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Participant observation at a youth HIV conference

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Abstract

Young people living with HIV in the US have the potential to live long and healthy lives. However, the psychosocial impact of an HIV diagnosis, complicated by poverty, inequality, stigma and marginalization, create structural and behavioral challenges for young people that can overwhelm them and their health care providers. This narrative provides a reflective analysis of insights and discussions captured through participant observation at a five-day conference for young people living with HIV. The manuscript provides practitioners with an additional interpretive lens, highlighting participant observation as a valuable methodology to better understand and design programs for young people living with HIV. The article calls for youth-led, peer-based approaches that focus on support for disclosure of HIV status, self-esteem in relationships and adherence to medication.

Keywords

HIV/AIDS participant observation, peer support, young people

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Background

Unlike 20 years ago, most of the nearly 40,000 young people, 13–24 years old, living with HIV/AIDS in the US (Centers for Disease Control and Prevention, 2011) have the potential to live through adulthood (Dowshen and D'Angelo, 2011; Wiener et al., 2011). Like their healthy peers, their lives are filled with exploration and anxiety. The importance of social networks, popular culture, 'fitting in,' and establishing independence is just as pronounced as it is with any young person. However, the psychosocial impact of an HIV diagnosis, complicated by poverty, inequality (Centers for Disease Control and Prevention, 2011), stigma and marginalization (Rao et al., 2007) creates structural and behavioral challenges for young people that can overwhelm them and their health care providers (Battles and Wiener, 2002; Dowshen and D'Angelo, 2011; Fielden et al., 2006; Vijayan et al., 2009). As young people begin to transition from pediatric or adolescent health care into adult care settings, they face services and health providers that are not always 'youth-friendly' (Gipson and Garcia, 2009; Peter et al., 2009; Weiner et al., 2009). This can deter them from accessing care and impact their ability to remain on treatment. Equally dangerous are the disproportionate rates of depression, anxiety (Earls et al., 2008; Pao et al., 2000) and sexual and other risk-taking behavior among young people with HIV/AIDS (Koenig et al., 2011; Mellins et al., 2003), which also jeopardize their health and their potential to succeed.

Though growing in number, studies of young people living with HIV/AIDS remain narrow in focus and approach. Most are either: a) descriptive studies that use chart reviews to characterize young people and the challenges they face (Brown et al., 2001; D'Angelo et al., 2003; Frederick et al., 2000; Thorne et al., 2002;); b) qualitative and quantitative studies that use individual interviews or focus groups to obtain information (Battles and Wiener, 2002; Dago-Akribi and Adjoua, 2004; Hosek et al., 2012; Kmita et al., 2002; Lyon and Woodward, 2003; Pao et al., 2000; Valenzuela et al., 2011); or c) program evaluations that are either over a decade old (Bettencourt et al., 1998; Bourdon et al., 1998; Rotheram-Borus and Miller, 1998; Tenner et al., 1998), or assess interventions tested only in clinical settings (Rotheram-Borus et al., 2001; Lightfoot et al., 2007; Woods et al., 2002). What these studies lack is the depth and dynamism found through intensive, peer-based programs. Camps are the closest example, and some qualitative studies from camps exist in the literature. Camps for young people living with HIV/AIDS offer settings for young people to access information about their condition and build a sense of community with peers (Gillard et al., 2011). However, camp curricula concentrate on recreational activities, designating just a fraction of the program to structured conversations about living with HIV/AIDS (Gillard et al., 2011).

In 2009, the One Love Project was created by Next Step in Cambridge, Massachusetts and the SPARK Center at the Boston Medical Center, in response to a World Health Organization (WHO) report that called for improved psychosocial support for young people living with HIV/AIDS (WHO, 2009). Written by the first author, Rena Greifinger, the report called for 1) youth-centered

approaches that engage young people in program design and delivery; 2) increased focus on the development of life-skills and transitions to adulthood; and 3) forums for young people living with HIV/AIDS to build strong communities of peers. One Love's signature program, designed in line with WHO recommendations, is a residential conference that brings together young people (16–25 years old) living with HIV/AIDS and adult allies¹ from throughout the US, for five days of youth-led activities that focus on key psychosocial issues, leadership and life-skills education. Held annually since 2009, and designed by young people living with HIV/AIDS, the conference provides a unique space for many young people who often experience, for the first or only time in their lives, a place for in-depth dialogue and the discovery of peers who share in their life experiences.

After two years of observing the impact this conference had on the participants and on us as health practitioners, we realized the need to capture and share the experience so that we, and our peers, could better understand this population and develop programs that meet their complex needs. We explored ethnographic research methods, particularly participant observation, that would allow us to communicate the thoughts and experiences of conference participants, without disrupting the organic nature of the peer environment. We hypothesized that by listening to young people create their narratives of living with HIV/AIDS, through discussions with one another rather than with a researcher, we could derive new or deeper insights about their experiences that may not germinate through structured interviews. Other researchers working with children and young people with health care needs lend support to this hypothesis. For instance, Carnevale et al. (2008), maintain that observation strategies are particularly effective for research involving children and young people because young participants can perceive interviews as socially awkward, intrusive, and a substantiation of the distorted power dynamic between young people and adults (pp. 19–20). They argue that research with young people must draw on methods that 'recognize their capacities as social actors' (p. 20), particularly when complex health phenomena are under examination (p. 21). In her reflections on using participant observation with disabled children in the UK, Cocks (2008) describes how 'mainstream' children occupy family and community spaces, while disabled children have an additional space – 'specialist care' – that is designed specifically for those children and is set apart from their local communities, schools and families (p. 165). She explains that it is in this specialized setting that the most poignant observations of children's behavior and peer interactions can be made. We view the conference setting in a similar vein. Though more traditional examples of participant observation report on everyday or naturally occurring sociocultural activities (Schensul et al., 1999), it is the very 'unnaturalness' of the conference setting that creates the safety and support for young people to open up, facilitating deep reflection and analysis in ways that home or clinical environments may not.

As a cornerstone of qualitative research, used throughout a range of disciplines (DeWalt and DeWalt, 2010), participant observation, and its place within ethnography's sphere, has been constructed and deconstructed for over half a century

(DeWalt and DeWalt, 2010). We sought a construct akin to *focused ethnography*, in which observation is focused on a single topic, in a specific setting, and conducted in a shorter time period (Simonds et al., 2012). Focused ethnography does not provide the holistic view that a method like *deep ethnography* (Block, 2012) does, in which a researcher combines participant observation, interviews, extensive field notes and long-term immersion in a community (p. 380). However, owing to the nature of the disease, there is no isolated community of young people living with HIV/AIDS to observe over a long period. While this would be the preferred method of ethnography, Forsey (2010) maintains that it does not have to be synonymous with it. He writes, ‘Sometimes fleeting engagement offers a more accurate reflection of lived experience than does any form of “deep hanging out”’ (p. 569).

We were less concerned with the debate concerning whether or not participant observation is synonymous with ethnography (Hammerlsey and Atkinson, 1983), but were struck by Forsey’s (2010) argument for a paradigm shift from a focus on participant observation to participant listening; something he coins as *engaged listening*. His contention that the core of good ethnography really depends on what is *heard* during conversation, rather than what is seen, is echoed by Cohen and Rapport (1995) who lament that listening is lost in the ‘cliché’ of participant observation (p. 12). We knew that the conference would provide us not so much with a vision but a ‘listened to’ narrative – a spoken and received aural history of life experiences, conflicts and personal goals. Our aim with this narrative, then, is to inform clinical and mental health practitioners of the self-reports, enriched by our visual observations, of young people living with HIV/AIDS and to make recommendations for program design. We also hope to promote the use of participant observation, and its core element of engaged listening, particularly in closed environments that have clinical boundaries when conducting research with young people living with HIV/AIDS.

Methodology

The 2011 conference took place between 31 July and 5 August at Babson College in Wellesley, Massachusetts. Thirty-two young people attended, just over half of whom were male (Figure 1). The majority identified as Black, heterosexual and infected with HIV at birth. They came from Massachusetts (20), New Hampshire (3), Rhode Island (4), Connecticut (1), New York (2), Indiana (1) and one international participant from Uganda. The conference was planned by a Youth Task Force, made up of eight young people living with HIV/AIDS and a coalition of health and social care providers from throughout New England.

Two observers, the third and fourth authors, were trained by the first author who provided an overview of the conference program, tips for taking field notes (Schensul et al., 1999), and a list of topics and issues that they should pay special attention to. Both had previous experience working with young people living with HIV/AIDS and were familiar with salient themes related to adolescent HIV disease. They were instructed to omit unique identifiers (e.g. name, age,

<p><u>Gender</u> Male: 17 Female: 15</p>	<p><u>Sexuality</u> Heterosexual: 24 Homosexual: 2 Bisexual: 3 Did not respond: 3</p>
<p><u>Age</u> 16-18: 11 19-21: 13 22-25: 8</p>	<p><u>Living Situation</u> Home with parent/guardian: 22 Permanent housing alone: 6 Shelter/Group home: 3 Did not respond: 1</p>
<p><u>Ethnicity</u> Black/African American: 15 Hispanic/Latino(a): 5 White: 4 Multiethnic: 7 Did not respond: 1</p>	<p><u>In School</u> Yes: 18 No: 13 Did not respond: 1</p>
<p><u>Transmission Group</u> At birth: 27 Sexual Activity: 3 Blood Transfusion: 1 Did not respond: 1</p>	<p><u>Education (completed)</u> K-8: 6 High school/GED: 20 Technical/vocational school: 1 Some college: 5</p>
<p><u>Residence</u> Massachusetts: 20 New Hampshire: 3 Rhode Island: 4 Connecticut: 1 New York: 2 Indiana: 1 Uganda: 1</p>	<p><u>Current Employment</u> Part-time: 16 Full-time: 3 Volunteer: 3 None: 10</p>
	<p><u>Has attended an HIV program before</u> Yes: 29 No: 2 Did not respond: 1 Returning participants: 21 New participants: 11</p>

Figure 1. 2011 One Love Project Conference Participants.

gender, race, ethnicity, place of residence and idiosyncratic details). The observers were cautioned against asking direct questions of the participants or speaking during the workshop sessions, but were encouraged to get to know the participants and engage with them outside of the workshop settings.

The daily program ran from 8.30 a.m. to 5.00 p.m. The observers sat in on the full-group sessions each morning and small group workshops during the afternoon. Figure 2 provides a list of the workshops and indication of which were observed. Participants were also observed during daily, full-group feedback sessions. The observers listened carefully during the workshops, taking brief typed notes on laptop computers and later typing out expanded notes to create a longer and

<p>Monday – Looking after Number 1</p> <p><i>Morning</i></p> <ul style="list-style-type: none"> - Being Young and HIV Positive* - Statewide HIV Advocacy* <p><i>Afternoon</i></p> <ul style="list-style-type: none"> - Yoga and Meditation - Living Independently* - Nutrition for Immunity - Keys to Treatment Success* <p>Tuesday – You’re Hired!</p> <p><i>Morning</i></p> <ul style="list-style-type: none"> - Interviewing Do’s and Don’ts* - Getting My Dream Job* <p><i>Afternoon</i></p> <ul style="list-style-type: none"> - Resume Writing - Managing Money* - Surviving College* - Non-School Options After H.S./GED 	<p>Wednesday – Relationships and Community</p> <p><i>Morning</i></p> <ul style="list-style-type: none"> - Disclosing My HIV Status* - Healthy Relationships* <p><i>Afternoon</i></p> <ul style="list-style-type: none"> - HIV and the Law* - STIs and Sexual Health - Healthy Relationships* - Future of HIV and Treatment <p>Thursday – Crafting My Message</p> <p><i>Morning</i></p> <ul style="list-style-type: none"> - The National HIV/AIDS Strategy* - HIV/AIDS in Other Countries* <p><i>Afternoon</i></p> <ul style="list-style-type: none"> - Public Speaking* - Spoken Word Poetry - Improvisation and Theater - Telling My Story through Advocacy*
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Figure 2. 2011 One Love Project Conference Program.

*Workshops that were observed

fuller narrative at the end of every day. They indicated exact quotes with quotation marks and observations with bullet points. Because there are many adult guest speakers and staff members at the One Love conference throughout the week, it is not uncommon or unusual for adults to observe, participate and type notes during conference workshops and activities. Thus note-taking would not disrupt the participants or the flow of events.

The two participant observers were blind to the analysis. The first and second authors read the complete field notes individually and used thematic analysis, a technique that focuses on developing ‘codes,’ to label sections of data and organize it into themes (Patton, 1990). We coded the field notes into four broad categories: peer support, disclosure, relationships and health care. Coded conversations for peer support included: belonging, feeling part of a community and identifying with others living with HIV/AIDS. Codes for disclosure included: being told they were HIV positive, and telling others about their HIV status. Coded conversations for relationships included: relationships with sexual partners, romantic partners, family members and friends. Codes for health care included: treatment and adherence to treatment, transitioning from pediatric to adult care, moving from one doctor to another, and preventing HIV transmission to others. As we coded, we also noted the discussions that seemed to elicit more emotion and engagement from participants, based on the note takers’ ongoing analysis. We met in-person to share our notes, compare similarities and resolve our differences, and to eliminate any analysis that we felt to be subjective or biased. During iterative readings and discussions, we interpreted the meanings that young people created within each code in order to construct general narratives to describe and instantiate codes more

fully. Direct quotes were extracted from the notes to strengthen and qualify the codes that were generated.

The Institutional Review Board at the Boston University Medical Center approved this retrospective analysis of data collected as part of the conference program evaluation.

Limitations

Our methodology does have its limitations. Primarily, Rena Greifinger, the first author, is the Founding Director of the One Love Project. Her close involvement with this program, and subsequent investment in its success, could have inhibited her objectivity as an interpreter of the data. To avoid this threat, the second author Gemima St. Louis, who is a trained clinical psychologist and experienced qualitative researcher, was kept at a distance from the program. While she is an employee of the SPARK Center, she has never attended a conference and has only engaged with a handful of conference participants in the past. Dr St. Louis had a dual role of analyzing the data collected, as well as cross-checking Ms Greifinger's analysis to ensure objectivity. The last author, Dr Martha Vibbert, was also responsible for validating the level of objectivity in the analysis based on her clinical expertise and distance from the conference program. Additionally, while the note takers did receive training and were familiar with both qualitative research methods and this particular population of young people, they were not experienced participant-observers. Their inexperience could have impacted the depth or quality of data collected. As such, with only two participant-observers and four concurrent workshops in the afternoons every day, we were unable to capture conversations from two workshops every day. To minimize any subsequent gaps, we strategically placed the participant-observers in workshops that we knew to be dialogue-driven, rather than more didactic.

Findings

We reached consensus on four broad themes, based on our coding process: 1) the power of peer support in helping young people living with HIV/AIDS develop confidence, self-esteem and a notion of community; 2) disclosure of HIV status, with particular attention to sexual partners; 3) building positive and healthy relationships; and 4) finding new ways to discuss adherence to medication. These themes are described with narrative details below, including direct quotes that support each theme.

Power of peers

Identifying with a peer community was a significant theme throughout the conference week. Participants spoke at length about their feelings of isolation and abandonment and their increased self-confidence and sense of empowerment during the

conference itself and during past conferences while among a group of HIV-infected peers. On the first morning of the conference, four of the returning youth asked if they could share with the rest of the group what the conference meant to them. One by one, they described how they felt when they arrived at their first conference in contrast to their feelings one or two years later. The conversation centered on initial statements, such as 'I was closed off' and 'I felt like I was the only one' and then ending with 'I know I'm not alone,' 'we share the same experiences,' and 'we are powerful.'

After the four youths spoke, without any facilitation, other young people stood up and shared as well. Some had never known other young people living with HIV/AIDS and that made them feel very alone. Others talked about not having a support system at home and experiencing discrimination within their families and communities:

I was homeless and had no support or family. I get the support here that I don't get at home.

I had no one to connect to and made the mistake of disclosing when I wasn't ready. Being here got me through it.

I knew about HIV but I had never come face to face with it before I was diagnosed. Coming here gives me power.

Just as this conversation kick-started the conference week, it also served as a lynchpin for all of the powerful discussions that followed. The moment the young people recognized, out loud, that they were part of something safe, powerful and greater than themselves, they were able to open themselves up to discourse that many had not engaged in before.

Disclosure

Questions surrounding the disclosure of their HIV status to others arose during many conversations throughout the conference week. Disclosure and the complexities surrounding it became the cornerstone of how youth described their fears and anxieties about the future. Issues of disclosure permeated discussions about relationships, family, the workplace, school, and accessing care. The majority of these discussions centered on disclosure to sexual partners, and the ethics and personal responsibility involved. During one conversation, participants debated whether it is necessary to tell a partner at all, and if so, when. Many remarked on the responsibility one has to his/her partner to tell:

In reality, you have to remember that disclosing affects other people in big ways. When you realize that you love them, you should feel comfortable disclosing.

If you don't tell your partner your status, you hold someone else's life in your hands. The amount of time you wait to tell them affects their life in significant ways.

It is selfish not to give your partner the choice and if you really love them, you would tell them from the beginning. It's not love not to tell.

While these participants drew connections between love, trust and the responsibility to disclose, others had different reasons for disclosing. In contrast, they related disclosure to distrust, abandonment and infidelity. It seemed as though participants assumed they would be hurt in a relationship, but that not disclosing would only prolong that pain. For example:

The benefit of telling them from the beginning is that there are not many feelings developed. It won't hurt as much if they leave you.

If you keep it to yourself and then tell someone, they wonder what else you've been keeping from them.

When you find out someone's been cheating on you, you have to deal with the possibility that you've infected other people through them.

Two young people disagreed with their peers, arguing that it is better to keep HIV a secret. One felt that disclosure caused an unequal power dynamic. The other felt that it was just not necessary:

Telling other people gives them some form of power over you.

If you are with someone for so long, they appreciate you for who you are without HIV. So it shouldn't matter.

One participant refuted this second response, arguing that HIV is something that affects one's partner in addition to oneself. Therefore, the partner deserves to know.

We'd all like to be in a situation where it doesn't matter, but it does. It's a secret that doesn't just affect you.

Multiple participants shared that they had not disclosed to anyone in their lives, but were eager for advice from their peers about how to begin. Others offered a number of suggestions such as: gauging reaction to HIV by talking about it more generally and exploring previous knowledge of HIV; leaving hints such as brochures and newspaper clippings that can start a conversation; bringing a peer along to help with the disclosure; staying healthy (taking medication) to mitigate the shock; testing the waters by saying a friend was just diagnosed (but being careful to not start a false rumor about anybody); getting tested with a partner; and making an audio journal.

Many participants shared their own stories of disclosure and became very emotional. They spoke of disclosing to friends who they trusted with the secret, but then learning that this information was shared publicly. Many spoke of the resulting discrimination they faced, such as bullying at school and not being allowed to visit their friends' homes. As the conversation progressed, one participant made the distinction between disclosure as a process rather than an end result. This participant explained that the 'telling' is easy. It is what happens with that piece of information over time that makes one vulnerable. Other participants enthusiastically agreed. They acknowledged that for many years, throughout their counseling

sessions and support groups, they talked about disclosure as a single event. They worked out the 'when, where and how to disclose,' but never concentrated their discussions around the 'what happens next.' They rarely thought about the 'journey' that their disclosure could take, and whether or not the person they are disclosing to was emotionally and mentally prepared to manage that information wisely. The participants discussed a strategy of providing those people with the support and information they need to keep the secret safe, as a way to also keep their own dignity safe:

There is an emotional rush associated with finding out that your partner has HIV. He or she needs space to process the information and this reaction is reasonable.

Relationships

Participants talked at length about their need to find friends and partners that they could trust and the difficulty they have had in doing so. Many talked about their inability to trust people in general. They spoke of negative experiences living with other people and ways in which they had been let down by others. Most of them concurred that they would rather live alone than with others, including their family members:

Usually I just walk away from problems instead of resolving them and I want to learn how to trust people.

Participants talked about the vulnerability they feel in having HIV and the fear of rejection if their partner were to learn their status. They also talked about the threats that a partner can make. They acknowledged that many young people with HIV/AIDS stay in abusive or unhealthy relationships because they feel as though no one else will be with them because of their status:

I'll smack you if you do this; I'll leave you; I'll tell someone.

I dated a guy who didn't like me to look nice. If I got dressed up or put on make-up he would get upset. He took his insecurities out on me.

I want to learn how to deal with an abusive partner. What are the alternatives? How do you leave?

Family relationships were a main topic of conversation throughout many of the workshops that focused on sexual and reproductive health, disclosure and thinking about the future. Many young people shared experiences of being rejected and let down by family members, particularly parents. Often, discussions about family members arose when young people told stories about finding out about their own HIV status. Those few participants that were infected with HIV during adolescence talked about rejection by their families once they were diagnosed, or fear of rejection

from parents who do not yet know about their child's HIV status. Some youth, both those infected at birth and during adolescence, shared that family members kicked them out of their homes, told them they did not love them or that they deserved to contract HIV. Others were told that they would never amount to anything, that they would never be successful or find anyone who would love them. These stories elicited much sympathy from the group, but even more, they catalyzed the audience to share their own stories of overcoming challenging family situations, finding support networks in other places, and even in changing the attitudes of their loved ones.

Adherence to medication

It was clear from the observations that young people were reticent about talking about adherence to medication. Despite its significance to their health and survival, they appeared to approach adherence discussions with an 'I've heard it all before' attitude, eye-rolling and disengagement from the conversation. However, when discussing new research that adherence to medication decreases an individual's risk of transmitting HIV to others (Cohen et al., 2011), they responded with great interest. When the facilitator spoke about the concept of treatment for prevention, hands shot up around the room. Participants were inquisitive and excited. One observer noted that it felt like something in the room suddenly 'clicked.'

One participant said:

It's important to maintain adherence to your meds because that behavior affects you and your partner.

The other instance in which participants engaged around the concept of adherence was when talking about disclosing to others. Participants agreed that taking medication to stay healthy is important for assuring family and friends that an HIV diagnosis is not a death sentence.

You have to show them [the people you tell] that you're going to be ok because that's what they're going to ask. You have to take care of yourself. If you look ok it'll be better.

Discussion

This article provides a thematic analysis of conversations and insights collected through engaged listening and participant observation at the 2011 One Love Project conference. By using this approach, rather than interviews or focus groups that ask predetermined questions, we were able to preserve the integrity and organic nature of the conference process, minimize power differentials for an age group that is especially vulnerable, and ensure ecological validity, as we collected valuable data. With vulnerable groups such as young people living with a

chronic illness, participant observation promotes the inclusion of every participant and recognizes his/her contribution without singling out those who may communicate better than others (Cocks, 2008). What emerges is a narrative about a sub-population of American youth, and a collective identity of living with HIV/AIDS, rather than individual stories.

Our aim with this analysis is to provide researchers and practitioners who work with young people living with HIV/AIDS with an additional interpretive lens, and new insights into how best to design programs that will support young people living with HIV/AIDS during their transition to adulthood. The observations reported here – particularly those involving the power of peers, disclosure, relationship challenges and adherence – confirm findings from other studies and reports outlining the needs and priorities of this population, and they offer expanded perspectives on program design and delivery. Below are some recommendations and implications supported by our findings.

Use a youth-led, peer-based approach when designing programs

The greatest impact this program had on young people is their increased connectedness to a community of peers, and the consequent psychological and emotional benefits. This was evident in the powerful testimony that young people gave about the role of peers in building their confidence, self-esteem and ability to face adversity. Creating a safe and supportive environment, where young people are able to fully express themselves without fear of judgment or misunderstanding, and to be among others with shared life experiences, was the cornerstone of this program.

Meaningful youth involvement was also key. The One Love conference was designed using a model of critical youth engagement (Fox et al., 2010), which facilitates a process of peer dialogue and leadership. Critical youth engagement places young people at the center of the design process, encouraging them to become actors and assets to the program, while adults stand by as allies. This not only ensures the impact of the program, but builds a sense of collective efficacy which in turn will likely improve young people's engagement with their health care (Zeller-Berkman, 2007). Crucial to youth engagement is the inclusion of peer-based models of support. In this case, we define peers as those within a created social network, rather than family or friends that would make up an embedded social network (Peterson et al., 2012). While many studies have found a link between general social connectedness and positive health and wellbeing (Berkman, 1995; Olsson et al., 2005; Uchino et al., 1996), especially with young people living with HIV/AIDS (Funck-Brentano et al., 2005; Robbins, 2003), peer-based, psycho-educational interventions with HIV positive young people have been found to successfully impact knowledge of HIV, adherence to medication (Simoni et al., 2009) and decreased risk behaviors among young people, in addition to the opportunity to socialize (Hyde et al., 2005). Equally, because so many young people living with HIV/AIDS are socially isolated, with limited family support

(Abramowitz et al., 2009), these types of peer-based interventions provide valuable support that is otherwise not available to them.

Develop strategies to support young people with disclosure

We argue that disclosure is one of, if not the most, pressing concern for young people living with HIV/AIDS as they navigate their teenage years and look toward adulthood. The decision to disclose HIV status is multifaceted (Fields, 2012) and impacted by stigma, existence of social support, nature of relationships (Chaudoir et al., 2011; Ostrow et al., 1991), and concerns about discrimination or violent reactions (Simoni and Pantalone, 2004). Hightow-Weidman et al. (2012) write that ‘such concerns may be particularly salient for youth, who are often still dependent on families for both emotional and financial support and may be motivated by a strong desire to fit in with their peers’ (p. 2). Questions about whom to disclose to, when, how and why were particularly poignant, especially among young people who are newly diagnosed with HIV. While several studies investigate the disclosure patterns of young people living with HIV/AIDS (D’Angelo et al., 2001; Dempsey et al., 2012; Lam et al., 2007), few offer clear recommendations for how to better support young people in their decision-making surrounding disclosure. We recommend a deeper interrogation of young people’s experiences with disclosing and youth-driven tools that help practitioners facilitate critical thinking, assertiveness, confidence and practical communication skills surrounding this sensitive topic.

Concentrate on building self-esteem and assertiveness in relationships

Discussions about relationships were wrought with concepts of stigma, both internal and external. The participants’ anticipation of rejection and inherent distrust of others revealed a level of vulnerability that extends far beyond their health diagnosis. A recent qualitative study conducted by Hosek et al. (2012) found that many HIV positive young women put themselves at greater risk and/or endure unhealthy relationships with friends, family and sexual partners because of their perceived lesser value within their communities. Teenage and young adult women living with HIV/AIDS also reported high levels of emotional, physical and sexual abuse, particularly associated with disclosure experiences, as well as an overall lack of trusting relationships (Hosek et al., 2012). While young people seem to be aware of these unhealthy relationships, they often lack the communication skills, confidence and experience with assertiveness to extricate themselves from them.

Address adherence through a new lens

Adherence to medication is a tremendous problem for young people living with HIV/AIDS and an acute threat to their quality and length of life. This is due to a

number of factors related to their psychosocial health and coping skills, stigma, levels of social support and developmental stage (Ferrand et al., 2007; Murphy et al., 2003; Murphy et al., 2005; Rao et al., 2007). However, participants would only engage in discussions about adherence, and place value on adherence, when they learned of adherence's potential impact on their peers and sexual partners. They also identified adherence as one strategy to reduce the negative impact of disclosure to others. We therefore learned that by reframing the conversation around their most poignant concerns – sexual relationships and disclosure – participants cultivated a new understanding about the importance of adherence, beyond the 'do it because it is good for you' paradigm that they have heard from caregivers and providers. This finding lends valuable credence to the design of future strategies that shift the paradigm of adherence support from one of individual survival to long-term engagement within a social structure.

Conclusion

As the landscape for young people living with HIV/AIDS continues to change, and as more young people with HIV/AIDS approach adulthood, it is crucial that we make efforts to support them through their transition. A key resource is the direct report and input of those who have lived the experience themselves. The meaningful engagement of young people living with HIV/AIDS in discussions and research about their care and support, alongside programs that promote self-esteem and life-skills, is paramount to ensuring they have healthy and successful futures.

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Note

1. The adult allies are some of the social workers and case managers that work with the young people, public health student volunteers, nurses and other health professionals that work closely with young people living with HIV/AIDS. They serve in multiple capacities. The first is as chaperones to provide supervision. The second is to provide an outlet for emotional support or triage in the case of a medical or psychiatric emergency. The third is to educate (as facilitators of workshops) as well as to learn.

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