIV care to the many PLWHA consumers who are not consistently receiving such care. Below we make a number of recommendations that emerged from evaluation findings.
## Recommendations

<table>
<thead>
<tr>
<th>#</th>
<th>Domain</th>
<th>Sub-Topic</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Provider</td>
<td>Diagnosis visits</td>
<td>It is very important for providers to manage diagnosis visits in a manner that is empathetic, taking the time to both support the consumer emotionally as well as to begin educating them on HIV because these first visits may impact whether and how soon they engage with HIV care.</td>
</tr>
<tr>
<td>2</td>
<td>Holistic provider</td>
<td>communication</td>
<td>Providers serve a vital role in the team of individuals who encourage consumers to maintain good health. Taking the time to talk to consumers about their mental health, personal lives, knowledge of HIV care topics, comorbidities, and showing them that you care about how they are doing in a holistic manner impacts if they perceive themselves to have a supportive provider that they want to return to for ongoing HIV care. Such relationships help to foster trust, a will to survive, and a positive outlook towards health care within consumers.</td>
</tr>
<tr>
<td>3</td>
<td>Comorbidities and</td>
<td>continuity of care</td>
<td>Consumers are often struggling with a number of comorbidities, even when they have their HIV under control. Better integration of care across health and social services providers could reduce the need for consumers to see many different providers for different health issues or to manage HIV at the expense of comorbidities. Additionally, plans should be in place to provide continuous care when providers leave a practice or when consumers transition between providers.</td>
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<tr>
<td>4</td>
<td>Mental health and substance use</td>
<td>Mental health illness and substance use addiction</td>
<td>Consumers with mental health illness or substance use addictions appear to be especially vulnerable to falling out of HIV care and may require more intensive support and services. Addressing mental health and substance use has the potential to lead to more timely linkage to care, to encourage consumers to remain engaged in care or to return if out of care, and it facilitates medication adherence. Mental health illness and addiction professionals should be knowledgeable about HIV care issues.</td>
</tr>
<tr>
<td>5</td>
<td>Expanded mental health support for all consumers</td>
<td>Mental health support needs to be expanded beyond just care for those with mental illness. Mental health, whether diagnosed as an illness or not, is an especially critical component of care and should be explicitly addressed at the time of diagnosis and at HIV care visits as part of a broader “mental health universal precautions” approach.</td>
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<tr>
<td>6</td>
<td>Family and peers</td>
<td>Family and peer support</td>
<td>Family and peer support are important to many consumers and thus supporting consumers in accessing these forms of support may aid providers in the work they themselves do to retain consumers in HIV care and help with consumers’ physical and emotional well-being. Family was shown to be especially important for emotional support and treatment adherence, while peer support was especially important for emotional support and education on HIV.</td>
</tr>
<tr>
<td>7</td>
<td>Stigma and disclosure</td>
<td>Most consumers had supportive family members and friends, although there were some that faced stigma and discrimination. Some participants did not disclose their HIV infection to their family initially due to fears of stigma. Enhancing consumers’ self-efficacy around disclosure has the potential to improve the physical and mental health of consumers. It enables another layer of</td>
<td></td>
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<tr>
<td>8</td>
<td>Consumer empowerment and engagement</td>
<td>HIV education and self-advocacy</td>
<td>Support that is additional to what providers can offer as family members and peers may spend much more time with consumers than providers do. Education on HIV and meaningful involvement in HIV advocacy work fostered a sense of empowerment and a feeling of pride in consumers. It helped them develop a desire to take care of their own health as well as the health of others living with HIV/AIDS. Providers should not only educate their clients on HIV, but also proactively connect them with support groups and HIV advocacy organizations.</td>
</tr>
<tr>
<td>9</td>
<td>Consumer-centered QI</td>
<td>Involve consumers in substantive and meaningful ways into quality improvement initiatives. Client satisfaction surveys or providers telling their versions of consumer experiences may not be sufficient to truly make HIV services client-centered. Consumer involvement has the potential benefit of making quality improvement activities more effective and also may further empower consumers.</td>
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</tbody>
</table>
VII. References


Appendix A: Anonymous survey of QI discussion participant characteristics

Please complete the questions below before the discussion begins and return the form to Darryl Wong. This is voluntary. You do not need to complete these questions if you do not feel comfortable doing so.

1. What is your age? ____________
2. What is your gender?
   a. Male
   b. Female
   c. Transgender, male to female
   d. Transgender, female to male
3. What is your race/ethnicity?
   a. Black/African American
   b. Latino/Hispanic
   c. White
   d. Asian/Pacific Islander
   e. Other ____________
4. What is your sexual orientation?
   a. Heterosexual
   b. Homosexual/Gay
   c. Queer/Questioning
   d. Other ____________
5. Do you live in New York City?
   a. Yes. I live in ____________ borough
   b. No, I live in ____________ County
6. What year were you diagnosed with HIV? ____________
7. Do you get your HIV health-related services from a provider in New York City?
   a. Yes
   b. No. I get my HIV services from ____________ County
8. What year did you begin taking HIV medications (leave blank if you have never taken medication)? ____________
9. Are you currently taking HIV medications?
   a. Yes
   b. No
10. At any point since starting to take your HIV medications have you stopped?
    a. Yes, but it never lasted 6 or more months
    b. Yes, and at least once it lasted 6 or more months
    c. No
Appendix B: Participatory analysis meeting schedule and tips for analysis

Analysis Meeting Schedule

12-2  Small groups review their assigned transcript pages and put similar comments into categories and give these categories descriptive titles. Continue this process until group feels they have a more or less final set of categories/themes.

2-2:10 Break

2:10-3:20 Get back together as one big group. Each small group gets 10 minutes to present on their categories/themes and to take comments and questions from other groups.

3:20-4 Everyone discusses how this process worked and didn’t work and ways it could be improved.

Tips for QI analysis meeting (project these on a screen while small groups work)

- Keep the overall goal in mind- What makes for a positive consumer-provider relationship from the perspective of PLWHA?

- You can start by separating statements into positive or negative comments, or by theme such as mental health, substance use, etc.

- You’re looking for similar statements to put together and after doing that for a bit try coming up with a descriptive title for the group of statements- ex. feeling emotional distress following diagnoses (descriptive) vs. mental health (not descriptive).

- You can always rearrange things or retile things later, so it doesn’t have to be perfect, you’re in brainstorming mode.

- Try to think from the perspective of the group of statements and not just your individual experience; you want the data to speak for itself and to represent the group.

- A statement doesn’t have to be common to be important. You are looking for common experiences, but also exceptions that you feel are important to represent as well.

- Since this is not a survey, you can’t attach numbers to the statements, ex. “50% of participants said X.” If an experience or feeling is common you can say things like “some”, “many”, etc. Can also say “A few participants said X.” Just because something is not expressed in the focus group, I would not point out that no one said it because that in fact may be the experience of someone outside the focus group.
• Good to acknowledge strengths, limitations, and potential biases of this group and of your experiences. Such as “we had no one diagnosed in the last 5 years, therefore the viewpoints of recently diagnosed individuals are not represented, etc.”
Appendix C: Budget for evaluation project (approximate budget for 30 participants)

<table>
<thead>
<tr>
<th>Expense Description</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Preparatory/Planning Meetings</strong></td>
<td></td>
</tr>
<tr>
<td>(2 meetings/month x 4 months = 8 meetings)</td>
<td></td>
</tr>
<tr>
<td>Space rental ($200/meeting)</td>
<td>$1,600</td>
</tr>
<tr>
<td>Lunch ($150 for 10 planning members)</td>
<td>$1,200</td>
</tr>
<tr>
<td>Local transportation for participants</td>
<td>$440</td>
</tr>
<tr>
<td>(8 x 10 x $5.50/round trip Metrocard)</td>
<td></td>
</tr>
<tr>
<td><strong>SUBTOTAL</strong></td>
<td><strong>$3,240</strong></td>
</tr>
<tr>
<td><strong>Facilitated Discussions</strong> (4 hours each)</td>
<td></td>
</tr>
<tr>
<td>Lunch ($300/event) x 2</td>
<td>$600</td>
</tr>
<tr>
<td>Transportation NYC (15 x $5.50/round trip)</td>
<td>$85</td>
</tr>
<tr>
<td>Transportation Tri County (15 x $15/person)</td>
<td>$225</td>
</tr>
<tr>
<td>Facilitator (DOHMH staff)</td>
<td>$0</td>
</tr>
<tr>
<td>Transcription of facilitated discussions</td>
<td></td>
</tr>
<tr>
<td>@ $1,800/each – expedited delivery</td>
<td>$3,600</td>
</tr>
<tr>
<td><strong>SUBTOTAL</strong></td>
<td><strong>$4,510</strong></td>
</tr>
<tr>
<td><strong>Transcript Analysis</strong></td>
<td></td>
</tr>
<tr>
<td>Lunch ($300/event) x 2</td>
<td>$600</td>
</tr>
<tr>
<td>Transportation NYC (15 x $5.50/round trip)</td>
<td>$85</td>
</tr>
<tr>
<td>Transportation Tri County (15 x $15/person)</td>
<td>$225</td>
</tr>
<tr>
<td><strong>SUBTOTAL</strong></td>
<td><strong>$910</strong></td>
</tr>
<tr>
<td><strong>Miscellaneous Supplies</strong></td>
<td>$100</td>
</tr>
<tr>
<td><strong>PROJECT TOTAL</strong></td>
<td><strong>$8,760</strong></td>
</tr>
</tbody>
</table>

a The facilitator donated his time therefore the cost was $0. Had we paid a facilitator we estimate that it would have cost $100/hour for paid facilitation x 2 times = $800.

b Due to time constraints we used expedited delivery. If we had used normal delivery the cost of transcription would have been 50% less ($1,800 total).

c Total costs do not include the salary costs for three DOHMH staff who assisted with this project.