The Clinic Environment as a Form of Social Support for Adolescents and Young Adults Living with HIV

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Abstract

Adolescents and young adults living with HIV (YLHIV) face numerous stresses that affect their care and medication adherence. The clinic social environment may play an important supportive role for YLHIV, influencing health outcomes. The aim of this article is to explore how YLHIV in Baltimore, Maryland understand the various forms of social support provided within the social environment of their HIV clinic. We used qualitative research methods including iterative, semi-structured in-depth interviews with 20 YLHIV interviewed up to three times each to explore HIV stressors, support systems, and medication adherence. We employed thematic content analysis to systematically code and synthesize textual interview data. We found that YLHIV experienced social embeddedness with their healthcare teams and through clinic activities. Participants largely perceived these social connections as support, acknowledging that these supports are available to them when needed. Support was enacted through the provision of instrumental support for issues outside of the young person's medical care (i.e., finding a crib for a participant's baby), appraisal (i.e., through respect of the young person's agency and decision making), and information about their HIV care and medication. Support was not always well received, however, as some young people found the support from clinicians demeaning. Limitations of the clinic social support environment included concerns about trust and privacy, and perceiving support as inappropriate or unwanted. Participants identified a number of ways in which the clinic provided meaningful social support. Future research should explore how these supports may improve care and medication adherence of YLHIV.

Keywords: youth, young adults, HIV, medication adherence, support

Introduction

ADHERENCE TO HIV treatment recommendations, crucial to treatment success, is alarmingly poor, resulting in preventable morbidity and mortality.^{1–5} A review of over 50 studies found that 42–80% of young people living with HIV (YLHIV) had suboptimal medication adherence.⁶ It is estimated that among YLHIV who initiate antiretroviral therapy (ART), only 54% achieve viral suppression,⁷ and virological failure after suppression is common among youth.⁸ Among all YLHIV in the United States, less than 6% are virally suppressed.⁷ Medication adherence may be particularly challenging for YLHIV, as it is affected by a complex interplay between social and developmental factors related to the normal developmental trajectory of adolescence and young adulthood (i.e., behavioral experimentation, risk taking, identity formation)⁹ and their infection with HIV.

The role of social support has long been understood to impact health, and among adults living with HIV has consistently been correlated with medication adherence. Barrera suggested that there are three types of support.¹⁰ Social embeddedness is the connections people have with others in their environment, or their social network. These network connections are believed to be associated with a person's sense of belonging; it is a person's "psychological sense of community."¹¹ While the social network represents potential support, perceived social support is the cognitive understanding of those network linkages (i.e., level of confidence in the availability and appropriateness of that support).¹⁰ Finally, enacted support refers to the behaviors or action of others as they express their support. Enacted support may be emotional, instrumental (i.e., aid with tangible needs), appraisal (i.e., feedback, helping decision making), or informational (giving advice or information in the service of particular needs).^{10,12} Researchers have

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proposed a number of pathways through which social support may affect adherence behavior, including positively influencing mood,¹³ providing hope or motivation,¹⁴ increasing confidence,¹⁵ providing tangible assistance,¹⁶ and providing information.^{15,16}

Few studies have considered the direct role of social support and medication adherence among YLHIV. These studies have found no direct effect of social support from family and friends and medication adherence, although its availability appears to affect depressive symptoms and social stigma, both of which are correlated with lack of adherence among YLHIV.^{17,18} Although research on social support is often focused on family and friends, medical providers may play an important supportive role for YLHIV and evidence suggests that the relationship between YLHIV and healthcare providers may affect medication adherence.^{19–21}

To improve all aspects of the continuum of care for YLHIV, including medication adherence and viral suppression, considerations of clinic spaces and the ways in which clinics approach youth-friendly healthcare have been investigated. Often, however, this research focuses on the structural aspects of the clinic, such as the clinic location, primary patient population (i.e., pediatrics, adolescent-only, HIV-only), waiting area and physical space, and availability of making appointments. The aim of this article is to explore how YLHIV in Baltimore, Maryland perceive the *social environment* of their HIV clinic and experience the different types of social support provided.

Methods

This qualitative sub-study was embedded in an ongoing parent randomized controlled trial to assess the efficacy of a mindfulness-based stress reduction (MBSR) intervention on ART adherence outcomes, including viral suppression, and psychological self-regulation among adolescents and YLHIV recruited from adolescent and young adult clinical care sites in Baltimore. The trial was designed with three arms (MBSR intervention, active control/health education, and standard of care control); the standard of care control arm was dropped after a short period of recruitment. Adolescents and young adults were eligible to participate if they were 13–24 years old, HIV-positive and aware of their HIV status, and were recruited from two university-based pediatric and adolescent outpatient clinics in Baltimore. In both locations, medical and social needs are assessed and met by a team of physicians, nurse practitioners, case managers, and social workers.

We conducted iterative semi-structured, in-depth interviews with 20 YLHIV participating in the trial. We utilized purposive sampling to create a stratified sample of adolescents and young adults from the intervention and control arms. We aimed to balance the sample in terms of both gender and mode of transmission (perinatal vs. behaviorally acquired transmission), as much as possible based on the characteristics of the parent trial population. We sought to interview the MBSR intervention participants up to three times each (preintervention, immediately postintervention, and 3 months postintervention), and control participants twice. In total we conducted 44 interviews with 20 participants (11 participants in the intervention arm and 9 participants in the control arm). Participant demographics are provided in Table 1.

Participants were interviewed by a researcher trained in qualitative methods using a field guide containing a series of open-ended questions in key domains such as participant's daily lives, current challenges and goals, relationships with family, friends, and their healthcare team, clinical care and services utilized, adherence barriers/facilitators including social supports, and perspectives on the dynamics and implications of the intervention to which they were assigned. Social support interview questions were predominately in the first interview, although at times discussions of social support were initiated by the participant in the second or third interview.

All participants provided written informed consent before being interviewed. Interviews took place in a private room within the clinical care facility where the participants were recruited and were audio recorded with participant permission. Participants received \$25 for each interview that they completed.

All digital audio recordings were transcribed *verbatim*, reviewed for accuracy, and imported into ATLAS.ti qualitative software. Thematic content analysis was utilized to approach the data.^{22,23} Textual data were coded for both a priori (informed by the field guides) and emergent domains of interest. Code output was synthesized and salient themes were extracted and developed. Thematic codes were compared within a single interview and between interviews,²³ and we considered variability within themes and subthemes by participant category (mode of transmission, gender, clinic of recruitment, and study arm). Variability by clinic of recruitment and study arm was not observed. Quotes were selected to illustrate consistency and diversity within themes and across study arms as relevant.

The Institutional Review Board of the Schools of Medicine at both the Johns Hopkins University and University of Maryland approved the study.

Results

Social embeddedness: the clinic as community

For many of the participants, the clinic housed a network of social connections that were valued and important to the participants. The clinic, for those participants, often formed a community:

Usually they just treat me like I'm a normal person...I just feel comfortable. I don't feel comfortable in too many places, but surprisingly I feel comfortable in the doctor's office. And it's funny because people are scared to go to the doctor, but I find it my sanctuary. (Male, 21 years, perinatal infection)

Many of these participants developed close relationships to healthcare team members:

We [the participant, clinicians, and staff] talk. Everyone here is very—we're all very like a family. (Female, 21 years, behaviorally acquired HIV)

For perinatally infected YLHIV this was tied to their team being present as they grew older:

My social worker—he's a very great guy. He's real friendly. He's always checking on me. He's one of the people that always tell me how good I look, because he knew me since I was in middle school, so he's seen me grow. Like, when he first started working here I was one of the first people that he worked with, so, of course, me putting myself in his shoes, he sees me

TABLE 1. INTERVIEW PARTICIPANT SOCIO-DEMOGRAPHICS

	<i>Male</i>	<i>Female</i>	<i>Total</i>
Age (mean, SD)	22.14 (1.22)	20.85 (2.41)	21.30 (2.13)
Intervention arm, <i>n</i> (%)			
Mindfulness-based stress reduction	3 (42.9)	8 (61.5)	11 (55.0)
Healthy topics	3 (42.9)	3 (23.1)	6 (30.0)
Usual care	1 (14.3)	2 (15.4)	3 (15.0)
Mode of infection, <i>n</i> (%)			
Perinatal	3 (42.9)	9 (69.2)	12 (60.0)
Sexually acquired	4 (57.1)	4 (30.8)	8 (40.0)
Race/ethnicity, <i>n</i> (%)			
Black/African American (non-Latino)	6 (85.7)	13 (100)	19 (95.0)
Missing	1 (14.3)	0 (0.0)	1 (0.5)
Sexual identity, <i>n</i> (%)			
Heterosexual/straight	3 (42.9)	10 (76.9)	13 (65.0)
Homosexual/gay/lesbian	2 (28.6)	0 (0.0)	2 (10.0)
Bisexual	1 (14.3)	1 (7.7)	2 (10.0)
Something else/haven't decided	1 (14.3)	2 (15.4)	3 (15.0)
Education, <i>n</i> (%)			
Currently in high school	0 (0.0)	1 (7.7)	1 (5.0)
Working toward a GED	1 (14.3)	5 (38.5)	6 (30.0)
Dropped out, not working on high school diploma/GED	0 (0.0)	1 (7.7)	1 (5.0)
Have high school diploma/GED, not enrolled in college	3 (42.9)	2 (15.4)	5 (25.0)
Have high school diploma/GED, enrolled in college	3 (42.9)	4 (30.8)	7 (35.0)
Employment, <i>n</i> (%)			
Not employed	3 (42.9)	8 (61.5)	11 (55.0)
Employed part-time	3 (42.9)	5 (38.5)	8 (40.0)
Employed full-time	1 (14.3)	0 (0.0)	1 (5.0)
Mother's education, <i>n</i> (%)			
Less than high school graduate/GED	0 (0.0)	4 (30.8)	4 (20.0)
High school graduate/GED	6 (85.7)	5 (38.5)	11 (55.0)
More than high school graduate/GED	1 (14.3)	3 (23.1)	4 (20.0)
Unknown	0 (0.0)	1 (7.7)	1 (5.0)

GED, General Equivalency Diploma.

growing and doing good things and not giving up or being a bad kid or anything. (Male, 23 years, perinatal infection)

In addition to the relationships built with healthcare team members, for many of the YLHIV the clinic provided an opportunity for social activities to engage, and connect, with other YLHIV. While a few of the male participants engaged in social activities within their clinic, the female participants discussed this support and its importance much more frequently. YLHIV who participated in clinic-based social activities with other YLHIV largely felt that these interactions provided a different level of comfort compared to regular social engagement as concerns about HIV-related stigma were largely removed. While these activities provide a positive social outlet for the adolescents and young adults, it also created connections with peers facing similar challenges and built their social network and support system.

Last night, we had a support group, and we got some of the old kids that I grew up with [in the clinic] and some new ones [younger and/or more recently diagnosed] to just have a game night and get away. (Female, 23 years, perinatal infection)

And then we also have the bigger group, that's with life, fitness and wellness and they have—we do trips, like we go to

the haunted houses and all that, stuff like that, Orioles games and stuff like that... It's good to be around people that are also HIV positive...to know that somebody down the street from you is going through the same thing. (Female, 21 years, behaviorally acquired HIV)

Perceived support of the clinic social network

The clinic social environment expanded the participant's social network, and provided opportunities to engage with other YLHIV. In addition to providing a safe place and sense of community or belonging these social networks were understood by the participants to be a source of support:

I can come to somebody that I don't feel like is a complete stranger but doesn't be in my everyday life but still can help me. But then again it's like they don't have to listen to what I have to say but they choose to. So it's the fact that, yeah, they're my doctors and they're more concerned about my health but the fact that they take the time out to say, "Well, hey, what's going on with this [issue in your life]?" (Female, 23 years, perinatal infection)

One person I love is one of the social workers here...All I've got to do is just call her and say "Hey, this isn't working" or "This isn't going well"... Yeah, you're going through something, but

someone actually cares. You don't get that too often. (Male, 22 years, behaviorally acquired HIV)

Thus, the social connections and embeddedness experienced are perceived to be sources of support for many of the participants. The perceived support in the clinic was not only from the healthcare team, but also from the other youth participants met through clinic activities:

So now you have this also support system of somebody that's going through some of the things that you going through, and that's probably in the same age group. (Female, 21 years, behaviorally acquired HIV)

Enacted support and the clinic social network

Instrumental support. For the participants, living with HIV was only one of challenge in their lives. Many had strained familial relationships, limited support networks, were single parents, faced economic challenges that limited availability of basic needs such as housing and food, and struggled with mental health needs. For many of the participants, the clinic was not just a place to treat their HIV. It also served as a support in other aspects of their lives.

While most of the participants were able to work with social workers to gain instrumental or informational support, often this support occurred organically through the relationships the participants developed with their entire healthcare team.

I love my doctor and my nurse, like they're the best. They're like, "[name] really?" when I come here one of my days crying and they like all right, let's see what we can do if we can help. [Recently] they helped me with [my son's] crib. (Female, 24 years, behaviorally acquired HIV)

Like the school and the roommate situation, I just talk to [my doctor] about it and my financial situation with dealing with school and stuff. She's given me—we went online and looked at different stuff that could help. (Female, 23 years, perinatal infection)

Appraisal and information. An important aspect of the relationship between the YLHIV, and particularly the behaviorally infected YLHIV, and the clinician was the sense of respect the clients felt regarding decision making. Many of the participants reported experiencing ongoing feelings of anger and blame toward themselves and perceived stigma from others as a result of their HIV infection. Thus, the respect from their provider was important for many YLHIV, and particularly those behaviorally infected who felt more responsible for their infection. While conversations about adherence provided the participant with information, they also demonstrated an acknowledgement and respect for the participant's decision making and agency:

Like she'll tell me that I need to take care of my medicine, but then she will sit back and ask me what I feel, how do I feel about it? ...like she'll ask me, am I ready to start the medicines...So, she'll be like, "Well, when is it best that you can start taking your medicine in order that you could continue to take them?" So, she'll ask me things like that, and we'll just sit down and talk about it...And then she's like, "Well, when you feel that you can take it and you're ready to take it and continue to take it on a daily basis, then we can discuss it." (Female, 22 years, behaviorally acquired HIV)

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In the middle of the week something hit me and said "I don't feel like taking this medication anymore. I want something different." ...For me it was just that moment where I was just like "I want something new, but I want to take that week off to figure out what I want." And then we found it, so I'm back on it and... I mean, my doctor make sure I'm in good health, and if something's wrong or if something's out of place we talk about it. She'll ask me "Have you been doing this, that and the third? If so, well, this is what happened, and we need to get this situated." (Male, 22 years, behaviorally acquired HIV)

Challenges to support in the clinic environment

Although most of the participants described the clinic social environment as safe, comfortable, and positive, some YLHIV shared concerns over the privacy of their information known by the healthcare team:

Nowadays doctors is just as worst. Tell your business... Nurses, people that run these buildings you supposed to trust the most, you can't really because I pick and choose who I trust. Like but if you was to come to me and you already know it, then it's nothing I can do about it...It took about a week before I even talked to a staff. (Male, 22 years, behaviorally acquired HIV)

In addition to concerns about privacy in relation to their care team, some participants expressed concern that participating in social activities with other YLHIV could disclose their HIV status to people they know in their personal life. However, most of the participants who experienced this or had concerns about this concluded that this disclosure would be acceptable since it meant, by virtue of the other person being involved, that the other person also is infected with HIV.

Finally, not all participants perceived the support provided by the healthcare team to be appropriate. One participant, for example, perceived some attempts of support to be demeaning:

[The doctor will] say, "Okay. Well, your viral load is this much, this much, and your T-cells is this much and this much." I'm like, "Okay." And she like, "Okay. Well, but can you come in this day and bring your pill?" No. I'm not doing that. I don't need you all to call me. I don't need you all to set up, sit in here like I'm fucking 12, and set up a pill box. If I'm going to take the f***ing pills, I'm going to take them. If I'm not, I'm not. Leave me the f*** alone.... when it come to take them [my pills] I'm either going to take them or I'm not. And that's what it is. (Female, 23 years, perinatal infection)

Participants who expressed challenges to support were less likely to discuss the clinic social network as a support, were less likely to attend social activities, and were less likely to perceive the clinic as a place for support. These participants did, however, provide examples of instrumental support (i.e., receiving bus tokens when needed).

Discussion

Findings from this study suggest that the clinic social environment serves as an important form of support for YLHIV and highlights areas of this support that are meaningful to adolescents and young adults. The majority of participants described the clinic as a shared community and overwhelmingly, these social connections were perceived as a source of support. Many of the perinatally infected participants attending the

clinics for years described the clinic as a comfortable space and demonstrated high levels of perceived support from their relationships with their healthcare team, as did many behaviorally infected youth despite having only engaging in the clinic more recently. Additionally, various types of enacted support were described, and these were not limited to the participant's HIV status (i.e., enacted support included help with the participant's personal issues not related to their HIV infection).

As a result of the unique challenges YLHIV face the potential supportive role of the clinic social environment may be important to promote medication adherence for YLHIV. One of these challenges is adolescent development and the various stages of psychosocial development. As a YLHIV moves into late adolescence and young adulthood, the need to establish independence and autonomy becomes very important and the supportive role of parents, caregivers, and/or family in medication adherence may become counterproductive if the youth feels his/her autonomy is challenged and/or not respected.^{21,24} Among our participants, the YLHIV who spoke positively about their communication and relationship with their clinician framed this positive support as one providing respect of autonomy and agency. While overbearing clinicians or other healthcare team members may also lead to a perceived challenge to autonomy and independence, as was also described by our participants, healthcare providers may be better equipped than parents to navigate this challenge in a way that promotes clinical care and viral suppression while respecting youth agency.

The unique challenges to medication adherence experienced by YLHIV are situated within a context of internalized, anticipated, and enacted HIV-related stigma. Among persons living with HIV of all ages, HIV-related stigma is a critical barrier to medication adherence.^{20,25–27} Additionally, although the magnitude of the correlation between stigma and social support varies across studies, the direction of the relationship is consistent: HIV-related stigma is negatively correlated with social support.²⁸ Considering healthcare satisfaction among female YLHIV, Martinez et al. found that satisfaction with their healthcare had a moderating effect on the negative impact of stigma on medication adherence, and thus argue that having a trusting, positive relationship with their healthcare providers may be an important tool to improve medication adherence.²⁰ In our study, we found the relationship with providers and the level of perceived respect most important to youth behaviorally infected with HIV, many of whom battle feelings of anger and blame toward themselves as well as experience perceived and enacted stigma from others resulting from their infection. Thus, the role of the clinic social environment as moderating stigma experienced outside the clinic may have important implications for interventions to improve medication adherence given the important role of stigma in medication nonadherence.

The findings of this study offer important considerations for future research and interventions. A greater understanding of the ways in which support received through the social environment of the clinical setting (and not simply from clinicians) may influence adherence behavior among YLHIV can aid in the development of interventions to improve this support and promote medication adherence among diverse populations. From our findings and additional support from the literature, however, there are several interventions that may improve medication adherence among YLHIV directly

and/or indirectly. Staff training related to the specific needs of youth, such as their developmental needs and unique social and structural challenges, and availability of clinicians with training in adolescent health and development may improve social connectedness, perceived support, and enacted support.^{29,30} Support may be extended outside of the clinic through mobile health applications that would allow YLHIV to connect with clinicians, staff, and other YLHIV while not physically in the clinic setting.³¹

Another approach that may be important in this environment for clinicians and staff is MBSR. MBSR is a group-based instructional program of meditation techniques to enhance participants' mindfulness, or present-focused, nonjudgmental awareness. Although MBSR is often conceptualized in healthcare to promote mindfulness in patients as a way to improve their ability to cope with a variety of ailments, mindfulness is imbued with an attitude of open-minded curiosity and an attention to kindness and compassion.³² As a result, organizations are increasingly offering MBSR training to improve the workplace.^{33,34} Training for clinicians and staff in MBSR may promote an environment of nonjudgmental and compassionate support to YLHIV, qualities participants in our study highlighted as important. Further research on the effects of MBSR on the clinical social environment, however, is needed.

This study included YLHIV in an urban setting receiving care at pediatric and adolescent outpatient clinics with abundant resources. Results may not be generalizable to YLHIV in other settings or receiving care in types of clinics. Additionally, since participants were recruited through their clinic, participants may have been hesitant to share aspects of their clinical care experience that were not positive.

Adherence to HIV treatment recommendations, which is crucial to treatment success, is alarmingly poor among youth resulting in preventable morbidity and mortality. There is no simple solution to address the challenges YLHIV face that impede their adherence. However, the findings of this research suggest that as researchers investigate barriers to care and identify interventions to improve the youth-friendliness of HIV clinics, the social environment of the clinic must be considered as this constitutes an important source of support for YLHIV and therefore may indirectly promote HIV care and medication adherence.

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