What happens when we ask? A phenomenological focus group on HIV prevention and sexual health education among emancipated foster care youth

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ARTICLE INFO

Keywords:
HIV
Sexual health
Arts-based
Advocacy
Awareness
Foster care youth

ABSTRACT

Youth of color who have recently been emancipated from foster care are among the most vulnerable group at risk for having poor sexual health outcomes. It is essential for researchers to understand how emancipated foster care youth receive messages about safe sex and HIV/STI prevention in order to tailor health promotion activities for this group. This study presents a strengths-based view of emancipated foster care youth of color who developed an empowering, arts-based campaign to prevent HIV in their community using Youth Participatory Action Research (Y-PAR) methods. The project was led by 10 emancipated foster care youth who participated in two focus groups that centered on understanding their knowledge of HIV. Five major themes emerged from the focus group. Implications for researchers include incorporating safe spaces for youth to develop ideas that can result in empowering activities relating to prevention.

1. Introduction

Studies have indicated that there is an increased risk of contracting sexually transmitted infections (STIs) and human immunodeficiency virus (HIV) among youth emancipating from foster care (Ahrens et al., 2010). Young people who have been emancipated from the foster care system have reported higher rates of engaging early in sexual intercourse, having multiple partners, having intercourse with a partner who has had or has an STI, having sexual intercourse for money or drugs, and having sex with a casual partner (Ahrens et al., 2010; Courtney et al., 2007). Another study found that emancipated youth reported twice the rate of STIs compared to their peers in the general population (Ahrens et al., 2012). Taylor et al. (2020) showed that youth emancipating from foster care reported rates of chlamydia at 27.3% compared to 1.6% for youth who are not in foster care, gonorrhea at 11.7% compared to 5%, and trichomonias at 13.6% compared to 4 percent. The higher prevalence of STIs for emancipated foster care youth have been linked to the lack of sexual socialization and lack of access to quality sexual education (Brandon-Friedman, 2019; Smith, 2017). Sexual socialization is defined as the process in which people acquire skills, knowledge, values, and beliefs about their sexuality and sexual relationships (Diamant-Wilson & Blakey, 2019; Grusec & Hastings, 2007). Supportive social networks such as parents, caregivers, aunts, uncles, grandparents, peers, health providers, and teachers play a significant role in young people’s sexual socialization (Diamant-Wilson & Blakey, 2019) and identified as a protective factor against engagement in sexual risk behaviors and substance use.

Black/African American youth are overrepresented in the foster care system. These youth also have the heaviest burden of mental health issues, substance use, STIs, and HIV infection (Diamant-Wilson & Blakey, 2019; Centers for Disease Control [CDC], 2016; Child Welfare Information Gateway, 2016). Furthermore, youth in foster care often experience disrupted and unstable relationships with adults and peers and experience various forms of trauma (e.g., sexual abuse, violence etc.) that increase the likelihood of engaging in negative health behaviors (Diamant-Wilson & Blakey, 2019; Elze et al., 2001; Winter et al., 2016).
including substance misuse and unprotected sex (Diamant-Wilson, 2017). For instance, Narendorf and McMillen (2010) conducted a study with youth currently in foster care and found that their risk of being diagnosed with a substance use disorder rose within the first year of leaving care. This suggests that transitions in living situations and life events have an impact on substance use. With the prevalence rates for substance use and drug dependency roughly 2 to 5 times higher for children and youth in foster care compared to their counterparts with no involvement in the foster care system (Kim, Buchanan & Price, 2017), these young people are at a compounded risk for engaging in sexual risk behaviors, violence, and crime—which can all lead to poor developmental outcomes among youth (Green et al., 2017). Due to these compounded risk factors, emancipated foster care youth and foster care youth in transition are positioned to experience higher levels of psychosocial instabilities, poorer health, and other adverse life outcomes, when compared to those not in the foster care system (Taylor, Shade, Lowry, & Ahrens, 2020).

Given the disparities that uniquely impact emancipated foster care youth, it is crucial that HIV and sexual health prevention interventions be adapted and designed specifically for this population. Very few studies have explored how foster care youth receive HIV and sexual health prevention education information. In addition, the few HIV prevention program studies that have been implemented among youth emancipated from foster care, have noted higher rates of attrition due to a potential disconnection between prevention programming information and these youth’s lived experiences (Thompson, Auslander, & Alonzo, 2012). One of the few studies conducted (e.g., Thompson, Auslander, and Alonzo, 2012) found that youth in foster care who were enrolled in an HIV prevention program preferred to incorporate life skills and independent living strategies within HIV prevention curricula. Therefore, it is critically important that HIV prevention programs for youth in foster care incorporate their voices and perspectives into the design and implementation of these prevention initiatives. Such programmatic adjustments would likely reduce attrition and most importantly, provide accessible, adequate, and quality preventive services to lessen the burden of adverse adult outcomes.

2. Youth participatory action research (YPAR)

HIV prevention interventions often use deficit frameworks which focus on reducing risk behaviors rather than highlighting resilience, strengths and empowering youth as a prevention strategy (Opara et al., 2021). In contrast, Youth Participatory Action Research (YPAR) is a critical research methodology that seeks to centralize and empower youth voices which can potentially lead to action for creating social change and improving health outcomes (Akom, Cammarota & Girwright, 2008). YPAR methods are intended to foster a collaborative partnership between youth and researchers by acknowledging youth as experts and co-leaders of research projects (Bautista et al., 2013; Cook et al., 2017). Within a disease prevention context, engaging youth as co-leaders in the research process can lead to identifying sustainable youth and community centered health solutions (Dang et al., 2019).

A systematic review of studies utilizing a YPAR approaches found that particularly among youth of color, youth were more likely to gain leadership skills and a sense of self-efficacy when they were a part of YPAR studies (Avery et al. 2018). In addition, literature has indicated that sexual health interventions utilizing YPAR methods, including HIV prevention interventions, can increase the acceptability and sustainability of the intervention within the community (Dang et al., 2018; Willmott et al., 2022). For foster care youth, limited research has incorporated YPAR methods in HIV prevention research for this group. YPAR has the potential to challenge negative stereotypes that are often placed on marginalized youth and highlight their strengths to overall improve health outcomes and contribute to a successful transition into adulthood. Centering the unique experiences of foster care youth and acknowledging them as contributors and co-leaders in the research process is crucial in creating sustainable HIV prevention interventions. Engaging foster care youth and emancipated foster care youth in HIV prevention using YPAR methods has the potential to not only improve health outcomes but allows for the engagement of youth to be change agents and advocates within their environment.

3. Purpose of the study

In this study, we examined focus group data generated from emancipated foster care youth living in an urban environment and to understand how they have received sexual health information. Although focus groups have been known to be an empowering method, little research has discussed how the focus group process can foster a sense of empowerment and resilience among emancipated foster care youth. This study seeks to understand and highlight the voices of a group of emancipated foster care youth who discuss their lived experiences and their views of sexual health education for their group. A secondary aim of this study involves the outcome of study participation and prolonged engagement which led to the use of youth participatory action research (YPAR) methods being used with youth to develop an art-informed empowering activity to promote HIV prevention in their community.

Within this study, we consider structural factors that place youth in high-risk situations of contracting HIV and STIs. We also provided participants a space to use their voice to express their thoughts on shaping prevention programming. Focus group themes are presented below along with artifacts in the form of artwork in the appendix. This artwork was created by youth in response to the focus group discussion about prevention in their community.

4. Methods

4.1. Research setting

The target city for this research study is one of the most diverse cities in New Jersey. About 57.7% of residents identify as Hispanic and 34.7% identify as African American/Black (U.S. Census 2010). Approximately 43.3% of residents living in this city were foreign-born (U.S. Census, 2010), and about 29.1% live below the poverty line, with a median household income of $33,000 yearly compared to 10.4% and $71,180 median income for the entire state respectively (U.S. Census, 2010). The city is one of the poorest cities in New Jersey, with a median income that is among the lowest in the state (U.S. Census Bureau, 2016). The city’s child poverty rate is 41%, which is higher than New Jersey’s rate of children in poverty, which is 16% (Advocates for Children of New Jersey, 2015). Within the state of New Jersey, African American and Hispanic/Latino youth comprise over 60% of the foster care system in New Jersey and about 50% of the general child population in New Jersey (Child Trends, 2017).

4.2. Sampling

Participants in the study were part of Project C.O.P.E. (Communities Organizing for Prevention and Empowerment). Project C.O.P.E. is an HIV, substance abuse, and Viral Hepatitis prevention program targeted for ethnic minority youth between the ages of 13–24 years old (Opara et al., 2019; Reid et al., 2014) (Opara ). Participants in this study were recruited from a support group housed in a community-based youth-serving organization, called the “Aging out-group”. The aging out group meets five times a week for two hours to work on various life skill activities. The group is led by the housing organization’s director. Participants completed seven sessions with the facilitator and were asked to be a part of a focus group after participation. The purpose of these focus groups were to understand their experiences as youth who have been emancipated from foster care and their knowledge of sexual health education.

Using a phenomenological framework (Patton, 2002), we engaged in
interviews (N = 10) with participants through a focus group design. The purpose of this focus group was to understand the lives and stressors of emancipated foster care youth living in an urban community. The goal of descriptive phenomenology is to describe the common features of participants’ experiences. Therefore, it is important that participants share a restricted range of demographic characteristics. We restricted participation to only youth who were a part of the intervention and a part of the emancipated foster care support group. Participants were not compensated by researchers for the focus group; however, the program staff provided dinner for participants after the focus group was completed.

5. Participant characteristics

The demographic characteristics of the participants are presented in Table 1. All 10 participants identified as either female (n = 6) or and male (n = 4). Four participants identified as Hispanic, five identified as Black, and one participant identified as primarily Black and biracial (both Black and Hispanic). Two participants were enrolled in a local two-year community college. The ages of participants ranged from 17 to 20. All of the participants aged out of foster care.

6. Researcher positionality

As part of a larger federal HIV/AIDS prevention grant initiative, we engaged with participants as educators, mentors, and/or advocates for their substance abuse prevention needs. We have working relationships with youth-serving community organizations. In establishing credibility, we needed to obtain trust and develop a rapport with the youth we serve through prolonged engagement (Lincoln & Guba, 1985). Through prolonged engagement in the emancipated foster care support group program, we built rapport with youth and program staff, which established trustworthiness strategies. Prolonged engagement, in conjunction with persistent observation (intense focus on the aspects of setting and phenomenon), allowed researchers of the study to spend considerable time in the field to thoroughly understand youths’ perspectives and to offset the researcher’s own bias (Lincoln & Guba, 1985; Wallendorf & Belk, 1989).

The first author was involved in all data collection, analysis, and advocacy efforts afterward. The second author, taking an objective stance, assisted in analyzing the data and was not involved in data collection. The third author was involved in member checking, advocacy efforts, and interpreting the data. The last two authors were the principal investigators of the grant and were also involved in advocacy efforts with the youth group. As researchers, the authors acknowledge that we come from privileged backgrounds. Although some of us identify with intersectional perspectives of race, ethnicity, and gender, and experiences in foster care. We acknowledge we are not experts, nor insiders, into the daily issues and lived reality of urban youth who were a part of the study.

Table 1
Characteristics of participants.

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Race/Ethnicity</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jamal</td>
<td>20</td>
<td>Black</td>
<td>Male</td>
</tr>
<tr>
<td>Sana</td>
<td>19</td>
<td>Black and Hispanic (Dominican)</td>
<td>Female</td>
</tr>
<tr>
<td>Maria</td>
<td>20</td>
<td>Hispanic (Puerto Rican)</td>
<td>Female</td>
</tr>
<tr>
<td>Miguel</td>
<td>20</td>
<td>Hispanic (Puerto Rican and Ecuadorian)</td>
<td>Male</td>
</tr>
<tr>
<td>Cassie</td>
<td>17</td>
<td>Hispanic (Dominican)</td>
<td>Female</td>
</tr>
<tr>
<td>Shawn</td>
<td>20</td>
<td>Black</td>
<td>Male</td>
</tr>
<tr>
<td>Keisha</td>
<td>19</td>
<td>Black</td>
<td>Female</td>
</tr>
<tr>
<td>Patrick</td>
<td>18</td>
<td>Black</td>
<td>Male</td>
</tr>
<tr>
<td>Shanna</td>
<td>19</td>
<td>Black</td>
<td>Female</td>
</tr>
<tr>
<td>Patricia</td>
<td>20</td>
<td>Hispanic</td>
<td>Female</td>
</tr>
</tbody>
</table>

7. Data gathering and analysis

All 10 youth were engaged in two focus groups that lasted approximately 120 min each. Youth were initially a part of a larger of an evidence-based HIV/AIDS, drug use and viral hepatitis prevention program (Reid & García-Reid, 2014). They were asked to participate in this study to understand their perspectives on sexual health and prevention of HIV/STIs among emancipated foster care youth. The first focus group was semi-structured, while the second focus group was unstructured in which participants were allowed to reflect on their responses from the previous group and provide more information to researchers about their views on sexual health. To establish trust and comfort, facilitators provided detailed information on the purpose of conducting these groups. These focus groups had two facilitators. The lead facilitator conducted the focus group interviews while the second facilitator’s role was to administer and collect the questionnaires, observe the moods and behaviors of the participants, probe as needed, and take observational notes.

Given the unique lived experiences that these participants occupied as emancipated foster care youth, it was difficult engaging youth and acquiring a large number of participants who fit this specific background. Literature supporting the use of a small sample of participants who belong to marginalized backgrounds guided our decision to restrict the number of participants in this study (e.g., Hedin, 2017; Lane, 2017). While there are some limitations associated with focus groups in relation to individual interviews (e.g., some participants contributing more to the discussion than others, group-think etc.), the use of focus groups in this study helped provide deep insight and understanding of the phenomena, as well as allowed for the examination of interactions among participants (Kevern & Webb, 2001). Interviewers during the data collection process ensured all participants had the opportunity to speak and elicited thoughts that contrasted from popular opinions within the group (Padgett, 2017). The interviewers left the direction of the discussion open to participants, probing when needed and ensuring the aims of the study were met while still allowing for free and open discussion (Munday, 2014). In this way, the interviewers continued to focus on empowering youth and regarding youth as experts, particularly related to their contexts (Munday, 2014). This allowed youth to collectively share their experiences and needs, while also remaining mindful of power dynamics and social hierarchies within the group; this assured all voices were recognized (Munday, 2014).

As per Institutional Review Board approval, because these youth were emancipated, they were all able to provide consent. These focus groups were recorded and transcribed verbatim. The research team kept additional field notes to refer to for information during the coding process (e.g., social interactions during focus groups).

7.1. Data analysis

Phenomenological research is a qualitative methodology that searches for the understanding of lived experiences related to a specific phenomenon. The inquiry ensues through a procedure of reduction, the study of specific statements and themes of the participants (Creswell, 2013). The researchers (first author and second author) completed the analysis and participated in continuous reflection of the data through conversations pertaining to biases and assumptions of emancipated foster care youth. Constant self-reflection through processing aided in gaining a depiction of the participants’ lived experiences.

Data from the interview were first analyzed by the research team using open coding, whereby concepts were identified and labeled as they emerged from the data and across the focus groups (Boyatzis, 1998). Data were coded using NVivo version 11 software. Each member of the research team read and re-read all the transcripts and developed initial codes in isolation. During the weekly research meetings, the initial codes were reviewed and discussed. There were no discrepancies in coding. The team agreed on the process of coding before analysis.
occurred. This was done in order to address inconsistencies and rule out any discrepancies during the data analysis. Direct quotations were used during the meetings to ground the findings and interpretations of the data. The researchers came to a consensus and reached 99% interrater reliability, because each identified nearly identical codes. Using multiple coders provided insight to finding consistency and minimizing researcher bias (Lincoln & Guba, 1985). To increase the rigor of the study, the researchers used prolonged engagement, regular team debriefings, and peer consultation.

Next, axial coding was used to further interpret the open codes and put the data back together considering a coding paradigm. Upon completion of axial coding, the research team constructed categories, which were based on recurring codes and themes that cut across all transcriptions. Although data were categorized initially, it was by similarity in this phase of analysis that the categories were further formed by their connections. Our inductive analysis resulted in concepts that were described by the participants as they defined their experiences and sensitizing concepts that we developed to represent patterns in the data (Patton, 2002). The final stage of inductive analysis entailed categorizing major themes by concept. As both a form of member checking and further interview probing, the researchers involved in the study held a second focus groups with participants to interpret findings and give participants the opportunity to share additional opinions about HIV prevention for their group.

7.2. Strategies of trustworthiness

Member-checking occurred after the focus group was completed. First, researchers visited the site four weeks after the focus group was completed to provide youth with a summary of the findings through an informal conversation with participants. All participants who completed the focus group were debriefed about the common themes. This was done to ensure findings reflected what they expressed to the researcher at the time of data collection. Memos and notes taken by the facilitator were used as preliminary analyses to report back to the participants. The researcher (first author) had prolonged engagement with study participants before and after the focus groups were conducted. During the second focus group, which was unstructured and initially used as an opportunity to member check while also giving participants the opportunities to discuss findings, participants expressed a desire to engage in empowering activities to spread awareness about HIV and substance use due to their participation in the focus group. One of the participants (Maria), whom was currently an art major at a nearby community college, provided a suggestion of using art as a form of advocacy. The participants in the study supported the idea which led to the development of an art group where participants worked together (with support from their aging out group staff leader) and painted artwork to spread HIV awareness in their community (see Appendix A). These artworks serve as an artifact to complement qualitative findings and put into perspective the role focus groups can have in not only centering youth voice but positioning youth to engage in some outward display of their thoughts, feelings and perspectives.

8. Findings

All participants in the study were involved in a private group that met weekly at a youth-serving organization, to support emancipated foster care youth. As foster care youth, they experienced significant disparities related to accessing sexual health and HIV prevention education information. As the extant research indicates, youth that have access to such sexual health and HIV prevention education programming often find themselves leaving these programs earlier than intended due to instability within their own life, or the relevancy of the program in addressing their current life concerns (Thompson, Auslander, & Alonzo, 2012). For youth in this study, it was clear that while they may not have had broad access to sexual health and HIV prevention education programming, the information they did access was often disconnected with their current lived experiences. Furthermore, youth in this study drew a linear path between limitations in both the quality and accessibility of sexual health and HIV prevention education programming and associated adverse health outcomes.

Five major themes emerged during analyses among emancipated foster care youth interviewed in this study: 1) Not learning about sex in the foster care system; 2) Unprepared for emancipation or adulthood; 3) Learning how to negotiate safe sex; 4) The value of the lived experience; 5) Engaging in Outreach and Prevention. Within the themes, youth described the ways they can empower themselves and their communities through outreach.

8.1. Not learning about sex in the foster care system

During these focus groups, it was evident that youth were critical of their families, the child welfare system, and schools in providing inadequate access to sexual health education. This critique centered on the importance of providing and engaging in open and honest conversations about sex and preventing transmission of STIs. As one youth stated, “there should be a no-judgment zone where kids can ask for condoms…They can just make it available…and we can talk about sex.” Further, there was a resounding agreement among all youth participants (N = 10) that adults avoided topics of sex and safe sex. This reality not only placed youth at-risk, but also placed the sole responsibility of learning about safe sex and sexual health on the youth themselves. As one youth noted, “[adults] avoid the topic of sex. Curiosity kills the cat.” Yet, youth were not deterred from vocalizing a desire to have adults in their life talk openly about sex and sexual health. As Maria noted, “I wish that parents were more open to talking to their kids. Like even at like once, the kid starts puberty, I feel that they should be talking about sex”. Another participant added, “a lot of parents try to shelter kids from that, like don’t have sex because it’s evil”.

While some of the conversation during the focus group focused on adults’ refusal to have conversations about sex, there were some youth (n = 3) who specifically described adults having a discomfort with talking about condoms, specifically. Miguel noted that it is important to “make kids aware and at least provide it [condoms]...different places that you can go for them. But it’s like what if you can’t get there?” Sasha further highlighted the importance of youth understanding what condoms are and being comfortable in talking about sex:

So, a lot of the things come from like people not knowing how to use condoms, so if you make that more accessible, than like more understood, even if it’s like, I understand okay condoms...is sex but it’s like you can’t be so scared of sex...it’s such a natural thing, we are all going to engage in one point or another.

Within these quotes we begin to hear that youth were not only articulating what they wanted to hear from adults, in regard to safe-sex practices, but in many ways were pleading to eliminate the stigmatization surrounding sexual health discussions and specifically conversations about condoms and appropriate condom use.

During these focus group interviews, it was evident that the youth lacked adult support around sexual health topics. However, in these focus groups, youth were vocal in calling upon adults to be both intentional and open to having conversations about sex and sexual health because as Sasha noted:

We [youth and adults] need to be able to talk about these things, openly, and not be scared to ask for advice about things, cause a lot of people don’t want to talk about sex, they feel like it is weird and I feel like America has a big problem that’s why we have so many issues that come with sex...I believe that education is most important thing in all.... if you’re not educated, you’re going to do what’s wrong.

From these youth’s perspectives, it was not the adults who would suffer the greatest negative outcomes due to limitations in accessing
sexual health information, but the youth themselves. Consequently, many of the youth in these focus groups felt that they were, because of these limitations in education, unprepared for emancipation, or adulthood.

8.2. Unprepared for emancipation or adulthood

In general, youth felt that they were not prepared to be independent after being emancipated from foster care. When asked the biggest concern with aging out of foster care Patricia stated, “living on your own, feeling unprepared.” Jamal further this by adding, “once you are out of the child welfare system, you are just dropped off a cliff.” Yet, while this is a sentiment shared in the extant research on youth in foster care, we were struck by the way in which youth tethered this lack of preparation with self-identified limitations in sexual health knowledge. It was so soberingly clear that they were being forced to navigate the world alone and without the appropriate tools and resources including sexual health information and knowledge.

Concerns related to being unprepared for independence after emancipation from foster care are not necessarily surprising, as noted previously; however, it was interesting to hear that they connected their lack of preparation for emancipation to limitations in sexual health knowledge. As Shawn admitted, he had a difficult childhood, “I never had parents, I was in foster care since I was three years old.” He added that consequently, “I really never had my own parents to tell me about sex. I have been in like seven different foster homes and sex was the last thing on their minds. I was just trying to survive, and they were trying to figure out whether they wanted me.”

Shawn was not the only group participant to bemoan this loss of education, all ten focus group participants agreed and wished the foster care system would have provided a mentor or supportive individual who was dedicated to talking about sex education. Patrick narrated a similar lived experience as Shawn but added that “For me, it was honestly teachers who told me about sex and that was when I was older and already had sex so it seemed too late.” Jamal echoed this experience and discussed that he was fortunate to eventually learn about sex by “reading a document about sex when I was 12. I was like oh that’s where babies come from?” Yet, despite some youth narrating experiences with accessing sexual health education, even if limited, most youth focus group members (n = 10) described a serious loss in knowledge due to having limited access to sexual health information in the foster care system.

Due to not having access to sexual health education, youth had to seek-out information on their own. As Maria noted, “I learned everything myself.” Shauna added “I learned about sex from pamphlets I picked up or from television, no one talked to me about it.” It was apparent that youth were left to individualized notions of identifying sources of sexual health information, which resulted in feeling unsure about transitioning to an emancipated status and adulthood. In short, this placed them at high risk of having sex without the appropriate knowledge to engage in safe and pleasurable sex.

8.3. Learning how to negotiate safe sex

Youth participants were open and honest about their sexual relationships. Those in sexual relationships with a partner discussed the impact of having limited or no sexual health knowledge, as well as questioned how to begin sexual negotiation conversations. Cassie who had a long-term boyfriend asked, “How do you say no to your partner that you have been having sex with?” Cassie was not alone in her limited knowledge about entering into and engaging in sexual negotiations with their partner. This limitation in knowledge was echoed by a majority of participants (n = 6), whom were all women, as these young people overwhelmingly acknowledged that learning about safe sex practices is beneficial but can be difficult to explain to their current sexual partners. Shauna mentioned her who struggle with negotiating sexual intercourse with her partner due to her living situation.

It’s uncomfortable because they expect you to have sex with them all the time, how do you say you want to wear a condom, when you are living with your partner and need a place to stay and he doesn’t want to do that? He may think I’m cheating, I don’t even know what to say

Youth in the group felt that they needed more training on navigating complex situations, such as being with their romantic partners to whom they are sexually attracted but not feeling comfortable enough to refuse sex. Sasha discussed a complex situation that frequently occurs among youth:

Let’s say you are talking (dating) to a person who you have been dealing with someone for years, they aren’t really sure how to tell their partner that they feel like they are having a little bit too much intercourse, and an unhealthy relationship, like that would be a realistic situation. A lot of people have been dating and they probably don’t know how to tell their partners, that they don’t want to have sex anymore, or that they want to start using condoms.

Other focus group participants immediately echoed Sasha’s experience. These youth provided additional insights into the difficulties of refusing sex with a partner and how they sometimes do not feel equipped to know how to respond to their partner. For instance, several girls engaged in an open dialogue and asked questions about engaging in sexual negotiations with partners:

Keisha: The conversation isn’t just no…you can say like no and then what if they start begging, what happens after that? like what if they say please…?

Patricia: or if they keep initiating it, they keep wanted to caress on you, and touch you? And then you like it but you don’t want to go further. What if you just want them to touch you for hours?

Cassie: and then you do it because you know that’s what they want and you’re in a relationship with the person so you’re thinking that at the end of the day I don’t know if that’s considered rape or not…like to me I really don’t know if that’s rape actually.

Maria emphasized at the end of this discussion that “If it’s not consensual then it’s rape…” From the researcher’s field notes, there was a brief moment of silence in the room after the discussion led to the transition of sexual negotiation skills. Based on facial expressions, it seemed as if participants were uncomfortable with Maria’s assertion of rape although her statement is factually true.

When asked how they wished to learn sexual negotiation skills, the youth emphasized the importance of having access to realistic sexual negotiation strategies to implement in their relationships. Participants felt that traditional ways of teaching negotiation skills through sexual health education was too simple. “These aren’t real-life scenarios, these scenarios are too clean,” said Sasha. Participants also felt like they would like to see different perspectives of sex and dating scenario as opposed to the generic heterosexual ones that are often include in HIV prevention programs. Sasha, who also identifies as a lesbian, added:

Different perspectives like we always any scenario is usually guy-girl, girl-girl, guy-guy, and its usually a situation where you’re just trying to say no. We are used to hearing about men being the ones that want to have sex all the time, but what about two women? What if one of them wants to have sex and the other doesn’t? how do we maintain the relationship but refuse sexual intercourse?

8.4. The value of the lived experience

As youth participants continued to reflect on experiences related to sexual negotiation skills development, as well as needs and desires with learning these skills and other sexual health information, youth were probed with a series of follow-up questions related to what they would like to see in an HIV prevention program and those elements that would positively impact their behavior. Youth collectively described wanting
to hear “real stories” from individuals who were, for example, living with HIV.

While youth were aware that the goal of an HIV prevention program is to prevent HIV transmission, they felt that they wanted to hear the “other side of the narrative” and hear from individuals who contracted HIV and live a healthy lifestyle. As Sasha stated, “there are people like him… They are living with it, ask them how you can prevent spreading it. I believe would be great.” Other participants also chimed in and added they would like to see people living with HIV to help prevent transmission. For instance, Keisha added,

Prevention… preventing transmitting it… that’s it. There’s nothing else really… You either have it or you don’t. I mean we can’t inform people of the risk, we are talking about what we didn’t cover, so… that’s all.

Youth acknowledged that because there is a lot of stigma in their community about HIV, they felt that hearing from people living with HIV would remove some of the stigma that is associated with HIV. Miguel mentioned that he felt that HIV sounds very scary and thought they needed to learn how people living with HIV are coping:

What we learn about AIDS is very one sided, or bias. More about how we shouldn’t get HIV and about preventing it. It makes it sounds scary, but we could also talk about, if you already have it, now what?

Sasha added in the affirmation that “We should talk about the HIV ‘positive’ lifestyle… being positive and living positive.”.

8.5. Engaging in outreach and prevention

Youth had a critical read of their context, acknowledging that their environment not only had soberingly high rates of HIV diagnoses and drug use, which they felt was indicative of a lack of access to sexual health information or discussions about sex. Youth understood there is an association with HIV and substance use in their community, as well as the lack of access points to prevention-intervention resources. At the conclusion of our interviews with these youth, participants were asked what they felt could be done within their community to prevent HIV and substance use. There was a general sense that they had a “duty” to support and engage in prevention efforts as peers within their community. Participants specifically mentioned outreach as an effective form of spreading awareness about HIV.

Youth were in overall agreement that outreach was important to prevention efforts. As Miquel, who was mostly quiet during the focus group, noted, “We shouldn’t hold this education to ourselves…” Later in this discussion, Miquel specifically indicated that the “group right here is an example of community outreach, you guys (interviewers) are like Jesus and we (participants) are the disciples,” and that the information learned throughout the education sessions should be disseminated outward.

The sentiment of disseminating and sharing information outward through outreach was agreed upon by all members of these focus groups. Maria added that community outreach and talking to others in the community was a great way to educate their peers based on what they know:

In order to inform an individual, you have to go outside of your comfort zone. My comfort zone would be here. We need to be outside on the streets, we need to be knocking doors, we need to be doing fundraisers, we need to be in the schools, afterschool programs mainly, Boys and Girls Club. Places that are like this that have the youth available.

More specifically, some youth emphasized being a “youth” and speaking to other youth about outreach and prevention. For instance, Jamal stated that “It has to be outreach and the only way you learn to stop this… if you go out there, youth will listen to us because we have been there and can speak their language.” Shawn further agreed and highlighted the importance of peers in shifting knowledge, “If you educate to 20 people and you change just 5 people minds, you’re still doing something great.”.

These opportunities for knowledge development were important to the youth in these focus groups. Youth seemed to visualize a link to outward opportunities for education and outreach of peers in their community. While there were no specific narrative data indicating a linear path between their own lack of access to sexual health information in their life and their drive to engage in outreach as “disciples”, it did, however, appear that youth connected their lack of access to sexual health information with bridging their newly acquired knowledge to peers in their community. In this instance, it may be that youth were attempting to fill this gap for peers. Consequently, there was a desire to spread awareness and participate in outreach as peer educators. For example, Jamal noted explicitly that it must be youth speaking to other youth about outreach and prevention education:

It has to be outreach and, in the field, the only way you learn to stop this, whatever you want to consider it being, if you go out there, youth will listen to us because we have been there and can speak their language.

Miguel also discussed the responsibility he felt he had in changing the world based on what he and his group have learned about HIV and sex:

We shouldn’t hold this education to ourselves, that’s just a waste as well. Yea u know it but you’re not doing anything to change the world and you’re going to run into people that don’t know it which can set us back.

This type of outward engagement and action may not have been fully facilitated by the focus group. Through our discussions, it was clear that participants felt empowered to think critically about the utility of their newfound knowledge.”.

8.6. Youth led HIV group art project

As a final point of participatory engagement following focus groups, youth were engaged to participate in youth-led HIV awareness group art project. This type of outward engagement and action may not have been fully facilitated by the focus group. Though our discussions were but it was clear that participants felt empowered to think critically about the utility of their newfound knowledge. For these youth, it seemed that through our discussions there was an increased desire to engage in outward voice, which for these youth was via creating a visual artistic image. This art activity, and the creation of a visual image, was a catalyst for youth to have more conversations about HIV and sexual health after these focus groups ended and after their participation in our own sexual health education program.

During the second focus group, Maria (see Table 1 for participant characteristics) expressed her thoughts on behalf of the group,

“thank you for asking us for our opinions. Sometimes we think no one cares what we have to say… after the focus group, we all felt like we had work to do. It was a feeling that just came over us. I love art and felt there could be a way for us to have fun and also spread the message about HIV”

Other participants, like Miguel added, “If you never gave us the space to talk about these things, we would have never realized that we have the power to do something about this. Even if we talk to just one of our friends, or share the knowledge with one person on the street, we are doing something right, someone can be saved”.

After the completion of the focus group, the lead author visited the group to debrief participants on the findings approximately four weeks afterward. The youth participants expressed their agreement with the findings and then told the lead author that they would like to work on an art project that promotes HIV prevention in their community. The art project was led by Maria, who, at the time of the study, was enrolled in a community college and majoring in art studies. Maria, along with support from her peer group and peer group leader, led her peer group twice a week for four weeks on their HIV prevention themed project. The organization in which the youth group was housed provided art supplies for the youth to embark on this project. Upon completion, the peer group invited the researchers back to review the artwork, and the artwork was
featured in a local HIV education town hall led by the first author of the paper (See Appendix A for artwork).

8.7. Artwork 1: “Balloons”

9. Discussion

The study sought to understand how youth emancipated from foster care learn about sexual health and, specifically, HIV prevention. Four major themes arose from the focus groups, which led to a collective understanding of the importance of HIV prevention programming that targets the unique lived experiences of foster care youth. Additionally, upon completing the focus groups, the study presents the results of providing youth a platform to speak about their experiences and opinions, which led to the formation of an empowering arts-based project led by the group. Overall, this extends the literature on HIV prevention through advocacy and empowering emancipated foster care youth who have been historically marginalized.

Youth in the study were adamant about their experiences within the foster care system, which had an impact on how they received sexual health information. The findings revealed that first, youth did not feel that the foster care system prepared them adequately about sexual health education. Consistent with research on youth in foster care, sexual health topics are typically not discussed, therefore increasing their chances of contracting HIV, or sexually transmitted infections (Ahrens et al., 2010). In addition, due to their backgrounds, which are often disrupted by housing and family instability, the youth felt collectively that they did not have a solid role model or guardian to talk to about sexual health topics. Within the literature, empirical evidence has shown that youth prefer to speak to their parents about issues related to sexual health (Boyd et al., 2018; Boyd et al., 2020). However, foster care youth are in a difficult predicament where they are removed from their biological parents and do not necessarily have immediate, intimate connections with their foster care parents/guardians. Therefore, this lack of emotional intimacy and trust can serve as a barrier to receiving adequate sexual health education within the home, leading to youth being most at risk of engaging in unhealthy sexual behaviors.

Secondly, youth also felt that the HIV prevention messages can indirectly contribute to HIV stigma. Youth felt that hearing the stories of individuals living with HIV and understanding their quality of life would be more relatable to them instead of always discussing the negative consequences associated with HIV. Additionally, sexual negotiation skills were important to youth in the study as they felt having discussions about safe sex with their partners is more complex and challenging than the scenarios commonly presented by prevention programming. This finding is consistent with research among youth of color as youth’s confidence in implementing high sexual negotiation skills are often a contributing factor to engaging in risky sexual behavior (Lardier et al., 2019).

Lastly, while engaging in the focus groups with researchers, youth began to reflect on their experiences in an HIV prevention program and their current understanding of discussing HIV within a focus group setting in which they felt empowered to spread prevention messages to other youth. Youth in the study developed their own art group after the second focus group, which was specifically intended to promote HIV awareness and prevention within their community. This is a common outcome of youth participatory action research (YPAR) which allows for youth to lead projects with guidance of adult allies to execute their ideas.

Various artwork and art-informed methods in research (Flicker, 2008; Holtby, Klein, Cook, & Travers, 2015; Wernick, Woodford, & Kulick, 2014; Wilson et al., 2014) have been used to facilitate underserved groups’ engagement on sensitive topics. However, very little research has explored how focus groups and asking participants about their role in prevention programming can initiate such empowering responses without prompts from the researchers. Arts-informed methods can be very useful in HIV prevention work as the utilization of art as reflective data to further analyze, understand, and disseminate findings to the wider community (Sakamoto, 2014), increasing the accessibility of research (Cole & Knowles, 2008). Among youth in this study, it was evident that artistic expression was a significant component of community building for emancipated foster care youth and engaged youth in
informal discussions about their sexual health.

9.1. Limitations, implications and future research

The aim of this study was to understand how youth who were emancipated from foster care learn about HIV prevention and sexual health and while findings contribute significantly to the literature, there are a few limitations. Findings cannot be generalized to the entire population of former foster care youth. We used a small sample of youth that participated in an HIV prevention education program and were a part of an aging out foster care youth. Due to their experiences of shared trauma and identity of being involved in the foster care system, it was important for the researchers to limit this group to a minimal number of participants. Research on marginalized backgrounds has shown the importance of including restricting sample sizes to small numbers (Abrams, 2010). In addition, the use of focus groups can be empowering for marginalized groups. Moreover, because of the issues that youth in this group face with housing instability and other environmental stressors, the decision to conduct one focus group instead of multiple individual interviews was done to reduce the likelihood of attrition.

By listening to the voices of youth who were in foster care, there are several implications for child welfare practice. First, it is essential that HIV prevention programming is implemented within the child welfare system. While it is difficult to establish an emotional connection between youth and foster care parents as this depends on many factors such as length of stay in the home, quality of parenting, we encourage policymakers to incorporate the use of health educators or mentors that can be a consistent figure in the lives of foster care youth. Second, youth in the study expressed their concern about engaging in effective negotiation skills when they are in romantic relationships. Third, youth expressed their need to hear from individuals who are living with HIV. By reframing HIV prevention to focus more on understanding the etiology of HIV and the importance of taking control of their sexual health as opposed to being disease prevention-focused, this may allow youth to receive information and reduce stigma associated with HIV. Lastly, as an unexpected finding of this study, the development of the art project was an example of how researchers can give youth the power to shape how they want to engage in prevention efforts. Though the arts project was in the focus group were very involved in the design and promotion of the art project, which allows for youth to have a central role in outcomes of a study related to social change and action (Akom, Cammarote, & Ginwright, 2008). In future research, we encourage more efforts to include foster care youth in research design from the beginning or formative stage of research projects by providing training in research and advocacy methods in prevention studies for this group (Ozer & Douglas, 2015). This approach utilizes foster care youth as the experts of their lived realities and identifies them as key stakeholders, along with support from adult allies, to design prevention programming and inform advocacy efforts. Incorporating a YPAR approach in HIV prevention programming and other types of prevention research for this population not only builds their leadership skills but has the potential to improve health and developmental outcomes for foster care youth (Anyon et al., 2018).

Strengths of this study include incorporating the voice of the population of interest and supporting their efforts to engaging in action work. Our sample—youth who were recently emancipated from foster care—offers a unique perspective on HIV prevention interventions. It is our hope to improve sexual health education resources within child welfare; thus, obtaining the view of individuals with lived experience will help augment any efforts to help those currently in care or recently emancipated. Their lived experiences, particularly involving the challenges they have faced in receiving quality sexual health education adds further validity to the building blocks of a successful intervention. This research reveals the importance of promoting participant involvement, collaboration, and researcher positionality (Singh et al., 2013). It will be important for researchers working with participants who belong to historically marginalized and disenfranchised backgrounds to be flexible in their creative approaches to working with diverse youth and maintaining their relationship with youth even after study completion. This allows for the researcher and participant relationship to remain consistent and therefore built on trust and support. Our study shows the natural evolution of empowering youth by merely providing them with tools and giving them a voice to relay their concerns. Striving for collaboration, integration, personal reflection, and creativity in prevention research can result in richer research processes and outcomes that amplify marginalized youth.

CRediT authorship contribution statement

Ijeoma Opara: Conceptualization, Funding acquisition, Writing – original draft, Methodology, Supervision. Ashley Lizarraza: Writing – original draft. David T. Lardier: Writing – review & editing. Andriana Herrera: Project administration, Writing. Pauline Garcia-Reid: Funding acquisition. Robert J. Reid: Writing – review & editing, Funding acquisition, Supervision.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

This study was supported by the U.S. Department of Health and Human Services (HHS), Substance Abuse and Mental Health Services Administration, Minority AIDS Initiative (Grant SP-15104). The first author is supported with funding from the National Institutes of Health, Office of the Director (1DP5OD029636) and partially supported by an education grant from the National Institute on Mental Health (R25-MH087217). Points of view, opinions, and conclusions in this paper do not necessarily represent the official position of the U.S. Government. The authors would like to thank Dr. Nkiru Nnawulezi, who provided thoughtful feedback on the conceptualization of this article to ensure that youth were truly centered in this work while also acknowledging the beauty of what happens when researchers ask and give youth the space to see their power.
Appendix A

“Balloons” by Maria
This painting represents the beauty of using condoms and how condoms are meant to protect us. The balloons represent condoms

“Unhealthy and Healthy Life” by Patricia
This portrait represents how important our choices are and how they can lead us to a healthy life or unhealthy life
“Love Project COPE” by Maria and Sasha
This portrait is about the Project COPE HIV education program and how the program made us feel confident to take control of our decisions

“Make the right choice”, by Keisha and Jamal
This picture is about how our choices can lead us to negative consequences like getting a STD, using drugs and alcohol and can even lead us to
death. I can either decide to go to school with and focus on the support of my family or do things that won’t lead me anywhere

“Say No to Drugs and Say Yes to Pizza!” by Cassie
I love how the Aging out groups gives us a place to come to everyday and eat pizza. We could be out in the streets but instead, we are in an environment that supports us and makes us feel good… and feeds us too! I rather be here than out on the streets using drugs

“U wrap it up” by Shauna
This artwork is about safe sex “wrap it” up before you regret it.

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