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# Learning as you go: building effective support groups for men living with HIV

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# Learning as you go: building effective support groups for men living with HIV

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An abstract of a thesis submitted to the Faculty of the Rollins School of Public Health of Emory University in partial fulfillment of the requirements for the degree of Master of Public Health in Global Health 2019

### Abstract

# Learning as you go: building effective support groups for men living with HIV By Christine Hooyman

# **Introduction:**

Social support is a critical component of treatment and care for people living with HIV. The Infectious Diseases Clinic at Emory University Hospital Midtown recently formed support groups for men living with HIV. This study seeks to explore how these support groups can better meet the needs of men living with HIV at the clinic.

# Methods:

This qualitative study consisted of 13 in-depth interviews with eight patients and five clinic staff, and covered topics including preferences for group format and demographics, perceived facilitators and barriers to participation and recommendations for improvement. Study participants were purposively sampled to represent key demographics at the clinic and included staff currently facilitating the men's support groups. Data were analyzed using thematic analysis to highlight themes within the data, working with MAXQDA 2018.2 software.

# **Results:**

Study participants identified four primary elements important for a support group: [1] an ability to relate to participants; [2] a sense of community; [3] a space where they could cope, and [4] a forum to openly exchange ideas, information and learn. Patients expressed preference for a support group format that allowed for patient-driven topic identification. Study participants determined six overarching facilitators and barriers to participating in a support group, which included personal readiness, food, transportation, scheduling, topics, and group members. Participants discussed how demographics affect group dynamics, with patients identifying socio-economic diversity as the most important characteristic to consider over ethnicity, age and sexual identity. However, participants opposed segmenting support groups on demographics beyond gender. Participants also established additional issues to assess when forming support groups, including dealing and coping with HIV, self-acceptance of HIV status, stigma and existing additional support sources for group members.

# **Conclusion:**

Study participants overwhelmingly agree that support groups at the clinic are a vital resource for men living with HIV. Providing avenues for patient ownership and iteratively collecting feedback from participants are important for the support group's success. Support groups provide critical spaces for men to receive empathy, exchange practical information and deal with HIV, contributing not only to their emotional wellbeing, but working towards sustaining a healthy life.

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Finally, and of greatest significance, to the patients at the clinic. For the male patients who participated in the study with open honesty and shared their experiences, perspectives and feedback with me: my intent is that we may hopefully continue to improve on the men's support group and services at the clinic to best meet your needs and priorities. I sincerely thank you for your willingness to participate and sharing part of your lives with me.

Introduction. Figure 1: The HIV Care Continuum	
Literature Review	6
Methods	
Introduction	
Study Site	
Population and Sample Table 1: Study inclusion criteria Table 2: Staff demographics Table 3: Patient demographics	
Procedures	
Instruments Table 4: Overview of in-depth interview guides	
Ethical considerations	15
Data analysis	15
Results	
Individual conceptualization of the role and purpose of a support group	17
Feedback on clinic-specific support group format	19
Support group facilitators and barriers	
Viewpoints on support group demographics	
Key concerns to consider when forming men's support groups Dealing with HIV Coping with HIV Then and now – learning and accepting one's status Stigma Support sources	
Summary	53
Discussion	
Quality improvement recommendations Table 5: Quality improvement recommendations for the clinic's support group	58 
Best practices to continue at the clinic Table 6: Best practices at clinic to note for continued implementation	
Strengths and limitations of study	61
Implications for public health practice Table 7: Future issues to explore with additional research	
Conclusion	63
References	
Appendix I – In-depth interview guides	

#### Introduction

It is estimated that 1.2 million people aged 13 and older in the United States currently live with HIV, representing approximately 3 percent of the global burden.<sup>1,2</sup> Across the United States, HIVrelated mortality rates peaked in the mid-90s and have since declined substantially, attributed to considerable advancements in treatment and care.<sup>3</sup> What once was seen as an inevitably fatal disease is now understood as both chronic and manageable. In recent years, new incident cases of HIV have generally stabilized in the United States, but certain key populations experience rising incidence rates, particularly intravenous drug users (IDUs) and men who have sex with men (MSM). Whereas new diagnoses amongst heterosexuals decreased by 35 percent between 2005 and 2013, diagnosis rates among MSM increased by 6 percent over that same time period.<sup>4</sup> Furthermore, men of color – particularly Black and Latino men – are disproportionately represented among new diagnoses within the MSM sub-group. A press release published by the Centers for Disease Control and Prevention (CDC) in 2016 anticipates that if current domestic HIV trends remain unchanged, approximately 1 in 2 Black MSM and 1 in 4 Latino MSM will be diagnosed with HIV in their lifetime.<sup>5</sup> Furthermore, the geographic distribution of HIV across the United States is heavily concentrated in the South. More than half of new HIV diagnoses in 2017 came from the South, with populations in Washington, D.C., Maryland, Georgia, Florida and Louisiana at the highest risk for a positive HIV diagnosis over their lifetime when compared with the rest of the United States.<sup>6</sup>

Currently, domestic-focused government spending for HIV is primarily funneled through mandatory federal funding, typically entitlement programs such as Medicaid and Medicare.<sup>7</sup> This accounts for approximately 62 percent of the total budget allocated to HIV (or \$19.7 billion) with the remaining 38 percent (\$12.3 billion) designated as discretionary funding and allocated by

Congress each fiscal year.<sup>7</sup> Included in this discretionary budget is the Health Resources & Services Administration (HRSA) Ryan White HIV/AIDS Program, the third largest source of the United States' federal funding towards HIV, behind only Medicare and Medicaid spending.<sup>7</sup> The Ryan White HIV/AIDS Program typically provides primary medical care and services to people living with HIV who are uninsured or underinsured.<sup>8</sup> President Trump's federal budget request for FY18 detailed a 10 percent reduction (\$794 million) in discretionary HIV funding but has yet to be enacted as Congress continues to operate on a Continuing Resolution.<sup>7,9,10</sup> The current FY19 budget allocates \$2.3 billion to the Ryan White HIV/AIDS Program, a marked \$43 million short of the FY18 Continuing Resolution budget, yet calls on the program "to continue to serve more than 50 percent of all people living with diagnosed HIV in the United States".<sup>10</sup> A 2016 report published by the CDC revealed that Georgia's rate of HIV diagnoses was the highest in the United States, at 31.8 per 100,000 people, with Atlanta claiming the fourth-highest HIV rate across the country.<sup>11,12</sup> The Southern HIV/AIDS Strategy Initiative estimates that nearly 22,000 people residing in Georgia utilized Ryan White funding for HIV treatment and prevention services in 2017.13 With Georgia electing to not expand Medicaid coverage across the state under the Affordable Care Act, programs like Ryan White become increasingly important in providing services across the HIV care continuum.



Figure 1: The HIV Care Continuum<sup>14</sup>

Deserving of further analysis, however, is what quality service across the HIV care continuum might look like.<sup>15</sup> The HIV care continuum models a progression of steps following a positive HIV diagnosis which culminates in achieving viral suppression, the end goal for those living with HIV. A key linkage in this process includes engagement and retention in care, where the former entails prompt enrollment in medical care following a positive diagnosis and the latter reflects medical visits in line with established standard of care recommendations. Data from Georgia's Department of Health in 2016 revealed that 64 percent of people living with HIV had received any care, defined as at least 1 medical visit in a year; 49 percent of people were retained in care; and 51 percent were virally suppressed.<sup>16</sup> Engagement and care retention must keep in balance multiple elements, including patient priorities, accessibility, equity and quality. Social support – one component of treatment and care – may work to address these elements via support groups, which are positively associated with retention in care for people living with HIV.<sup>15</sup> This study examined a new initiative at Emory University Midtown's Infectious Diseases Clinic, surrounding the formation of support groups for men living with HIV.

Emory University's Infectious Diseases Clinic is a large provider of HIV services for people living in the Atlanta metropolitan area. It currently serves over 2,000 people living with HIV, providing comprehensive care. The majority of the clinic's patients are Black men, many of whom identify as MSM. The clinic offers multiple support services for patients living with HIV, including case management, a cooking class, and a support group for females. However, while a large percentage of patients seen by the clinic are males living with HIV, a support group for men did not exist until 2018. The staff acknowledged this gap in services and identified two staff willing to facilitate support groups for men. The clinic's Community Advisory Board (CAB) also voiced the need for men's support groups at the clinic. CABs are a mandated requirement for recipients of Ryan White funding and intend to serve as a feedback mechanism that convenes staff and patients to guide services and care provided.

Initially, in May of 2018, the clinic hosted two separate groups. One was facilitated by a social worker and followed a "typical" support group format wherein the topics were driven by the patients. The second was facilitated by a mental health clinician and followed a skills-based format centered in dialectical behavioral therapy. This approach entailed four modules: mindfulness, emotional regulation, distress tolerance and interpersonal effectiveness.<sup>17</sup> The clinic's social workers primarily led patient recruitment for the support groups, informing the patients about the groups during scheduled appointments. Patients enrolled in therapy with a mental health clinician were also informed about the support groups during their scheduled appointments. These support groups were open to any self-identified male living with HIV currently receiving care at the clinic. Beyond that, group members were not further segmented. Each group met once a month, with separate dates and times to allow patients the opportunity to attend both groups. However, both groups experienced inconsistent attendance and buy-in from the patients. Thus, this study aims to explore perceptions and collect feedback about the newly formed men's support groups. Ultimately, the data collected seeks to provide quality improvement recommendations to better meet the needs and priorities of men living with HIV at the clinic, and thus, increase buy-in for the men's support group. Several months into data collection for the study, the support group and skills-based group merged into one support group, which combined elements from their distinct versions.

The foundational research question guiding this study is: How can the Emory Ryan White Program men's support groups best meet the needs of HIV-positive patients at the clinic? By collecting

viewpoints from patients and staff alike, I hoped to gain insight into potential gaps, barriers, strengths and assets that could work to improve the men's support groups provided at the clinic. If the clinic could bolster this source of support for men living with HIV, perhaps this might positively contribute to their engagement in care, a crucial step to achieve viral suppression.

### **Literature Review**

The factors affecting the high HIV rates among men who have sex with men (MSM) across the Unites States are contested, particularly when attempting to explain discrepancies across geographies and sub-populations. Research conducted to explore rates of new HIV infections in the United States often focuses on key populations, particularly MSM, normally coupled with a race lens during analysis. In states like Georgia, males represented 79 percent of all new HIV diagnoses in 2016, 83 percent of which were attributed to male-to-male sexual contact. Black individuals – inclusive of all genders – represented 71 percent of all new diagnoses.<sup>18</sup> However, conflicting studies make it difficult to draw conclusions about why MSM are disproportionately affected by HIV. In a meta-analysis and critical literature review of HIV infection and risk amongst Black MSM (BMSM), Millet et al. present twelve common and recurring hypotheses, labeling each hypothesis as either not supported by scientific evidence, supported by scientific evidence or having insufficient or conflicting evidence.<sup>19</sup> Many behavioral-based hypotheses were discredited, such as claims that BMSM are more likely to engage in high-risk sexual behavior or abuse substances, increasing their risk for HIV acquisition. Millet et al. found inconclusive data surrounding the extent to which structural factors, such as healthcare access, may affect HIV infection rates.<sup>19</sup> Another study found that health insurance status and a partner's race explained racial disparities amongst Black and white men surrounding HIV incidence, ultimately calling for a further exploration of structural factors and moving away from individual risk behaviors.<sup>20</sup> Studies also assessed effective treatment and care amongst men living with HIV. Like studies on HIV incidence, proper treatment and care for those living with HIV must move beyond individual behaviors and address the broader structures that influence how people experience, cope, and live with HIV.<sup>21</sup>

Perhaps then, an intersectional approach is better suited for HIV research in the United States in regard to BMSM, who often oscillate between competing identities, afforded different levels of privilege associated with their race, gender and sexual identity. Buseh et al. state that BMSM must contend with a triple jeopardy of racial prejudice, HIV stigma and homophobia, which interact to affect treatment and care.<sup>22</sup> Racism and hierarchy within the gay community is well established in research literature, favoring white men in both subtle and overt ways.<sup>23,24</sup> Research on sexual networks have reinforced problematic beliefs that associate BMSM with high HIV prevalence and thus, greater risk as potential sexual partners, reinforcing stigma that BMSM experience.<sup>20</sup> Further, BMSM may feel pressure to assimilate within a white-dominated gay community and suppress elements of their identity and lived experience to feel part of the in-group.<sup>25</sup>

Also mentioned is the persistent tension that many BMSM experience between their Black and gay identities.<sup>19</sup> The Black church, a source of social support and brief respite from the racism Black Americans experience, is also described as a place that fosters homophobia and homonegativity, a form of internalized stigma.<sup>26,27</sup> Wilson et al. go so far as to argue that the Black church is "perhaps the greatest stigmatizing force with regard to BMSM's sexual behaviors and identities," highlighting the social power and influence of the Black church amongst Black Americans.<sup>28</sup> In response to race-based disparities with HIV, education and prevention efforts began to appear within the Black church community in the late 1990s, but these often failed to acknowledge the sexuality and experiences of MSM.<sup>29</sup>

While there is a breadth of quantitative data surrounding BMSM and HIV in the United States, there is noticeably less qualitative data to provide context and nuance to the experiences of BMSM living with HIV in relation to the care they receive. In one qualitative study exploring the experiences of BMSM living with HIV, Han et al. noted a recurrent theme of challenges resulting from a lack of information and understanding about being HIV positive.<sup>23</sup> These challenges range from individual-level perceptions and misinformation about HIV to broader problems that arise from misrepresentation of HIV by the media, including the tendency to minimize the hardships that many people living with HIV still experience despite advances in medical treatment. Their findings highlight gaps that may be addressed at various societal levels, but certainly provide an avenue for clinical care to better meet the needs of BMSM living with HIV. Han et al. remark the prioritization of biomedical needs, such as prevention and medical adherence, often leads to the broader dynamism of life for individuals who are HIV positive being overlooked.<sup>23</sup> Using intersectionality as a theoretical underpinning of how to provide HIV services enables us to redefine treatment and care beyond biomedical interventions alone and also acknowledge the intersecting, shifting – and often competing – identities that people living with HIV experience.<sup>24</sup>

Support groups create an avenue to provide care and support to people living with HIV. Indeed, social support has been linked to positive outcomes associated with retention and treatment for people living with HIV.<sup>30</sup> A support group can be understood as a type of safe space, where information-sharing, guidance and practical skills are shared. Garcia et al. define a safe space as having three primary components: to [1] promote empowerment and community mobilization against stigma and discrimination; [2] enable human development via skill-building opportunities; [3] promote supportive social norms and peer networks that are culturally relevant.<sup>27</sup> Ultimately, support groups work to build resilience amongst their members, equipping people with strategies, skills and knowledge to manage and address experienced adversity in their lives. While the protective role of groups as supportive safe spaces for men living with HIV is routinely mentioned in the literature, few studies have explored what the actualization of a successful support group

might look like. Hays et al. delineate three primary categories of social support provided to MSM: emotional, informational, and practical. These interact to provide holistic support for MSM living with HIV.<sup>31</sup> Structural issues and disenfranchisement experienced by many BMSM are readily mentioned but seldom unpacked, with little to offer beyond an appeal for programming that's responsive, inclusive, and effective. These studies routinely close with a call for effective social support and mental healthcare provision for BMSM without actionable steps or best practices. Further, while BMSM are clearly a prioritized sub-group amongst current HIV research efforts, there is a lack of data about BMSM preferences for the delivery of support groups and insufficient data demonstrating that organizing support groups by these demographics is effective or leads to greater impact for these men.<sup>22,25</sup> In fact, this approach seems to contradict studies that present BMSM as a heterogeneous group, rather than a monolithic entity to which a singular intervention strategy might apply.<sup>19,21,28</sup>

Thus, this study builds on the acknowledgement that support for people living with HIV is a critical component for care retention and seeks to explore what effective clinic-based support strategies might look like for male patients. Social relationships are a key component of building resilience and present layered benefits of providing support to people living with HIV, which is positively associated with service retention.<sup>32</sup> There is a need to explore and better define "the types of support that are most effective in buffering HIV-related stresses" so that we can best meet the needs of people living with HIV.<sup>31</sup> The priorities and needs of people living with HIV are dynamic, thus, the types of support provided must be flexible and nimble in response. As the Ryan White HIV/AIDS Program at Emory Midtown's Infectious Diseases Clinic has a diverse patient population, I intend to use an intersectional framework to address how the clinic's men's support groups can best meet patient needs.

#### Methods

#### Introduction

The purpose of this study is to examine perspectives of and preferences for the support groups for men living with HIV at Emory University Hospital Midtown's Infectious Diseases Clinic. The overarching research question for this study is: How can the Emory Ryan White Program men's support groups best meet the needs of HIV-positive patients at the clinic? To best capture the unique perspectives of patients and staff, I conducted qualitative in-depth interviews with these two population groups. The data collected and analyzed in this paper will ultimately result in quality improvement recommendations presented to the clinic and CAB for further discussion and evaluation with the aim of generating actionable adjustments.

#### Study Site

The Infectious Diseases Clinic at Emory University Hospital Midtown was the sole study site. Emory University Hospital Midtown is located in the Midtown neighborhood of Atlanta, Georgia. In collaboration with my advisors, I selected this site initially due to Dr. Ameeta Kalokhe's role as the Ryan White Program Medical Director at the Infectious Diseases Clinic. She served as a critical gatekeeper and with her buy-in, I had an entryway to conduct the study.

Additionally, the Infectious Diseases Clinic is a prominent provider of HIV care for residents of Atlanta. With federal funding through the Ryan White Program, Medicare, Medicaid and the Affordable Care Act, the Infectious Diseases Clinic at Emory University Hospital Midtown is able to provide a range of services for its patients, including those with a lower socio-economic status. Approximately 54 percent of patients living with HIV at the clinic are recipients of Ryan White funding. The clinic currently receives Ryan White Part A and C funding. Atlanta is eligible for Part A funding, as a city identified as most severely impacted by HIV. Part A eligibility requires

an income at or below 400 percent of the Federal Poverty Level with no additional payer source

for HIV-related healthcare.8 Part C funding eligibility occurs at an individual agency level and

does not have specific income requirements but aims to also support low-income un- and under-

insured patients.

### Population and Sample

The study had two target populations: current patients at the Infectious Diseases Clinic and current

staff at the Infectious Diseases Clinic. Inclusion criteria for these two populations are detailed in

the table below.

Table 1: Study inclusion criteria

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INCLUS	ION CRITERIA FOR STUDY PARTICIPATION
Staff	• Current employee at Emory University Midtown Hospital, Infectious Diseases Clinic
	• Role and responsibilities must include work with the Ryan White Program, which may include patients funded via the Ryan White Program
Patients	• Self-identify as male
	• Currently living with a positive HIV diagnosis
	Currently enrolled in the Ryan White Program
	• Eligible for participation in the clinic's men's support group (open to all males
	living with HIV)

I selected these populations to represent two crucial groups at the clinic: patients and providers. Both these groups are key to implementing a support group at the clinic. Therefore, it was important to collect data from these two groups in order to capture their perspectives. Within each group, I employed purposive sampling techniques to gather data from a variety of individuals.

For the staff interviews, I deliberately sought out individuals who were well connected to patients and/or directly involved with the support groups. I was also interested in diversity of tenure at the clinic, as I thought this might generate useful information. I interviewed five staff, including the two current facilitators of the men's support group and three staff involved with social work at the clinic. These staff all had frequent contact with patients on a daily basis and held positions that required them to interact with staff in other departments across the clinic. Staff interviewed ranged from relatively new hires who had worked at the clinic for less than a year to staff who had been with the clinic for a decade.

I conducted eight patient interviews. The majority of patients seen at the clinic identify as Black MSM, thus I sought a sample reflective of the clinic population which enabled my application of intersectionality theory to examine how to enhance the effectiveness of the support groups for men. I also purposively sought out members of the CAB, generally seen as adherent, engaged patients, who help drive the direction of the clinic. I interviewed three current members of the CAB and one former member. I also interviewed a newly diagnosed patient, as well as patients defined as less engaged, all of whom were referred to me by staff. I further selected patients who represented socio-economic diversity, in an attempt to mirror the types of patients seen at the clinic. Lastly, I sought out patients who had previously attended or were currently attending the men's support group at the clinic to understand their motivators, facilitators and barriers to participating, while also collecting concrete feedback on their experience with the clinic's support group. Detailed demographics of both staff and patients interviewed are displayed in the tables below.

DEMOGRAPHICS OF STAFF INTERVIEWED				
Staff Number	Gender*	Ethnicity*	New hire (< 2 years)	Current men's support group involvement <sup>†</sup>
1	Female	Black	Yes	No
2	Male	Black	Yes	No
3	Male	Non-white	No	Yes
4	Male	Black	Yes	Yes
5	Female	White	No	No

### Table 2: Staff demographics

<sup>\*</sup> Self-reported in the interview or recorded by the interviewer

<sup>&</sup>lt;sup>†</sup> Refers to the men's support group at the Infectious Diseases clinic

DEMOGRAPHICS OF PATIENTS INTERVIEWED					
Patient	Ethnicity*	Sexual	Recently	Age	Participate(d) in
Number		identity <sup>‡</sup>	diagnosed	(< 50 years) <sup>‡</sup>	men's support
			$(< 2 \text{ years})^{\ddagger}$		group <sup>†,‡</sup>
1	Black	Heterosexual	Yes	No	No
2	Black	Homosexual	No	No	No
3	Black	Homosexual	No	Yes	No
4	Black	Homosexual	No	Yes	No
5	White	Homosexual	No	Yes	Yes
6	White	N/A	No	Yes	No
7	Black	Homosexual	No	Yes	No
8	Black	Homosexual	No	No	Yes

*Table 3: Patient demographics* 

### Procedures

I utilized purposive sampling techniques to recruit study participants but deployed different strategies for the two population groups in the study. For staff, I initially attended several all-staff meetings, to introduce myself and promote the study. Dr. Kalokhe also introduced me to several key staff at the clinic to help build rapport and further explain the study's purpose. I sent emails to the clinic team, which led to the recruitment of two study participants. I purposively sampled the remaining three, which included the current men's support group facilitators and a well-established social worker at the clinic. For patients, I created informational flyers that we hung inside patient rooms at the clinic. I gave social workers informational flyers about the study, along with an initial consent form which allowed me to contact patients interested in participating. Social workers assisted with purposively selecting patients to refer into the study, including members of the CAB, individuals they believed would benefit from the men's support group, and previous participants of the men's support group.

I conducted all the study interviews on site, at Emory University Hospital Midtown, between

<sup>‡</sup> Self-reported

October 2018 and February 2019. Interviews either occurred in private conference rooms at the hospital or inside private offices within the Infectious Diseases Clinic. Interviews lasted approximately one hour, including the consent process prior to the start of the interviews, and were audio-recorded. All participants received a small monetary incentive (\$15) as part of their participation in the study.

#### Instruments

I conducted an initial literature review to inform the development of the in-depth interview guides. I developed two separate guides, one for each population group. While several topics overlapped, such as needs and priorities for a support group, some topics were only asked of one group. For example, I prompted patient study participants to talk about current sources of support in their lives but did not ask this of staff study participants. I reviewed the draft in-depth interview guides with key clinic staff members, including Dr. Kalokhe, the head of the social work department, and the two facilitators of the men's support groups. Their feedback enabled me to further refine the guides. The final iterations of both guides contained 15 questions with three primary sub-topics. The in-depth interview guides were intended to guide a conversation for approximately one hour. An outline of each guide can be found in the table below, with the complete guides attached as appendices at the end of this thesis.

SUMMARY OF IN-DEPTH INTERVIEW GUIDE TOPICS			
Shared topics	Patient-specific topics	Staff-specific topics	
<ul> <li>Characteristics of an ideal support group</li> <li>Needs and priorities for the men's support group</li> <li>Obstacles and barriers for the men's support group</li> </ul>	<ul> <li>Personal benefits of participating in a support group</li> <li>Sources of support since learning about positive HIV diagnosis</li> <li>Experienced stigma related to HIV status</li> </ul>	<ul> <li>Strategies to increase awareness of men's support group</li> <li>Staff interest in the men's support group</li> </ul>	

Table 4: Overview of in-depth interview guides

### Ethical considerations

While this study (IRB00105296) is human subjects research, it received an exemption from the Emory University Institutional Review Board on August 22, 2018. I conducted all data collection, transcription and analysis. While interviews were recorded, all transcriptions were de-identified prior to analysis.

Prior to each interview, I completed a consent process with each participant. I reviewed the purpose of the study and explained what their participation entailed. Participants had an opportunity to ask questions, as well. Each study participant completed consent paperwork reviewed and approved by IRB and gave oral consent to having the interview recorded. At the close of each interview, participants were again given an opportunity to ask any questions. In addition to the monetary participation incentive, each participant received contact information with my information, as well as contact details for Emory's IRB.

#### Data analysis

Following data collection, I transcribed all interviews and imported the data into MaxQDA 2018.2, a qualitative data analysis software. I conducted data analysis using a thematic analysis approach, which Braun and Clarke define as "a method for identifying, analyzing and reporting patterns (themes) within the data".<sup>33</sup> I developed codes via both inductive and deductive processes, drawing from recurrent concepts in the data and questions and topics from the interview guide. I employed open coding to map out emerging elements and sort these into categories. Initially, I created a provisional codebook to highlight all codes and define when codes should be utilized. After coding a subset of the data, I reviewed the codebook, modifying both codes and definitions as necessary, utilizing axial coding to further assess and analyze the data, to clarify and reconceptualize codes and the relationships between categories and sub-categories.<sup>34</sup> Thus, coding was an iterative process, and I routinely returned to the data to fine-tune the codebook. After completing coding, I

reviewed the themes, developing descriptions and concepts for each theme, and exploring patterns both within and across the themes. I reviewed each code to develop a thick description, which encapsulates four key components: breadth, depth, context and nuance. Breadth reveals the variation, depth demonstrates the detail, context shows the meaning and nuance depicts distinction within a theme.<sup>35</sup> After developing thick descriptions for the primary themes that emerged from the data, I completed a final analysis, which appears in the Results section of this thesis.

#### Results

The results presented below are organized by key themes: individual conceptualization of the role and purpose of a support group, feedback on the clinic-specific support group format, support group facilitators and barriers, views on support group demographics and key concerns to consider when forming men's support groups.

### Individual conceptualization of the role and purpose of a support group

I opened the interview with asking participants to define a support group to better understand their conceptualization of support groups and assess alignment with current implementation. Several patients (5 of 8) had previously participated in a support group, which they all mentioned when prompted to conceptualize a support group. The data within this deductive code highlighted overlap between all patients interviewed and how they understood the role of a support group, with a demonstrated consistency of responses between participants. The majority of patients interviewed (7 of 8) mentioned a shared interest or characteristic as a central feature to justify creating a support group. A shared interest amongst members was described as leading to four components important for a support group identified by the study participants: [1] an ability to relate to participants; [2] the creation of a sense of community; [3] a place understood as a coping mechanism; [4] a forum to openly exchange ideas, information and learn.

Patient: "...you're in a space where you're not judged...no one points fingers at you, regardless of whatever your lifestyle is or how you look at yourself...how I look at myself...I'm the type of person when it comes to a support group and we're in our setting...I don't like to see people point fingers at the next person. Because my thing is this, we all have something in common."

Patients believed sharing their experiences and relating to their peers would be validating. Relating to group members would build community, acknowledging everyone was participating in the

support group to seek help. Several participants (3 of 8) discussed that trust would develop once a sense of community was established, particularly important for support groups based around a stigmatizing issue, such as a positive HIV diagnosis.

The vast majority of patients interviewed (7 of 8) saw support groups as a coping mechanism, a place where they could deal with adversities in their own lives. Several patients (3 of 8) who had ever participated in a support group before mentioned that meeting with regularity provided a routine structure they could rely on, which enabled a support group to become an effective coping mechanism.

All patients interviewed also saw value in support groups and the feedback received from members as being educational, informative, and skills-building. Men provided examples of learning from a support group in both abstract and specific ways. The first quote below speaks to the generalized learning gained from participating in a support group, while the second quote provides a particular example of an educational exchange.

> Patient: "We meet every Wednesday. And I would say...the next seven days...what you've learned in the room, or what you've heard in this room, you take what is best for you. I take what is best for me. And what I hear. And then when I take those things that I hear I can adhere to for me...then I go back out. And I practice those things. And when a situation comes up and the lightbulb goes off in my head...it's like, 'okay, I learned that in group. Okay, here's another tool.'"

> Patient: "...because I remember one discussion, one discussion which was really interesting to me...it was a discussion about preparing for sex. And...um...there were a few young guys in the group and the older guys were talking about...the process. And these younger people were like, 'hell, I didn't know that'. You know, and it was interesting how they just kinda sat back and listened and then, you know, we started asking them, 'What do you do? How

do you approach it?' And it was just kind of fascinating that they had no idea. Um. But, it became a teaching situation for everybody."

### Feedback on clinic-specific support group format

Both patient and staff participants shared their perspectives and feedback regarding the existing men's support groups at the clinic. As mentioned earlier, when the study initially began, the clinic had two active men's support groups: a support group where the topics were patient-driven with a less structured format and a skills-based support group, which employed dialectical behavior therapy (DBT). Following initial low turnout, the two facilitators decided to merge these separate groups into one support group, now called the men's support group.<sup>§</sup> Thus, the data collected for this study cover the period when the clinic had two men's support group and one consolidated support group.

Participants who had yet to participate in a men's support group at the clinic, either as a facilitator or patient, overwhelmingly spoke in favor of a topics-driven support group. In earlier interviews conducted before the groups merged, participants spoke interchangeably about the topics-driven support group and a support group. In other words, they understood a support group as aligning with the topics-driven support group, and not necessarily the skills-based support group. Feedback from all patients echoed their earlier descriptions and definitions of a generalized support group as a place where they could be understood, receive guidance from their peers and feel a sense of community. Staff also recognized the potential benefits this type of support group could offer their patients.

<sup>&</sup>lt;sup>§</sup> For clarity, the patient-driven support group will be referred to as the topics-driven support group. The DBT skillsbased support group will be referred to as the skills-based support group. The merged support group will be referred to as the men's support group.

# Patient: "...and until you've been in our shoes and walked our path, you will absolutely have no idea. So the patient-oriented group [i.e. topics-driven support group], that would be excellent."

When prompted to discuss the skills-based groups, participants seemed less enthusiastic. Perhaps a general confusion or lack of clarity on what a skills-based group entailed contributed to the lack of enthusiasm. The majority of patients interviewed (6 of 8) either asked me to further explain what was meant by a skills-based group or assumed the skills referred to technical or career-based skills, such as how to address an envelope or properly write a formal letter. The staff facilitator of the skills-based group explained initial patient feedback regarding this group aligned with the reactions of patient study participants. People were unclear on what skills might be taught and how a skills-based support group might function. One staff elaborated that a skills-based group would not be as beneficial to patients as a topics-driven support group, while another staff contested that a skills-based group, as envisioned by its facilitator, intended to teach life skills via role playing, covering topics like conflicts with partners or disclosing one's HIV status to a family member. Overall, the lack of clear understanding of a skills-based support group's purpose and format led to less enthusiastic buy-in and feedback from patients interviewed.

Staff: "you wanna give people the opportunity to share what's going on with them. Skills building groups are important too. ... But I'm just not for sure...how important, or if it's anywhere as near as important as a group that allows them the opportunity to talk."

The merged support group – the men's support group in its current iteration – received positive feedback from patients and staff alike. The men's support group is co-facilitated by a social worker and mental health clinician. While the group primarily functions to be responsive to patients and

is driven by their discussions, the mental health clinician inserts DBT skills when appropriate. The two support group facilitators especially saw these two approaches as working hand-in-hand, creating a space where people could receive empathy, advice and skills. Both patients and staff appreciated how the current group is patient-driven and intentional about incorporating patient ownership into the group. For example, during each meeting, the primary topic for the upcoming meeting is decided by the patients, who propose certain topics and then vote, with the most popular topic chosen as the theme for the next meeting.

One aspect that several participants (3 of 8) mentioned included expanding the role of the support group beyond the confines of the clinic. These men hoped to build relationships with fellow participants that could integrate more with their daily lives. That way, following a particularly difficult day, men could receive direct support rather than waiting until the next support group meeting. One patient also expressed interest in playing a mentorship role for other support group participants, remarking that he gets satisfaction knowing he can help another. A staff facilitator mentioned that current support group members were planning a social event independent of the support group. He took a hands-off approach, wary that the men might violate a participation stipulation which forbids sexual contact between group members. This also highlights a repeated tension between priorities of patients and staff perceptions of the social activities as potentially violating strict HIPAA<sup>\*\*</sup> and Emory regulations. Regardless, these perspectives reveal that patients were interested in creating new sources of support in their lives, and the clinic's support group might help to foster those relationships.

<sup>\*\*</sup> The Health Insurance Portability and Accountability Act of 1996, federal legislation concerning medical data privacy and security.

Patient: "Maybe have a support group where people communicate, like I said, like a buddy thing or, maybe the group could lead into a buddy connection where you have such-and-such, you know, if anything, this is somebody you can also count on. This is who you can call if you're going through this or something or whatever the case may be."

The staff interviewed often shared their perspectives with practicality at the forefront, while patients regularly saw this as an ancillary benefit in addition to receiving emotional support. For example, one staff believed men could share their experiences with various support services and aid organizations in Atlanta. If a participant was worried about paying rent and the reliability of a specific organization, perhaps other members could comment, adding perspectives unknown to the facilitators or staff themselves. One staff also discussed the precarious balance an ideal support group must seek – trying to avoid exchanges that became too personal or too deep. Such exchanges would be ideal for one-on-one therapy rather than a group setting. The staff voiced concern that a participant oversharing might disrupt the overall group and pressure other members not comfortable matching that level of vulnerability. These points of divergence between patients and staff reveal places where expectations were often misaligned.

Staff: "I mean, groups are a challenge. Um. And, and I think a lot of times people, you know, well at least when they're working with me, and they've never been in a group, they think it's a therapy group, but it's not a therapy group, right? And I try to make that distinction with them...we're not gonna dive deep into your thoughts and your emotions and be vulnerable there in front of eight other people. That's not the goal. And as the facilitator, that's something that I, that I look for in the group, right?"

### Support group facilitators and barriers

I asked all study participants what might motivate or facilitate men to attend the clinic's support group, alongside what some obstacles or barriers might be. While the interview guide prompted participants to answer these questions, their responses and the themes that emerged as a result are inductive. All responses fell under one of six sub-themes: [1] personal readiness, [2] food, [3] transportation, [4] scheduling, [5] topics, and [6] group members. Each theme is discussed in more detail below.

#### Personal readiness

Personal readiness referred to a participant's individual commitment to attend and participate in the men's support group. Personal readiness manifested in many ways, such as the prioritization to attend above other commitments. Personal readiness was also understood through certain types of attitudes, such as a willingness to be receptive or open. Furthermore, study participants believed a desire for community might drive a participant's personal readiness. Underlying this theme was the belief that participants must want to participate themselves – and it should not and cannot be forced upon them.

Patient: "They might not be serious about attending the group. If you're serious about something, you will do everything in your power to make it happen. It's just important, you know, you have to have that mindset you know."

A couple participants mentioned their will to live after being diagnosed with HIV as a driver to participate in the men's support group. They were on board with anything and everything the clinic recommended as being beneficial to them and contributing to a long and healthy life. One patient remarked that both receiving and giving support via a support group helped him remain sober, something he was keenly dedicated to. Both patients and staff interviewed discussed a patient must first admit help is needed before they can be in a position to receive any assistance. For some, this may require a buildup of events that become unmanageable, which leads to a self-realization that things must change. One staff remarked that patients must not only accept but embrace their reality of being a person living with HIV to truly be receptive. Similar to receiveness, one staff described

openness as a willingness to be vulnerable, especially amongst other men. Thus, openness was birthed from self-confidence, comfort and acceptance of one's diagnosis. Attending the support group required the man to be ready to accept and share his status not only internally, but with other groups members as well, just by virtue of his attendance. One staff also discussed the progression of developing a sense of openness during one-on-one therapy, which might mature and transition to openness within a group setting.

Staff: "Because that also means that they're ready to …work, um, whatever issues they are having. And, um, and I think a lot of, specifically for this support group, it's …when you open the door, you are admitting to the fact that you have HIV. So, it's only for patients that are, you know, ready, ready to face the diagnosis and accept diagnosis and then move beyond and whatever they need to work on, because by default, they immediately know that everyone that I'm seeing here is HIV positive and I'm letting everyone here know that I'm also HIV positive. And, and some men…are just not, not ready for it. And we may have 20 different groups and if you're not, if you haven't accepted the HIV diagnosis yourself, the group is not going to help you."

Community was discussed in two primary ways. First, one patient believed it was valuable to feel connected to Emory, to the clinic and to keep abreast of current issues for men living with HIV. As a new resident of Atlanta, he saw the support group as a great avenue to achieve that sense of community. A handful of other patients thought they could build community at a support group via sharing their life experiences with others. As men who have lived with HIV for more than a decade, they were eager to share the lessons and skills they had developed thus far.

Patient: "And, you have to want it. You know, you can't push people into meetings, you know. You can't require them. Um. My hope is, that somebody attending their first meeting will walk away with a little less weight on their shoulders and that will be the incentive for them to come back. And then, a little less weight and maybe they'll be able to share a second time with somebody. And, uh...and, you know, there's just so much satisfaction knowing One participant spoke about the importance of free time. He saw himself as not yet ready to regularly attend a support group at the clinic due to his existing regular commitments, including daily Alcoholics Anonymous meetings. Two patients shared they felt well supported in their lives and self-accepting of their HIV positive status. Therefore, neither identified as ready to attend a support group, as they felt they did not need additional sources of support in their lives at the moment. However, staff felt it important to still engage these patients as these other support sources might be fluid, while the support group offered regularity and stability. Further, staff mentioned that while patients may not feel ready in the present moment, readiness should not be understood as a fixed state. One staff saw personal readiness as the most prominent factor affecting support group participation. Even if patients couched their disinterest in the support group in other ways, ultimately, this was the barrier.

Staff: "I would try to find out exactly where their meter is going. Even though they are feeling a way for themselves, but how do they really feel about it for someone else. Because their own issues might just be for that time, because I've learned that, um, a no doesn't mean no, it just means not right now."

### Food

The current men's support group provides lunch to both the participants and facilitators as part of the meeting. Two patients believed food was a strong incentive for participation and would successfully motivate people to attend. A couple of other patients agreed that food was a draw but had reservations about food during meetings. One patient remarked he found food distracting and did not enjoy hearing the sounds of people eating during meetings. The other patient thought food would be a draw for some more than others, particularly individuals who were food insecure and/or

of a lower socio-economic status. One staff shared this patient's beliefs, remarking that food has historically been a successful and popular motivator for people living with HIV, particularly those who are poor. He wondered if food could possibly attract too many participants, creating a group too large for two facilitators to effectively manage. The group facilitators thought food was a successful facilitator and helped to create a positive atmosphere during the support group meetings. One stated that while food was a draw, he did not believe anyone was coming just for the food. He further shared that lunch was served at the end of the meeting, creating an unexpected community-building benefit when the men casually chatted over the shared meal.

Staff: "And so what's happening, is, we have the room from 11 to 12:30, and then so, what's happened the last couple of times is that the food gets to us around 12:30ish or so. Um, and so, from 12:30 to 1 we just sit around and just eat. And people just talk and eat and it's turning out to be, and everyone stays for that...And so that's been a really interesting development, too, that people, you know, are just casually eating and talking. And I feel like there's a lot of connections that are being made in that time. Um. And so, it's, it's been a good thing I think."

#### **Transportation**

The men's support group meets at the Emory University Hospital Midtown campus, where the Infectious Diseases Clinic is also located. Transportation was mentioned as a barrier by almost all study participants, patients and staff alike (5 of 8 patients, 5 of 5 staff) – with one patient claiming transportation was one of only two real barriers participants might face (the other being stigma). The clinic provides MARTA<sup>††</sup> vouchers and validates parking passes in the hospital's parking deck for patients when visiting the clinic, including for support group meetings. Both patients and staff seemed well familiar with this policy. However, one patient shared that his current

<sup>&</sup>lt;sup>††</sup> The Metropolitan Atlanta Rapid Transit Authority, Atlanta's public transit provider. The hospital is located a block away from a MARTA station.

unemployment made it difficult to pay the initial MARTA fare, even though he would be later reimbursed. Thus, even when the clinic provided transportation reimbursement, fronting transportation costs still was a barrier for some participants. Patients also discussed travel and transportation-related time commitments. For patients with jobs or other obligations, transportation travel times were a clear barrier. One patient remarked that after a full day of running errands or driving around for work, he was unwilling to sit in traffic for almost an hour to attend a support group meeting.

One staff member commented that Emory University Hospital Midtown's location carried a lot of stigma, being located in an affluent part of Atlanta that seemed less accessible to much of the clinic's patient population. He added that his patients often question why they have to travel to Midtown to receive services, rather than have services come to them. These viewpoints were not expressed by any other study participant.

Staff: "And I suspect that our participation would be greater if we had these support groups in the community as opposed to the hospital. For some, this hospital is downtown...and for some people, downtown seems like a long way away. Even though it's really only a couple miles away. It's just, it's downtown...and downtown also has...comes with a stigma. It's, uh, viewed as being affluent, um, and these are communities where people, like I said earlier, are low in socio-economic status. So, I mean, if you talk to them – and hopefully you will – you'll find out that they have some issues with always having to go somewhere to get their care. They don't understand why sometimes that care sometimes can't be...brought to them."

#### Scheduling

The theme of scheduling incorporated several issues, including scheduling conflicts and frequency of meetings. Initially, both men's support groups met at 7 pm on a particular weekday each month. Following low turnout, the consolidated support group now meets at 12 noon on a weekday. Nearly all study participants (12 of 13) acknowledged probable or actual work conflicts with a midday

support group meeting time. One patient mentioned this was the only barrier preventing him from participating. Several patients remarked they would not or could not take off work to attend a men's support group, with one patient expressing discomfort in having to potentially disclose to his Human Resources department why he would be missing work on a regular basis. Even if a patient might be able to align a work break with the support group meetings, one patient joked, he doubted anyone would want to spend their lunch in a support group meeting.

However, the support group meeting's initial 7 pm time also received poor feedback from patient participants. Many patients shared the traffic at that time made coming to the hospital difficult. Several patients also said that after a full work day, they lacked the energy or will to come to another meeting. One patient, although retired, shared that 7 pm was too late. Patients also expressed an aversion to traveling at night. To address work-related scheduling conflicts, a couple of participants mentioned possibly having the support group meeting on a weekend, both suggesting Saturday mornings. Several staff also echoed this suggestion, although added it would be difficult to find staff members willing to facilitate on the weekends. The clinic is only open from Monday to Friday. Staff discussed the possibility of multiple meeting offerings at various times to try and accommodate work schedules. One facilitator mentioned that only three or four men would typically show up for a 7 pm meeting. Some meetings, no one would attend. This was particularly difficult on the staff who committed to stay beyond their traditional work hours. The facilitators remarked that no participants were lost from the transition to the midday meetings, and in fact, their group grew in size.

Both patient and staff participants discussed meeting frequency and timing as a crucial issue, with most agreeing that meeting once a month – as the group currently does – is not enough. One staff

remarked that research literature supports that meetings ought to happen more frequently, even on a weekly basis. Most patients believed twice a month would be sufficient. Not only would more frequent meetings work to build rapport between participants, but their acute issues would probably smooth over between meetings if spaced a month apart. Thus, if the meeting is only scheduled once a month, it would be unable to meet their expectation for a support group. One staff facilitator mentioned that he did not think the group should meet more frequently until more than half the current group members voiced interest, or if group membership grew rapidly. He seemed wary to make any changes, as the group in its current format and time is still quite new. The other facilitator defined this is a trial-and-error period and agreed that more time was needed before making adjustments. Participants also shared concerns that an hour was insufficient to receive the support they require, especially if the meetings only occur on a monthly basis. None of the staff commented on the length of meetings.

### **Topics**

Both patients and staff shared their views on desired topics for the men's support group discussions. Patients talked about topics as both facilitators and barriers, mentioning that topics had the ability to sway their choice to attend or not. One patient mentioned that the right topics could be a strong enough motivator for him to attend the support group at the clinic for the first time.

Patient: "That's probably the biggest thing for me that...I wouldn't, I don't – I don't want to sound rude but if it's not a topic that applies to me, I'm not sure that I'd be interested."

Currently, the attendees vote on the upcoming meeting's topic. Patients and staff agreed that patients providing this input was important, and a great way to meaningfully involve patients.

However, the upcoming topic is only known by the attendees of the previous meeting and the support group facilitators. Several patients suggested it would be nice to know the topic in advance for new group members. A couple patients mentioned their good health and undetectable viral load meant they weren't at the clinic each month, and it was nearly impossible to know what the meeting's topic was unless they blindly attended, which seemed unlikely. One staff facilitator thought patients knowing the topics in advance was also beneficial as it allowed patients to reflect on the topic and come prepared to the meeting ready to discuss. Desired topics fell into three broad categories: practical knowledge, general support, and how to live with HIV.

Common suggested topics addressing practical knowledge included medication adherence, maintaining a healthy lifestyle, resources available to people living with HIV and tangential skills, such as credit repair. Both patients and staff identified medication adherence as a key topic for support groups, although one patient mentioned that while this topic was important, it seemed less relevant for him and he would not want to attend a support group meeting where this was discussed. A staff also added that certain topics were more popular with men newly diagnosed, such as medication adherence. Maintaining one's health and living with HIV encompassed several facets, including healthy eating, HIV and aging, and the importance of keeping doctors' appointments. One patient was particularly interested in discussing medical care other than HIV care. Here, the patient acknowledged that his HIV diagnosis was only one component of his medical history, an important point to perhaps extrapolate for the support group. A positive HIV diagnosis may be the common thread between group members, but not always the sole underlying need for support during group meetings.

> Patient: "Um, finding health professionals that you can relate to or...understanding when you get a physician or a health professional that

wants to attribute everything that happens to you to HIV. You got a damn cold, 'oh, that's because you're HIV positive'. No, hell no! It's because I touched someone that had a virus. But you know, how do you manage that?"

Both patients and staff identified information exchanges about resources available to patients both via the clinic directly and outside organizations as another key topic. Specifically, housing, insurance and credit repair were mentioned. In contrast, one patient seemed less interested in specific topics associated with each meeting, and preferred a less structured format. A conversation-driven support group that created space for the men to share whatever was on their mind was most important to him.

Topic suggestions addressing living with HIV were primarily centered around concepts of selfcare and self-respect. Study participants discussed the period following a positive diagnosis as stressful, especially because there are few resources that prepare you how to deal with that news. Both patients and staff recognized the stigma associated with HIV, which makes many patients reluctant to disclose their status to other people in their lives. This often means newly diagnosed patients in particular feel overwhelmed and are in need of acute support.

Several patients mentioned their desire to discuss relationships, dating, and sex in a support group. One patient remarked that the clinic often treats sex as taboo and fails to embrace the reality that most people are sexually active and seeking relationships. Other patients voiced concern about finding future partners who would accept them and wanted peer support on this topic in particular. A couple patients asked for specific meetings focused on maintaining a healthy relationship, both with another HIV-positive partner or HIV-discordant partner. Without a directive manual on how to live with HIV, men felt like they were navigating each new experience on their own and saw the support group as a place where they could share coping mechanisms and strategies for dealing with their positive diagnosis.

Patient: "I would say to be a little bit more open about sex because, um, I guess because people already feel judged already. They make it seem like it takes...sex is so taboo and so strange, but it happens. Everybody has sex, you know. People, some people have STDs and stuff and they're embarrassed but they don't, they don't...they want to make it seem like they're not doing anything but clearly you're doing something. So I think that people should really embrace...what they're doing and be protected and understand that every cause has an effect. So, I guess moreso into making sex a more, something more common and not so taboo, like, nobody wants to talk about sex. Nobody wants to talk about sex."

All staff interviewed emphasized the patient's overall health and building towards a healthy life as critical topics. These sentiments appeared much more explicitly in staff interviews than patient interviews. One staff believed there was a direct correlation between openness about one's status and one's health. Thus, getting patients to a state where they could openly discuss living with HIV, like in the support groups, was of utmost importance to keeping them retained in care.

Staff: "The recognition of the need is there. Um, and I think it goes from patient to social worker to therapist to provider to nurse...we all know that, um, mental health and...I consider support groups to support mental health...um, supportive services are essential to our patients feeling better, moving forward with their life and staying engaged in care and just feeling better."

Staff also were acutely aware of the probable longevity of living with HIV, and prioritized topics that address the chronic nature of HIV. One patient mentioned this as well, as he initially learned of his diagnosis decades back, when the projected lifespan of a person living with HIV was much

shorter. Staff wanted topics that would build skills and coping mechanisms for their patients with

longevity and resilience in mind.

Staff: "...the ultimate goal is to enable you to move forward. Because HIV is not terminal now, it's chronic. And we want you to, as the song says, live your best life. And, you know, live your best life is being responsible. Uh, so that's you know, my vision for the group. Whether that entails, you know, talking about things as far as you know, being promiscuous. [...] My goal is to ...enable, to ...hold you accountable."

Staff: "I would like to have things talking about prevention and also talking about...chronic illness. I am a little bit concerned that...I'm extremely excited that we can control HIV very, very well. But I'm also concerned that...for some of the young generation, um, they come with the expectation, 'ok, I need a pill and just leave me alone.' Um, completely normalizing it is something that bothers me. [...] I'm also concerned that just saying... 'give me the pill, this is normal, I don't want to hear anything!' is just making it too...vague? And that concerns me. So, I think that having some education about, um, you know, how to...deal with the diagnosis long term. Because it's obvious if you're in your 20s right now, you probably will have it for the next 50, 60 years.

Furthermore, the staff in particular thought it important to explore sense of self and identity as a man living with HIV. A couple staff suggested topics that emphasized identity, which was not voiced by any patient study participants.

Staff: "As well as, you know...just how you view yourself now, with the viru – with the diagnosis – has the view of yourself changed, um, since receiving the diagnosis? Or has it, um, stopped you in any type of way, or you know...how do you feel, about, you know, when you look in the mirror knowing that you have a – a diagnosis, and you know, when you come here to the doctor's office, how does it feel whenever you are coming in and you are being faced with the truth of the uh, you know, the diagnosis. Whereas when you're out in the world you don't really need to deal with it. Especially if you're not...the only time I feel like they probably really have to mentally deal with it, maybe and I could be way off, is when you're actually looking in the mirror because, you know, you see anytime – anytime anyone looks in the mirror – whether you have a diagnosis or not, you know your inner self. So, you're looking back at yourself, whereas when you look at other people, they only see what you put out."

#### *Group members: participants*

Group members comprised both the participants and facilitators of the men's support group. Issues with participant group members covered confidentiality and comfort. The vast majority of study participants (7 of 8 patients, 4 of 5 staff) underscored confidentiality as a principal participation barrier. Several patients discussed social media and fears around other participants sharing information about the group with their social media networks. One patient who was recently diagnosed shared that he was still coming to terms with his diagnosis and was incredibly nervous about sharing his status with other men – even if they too were living with HIV – out of fear that his participation in the group might not remain confidential. Multiple patients and staff alike stated it was difficult for patients to trust people, and this was often rooted in previous experiences with others betraying their trust regarding HIV disclosure.

Staff: "Um, but I think that, um, the biggest barrier, I think, is just, um, confidentiality. Their fear of knowing someone or you know, in their social groups, knowing people who have, who they've entrusted with information and then, and then they go out and they hear that...you know, so I think those kind of instances, kinda really affect people a lot. Um, and then, so, and then they feel like where else can they go? They can't say anything about their lives, then everybody is gonna know about it. And so. Their personal experiences in, you know, in somebody breaking their trust really impacts their ability to take another risk, right?"

Patients indirectly spoke about the community or running into someone they knew. When probed, the patients clarified they meant the gay community. One patient believed only mature participants could be confidential, defining maturity as members willing to take the group seriously and be respectful of others. He believed many of his peers in the gay community were immature, although

did not clarify if this included other patients at the clinic specifically. He further stated he didn't want to be part of a group where men were there for the wrong reasons, such as looking for a hook up. A staff also shared this viewpoint, stating that several of his patients were reluctant to join a support group for fear that it would be a hook up place where their business would be spread within the gay community in Atlanta.

In the context of creating a more accessible support group outside the clinic, one staff argued that confidentiality was not a concern for men in their own communities. This opinion was an outlier and not echoed by any other study participant. He discussed confidentiality in the context of hosting a support group outside the clinic, within a community-based setting.

Staff: "Now, there are some staff who...seem to think that there might be an issue with confidentiality if we moved it to the community. But, you would be surprised or maybe you wouldn't be surprised, to how many of them, that that's not an issue at all – [...] It's almost like, for many of them, they're like, 'well everyone in the neighborhood knows I'm positive.' So that doesn't seem to be a concern to them. It just seems to be a concern for some of the staff here. I'm not for sure where that concern comes from, because it's not supported by the people that I talk to. That is not a concern from them."

Achieving an acceptable level of comfort was another priority for patients. Beyond confidentiality, patients remarked that it was difficult to share with others and further difficult to be in a group of strangers. However, patients believed they could relate to fellow men living with HIV moreso than men who were HIV negative. Being comfortable with group members was essential to discussing and sharing. One patient thought comfort was rooted in honesty and trusting that the other support group members had his best interests at heart. Several patients mentioned fear of judgement from other support group members. One was nervous of other group members not sharing their own

lives, leaving him to feel vulnerable and uncomfortable to share his own story. Another compared support group members to middle school students, not fully knowing if he belonged.

Patient: "And also, the comfort level would be a big thing. Um…even within folks who are...HIV positive, there is a lot of discrimination and, you know, whispering and things. And...it's hard. That's a hard hurdle sometimes. And so it's kinda that, I jokingly say that it's a little bit like going to middle school, you know? That you don't know who you can trust, who's your friend, who's going to be an ally...who...might know somebody that you know, that it ends up, you know, getting back to somebody...they don't need to know your business. So that's been probably my reluctance in going, or not going, rather."

#### Group members: facilitators

Presently, the group is facilitated by two staff members, who both identify as male. Patients understood the role of the facilitator as keeping control and taking an active role as moderator. No patients voiced concern with staff being part of the group, and some even insisted that a staff must be present to ensure the group stayed on track. Confidence in the staff facilitator affected patients views of the support group, noting rapport, being knowledgeable and not being condescending as key characteristics of an ideal facilitator. Several patients mentioned trust in the facilitator would propel them to participate in the men's support group. A couple staff questioned if patients would be more comfortable if the facilitators matched certain demographics of the patients. Both staff agreed gender was important, but seemed unsure if ethnicity, sexual identity or HIV status mattered. One staff contended that while it might matter for some patients, it wouldn't for others and therefore wasn't necessary to demographically match the majority of group members. Another staff emphasized that facilitation skills and empathy mattered more than also being a male living with HIV. The two current facilitators saw their roles as an important component of the group membership and treated their responsibilities with conviction. One means of doing this was to remain consistent and prepared for support group meetings. One staff member who does not currently facilitate a group questioned if staff facilitators were really necessary. Their viewpoint was not expressed by any other study participant, but certainly echoes models that many other Atlanta-based support groups utilize.<sup>‡‡</sup>

Staff: "The groups are currently being run by staff, I think. At least the men's group... What do I think about that? ... I'm gonna tell you what I think about that. I think that in, uh, 2018, in the HIV treatment field, we should have learned a long time ago, that the best facilitators of groups are well trained people who are [HIV] positive to facilitate those groups. So, I would say, that the real role of this clinic, this Ryan White program, the staff here...is to identify...patients who are positive, who are doing well, who we can train to be facilitators of these groups, who we can pay a stipend to and they can do this twice a month."

## Viewpoints on support group demographics

During interviews, I prompted participants to share their perspectives on ideal demographics for the support group at the clinic. After several interviews with both patients and staff, socioeconomic status emerged as a demographic characteristic frequently mentioned. Therefore, aligning with the iterative approach common in qualitative research, I probed all subsequent study participants on their views regarding socio-economic status. Patients and staff agreed that a successful support group should aim to make its members comfortable. For some, this might mean being in a group with people who share similarities and identities beyond just a positive HIV diagnosis, while other study participants believed that a shared diagnosis alone was hugely unifying. Several patients discussed the importance of groups appearing open and accepting to all.

> Patient: "Who shows up is up to the person. They're not doing anything wrong. You can't control who comes, you can't help how old they are, what color they are. You can't help, like, I think the hospital itself is doing the right thing by at least...making these programs readily available and, you know, at

<sup>&</sup>lt;sup>‡‡</sup> Examples include organizations like Positive Impact and Thrive SS, who run support groups facilitated by men living with HIV

no charge. Like, I think that's a beautiful thing. You really have to hold the person accountable to be there. You can't really control who shows up. It's up to the person to come. [...] The people should just – people as individuals should be more open to things like that. Because there's nothing wrong with therapy or counseling or support groups, because err'body need some type of support.

The six demographics discussed represent both inductive and deductive themes and include: [1] ethnicity, [2] socio-economic status, [3] age, [4] sexual identity, [5] addiction, and [6] relationship status.

#### **Ethnicity**

When asked if the clinic should consider ethnicity when forming men's support groups, several patients remarked no, stating that ethnicity should not matter. These patients were all Black men. One patient discussed the importance of diversity and moving beyond racial tribalism. While he stated that men often feel most comfortable with other men who share their ethnicity in group settings, he believed it important to move beyond the proverbial echo chamber and be exposed to various viewpoints. The one patient who thought ethnicity should be considered, spoke about the need for more average white folks. He commented that he often felt like a minority at the clinic, whose patients are predominantly Black. As a new member of the CAB, the patient also believed his ethnicity was part of the reason he had been asked to join the CAB, to ensure ethnic diversity and representation within the membership. One Black patient oscillated between wanting the men's support groups to separate by ethnicity. He voiced concern that a support group for Black men was likely to have gossip and members break confidentiality. However, he later stated that ethnicity was not an important factor to consider when forming groups and would not sway his participation either way.

Patient: "Like, if it's like a group of Black or a group of white...I would go with the white group, because I be thinking like...they won't be, to say, and I

use the word messy, at all. And maybe it's not the case, but I hear stories and I hear – I don't have time for all that."

One staff contended that research shows Black men communicate better with other Black men. While he didn't believe the groups should immediately separate out based on ethnicity, he thought it could be effective. The facilitators believed ethnicity was not currently affecting group dynamics or participation, but it could. One facilitator mentioned that of the regular attending members, the majority identified as Black. In all feedback regarding ethnicity, only Black and White ethnicities were mentioned, and I did not probe further on other ethnic groups.

### Socio-economic status

Over half of patients seen at the clinic receive Ryan White Part A funding, which has an income eligibility threshold of 400 percent above the Federal Poverty Level. Based on 2019 rates, an individual may make nearly \$50,000 annually and meet the income eligibility requirements for the Ryan White Program.<sup>§§</sup> A couple staff remarked that the Infectious Diseases clinic sees patients with more socio-economic diversity than other large providers of HIV care in Atlanta, such as Grady Hospital.

Staff: "And, um, we have, um, a significantly different type of Ryan White patient here. Some of our patients are well-educated...high in socio-economic status...gainfully employed...articulate...uh, successful...positive contributors to the community...payin' taxes, some of 'em. Uh, a lot of them, we have a significant number of those who are low in socio-economic status too. That's the ones who are on that fallout list. The majority of those are folks who aren't any of that what I just described."

Several patients believed socio-economic status might be important to consider but did not elaborate when prompted. One patient shared that acknowledging socio-economic diversity when

<sup>&</sup>lt;sup>§§</sup> The 2019 Federal Poverty Level for a single individual is \$12,490.

forming support groups could be beneficial. He believed certain topics that might be appealing to some support group members might not be to others, such as resources for the homeless or rent assistance. However, he also believed it might be problematic to segment the groups and stigmatize certain people. He shared, however, that when he visited the clinic, he felt different than the other men in the waiting room and would appreciate a support group where he could relate to others. The difference he referred to encompassed both ethnicity and socio-economic status. Staff also recognized that some patients had expressed difficulties relating to men or feeling connected to men with socio-economic statuses greatly different than theirs. One staff facilitator believed current members in the men's support group shared a similar socio-economic status, and the other facilitator believed that socio-economic status did not matter.

One particular patient participant was especially vocal about the importance of considering socioeconomic status at the clinic. This patient was retired and had self-reported financial stability. He believed scheduling the support group meetings during the day was preferential towards men with a lower socio-economic status, who probably were unemployed or without regular employment. He contended that those who are financially secure are equally deserving or needing of support, and implied that it's often assumed that men who are financially secure are in less need of a support group.

Patient: "Yeah. Um, so ... and that was one of the ... I said it before. That was one of the issues I had with the organization ... that they tend to primarily deal with a certain population. And then there are people out there, um, like professionals and other people that have the same issues. But, because of their circumstances, are not able to avail themselves of those services. That could be financial based, that could be whatever. But they can't do it. Um. And then there's no effort to include them because they got the population that they need to serve and they're meeting their guidelines by serving them, by serving those people. And so um those other people basically just get ignored. Um, because I had issues with, um, people living with HIV and their mental health issues and how those are just like, you know, here. [...] Um. Those people get lost in those kind of situations where meetings are at lunch time, you know, where you're being at work and work in Buckhead and can't get away from that, so how do you, how do you do that? How do you get involved?"

### Age

The majority of patients (5 of 8) desired age diversity in the men's support group at the clinic. Patients believed older men had knowledge to offer through lived experiences, particularly those who have been living with a positive diagnosis for decades. A couple of the patients who identified as older than 50 years of age also felt appreciated and valued in support groups. One remarked that he enjoyed sharing his perspectives, which were often well-received by younger men. Several staff echoed these sentiments, believing that age diversity brought richness and value in views and perspectives for a men's support group. One staff reflected that HIV had changed dramatically in the past couple of decades, and seniors can offer a lot of insight through their participation. One patient commented that age was not necessarily synonymous with maturity, however. Another younger patient felt he would be most comfortable in a support group with younger men but understood if the clinic did not separate out members by age. Still coming to terms with his diagnosis, this patient was very concerned he would be unable to find a partner or have a family. He believed younger men could relate to this issue moreso than older men. Another staff believed that seniors might be more comfortable amongst other seniors, and another staff gave a particular example of a recent patient who specifically asked for a men's support group for long-term survivors.

#### Sexual identity

Nearly all the patients interviewed stated they would feel comfortable in a group open to all sexual identities. It should be noted that the vast majority of the patients I interviewed self-identified as gay. The only self-identified heterosexual did not see a problem attending a support group with gay men and stated he would still feel comfortable. However, three patients thought it would be

best to give men the option to separate by sexual identity. All three patients assumed that heterosexual men would be less comfortable or open to hearing about the experiences of gay men, although these patients said they would still be comfortable sharing amongst heterosexual men. One of these patients touched on the stigma against what he termed the gay lifestyle, supported by other patients who experienced homophobia.

A staff facilitator shared that all current support group members identify as gay. While the group is still open to new members, he suggested that a heterosexual man might be more comfortable in a different support group. Professionally, all the heterosexual men he has worked with who contracted HIV through heterosexual sex felt more comfortable in a group with both men and women, a format currently not offered by the clinic. He added that members all sharing the same sexual identity strengthened the sense of connection between members.

Staff: "I think everyone in there has been open about their sexuality, too. Everyone in the group is gay, is a gay male. So I think there's a lot of commonalities around that. And so I think that there are, um, um, specifics to, you know, to the gay men, HIV, um challenges. And I think that having all men can really, can really give people a more sense of, I guess connection?"

The clinic predominantly treats males who identity as gay, which mirrors epidemiologic patterns of HIV trends in Atlanta. While a couple staff acknowledged the possibility that heterosexual patients might not feel comfortable in a support group with a majority of gay men, they did not seem overly concerned. One staff stated if a patient seemed discriminatory against gay men, then he probably wasn't ready for a support group and required some one-on-one therapy first to unpack stigma associated with HIV.

Staff: "Meaning, um, I've heard from heterosexual patients of ours that they don't mind going to a support group with gay men. And I've heard, you know, 'sometimes I look at them and I'm like whoa! you know... that was really tough'. They were like, 'I will never share the room with...I'm not gay!' You know, and. And probably the support group is not for you and probably in individual therapy you need to talk about some of the, you know, stereotypes that you are holding in your head."

#### Addiction

A couple patients interviewed mentioned their sobriety throughout their interview. One patient previously attended a men's support group for HIV positive men who also identified as addicts. He greatly appreciated this level of specialization and thought the men could relate to him more than a sober person living with HIV. Another patient currently attends daily Alcoholics Anonymous meetings. He noted he was surprised to learn how many addicts also were HIV positive. These patients, however, did not explicitly express desires for an addict-specific support group at the clinic. Conversely, another patient who did not identify as an addict thought that a group for addicts might be beneficial. None of the staff mentioned addiction during their interviews.

#### *Relationships*

The patients interviewed who currently had a serious partner (2 of 8) both mentioned value in a support group they could attend with their significant other. Both patients identified their partners as primary sources of support in their lives and wanted to include them in the clinic's support group. One patient's partner was HIV negative and he expressed interest specifically discussing how to remain healthy in a HIV-discordant relationship and believed his partner would benefit from receiving support from others, particularly related to stigma associated with HIV. Another patient's partner was also living with HIV, but not receiving services at Emory University and therefore not eligible for the clinic's support group. He spoke about his partner as a critical support

source, from daily reminders to take medicine to overcoming broader stigma about dating as a couple living with HIV. Staff interviewed did not have direct comments about a support group for couples, other than previously stated concerns about men possibly seeking sexual partners in a support group.

## Key concerns to consider when forming men's support groups

This theme entails five sub-themes, which represent important aspects of living with HIV that should be considered when forming and guiding the content/focus of the men's support groups. They are: [1] dealing with HIV, [2] coping with HIV, [3] self-acceptance of HIV status, [4] stigma, [5] additional support sources. Three sub-themes (dealing with HIV, coping with HIV, self-acceptance of HIV status) are all inductive from data collected and two sub-themes (stigma and additional support sources) are deductive, as I prompted participants to speak on these topics.

### Dealing with HIV

Dealing with HIV was a clear in vivo code identified during data analysis. All patient participants used this phrase multiple times during their interviews, which also appeared in more than half of staff interviews. ("In vivo codes" refer to a repeated term or concept that is stated by the participant, rather than introduced by the interviewer, and highlights the word selection chosen by study participants).<sup>36</sup> Dealing with HIV or dealing with living with HIV was discussed both conceptually and practically. Patients and staff alike acknowledged that dealing with HIV was often difficult, and one patient remarked that the idea of dealing with being HIV positive for the remainder of his entire life was daunting.

Patient: "However you deal with it, cope with it, end your life or whatever may you choose to...deal with it. And a lot of people...and I know this for a fact, they're still broken by it. You know. So you just have to find that support within yourself or if you know someone else who is in that boat who can go ahead and...reach out that you trust that conversation with, to reach out and communicate with and, you know what I mean, hopefully they would be a good eyes, ears and buddy or family system to you."

Men living with HIV all deal with their diagnoses differently. One patient explained that his partner failed to deal with this reality appropriately, regularly breaking the monogamous expectation of their relationship. The patient then discussed how he would immediately seek out medical care to ensure he himself was not exposed to any sexually transmitted infections. Dealing with being HIV positive led to an urgent response each time his partner had a concurrent sexual partner to protect his health.

Patients and staff also discussed the reality of dealing with the situations that come as a result of living with HIV. This included a laundry list of situations and relationships, including disclosing one's status to family and friends, seeking new partners, experiencing stigma, interacting with medical professionals, losing people in their lives to HIV, managing their mental health, and meeting basic living needs. One staff remarked that men living with HIV were often also dealing with many other things and their positive diagnosis is only one part of their story. Several patients and staff referred to the intersectional nature of their lived experiences, dealing with their diagnosis, their sexual identity and ethnicity all at once.

Patient: "Um, because I had issues with, um, people living with HIV and their mental health issues and how those are just like, you know, here. Here's your diagnosis, here's some pills, live with it, have fun. Um, and um, there's no effort to deal with all the other stuff that comes along with it. Um, yeah people need housing, people need food. Um, but what about the whole stigma of dealing with it? With the idea of, uh, uh, the seclusion that comes with it? Um, the – being able to talk about it with different people? Not a lot of people just sit around talkin' about, 'oh man, I have HIV. What are you doing with it? And how are you handling it?' You know, it doesn't happen." One patient suggested that dealing with HIV really meant the realization that you have to learn as you go. A positive HIV diagnosis seemed to seep into men's lives in ways they might not have imagined. A seemingly innocent conversation with colleagues could reveal discriminatory views about those living with HIV that left him doubting his self-worth and feeling incredibly hurt. Or, another patient shared an incredibly painful experience of dealing with the loss of his longtime partner to HIV, while also contending with his late partner's family members' refusal to acknowledge their decades-long relationship and include him in the funeral.

The majority of patients saw support groups as a place where they could deal with HIV in community with other men sharing this diagnosis with them. While many believed that each person must deal with their positive diagnosis individually, the patients recognized a men's support group could help them deal with living as an HIV-positive man.

#### Coping with HIV

Closely related to dealing with HIV is coping with HIV. This sub-theme frequently overlapped with dealing with HIV. Several patients directly identified support groups as a place where they could get help coping with whatever was happening in their lives. A couple patients mentioned support groups as particularly effective when they're feeling overwhelmed and unable to individually cope with the stressors in their lives.

In contrast, one staff member talked about a coping strategy she frequently observed amongst patients. Many men coped with their diagnosis by trying to avoid it, failing to acknowledge the reality of being a man living with HIV. By building up walls and isolating oneself, these men coped with their diagnosis by becoming withdrawn. She identified this behavior as problematic and dangerous to their health and wellbeing. Pragmatically, this coping strategy might also prevent men from participating in a men's support group.

Staff: "Because when they, because what I mean by that is if they're, that's their way of dealing with it, complaining about it or saying that they don't have... or rather than finding a solution, always talking about the problem. It's their way of managing, rather than trying to figure it out. [...] And they feel comfortable, it's become their norm to dwell in that space of self-pity and doubt and fear and you know...I don't know what it would look like if I, if I'm no longer here. But if I'm over here, I haven't seen that. But I know what this looks like, so I know how to handle that. Even if it means, you know, just complaining about it. That's my norm. So I want to stay right here. Because this, I haven't seen this before."

## Then and now – learning and accepting one's status

Patients frequently referred to their HIV status as a demarcation in their timelines, discussing life before and after learning about their positive status. Other patients further distinguished between life before knowing their status, knowing their status, and accepting their status. Initially learning about their positive status, most men conveyed feeling negative emotions, such as hopelessness, despair, anger or sadness. The reality that they would have to live with HIV for the rest of their lives was hard to accept. One patient mentioned feeling completely overwhelmed and unable to process all the information initially presented by his medical team. Another patient stated he initially didn't even feel like himself, and felt totally lost, unable to share his feelings with anyone else in his life.

Patient: "But at least I can remember the day when I came out of the rain, and I stopped using, I stop doing things and reacting to things at what I heard and then I would react. Okay? I changed my way of thinking and once I changed my way of thinking, along with that...my behavior changed. And, when I start applying all of that...it was a...inside change to the outside."

Once the initial shock passed, all patients interviewed saw their lives improving. One patient discussed how they could now manage their health, rather than just react. Several patients discussed that accepting their status was not an easy process, nor was it always a linear path forward. However, once patients began to accept themselves, they believed they were ready to

receive support from others. Several patients remarked they still had not disclosed their status to their families but felt comfortable attending a support group and sharing with other men living with HIV. This point is important to acknowledge, as it relates to their personal readiness to attend a men's support group. Other patients stated that disclosure was no longer the seemingly insurmountable obstacle it once was. A patient remarked that he's living day by day, one step at a time – but always moving forward.

Patient: "So, um...I get depressed. I do. I get depressed, and I even said to my aunt today, 'I'm going through to get through'. So right now, I'm just going through it, alright? And there's nothing wrong if I have negative feelings like, feeling guilty or feeling shame or feeling hopeless or feeling sad. There's nothing wrong with those feelings. I've learned that it's okay to feel that. But I don't stay in that."

Other patients talked about setbacks, and still having days where they struggle with their diagnosis. However, men all agreed that life becomes easier after beginning to accept your diagnosis, even if the progress seemed minuscule at times.

#### Stigma

Stigma associated with HIV is well established in the literature and I felt it important to prompt participants to share their experiences with HIV-related stigma and get a sense of how this may impact patient participation in the men's support group. Study participants discussed stigma either as internalized stigma or experienced stigma. Internalized stigma refers to stigma that occurs when an individual embodies or internalizes societal stigma, leading to poor self-esteem or poor self-worth. Experienced stigma refers to discriminatory or prejudicial treatment that an individual experiences.<sup>37</sup> Participants discussed stigma related to specific locations, tied to particular relationships, and in relation to cultural norms.

Patients shared stigmatizing experiences at the workplace, related to medical care and trying to date. One patient talked about a recent social event with his colleagues. They were discussing ideal partners and he asked how they would react if they met their perfect match, but they also happened to be living with HIV. Every single colleague remarked that they would not date someone who was HIV positive. While the patient had not disclosed his status to any of his colleagues, he was very hurt by their opinions and continued to be bothered by the exchange after much time had passed. He also remarked that sometimes he felt unprepared and caught off guard to deal with stigma, recounting an interaction at work where he saw a newlywed couple expecting their first child. He went home after work that day and just cried, afraid that he would never be able to have his own family and that no one would ever be able to accept him now that he was HIV positive.

Several patients shared stigmatizing experiences related to medical care. Patients remarked that even medical staff could be ignorant about HIV, for example, refusing to touch a patient's intravenous line. Another patient talked about a non-infectious diseases doctor making a joke about his HIV status, resulting in him immediately leaving the appointment. Patients talked about the Emory Clinic, sharing a hospital floor with other departments. They shared experiences of overhearing other patients speaking disparagingly about the HIV materials in the waiting room. One patient even recalled watching a couple walk out before being seen by the travel clinic, after realizing that HIV services were also provided. One staff talked about elitist attitudes of some staff at the clinic, noting that patients complained about feeling condescended to. He remarked that sometimes staff assume all patients are dishonest and develop problematic biases, following poor interactions with patients.

Patients frequently discussed stigma and fear of rejection as the primary barriers to disclosing their

status to family members. Several patients shared that disclosure required also telling family members they were gay. For other patients, they felt comfortable disclosing their sexual identity with family members, but not their HIV status. One patient recalled an incident where he accidentally got some saliva in his sister's food while enthusiastically talking over a shared meal. His sister was one of three people he had disclosed his status to. She was so worked up by the incident that she called an HIV hotline to confirm it was not possible to transmit HIV via his droplets of saliva. In retelling this story, the patient got emotional, showing the pain that someone he thought he could trust felt so unsafe around him. Staff believed patients who had not yet disclosed to their families might struggle to attend a support group if still living at home, having to rationalize regular visits to the hospital.

Staff: "You know, a lot of times you, you know, you ...I had a patient not long ago telling me, 'okay, yes my, you know, I'm thinking about telling my parents ...but, if I tell them that I have HIV, I know that the next question will be, how did you get it?' And, he is ...from [[African country]] and he, culturally, um, has, you know, particular norms that he's breaking right now. And he told me, so, both of my parents are educated and I basically have an option of telling them I'm a drug user – which I'm not – or I have to tell them that I'm gay. And ...he's like, 'and I really don't know what to do.' And I'm looking at it from a perspective not only of social worker, but also a mother. You are, you know, looking at the bigger picture and thinking, 'oh my god, you're going to carry it for 10? 20? 50? years? How long is it gonna take you?' And there are still people here...fully grown...elderly men...that still cannot do certain things just because their 93-year-old father is still alive. ... And that's sad. And I guess emotionally, it has to have great impact on your mental health."

Patients also experienced cultural-related stigma, tied to either their ethnicity, their sexual identity or both. Several patients mentioned stereotypes and stigma that exist within the gay community, implying that even within groups they identify with, they can still feel stigmatized by their peers. Several Black patients mentioned stigma within the Black community surrounding both HIV and being gay. This was inescapable and seemed amplified by being located in Atlanta, a city that several participants remarked had a large Black population. One staff also added that Atlanta is seen as the gay capital of the United States, especially for Black men, noting that the city itself carries that stigmatizing reputation within the Black community.

Staff: "Uh, there's a television show called "Empire". It's a Black show. And last Wednesday the show was about...the mother finding out that her gay son's lover was HIV [positive]. And she went into a frenzy. Start moving stuff around, start – every time he would touch somethin' her – her friend, her son's boyfriend, she would wash it...It's full of all kinds of stigmatizing images. And he axed me, he said... 'did you see that...do you watch "Empire"?' I said, 'yeah, I like that'. And he said, 'did you see it the other day when the mother find out the boy is HIV?' Yeah...he said... 'that just how my family would act. I know they would do that same thing.' He said, 'I almost turned the tv off!' He couldn't stand it. He...he uh, got emotional. He said, 'even if I wanted to tell them, my family, I'm certain this is how they would respond. So, I'm just not gonna tell anybody.'"

Patients believed it was hard to ignore the stigma and not internalize it. One patient remarked as a Black gay man, he had many friends who were suicidal or had intense feelings of self-hatred due to their positive diagnosis. Another patient stated he was initially disappointed with himself after learning about his status and felt like another statistic – the next gay, Black man to be diagnosed with HIV. One patient talked about being hyperaware about his own blood. He frequently picked at his nails and cuticles, which sometimes caused them to bleed. Even without an undetectable status like he had, it would be nearly impossible to pass HIV to another person this way. Nonetheless, he remarked that he was extremely worried about infecting another.

A facilitator recalled a previous meeting where the room they had reserved was occupied upon arrival. While frustrated in the moment, he did not initially realize the extent of distress it caused the patients, who felt de-valued. Staff: "And so then, I heard from patients that they just, you know, they...it really broke them, I think. I mean, it frustrated me. But it felt like it really reinforced some of these negative ideas that they have about themselves is that, what they're involved in, isn't important. What they're doing...they're second class or whatever. Because other things take priority, right? And so that, that was not healthy for the group, and you know."

One staff believed getting patients to attend a support group at the clinic could push back against internalized stigma, as it required a certain level of acceptance and personal willingness to participate. The patients were not as explicit in discussing how they deal with or overcome stigma.

Staff: "I think that once they come to the group, it's already kinda destigmatizing it by joining the group. And I think that, it's ...important to have time to ...share some of these personal experiences, because even though this feels and is very personal ...a lot of people are going through the same things. And yes, there's a huge stigma around HIV, there's a huge stigma around um, being homosexual, um. But there are other stigmas as well, um, and just realizing that we all have to face them to a certain extent, doesn't excuse it, doesn't normalize it ...but helps us to develop skills to um, face it and not to avoid it. Because if you're avoiding it, um, I think you're gonna have a really difficult time."

#### Support sources

I asked the patients to share where they sought support in their lives, to examine how the men's support group might fit into their existing support systems. The vast majority of patients (7 of 8) were able to list at least one additional current source of support other than themselves. The patients in committed relationships stated their partners were prominent sources of support in their lives, even more than family members. Patients talked about various levels of support from family members. Most patients had only disclosed to certain family members, while a couple patients had disclosed their status to their entire immediate family. Patients described the support from their families as incredibly important to them, even if only a few family members knew. One patient had other members in his family who also were living with HIV, which he drew comfort from.

Patient: "Ummm. Kinda just like when I came out, like once I had the validation of my family, I don't care what anybody else thinks at all, because like...so it's kinda just like...all these...people in my life, love me. They care, they support me and accept me for who I am, so. If you're walking down the street or me coming to a support group, I don't really care what anybody thinks about me. Um. I just try my hard – my best to hold myself in a positive light, so. That's the only thing that I can do. Cuz, I can't change what's inevitable. Like, I can't change my status, so I embrace it."

Patients who were currently part of a support group also mentioned those groups as a crucial source of support. While I interviewed two men who had attended the support group at the clinic, neither mentioned the group as a current source of support in their lives. One patient mentioned that he was not inclined to rely on others for support, especially as many people in his life relied on him. He currently acts as the caretaker for his elderly mother and had also cared for other elderly relatives before they died. He cited his independence and self-reliance as hallmarks of his personality, although shared that he routinely attended one-on-one therapy with a mental health clinician at the clinic.

#### <u>Summary</u>

While participants revealed nuance in their individual preferences for a men's support group at the clinic, patients and staff alike recognized the pivotal importance support groups offer to men living with HIV. Providing a men's support group at the clinic creates a critical resource to patients navigating their lives living with HIV and an opportunity to build community, receive peer support, and grow and learn with others.

We share ... we love ... we give ... we take ... the whole nine yards. And, so I - I for me, a support group it's like ... it's an outside family, okay. And ... I just would be elated to be a part of a men's group. And to share my strengths and my hopes and my experiences.

#### Discussion

This qualitative study provided data on the perceived purpose and role of support groups, possible motivators or barriers for patients to attend a support group at the clinic, recommendations for improvements to the existing support group, and insights into the lives of men living with HIV. The data collected demonstrated the importance of support for men living with HIV. Currently, the men's support group provides emotional, informational and practical support, aligning with existing research which identified these as core categories to cover to achieve holistic support for MSM.<sup>37</sup>

While initially the clinic offered two distinct men's support groups with different formats, patients voiced a clear preference for the topics-driven support group, where discussions were driven by the patient participants. Particularly for men still coming to terms with their HIV diagnoses or men without consistent support sources in their lives, a topics-driven support group provides a much-needed opportunity to receive support and empathy from others in a judgement-free, confidential space on topics of importance to them. The introduction of teaching skills via a specific therapeutic approach (in this instance, DBT) was an idea initially driven by a group facilitator with a clinical therapy background. The facilitator remarked that he had previously facilitated a successful DBT-based support group for years at another organization providing HIV care to men in Atlanta and expected a similar group to be successful at Emory Midtown. To date, there is a lack of research that addresses the effectiveness of using DBT in HIV-related support groups beyond a study which employed this approach for HIV-positive patients also diagnosed with borderline personality disorder.<sup>38,39</sup>

Miscommunication and inadequate description of the skills-based group on flyer advertisements

further contributed to low turnout for the skills-based group, with several men expecting to learn professional skills. Patients interviewed also were initially apprehensive when asked about a skillsbased group, but voiced interest once its intent and focus were clarified. For example, several patients interviewed expressed interest in opportunities to role-play and develop emotional regulation and conflict resolution skills, in line with the original format and content of the skillsbased support group. Thus, the skills-based group's low turnout seemed to be considerably impacted by miscommunication and confusion over its purpose and intent, rather than an outright rejection by patients over its content. Nevertheless, patient participants clearly demonstrated preferential interest in a topics-driven support group, which accurately reflects the format of the current men's support group.

The merging of the two separate support groups appears successful, as both facilitators reported a cohort of men consistently attending the group, willing to engage and participate. I believe this may be attributed to several factors, but especially that the participants are building community and trust amongst themselves, even planning external social events in addition to the support group meetings. The adjustments to the support groups at the clinic since their inception reflect the importance of creating interventions that remain nimble and responsive to the unique priorities and preferences of each community, rather than a one-size-fits-all approach to successful HIV programming.<sup>24</sup>

The facilitators and barriers affecting support group participation enumerated by study participants were not surprising and matched common themes mentioned in research literature. However, the nuance and detail offered via their perspectives provide insight and clarity relevant to the clinic. One interesting dynamic illuminated included the tension between various staff at the clinic. One staff interviewed shared that a particular doctor refers every patient to a mental health clinician, whether the patient asks for this service or not. From the doctor's perspective, mental health is a critical component of a patient's overall care and wellbeing, which may affect their retention. However, the staff observed that not all patients want to see a mental health clinician, and this referral often is ignored. This disconnect is noteworthy, particularly in the context of support group attendance, which is not mandated by the clinic. Staff, especially the facilitators, informally evaluated the success of support groups based on attendance. Yet, even when other barriers (such as providing transportation reimbursement or offering the groups at an alternative meeting time) were addressed, men still did not attend. Thus, it is important to take into account the personal readiness of men at the clinic to attend a support group, as attendance numbers alone may be an insufficient metric for support group success.

Feedback regarding the scheduling and frequency of support group meetings is important for the clinic to consider. The current support group meeting time seems to work for both the facilitators and current group members, reflected in the steady attendance. The facilitators remarked that no patient was lost in the transition from evening to midday meetings. Hosting the meeting during the facilitators work hours also allows them flexibility to return to work if patients don't attend a meeting and lessens the burden of having to stay after traditional working hours to facilitate. However, men with traditional work schedules find it difficult if not impossible to attend a midday support group meeting, which automatically excludes a subset of patients from this service. While scheduling a second group at an alternative meeting time is arguably ideal, it is important to remain cognizant of the bandwidth of available staff. Technology-based solutions, such as remote participation or a virtual support group, might be worth exploring.

Generally, patients appeared averse to formats that further segment the groups, including by demographic factors. However, study participants also acknowledged that considering certain demographic identities might help with the comfort levels of participants. Current research overwhelmingly cites ethnicity and sexual identity (and to a lesser extent, age) as important elements to consider when forming support groups. Some articles even contend that failing to incorporate an intersectional framework into HIV programming reinforces the marginalization that these men experience in their daily lives, leading to ineffective treatment and care.<sup>40</sup> Indeed, study participants confirmed intersecting and sometimes dueling identities. However, the shared experience of living with HIV seemed to take priority over their other distinguishing characteristics. While patients expressed varying levels of comfort in hypothesizing about different group demographics, the two most salient elements affecting their comfort level and willingness to participate were personal readiness and confidentiality – neither of which are directly linked to specific group demographics.

Still, several patients cited socio-economic status as important to consider when forming support groups, particularly at the Emory University Midtown Infectious Diseases Clinic. In conducting the literature review for this study, socio-economic status did not receive much attention and was rarely discussed. However, the belief that people with similar socio-economic status find consistency in their views more than people with similar ethnicities is already established in research literature.<sup>41</sup> Both patients and staff interviewed seemed aware that the clinic provided care to a socio-economically diverse population, ranging from men who were homeless and unemployed to men who owned their homes and held a steady job. Patients interviewed believed certain topics might be more appropriate for separate groups. The belief that the clinic prioritizes patients with lower socio-economic status is deserving of further exploration. These opinions were

bolstered following the updated meeting time for the support group. Keeping enthusiastic and interested patients engaged should be a priority for the clinic and failure to properly address these concerns may lead these patients to feel further isolated and deprioritized.

The variability and unique lived experiences of individual men living with HIV is especially imperative to acknowledge. Too often it's assumed that their status is their most distinguishing characteristic or sole issue in need of support. However, this study demonstrates the dynamic experiences of men living with HIV and their need for support across a range of different experiences, not unlike any other human being. Nonetheless, the patients did refer to their lives as before and after learning of their diagnosis, recognizing that their status will be forever part of their lives moving forward. With time comes acceptance and the development of coping strategies. Patients highly valued the opportunity to learn from others and hear stories of others overcoming similar adversities.

HIV is a highly stigmatized disease, which was often compounded by stigma related to other identities or characteristics patients interviewed held, such as their sexual identity or ethnicity. Support groups work to confront stigma both directly and indirectly, providing a space where men can meet and hopefully receive non-judgmental support from peers while also building resilience and bolstering self-worth. Patient participants spoke about the stigma they experienced as ubiquitous, manifesting in multiple facets across their lives.

#### Quality improvement recommendations

In seeking to answer the study's research question – how can the men's support group best meet the needs of patients living with HIV at the clinic – I have several recommendations incorporating my analysis alongside direct feedback from study participants (Table 5).

# Table 5: Quality improvement recommendations for the clinic's support groupQuality Improvement recommendations

1 Invest resources to provide additional support opportunities to patients. This may include offering another group that meets outside traditional working hours, a hotline that patients may call into to receive support or an online group or forum. While patients expressed clear interest in receiving support or participating in a support group, the current schedule is inaccessible for most patients with traditional work hours. The possibility of hosting the support group outside the clinic facility in local community spaces should be explored, while acknowledging potential barriers with HIPAA and Emory University hospital policies.

2 Create feedback and evaluation mechanisms for the current support groups. Patients and staff alike repeatedly voiced an appreciation for the opportunity to offer their input and views regarding the men's support group via this study. Whereas some current support group participants provide feedback directly to the facilitators, it would be worthwhile to formalize and document this for possible future facilitators or additional support groups at the clinic. Furthermore, patients should be given routine opportunities to provide feedback, as their priorities and needs may shift over time. The clinic should invest in developing a tool, which may be used to evaluate the support groups over time. This will work to ensure the group is meeting its intended purpose and allow for iterative improvements and modifications as needed.

3 Continue to incorporate opportunities for patients to take ownership over the support group. For example, the current topic-selection process allows patients to determine relevant topics beneficial to the group. As the group matures, it would be interesting to explore the feasibility of training patients to become co-facilitators and/or other methods to increase patient responsibilities and leadership within the support group.

- 4 Integrate the men's support group more directly with the new patient orientation. This is a great opportunity to promote the men's support group to many patients simultaneously. While the men's support group is briefly discussed by a staff during the orientation, a patient participant providing their perspective and experience in the support group could be more compelling to the audience.
- 5 Develop additional communication methods regarding the men's support group. Patients consistently mentioned a desire to know the upcoming meeting's topic, which currently can only be known if a patient attends the previous meeting. Furthermore, patients who are virally suppressed may not attend the clinic frequently but are still interested in attending a support group. Exploring ways to disseminate information perhaps through a secure website may be effective at engaging patients at the clinic more broadly.
- 6 Further explore if patients might benefit from separate support groups delineated along socio-economic status. Data from the study indicated socio-economic diversity as a

potentially divisive factor for group dynamics, but study participants overall did not strongly support separating groups by personal characteristics or demographics.

7 Routine and consistent room reservations is important to guarantee a space for the support group meetings. Last minute adjustments to the meeting location frustrates and discourages group members and makes it difficult for new members to locate the correct meeting room. If possible, developing a consistent room location reservation for the support group meeting will help avoid scheduling confusion amongst other hospital staff and communicate to support group patients that they are valued at the hospital.

## Best practices to continue at the clinic

Data from the study also illuminated current practices and elements of the men's support group

deemed successful by both patients and staff interviewed (Table 6).

Table 6: Best practices at clinic to note for continued implementation

Best	practices	at clinic	's suppor	rt group
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- 1 Support group participants voting on the upcoming meeting's topic. Not only does this build ownership amongst participants, as mentioned above under Quality Improvement Recommendation 3, but it works to ensure that topics discussed are reflective of participants' interests and priorities.
- 2 Ensuring personal readiness before a patient attends a support group meeting for the first time. Currently, all new members are prompted to contact one of the staff facilitators as meeting specifics (such as meeting dates and location) are not published on flyer materials or directly communicated to patients. This allows staff to assess whether a patient is ready to attend the men's support group.
- 3 Food is well liked by current support group members, facilitators and patients alike. It has the unintended benefit of providing additional unstructured relationship-building amongst participants.
- 4 Transportation reimbursement (both MARTA passes or parking vouchers) are well appreciated by the patients and work to mitigate cost barriers associated with attending the support group meetings.
- 5 Clinic staff are well aware of the men's support group and routinely inform male patients about its existence. Patients interviewed reported initially hearing about the men's support group through a clinic staff member. Multiple staff currently inform men about the support group nurses, doctors, social workers and mental health clinicians providing multiple touchpoints for patients to hear about the men's support group while seeking services at the clinic.
- 6 Establishing ground rules and group norms for the men's support group. It is clear that confidentiality is a key concern for many male patients at the clinic. Having participants

agree to shared expectations and rules for the men's support group works to combat this and create a supportive atmosphere.

## Strengths and limitations of study

Qualitative research allows for the emic perspective, providing insight that cannot be gained through a quantitative approach. The study design consisted of in-depth interviews in an effort to build rapport and provide an opportunity to gather sensitive data confidentially. In-depth interviews enabled me to ask personal questions and seek honest feedback, even if negative. The detail, nuance and depth of data collected would not be possible using a quantitative survey. I was able to build rapport with all participants, evidenced by successfully conducting all interviews with no skipped questions or early termination of interviews.

I employed an effective recruitment strategy for the patient participants and purposively sampled to achieve diversity along several axes of interest. Based on initial meetings with clinic staff and following a literature review, I hoped to interview men of different ethnicities and sexual identities. Knowing that the majority of men seen at the clinic identify as BMSM, I wanted to represent this group in my study. I also sought men who had previously participated in a men's support group at the clinic, knowing their motivations for participating would be important. Working with key gatekeepers at the clinic, such as the Ryan White Program Director and current facilitators of the men's support group helped achieve buy-in with other staff, who assisted in referring patients into the study.

I worked closely with Dr. Ameeta Kalokhe over the course of this study, the Ryan White Program Director at the clinic, who also served as one of my faculty advisors on the study. As a result, it is possible that study participants were reluctant to share negative views or participate in the study due to our relationship.

I failed to collect biographical data of study participants, beyond their name and contact information for the consent paperwork. During data analysis, I realized certain information would have been helpful, like a patient's age or annual income. Some patients self-disclosed biographical data throughout the course of the interview, such as their age or sexual identity. Others selfidentified as having a higher socio-economic status, but it became difficult to compare their data with other patients who did not self-disclose this information. While still able to conduct a thematic analysis properly, the results would be made stronger with the inclusion of this information during analysis.

#### Implications for public health practice

I believe this study and its findings illuminated several issues deserving of further exploration:

# Table 7: Future issues to explore with additional researchIdentified issues to further explore

- 1 The effect of socio-economic status in support group dynamics. The potential impact of socio-economic status affecting group relationships has not yet been properly investigated in the context of HIV support groups. Current research heavily focuses on sexual identity and ethnicity for male support groups. However, data from this study demonstrates the need to include socio-economic status in the conversation. Perhaps preliminary research should be conducted to confirm that indeed socio-economic status is a demographic of concern for others and then further explore the impact of socio-economic status within support groups.
- 2 Relationships between support group participation and health outcomes. Building off this study, it would be interesting to see if causal or correlational relationships exist between active support group participants and positive health outcomes, such as medication adherence or retention in care. In combination with the perspectives gleaned from a qualitative study, quantifying a health outcome by demonstrating direct linkages with support groups would help make a compelling case for service providers and funders to prioritize support groups for patients.
- 3 Managing patients' intersecting identities to create functional support groups. Patients clearly expressed the need for spaces that are welcoming, confidential and non-judgmental. Previous research elaborates how many men living with HIV balance intersecting identities, which data from this study also supports. However, a path forward on how best to manage intersectional identities in a support group setting is less clear. The men in this study were averse to segmenting groups by demographics, but also mentioned they felt

best understood by men similar to them. Identities by their nature are fluid and therefore a single approach to handle intersectionality seems lofty. Documenting best practices and success stories from other support groups and compiling these results may help current and future implementers organize groups that remain flexible enough to respond to patients' needs, but also offer basic parameters to begin effective groups.

Both practitioners and researchers must remember, however, to not treat men living with HIV as a monolithic, homogeneous group. We must seek a balance between acknowledging and incorporating documented successes and best practices with being nimble and responsive to context-specific priorities. This study reaffirms that support groups will be most successful when meeting patient needs – and the only way to truly collect that data is from the patients themselves, rather than merely extrapolating and repurposing findings. As one patient elucidated, living with HIV is learning as you go.

#### Conclusion

This study contributes to a breadth of research working to provide effective care and services for men living with HIV. By proposing quality improvement recommendations for the clinic from the data, this study seeks to directly infuse feedback from patients and staff alike into the management and implementation of the men's support group. Support groups provide critical spaces for men to receive empathy, exchange practical information and deal with HIV, contributing to not only their emotional wellbeing, but working towards sustaining a healthy life.

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## Appendix I – In-depth interview guides

# IN-DEPTH INTERVIEW GUIDE – CLINIC PATIENTS EVALUATION AND QUALITY IMPROVEMENT OF EMORY RYAN WHITE PROGRAM MEN'S SUPPORT GROUPS

# RESEARCH QUESTION: HOW CAN EMORY RYAN WHITE PROGRAM MEN'S SUPPORT GROUPS BEST MEET THE NEEDS OF HIV POSITIVE PATIENTS AT THE CLINIC?

## Introduction

First, I want to thank you for your time today. My name is Christine and I am currently a student at Emory University. I'm working with staff members of the Ryan White clinic to conduct a study that explores the strengths and weaknesses of the new men's support groups. We're interested in hearing more about your experiences and ideas and ultimately hope information from these interviews will benefit the support groups by highlighting what's working well and suggesting changes if necessary with clinic staff.

I want to emphasize that your participation in this interview is completely voluntary. If there are questions you don't feel comfortable answering or would like to stop the interview at any time, please let me know. I'm expecting our conversation today to last between an hour and an hour and a half. After our interview, you will be provided \$15 for your time today. I'd like to pause here and confirm your willingness to participate again.

I would like to record our discussion if that's okay with you. This will help me out, because I don't want to miss anything you say and may not be able to write down notes quickly enough. However, this discussion and the recording will be kept confidential – even from the staff here. I will be the only person who has access to the recording. Once the recording is transcribed with all identifying information removed, the recording will be deleted. Your name will be kept anonymous throughout the entire study process. Is it okay if I start the recording now? Do you have any questions for me?

I have a list of topics I'm hoping to discuss, but please feel free to bring up other issues that you believe are important to share. There are no right or wrong answers. I'm looking forward to hearing what you have to share and your views!

## Warm Up

To get us started, I'd like to hear a bit about your views on support groups in general.

- 1. How would you define a support group?
- 2. How might a support group be helpful to you or others?

# Topic 1: Support groups – needs/priorities

Next, I'd like to talk specifically about needs and priorities that you have for support and support groups. As you may have heard, the clinic currently has two support groups. Both are led by clinic staff here, either a social worker or a mental health counselor. One is less structured and the patients decide what to talk about each meeting. The other support group is skills-based.

- 3. What are your thoughts on a support group where patients lead the conversation?
- 4. How do you feel about a skills-based support group?
  - a. What type of skills do you think are important for men like you to know?
- 5. How would you feel most comfortable in a men's support group?
  - b. Probes: Age, race, sexual identity

# Topic 2: Support groups – challenges

I'd like to get your thoughts on some of the obstacles and barriers that may prevent you from participating in a men's support group.

- 6. The men's support groups currently meet [FILL IN HERE]. How do you feel about coming to the clinic to attend a group?
- 7. Which type of support group would you rather join and why?
- 8. Do you have any ideas about what we could do to make it easier to attend a men's support group regularly?

# Topic 3: Personal history and experiences

Now, I'd like to talk about how your personal history and experiences affect the support you receive and support you may want.

- 9. When you learned about your HIV status, how did you feel supported?
- 10. How are you currently getting support in your life?
- 11. Have you recently felt discriminated against?
- 12. Currently, do you feel like you can openly talk about your HIV status?
- 13. How do you believe a men's support group could best support you right now?

# Conclusion

We are wrapping up soon, but I have a couple more questions.

- 14. What advice would you give to other men at this clinic?
- 15. If there's one thing the clinic could do to better support you, what would that be?

Do you have anything else to share that I might have missed today? Any questions for me? I would like to thank you again for your time today. Your insights were great and helped shed some light about how the clinic can hopefully better support you.

# IN-DEPTH INTERVIEW GUIDE – CLINIC STAFF EVALUATION AND QUALITY IMPROVEMENT OF EMORY RYAN WHITE PROGRAM MEN'S SUPPORT GROUPS

## RESEARCH QUESTION: HOW CAN EMORY RYAN WHITE PROGRAM MEN'S SUPPORT GROUPS BEST MEET THE NEEDS OF HIV POSITIVE PATIENTS AT THE CLINIC?

## Introduction

First, I want to thank you all for your time today. My name is Christine and I am currently a student at Emory University. I'm working in collaboration with the clinic here to conduct a study that explores the strengths and weaknesses of the new men's support groups. I've also been carrying out one-on-one interviews with patients here to gather their perspectives as well. Today, I'm interested in hearing more about your experiences and ideas about how we can ensure these men's support groups are best meeting the needs of your clients.

I want to emphasize that your participation in this interview is completely voluntary. If there are questions you don't feel comfortable answering or would like to stop the interview at any time, please let me know. I'm expecting our conversation today to last between an hour and an hour and a half. After our interview, you will be provided \$15 for your time today. I'd like to pause here and confirm your willingness to participate again.

I would like to record our discussion if that's okay with you. This will help me out, because I don't want to miss anything you say and may not be able to write down notes quickly enough. However, this discussion and the recording will be kept confidential – even from the staff lead. I will be the only person who has access to the recording. Once the recording is transcribed with all identifying information removed, the recording will be deleted. Your name will be kept anonymous throughout the entire study process. Is it okay if I start the recording now? Do you have any questions for me?

I have a list of topics I'm hoping to discuss, but please feel free to bring up other issues that you believe are important to share. There are no right or wrong answers. I'm looking forward to hearing what you have to share and your views!

## Warm Up

- 1. Before we dive in, would you mind telling me about your role here at the clinic?
- 2. Could you tell me about your involvement so far with the men's support groups?

## Topic 1: Support groups – needs/priorities

Next, I'd like to talk specifically about needs and priorities that you have for the support groups here. Currently, there are two support groups being run by a social worker and mental health

counselor respectively. One group is less structured and patient-driven, while the other group is skills-based and content-driven.

- 3. What kind of content do you believe would be most beneficial for patients here?
- 4. Describe the characteristics of your patients that might make them suited for a men's support group.
- 5. How could we better identify patients in need of a support group?
- 6. If you were to generate topics for future meetings, what are some of the topics you would prioritize?

# Topic 2: Support groups – challenges

I'd like to get your thoughts on some of the obstacles and barriers that may prevent patients from participating in a men's support group.

- 7. To date, the men's support groups have experienced low turnout. What are your thoughts on this?
- 8. What could we do differently to make patients more comfortable attending a men's support group?
- 9. Are there identity or other personal attributes that we should consider when forming these groups?
- 10. Do you believe the clinic currently has the bandwidth necessary to make these men's support groups a success?

# Topic 3: Stigma and barriers of patients

One of the issues I'm addressing with the patient interviews is the stigma and discrimination they experience because of their HIV status.

- 11. I'd like to hear your thoughts on what issues are especially relevant for your patients here in Atlanta at this clinic.
- 12. What are barriers that your patients experience that might further impede their participation in a men's support group?
- 13. Do you have any ideas about what the clinic can do to address these barriers?

# Conclusion

- 14. We're wrapping up now, but before I close...if you could make one adjustment to the men's support groups, what would it be and why?
- 15. Are there any other thoughts anyone would like to share? Any issues we missed?

I want to thank you again for your time today. Your insights were great and helped shed some light about how the clinic can hopefully better support its patients.