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RESEARCH ARTICLE **OPEN ACCESS**

Impact of a Multidisciplinary Healthcare Program on Healthcare Engagement of Young Adults Living with HIV

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Abstract:

Introduction: Young adults (YA) living with human immunodeficiency virus (HIV) experience significant challenges with healthcare engagement. This population experiences lower rates of retention in care compared to their adult counterparts, resulting in poor adherence to antiretroviral therapy, higher viral load, and lower CD4 counts that negatively impact their health. This study explored how involvement in a multidisciplinary healthcare program, the HIV Adolescent Provider and Peer Education Network for Services (HAPPENS) program, impacts healthcare engagement, and identified facilitators and barriers to retention of care from the perspectives of YA living with HIV.

Methods: Participants were recruited from the HAPPENS program embedded within an adolescent/young adult medicine clinical practice affiliated with an urban, tertiary care, academic free-standing children's hospital. Semi-structured qualitative interviews were conducted with 20 YA living with HIV aged 21-32 years (65% Black, average age 25.8 years). Interview questions queried facilitators and barriers to care and recommendations for improving this multidisciplinary care model.

Results: Overall, participants reported positive experiences with the HAPPENS program, emphasizing how resources being linked to care motivated them to consistently attend medical appointments. Most participants commented on how mental health challenges were a barrier to consistently engaging in care. Some recommendations emerged, including creating an open access care model in terms of scheduling and being aware of and avoiding paternalistic care.

Discussion:: Participants' narratives highlight the value of integrated, multidisciplinary care in supporting retention and re-engagement in HIV care—an ongoing challenge for YA living with HIV.

Conclusion: Multidisciplinary healthcare programs that focus on YA living with HIV can help improve healthcare engagement and retention for this vulnerable population.

Keywords: human immunodeficiency virus, young adults, multidisciplinary care team, qualitative research, adolescent health services, delivery of health care.

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1. INTRODUCTION

Young adults (YA) living with human immunodeficiency virus (HIV) experience significant challenges with healthcare engagement. This population is known to have lower rates of retention in care compared to their adult counterparts, resulting in poor adherence to antiretroviral therapy, higher viral load, and lower CD4 counts that negatively impact their health [1–3]. Retaining YA living with HIV in care helps them maintain good medication adherence that leads to viral suppression, improved health outcomes, and reduces the risk of horizontal transmission [4].Understanding constraints and barriers to care through the lens of YA living with HIV is vital to improving access to care and can inform future interventions to address these identified barriers.

In an effort to reduce barriers to care for adolescents and YA living with HIV, the HIV Adolescent Provider and Peer Education Network for Services (HAPPENS) multidisciplinary HIV program was created. The program is embedded within an adolescent/young adult medicine clinical practice affiliated with an urban, tertiary care, academic free-standing children's hospital, and our patients range from age 12 - 32 years. The HAPPENS program is a citywide network of culturally and developmentally appropriate young adult-specific care, including: (1) outreach and risk-reduction counseling, (2) mental health services, (3) health status screening and services needs assessment, (4) patient-focused, comprehensive care and support, and (5) a dedicated case manager for each patient who assists with navigating the health care system to ensure continuing care. Additionally, this program is composed of infectious disease providers who provide HIV-specific care, a dietician who crafts individualized nutrition plans and counseling, a dedicated mental health provider, health service advocates, and a nurse. A defining strength of the HAPPENS program is its integrated adolescent medicine–led primary care, linkage to primary care, and partner support spanning adolescence through young adulthood.

High-quality care for YA living with HIV necessitates deliberate attention to their specific health needs. In addition, comprehensive support services that are individually tailored are necessary to complement medical services to facilitate the initiation and retention of care for YA living with HIV who often face additional challenges of provider bias, structural and institutional racism, and other social determinants of health [5, 6]. Among the commonly cited barriers to care engagement among YA living with HIV are challenges related to mental health, health literacy, and a lack of collaboration among providers [5, 6]. Fostering a positive healthcare experience is essential to mitigating these barriers and reducing health disparities. This study sought to explore the experiences of YA living with HIV who are currently or were previously engaged in our multidisciplinary care model. Specifically, we wanted to understand their experiences with HIV-related healthcare engagement and retention, including facilitators and barriers to receiving care, and elicit their feedback for improving this care delivery model.

2. METHODS

2.1. Participants

Twenty YA living with HIV aged 21-32 years (M=25.8 years, SD=2.7 years) were recruited from the HAPPENS program to participate in this study. Participants were required to be current or former HAPPENS patients and speak English. There was a total of 42 patients who met the eligibility criteria. Sample size was determined by thematic saturation [7, 8]. All eligible HAPPENS participants were invited to participate in the study. Potential participants were contacted a maximum of three times by case managers in our program via telephone or a HIPAA-compliant message system or approached during an in-person clinic visit to provide adequate opportunity for participation while minimizing participant burden and avoiding excessive contact. Saturation was defined as the point at which no new themes, codes, or concepts emerged from successive interviews. This occurred after 20 participants had completed interviews, and this sample size was sufficient to address the study objectives.

Patients who were able to be contacted were informed about the study and asked if they would be willing to participate. No patients were deemed ineligible after agreeing to participate in the study. Participants were primarily ages 26-30 years (90%), men (65%), Black (65%), had perinatal HIV transmission (80%), and were current patients of the program (65%). Additional participant demographics are in Table **1**.

Table 1. Demographics of current and former happens patients who were interviewed regarding their experiences with the program, N=20.

Variable	n (%)
Age (years)	
21-25	1 (5)
26-30	18 (90)
>30	1 (5)
Gender identity	
Women	7 (35)
Men	13 (65)
Race/ethnicity	

Variable	n (%)
Black	13 (65)
White	4 (20)
Mixed race/ethnicity	1 (5)
Another race/ethnicity	2 (1)
Hispanic	
Yes	6 (30)
No	14 (70)
HIV Acquisition	
Perinatally acquired	16 (80)
Behaviorally acquired	4 (20)
Patient Status	
Current patient	13 (65)
Former patient	7 (35)

2.2. Study Procedures

Following informed consent, each participant completed a brief demographic survey that included questions about (1) preferred name; (2) date of birth; (2) gender identity; and (3) race/ethnicity. Participants then completed a one-time semi-structured interview lasting 30- 60 minutes between October and December 2023. Interviews were conducted in English virtually via Zoom by a trained interviewer, and all participants reported that they were in a private location where they could speak confidentially. During the interview, participants were asked to describe their experiences working with the HAPPENS program, facilitators and barriers to receiving care, and recommendations for improving the program. An example question inquiring about barriers to receiving care was “Can you tell me about a time you experienced challenges that made it difficult for you to make it to your [HAPPENS] appointment?” An example question inquiring about recommendations for improving the program was “What are some things that could be improved about the Boston HAPPENS program?” Additional questions and probes were tailored based on participants' responses. Interviews were audio-recorded and professionally transcribed, and interview transcripts were masked to remove identifying information before analysis. This study protocol was approved by our institution's Institutional Review Board.

2.3 Researcher Positionality

The authors approached this work with expertise in Adolescent and Young Adult Medicine, a field grounded in trauma-informed care principles and multidisciplinary team-based practice. The HAPPENS program is grant-funded and places strong emphasis on non-biased, equity-focused care. Four members of the authorship team are providers and supporting staff who routinely participate in educational seminars focused on caring for YA living with HIV. Other fields of expertise in the authorship team include developmental psychology and gender studies. The research team members bring varying degrees of clinical and research experience working with YA living with HIV. To enhance reflexivity, at the outset of the analytic process, the authors engaged in structured discussions to identify and reflect on their own assumptions, professional lenses, and potential biases related to the population.

2.4 Analytic Method

We coded the interview transcripts using the online mixed-methods platform Dedoose and analyzed transcripts using a reflexive thematic analysis approach [9]. We first engaged in data familiarization with a subset of four transcripts, identified by the lead analyst to ensure a variety of experiences were represented, which were then used to develop a draft codebook. The codebook included deductive codes based on the goals of the study and the interview questions (e.g., *care engagement*: engagement with care within the multidisciplinary program, and *adherence*: adherence to medication used to manage HIV), and inductive codes that we identified during data familiarization (e.g., *parental role*: role as a parent living w/ HIV) [10]. We then tested the draft codebook with the same subset of transcripts and made revisions as needed.

The revised codebook was applied to the full set of transcripts. Each coder independently coded half of the transcripts and reviewed the other half of the transcripts coded by the other study team member. Discrepancies in coding were discussed and resolved through frequent meetings. We also used these meetings to further refine the codebook, adding, deleting, and merging codes as necessary. Any new codes added during the coding process were retroactively applied to previously coded transcripts. After all 20 transcripts were coded with the full codebook, we independently identified potential themes and met to discuss and compare them. Through ongoing meetings, we refined and finalized the themes, which are described in the results below.

3. RESULTS

We identified four themes that encapsulated participants’ experiences with the HAPPENS program: 1) Challenges to accessing and utilizing care, 2) Facilitators to accessing and receiving care, 3) Impact of receiving care with the HAPPENS program, and 4) Comparisons of care: HAPPENS *vs*. other healthcare settings. Each theme is illustrated in Table **2** and with examples below. Additionally, we outline recommendations that participants shared for improving the program.

Table 2. Qualitative themes, subthemes, and illustrative quotes.

Theme	Subtheme	Illustrative Quotes
Theme 1. Challenges to accessing and utilizing care: Challenges to accessing and utilizing care related to their relationship with providers, personal experiences and mental health, medication adherence, and insurance and system navigation.	Relationships with providers	"I was just over everybody and the things that they were telling me, and I was just really frustrated.I had to understand that my main doctor and my HIV doctor are different, and I really didn't get along with my HIV doctor" (22-year-old current patient, recently acquired HIV)
	Personal and mental health challenges	"There were times where, you know, I've missed appointments just because I didn't want to be in the hospital at all. It's more stressful mentally just to have to accept or just process a diagnosis. And then, you know, just coming from a normal, healthy standpoint to, you know, processing the diagnosis, to coming to appointments every other month, thereabout…To just discuss your health every second, a little bit of rub in the face" (24-year-old current patient, recently acquired HIV)
	Medication adherence	"I think the big moments are I'm not actively thinking… "Oh, put my pill in my purse and go out." I think it's just that I'm not around. And these moments are very rare, where I quite… Like, not… What am I trying to say? Like, I literally purposely not take it because I'm like, "I don't feel like being diagnosed." (25-year-old current patient, perinatally acquired HIV)
	Insurance and system navigation	"So, a big thing with being an international student is that you can't work in the United States. And people don't understand the international space. And so, how do I get assistance? without you having some sort of schooling attached to it. And once I, you know, graduated and had gone through my year of work, I could no longer qualify for health insurance, so I no longer had private insurance or a company's health insurance" (25-year-old current patient, perinatally acquired HIV)
Theme 2. Facilitators to Accessing and Receiving Care: Positive experiences in the HAPPENS program and staff who facilitated positive experiences accessing and receiving care	Communication with the multidisciplinary care team	"And as recently I needed to be seen… by the doctor, my primary, and she wasn't available. So… [case manager] had scheduled me an urgent care appointment. And as I said, all this is through text, which is, like I said, phenomenal, because they respond very quickly. And I can't always just call, especially if I'm out in public, too. I don't want to just be making… an important appointment out loud. So… The fact that I can text them is just great, and that they text back very quickly." (26-year-old current patient, perinatally acquired HIV)
	Appointment reminders and assistance getting to appointments	"And it's been pretty decent since… like, I'm able to, like, make my schedule, and then, I have HAPPENS as a reminder. And they also help me schedule things when I forget. So, it's really been super helpful." (22-year-old current patient, perinatally acquired HIV)
	Financial assistance and support in navigating health insurance	"I actually got off the phone with her [case manager] just now… I think that HAPPENS in general is just amazing at providing resources. And so, I know there was like a utility payment assistance program, and I got to take advantage of that, which was so much help. You have no clue. I think that even with questions about my insurance and what I may or may not qualify for. I think we just applied for the Forgiveness Program with National Grid, because I do qualify for it as someone with MassHealth. So, I wouldn't have known that on my own had [case manager's name] not suggested it and figured it out. "Hey, [client #14's name], what works for you? What's doable for you? What do you need?" And we were able to apply for that together. And she was with me on the phone, where she could jump in if there was something that I didn't" (25-year-old current patient, perinatally acquired HIV)
Theme 3. Impact of Receiving Care with the HAPPENS Program: How engaging in care with the HAPPENS program impacted the health of YA living with HIV.	ARV adherence	"I've learned that I need to take… food with the medicine. And it was really important. And I really didn't understand how important that was until I started taking the medicine. And I started feeling sick when I wasn't eating anything on the medicine. that I've learned how to eat and learned when I need to eat and make sure that I eat, that's helped me" (24-year-old current patient, recently acquired HIV)
	Improved HIV care knowledge	"So that was another thing that I learned, that, you know, I could have children that didn't have to be born with HIV. So, I feel like ever since then, I feel like I was more in control." (22-year-old current patient, recently acquired HIV)
	Services kept patients engaged in care	"Yeah, it has made it easier for me to reach out instead of having to come in all the time… There have been multiple ways to reach out." (24-year-old current patient, perinatally acquired HIV)
	Improved healthcare system navigation	"I feel like Boston HAPPENS helped provide some sort of structure in my life because, uhm, you know, a lot of the things. I'm still young and still trying to, you know, maneuver on adulthood and they kind of, in a way helped me with some sort of routine, like even with my doctors or like just being on top of things and like, I don't know, it was just super helpful just to have them in place to just help me keep the train going, because I feel like if I didn't have them, I probably would be stuck in certain situations, wouldn't have assistance with this and that, and just would just be all over the place." (27-year-old current patient, perinatally acquired HIV)
Theme 4. Comparisons of Care: HAPPENS *vs.* Other Healthcare Settings: Former participants discuss their current care compared to previous care at HAPPENS, and current participants transitioning to adult care after HAPPENS	--	"I only don't like that because that actually just really means adulting. I think I'm capable of doing it. But as I said, I like the staff. I feel like I have a good rapport with the staff, and so just trying to find another doctor that makes me feel that comfortable and another staff that's as supportive probably doesn't really exist for adults." (25-year-old current patient, recently acquired HIV)

3.1. Theme 1: Challenges to Accessing and Utilizing Care

Participants discussed challenges in accessing and utilizing care related to their relationship with providers, personal experiences and mental health, medication adherence, and insurance and system navigation.

3.1.1. Relationships with Providers

Relationships with providers often posed challenges with initial and ongoing care engagement for YA living with HIV in care. Experiencing paternalistic care where YA living with HIV felt like they were not being treated as adults often resulted in them feeling like they did not have autonomy in their care. A 22-year-old perinatally acquired current patient stated, *"I'm not good with being told something, and then, you like pressing the issue on me as if I'm not an adult. Like, I understand what you're saying, but you're not going to keep pressing the issue on me and making me upset because it's going to make me not want to do it."*

Provider turnover was a related challenge, which necessitated reestablishing care with someone new and often resulted in patients disengaging from services. Participants described how provider turnover often had a significant impact on their care engagement. One 30-year-old perinatally acquired former patient reflected on this, *"The only thing that I would say is that it's really hard and it's kind of unavoidable to find someone that you click with, and they got to leave. Do you know what I mean? I know it's like, kind of unavoidable, but if there was anything that y'all could do with that, that'd be great."*

3.1.2. Personal and Mental Health Challenges

Personal challenges (e.g., housing insecurity, family schedules, and transportation) and mental health challenges often impacted the care engagement of YA living with HIV. One 30-year-old former patient participant noted the impact of housing insecurity on care engagement, *"I was homeless and, you know, it was just rough to really do anything. So, I was missing those appointments, you know."*

Another former patient, 26-years-old, perinatally acquired former client described how he sometimes prioritized attending his mental health visits rather than his medical visits: *"I always enjoyed talking to you guys and stuff like that, but you know the depression and stress were more towards my clinical side. So, my missing a clinical day was more about the medical side. It was never about missing therapy. For example, if I were to miss a medical appointment and still be able to go to my therapy appointment, I would make sure I made my therapist appointment."*

Lastly, one 25-year-old current patient who recently acquired HIV discussed the personal challenge of accepting their HIV diagnosis and the burden of the responsibilities that come with managing HIV, which often affected their engagement in care: *"There were times where, you know, I've missed appointments just because I didn't want to be in the hospital at all. It's more stressful mentally just to have to accept or just process a diagnosis. And then, you know, just coming from a normal, healthy standpoint to, you know, processing the diagnosis, to coming to appointments every other month, thereabout… To just discuss your health every second, a little bit of rub in the face."*

3.1.3. Medication Adherence

Challenges to HIV medication adherence were often impacted by a variety of factors that complicate HIV management. Some participants described choosing not to disclose an accurate depiction of their medication adherence to providers or not taking their medications because they were feeling good in terms of their overall health. One 26-year-old perinatally acquired former patient described how he often stopped taking his medication when he was feeling good, *"Even when I was off meds for, I think six years. I didn't take a lick of medicine at all. Six years. [My health] wasn't bad in my sense. I think I was looking good, and I was feeling great. You know, people say, oh, you know, you look a little skinny, you tell them, 'Hey, I'm not taking my medicine', when I'm telling my doctors, 'Hey, I'm taking my medicine.'"*

3.1.4. Insurance and System Navigation

Navigating the insurance system was often described as a difficult task for YA living with HIV. Participants described how co-pays often posed a financial burden and directly impacted their ability to adhere to medications or even attend appointments. The lack of a clear understanding of how insurance works, combined with the complexity of medical systems, left many feeling lost or overwhelmed, making it harder to seek care when needed. A perinatally acquired, current patient, aged 27 years, said, *"I had a problem recently where my insurance switched. So, my pharmacy I've been going to for, like, I don't know how long now, refused to give me meds because they said my insurance no longer, uhm, they don't [any] longer accept my insurance there. So, I did go a little bit of time without my meds."* A 28-year-old perinatally acquired former patient also described challenges related to navigating insurance: "*Even almost being 30 years old, every time I need to renew my insurance, it's still such a confusing thing."*

3.2. Theme 2: Facilitators to Accessing and Receiving Care

While some participants described the challenges of receiving care, many participants described positive experiences in the HAPPENS program and staff who facilitated positive experiences accessing and receiving care. Some of the most salient facilitators included communication with the multidisciplinary care team, appointment reminders and assistance getting to appointments, and financial assistance and support navigating health insurance.

3.2.1. Communication with Multidisciplinary Care Team

Participants described the multidisciplinary nature of the HAPPENS program as beneficial, with some sharing their appreciation for this care model. Even when patients did not interact with all team members, participants noted that it was helpful to know resources existed if needed. One 25-year-old patient who has been a patient of the program for more than five years and recently acquired HIV said, *"So, I do like the staff, like I said, [DOCTOR], I like the team. I don't overly like all of the support staff, but it's nice when they're there. It's also just strangely nice to get offered things, or like, know that they can help me do things if I need it. Or just like talk me through how to do things."*

Participants noted the positive impacts of open communication with the program staff on their health. They described how the openness and comfort they feel have been important for developing an effective medical plan with their care teams. For example, a 23-year-old perinatally acquired patient who has been a patient in the program for more than five years shared, *"Anything I need or want for my care, I just ask, and it's talked about, and then I get it. So, I mean, I've been able to be on the best meds that are out there at the moment, each time they're available. And it's been great. I have no complaints."*

The multidisciplinary nature of the care team allowed patients to receive referrals and information about the most up-to-date treatment options. Participants described how the program has been particularly useful for populations who may be more likely to have inconsistent care, such as college students. One 22-year-old college student who is a relatively new patient (between 1-3 years) and recently acquired HIV, shared her experiences communicating with her care team, *"They're pretty good, and they're convenient for me. As a person who is a college student, I'm always on the go, and I always have someone to text or to call and figure something out."*

3.2.2. Appointment Reminders and Assistance Getting to Appointments

While many participants discussed the challenges of getting to appointments, some shared how the team assisted in mitigating these issues. Appointment reminders, specifically from case managers, were very helpful for participants. Assistance getting to appointments was also appreciated, as some participants found it difficult to get to the clinic for their appointments due to factors such as work schedules, lack of consistent public transportation, and traffic. A 24-year-old patient who has been a patient of the program for more than five years and recently acquired HIV, discussed the assistance he received getting to the hospital, *"I've had the program call me an Uber from my house to the job to go to the hospital. I've been given multiple, multiple bus tickets. There have been times when I'm like, 'Oh, I didn't eat before I left the house.' I've been given food vouchers."*

3.2.3. Financial Assistance and Support Navigating Health Insurance

The program's financial assistance initiative proved to be important for the well-being of patients. Participants also described how case managers assisted patients in navigating the sometimes overwhelming and confusing systems of health insurance and the HIV Drug Assistance Program (HDAP). One 25-year-old current patient who has been in the program for 1-3 years and recently acquired HIV reported on the assistance they received navigating the hospital's billing department and health insurance, not only for herself, but for her child as well: *"So, they helped a lot when it came to... not just myself, but for my son. When I had to get in touch with a certain billing department, I wasn't able to get through to them. Or when it came to the medical, having to go to the insurance and get questions and things from them. They kind of helped navigate me with being on the phone with me and actually getting the help and getting the questions answered that were needed."*

3.3. Theme 3: Impact of Receiving Care with the HAPPENS Program

We identified various subthemes representing how engaging in care with the HAPPENS program impacted the health of YA living with HIV. It improved their ability to adhere to an antiretroviral (ARV) medication regimen and their knowledge of HIV care. Services offered through the HAPPENS program also kept patients engaged in medical care and improved their ability to effectively navigate the healthcare system.

3.3.1. ARV Adherence

There were many reasons YA living with HIV gave related to poor adherence to ARV regimens, including mental health challenges, availability/accessibility, and pill burden. Although participants described experiencing these challenges, they also described how being engaged with the HAPPENS program, with many touchpoints for reminders, resulted in improved ARV compliance. A 30-year-old perinatally acquired former patient discussed her struggles with adherence, sharing, *"I struggled a lot growing up with [medication] adherence. So, after years of working with the [HAPPENS program], I have those types of skills that I can turn to. So, they helped me, like with those types of things, like putting in a reminder in your phone, you know?"*

One 27-year-old former perinatally acquired patient shared how the HAPPENS program was instrumental in motivating him to take his medication, *"So definitely, you know, every time I had mental health breakdowns or anything of that nature, just speaking with my team I was working with helped. They motivated me to actually take my medicine, even if my mental space was down for a week. It was them, the reason why I was taking [medications], even just for a week or three days. That was the motivation I needed, even just for like the three days I was taking them...They built my confidence to actually do it, you know. Not speaking to them every day, you end up* *losing motivation and think, 'I'm not going to take [my medications].' I'm going to take it later or whatever the case may be. But every time I did speak to them, it was definitely better for my health. 100%"*

3.3.2. Improved HIV Care Knowledge

Participants described how being well-informed on evidence-based medicine positively impacted their lives. Oftentimes, YA living with HIV inquired about how HIV would affect various aspects of their lives, from schooling to reproductive health. Participants also discussed how HIV has transformed into a chronic disease that can be managed with medications. Being engaged in the HAPPENS program provided positive insights to many patients. A 28-year-old perinatally acquired former patient discussed how she learned about crucial health information, *"You know, another thing I learned in that group was that you could have kids that weren't born with it. I just assumed that if you have children, it's in your blood, it's going to go in their blood, you know what I mean? So that was another thing that I learned, that, you know, I could have children that didn't have to be born with HIV. So, I feel like ever since then, I have been more in control. I was literally in control of whether my children we're going to have to deal with the stigma or not, you know?"*

3.3.3. Services Kept Patients Engaged in Care

Participants described the benefits of services being linked to care for their healthcare engagement. A 30-year-old perinatally acquired former patient shared, *"I definitely made more of my doctor appointments and was more on top of it, you know, because I did have multiple things tied into it. So, it was kind of like, I'm going to access these services, so I might as well come to the appointments too, you know."*

3.3.4. Improved Healthcare System Navigation

Participants described how the HAPPENS program offered many resources to assist patients with navigating the healthcare system, such as case managers who were easily accessible. Discussing how the program helped her navigate the complexity of healthcare systems, a 25-year-old current perinatally acquired patient shared, *"I think [HAPPENS] does a really amazing job at making me feel supported and empowered because I can ask them questions, they can educate me. And if there is something that I need assistance with, they will never shut it down, really. It's all a learning opportunity. And we figured it out together, so I love them...And I think that's just because of the ease of access, and how I don't have to think too hard about a particular need of mine and ponder...I can easily just text the [HAPPENS] team and say, like, 'Hey, is this something that I can talk to you guys about? Or which resource could you possibly point me to ask this question?' Right? So, it doesn't give space for a lot of pondering, which gives me peace."*

3.4. Theme 4: Comparisons of Care: HAPPENS *vs.* Other Healthcare Settings

Participants represented both current and previous patients in the HAPPENS program, some of whom had already transitioned to adult care. Current patients were asked how they felt about having to transition to adult care. Many participants expressed hesitancy about transitioning due to the positive experiences with the HAPPENS program, and uncertainty about receiving care in the future in other healthcare settings. For example, one 30-year-old perinatally acquired current patient shared her feelings on having to soon receive care elsewhere, *"I've been going to the same doctors for my whole life, basically... But yeah, I mean, it's nerve-wracking, but it's part of being an adult, I guess."* This participant was not alone; when asked how she feels about leaving the program in the future, another 25-year-old perinatally acquired current patient shared, *"I don't want to...but I know eventually I have to. It's just mostly for me, kind of getting mentally prepared for that rather than physically prepared. Because I'm not ready to leave what I've known for so long... And actually, have to go out into the real adult type of world for that side of our life. Only because I know everybody from growing up."*

Some participants left the program because they moved to a different state and were no longer eligible to receive services. One 26-year-old participant, a perinatally acquired former patient, left the program due to relocating to another state. When asked about his experiences after leaving the program, he shared about his lack of current care and the benefits he received while receiving care, *"Yeah. I mean, I'm still getting used to everything, so I really don't honestly get any care [currently]. It's like [now] I just see my doctor, they tell me this, they tell me that, I don't have no resources, no help, so when I was out there [state where HAPPENS program is located] and I was receiving the care and I was with the [HAPPENS] program there was better help, it was definitely more, beneficial than now."*

3.5. Recommendations

In addition to the themes identified above, participants shared recommendations to improve the HAPPENS program. Multiple participants suggested offering more appointment times outside of the one clinic day, as single-day availability often posed conflicts with their schedules for work, family, or school. Some participants also suggested increasing the number of virtual appointments offered. Another recommendation came from a participant while discussing fears about transitioning to adult care in the future: a 25-year-old, perinatally acquired current patient recommended that the program provide resources on navigating adult care and provide guidance on self-advocacy in adult healthcare spaces.

4. DISCUSSION

This study aimed to explore the lived experiences of YA living with HIV who are currently or were previously engaged in a multidisciplinary care program, with a focus on factors influencing healthcare engagement and retention and opportunities to improve care delivery.Overall, participants' narratives highlight the value of integrated, multidisciplinary care in supporting retention and re-engagement in HIV care—an ongoing challenge for YA living with HIV. The HAPPENS program facilitates linkage and continuity by intentionally integrating medical and supportive services, creating a pathway for individuals who are disengaged from care to re-enter the healthcare system. Although our sample consisted of participants currently engaged in care, their experiences align with prior literature on YA living with HIV, suggesting broader relevance across care settings. [1, 11]

A consistent theme throughout participant narratives was the critical role of ancillary providers, particularly case managers and mental health professionals. These providers offered both logistical and emotional support that extended beyond the scope of traditional medical care. Many participants reported preferring to engage with their therapist or case manager rather than their medical provider, underscoring the importance of non-medical relationships in sustaining engagement. This finding was illustrated in other studies, showing that ancillary providers play a critical role in patients' care experiences. [12, 13] Participants also highlighted how being engaged in a multidisciplinary program improved their ARV adherence. Consistent reminders from case managers and tools to help with medication adherence (e.g., pill boxes) were resources patients found particularly helpful. At the same time, perceived barriers to ARV adherence emerged, particularly among participants who felt asymptomatic and therefore questioned the necessity of strict medication adherence. This perception is consistent with other research indicating that many YA living with HIV have not had personal experience with morbidity and mortality associated with untreated HIV infection, resulting in reduced urgency in managing their HIV care [14].

The patient–provider relationship emerged as a significant factor in care engagement. Similar to findings in other studies, participants emphasized that interactions perceived as paternalistic or patronizing were perceived as barriers to ongoing engagement to higher retention rates in the program observed among participants in the current study. [12, 13, 15]

The HAPPENS program has implemented several changes based on participants' recommendations. The program expanded appointment availability beyond a single clinic day, increased access to satellite clinic locations for visits and laboratory testing, and broadened the availability of virtual visits. This improved open access model has been well-received by current patients.

This study has limitations. Participants were recruited from a single multidisciplinary program in the New England region of the US, limiting the generalizability of findings to other regions or clinical settings. Additionally, the sample was predominantly composed of Black males, which may not reflect the full diversity of YA living with HIV. Although our qualitative design prioritized understanding shared lived experiences within a multidisciplinary care model, participants were recruited exclusively from the HAPPENS program, and no comparison group by mode of HIV acquisition was included. Future research should intentionally examine differences in experiences between perinatally and recently acquired HIV to further inform tailored care approaches, and aim to capture perspectives from a broader range of identities and lived experiences, and from those not currently engaged in care. Despite its limitations, this study had several strengths. The sample population provided invaluable firsthand perspectives about care engagement in the setting of a multidisciplinary care program. It also provides narratives on transition from pediatric/adolescent care to adult services—a critical phase in the HIV care continuum for YA living with HIV, during which care is often lost.

CONCLUSION

This study contributes important qualitative insights into the experiences of YA living with HIV in a multidisciplinary care setting. Our findings can inform the development of targeted interventions to enhance medication adherence, engagement in care, and overall well-being among YA living with HIV. The results also highlight the importance of holistic, young adult-centered care models that integrate medical, mental health, and social services; these models should not be limited to adolescent/young adult care but should also be expanded to adult care. Future efforts should focus on expanding access to comprehensive care and implementing scalable interventions to improve retention of care for YA living with HIV.

AUTHORS’ CONTRIBUTIONS

The authors confirm their contributions to the paper as follows: J.A.: Drafted the initial manuscript, analyzed the data, contributed to the interpretation of the results, and approved the final manuscript as submitted; R.K.: Analyzed the data and contributed to the interpretation of the results, wrote the methods section, and edited the manuscript; I.A., A.B., S.F., and S.K.W.: Critically reviewed and revised the initial manuscript and approved the final manuscript as submitted.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

Our study was approved by the Boston Children’s Hospital Institutional Review Board (approval no. IRB-P00044717)

HUMAN AND ANIMAL RIGHTS

The study was conducted according to the principles of the Declaration of Helsinki.

CONSENT FOR PUBLICATION

All participants provided written informed consent before enrollment in the study.

STANDARDS OF REPORTING

Strobe guidelines were followed.

AVAILABILITY OF DATA AND MATERIALS

The data and supportive information are available within the article.

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CONFLICT OF INTEREST

The authors declare no conflict of interest, financial or otherwise.

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REFERENCES

[1] Laurenzi CA, du Toit S, Ameyan W, *et al.* Psychosocial interventions for improving engagement in care and health and behavioural outcomes for adolescents and young people living with HIV: A systematic review and Meta-Analysis. J Int AIDS Soc 2021; 24(8): e25741. http://dx.doi.org/10.1002/jia2.25741 PMID: 34338417

[2] Ritchwood TD, Malo V, Jones C, *et al.* Healthcare retention and clinical outcomes among adolescents living with HIV after transition from pediatric to adult care: A systematic review. BMC Public Health 2020; 20(1): 1195. http://dx.doi.org/10.1186/s12889-020-09312-1 PMID: 32746881

[3] Johnson-Peretz J, Lebu S, Akatukwasa C, *et al.* "I was still very young": Agency, stigma and HIV care strategies at school, baseline results of a qualitative study among youth in rural Kenya and Uganda. J Int AIDS Soc 2022; 25(Suppl 1): e25919. http://dx.doi.org/10.1002/jia2.25919

[4] Crum NF, Riffenburgh RH, Wegner S, *et al.* Comparisons of causes of death and mortality rates among HIV-Infected persons: Analysis of the pre-, early, and late HAART (highly active antiretroviral therapy) eras. J Acquir Immune Defic Syndr 2006; 41(2): 194-200. http://dx.doi.org/10.1097/01.qai.0000179459.31562.16 PMID: 16394852

[5] Soomar SM, Qamar W, Azizullah Z, Ali TS. Challenges in healthcare access for young people living with HIV: A review. J Glob Health Econ Policy 2023; 3 http://dx.doi.org/10.7189/001c.117353

[6] Harrison SE, Muessig K, Poteat T, *et al.* Addressing racism's role in the US HIV epidemic: Qualitative findings from three ending the HIV epidemic prevention projects. J Acquir Immune Defic Syndr 2022; 90(S1): S46-55. http://dx.doi.org/10.1097/QAI.0000000000002965 PMID: 35703755

[7] Aldiabat K, Le Navenec CL. Data saturation: The mysterious step in grounded theory method. Qual Rep 2018; 23(1): 245-61. http://dx.doi.org/10.46743/2160-3715/2018.2994

[8] Hennink M, Kaiser BN. Sample sizes for saturation in qualitative research: A systematic review of empirical tests. Soc Sci Med 2022; 292: 114523. http://dx.doi.org/10.1016/j.socscimed.2021.114523 PMID: 34785096

[9] Virginia B, Victoria C. Thematic analysis: A practical guide. Thematic Analysis. London: SAGE Publications Ltd 2021.

[10] Borkan JM. Immersion–Crystallization: a valuable analytic tool for healthcare research. Fam Pract 2022; 39(4): 785-9. http://dx.doi.org/10.1093/fampra/cmab158 PMID: 34849754

[11] Kapogiannis BG, Koenig LJ, Xu J, *et al.* The HIV continuum of care for adolescents and young adults attending 13 urban US HIV care centers of the NICHD-ATN-CDC-HRSA SMILE Collaborative. J Acquir Immune Defic Syndr 2020; 84(1): 92-100. http://dx.doi.org/10.1097/QAI.0000000000002308 PMID: 32267659

[12] Rajabiun S, Mallinson RK, McCoy K, *et al.* "Getting me back on track": The role of outreach interventions in engaging and retaining people living with HIV/AIDS in medical care. AIDS Patient Care STDS 2007; 21(s1): S-20-9. http://dx.doi.org/10.1089/apc.2007.9990 PMID: 17563286

[13] Hall BJ, Sou KL, Beanland R, *et al.* Barriers and facilitators to interventions improving retention in HIV care: A qualitative evidence Meta-Synthesis. AIDS Behav 2017; 21(6): 1755-67. http://dx.doi.org/10.1007/s10461-016-1537-0 PMID: 27582088

[14] Shacham E, Estlund AL, Tanner AE, Presti R. Challenges to HIV management among youth engaged in HIV care. AIDS Care 2017; 29(2): 189-96. http://dx.doi.org/10.1080/09540121.2016.1204422

[15] Mallinson RK, Rajabiun S, Coleman S. The provider role in client engagement in HIV care. AIDS Patient Care STDS 2007; 21(s1): S-77-84. http://dx.doi.org/10.1089/apc.2007.9984 PMID: 17563293