



Growing up with HIV: Building on the Strengths of Therapeutic Programming for Youth

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Evaluation of Support Groups held at Sick Kids HIV clinics led by Teresa Group Staff

Study Objectives:

1. To evaluate the experiences of children and youth who have participated in groups by eliciting feedback from:

- Children/youth who attend the groups and their parents/caregivers.
- Children/youth who chose not to attend the groups and their parents/caregivers.

2. To inform planning for future psychosocial supports for this group of children/youth.

Literature on support groups for children & youth with HIV

Importance of developing:

- a sense of belonging.
- a safe place to discuss a highly stigmatized condition which is usually kept secret, especially from peers at school (who are normally an important source of support for youth with difficult issues).
- a source of information to assist with treatment adherence and healthy approaches to living.

Study Participants

- 8 teens **Group 1 ages 15-18**
- 8 children **Group 2 ages 11-14**
- 2 children who did not attend
- 9 parents
- 2 parents whose children did not attend
- 3 Teresa Group staff
- 6 Sick Kids staff



Quotes from Group Members

“I can compare my life to their life, and they can do the same with me, and they can see what is going on, you know. If they had the same problems that I had or have still, we can go through it together or I can tell them what happened with me and how I got through whatever, or they can tell me what happened with them and how they got through whatever. And it helps a great deal actually.”

“We all basically go through the same thing because we all have the same thing.”

Quotes from Parents:

“Especially the teenagers. I am not the only one in the world that this has happened to, there are other kids out there, they are having a good life so that kinda opened her up and gave her a more positive light that this is not the end of the world for me. I can go on with my life. I can do things and they touch on everything in the group.”

“I mean one important part of the treatment, it is not only treating by medication, but psychologically you have to be treated too, and I think it is a positive program.”

Convenience: Attending groups during clinics

“Well, the benefit is because they hold it on clinic day, so we are not making a special trip.”

“I think it’s a really good to have it in clinic, the way they schedule it with the kids of a certain age to come in at this time so that way they can meet.”

**Children's Group Themes
(ages 11-14)**

Education/Learning

Safety/Support

Normalization

Adherence

Fun

Convenience

Empowerment/Mutual Aid

Adherence

“Yeah like if I stop taking it, I can get AIDS and then like the chance of dying, so it’s a problem.”

Fun

“It’s really fun and you should actually join it cause you feel open when you go into the group, it’s like a new world out there.”

Normalization

“You can just have other kids that are like you, you can just sit there and talk with them. You could see how they are and are no different than anybody else.”

Convenience

“I am already coming here so it doesn't make a difference, like if I had to go somewhere else I would have to go to 2 places.”

Teen Group Themes (ages 15-18)

Education/Learning

Family/Relationships

Safety/Support/Comfort

Normalization

Confidentiality

Transition

Adherence

Location

Fun/Rituals

Mutual Aid

Education

“My view on HIV has changed since I first started coming to the group. Basically for the better I guess. I have a more clear understanding of it, I understand the risks, I understand the benefits, it’s got benefits to it as well, I have all of these friends now, I have learned a lot just coming here.”

“When I was a little girl I was really kind of confused about like I thought that I could give HIV to my little sister by sharing the same drink, and when I was little I never wanted to share with her and stuff and **now** they made me understand the different things like how you can get it and how you can prevent someone else from getting it. So they helped me with that.”

Support

“Everyone should have that kind of support and comfort. No kid should grow up alone, dealing with this by themselves internally because that is not good at all. They should all have someone or someplace where they can talk with other people who know what they are going through. That is really helpful for everyone.”

Friendship/Fun

“Coming to clinic isn’t that big of a deal but like since the group has started it has definitely been, like it has definitely made my enthusiasm for coming to clinic a lot better.”

Normalization

“It’s very helpful. It helps in the fact that you have the knowledge that there is someone else that has the same thing that you have and you kind of have the same problems, right? and so it allows for amazing levels of interaction between two different people”.

Adherence

“Sometimes like even, like sometimes people will be like I don’t want to take my medication man, and I’ll be like, I’ll take my medication because I know like, I’ll come back here and my friends are all taking their medication and I don’t want people, like even when they grow up, I don’t want people to feel like they are alone, and they are taking these medications, and they don’t want to take it, and then they end up bad, like that’s not going to be good at all.”



Transition (to adult health care)

“Yeah, that’s one of those topics we talk about the most because we all sort of feel the same because these are the kind of hospitals where we won’t have groups anymore”

“We even talked about having a group outside this, after this. We talk about stuff like this and it’s really good”

Lessons Learned:

Children/Teens

- Tell us it's worth the effort to get kids into groups
- Groups reduce HIV stigma, isolation, and increase HIV knowledge and support.

Parents:

- Want their children to meet other kids, learn more about HIV
- Like the convenience of having children attend groups during clinics.

To inform planning for future psychosocial supports for this group of children/youth:

- Was the group effective for the members?
- Did it provide key components of support required by children and youth living with HIV?
- Is this a program that can be replicated in other clinics?
- How can this group effectively help youth transition to adult care?