

Falling Through the Cracks of the Big Cities

Who is Meeting the Needs of HIV-positive Youth?

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ABSTRACT

Background: Globally, half of all new HIV infections occur among youth under 25. As of June 30, 2002, more than 13,000 youth and young adults had tested positive for HIV in Canada. Despite this prevalence, there is a lack of resources for Canadian HIV-positive youth.

Objective: To investigate what can be done to better support the needs of HIV-positive youth in Canada.

Methods: A community-based participatory research approach was adopted. Thirty-four qualitative in-depth semi-structured interviews were conducted with youth (ages 12-24) living with HIV in Ontario. A stakeholder group of youth living with HIV, professionals and researchers collaboratively analyzed the data for emerging themes.

Results: When asked about areas in their lives where youth needed support, three major themes emerged: 1) Personal feelings about HIV: Youth identified a wide range of emotional response to their HIV status; however feelings of isolation, loneliness and hopelessness were dominant. 2) Barriers to full participation in society: Youth described a number of social and structural barriers to their full participation in society. 3) Specific support needs: Youth had difficulty accessing appropriate support services; they had very mixed feelings about both youth- and AIDS-serving organizations.

Interpretation: The youth we interviewed are interested in targeted programs, have difficulty accessing appropriate resources and would benefit greatly from increased social support. Specialized health and support services that are developmentally appropriate may be necessary. Where specialized services do exist, more research may be necessary to understand why they are underutilized and/or perceived as inappropriate. While this was a small exploratory study, our data suggest that better supporting the needs of HIV-positive youth might directly benefit this vulnerable population.

MeSH terms: Youth; HIV; support; community health services; stigma

La traduction du résumé se trouve à la fin de l'article.

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Globally, half of all new HIV infections occur among young people.¹ Youth represent a growing population in Canada to experience HIV and AIDS.^{2,3} As of June 2002, 13,279 Canadians under the age of 29 had tested positive for HIV.⁴ As a result of major improvements in HIV therapies, the first generation of perinatally infected youth are maturing to adolescence.^{5,6}

HIV-positive youth are particularly vulnerable: they experience disproportionate rates of homelessness,^{7,8} sexual and physical abuse,^{9,10} financial difficulties,¹¹⁻¹⁴ addictions,¹⁵ legal concerns,^{13,16} social isolation and stigma,^{16,17} and mental health concerns.^{9,18} Youth with HIV have a wide range of specific service needs, ranging from medical care, financial/housing support and vocational training to social support, substance abuse counselling and mental health resources.¹⁹⁻²² Programs targeting American HIV-positive youth have been able to demonstrate significant reductions in risk-taking behaviours and significant improvements in quality of life indicators.^{15,20,23}

Despite this prevalence, incidence, vulnerability and opportunity, there is a lack of resources for HIV-positive youth in Canada.²⁴ Few studies have investigated the needs of Canadian HIV-positive youth. Two exceptions include a program evaluation conducted by Positive Youth Outreach¹¹ and a study investigating HIV-positive lesbian, gay, bisexual and transgendered youth (LGBT).¹⁶ While both confirmed much of what has been found in the American literature, they were focussed on specific subpopulations. The aim of this qualitative study was to investigate what can be done to better support Canadian HIV-positive youth. A diverse group of Ontario youth were studied.

METHODS

Approach

A community-based participatory research model^{25,26} was adopted. A stakeholder group of HIV-positive youth, supporting professionals and university-based researchers collaboratively developed the research protocol and were involved in all aspects of data analysis and interpretation.

Youth were recruited through community-based agencies, hospital clinics, and youth networks through flyers and personal invi-

tation by providers. In all cases, youth approached the research team directly.

Before participation, informed consent procedures were followed (approved by University of Toronto and the HSC Ethics Review, Ref #9432).²⁷ Parental consent was sought for youth under the age of 18 whose guardians already knew about their HIV status. All interviews were conducted by a doctoral student who had no prior relationship with any of the youth interviewed.

Interviews were semi-structured and lasted 35-95 minutes. They were audio-taped and transcribed verbatim, with two exceptions: one wrote out his own answers, and in the other, copious notes were taken by the interviewer. At the conclusion of each interview, youth completed a brief demographic survey. Interviews probed around four areas of interest: a) goals for the future, b) support needs, c) treatment and self-care, and d) Internet use. This paper focusses on results of our "support" themes. For a more in-depth discussion of methods, the interview guide and a list of codes, please see Flicker et al.²⁸

Participants

A sampling frame was developed that ensured diversity in age, sex, sexuality, age of diagnosis, ethno-racial identity and geographic region.²⁹ Youth was defined as between the ages of 12 to 24, to understand the wide range of issues that face HIV-positive adolescents as they mature to adulthood. Participation was limited to youth who: a) identified as HIV-positive through self-report; b) had the ability to communicate in either English or French; and c) had lived in Ontario at least three months prior to the study. Youth received a \$20 honorarium for participation. In total, 34 youth participated, (see Table I for sample description).

Analysis

A modified grounded theory approach guided the analyses.³⁰⁻³² Specifically, modifications were made to accommodate a collaborative group process as follows: a random subsample of 10 transcripts stripped of identifying names and places were shared with the stakeholder group (of youth, professionals and researchers) for preliminary analysis. Based on emerging themes, commonalities and major differ-

ences, a preliminary coding framework was developed.³³ Data were coded using NUD*IST qualitative data analysis software.³⁴ Issues with the coding scheme (such as category confusion and missing themes) were brought back to the group and the scheme was refined and subsequently applied to the remaining transcripts. In total, there were 19 main codes and 108 sub-codes.

Coded data were returned to the stakeholder group for analysis. Weekly meetings were held to discuss main themes, relevance and implications for each code. Collectively, summary tables were constructed to capture the most common themes, gaps and issues. As a form of 'member checking,' tables were returned to the wider 'community' for feedback at a youth Roundtable convened to reflect on results. The Roundtable was attended by 45 HIV-positive youth (a mix of study participants and non-participants) and supporting professionals.

RESULTS

When asked about areas in their lives where youth needed support, three major themes emerged: personal feelings about HIV, barriers to full participation in society, and specific support needs.

Feelings about HIV

Participants described a range of emotional responses to their HIV status (see Table II). Several who acquired HIV during adolescence found the news extremely difficult. Many expressed regret, shame and guilt over the behaviours that facilitated transmission. Participants talked about how they wish they had done some things "differently," particularly around substance use, using condoms and sex work.

Other participants described the diagnosis as an empowering 'opportunity.' A small sub-group described their transition from initial depression to feeling like they had a 'new lease on life' after their diagnosis. For these youth, the diagnosis was seen as an opportunity to re-evaluate what was 'important' and make concrete 'positive' changes.

Finally, some participants, particularly those who were perinatally infected, talked about HIV as being a relatively small part of their identity. For them, living with

TABLE I
Participant Characteristics

| Characteristic | Number Interviewed (Percentage) |
|---------------------------------|---------------------------------|
| Sex | |
| Male | 21 (62%) |
| Female | 13 (38%) |
| Age | |
| 12-15 | 6 (18%) |
| 16-19 | 12 (35%) |
| 20-24 | 16 (47%) |
| Sexuality | |
| LGBTQ* | 8 (24%) |
| Heterosexual | 26 (76%) |
| Diagnosis | |
| Last 12 months | 15 (44%) |
| Longer than 12 months | 12 (35%) |
| Perinatal | 7 (21%) |
| History of Street Involvement | |
| Yes | 23 (68%) |
| No | 11 (32%) |
| Ethno-racial identity | |
| White, European, Canadian | 19 (56%) |
| African/Caribbean | 10 (29%) |
| First Nation/Aboriginal | 2 (6%) |
| Unknown/Other† | 3 (9%) |
| Geographic Location (residence) | |
| Large urban | 27 (79%) |
| Small urban/Rural | 4 (12%) |
| Northern | 3 (9%) |

* Lesbian, Gay, Bisexual, Transsexual, Queer or Questioning

† Unspecified, Chinese, South-East Asian

HIV is just a part of their regular routine that they rarely reflected upon.

Participants felt that they had a number of things in common with other HIV-positive youth that distinguished them from their peers. These included feeling lonely and stigmatized, having the burden of keeping a big secret, experiencing a strong sense of mortality, constantly having to take medications, and needing to take special precautions when negotiating with sexual partners (Table III).

Isolation was a common theme. For some, isolation was self-imposed. Participants described feeling sad and depressed; these feelings made connecting with others difficult. However, isolation was often also the result of traditional support networks distancing themselves after learning about a youth's HIV status. Consequently, participants were generally reticent about disclosing their HIV status to people in their lives, and often felt the burden of keeping 'a big secret.'

Several also felt that their diagnosis made them more aware of their mortality than their peers. This resulted in a sense of urgency to live 'more fully in the moment.' For some this meant 'partying' as much as possible, while for others this meant focussing on the attainment of personal goals.

TABLE II

How HIV-positive Youth Feel About Their HIV

| | |
|-----------------------|--|
| Regrets & Guilt | "Myself, I feel ashamed because I shouldn't have gone into prostitution that was just stupid." |
| Anger & Resentment | "Like I feel like I have been ripped off, I'm really, really young and it's like – I feel like it's different if you have HIV when you're like thirty or forty." |
| 'A new lease on life' | "For the first month it was like oh my god my life is over, might as well give up on everything... I finally walked out, you know, this is a brand new day, let's just start my life again and this time I'm going to make something of myself. So yeah, it changed in the sense that it made me stronger to do what I wanted and made me go forward more. It took me a step back for a month and then put me four steps forward." |
| 'No big deal' | "I am always just doing my thing. I never stop and think – hey I got HIV." |

TABLE III

What HIV-positive Youth Say Makes Them 'Different' from Other Youth

| | |
|------------------------------------|---|
| Stigma | "I guess like people don't want to be around you because they think you are queer or something; or you do like injections, or they might catch it too or something. By coughing in the air or something... they get scared." |
| Loneliness | "I think we feel the same sometimes, as like, being alone, sometimes you feel no one knows you. You have something but you know, other people won't think it. But you know yourself and then you act differently among people, you're conscious about what you say." |
| Burden of keeping a big secret | "It's not an everyday thing to have HIV. You know, some people might be scared. I don't know. I just never really told anybody." |
| Sense of mortality | "I feel like I'm in retirement, you know. I feel like more in sync with senior citizens than I do with people my own age. I feel ridiculous talking with people my own age and they, you know, they think they're invincible or something... I don't feel like I'm in sync with my peers developmentally. ... I have this little piece of information that separates me from these other people." |
| Sense of urgency | "People all have this goal to live every day, you know, like it was their last day... So every single day we go out, we do what we dream and at the end of the day if we can't say that we did something towards that dream, then we've wasted the day. And it's a horrible thing..." |
| Needing to negotiate with partners | "If I was to come in contact, like have any sexual relationship or any thing, that would be the person I'd have to tell, just because, why should I put someone else through it?" |
| Taking medication | "I think that everyone that has this disease has stuff in common – because we all take medication that we don't want to take – because it is hard to, especially when you are a kid." |

TABLE IV

Perceived Barriers to Full Participation in Society Among HIV-positive Youth

| Social Barriers | Structural Barriers |
|-----------------------------------|---------------------------------------|
| Fears of disclosure | Poverty |
| Stigma around HIV | Homophobia |
| Lack of social & familial support | Sexism |
| Difficulty finishing school | Racism |
| Maintaining employment | Ageism (discrimination against youth) |
| Being accepted | Housing |
| | Treatment access |

Barriers to full participation in society

Participants described a number of social and structural barriers to their full participation in society (Table IV). Stigma around HIV was seen as a major barrier. Most participants described painful disclosure stories or situations of overt harassment, abuse, discrimination and/or cruelty upon disclosing their status to a loved one or someone in a position of power (e.g., parent, partner, friend, teacher, boss, shelter worker, etc.). Fears

around disclosure and what might result kept many youth from participating in activities, finishing school, finding/maintaining employment, or building close social networks.

Many participants had a history of street involvement, drug use and/or sex work. They often understood their HIV status within the context of much larger systems of injustices that they faced every day – including poverty, homophobia, sexism, racism, and youth discrimination.

TABLE V

Desired Services for HIV-positive Youth

| |
|--|
| Safe spaces to be "out" about having HIV |
| Peer-based services |
| Financial support services |
| Housing support |
| Recreational programming |
| Food security |
| Educational support |
| Counselling services |
| Information sessions |
| Referrals to appropriate services |
| Treatment decision-making resources |

Support networks

Despite these barriers, many participants described rich and complex (sometimes alternative) supportive social networks. Most were able to turn to their parents or other family members for support. Those who had strained family relations highlighted the importance of close friends and/or partners. Participants who knew other HIV-positive youth described peer support as extremely valuable. When probed, few were truly 'alone.'

Participants generally had positive things to say about targeted youth services. Almost all were involved with youth-, health- and/or social services organizations. Most were regular users of at least one specialized youth service (e.g., youth drop-in, shelter, substance abuse clinic). As a result, they had regular contact with at least one professional who provided some support (e.g., nurses, social workers, therapists, case workers). While most of these relationships were quite nurturing, others described situations where they felt uncomfortable about disclosing their status to their support workers. Participants from smaller urban and rural communities were less likely to disclose to support workers.

Several participants voiced concerns regarding their experiences with AIDS service organizations (ASOs). Generally, they were not seen as being particularly "youth-friendly." As one young man articulated, "It looked like it was for sick people... It was just not a good atmosphere. The colours of the walls were awful, people were grumpy..." In addition, participants were worried about issues of anonymity and confidentiality should they be seen entering an ASO.

Participants liked the idea of targeted programs, such as summer camps or tailored local drop-ins. As one youth articulated: "I wish there was ... some sort of place where you can just chill out and..."

talk to some people and they'd have programs, discussions, maybe information sessions, different things like that but all on HIV type of things, because they have them for like regular youth...." Many participants, however, did not know that some of these services actually existed. Those who attended these specialized services tended to be most satisfied.

When specifically probed about their service needs, participants were very clear (Table V). They wanted educational and financial support services, food security, and housing assistance. They asked for recreational programming where it was safe to be "out about having HIV." They wanted specialized counselling, workshops, information sessions, and referral services for managing their HIV. In particular, topics around treatment and self-care issues were seen as priorities. Participants wanted programming to be age-specific, sensitive to issues around HIV and, where possible, peer-driven.

DISCUSSION

This study took a qualitative approach to understanding HIV-positive youths' support needs. The sample size was large and diverse enough for the generation of many themes. Youth living with HIV were involved as co-researchers and this provided greater depth and understanding to the analyses. One limitation of a qualitative design is that it is difficult to generalize results to a wider population. Another limitation is that this sample was largely recruited through community agencies and health care facilities, and, as such, nearly all the youth interviewed were already supported by at least one specialized service.

Nevertheless, our findings suggest that the youth we interviewed are interested in targeted programs, have difficulty accessing appropriate resources and would benefit greatly from increased social support. This study supported the findings of other studies^{16,20,35,36} that have shown that youth face many barriers in accessing appropriate health and social services, particularly HIV/AIDS-specific resources. A new finding of this study is that while participants were users of youth-serving agencies, they often do not necessarily feel safe about disclosing their HIV status in these environments.

Although these findings cannot be generalized, it may be that new models of collaboration between youth-serving and AIDS-serving agencies are necessary to better target young people. In addition, where comprehensive programs in large urban areas do exist, more attention needs to be focussed on why they are underutilized and/or perceived as inadequate. Finally, services reaching young positives need to be sensitive to the wide range of youth experiences and responses.

Better supporting the needs of HIV-positive youth might directly benefit this vulnerable population. Additionally, it may prove to be an effective model for preventing the further spread of HIV. Programs that are targeted specifically to HIV-positive youth show significant reductions of risk-taking behaviour, increased condom use, fewer medical care contacts and a number of positive lifestyle changes.²³ Other programs targeted to HIV-positive youth have shown significant impacts on quality of life indicators.^{15,20} An evaluation of 10 American adolescent HIV/AIDS programs emphasized the importance of peer-driven programming and tightly-linked professional medical-social support networks.¹⁹

In conclusion, as the Canadian prevalence of adolescents living with HIV continues to grow, it may be time to re-evaluate our current tertiary prevention strategies. Young HIV-positive people need to be supported and barriers to their full participation in society ought to be minimized. Specialized health and support services that are developmentally appropriate are necessary. In addition, we need to better understand why specialized services that do exist are underutilized and/or perceived as inappropriate.

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RÉSUMÉ

Contexte : À l'échelle planétaire, les jeunes de moins de 25 ans contractent la moitié des nouvelles infections à VIH. Au 30 juin 2002, plus de 13 000 adolescents et jeunes adultes étaient séropositifs pour le VIH au Canada. Malgré cette prévalence, on manque de ressources pour les jeunes Canadiens séropositifs.

Objectif : Examiner ce qui peut être fait pour mieux répondre aux besoins des jeunes séropositifs pour le VIH au Canada.

Méthode : Nous avons utilisé une méthode de recherche participative communautaire. Trente-quatre entretiens en profondeur semi-structurés ont été menés auprès de jeunes (de 12 à 24 ans) vivant avec le VIH en Ontario. Ensuite, des jeunes séropositifs pour le VIH, des professionnels et des chercheurs ont analysé ensemble les résultats de ces entretiens pour en dégager les grands thèmes.

Résultats : Trois grands thèmes se dégagent des réponses des jeunes à la question sur les aspects de leur vie où ils ont besoin d'aide : 1) Les sentiments personnels à l'égard du VIH : les jeunes présentaient un vaste éventail de réactions émotionnelles à leur état sérologique relativement au VIH, mais l'isolement, la solitude et le désespoir étaient leurs sentiments dominants; 2) Les obstacles à la pleine participation à la société : les jeunes ont cité plusieurs obstacles sociaux et structurels à leur pleine participation à la société; 3) Les besoins de soutien spécifiques : les jeunes avaient du mal à obtenir les services de soutien dont ils auraient eu besoin; ils nourrissaient des sentiments très contradictoires envers les organismes de service aux jeunes et/ou aux sidéens.

Interprétation : Les jeunes que nous avons interrogés manifestent un intérêt pour les programmes ciblés, ils ont du mal à obtenir les ressources appropriées, et ils ont un besoin pressant d'un soutien social accru. Des services de soutien et de santé spécialisés, adaptés à leur niveau de développement, pourraient être nécessaires. Il faudrait pousser la recherche pour comprendre pourquoi de tels services, lorsqu'ils existent, sont sous-utilisés ou considérés comme étant inadaptes. Même si la présente étude est préliminaire et très restreinte, les résultats obtenus donnent à penser qu'une meilleure réponse aux besoins des jeunes séropositifs pour le VIH pourrait procurer des avantages directs à cette population vulnérable.

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