BARRIERS IN ACCESS TO PRIMARY HEALTH CARE FOR YOUNG HIV+ WOMEN:
A QUALITATIVE RESEARCH STUDY

YOUTHCO/PWN WISE PROJECT

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EXECUTIVE SUMMARY

The YouthCO AIDS Society (YouthCO)/Positive Women's Network (PWN) WISE Project works to increase young women's access to integrated care, treatment, support and prevention within clinic-based settings. WISE Project staff and volunteers work in direct partnership with clinics throughout Vancouver to better ensure that young women (aged 15-29) are receiving proper medical care and HIV treatment. The WISE Project utilizes a peer-based model to promote community and provide important information for young HIV+ women, and helps them define what support means for them.

In late 2007, as an extension of the WISE Project YouthCO and PWN commissioned a research project to describe, explore and explain the barriers that young women living with HIV/AIDS face in accessing primary health care services.

In an attempt to explore the questions a) what are the barriers experienced by clinicians and health care providers when delivery services to young women living with HIV/AIDS, and b) how do these compare to the barriers identified by HIV+ women attempting to access clinical services, we employed a combination of primary and secondary research methodologies. Primary research included interviews with health care providers (n=5), related community-based organization service providers (n=7), and HIV+ women themselves (n=10), all within the Vancouver area. Subsequently, we undertook a comprehensive literature review to highlight the themes and trends arising from the primary research data, and to present possible conceptual frameworks for our analysis of the results.

Findings from the primary data collection revealed the following barriers affecting young HIV+ women's access to clinical services within the Vancouver area:

- prioritizing other more pressing needs, especially when living with addictions and/or violent/abusive partners;
- navigating the complexities in health services and staffing structures;
- navigating life transitions and identities including perceptions, stereotypes and expectations with being a "young woman", as well as the generational and long term effects of colonization and racism on young Aboriginal women;
- prioritizing childcare and parenting realities, including the fear of custody loss when accessing services;
- building trust, effective communication and relationships with doctors and health care providers;
- locating and accessing women-specific clinics and services;
- overcoming inflexibilities in clinic logistics and appointments, and creating appropriate opportunities to "meet young HIV+ women where they are at" with their health care needs;
- finding and accessing doctors with HIV/AIDS comfort and competency, both within the Downtown Eastside and throughout the province;

- overcoming ageism, and finding and accessing youth-specific services and role models for young HIV+ women; and
- overcoming HIV/AIDS stigma and discrimination, and finding and accessing confidential clinical services.

Clinicians reported the following challenges to providing services to young HIV+ women:

- avoiding burn-out and high turn-over among Downtown Eastside service providers;
- maintaining hope and optimism when providing support and counselling services;
- overcoming the challenges associated with clinic sites, structures and logistics; and
- overcoming population-unique challenges, such as population size and invisibility, as well as transience, tracking and follow-up.

Interviewees also identified a number of “best practices” within existing models and services, with particular focus on the elements and services provided by both Oak Tree Clinic (including its multidisciplinary, child-inclusive, non-judgemental approach) and the Vancouver Street Nurse team (including the team’s proven ability to bring primary health “into the hands and onto the door steps” of young women living with HIV/AIDS).

Recommendations from persons interviewed included the following strategies and ideas for clinicians, health care providers and related community service providers:

- increasing opportunities for capacity-building among primary health care professionals in the areas of HIV/AIDS knowledge development and knowledge transfer/exchange, training forums which feature the voices of young HIV+ women and Aboriginal/First Nations cultural sensitivity training;
- increasing the number of women-specific services in both clinical/medical settings as well as with regard to the other determinants of health (i.e. housing); and specific services for young women who are newly-diagnosed;
- increasing education and training for young HIV+ women;
- increasing opportunities for peer and community-based initiatives; and
- integrating fun activities that do not necessarily focus on HIV.

Finally, building on the findings and interpretations of this initiative, this report also provides opportunities and recommendations for future areas of research and exploration, with particular regard for how community-based organizations like YouthCO and PWN may best support primary health care professionals in their work with young women living with HIV/AIDS.

INTRODUCTION

THE WISE PROJECT: A HISTORY OF SUCCESSFUL PARTNERSHIP

With the financial support of the Public Health Agency of Canada (PHAC), PWN and YouthCO have collaborated on the Women's Initiatives for Support & Education (WISE) Project since April 2003.

During the first two years of the project, WISE focussed on developing the Bases Covered Campaign, an HIV/AIDS prevention campaign targeting high-risk young women including Aboriginal women and IDUs. Subsequently, the WISE Project utilized the prevention themes and initiatives of Bases Covered to foster the creation of peer-driven safe and supportive environments for young HIV+ women.

The current goal of the WISE Project is to increase young women's access to integrated care, treatment, support and prevention within clinic-based settings. WISE Project staff and volunteers work in direct partnership with clinics throughout Vancouver to better ensure that young women (aged 15-29) are receiving proper medical care and HIV treatment. The WISE Project works from a peer-based model to promote community and provide important information for young HIV+ women and help them define what support means for them.

WISE strives to reach women living in the Downtown East Side (DTES)/Downtown South (DTS) areas of Vancouver, with a focus on First Nations/Aboriginal women. The goal of the project is to not only increase women's access to integrated care and treatment but to also support young women in the development of their own network of support systems that work with their own unique needs.

Young women are among the fastest growing demographic contracting HIV, and usually the last to get tested and receive treatment. The WISE Project supports newly diagnosed women, connecting them with accessible and culturally appropriate services where they feel supported and cared for.

As an extension of the WISE Project, YouthCO and PWN recently commissioned a research project exploring the barriers in access to primary health care services for young women living with HIV/AIDS in Vancouver.

RESEARCH PROBLEM

What are the barriers experienced by clinicians and health care providers when delivering services to young women living with HIV/AIDS?

What are the barriers identified by HIV+ women attempting to access clinical services, as well as by the community service providers most closely involved with delivery of related services (i.e. housing, food security, advocacy, etc.) ?

How do the experiences of these groups compare?

INTENDED OUTCOMES

1. Identify, describe and compare the phenomena (i.e. perceived barriers in service provision and access) and identify common themes of participant meanings

2. Describe and explain any patterns related to the phenomena including what events, beliefs, attitudes or policies are at play as well as how participants explain the phenomena

3. Create opportunities and the will to initiate change by examining how participants describe and explain the challenges and how they can take positive action to address the challenges.

METHODOLOGY

This was a qualitative research case study which worked to describe, explore and explain the existing barriers in access to primary health care services for young HIV+ women. We collected data primarily in the form of words rather than numbers, data that is informed by the voices of young HIV+ women as well as those of the clinicians, health care providers and community partner organization staff working to promote their health and well-being.

Primary Data Collection

The case study is intended to provide a detailed narrative description, analysis and interpretation of the phenomena experienced by clinicians and health care providers along with young HIV+ women attempting to access clinical services.

Young women involved in the sex trade, who are homeless or hard-to-house and/or who use drugs, are some of those most marginalized in our society, as well as the hardest to reach with health care services. Accordingly, the focus of the research project was on clinicians and service providers delivering services in the DTES and DS regions of Vancouver. We also worked to address issues distinct to young Aboriginal women.

The primary data collection techniques for the case study were as follows:

1. Purposeful sampling of in-depth interviews with clinicians and health care service providers

Potential interview candidates were identified by the researchers in consultation with staff at YouthCO and PWN. A list was generated and those persons were then sent a letter of introduction by the researchers (see Appendix A). One week later candidates were contacted by telephone to ascertain their level of interest and where appropriate, to book a time to conduct the interview.

Each person asked to participate in an interview was offered a $75 honorarium to compensate them for their time. In most cases this honorarium was declined.

The approach to the interviews was a “conversation with a goal”: to have participants identify and describe for themselves the barriers and challenges they experience when delivering health care services to young HIV+ women. We used a general interview protocol with a series of common questions (see Appendix B) while allowing for considerable latitude to explore the issues identified by the participants.

The interviews were conducted either in person or over the telephone, and lasted an average of one hour. During the course of the interview, notes were taken. These notes were then organized and returned to each interviewee for review and approval. On several occasions changes were suggested by the interviewees that were incorporated into the final iteration of the transcript.

The following clinicians and health care providers were interviewed:

- Dr. David Burdge, Medical Co-Director of Oak Tree Clinic and the Director of Adult Service and the Oak Tree Clinic Research Program

- Dr. Trevor Corneil, Clinician, Three Bridges Community Health Centre & Medical Director for Urban Primary Health for Vancouver Coastal Health
- Lian McKenzie, RN, Pender Community Health Centre
- Paul Harris, Street Nurse with the BCCDC, Bute Street Clinic
- Jen Quesnelle, RN, Pender Community Health Centre

2. Purposeful sampling of in-depth interviews with representatives from community partner organizations working in the field

As with the clinicians, possible interviewees from community based organizations (CBOs) were determined by the researchers in consultation with staff at YouthCO and PWN. Those persons were sent a letter of introduction by the researchers (see Appendix A) and contacted one week later to book a time, where applicable, for an interview. .

Each person asked to participate in an interview was offered a $75 honorarium to compensate them for their time. In most cases this honorarium was declined.

As with the clinician interviews, questions were developed to guide the exchange but allow for the flow of information from CBO staff (see Appendix C). The format and protocol for the interviews with CBO staff was the same as for the clinicians. Again, interviews lasted approximately one hour and interview notes were provided to the interviewees for their final approval. On several occasions changes were requested that were incorporated into the final transcript.

Interviews were conducted with the following CBO representatives:

- Bronwyn Barrett, Support Program Co-ordinator, Positive Women's Network
- Hayley Sinclair, Co-ordinator, Maka Project
- Jodi Loudfoot, Outreach Worker, Oak Tree Clinic
- Rachel Croy, Supervisor, The Vivian
- Bronwen Tigar, Homeless Outreach Support Worker, Rain City Housing and Support Society (formerly known at Triage)
- Heather Hoiness, Case Management Supervisor, Client Services, AIDS Vancouver
- Bambi Tait, HIV Educator, Healing Our Spirit BC Aboriginal HIV/AIDS Society

3. Focus groups with young HIV+ women and older HIV+ women who sero-converted in their youth

Two focus groups were conducted with WISE project participants with the intention to focus-test the groups' experience with health care providers/the medical system, and to ascertain what barriers, if any, they had experienced accessing services. Focus group participants were also invited to provide suggestions as to what changes they would like to see to improve their own or others' experiences.

A basic set of questions was developed for the focus groups (see Appendix D), however there was considerable effort made in the facilitation to have the session guided by the focus group participants. The women themselves who shaped the content of the data collection session by focussing on topics of importance or interest to them.

At the beginning of the focus group, the facilitator informed the women participating that their comments would be kept confidential and that their names and any identifying information would not be published in the case study. Arrangements were also made to collect participants contact information (where possible) in order that a copy of the final case study could be provided to them.

a. Focus group one: Thursday, February 14th at drop-in lounge at YouthCO, 1104 Hornby Street

Four participants including two members of PWN attended. Participants were provided with a $75 honorarium. Child care subsidies and transportation (bus tokens) were also made available to women who required them.

b. Focus group two: Saturday, March 22nd at CNIB retreat centre on Hornby Island (as part of WISE Young Women's Wellness Retreat) – four participants

Four participants were present. No honorariums were offered to the focus group as those who attended were part of a three day wellness retreat organized by YouthCO and PWN. It was made clear to women at the retreat that participation in the focus group was entirely optional and not in any way compulsory.

Each focus group lasted approximately 90 minutes.

Literature Review

In addition to these primary data collection techniques, we conducted a preliminary literature review (see Appendix E) to present possible conceptual frameworks and to help frame the data and the results.

The methodology for the literature review was as follows:

We systematically reviewed primary HIV/AIDS-related literature searching for studies that identified barriers experienced by clinicians and health care providers when delivering services to young women living with HIV/AIDS. We restricted our search to peer reviewed journal articles or books chapters.

We searched in the EBSCO database relying on the following journals: Academic Search Premier, CINAHL, ERIC, Family & Society Studies Worldwide, LGBT Life, MEDLINE, PsycARTICLES, PsycBOOKS, PsycINFO, PsycEXTRA, Family & Society Studies Worldwide, Social Work Abstracts, and Women's Studies International.

Descriptors used for the search were terms relating to young women, terms relating to HIV/AIDS, and/or terms relating to primary health care services and delivery.

FINDINGS AND INTERPRETATIONS

COMPETING PRIORITIES

Prioritizing Addictions & Basic Needs

Overall the individuals interviewed placed young HIV+ women's primary health care services within a matrix of competing needs and priorities, such as addictions, housing, childcare, relationships, sex work and violence. A common theme that arose from these discussions was that HIV and/or health care often did not carry the same level of urgency and importance, especially for young women. The daily struggle to attend to other basic needs, particularly for young women in the DTES, was consistently prioritized over accessing both preventative and acute care.

> "Coming into the clinic for health care is also often not a priority for young women. Depending on what is going on for them, addiction problems, survival… maybe they have to meet their johns. Or feed their addiction. There is often something more important than going to the clinic." (Service Provider)

> "If you're homeless and don't have food, your two priorities are to get food and shelter - everything else falls to the third, fourth, tenth slot on the list of priorities." (Service Provider)

Living with Addictions

There is a significant body of evidence (Rastegar et. al. 2003, Sohler et. al. 2007) describing the links between HIV treatment failure and missed appointment rates, unmet support services needs and injection drug use. One interviewee in our study noted that addictions are often the primary focus of many young HIV+ women's lives, especially within the DTES. She observed that older HIV+ women tend to be better able to manage their addictions amid the various priorities in their lives, including health care.

> "One of the biggest things we see... is around women who are really in their addiction. Older women tend to have an understanding of how addiction works in their lives. Those women know themselves a bit better and can manage their addiction better. Young women they tend to be in a bit more of a cycle of 'where is their next fix?' It is more of a crisis energy.... They are going up down up down." (Service Provider)

> "The reason why women go to clinics? Addictions – only going for methadone maintenance. Wound care is also very big one [reason why women are going to the clinic]. But often, even when women are really sick they won't go to the doctor." (Service Provider)

> "It's about the addiction, not health care." (Service Provider)

> "While I was using I just saw a methadone doctor, nothing regarding HIV. I only started checking my counts four years ago when I got pregnant with my daughter." (HIV+ Woman)

Living with Violence

Interviewees discussed the role that violence plays in young HIV+ women's lives and the impact that this has on their ability/willingness to access primary health care. In their study, "Domestic Violence and Childhood Sexual Abuse in HIV-infected Women and Women at Risk for HIV" (2000), Cohen et. al. found that the lifetime prevalence of domestic violence was two-thirds within their cohort of women living with HIV, with one quarter reporting recent abuse and over 30% reporting childhood sexual abuse. They found that childhood sexual abuse was strongly associated with a lifetime history of domestic violence and high-risk behaviours, including drug use, having more than 10 male sexual partners, and exchanging sex for drugs, money or shelter.

Findings from the study conducted by Lichtenstein et. al. (2006) showed that abused women were reluctant to keep appointments if they were afraid of their partners, if they were depressed, feeling ill or "too worn down", or if they were ashamed of being abused. Moreover, abusive partners were sometimes reported to sabotage women's efforts to seek care, keep appointments or take medications.

Interviewees commented on the challenges young women face in following-up with medical appointments when dealing with issues including violence, living with a controlling partner (including their pimps), fear of losing their children, or no housing.

> "It is really violence that is the issue that is so pervasive for the women we are working with. It is so systemic and long-standing and generational, and even worse for Aboriginal women …. And I'm talking about all the levels of violence – coercion, bullying, and control." (Service Provider)

While several interviewees noted that controlling and violent partners play a very real role in preventing access to services, one interviewee also highlighted how women-only spaces may be perceived as a threat to their partners.

> "One limitation of women-only spaces is for women who are being exploited, or abused; sometimes their partner or their pimp won't let them go. Or they say, 'you can and be there for 15 minutes and get your plate of food and bring me one too when you come out'. Lots of control issues. So women-only spaces can't be the only solution." (Service Provider)

NAVIGATING COMPLEX HEALTH SERVICES & STAFFING STRUCTURES

Many young women arrive in the DTES and DS unfamiliar with the workings of the current primary health care system and its respective bureaucracies. Health care teams are often multi-disciplinary, and interviewees commented on the difficulties that young HIV+ women face in determining "with whom to speak about what". Interview participants observed that the time and follow-through required of young women in determining the correct process, getting the correct forms to the correct people, etc. often proved too demanding, overshadowing HIV health needs.

> "A fair number of clients we see don't have BC medical. Either because they are transient or because they can't afford it or don't do their income tax. Youth are challenged in knowing the ropes – figuring out where can they get or see a doctor where they don't have to pay for it. For youth not on 'the system', connecting them to doctors is a challenge." (Registered Nurse)

> "Paperwork is what I get really choked about. The doctor didn't sign the papers and I ended up being homeless.... It took five months. They need to get that shit done. I have had to wait two or three weeks to get a half hour appointment, but, you know, the form is going to take more than half an hour." (HIV+ Woman)

NAVIGATING IDENTITIES VIS-A-VIS PRIMARY HEALTH CARE

Navigating Life Transitions

One service provider interviewed noted that young HIV+ women have the added challenge of navigating and negotiating a variety of major life transitions, such as moving in and out of care, family structures, and points of their own identities. Focusing on balancing these major issues in one's life can further work to put HIV health-related issues on the "back burner".

> "Young women are often still coming to terms with being HIV+. They may still be navigating their own bodies, sexualities, family. Older women are more likely to have already done this sort of work." (Service Provider)

Living Up to Expectations: Being Strong and Healthy

Several interviewees commented on the interconnections between the stereotype of being a "strong and healthy young women", the sense of internal fear and denial, and the stigma attached to being HIV+.

In particular, several persons talked about the need for many young HIV+ women to be “tough”, especially young street-entrenched women living in the DTES. As identified within these interviews, being “tough” sometimes translates into not asking for care, help or support, and/or refusing to acknowledge the future health consequences of engaging in harmful and risky behaviours.

> “One girl at [our clinic], she’s very ‘tough’. She feels like she can ‘deal with things on her own’ because she is physically strong and able.” (Registered Nurse)

> “Young persons, with their health, they are: ‘I don’t want to know.’ You have that attitude where – it is not so much infallible – but that you just don’t want to know. Denial or something. And as I said, I think there are so many more important things, like survival. They need to know how and work on just how to survive.” (Physician)

> “For young, positive women, I think that it really is stigma. The fear that ‘I’m not supposed to be positive’, and ‘Not only am I 19 or 22, but I’m not gay and I’m not an injection drug user.’ All you can do is just offer and open the conversation up. Create a safe space, which we do. But that doesn’t necessarily solve the overall stigma for that group.” (Physician)

Two interviewees also commented specifically on the perception that is placed on young women by society: “Being young means being healthy”, and increases their “attractiveness” and “marketability”, namely within sex work. Disclosing one’s + status can result in loss of hook-ups, stigmatization, etc., and provides a very real barrier in a young women’s willingness to get tested.

> “There’s this perception that’s put on them by johns, boyfriends, the community, etc. that, because they’re young, they are healthy and not positive - coupled with their own sense of invincibility. It gives them ‘credibility’ and ‘status’ and ‘sex work’ within the community, so that they don’t go get tested for fear of losing this ‘cred’. It’s just another one of those things that makes it more challenging for young women to access primary care, to get tested, to disclose their status, you know?” (Service Provider)

Moreover, interviewees also observed that, as healthier individuals, young women have the advantage of staying out longer and may not require health care with the same frequency or urgency as older women. Subsequently, healthier bodies and immune systems mean that younger HIV+ women are often managing very full and active lives and commitments, and may encounter increased difficulty when attempting to fit their health care appointments into their daily lives.

> “Young women are often really busy working - it’s often easier for them to get [sex] work. They tend to be healthier, can stay outside longer, and may not be actively seeking health care. Their appointments may be too demanding; they need to come every week.” (Service Provider)

> “Young women tend to be busy thinking about their immediate needs versus long-term health care.” (Service Provider)

Refusal to Access HIV Health Care Unless Very Ill

Several interview subjects commented on the reluctance of young HIV+ women to access health care until they become very ill, which often does not occur until later in life with the onset of an opportunistic infection or AIDS-related illness, such as pneumonia. Accessing services at this phase often results in hospitalization versus clinic-access.

> “[With] young women, it is tricky – you will see them seek out help (for HIV, other conditions) for the first time only when they get really sick. For most of the women who sero-convert in their late teens or early 20s, because they are young they tend not to feel it until later on. So they don’t see it as a need to see a doctor. It just isn’t a priority. This isn’t true with everyone.... There are instances of people who contract the virus in their late teens and are at full blown AIDS by the time they are 23.” (Service Provider)

Long-term and Generational Effects of Colonization and Residential Schools

Research indicates that many Aboriginal persons living with HIV/AIDS go without treatment in Canada. In British Columbia, as documented by Wood et. al. (2003), Aboriginal people living with HIV are more likely to die from AIDS without ever accessing anti-retroviral therapy despite the distribution of these medications free-of-charge. Even when accessing antiretroviral therapy, Miller et. al. (2006) demonstrate that Aboriginal people are more likely to receive double versus triple combination therapy, be less adherent in the first year on therapy, and have a physician less experienced with treating HIV. In their article, “Burden of HIV Infection among Injection Drug Users in Vancouver, British Columbia” (2008), Wood et. al. conclude that Aboriginal persons in the area have a significantly elevated burden of HIV infection, demonstrating the need for a culturally-sensitive and evidence-based response.

Consistent with the epidemiology and mortality rates, several interviewees spoke to the specific challenges facing young HIV+ Aboriginal women with regard to the effects of colonization and residential schools. Generational violence and addiction, for example, not only increase young Aboriginal women’s vulnerability to HIV infection, but also serve as very tangible and daily-lived barriers in accessing primary health care.

> “Young Aboriginal women, young women with substance use issues... the reason why women are at risk is all those other indicators, i.e. addiction, them ending up on the street at a young age, violence in the home.” (Service Provider)

> “The effects of colonization and residential schools are still on the surface for a lot of Aboriginal people” (Service Provider)

CHILDREN AND PARENTING

Prioritizing Children's Health Needs

Several interview subjects commented on women's tendencies to put their own health care needs on the "back burner", and to prioritize the health needs of their children and partners. One interviewee suggested that women sometimes feel as though they must "give up their role as a caretaker in order to receive care themselves".

> "Women often don't go to the doctor or a clinic because they are looking after other people (i.e. their children). Women will get care when they are pregnant but seeking out health care at other times is far less frequent." (Service Provider)

Lack of Childcare/Child-Inclusive Services

A common theme that arose from the interviews was the need for childcare and child-inclusive services. Many community-based HIV/AIDS Service Organizations (ASOs) offer "child-friendly" services (i.e. services for young women that allow them to bring their children) or "child-inclusive" services (i.e. simultaneous or parallel services for the children of HIV+ young women). However, with the exception of Oak Tree Clinic, there are still very few clinics that provide childcare resources and waiting rooms that address the needs of children or are "kid-friendly". As such, young HIV+ women may find that they must choose between minding and providing for their children, and attending their own doctors appointments.

> "For young women with kids, the waiting rooms in clinics or other services are often not set up to be child-friendly, Oak Tree being one exception." (Service Provider)

Adding to this dilemma is that even when child-inclusive services are in place, the needs of the child often overshadow the needs of their HIV+ mother. One service provider commented on the difficulties in striking a balance:

> "There is still a long way to go to understanding that taking care of the woman is also taking care of the child. But often at clinics, the perceived needs of the kids are put way ahead of the needs of the woman." (Service Provider)

Threat of Custody Loss

Many young HIV+ women are also living with addictions challenges, which may place them in direct and immediate conflict with child protection services. Faced with the fear of having their child or children apprehended, many young HIV+ women may refuse essential care for either themselves or their children.

> "Many women are afraid that accessing services will result in their kids being apprehended around their substance use. Therefore, they may steer clear of natal care." (Physician)

BUILDING TRUST AND RELATIONSHIPS WITH DOCTORS

In their examination on the factors associated with HIV+ women's adherence challenges, Douglass et. al. (2003) found that the quality of the relationship between women and their primary health care providers makes a substantial difference in what each woman will learn as a patient and how she will set personal health goals for a positive outcome. The researchers highlight the important role that communication plays within the doctor/patient relationship, including the recognition of barriers to communication and health-seeking behaviours. They argue that primary health providers must elicit feedback about treatment problems to facilitate adherence and to empower the HIV+ woman to make informed choices, and that individualized regimes are necessary in assessing how medications fit into the woman's life.

Further, Schneider et. al. (2004) found that multiple, mutable dimensions of the physician-patient relationship were associated with medication adherence in HIV+ individuals, suggesting that the physician-patient relationship quality is a potentially important point of intervention to improve patients' medication adherence. The researchers conclude that it is critical to investigate and incorporate patients' belief systems about antiretroviral therapy into adherence discussions and to identify and treat mental disorders.

Finding the Right Doctor

The challenge of building meaningful and trusting relationships with doctors was identified by all of the individuals interviewed. Several interviewees commented on the lack of empathetic doctors, who are able to take the time with their patients to effectively build relationships. Several young HIV+ women commented on reluctance to talk with their doctors about sex, sexualities, substance use, etc. One interviewee noted that it is difficult for most people in today's reality to just find a doctor in whom they trust and with whom they connect, let alone a young HIV+ woman who is searching for an available specialist:

> “I really think with a lot of women it is hard for them to find a doctor that they trust; it really takes time to build that up.” (Service Provider)

> “All of us providing services have to take more time, extra steps to build trust and rapport. Have to be proactive about that. There may not be an assumption on a young women’s part that we are trustworthy; we need to be prepared to prove ourselves and be proactive about that sort of stuff.” (Service Provider)

> “I have had experiences at my clinic where I was bounced around a lot; never saw the same doctor when my doctor was travelling a lot. This was very frustrating at the time. I remember saying, ‘I am not coming in unless I am seeing my doctor. I won’t see a fill-in or a nurse practitioner. I want to see the doctor that I want to see especially when I have booked this appointment three months in advance’.” (HIV+ Woman)

> “I feel very privileged to have as many doctors as I do. Some people are fighting for just one. But they don’t have my problems. I am very happy with the health care that is provided to me.” (HIV+ Woman)

Several of the young women interviewed commented on their challenges in communicating openly and honestly with their doctors. Marelich et. al. (2003) note that, although patient-provider partnership building has been shown to increase medical compliance and yield positive health outcomes, there are instances where question asking by providers may have a negative influence on compliance and recall/understanding of information given by the provider.

> “I didn’t talk to doctors about addiction challenges. They would ask me about it but I was ashamed. I was really good at deflecting when I was using. I got support from [the support workers at YouthCO] in terms of information about substance use, etc.” (HIV+ Woman)

> “I was like, ‘Don’t talk to me about my addiction. I am here about something else. I really like you and want to come back’.” (HIV+ Woman)

> “I have been celibate since I became positive and lost my boyfriend. Do talk about it in [my support/therapy] group. This never comes up with my doctor. I have never talked about sex at my doctor’s office. Pap test and pap smears and that’s good enough to get over fast.” (HIV+ Woman)

> “I have to be honest with someone about what I am doing all the time. I can’t do that with my mom. I always need to be honest with one person, and right now I choose her [my counsellor]. I will be honest. This should be your doctor or your counsellor. When you get fucked up and they don’t know what is going on, it fucks you up.” (HIV+ Woman)

Dealing with Invasive Questioning during Appointments

Other interviewees commented on the invasive questioning to which young women can be subjected. One interviewee suggested that doctors need better training on how to conduct interviews, especially when dealing with women who are in vulnerable situations, such as the newly-diagnosed. Questioning that feels invasive can increase the shame and stigmatization many young women feel upon learning of a new diagnosis, and undermine their willingness to access care.

> "I am sure the justification for asking this question ['how did you get HIV?'] from the doctor's perspective is not 'I want to know so I can label you', but rather, 'we need this demographic information'. But this is a question that is hard and should not be asked, at least not on the first time you see somebody. It is such an invasive thing. 'What are you? You are not a woman - you are an IDU, etc.' It is a way of talking to women. The other thing is women may not know how they became infected. They can't pinpoint – had multiple risks. Women are so literally vulnerable to HIV they don't always know. What I am trying to get at is around doctors needing to have better training. Training on how to do interviews. To ask themselves, 'What is the justification for asking certain questions?'." (Service Provider)

> "Many Aboriginal women don't know that they have the option not to answer the question, 'how did you get HIV?'." (Service Provider)

> "I am not still seeing the same doctor I had when I tested positive. My last doctor was too much of a stress. She would ask all these questions. Whenever I had a problem it didn't feel like she was helping my problem. I would be waking up with stomach paints, chest and back pains. She just said that could be from my using. I felt neglected by her so switched doctors." (HIV+ Woman)

Being Assertive with Doctors

The doctor-patient relationship is often marked by a pervasive power differential which can heighten a young woman's aversion to access clinical services. Several individuals interviewed discussed the discomfort many women face in challenging the authority of their doctors.

> "As women in general we are socialized to be nice; we're not supposed to challenge the doctor [with questions such as], 'Well, what does that mean?' Women don't feel comfortable asking that question. Or if there is a recommendation around a course of care, going to a test, going on medication, I hear women saying all the time, 'I don't really know why I need to do that', but they aren't comfortable second-guessing someone in authority." (Service Provider)

> "Tell women they are in charge of their health. When women go to the doctor, there is that sense that 'I am not the person who is charge of my body'. The health care profession is still very gendered." (Service Provider)

At the same time, several young women also articulated the ways in which being HIV+ and having to navigate clinical services has helped them to develop their own assertiveness strategies and self-advocacy skills when dealing with their health care providers.

> "I needed a referral to see a gynaecologist.... Took a long time to get the appointment... still waiting for the phone call. I have had to do that a few times - get the phone number where they sent the referral and ask, 'Hey, what's up? Why didn't you call me?' Waiting for an actual place to call you - you usually have to be the one to call." (HIV+ Woman)

> "I pretty much demand it now [that doctors listen to me]. I have learned to be really assertive with my health. I know my body and I know what is going on. If someone is not listening I will be assertive about it. Before I was just a junkie and no one gives a shit. So I didn't give a shit. But since then I have been really good about listening and understanding my body and knowing when too much is too much. It is a learning process." (HIV+ Woman)

> "I am happy. I won't wait a week anymore. I will call back the next morning and say, 'Can you go get my file?' And when I have my appointments I make sure that everything is written down. It has all already been documented. Get it written down when we talk about it. I will not wait longer than the next morning. [These strategies came] through trial and error. It is my health and if I am not on top of it, who is? It is my health and I want to give them all the information and I can inform them of what they need to know to help me." (HIV+ Woman)

In their study on the effects of empowerment among HIV+ women on the patient-provider relationship, Marelich et. al. (2003) found that HIV+ women who exhibit empowered behaviours received more information from their health care providers and reported better patient-provider communications. As such, the authors recommend that health care providers help cultivate empowered behaviours with their patients, and move toward developing treatment partnerships.

THE NEED FOR WOMEN-SPECIFIC SERVICES

Need for Women-Only Spaces

Almost all the people interviewed commented on the need for women-specific services. Service providers agreed that clinics in the DTES provide too few women-only spaces, and waiting rooms are often small, busy, and over-crowded with wait times which can exceed two or three hours. Young HIV+ women accessing services at these clinics can find themselves surrounded by current and former partners (often the perpetrators of the violence these young women are experiencing in their lives), their pimps or people they may be trying to avoid. This fear can result in young women avoiding clinics and services within the DTES community.

> "Waiting rooms are often or typically full of men. This can be daunting for women especially when you are young or sensitized because of getting more unwanted attention. Seriously off-putting." (Service Provider)

> "Very few women-friendly clinics or medical places. Women don't feel comfortable. Look at the DTES, there are the confidentiality issues, scary men sitting around. They are dealing with violence in their lives all the time." (Service Provider)

Need for Female Doctors and Clinic Staff

Additionally, service providers noted that men tend to be in positions of authority within clinic environments (e.g. as doctors, security guards, etc.) which can add to young HIV+ women's discomfort when accessing services. One female service provider interviewed observed that while she works in a team with two men, the women tend to want to work with her, commenting, "I definitely have more women in my caseload and that's not on purpose".

> "Depending on the health clinic or health care facility, most of the doctors are men. Dr. Burdge is so great but he is an exception and even then you have to meet him to know how good he can be. This means that for other physicians, you need a female outreach [worker] to take you to help you be comfortable. If there were more women doctors period, it could possibly alleviate that a bit." (Service Provider)

> "Female doctors in the DTES are incredible, but we need at least five more of them." (Service Provider)

Need for Women-Specific Services

Other interviewees commented on the gap between services available for women and men, noting that tensions can arise when the two groups find themselves advocating for increased or targeted services.

> "Many services are geared towards gay/two-spirited men so women often need to become these super strong advocates [for their own quality of service]. Can lead to tensions and be off-putting." (Service Provider)

> "Young positive women are not the stereotypical face of any one thing (for example, the 'typical' face of HIV, of street involved people, of addiction). So services do not get designed for them or around them. They might be 'added on', or they might not. Often there is very little that speaks directly to them, and there is a lack of awareness of what their particular issues might be." (Service Provider)

Breaking Down HIV Stigma for Young HIV+ Women

One individual interviewed linked young HIV+ women's lack of willingness to access services to issues of stigma and discrimination. Increasing young HIV+ women's comfort and safety in engaging in services was therefore seen as critical.

> "People come into [our clinic] who are gay and HIV+, they don't have a problem. We have people who are addicted, trans, etc. They have no concerns about coming in and talking about it. But I just think youth, whether men or women, who are not addicted and who are not queer, would... still have a hard time bringing HIV up. Again it is up to the clinician to pull the information from them. Young woman need to feel safe enough to bring it up. How to do that is difficult to say." (Physician)

MEETING YOUNG HIV+ WOMEN "WHERE THEY ARE AT"

Need for More Flexible Clinical Hours

In their study, "Surviving the Sex Trade: A Comparison of HIV Risk Behaviours among Street-Involved Women in Two Canadian Cities who Inject Drugs" (2003), Spittal et. al. conclude with a call for innovative harm reduction strategies addressing both sexual and drug-related harms, and recommend the development of "client-driven, round the clock drop in centres".

This study reflects a common theme that arose in our interviews with regard to the need for clinic services that reflect the schedules and lives of young women living with HIV. Service providers interviewed agreed that clinics' hours of operation tend to be very limited (e.g. 8:30 am - 4:30 pm), making access difficult for women who may have daytime employment or school commitments. Moreover, women involved in sex work may have difficulties in accommodating clinic appointments into their schedules, leaving hospital emergency rooms as the only option for health care needs before, during and after sex work hours.

> "Community organizations and services, we try our best to accommodate the realities of our clients' lives. But at medical clinics, typically appointments are set up to meet the needs of the doctors, not the clients. This means that sacrifices have to happen, a young woman might not make her ESL class, or she has to drop off two kids first, or take a bus for two hours. There are attempts to address that but it is not enough." (Service Provider)

> "The hours are not as conducive to out-patient operation at any of the clinics as they are normal business hours. This makes us inaccessible to young women working on the streets until three, four, five in the morning. And let alone the chances of one of these women making an appointment with the infectious disease consultant who is there just two days a week. We are simply not accessible enough." (Registered Nurse)

Need for Manageable Appointment Lengths

In addition to the challenges of long wait times within DTES clinics and despite the need for longer appointments with doctors, interviewees commented on the challenges associated with comprehensive, multidisciplinary appointments. While Oak Tree, for example, was identified as providing a standard of excellence in comprehensive services, their appointments, sometimes running two to three hours in length, were also acknowledged as potentially unmanageable for many young HIV+ women.

> "Oak Tree is really best suited for women who are very high functioning. Because they are so comprehensive and thorough, you have to be there for hours and hours. Hard for women with mental health issues or substance use to be there and sustain a three hour appointment. But at the clinic they want the women to see everybody (e.g. the dietician, the nurse, the doctor, etc.)." (Service Provider)

One service provider also recognized that these challenges are further underscored when a young HIV+ woman is also managing the health needs of her children.

> "If you have a positive kid, the day at the clinic or doctor's office is going to be longer still. Or you will go in for your own health care, and then maybe the next week have to do it all over again for your child." (Service Provider)

Need for More Time with Doctors

Almost all of the persons interviewed spoke to the challenges women face in getting adequate time with their HIV doctors. Specialists often have large and nearly-unmanageable patient loads, research obligations and other professional duties that can take them away from their practices. Appointment times are typically 15 minutes in duration, leaving very limited time for women to discuss health concerns, ask questions, review and understand blood work, and manage other issues affecting their HIV care.

> "Doctors [need] to take more time to be with the women. In fairness to them, this is hard because they have a lot of demands on their time. Nursing could fill in the gap." (Service Provider)

> "It's that radical training around anti-oppression work. Once you leave medical school, it's as though no matter who you are as a person – all of a sudden you have this authority, you are in a different league, and you have this power. There is really that pervasive dynamic... it's always that thing. What is it about being a doctor that you have the power to treat people differently, or brush people off? 'I only have 10 minutes with you so tell me your biggest medical issue right now, but I can't deal with how it might be for you when I tell you to go take these million of tests'. Young women – all that authority stuff is so huge. It is so vulnerable-making to see a doctor." (Service Provider)

> "Doctor goes on holidays. Stepmom, me and her are arguing over meds.... I have bottles for three months worth of all my meds. Tells you how much. Seeing the sub for [my doctor]. Had to go to the trouble to show the substitute doctor. She is like, 'Fine, I'll give it to you'. Said to [my doctor], 'Did you know I had a hard time getting my meds?' She said she would put a 'note in my file'.... Three months worth." (HIV+ Woman)

> "They asked me to change my meds and I agreed, and now I'm in this waiting game. I feel like I am not a priority. Like, don't ask me to start something if you are not going to follow through. It would have felt better if it was followed up on in a timely manner.... It is around decision-making, like when I was having all of that trouble before; he kept putting it off, putting it off." (HIV+ Woman)

> "[My doctor] is a really 'in and out' doctor. Fifteen minutes, you are lucky to get that. Not impersonal because she remembers you every time, but everything goes in one ear and out the other." (HIV+ Woman)

> "[If I could change one thing about seeing my doctor, it would be] more time, make it about me. I just want to be heard and not rushed out of the office. Because then I don't want to come back." (HIV+ Woman)

Highlighting the need for more time with their HIV doctors, Miller et. al. (2006b) found that HIV+ women who saw the same doctor for their care and who saw them more frequently reported higher subsequent satisfactions with those providers, suggesting that the frequency of primary care visits is significant in terms of both patients' satisfaction and their use of the most potent and effective forms of antiretroviral therapy.

Need for HIV-Specific Time and Care during Appointments

One service provider commented on the need for more time during appointments in order to balance addiction/methadone care with HIV-specific care:

> "Clinics are so busy now, plus women are on methadone. They only get about 10 -15 minutes with their doctors and need to prioritize their time with their docs. HIV care tends to fall second to addictions, methadone. HIV care, primary care, it slips through the cracks. It'd be great to have a DTES clinic that focused more specifically on HIV, HCV. Maybe with an in-house pharmacy and lab. This might enable women to have more time with their docs - get them to talk about side effects and adherence. Not sure if this would end up fragmenting their care or not." (Registered Nurse)

Need to Take Time to Bridge Understanding/Literary Challenges

Another interviewee discussed the literacy challenges facing many young women in the DTES and DS, especially young Aboriginal women. Doctors often have less than 15 minutes per appointment and newly-diagnosed young women can be presented with a pile of HIV/AIDS literature with little time to go over that material with the doctor. Shame around low literacy levels, a doctor's impatience and the trauma of a new HIV diagnosis can result in fear and overwhelm. When a doctor is available for longer periods of time with each patient, it makes a significant difference in patient satisfaction. This theme is underscored by Mallinson et. al. (2005) who urge health care providers to screen for health literacy and intervene appropriately to increase client understanding of the fundamentals of HIV disease (e.g. viral replication, medication resistance, immune functioning, etc.), and to build that individuals' confidence to engage in discussion around the pros and cons of various therapeutic options.

> "My doctor helped me understand my medical file and what the information is in my file. This made me feel more empowered." (HIV+ Woman)

Need to "Bring Primary Care to Young HIV+ Women"

Several service providers discussed the need to "bring the health care system to the women", and the need to work within the busy schedules and lives of young HIV+ women versus the busy schedules and lives of health care professionals (i.e. working on "patient-time" versus "doctor-time"). The established systemic practice, which provides a very limited window of access for young women, was identified as a significant barrier in providing health services to this population, especially within the DTES.

> “Doctors appointments or with nurses, etc., having a scheduled appointment does not work super well. They don’t tend to make them. Young women, you need to ‘strike while the iron is hot’ around their health care. You can have one moment where it is really opportune, and then that opportunity is lost if you wait.” (Service Provider)

> “[My counsellor,] she gives a fuck.... No guilt trip if I miss the appointment. She will see me spontaneously. Finding someone who actually ‘gets me’. I won’t bullshit her.” (Young HIV+ Woman)

One service provider noted that the more complex the health and addictions needs of young HIV+ women are the more challenges there are in providing her with comprehensive care/attention within the limits of a clinic-based appointment.

Another service provider commented on the need to be responsive and flexible with the type of service offered to young HIV+ women.

> “[We] are very task oriented... filling out disability forms, welfare forms, etc., etc. That is our strength; but at the same time, a young woman may need to just call in and chat. For her that psycho-social support might be just as valuable as the practical supports, if not more so.” (Service Provider)

> “That is a trend; the young women will just call me. And we will chat and talk about some things, and they will set up an appointment and maybe won’t come to the appointment, which is disappointing. But recognizing that what they wanted was just to chat, just to talk to someone.” (Service Provider)

THE NEED FOR DOCTORS WITH HIV/AIDS COMFORT AND COMPETENCY

Shortage of HIV Doctors throughout Lower Mainland and Province

Jones et. al. (2002) suggest that the competence of health care providers experienced in HIV/AIDS specific care is an important factor in patient satisfaction. Interviewees identified a general and systemic shortage of doctors throughout the province, as well as the Lower Mainland, notably ones able to provide care to HIV+ women. They noted that HIV+ women are dispersed throughout the province, and may be linked to primary health practitioners who have limited HIV knowledge, comfort and understanding. In particular, service providers noted the challenges in providing support and care to young Aboriginal women in rural/remote regions of the province or on reserve where communities are often small and with fewer support systems.

> “So much has changed in terms of treatment. So the docs are saying, ‘What do I do if I have a positive test result? Not only did I not get any training around HIV when it first came out but now I know even less.” (Physician)

> “Women on reserve may face increased difficulties because people only see an HIV label.” (Service Provider)

> “At least we talk about HIV in the DTES. In the West End and the DTES, we recognize that culture has a place in health services. Thank God for gay men … otherwise we’d all be boring, stuck-up health care workers. They’ve left room for a bit of creation and innovation [in HIV/AIDS work] and opened the door to the idea of community input and consultation.” (Service Provider)

> “Before I had trouble [getting the HIV care that I needed]. The doctor I have now is an HIV specialist, so when I do have questions she can answer them quickly. My old doctor was: ‘I will give you an answer in a week because I have to call these people’.” (HIV+ Woman)

> “I live in the Suburbs. Just mentioning that I am positive is not okay. So I use walk-in clinics or Emerg in the Suburbs and see my HIV specialist at Oak Tree.” HIV+ Woman)

> “I was sick of going through that [educating doctors about HIV and my HIV status] and having to explain that over and over again. One GP kept acting surprised that I was HIV+. Tired of having to repeat this over and over again.” (HIV+ Woman)

> “I know more than they [doctors] do most of the time.” (HIV+ Woman)

> “I live in POCO – my health is pretty good and I can get to Oak Tree. But if you live in Mission, it’s impossible. I even had an HIV doctor in Abbotsford – it was horrible.” (HIV+ Woman)

Shortage of HIV Doctors throughout DTES

This identified shortage also affects the availability of care in the DTES. While interviewees acknowledged the Metro Vancouver region as an area that was "resource rich" with HIV/AIDS services, they also underscored a local geographic imbalance with regard to HIV specialists.

> "Good, stable HIV care is concentrated in Vancouver's West End - this care is focused on gay men." (Service Provider)

> "In the DTES there are doctors there that are not infectious disease doctors but they are doing the HIV care. It is odd they are not always referring and consulting with Oak Tree or infectious disease doctors. Doctors down there are taking condensed courses on HIV/AIDS. To be honest, it is not somewhere I would choose to get treated for HIV. I would choose a specialist, not someone who 'kind of' knows." (Service Provider)

> "There needs to be more doctors, more time [with doctors during appointments]. And yet Vancouver is so much better than anywhere else in this country. So complaining feels a bit weird…. Yet Vancouver has great care... some of the best in Canada." (Young HIV+ Woman)

AGEISM AND THE NEED FOR YOUTH-SPECIFIC SERVICES

Recognizing Young HIV+ Women as the "Experts of their Own Experiences"

Several interviewees spoke about ageism, how it affects young HIV+ women's access to primary care services, and the tendency of health care providers to be more authoritarian and directive with younger HIV+ women than with older HIV+ women, including being more dismissive of young people's voices and opinions. This lack of willingness to consider young HIV+ women as "experts" of their own health experiences can contribute to an unwillingness on the part of young women to work in collaboration and consultation with their doctors about their health needs.

> "Some of the young women I work with are reluctant to give out info. Then the docs say, 'She's withholding, what's going on?' Then they try to figure that out. They are acting like case managers where the woman doesn't even know she is being case managed. Without the women's input knowledge and direction, often the plan is inappropriate and falls apart." (Service Provider)

> "Going into an institution like the hospital, it is hard for youth; there are not a lot of rights or decision-making." (Service Provider)

> "I don't know what to do with them [my doctors] anymore. 'When are you going to go back on your meds? When are you going to find a stable place to live?' It is the same thing over and over.... I don't like scare tactics. Don't scare me...." (HIV+ Woman)
>
> "Dude, you have gone so far now. You are lucky to be alive." (HIV+ Woman, in response)

> "I was on a cocktail that had really bad side effects. They dried up my mouth so bad I couldn't masticate so I couldn't eat properly. My doctor told me to 'hang in there'. I said I need to get a feeding tube. I felt like I was not being heard or he did not try to find a solution. Kept saying to just 'hang in there'.... 'I ended up getting a feeding tube. While I was in the hospital I got taken off my meds.... So I stopped taking the meds, was on the feeding tube then they finally changed my cocktail. That situation could have been avoided. I am still pissed about this." (HIV+ Woman)

The Need for Youth-Specific and Peer-Driven Services

Interviewees commented on the continued need for population-specific services, the lack of young people as clinic staff, and the importance of having young women's identities reflected back at them when accessing services.

> "The medical profession is predominantly male dominated faces. Female doctors are not as plentiful. And there is not a lot of peer support. If you are receiving services from a group of people that you are not relating to or you are under their power, which plays into a lot of not wanting to be there or access those services." (Service Provider)

The Need for Patient-Centred Approaches

In their article, "Maintaining Normalcy", Mallinson et. al. (2005) maintain that "what it means to have a 'normal' life while living with HIV is not to be determined by the nurse; it will vary by the uniqueness of each client." In a similar vein, one interviewee observed a tendency for doctors and health care providers to prioritize their own agenda over the specific needs of a young HIV+ woman.

> "Young women are also more vulnerable to a different type of exploitation, i.e. they might still be 'pretty', and can be targeted by 'do-gooders' who want to save them a little bit more than other people. Young women in general can be subject to more unwanted attention. Service providers may also react to them differently, even those who are generally very client-centred and aware of issues of self-determination. Perhaps be more judgemental or more directive, be more maternal/paternal, struggle with allowing the younger woman her autonomy." (Service Provider)

> "What usually ends up happening [during appointments with a doctor] is the doctor takes on this sort of care-giving role that isn't really helpful, [like being] patronizing or taking on a mother or father role without being aware of it. Not talking about the real issues for the woman, but rather the doctor or nurse comes up with what they think the woman needs, i.e. 'They just need a big sister,' or 'Wouldn't it be nice if they had a family?'. And the reality is that family is or may not be the issue for these women, but the

> docs and nurses are not working from the agenda of the women, but rather working from their own personal agendas. When it comes to youth clients, they are not looking at the woman in front of them as an adult." (Service Provider)

Challenges to Accessing Services alongside Older HIV+ Women

Two interviewees commented on the challenges presented in many of the intergenerational services for HIV+ women. One service provider observed that older women within the DTES community often have long-term, established relationships with each other that can create "walls" that are not easy for younger women to break through. With regard to intergenerational services, she noted that young HIV+ women are often excluded from leadership opportunities (e.g. peer mentorship roles) in the community. This situation may prevent young HIV+ women from connecting to a sense of community, impeding their ability to feel strong and empowered decisions affecting their health.

> "The older women have these long-term relationships with each other – it's like 'walls' for the younger ones. They may not feel like the older ones are taking them seriously." (Service Provider)

Lack of Community, Role Models and Advocates for Young HIV+ Women

One interviewee observed that older HIV+ women tend to have stronger community ties, noting that the DTES community is small and affords few opportunities for relationships among young HIV+ women. While older women often have had more time to connect with other women in similar situations, younger HIV+ women may not have had as many years to process their diagnosis and reach out for support and community among their peers. This lack of a readily available community of peers can be a barrier to young women in accessing peer support and influential role models who may provide positive examples with regard to accessing primary health care.

> "It's often harder for young HIV+ women to build community and disclose their status. It's often hard to find places that they can be around other young women." (Service Provider)

> "Older women have more friends living with HIV, while young women may experience more difficulty in finding other young women like themselves. They're recently diagnosed and haven't lived as long with HIV." (Service Provider)

One service provider commented in particular on the lack of visible role models for young HIV+ women, either locally or in the media (unlike, for example, a greater availability of role models for young HIV+ gay men). This makes it more difficult for a young HIV+ woman to envision herself accessing comprehensive health care, transitioning into school, employment, or just being open about her status.

> “You just don’t see young, out, HIV+ women doing cool shit. It’s difficult to get out or move forward because you think, “That’s it [being HIV+].” (Service Provider)

Another service provider noted the need to “shake things up” via a strong, passionate and networked advocate for young HIV+ women.

> “Young positive women need a passionate advocate, someone who is focused and passionate about this group. Someone who has not just the passion but the access to the power players, i.e. someone who [they] would listen to.” (Service Provider)

HIV/AIDS STIGMA AND DISCRIMINATION

Lack of Confidentiality

Interviewees discussed at length the systemic effects of HIV/AIDS stigma and discrimination. The fears associated with a lack of confidentiality were a primary theme in the interviews. Interviewees identified the difficulties women outside the Metro Vancouver area face in accessing care within their local communities, be that in the suburbs, in rural/remote regions, or on reserve. Fear of disclosure was also identified as a barrier within the DTES, where HIV clinics and testing sites are well-known to the general public/community at large.

> “Stigma around HIV is a huge issue. I think a lot of the times... [there is this] suggestion or belief that they have done something wrong. I also know a lot of people still think getting HIV is a death sentence. It is a chronic disease; it can be managed but people don’t understand that. Unless they are educated and have all the facts, young people feel doomed.” (Registered Nurse)

Even within the DTES, one service provider noted on the lack of confidentiality in HIV clinics and testing sites, commenting on the “need to take stigma out of testing”. She further commented that while the location of Oak Tree Clinic provides a safer, more confidential space for services outside of the DTES community, it also poses transportation and access Challenges.

> “It’s difficult to go to the same HIV doctor, clinic without everyone knowing; figuring out a young woman is HIV+.” (Service Provider)

> “I have a regular GP doctor [in the Downtown South]. I find Oak Tree hard to access because of the bus.” (HIV+ Woman)

Facing Stigma and Discrimination at Clinics

Relf et. al. (2005) found that race/ethnicity and the number of years since testing positive were significant contributors to HIV stigma, particularly personalized stigma and negative self-image. This finding highlights young Aboriginal women's fear of judgement and stigma as noted previously. Further, they found that HIV+ individual's satisfaction with health care services was undermined by providers who either failed to address HIV-related stigma or contributed to it. The reality of HIV stigma is also exemplified by the experiences of young HIV+ women with clinic staff:

> "If a young woman has experienced prior discrimination or had a negative experience in a clinic, then this can be a barrier to accessing health care. Doctors and health care professionals may discriminate against a woman based on her class, race, sex work, etc. This may make it more difficult for her to access primary health care further down the road. Empathy is an important quality for doctors doing this type or work." (Service Provider)

> "Don't ever go [to that clinic] because they hate you there .... They hate anything drugs, anything junkie. They kick you out and treat you like such shite. Nurse was screaming at me because I was sliding off the chair. I was overdosing." (HIV+ Woman)

> "If you [clinic staff] don't like it then why do you work there? Because a bad experience is going to fuck someone up. They treated me like a bag of shit." (HIV+ Woman)

> "I had a problem there [at a pharmacy].... The lady just looked at me: 'I don't want to deal with you because you are HIV'. She read my 'script' and just backed off." (HIV+ Woman)

> "I know that there is education out there and the doctors can take extra courses but it should be mandatory that there be posters in the doctor's office as a regular thing for regular doctors... like in the 'burbs. It would be so much better if it was a health topic not a stigma topic. It is so stigmatized and doctors are supposed to be there to help people. This is a health issue just like cancer." (HIV+ Woman)

CHALLENGES FACING CLINICIANS & SERVICES PROVIDERS

In their study on the common challenges experienced by nurses in providing HIV/AIDS services, Olivier et. al. (2003) found that health care service providers experience numerous and varied problems and stressors, including feeling helpless, a lack of up-to-date information, grief due to the death of clients, inadequate referral resources and not knowing where to refer clients to. Similar challenges were also identified by the health care professionals interviewed in this project.

Burn-Out among Service Providers/Outreach Workers

One interviewee discussed the challenges associated with the overwhelming and cyclical workload, leading to burn-out. This service provider noted that burn-out can lead to a lack of empathy and compassion, as well as a loss of inspiration and vision.

> "Burn-out, it makes workers jaded, lose their vision - why they're doing what they're doing and the significance of their role. [Lack of] empathy and compassion is big here." (Service Provider)

High Turn Over among DTES Workers

One service provider commented on the high rate of turn-over among DTES service providers and outreach workers, and the negative impact this has on trust and relationship-building with young HIV+ women.

> "Workers come and go very frequently in the DTES, and the women, they just get referred on over and over again. Leads to broken trust with the women, and really affects their long-term care. It's also linked to the larger need for programming with longer term support." (Service Provider)

PROVIDING SUPPORT AND COUNSELING TO YOUNG HIV+ WOMEN

Providing Ongoing Hope, Support and Coping Strategies

One interviewee talked about the frustration and feelings of helplessness in providing ongoing hope, support and coping strategies to young HIV+ women at various stages of their illness.

> "It's difficult to help women come to terms with having a reasonably normal life (e.g. sexual partners, sexualities, parenting, disclosing, etc.)." (Physician)

Internalizing Women's Anger and Frustration

One service provider discussed the challenge of remaining open, empathetic and compassionate, and not internalizing the anger and frustration that many young HIV+ women experience and bring to appointments.

> "It's hard not to take on/feel some of that generalized resentment or anger that women experience when their family or community isn't ready to hear about HIV." (Service Provider)

CLINIC LIMITATIONS

Physical Plant/Site Limitations

Several interviewees commented on the difficulties in providing specific, comprehensive and quality services to young HIV+ women, given the physical plant/space limitations of clinics in the DTES, including the inability to accommodate the demand for service and necessary medical interventions.

> "We nurses are trained to do a lot of things, pelvic examinations, and STD stuff. Some challenges are that we are short of rooms, running out of space. We only have one nursing room, not very private. We have a stretcher, not an examination table. In order for us to do any kind of women's health, we need to book a room. Logistics are very challenging. There is no space." (Registered Nurse)

POPULATION-SPECIFIC CHALLENGES

Difficulty Tracking DTES Clients/Patients

One interviewee spoke to the challenges of following up with young HIV+ women in the DTES, given the transient nature of their lives, and the impact that this presents with regard to the provision of test results, care and partner notification.

> "Life is so transient for many of our patients and clients. It is very challenging for us to try and contact them, even once we get positive test results. This makes partner notification very challenging." (Registered Nurse)

Population Size

Many of the services providers interviewed commented that they work directly with very few young HIV+ women. Several commented on the difficulties in finding time to provide meaningful and targeted services to young HIV+ women when dealing with an overwhelming workload consisting of various demographics. One noted that, while she recognized that dedicating the time, energy and resources to working with this population would result in more young women accessing services down the road, it was difficult to rationalize this time and expense to funders who like to see quantifiable results.

“The numbers [of young HIV+ women] are smaller [than those of older HIV+ women] so it’s hard to justify the time (e.g. outreach at night might only garner one [contact] with a young women whereas onsite services might bring in six older HIV+ women.” (Service Provider)

“It is difficult to focus on young women when the program is not specific to young women.” (Service Provider)

IDENTIFIED BEST PRACTICES

OAK TREE CLINIC

Sullivan et. al. (2000) found that patients who were more comfortable discussing personal issues with their physicians, who perceived their primary care physicians as more empathetic, and who perceived the primary care physicians as more knowledgeable with respect to HIV were significantly more satisfied with their primary care physicians. Further, they note that this satisfaction was not associated with patients' socio-demographic characteristics, HIV risk characteristics, alcohol and drug use, health status, quality of life or concordant patient-physician gender and racial matching.

In her article, "HIV-Positive Patients and the Doctor-Patient Relationship: Perspectives from the Margins" (2005), McCoy comments on the delivery of comprehensive, multi-disciplinary clinical HIV services:

> "[There is a] crucial difference between just giving information and facilitating understanding.... [F]rom the standpoint of patients, there continues to be an important role for doctors to play in this area. Hospitals and large clinics often establish a division of labour, with the more time-consuming work of patient counselling allocated to social workers, nurses, and pharmacists. People trained in these professions often acquire expertise as educators and counsellors. In the typical family practice or specialist's office, however, such designated personnel are rare - and these are the sites of outpatient health care that most participants visited most of the time."

The results of these studies are salient when read against the response and feedback we received with regard to Oak Tree Clinic and its staff. Oak Tree was recognized across the board, particularly among the young women interviewed, as a best practice in and of itself. Many of the strategies identified below already exist and are integrated into Oak Tree's programming. Notably, Oak Tree was named for its comprehensive services, women-only and child-inclusive environment, its outreach strategies, as well as for its excellence in patient care, namely by Dr. Burdge, whom young HIV+ women and service providers consistently described as "patient", "personable", "great" and "non-judgemental".

> "I like Oak Tree – that's my clinic, people are nice. I get everything I need taken care of there. There is a whole team there - nurse practitioner, [the HIV doctor], gyno, pharmacist, ob, nurse, social worker, nutritionist, dietician...." (HIV+ Woman)

Non-Judgmental, Open and Empathetic Approach

Being non-judgemental, open and empathetic in one's approach as a primary health care provider was considered an essential component to realizing long-term, quality care with young HIV+ women, and in this regard the clinicians and support staff at Oak Tree Clinic were repeatedly praised. Douglass et. al. (2003) argues that in order to increase women's' adherence, a doctor's support should be comprehensive, non-judgemental and considered a high priority of HIV primary care. Additionally, Dyer et. al. (2004) suggest that HIV+ individuals who are able to connect with providers who believe in the inherent strengths and competencies of their patients, are resilient themselves, exhibit flexible boundaries and are willing to partner with patients to show that "things can be different" demonstrate positive outcomes related to daily living and disease management.

Interviewees commented on how this approach opens avenues through which young women meet with their doctors in an open and frank manner, and remain honest about current life challenges, transitions, sexualities, etc.

> "Dr. Burdge makes us all feel like we're #1." (HIV+ Woman)

> "I go to Oak Tree.... Dr. Burdge is great, very personable." (HIV+ Woman)

> "They are friendly and helpful at Oak Tree. You do feel welcome." (HIV+ Woman)

> "The receptionist at Oak Tree is very personable. He is great." (HIV+ Woman)

McCoy (2005) emphasizes that openness, non-judgement and respect are fundamental to the doctor-patient relationship:

> "For people in difficult circumstances, when the result of those troubles is less health work and even overtly unhealthy practices, the experience of respect at the doctors' is very much about doctors' understanding and acknowledging the weight and force, the obduracy of difficult life circumstances, like poverty or depression or emotional pain. Indeed, the achievement of this sort of respect can be an important aspect of access to health care for marginalized patients when it contributes to a level of interactive comfort in which patients feel able to divulge medically relevant information about medication lapses or unhealthy practices."

VANCOUVER STREET NURSES

Vancouver's team of street nurses were also identified as a best and meaningful practice in reaching out to young HIV+ women in the DTES and DS. One interviewee noted that street nurses are often "considered by young women to be their primary care givers". This team provides the street-level and home-based flexibility that often proves essential to many young HIV+ women when receiving primary health care services.

> "I've heard anecdotally from many women: 'I love my street nurse' or 'Without my street nurse, I would be dead'. We don't need more peer outreach workers in the DTES. We need more professionals who can do the hard, primary care work. It takes a special person who can stay - many street nurses turn over every three to four years." (Service Provider)

> "[My] room was in The Sunrise [Hotel].... I didn't access anything – one thing, when you are living down there, you can't really go anywhere. Went to Blood Alley Clinic even before I was on methadone. The doctor kept telling me to go off of drugs. I was like, 'Fuck you, I am not coming back'.... When I had my abscess, there was a nurse coming into the building anyway, I asked if they could take care of this abscess for me. It felt like quite the invasion – when you are using like that you don't want anyone to see your room. It is the only thing you have you don't let anyone into that space. But that nurse was amazing." (HIV+ Woman)

Outreach

Several researchers (Napravnik et. al. 2006, Anderson, M, et. al. 2005, Tobias C, et. al. 2004, Davidson, A. J., 2998) have found that outreach, including home visits by nurses to locate women, is an effective way to increase access to primary health care. Providing transportation for women to and from their health care appointments is another.

Outreach, whether through the street nurse team or community-based organizations, was identified as a core component of providing care for young HIV+ women. It is a strategy that meets their needs, fits their schedules, and relates to their interests.

> "Outreach is a core function of doing this kind of work. Need to have workers who are relatable, i.e. young, hip, street-savvy, cool and women-centred." (Physician)

> "You need to be able to discuss things that the young women are interested in. For example, we have this one client who is really into reading. So we talk about what she's reading. And we've got this one young woman who's really into skateboarding - she likes to show staff her new tricks. You need to get to know the young women personally and what they're about. Talking to them more and [talking to] them personally and not talking about their health status.... I think that they get tired of talking about it." (Registered Nurse)

> "There is strength in nurses and doctors going to where young women live, as getting to a clinic can be difficult for them. Being positive and dealing with severe social phobia can be difficult when you're trying to get to a clinic." (Service Provider)

CONSISTENCY OF CARE AND RELATIONSHIP-BUILDING

Interviewees commented on the importance of consistency of care in building strong, long-term, sustainable, meaningful and forward-moving relationships with young HIV+ women.

> "Working with someone means checking in weekly with them. Relationship-building needs to continue after women disclose their status. It's not over once their health goals are achieved or once they're housed." (Service Provider)

CHILDCARE

Childcare and child-inclusive services were seen as important elements in increasing and sustaining young HIV+ women's access to primary care services. Interviews stressed the importance of designing services that feel welcoming and inclusive to children, and underscored the value in ensuring that children "know their options", such as access to food and counselling.

FOOD

Food was identified as a necessity to bringing young HIV+ women in for clinical services, both as an incentive as well as for its general nutritional value. For many young HIV+ women in the DTES and DS, food provided at a clinic may be their only meal of the day.

> "Women often arrive hungry." (Physician)

IDENTIFIED RECOMMENDATIONS

Through the course of conducting the interviews with health care providers and clinicians, related community service providers, and HIV+ women, a substantive number of recommendations were identified and documented. Some of the recommendations pertain specifically to the question of how to promote access to primary health care, while others relate to promoting access to related services.

This is consistent with a common theme that emerged across all the three groups of interviewees, namely that primary health care and clinical services very much exist on a "continuum of care". Interviewees identified that the prognosis for a young HIV+ women is tremendously impacted by the other determinants of health (housing, social support networks, personal health practices and coping skills, etc.) in addition to primary health services.

RECOMMENDED AREAS OF CAPACITY BUILDING FOR PRIMARY HEALTH CARE PROFESSIONALS

HIV/AIDS Knowledge Development

Interviewees and in particular each of the doctors and nurses interviewed commented on the need to build the care, treatment and support-related skills and knowledge of health care professionals. All health care providers agreed that increased knowledge in the areas of care, treatment, prevention and awareness were crucial to improving the HIV/AIDS capacity for general practitioners throughout the province. One nurse suggested that all RNs providing HIV/AIDS care should be active members of the Canadian Association of Nurses in AIDS Care (CANAC). Doctors spoke at length about the need for increased training for colleagues, especially older physicians and clinicians who did not receive HIV/AIDS training and education in medical school.

> "I think this is not a stigma against HIV or positive persons but it is almost a fear of doing it wrong. How to get family physicians to feel confident in the area of HIV that is just as relevant as any other health issue? This goes to education. For the majority of family doctors HIV is not on their radar. Knowing as much about HIV as they do about scleroderma. They just need to know the basics, how to recognize it and get the ball rolling. They say it is because it is really rare but so is scleroderma. So why not know about HIV/AIDS?" (Physician)

> "There is now a new cohort [of doctors] coming through – majority of family docs are over 40 and HIV was not part of their training …. The older docs, they feel they haven't seen it - it is all about exposure. Even if the GPs could do the primary and secondary prevention and then know where to refer to (in the event of a positive test result), that would be a big one. Just knowing where they can send people. But first, they need to please just ask these questions of all women and this is how you ask the question. Asking the

> question in the right way, i.e. to get tested. Secondary prevention (testing, screening). Primary – knowledge of disease and how to teach people to not engage in high-risk behaviours. Then if a positive test [occurs] this is where you refer [out to a specialist]. Interdisciplinary shared care/outreach in this same GP environment would be a big plus." (Physician)

HIV/AIDS Knowledge Transfer and Exchange

Several specific strategies were identified for the transfer and exchange of HIV/AIDS knowledge, including capitalizing on existing leadership and best practices within the community. Via an existing partnership between Oak Tree Clinic and the BC Centre for Excellence in HIV/AIDS (BCEHA), efforts are already underway to assess the feasibility of distributing a survey throughout the province in order to identify specific health care professionals who are interested in building their capacities and cultivating better relationships with Oak Tree and BCEHA. It is envisioned that this survey may lead to the co-ordination of a provincial conference, targeting doctors and other health care professionals, to specifically focus on the issues affecting women and HIV/AIDS.

> "We're trying to make personal connections with other caregivers throughout the province in order to be more supportive and to make them feel more supported in their HIV/AIDS care." (Physician)

HIV/AIDS Training/Forum Featuring the Voices of Young HIV+ Women

One interviewee suggested the co-ordination of an HIV/AIDS forum for health care providers featuring the involvement and integration of young HIV+ women.

> "[It would be great to have a] forum of young women who would train doctors on what would work for them in terms of health care. Women have so much to say, it would be useful for doctors to hear that. Doctors in the DTES are so great, but they are often going against the grain. The challenge is the systems that they are working within. For example, Dr. Burgess had to fight to do outreach." (Service Provider)

Aboriginal/First Nations Cultural Sensitivity Training

Service providers recommended the co-ordination of cultural sensitivity training for health care providers, particularly with regard to service provision for young HIV+ Aboriginal women. One service provider in our study discussed the multiple complexities related to colonization, racism and HIV/AIDS stigma and discrimination, and stressed that doctors try to take more time with their young Aboriginal patients, as these women may require more time to build trust with their care providers.

> "It's easy to read about Aboriginal women's issues but it's valuable to be able to go through it with doctors and take the time to fully understand and appreciate these issues and their context." (Service Provider)

> "Young Aboriginal women have so much more shame around their bodies and often require so many more teachings. Doctors need to be more understanding and patient with them as they sometimes need more coaxing. They need to take time to connect with their young female patients – HIV is a symptom of unbalance within the Mind/Body/Spirit/Heart and this affects risk behaviours. Young HIV+ women are not always ready to talk about their HIV." (Service Provider)

> "Doctors need to treat young Aboriginal women as a whole, giving them the respect that they deserve. In the end, young HIV+ women have a gift and a story to share with us and we need to be patient in order to hear their stories." (Service Provider)

In their research on Canadian Aboriginal women's perspectives on culturally appropriate HIV counselling and testing, Bucharski et. al. (2006), explore the significance of properly understanding the historical and present life experiences of indigenous peoples as a key component to culturally appropriate care, noting that this lack of understanding remains at the heart of many of the barriers and responses to HIV testing and care for Aboriginal women. They emphasize the need for health care providers to understand how colonization and generational trauma has marginalized Aboriginal people across generations, in order to shift the discourse on "culturally appropriate" care to a focus on "cultural safety" in care.

Similarly, in their research on antiretroviral therapy use among Aboriginal populations, Miller et. al. (2006) identify several unique characteristics important to the management and care of HIV among HIV+ Aboriginal women. These characteristics include lower antiretroviral access rates, childcare concerns while attending medical appointments, adherence issues, histories of sexual abuse, past and current domestic partner violence and self-medication issues related to post-traumatic stress disorder. Consequently, the authors recommend the incorporation of these potential concerns into patient care and management of HIV in order to help increase access rates, adherence and treatment outcomes for HIV+ Aboriginal women.

RECOMMENDED SPECIALIZED AND TARGETED SERVICES FOR YOUNG HIV+ WOMEN

The following strategies were recommended by many of the individuals interviewed for developing, augmenting and enhancing existing health care as well as more generalized services for young HIV+ women:

Increased Women-Specific Health Services

Almost all the individuals interviewed advocated for increased services that are women-specific. Activities and suggestions included allotted women-only times at clinics, a "bill of rights" for HIV+ women, and a young women's health clinic in the DTES.

> "A health care team that is really woman-centred." (Service Provider)

> "One thing that will hopefully happen soon is where women will come up with their own Bill of Rights for clinics and hospitals, and the clinics will be bound by them. We are trying to implement rights for positive women within the systems. It is just like the legal system right now, there are laws and guidelines but once you go in and try to implement them you find it is very individual and case by case. Something for the Bill of Rights would be: 'You can't call threaten to call the Ministry on me if I don't do so and so'." (Service Provider)

> "Everyone I am sure has an analysis around the issues dealing with young women. As far as young women in general, need to have more (any!) programming that is specific to young women. A health clinic for young women." (Service Provider)

Creation of Specific Services for Young Women Who Are Newly-Diagnosed

Several service providers suggested the creation of services specific to the needs of newly-diagnosed women.

> "Overall, there is not a lot of services, health care or otherwise, set up for people who are newly-diagnosed... period. And most young women are going to be newly diagnosed." (Service Provider)

In their study on post-traumatic stress and trauma history in youth living with HIV/AIDS, Radcliffe et. al. (2007) found that over 93% of study participants reported that receiving a diagnosis of HIV was experienced as a traumatic event; of these, over 13% met the criteria for post-traumatic stress disorder in response to HIV diagnosis, while an additional 20% showed significant post-traumatic stress symptoms. The authors note that these symptoms may interfere with adherence to medical care (e.g. missing clinic visits due to mental health symptoms), and recommend that counselling resources be made available as a component of providing comprehensive care to youth living with HIV.

Increased Women-Specific Housing & Other Services Addressing Determinants of Health

Almost all of the service providers interviewed discussed the need for safe and protected housing for young HIV+ women.

> “Housing - not just warehousing. We need many smaller housing projects (rather than one or two huge ones), more peer involvement, truly supportive housing, with each floor having peers, mentors, sisters to the others who can play a leadership role. This would also put fewer burdens on the staff.” (Service Provider)

> “Supportive housing – meaningful places to send people, especially for youth with chemical dependency issues. Try to get youth into a safe place and this is not easy. It is a big hole. What it is like is that you end up giving them a phone number, detox, BCPWA, AV, etc. and that’s just not very good. This is my ability to create a meaningful pathway for someone who has been hit on the head with a two-by-four. Don’t like telling them someone that they are positive, ‘Your life is changing’… and then just saying, ‘Here are some things you can do, and a few phone numbers. Have a nice day’.” (Registered Nurse)

> “It’s a crime for a 21 year old to be living in her drug dealer’s house.” (Service Provider)

Increased Number of DTES and DS Outreach Workers

Almost all of the interviewees commented on the need for more outreach workers and street nurses who can act as a bridge between young HIV+ women and primary care. Service providers noted that it generally takes more time to connect with young women and youth in general; outreach workers specific to this population were recommended. Some interviewees recommended more peer outreach workers, while others called for more outreach by health care professionals (e.g. doctors, nurses, nurse practitioners).

> “I see people downtown all the time that I don’t recognize and I wonder, ‘Where do they go?’.” (Registered Nurse)

> “Youth need to be sought out often, but outreach workers and also the rest of us, there is no time to go and seek out clients because you are busy dealing with all the clients you presently have. With women in general and young women in particular we tend to sometimes be passive in our follow-up. There needs to be more pro-active follow up, i.e. recognition that if a woman or young woman is not calling after an appointment, it doesn’t necessarily mean that they are okay. Recognizing that young women don’t tend to have the sense of entitlement to a worker’s time, services and resources that others may have. And because the spaces are not safe for them, it also means that they are not going to just drop in or if they do, it might only be one time so you really have to make the most of that initial connection. Or they may not wait if someone isn’t available to see them relatively quickly. Or the work they need done might require an appointment (i.e. disability application) but they are so focused on immediacy that it is hard for them to make it back for an appointment, at a scheduled time as opposed to dropping in.” (Service Provider)

> “More outreach. Young women are so difficult to connect with for so many reasons. There are so many other issues that are more pressing and health care is not a priority (e.g. sex work, addiction). This is about survival.” (Service Provider)

> "It would be great to have more in-house or in drop in health care services with less pressure re: deliverables (i.e. pressure to 'do' something right away). For women in the DTES that doesn't work. It can take women months and months to get comfortable to talk about their day, let alone their health care issues." (Service Provider)

In their study on HIV+ women's dissatisfaction with primary care, Burke et. al. (2003) argue for the provision of specialized, targeted supports and services to highly marginalized women, such as "sensitive outreach to women who fail to keep medical appointments" and the restructuring of "the health care environment so that continuity of care is promoted and women can spend more time with their providers". They further suggest that such efforts also have the potential to improve the providers' satisfaction with care-giving, which has been shown to be associated with patient satisfaction.

Increased Education and Training for Young HIV+ Women

Service providers suggested increased training for young HIV+ women in a number of areas. Several recommended more education, including information on treatment, adherence and side effects, for both Western (e.g. antiretrovirals) and natural/complementary medicines.

> "Young HIV+ women also need to know the importance of having good relationships with their doctors as they need to be able to tell doctors which natural meds they're on in order to discuss how those meds are also affecting their bodies and immune systems." (Service Provider)

Service providers also suggested increased education in the area of holistic and positive messages with regard to sex and sexualities.

> "Would love to get holistic and positive sex messages (e.g. sex, mechanics of sex, embracing more than physical sense) out to young women a lot sooner. This would really go a long way in empowering women and increasing their comfort in negotiating HIV. Boost low self-esteem and self-worth as it affects how young HIV+ women access service and advocate for self. This in turn will also go a long way to changing the face of HIV stigma and discrimination." (Service Provider)

Peer- and Community-Based Initiatives

Interviewees strongly agreed on the call for the development of more peer and community-based initiatives. Activities that were suggested included support groups, counselling meetings, outreach, etc.

> "These initiatives are difficult thing to get off ground if community doesn't organically already exist but young HIV+ women are still often alone and isolated in their experience." (Service Provider)

> “Need to remind young Aboriginal women that they are their own experts and all that they need is the space to share individual experiences. Perhaps more mentorship/training initiatives with young women so that they may teach themselves and empower themselves. Young women have their own gifts and strengths that they can share and receive. HIV inevitably changes people’s lives and this experience can have both negative and positive impacts - young HIV+ women can share these stories and experiences.” (Service Provider)

> “Peer support if they can get it. That has always seemed to work really well. The connections that have been made in the course of the WISE Project have been good. Buy-in from young women is what helps. Getting young women together, breaking down those barriers. Having a peer group for women so they don’t feel so alone.” (Service Provider)

> “Provide people with peer support, someone who you can talk to, who can bring you through – so the ‘system’ is not all white, male, etc.” (Service Provider)

> “Peer-based programming, but not necessarily, just young women peers. Rather, intergenerational programming, with older women acting as peers or mentors. Lots of young positive women, they don’t have contact with their family of origin, trauma around family issues, and abuse with family; or refugee clients are cut off from their family or culture. Value of intergenerational support, i.e. peer-based, older positive woman mentoring and providing support to younger women… the value of the intergenerational programming and when there is an elder or grandma involved. There is a trust and caring and mutual respect.” (Service Provider)

Integration of Fun Activities

Several interviewees suggested integrating activities into related community services that were more light-hearted and fun, with a social component that provided opportunities for the creation of informal support networks. Some ideas included crafts/art therapy sessions, lunch and beach outreach visits, and beauty nights. Several service providers called for more activities which provide a break for young HIV+ women to allow for the building of social and community networks as well as nurturing the positive relationships in their lives.

> “Fun stuff and activities can go a really long way. Being able to go out to the water for a day and go for lunch goes really, really far. Need opportunities for building a community through activities … like the [YouthCO/PWN] WISE retreat – that sort of stuff needs to happen way more. Fun activities, chill out for a few days without stressing about the things that are going on in the city. Not always talking about the intense things in life.” (Service Provider)

> “Taking someone out for lunch (e.g. eating too much poutine and bubble tea and laughing) versus offering someone a pamphlet – this can go a long way.” (Service Provider)

> “Beauty nights – it’s nice to be treated like a queen for a day alongside other people with similar experiences.” (Service Provider)

CONCLUSIONS & AREAS OF FUTURE RESEARCH

The results of this report highlight a common set of themes with regard to the challenges and strategies affecting young HIV+ women's access to primary health care (and related community services). Interestingly, identical or common themes were identified throughout the broad cross-section of stakeholders interviewed as part of this study - from community-based service providers to registered nurses to doctors to young women living with HIV/AIDS. These same themes were also consistent within the literature that was reviewed on women and HIV/AIDS.

It is also important to mention that nearly all of the individuals interviewed in the course of this study expressed their appreciation and esteem for the respective and combined efforts of YouthCO AIDS Society and Positive Women's Network in addressing the gaps young HIV+ women face in accessing primary health services.

For over five years, YouthCO and PWN have been working the front lines addressing the health needs of young women living in the Downtown Eastside and Downtown South areas of Vancouver, demonstrating the integral role that community-based organizations play in relation to the health care system. This study worked to document and articulate the needs of young women living with HIV/AIDS. The results of this endeavour suggest a "timeliness" in bridging this "front-line" experience and insight with the "behind-the-scenes" work of clinics serving this population.

Future work and research might explore the question, "How can community-based organizations like YouthCO and PWN best support the work of insider, clinic-based champions of young HIV+ women's health?". Additionally, other opportunities were identified during the course of our interviews, notably: creating more effective partnerships with street nurses, the MAKA Project, etc. to "bring health care to young women" (both within the DTES,DS and the broader Metro Vancouver area), as well as facilitating social support networks between older HIV+ women and young HIV+ women. Consequently, the provision of resources to explore these initiatives is recommended as a "second step" in addressing the health care and related needs of young women living with HIV/AIDS.

APPENDIX A: LETTER OF INTRODUCTION

[Name & Title]
[Address]

[Date]

Dear [Name]:

Greetings! We have been hired as consultants by the Positive Women's Network and YouthCO AIDS Society to explore the barriers facing both health providers as well as young women living with HIV/AIDS around access to primary health care in the Vancouver area.

Funded by the Public Health Agency of Canada (PHAC), we hope that the research results will prove to be of benefit both in identifying the gaps in service that may exist as well as highlighting some of the successes that are being realized. It is anticipated that this qualitative case study will accomplish three main outcomes:

1. Identification of perceived barriers in primary health care service provision and access to young women living with HIV-AIDS;
2. Description and analysis of patterns or themes related to young HIV+ women's access to primary care;
3. Creation of opportunities and recommendations for change.

Given your work at [Clinic Name], you have been identified as an important stakeholder and potential key informant by [Name]. As such, we are hoping that you will consider contributing to this research project by participating in a one hour interview with us. We are committed to honouring confidentiality and your comments from the interview will be kept anonymous unless you indicate otherwise. We are hoping to complete our interview series by the end of March 2008. The interview may be conducted in person or over the phone, at a time that is most convenient to you. In recognition of your time we would be pleased to offer yourself or [Clinic/Organization Name] a modest honorarium of $75.

The data mined from these interviews will be combined and contrasted with results from a focus group with young women living with HIV/AIDS. The final report will also include a literature review on the subject from North American peer-reviewed sources. All participants will be provided with a final copy of the report; it will also be delivered to representatives at PHAC and Vancouver Coastal Health.

We will be following up with you to discuss your potential involvement with this project. Thank you in advance for your time in considering this request.

Sincerely,

Sheena Sargeant
Consultant

Jennifer Evin Jones
Consultant

APPENDIX B: CLINICIAN INTERVIEW QUESTIONS

Please describe your role at the ___________________________ clinic.

Very roughly, what % of clients of the ______________________ clinic do you believe to be young women (aged 15 to ____) who are HIV+ or living with HIV-AIDS?

How much contact do you have day-to-day with young + women?

Are there any specialized services you offer to people living with HIV-AIDS overall…to youth … to young women

What challenges if any do you think that young + women might experience in accessing primary health care or clinical services in general?

Any challenge specific to more high-risk youth?

Do the challenges for young + women look different than for other + persons?

What challenges if any do you think may be experienced by young + women in accessing health care services at the _________________________ clinic?

What challenges if any have you yourself experienced as a clinician ___________________(fill in blank) in delivering services to young + women?

What would you like to see happen to address those challenges or barriers – at you clinic in particular; broader or more general changes – by way of resources, support, etc.?

If you or your staff or colleagues were offered training to build your capacity to work with young + women is this something you would want to access?

APPENDIX C: INTERVIEW QUESTIONS FOR SERVICE PROVIDERS

Please describe your role at ___________________________.

Very roughly, what % of your clients do you believe to be young women (aged 15 to ____) who are HIV+ or living with HIV-AIDS?

How much contact do you have day-to-day with young + women?

Are there any specialized services you offer to people living with HIV-AIDS overall…to youth … to young women

What challenges if any do you think that young + women might experience in accessing primary health care or clinical services in general?

Any challenge specific to more high-risk youth?

Do the challenges for young + women look different than for other + persons?

What challenges if any have you yourself experienced at ___________________(fill in blank) in delivering services to young + women?

What would you like to see happen to address those challenges or barriers by way of resources, support, etc.?

What would you like to see happen to build the capacity of health care providers in providing clinical services to young + women?

APPENDIX D: FOCUS GROUP INTERVIEW QUESTIONS

I. Welcome & Introductions (15-30)

- A. Straggling in, getting settled, eating food, etc.
- B. Facilitator Intros - brief overview of purpose, focus group format, assurance of confidentiality
- C. Intro to FG participants - names and ages

II. Background Questions (10 mins)

- A. Where do you usually go when you have questions about your health?
  - Clinic? Doctor? (Street) nurse? Pharmacist? Family? Friends? Partner? ASO/CBO? Support worker?
- B. How long have you known that you were HIV-positive?
- C. Where did you get tested?
- D. Are you currently on meds for your HIV?

III. Initial Access (10 mins)

- A. Where do you go for your HIV health care?
  - Clinic? Doctor's office? Street nurse? Hospital? N/A?
  - Which clinic/hospital/etc?
  - Is it women-only? Youth-only? Mixed?
- B. Why did you start going there? How did you get hooked up to services?
  - Recommended by nurse? Friend? Support worker? Always went there?
  - Was it hard to find a doctor?

IV. Current Access (15 mins)

- A. How often do you see your doctor/health care provider?
  - If you would like to see your doctor more often, what sorts of things would help?
    - Child care? Bus tickets? Rides? Addiction management?
- B. What sorts of things to you see your doctor/health care provider about?
  - What kinds of services do you access?
  - What does your clinic/doctor do for you?

V. Talking with Doctors (25 mins)

- A. What kinds of questions do you ask your doctor about HIV?
  - Treatments? Adherence? Acute illness?
  - Do you plan/write out your questions in advance?

- Are you comfortable asking your doctor questions?
- What level/kind of input do you feel you have in your health care?
- Do you feel that you have access to good information about your HIV treatment options? Do you feel that you are able to make informed decisions about your treatments?

B. Do you talk with your doctor about other things in your life besides your body-health?

- Living situation? Money/work/etc? Family/partner/kids? Legal challenges (custody, etc.)? How you’re feeling emotionally?
- Do you talk with your doctor about drugs/alcohol?
- Do you talk with your doctor about sex/sex work?
- Do you access your doctor for sexual health care (PAP, etc?)

C. Do you find the staff (reception, nurses, lab, etc.) at your clinic friendly and helpful? Do you feel welcome there?

VI. Community Supports (15 mins)

A. Do you feel that your partner/family/friends are helpful/supportive of your visits to your clinic/doctor?

- Are you comfortable talking with them about your health care?
- Do they help with childcare/transportation?
- Do you talk about your appointments/test results/treatment plans with them?

B. Do you ever take a friend or support worker into your appointments with you?

- Do they help you to understand what your doctor told you?

C. In what ways has your ASO support worker helped you with your health care? What are some other things he/she could do to help?

VII. General Satisfaction (15 mins)

A. Are you happy with the care you receive from your clinic/doctor?

- What sorts of things/information are helpful/useful to you? What do you like about visiting your doctor?
- What would you like to see happen that would look different for you so that you could access more or better services? What would you change?

B. What would you like to see happen or look different for other young HIV-positive women?

C. If you could change three things about your experiences with clinics/doctors since you tested positive, what would those things be?

VIII. Wrap-Up/Close (10 mins)

A. Other comments/questions

B. Distribution of honorarium forms

C. Closing Round

APPENDIX E: LITERATURE REVIEW RESULTS

1. **Obtaining a history of sexual victimization from adolescent females seeking routine health care. Can J Hum Sex. 2004; 13:62-63.**

   This study examines one physician's clinical practice of direct inquiry about sexual victimization of adolescent females who presented for a routine medical examination in a primary care setting.

   The study sample consisted of 146 consecutive female patients ranging in age from 12 to 22 years (mean=16) attending a primary care clinic in New York City. The sample was 58% Latino, 39% African American, and 3% Caucasian.

   While not specifically HIV-related, the study does underscore the need for physicians and other health care providers to inquiry about sexual victimization with adolescent females as part of routine health assessment. As the authors note the health care provider may be one of the few available confidants for a young person. The medical setting may also provide an environment where the subject of sexual victimization can be broached with younger patients in a less threatening manner. They note that health care providers must be better trained to elicit abuse history, react to disclosure in a professional yet compassionate manner, and ensure their patients see the appropriate follow-up.

2. **Andersen M, Tinsley J, Milfort D, et al. HIV health care access issues for women living with HIV, mental illness, and substance abuse. AIDS Patient Care STDS. 2005; 19:449-459.**

   The purpose of the research was to study factors related to health care access in women (young and otherwise) not participating in regular health care for their HIV infection.

   Nurses at the Well-Being Institute, a community-based nursing outreach clinic in Detroit, Michigan, located 75 women living with HIV, mental illness, and substance abuse who were lost to follow-up at their HIV medical clinic as part of a nursing research study. Women who had been scheduled for an appointment in the last 4 months but who had missed that appointment were considered "lost to follow-up" in the HIV clinic. Women were randomly assigned to two study groups. Women assigned to "care as usual" study group (n = 37) received no additional services beyond study interviews for 1 year. Women assigned to the "nursing intervention" group (n = 38) were provided with nursing services designed to facilitate their return to and continued connection with their HIV clinic.

   Findings showed that factors related to the women's vulnerability, such as mental illness and drug use, were more related to their use of expensive health care services such as hospital emergency departments or hospital inpatient admissions than was assignment to either the "nursing intervention" or "care as usual" study groups. Two case studies describing the cost of care for 2 of the multiply diagnosed women in the study is presented. The women differed on whether they had stable housing and were accessing care for their mental illness.

3. **Bucharski D, Reutter LI, Ogilvie LD. 'You need to know where we're coming from': Canadian aboriginal women's perspectives on culturally appropriate HIV counselling and testing. Health Care Women Int. 2006;27:723-747.**

   The purpose of this qualitative descriptive study was to determine Canadian Aboriginal women's perspectives on culturally appropriate HIV counselling and testing.

   Data were collected through semi-structured individual interviews with 7 Aboriginal women, and one focus group, in a western Canadian city. Four major categories were elucidated through thematic content analysis: Aboriginal women's life experiences that may influence their risk of HIV infection and their response to testing; barriers to HIV testing; guiding principles of the ideal HIV testing situation; and characteristics of culturally appropriate HIV testing.

The fear of being judged by both the Aboriginal and non-Aboriginal communities and the need for sensitivity to the historical and current context of Aboriginal women's life experiences were pervasive themes throughout the findings.

4. **Burke JK, Cook JA, Cohen MH, et al. Dissatisfaction with medical care among women with HIV: Dimensions and associated factors. AIDS Care. 2003; 15:451-462.**

   Studies have shown that women with HIV/AIDS in the USA are less likely than men to have access to appropriate health care and to utilize services, including the latest antiretroviral drug therapies. One explanation for this under-utilization is patient dissatisfaction with medical care. Dissatisfaction with care has been shown to be associated not only with treatment under-utilization, but also with discontinuity of care and poor clinical outcomes.

   Using Patient Satisfaction Questionnaire data from a national cohort of women with HIV, this study examined levels of dissatisfaction across seven established dimensions of care, and uses multivariate analysis to identify patient characteristics associated with these dimensions (N = 1,303).

   The researchers found that women were most dissatisfied with access to care and the technical quality of care, and least dissatisfied with financial aspects of care and their providers' interpersonal manner. Women who reported poor health, who had depressive symptomatology, who were not receiving antiretroviral therapy (ART), who had no consistent care providers or who were Hispanic/Latina were more likely to be dissatisfied across most dimensions of care. Implications for enhancing clinical care for women with HIV/AIDS and overcoming barriers to utilization of care and treatment are discussed.

5. **Cohen M, Deamant C, Barkan S, et al. Domestic violence and childhood sexual abuse in HIV-infected women and women at risk for HIV. Am J Public Health. 2000; 90:560-565.**

   The purpose of this study was to determine the prevalence and effect of domestic violence and childhood sexual abuse in women with HIV or at risk for HIV infection.

   Participants with HIV or at risk for HIV infection enrolled in the Women's Interagency HIV Study. Childhood sexual abuse; all physical, sexual, and coercive violence by a partner; HIV serostatus; demographic data; and substance use and sexual habits were assessed.

   The lifetime prevalence of domestic violence was 66% and 67%, respectively, in 1288 women with HIV and 357 uninfected women. One quarter of the women reported recent abuse, and 31% of the HIV+ women and 27% of the HIV- women reported childhood sexual abuse. Childhood sexual abuse was strongly associated with a lifetime history of domestic violence and high-risk behaviours, including using drugs, having more than 10 male sexual partners and having male partners at risk for HIV infection, and exchanging sex for drugs, money, or shelter.

   The researchers conclude that the data support the hypothesis of a continuum of risk, with early childhood abuse leading to later domestic violence, which may increase the risk of behaviours leading to HIV infection.

6. **Douglass JL, Sowell RL, Phillips KD. Using peplau's theory to examine the psycho-social factors associated with HIV-infected women's difficulty in taking their medications. J THEORY CONSTRUCT TEST. 2003; 7:10-17.**

   Although combination therapies slow progression of HIV disease, HIV-infected women face new challenges that must be overcome to increase their life expectancy. One challenge is adherence to strict, and often unpleasant, drug regimens. Peplau's Theory of Interpersonal Relationships provides a framework for identifying and examining factors that influence medication adherence, in particular difficulties in taking medication.

   A descriptive, correlational design was used to test associations between difficulty taking HIV medications and a woman's relationship with her primary healthcare provider (PHCP), depression, HIV-specific emotional and tangible support, present life satisfaction, family functioning, HIV-related symptoms, AIDS beliefs and perceptions, medication side-effects, and hope. Relationship with PHCP ($F = 5.30$, $p = .0235$) and present life satisfaction ($F = 11.32$, $p = .0011$) explained 22% of the variance in HIV-infected women's difficulty in taking medications.

This study supports the importance of a therapeutic relationship between primary health care providers and patients in overcoming difficulties associated with taking HIV medications.

7. **Dyer JG, Patsdaughter CA, McGuinness TM, Connor CA, DeSantis JP. Retrospective resilience: The power of the patient-provider alliance in disenfranchised persons with HIV/AIDS. J MULTICULT NURS HEALTH. 2004; 10:57-65.**

   Dyer and McGuinness (1996) published a concept analysis of resilience defined as a process whereby people bounce back from adversity and go on with their lives. It was hypothesized that resilience is based, in part, upon (a) the presence of natural mentors, and (b) inherent pro-social skills. HIV clinicians have called into question the availability of mentors and pro-social skills in HIV+ individuals who are members of marginalized populations. This study addressed the role of providers as role models and supports for the development of resilience in persons with HIV

   Characteristics of resilience are reviewed. Case studies of patients from different age and ethnic groups as well as attributes of providers who are successful in promoting retrospective (i.e., acquired) resilience in marginalized HIV+ individuals were presented.

   The researchers found that HIV+ individuals who are able to connect with providers who believe in inherent strengths and competencies of individuals, are resilient themselves, exhibit flexible boundaries, and are willing to partner with patients to show that "things can be different" demonstrate positive outcomes related to daily living and disease management. They conclude it is important that providers and academicians/researchers jointly examine generic concepts and models for relevance with particular populations and contexts.

8. **Felderman-Taylor J, Valverde M. A structured interview approach to evaluate HIV training for medical care providers. J Assoc Nurses AIDS Care. 2007; 18:12-21.**

   The purpose of this study was to explore how training in HIV/AIDS among primary health care providers may be enhanced.

   HIV/AIDS education trainings and self-reported changes in provider behaviour resulting from the trainings were evaluated in a structured interview with 24 health care providers. The participants were asked to provide concrete examples of behaviour changes related to eight specific areas in the provision of HIV/AIDS medical care. The structured interview process also served as an effective needs assessment of future training topics and of the modalities desired by the providers.

   The authors' suggest that by carrying out a structured interview of training attendees, training programs can be more precisely evaluated, and strengths and gaps in overall HIV/AIDS provider education can be better identified and addressed.

9. **Fitzgerald T, Lundgren L, Chassler D. Factors associated with HIV/AIDS high-risk behaviours among female injection drug users. AIDS Care. 2007; 19:67-74.**

   This study examined factors associated with reporting engaging in HIV/AIDS high-risk behaviours at two different time points spaced one year apart for a sample of 185 women who were active injection drug users (IDUs). The high-risk behaviours included injecting drugs in the past six months, having shared needles in the past six months and having engaged in unprotected sexual activity in the past thirty days.

   Through logistic regression modelling it was identified that living with a spouse at year one was significantly and positively associated with high-risk behaviours at both time points. Being prescribed medications for psychological or emotional problems as well as testing positive for the HIV/AIDS virus were significantly and negatively associated with reporting high-risk behaviours at both time points.

   These results suggest that spousal relationships may play an important role in HIV/AIDS high-risk behaviours of women drug users. An implication of this study is the need to focus on how spousal relationships and issues such as gender and empowerment should be incorporated into the design and implementation of HIV/AIDS prevention and treatment programs. The benefits of comprehensive mental health diagnosis and treatment services as well as HIV testing in reducing harm to female IDUs and their partners are also discussed.

10. **Jones SG, Messmer PR, Charron SA, Parns M. HIV-positive women and minority patients' satisfaction with inpatient hospital care. AIDS Patient Care STDS. 2002; 16:127-134.**

    Although patient satisfaction has been examined in relation to HIV services for ambulatory and managed care, less is known about perceptions of hospital care, particularly for HIV+ women and minorities. The purpose of this study was to examine HIV+ women and minority patients' satisfaction with hospital care. The study was part of a larger funded study that explored potential health care disparities for HIV+ women and minority persons in the era of HIV combination drug therapy.

    A convenience sample of 50 HIV+ persons was recruited from four medical centres/hospitals in a South Florida community. The multi-ethnic sample included 31 women and 19 men. The survey tool used was Cleary's HIV-Infected Patient's In-Hospital Questionnaire.

    Findings revealed that participants were generally satisfied with their hospital care. Physicians, nurses, and the hospital environment received satisfactory ratings. However, several problem areas were identified, including pain management and education on side effects of HIV medications, indicating the need for interventions to improve care.

    Experimental AIDS drugs were discussed with less than half of the participants, suggesting that HIV+ women and minority patients may not have equal access to clinical drug trials. Further research is also needed to determine whether attitudes conveyed by health care providers influence HIV+ patients to be wary of advance directives. The competence of nurses experienced in acute-care nursing of persons with HIV/AIDS was an important factor in patient satisfaction. A lack of experienced acute-care AIDS nurses may ultimately lead to a decrease in HIV+ patients' satisfaction with hospital care.

11. **Lichtenstein B. Domestic violence in barriers to health care for HIV-positive women. AIDS Patient Care STDS. 2006; 20:122-132.**

    Few studies have addressed the issue of domestic violence and health care for HIV+ women. However, such women are at increased risk of clinical progression when domestic violence prevents access to health care or their ability to take HIV medicines on a consistent basis.

    To address this issue, 3 focus groups and 50 in-depth interviews were conducted at a public health clinic with HIV+ women clients who had experienced domestic violence.

    The results are illustrated in 4 case studies of how domestic violence diminishes women's ability to obtain regular health care. Abused women were reluctant to keep appointments if they were afraid of their partners, if they were depressed, feeling ill or "too worn down," or if they were ashamed of being abused. Abusive partners were sometimes reported to sabotage women's efforts to seek care, keep appointments or take medications.

    The researchers conclude that domestic violence is an under-recognized barrier to women's ability to obtain regular medical care for HIV/AIDS. Effective HIV treatment is dependent on consistent HIV care, and domestic violence is a crucial barrier for some women. More research is needed to determine the most effective interventions for domestic violence in relation to HIV+ women.

12. **Mallinson RK, Relf MV, Dekker D, Dolan K, Darcy A, Ford A. Maintaining normalcy: A grounded theory of engaging in HIV-oriented primary medical care. ANS. 2005; 28:265-277.**

    Despite advances in the medical treatment of HIV disease, marginalized populations continue to shoulder a disproportionate burden of HIV/AIDS-related morbidity and mortality. This study explored the process by which clients at HIV-oriented primary care clinics transition from being sporadic users of care to engaging as regular users of care. A model illustrating how participants were striving to maintain normalcy, manage perceptions, and develop life mastery skills contributes to an understanding of living with HIV disease in a social context. Elements of the model are sensitive to nursing interventions aimed at improving health outcomes and reducing health disparities among persons at highest risk.

13. **Marelich WD, Murphy DA. Effects of empowerment among HIV-positive women on the patient-provider relationship. AIDS Care. 2003; 15:475-481.**

An assessment of the effects of HIV/AIDS patients' empowered behaviours on the patient-provider relationship was undertaken.

Participants were 50 HIV+ women ranging in age from 23-48 yrs, with 60% of the sample African American, 24% Latina, 6% White and 10% mixed/other race. Descriptive and canonical correlation analyses mere used to investigate the interrelationships between patients' empowered behaviours and self-reported interactions with their providers.

Positive associations were noted between patients' medical decision-making involvement and patient-provider interactions. Patients reporting greater decision-making involvement, had higher levels of communication with their providers, and received more information and positive affect from their providers. Health care providers of HIV+ women are encouraged to cultivate empowered behaviours in their patients.

14. **McCoy L. HIV-positive patients and the doctor-patient relationship: Perspectives from the margins. Qual Health Res. 2005; 15:791-806.**

    The doctor-patient relationship and the medical consultation are important resources for the health work of people living with chronic illness. In this article, the author examines physician-based outpatient health care from the standpoint of women and men who live with HIV in conditions of economic and social marginality.

    The research encompasses focus group and interview conversations with 79 HIV+ individuals in southern Ontario. Using the approach of institutional ethnography, the author offers a close reading of patients' descriptions of what they consider good doctoring.

    Areas of best practice that enhance access to health care examined here include doctors' inter-actional styles, ways of providing treatment options and treatment information, and ways of addressing the specific needs and life circumstances of patients living in poverty and social marginality.

15. **Miller CL, Spittal PM, Wood E, et al. Inadequacies in antiretroviral therapy use among Aboriginal and other Canadian populations. AIDS Care. 2006; 18: 968-976.**

    The researchers undertook this study to provide a profile of Aboriginal people initiating antiretroviral therapy and their response to treatment.

    Aboriginal peoples were identified through self-report. Baseline socio-demographics and risk factors were compared between Aboriginal and non-Aboriginal participants as were baseline factors associated with two consecutive plasma viral load measures below 500 copies/ml using contingency table analysis. Multivariate survival analysis of the prognostic factors associated with time to two consecutive plasma viral load measures below 500 copies/ml among eligible participants was undertaken to characterize response to antiretroviral therapy. There were 892 participants with available data for this analysis, of those 146 (16%) self-identified as Aboriginal.

    Aboriginal participants were more likely to be female (p 10K CDN (p </= 0.001) per annum. Aboriginal people were less likely to report men who have sex with men (p </= 0.001) and more likely to report injection drug use (p </= 0.001) as a risk factor for HIV infection. Aboriginal participants were more likely to receive double versus triple combination antiretroviral therapy (p = 0.002), be less adherent in the first year on therapy (p = 0.001) and to have a physician less experienced with treating HIV (p </= 0.001). When these factors were controlled for, Aboriginal people treated with triple combination therapy were as likely to respond and suppress their viral load below 500 copies. In the era of HAART, the authors conclude that research results indicate that Aboriginal people living with HIV/AIDS were less likely to receive optimal therapy. However, when Aboriginals did receive triple drug therapy they suppressed just as well as non-Aboriginals.

16. **Miller JK, Cook JA, Cohen MH, et al. Longitudinal relationships between use of highly active antiretroviral therapy and satisfaction with care among women living with HIV/AIDS. Am J Public Health. 2006; 96:1044-1051.**

    The researchers used longitudinal data to examine the roles of 4 dimensions of patient satisfaction as both predictors and outcomes of use of highly active antiretroviral therapy (HAART) among women in the United

States with HIV/AIDS. Generalized estimating equations were used to analyse time-lagged satisfaction-HAART relationships over 8 years in the Women's Interagency HIV Study.

Multivariate models showed that, over time, HAART use was associated with higher patient satisfaction with care in general, with providers, and with access/convenience of care; however, patient satisfaction was not associated with subsequent HAART use. Symptoms of depression and poor health-related quality of life were associated with less satisfaction with care on all 4 dimensions assessed, whereas African American race/ethnicity, illegal drug use, and fewer primary care visits were associated with less HAART use.

The researchers suggest that dissatisfaction with care is not a reason for underuse of HAART among women with HIV and that providers should not be discouraged from recommending HAART to dissatisfied patients. Rather, increasing women's access to primary care could result in both increased HAART use and greater patient satisfaction.

17. **Napravnik S, Eron J,Jr., McKaig RG, Heine AD, Menezes P, Quinlivan EB. Factors associated with fewer visits for HIV primary care at a tertiary care centre in the southeastern U.S. AIDS Care. 2006; 18:S45-50.**

    In this the authors sought to evaluate sociodemographic and clinical characteristics associated with decreased access to HIV outpatient care in a University-based clinic in the Southeastern U.S.

    The number of HIV outpatient clinic visits per person-year was estimated among 1,404 HIV-infected individuals participating in a large observational clinical cohort study. On average, participants attended 3.38 visits per person-year (95% CI = 3.32, 3.44), with 71% attending fewer than 4 visits per year.

    Researchers found that younger persons, of Black race/ethnicity, with less advanced HIV disease, and a shorter time from entry to HIV care, had poorer access to care, as did participants without health insurance and residing a greater distance from care. Vulnerable subgroups of HIV-infected patients in the South have decreased access to ongoing HIV health care. Interventions including more intensive counselling and active outreach for newly HIV diagnosed individuals and support with obtaining health insurance and transportation may lead to improved outcomes.

18. **Olivier C, Dykeman M. Challenges to HIV service provision: The commonalities for nurses and social workers. AIDS Care. 2003; 15:1.**

    This article explores the experiences of health service providers in caring for HIV+ persons. Service providers' report fear of contracting HIV, feeling helpless, problems getting up-to-date information, grief and inadequate referral resources.

19. **Radcliffe J, Fleisher CL, Hawkins LA, et al. Posttraumatic stress and trauma history in adolescents and young adults with HIV. AIDS Patient Care & STDs. 2007; 21:501-508.**

    This study examined trauma history and posttraumatic stress in a sample of 30 adolescents and young adults with HIV/AIDS, recruited from December 14, 2004 through May 3, 2005.

    Overall, participants reported a mean of 5.63 traumatic events, with 93% of the sample reporting that receiving a diagnosis of HIV was experienced as traumatic. Of these, 13.3% met criteria for posttraumatic stress disorder in response to HIV diagnosis, while an additional 20% showed significant post-traumatic stress symptoms. Even greater rates of posttraumatic stress were reported in response to other trauma, with 47% of youth surveyed reporting symptoms of posttraumatic stress in response to such traumatic events as being a victim of a personal attack, sexual abuse, or being abandoned by a caregiver.

    These findings may inform professionals about the potential impact of the HIV diagnosis on adolescents and young adults, particularly as this may impact participation in medical care and need for mental health support.

20. **Rastegar DA, Fingerhood MI, Jasinski DR. Highly active antiretroviral therapy outcomes in a primary care clinic. AIDS Care. 2003; 15:231-237.**

    This paper compares antiretroviral outcomes of patients at a primary care clinic with those previously reported at HIV specialty clinics and examines risk factors for treatment failure.

A retrospective medical record review was undertaken at an academic primary care practice in Baltimore, Maryland. One hundred and twenty-three patients were included who had not previously received HAART and who were started on a regimen that included a protease inhibitor or a non-nucleoside reverse transcriptase inhibitor and at least one other new antiretroviral medication. HIV RNA levels, CD4 lymphocyte counts, missed appointment rate, HAART regimen, demographic variables, and their association with the achievement of a viral RNA of 500 or less at 7-14 months were analysed. Forty-seven per cent of the patients had an HIV RNA level of 500 or less at 7-14 months after initiation of HAART.

Factors associated with treatment failure included missed appointment rate, injection drug use and previous exposure to antiretroviral medication. On multivariate analysis, only missed appointment rate and lower baseline CD4 lymphocyte count were independently associated with treatment failure. The antiretroviral outcomes of patients started on HAART by experienced health care providers in this primary care practice were comparable to those reported in specialty clinics. As with previous reports, most patients did not maintain viral suppression. Missed appointment rate was the most important risk factor for treatment failure.

21. **Relf MV, Mallinson K, Pawlowski L, Dolan K, Dekker D. HIV-related stigma among persons attending an urban HIV clinic. J MULTICULT NURS HEALTH. 2005; 11:14-22.**

    HIV-related stigma (HRS) is rooted in the socio-cultural constructions associated with infectious diseases, particularly in the HIV/AIDS epidemic. The purpose of this study was to determine the level and impact of HRS in a culturally diverse sample of persons attending an urban HIV clinic.

    Using a combination of quantitative (n=87) and qualitative (n= 27) methods, this study examined the level of HIV-related stigma in four domains: personalized, disclosure-related, negative self-image, and public attitudes. Relationships between HRS, depressive symptoms, and quality of life were explored. Interviews were used to identify sources of HRS and processes utilized to manage HRS.

    The authors conclude that HRS is a significant problem for persons living with HIV/AIDS. Persons with higher levels of HRS are more likely to experience depressive symptomatology and a lower quality of life than persons who perceive fewer stigmas. HIV+ persons experience various forms of stigma in meeting family, societal, and cultural expectations. Nursing interventions can reduce HRS and promote coping as well as connectedness to family, community, and the health care system.

22. **Schneider J, Kaplan SH, Greenfield S, Li W, Wilson IB. Better physician-patient relationships are associated with higher reported adherence to antiretroviral therapy in patients with HIV infection. JGIM: Journal of General Internal Medicine. 2004; 19:1096-1107.**

    There is little evidence to support the widely accepted assertion that better physician-patient relationships result in higher rates of adherence with recommended therapies. The researchers wished to determine whether and which aspects of a better physician-patient relationship are associated with higher rates of adherence with antiretroviral therapies for persons with HIV infection.

    A cross-sectional analysis was undertaken across 22 outpatient HIV practices in a metropolitan area, working with 554 patients with HIV infection taking antiretroviral medications. Adherence was measured using a 4-item self-report scale ($\alpha = 0.75$). The researchers measured core aspects of physician-patient relationships using 6 previously tested scales (general communication, HIV-specific information, participatory decision making, overall satisfaction, willingness to recommend physician, and physician trust; q>0.70 for all) and 1 new scale, adherence dialogue ($\alpha = 0.92$). For adherence dialogue, patients rated their physician at understanding and solving problems with antiretroviral therapy regimens. The mean patient age was 42 years, 15% were female, 73% were white, and 57% reported gay or bisexual sexual contact as their primary HIV risk factor. In multivariable models that accounted for the clustering of patients within physicians' practices, 6 of the 7 physician-patient relationship quality variables were significantly (P0.70 for all) and 1 new scale, adherence dialogue ($\alpha = 0.92$). In multivariable models that accounted for the clustering of patients within physicians' practices, 6 of the 7 physician-patient relationship quality variables were significantly (P<.05) associated with adherence. In all 7 models worse adherence was independently associated (P<.05) with lower age, not believing in the importance of antiretroviral therapy, and worse mental health.

This study demonstrates that multiple, mutable dimensions of the physician-patient relationship were associated with medication adherence in persons with HIV infection, suggesting that physician-patient relationship quality is a potentially important point of intervention to improve patients' medication adherence. In addition, the researchers suggest that it is critical to investigate and incorporate patient's belief systems about antiretroviral therapy into adherence discussions, and to identify and treat mental disorders.

23. **Sohler NL, Wong MD, Cunningham WE, Cabral H, Drainoni M, Cunningham CO. Type and pattern of illicit drug use and access to health care services for HIV-infected people. AIDS Patient Care STDS. 2007; 21: S-68-76.**

    Approximately 28% of HIV-infected people in treatment in the United States report using illicit drugs. Illicit drug users have poorer course of HIV disease than non-drug users, which is thought to be due to their irregular use of HIV medical services.

    The researchers examined associations between type (cocaine versus opioids) and pattern of drug use (drug use at baseline, 6-month follow-up, both periods, and non-use) and health care utilization for a large sample of HIV-infected individuals drawn from a multisite project that evaluated the impact of medical outreach interventions for populations at risk of poor retention in HIV care.

    Across all types and patterns of drug use, drug users were more likely to have sub-optimal ambulatory care, miss scheduled appointments, use the emergency department, have unmet support services needs, and were less likely to take antiretroviral medications. Additionally, while people who started using drugs during the follow-up period and consistently used drugs across both periods differed from nonusers on missed appointments (odds ratio [OR] = 2.20 for starters versus nonusers, OR = 2.92 for consistent users versus nonusers), emergency department use (OR = 4.93 for starters versus nonusers, OR = 2.24 for consistent users versus nonusers), and antiretroviral medication use at follow-up (OR = 0.23 starters versus nonusers, OR = 0.19 for consistent users versus nonusers), those who stopped using drugs after the baseline period did not differ from nonusers. The authors conclude that health care utilization is poorer for people who use illicit drugs than those who do not, and stopping drug use may facilitate improvements in health care utilization and HIV outcomes for this population.

24. **Spittal PM, Bruneau J, Craib KJP, et al. Surviving the sex trade: A comparison of HIV risk behaviours among street-involved women in two Canadian cities who inject drugs. AIDS Care. 2003; 15:187.**

    In Canada, very little is known about the factors and processes that cause drug-related harm among female intravenous drug users (IDUs). Women who inject drugs and participate in the survival sex trade are considered to be at increased risk for sexual and drug-related harms, including HIV infection.

    Between September 1999 and September 2000, women participating in the VIDUS cohort in Vancouver and the St. Luc Cohort in Montreal completed interviewer-administered questionnaires. Analyses were conducted to compare the demographic characteristics, sexual risk behaviours, risky injection practices and drug use patterns among women who self-identified as participating in the sex trade with those who did not identify as participating in the sex trade. Logistic regression was used to identify factors independently associated with exchanging sex for money or drugs. HIV prevalence at the study visit (September 1999-2000) was 29% for sex trade workers and 29.2% for non-sex trade workers.

    The researchers found that while patterns of sexual risk were similar, the risky injection practice and drug use patterns between sex trade workers and non-sex trade workers were markedly different. Logistic regression analysis of cross-sectional data revealed that independent behaviours associated with the sex trade included: greater than once per day use of heroin (adjusted OR 2. 7), smoke able crack cocaine (adjusted OR = 3.3) and borrowing used syringes (adjusted OR = 2.0). They conclude that creative, client-driven interventions are urgently needed for women who trade sex for money or for drugs.

25. **Sullivan LM, Stein MD, Savetsky JB, Samet JH. The doctor-patient relationship and HIV-infected patients' satisfaction with primary care physicians. J Gen Intern Med. 2000;15:462-469.**

The goal of this research was to assess the extent to which perceptions of specific aspects of the doctor-patient relationship are related to overall satisfaction with primary care physicians among HIV-infected patients.

A longitudinal, observational study of HIV-infected persons new to primary HIV care was conducted at two urban medical centres in the North Eastern United States, with data collected at enrolment and approximately 6 months later by in-person interview. The participants to the study were patients seeking primary HIV care for the first time. The primary outcome measure was patient-reported satisfaction with a primary care physician measured 6 months after initiating primary HIV care.

Patients who were more comfortable discussing personal issues with their physicians (P =. 021), who perceived their primary care physicians as more empathetic (P =.001), and who perceived their primary care physicians as more knowledgeable with respect to HIV (P =.002) were significantly more satisfied with their primary care physicians, adjusted for characteristics of the patient and characteristics of primary care. Collectively, specific aspects of the doctor-patient relationship explained 56% of the variation in overall satisfaction with the primary care physician.

Patients' perceptions of their primary care physician's HIV knowledge and empathy were highly related to their satisfaction with this physician. Satisfaction among HIV-infected patients was not associated with patients' sociodemographic characteristics, HIV risk characteristics, alcohol and drug use, health status, quality of life, or concordant patient-physician gender and racial matching.

26. **Wood E, Montaner JSG, et al. Burden of HIV Infection Among Injection Drug Users in Vancouver, British Columbia. Am. J. Pub. Health. 2008; 98: 515-519.**

The researchers sought to examine whether there were differential rates of HIV incidence among Aboriginal and non-Aboriginal injection drug users in a Canadian setting.

Data were derived from 2 prospective cohort studies of injection drug users in Vancouver, British Columbia. Using the Kaplan-Meier method and Cox proportional hazards regression, the authors compared HIV incidence among Aboriginal and non-Aboriginal participants.

Overall, 2496 individuals were recruited between May 1996 and December 2005. Compared with that of non-Aboriginal persons, the baseline HIV prevalence was higher among Aboriginal persons (16.0% vs 25.1%; P<.001). Among participants who were HIV negative at baseline, the cumulative HIV incidence at 48 months was higher among Aboriginal persons (18.5% vs 9.5%; P<.001). In multivariate analyses, Aboriginal ethnicity was independently associated with elevated HIV incidence (relative hazard=1.59; 95% confidence interval=1.12, 2.26; P=.009).

The authors conclude that Aboriginal persons in Vancouver had a significantly elevated burden of HIV infection, which calls for a culturally sensitive and evidence-based response. Policy-makers in other settings with at-risk Aboriginal populations should seek to avert similar public health emergencies by being proactive with evidence-based HIV-prevention programs.

27. **Wood E, Montaner JSG, et al. Prevalence and correlates of untreated HIV-1 infection among persons who have died in the era of modern antiretroviral therapy. Journal of Infectious Diseases. 2003; 188 (8): 1164-1170.**

The researchers evaluated all human immunodeficiency virus (HIV)-related deaths over the period 1 January 1995-31 December 2001 in a Canadian province in which all HIV care and antiretroviral therapy are provided free of charge. Persons who had received antiretroviral drugs before death were compared with those who had died without ever receiving HIV treatment, by fitting a logistic model. Overall, 1239 deaths were attributed to HIV infection during the study period. Of these, 406 (32.8%) occurred among persons who had never received any HIV treatment. In adjusted analyses, aboriginal ethnicity, female sex, and lower median income were negatively associated with receiving HIV treatment before death. Furthermore, among the 833 individuals who received treatment before death, only 379 (45.5%) received antiretroviral medication -> 75% of the time during their first year receiving therapy. The data demonstrate the need for novel interventions to expand HIV care to specific populations.

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