

A lived experience
update for the TAOS Institute

June 1, '2020

Author's Note: We would like to thank the TAOS INSTITUTE for the funds received to support the emerging adult's HIV group. The support and experience has been transformative for all of those involved in the experience of running the group, experience the benefit of the group and those in the larger community of people supporting those, who live with HIV.

The People Involved

The Emerging Adults group consists of two, female-identified, co-facilitators. One with a lived experience of HIV and one that does not, who is an MSW student, within a practicum placement under the supervision of Dr. Patricia Miller. The two co-facilitators developed the group content, planned events, ensured attendance by supporting the participants to be active in developing safe relationships with the group, and de-briefed with each other, after each event. There are currently 5 female-identified, active participants between the ages of 18-30, and 1 in-active participant. The majority of the participants were of African descent and had immigrated to Canada with their respective families. Active participant is defined as an individual who has been in contact with either of the co-facilitators. An in-active participant is defined as an individual who has not be in contact with either co-facilitator for 60+ days. We asked that all participants, regardless if they can attend the upcoming session or not, communicate their intentions of being a part of the group in order to stay connected to the community of emerging adults that are living with HIV.

The Lived Experience of the Group

The group has been successfully running since November 2019. It has encompassed generative topics that include components of: what is the lived experience of being an emerging adult as you live with HIV and were born with HIV, how to develop, contribute and expect to be in healthy relationships, mental health and the lived experience, CBT and mental health responses, understanding how we are coping with stigma and isolation, how to make our own goals and manifest those goals, and how to identify safe and meaningful ways of living within a community of people that are HIV positive and/or not.

Cognitive behavioral therapy has supported the mental health component for the emerging adults' group. Introduction of SMART Goals was an essential strategy for teaching participants why it is important to set goals as self-determined by their own needs. Along with this key component, a lot of participants expressed that they see the importance of defining a goal and to make it achievable in the future. This helped to facilitate a process of hopefulness as they live with HIV across the lifespan.

Healthy relationship identification provided participants with an opportunity to learn about different forms of abuse, how to recognize abuse, and how to develop safety plans to exit relationships

that may not be healthy for them at this time. This part of the group sessions took a narrative approach in order to identify and making meaning of all our participants lives. Shared experience was a key part of success for these groups. They sought to understand how others had experienced themselves, within their interpersonal relationships such as family, dating, sex-positive intimacy, community and other-professional relationships that they engage because of their HIV care. Understanding the stigma, racism and oppression that they experienced as young emerging adults was key to their co-empowerment with each other.

Self-determination and the Power of Resiliency

The resiliency of the group has been substantial as they shared and fostered their ability to change and adapt to expected changes. The peer-facilitator that lived with the experience of HIV, acknowledged and provided life experiences and examples to the younger adults living with HIV. The group had brought the participants together, and their relationships have flourished outside of the group. This further supported the development of a community of support and acceptance. The MSW student, who was a co-facilitator had been involved in the entire group process. They experienced the group as an invaluable resource for the emerging adult participants. The co-facilitators have put in efforts to spread awareness of the emerging adults' group to other organizations (medical and non-profit) and agencies in the Calgary area in order to facilitate more awareness of the community-based resource.

Because of the current limitations around social distancing, which is talked about below, we can look at offering our program to those who may not be directly in the city of Calgary, through zoom and other telehealth services. The participants in the group processes, self-determined various social gatherings outside of the ongoing groups. They identified that living with HIV as a young adult at times made them feel different from their non-positive peers. In order to feel more "normal" they sought to gather in social situations beyond the formal group process. This self-determined social-relational response came from some of the support they felt in the group.

Understanding the Barriers

A major limitation for the group has been the inconsistency in attendance. The participants were given opportunities to answer feedback forms confidentially, without giving their name or any other information. Attendance and participant communication have been the biggest limitation, due to time, travel and not being able to attend, due to other commitments. Additionally, another limitation would be the lack of community space that provides the confidentiality of such a group. The group was primarily held at the new library in downtown Calgary, which has free space and is easy to access via the c-train and other bus transportation. The facilitators have adjusted the needs of the participants by ensuring that any community booked space and/ or area maintains the confidentiality agreements that were made. The co-facilitators believed that many other factors which could be contributing to participants not coming out to each group.

COVID-19- A Mitigated Crisis

Due to the limitations of social gatherings in Canada because of the COVID-19 outbreak, the emerging adult's group has adjusted and adapted, specific to the way that it could provide support to the participants. Over the last two months the social distancing measures were a requirement in the province of Alberta and in turn, the group did meet online via Zoom (twice). This altered the way the group was thought about, and how the facilitators could provide support. They developed a system that would update the confidentiality processes in order that Zoom and/or On-Call Health platforms could be used for participants to engage with the group online. The facilitators asked each participant to give their comments and questions to us via the feedback form that was developed, if they felt comfortable. Additionally, they developed a system where one facilitator had addressed the participant and asked, who feels comfortable receiving their \$10.00 gift card for participating via mail. If they are not receiving their gift card via mail, the facilitator had offered to meet them in the community for this to be an option for them. The facilitators believed this is an essential part of recognizing the efforts made by the participants at this time.

Because of these changes, our allotted funds for each monthly session are a lot less. The facilitators have mailed out a few gift cards to the participants who wanted them. They will have extra funds leftover because they have not been spending money on food or other items. Their additional gift cards are going to be gifted out to the participants as required.

Future Shaping Possibilities for the Emerging Adults HIV Group

As of May 1, 2020, the co-facilitator who was providing the peer support/ lived experience perspective has resigned from the emerging adults group, due to needing to address issues that she had experienced in her own community, due to racism and discrimination. The other co-facilitator has maintained the group efforts and will continue to do so for the remaining timeline of the project. There has been a request from the larger HIV community to have a male-identified emerging adult group as there is a significant need for this population group. The larger HIV community has also expressed that they would like to continue to develop this group. They would like to find other funding to continue to support these future leaders that instill legacy work that would build in more resources for the emerging adults that are born, with HIV.