

# Sustainability of an HIV PEP Program for Sexual Assault Survivors: “Lessons Learned” from Health Care Providers

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**Abstract:** This study explored challenges to continuing an HIV post-exposure prophylaxis (PEP) program of care provided to sexual assault survivors in the province of Ontario, Canada. Data were collected as part of an implementation and evaluation of a universal offering of HIV PEP (known as the HIV PEP Program) at 24 of 34 provincial hospital-based sexual assault treatment centres. Experienced health care providers were surveyed (n = 132) and interviewed in four focus groups (n = 26) about their perceptions of what, if any, factors threatened their ability to maintain the HIV PEP Program. All focus groups were audio-recorded and the recordings transcribed. The transcriptions and open-ended survey responses were analyzed using content analysis. Administrator, nurse, physician, social worker, and pharmacist respondents perceived important barriers to sustainability of the HIV PEP Program. Eight constructs were identified within four broad themes: resources (inadequate funds, overworked and unacknowledged staff), expertise (insufficient external supports, insufficiently trained and knowledgeable staff), commitment (lack of institutional support, physician resistance to offering HIV PEP), and accommodation (lack of flexibility in addressing specific client and community needs, inaccessibility and lack of clarity of tools). We discuss the implications of these findings and the actions that were taken to address the challenges.

**Keywords:** Focus groups, HIV, knowledge translation, post-exposure prophylaxis, sexual assault, surveys.

## INTRODUCTION

Sexual assault is a wide-spread human rights problem with potentially devastating health consequences [1, 2]. Persons who have been assaulted may experience depression, post-traumatic stress disorder, suicidality, substance abuse problems, eating disorders, gynaecological problems, genital and extragenital injuries, as well as sexually transmitted infections (STIs) [3-14]. Particular characteristics of sexual assaults may increase the likelihood of transmission of HIV specifically: those involving multiple assailants; perpetration of multiple sex acts, including anal penetration; occurrence of injury to mucous membranes; and the presence of preexisting STIs [7, 8, 15]. Research has shown that sexual assault survivors are often afraid of contracting HIV infection and that they want access to appropriate antiretroviral therapies [16-23].

The World Health Organization [24] maintains that “all countries should have a policy on the services provided for people who have been sexually assaulted and that these policies should include post-exposure prophylaxis for HIV whenever sufficient resources are available” (p. 54). In fact,

guidelines and protocols for HIV PEP following sexual assault have been increasingly developed over time [7, 11, 24-37]. There is also a growing number of studies that have evaluated such guidelines and protocols, although most of these have been retrospective chart reviews [18, 32, 38-52], many focussed on children and/or adolescents only [40, 42, 45, 47, 52-56], or conducted in mid-to-high HIV prevalent countries [38, 53, 54, 57-59]. Although most of these studies have concluded that there is a need to further “evaluate and improve appropriateness of HIV nPEP administration and follow-up” (41: p.640), none have interviewed and surveyed health care providers about their opinions and experiences of offering PEP to sexual assault survivors.

## THE HIV PEP STUDY

The HIV PEP Study, as it was known, was the first large, systematic, and prospective research to address a program of offering HIV PEP to women, men, and children after sexual assault in a country with a low prevalence of infection. In 2003, concern about this issue of HIV for sexually assaulted persons prompted the Ontario Network of Sexual Assault/Domestic Violence Treatment Centre (SA/DVTC)s to partner sexual assault experts with infectious disease specialists to implement and evaluate a provincial program of universal offering of HIV PEP medications (known as the HIV PEP Program). Protocols were developed and operationalized to offer sexual assault survivors HIV risk

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counselling and the option of antiretroviral medications (Combivir<sup>®</sup> and Kaletra<sup>®</sup>). Standardized medical guidelines, counselling tools, client handouts, and data collection forms assisted clinicians in providing consistent HIV PEP care. The primary purpose of the study was to generate scientific evidence for the practices needed to sustain a province-wide HIV PEP Program at SA/DVTCs (see 60 for more details).

The HIV PEP Program was characterized by the following specific characteristics: all clients were to receive counselling about potential HIV risks; all clients whose assault posed any risk of HIV infection (known or unknown) were to be offered prophylactic medication; prophylaxis was to be initiated within 72 hours of exposure and to be prescribed for a period of 28-days; an intensive schedule of five follow-up visits was to assist clients who chose the prophylactic drugs to cope with side effects and complete the medication course; and prophylaxis was to be provided at no cost to clients. The HIV PEP medications were dispensed through the hospital pharmacies and costs were reimbursed through the study. To ensure that the protocol was implemented consistently, an experienced sexual assault nurse examiner (SM) and/or infectious disease specialist (ML) held six regional train-the-trainer sessions involving three core staff from each participating center. These individuals in turn trained the front line staff at their sites [see 60 for more details].

Of Ontario's 34 SA/DVTCs, 24 (70%) were enrolled in the HIV PEP Study. These centres, administered by program coordinators, provided around the clock emergency medical care, counselling, and medical forensic examination to sexually assaulted women, men and children. The clients served were representative of the province's rural, remote, and urban communities and ethnically diverse populations [61, 62]. Information was collected from 1,238 sexual assault survivors from September 10, 2003 to January 31, 2005. Data from 135 of these clients were excluded from analyses because of inconsistent data collection practices at 6 SA/DVTCs, leaving a final total sample size of 1,103. Findings showed that 347 (44%) of the 798 clients who met the HIV risk criteria and were offered HIV PEP, accepted; 111 (32%) of this latter group completed the full 28-day regimen [see 60 and 63 for more details]. These findings compare to a 28% acceptance rate and an 11% completion rate reported in a smaller retrospective study conducted at the British Columbia Sexual Assault Service between 1996 and 1998. The higher rate of adherence in the HIV PEP Study may be related to the fact that clients were tracked prospectively and provided a rigorous schedule of follow-up that included both emotional and physical support, as well as offered a newer drug regimen that may have been easier to tolerate [50].

As part of the HIV PEP Study, different health care providers were surveyed and interviewed in focus groups about their experiences implementing the protocol, offering some insight into challenges that were encountered (administrators, nurses, physicians, social workers, and pharmacists). Their perceptions and experiences were solicited to help ensure that any recommendations regarding standards of care that emerged from the HIV PEP Study findings could be implemented at all SA/DVTCs across Ontario. Knowledge gained from understanding the barriers

to rolling out such a program of care could inform those embarking on similar processes in other jurisdictions.

## METHOD

This study was approved by the Institutional Review Boards of all participating hospitals as well as by their Medical Advisory and Pharmacy and Therapeutic Committees.

### Measures

#### Survey

A survey was developed to capture the different health care providers' views regarding the universal offering of HIV PEP. Topics covered by the survey included: 1) client ability to make informed decisions about HIV PEP; 2) health care provider ability to provide sufficient counselling about HIV PEP; 3) influence of health care provider strength of recommendation on client decision to take HIV PEP; 4) client satisfaction with HIV PEP care received; 5) impact of HIV PEP care on other aspects of care offered; 6) importance of offering HIV PEP to unknown risk group; 7) optimal strategy for offering HIV PEP; and 8) sustainability of an HIV PEP program. With regard to the latter, the following question, specifically, was asked: "Thinking about the impact that the HIV PEP and universal offering had on the nurses, physicians, administrators, pharmacists, and social workers at your hospital, do you think universally offering of HIV PEP to SA/DVTC clients is sustainable at your hospital on a long-term basis?" This question was followed by space for the respondent to comment further or explain their response. Prior to distribution, the Health Care Provider Survey was piloted in October 2004 with the assistance of SA/DVTC program coordinators and staff members across the province. Based on their feedback, small changes were made to the survey design and content.

#### Focus Group Interview Guide

The intent of the focus groups was to allow for an in-depth exploration of the experiences and perceptions of health care providers in delivering the universal HIV PEP Program. A semi-structured interview guide was developed to elicit information about the following: 1) the satisfaction of clients with the HIV PEP Program; 2) optimal strategy for offering HIV PEP to clients; 3) validity of HIV PEP universal offering strategy; and 4) sustainability of an HIV PEP Program. Regarding sustainability, specifically, health care providers were asked: "Now I'd like you to think for a minute about HIV PEP as an *ongoing* program. Do you think your centre can keep it going?" Probes included: Do you think that your host hospital and centre would be supportive? Would your centre be able to continue providing the kind of support and counselling that are needed to continue with "universal offering"? The guide was piloted in a November 2004 focus group and based on feedback slight changes were made to ensure that any pertinent feedback from health care providers was captured.

### Procedure

#### Survey

All health care providers (i.e., administrators, nurses, physicians, social workers, and pharmacists) who had

participated in the HIV PEP Study were invited to complete the anonymous and voluntary survey. In November 2004, program coordinators at the 24 participating sites distributed surveys, which included an attached pre-addressed, postage paid return envelope, to program health care providers. Reminders to distribute surveys among staff were sent *via* e-mail 2, 6, and 8 weeks post-distribution. As well, a section in the quarterly HIV PEP Study newsletter was devoted to reminding health care providers about the importance of their feedback *via* the survey. Completed surveys were returned to the central study coordinator, entered into a MS Access database, and then filed in a secure cabinet. Only members of the research team had access to the surveys and the database, the latter of which was restricted by password.

### **Focus Groups**

All health care providers who had participated in the HIV PEP Study were invited to take part in one of several proposed focus groups. An effort was made to set up varying days and times to reach as many health care providers as possible. Once the schedule had been established, an email was sent to all program coordinators to enlist their help in publicizing the upcoming focus groups. A flyer was also sent as an attachment to be posted at all participating sites and a section in the HIV PEP Study newsletter was devoted to reminding health care providers about the importance of their feedback *via* focus group participation. Focus groups, which were held in November and December 2004, were teleconferenced to ensure that as many health care providers as possible could participate. All focus groups were recorded and later professionally transcribed verbatim. A research assistant experienced in qualitative research reviewed the recordings to check for transcription errors. Focus group recordings and transcripts were secured in a locked cabinet; only members of the research team and the transcriber had access to them.

### **Data Analysis**

The first author and a research assistant experienced in qualitative research read the comments made on the surveys and each interview transcript twice. All qualitative data from the survey and focus groups related to barriers to sustainability and further implementation of the HIV PEP Program were then manually extracted and organized into a grid based on an initial manifest content analysis [64]. Emergent patterns were identified from this data, beginning at the higher order of categorization with four broad conceptual themes: 'Resources', 'Expertise', 'Commitment', and 'Accommodation'. A theme sheet was produced in which all data relating to those concepts were placed. Drawing on meaningful commonalities found across responses within each cluster, a series of lower order constructs were independently derived. These constructs were compared and any differences that emerged were resolved through consensus. Finally, responses identified in each construct were referenced back to the transcripts for further context and extraction of relevant quotations for latent content analysis.

## **RESULTS**

### **Description of Respondents**

A total of 35.2% of the health care providers contacted agreed to participate and completed the survey, resulting in a sample size of 132. Respondents included 18 program

coordinators (15 of who were Sexual Assault Nurse Examiner [SANE]s and 3 social workers), 94 nurses (64 of who were SANEs), 11 physicians (5 of who were program medical directors), 4 social workers, and 5 pharmacists. Most had had direct patient contact: 94 had provided initial and 40 follow-up care.

Focus groups were also held with 26 health care providers representing nine centres from across the province. Focus Group 1 (n=14) included one program coordinator (also a social worker), ten SANEs, two social workers, and one physician; Focus Group 2 (n=2) included one program coordinator (also a SANE) and a SANE; Focus Group 3 (n=6) included three program coordinators (also all SANEs), a SANE, a nurse, and a pharmacy manager; and Focus Group 4 (n=4) included two program coordinators (also both SANEs) and two nurses.

### **Thematic Overview**

The majority of health care providers surveyed (65.2%) and interviewed who answered the question, "Is universal offering of HIV PEP sustainable at your hospital on a long-term basis?" believed the HIV PEP Program could continue and be further implemented across the province. However, many qualified their affirmative responses stating that viability of the program in the longer-term would be contingent upon several conditions being met. Along with those who did not believe the program was sustainable or who were unsure of its sustainability, their concerns, as captured in both the survey and focus groups comments, centered primarily on the need for the program for increased resources, expertise, commitment, and accommodation.

### **Resources**

#### ***Inadequate Funds***

Several health care providers were concerned about the monies to support the program, as indicated by one SANE's comment, "what I see as the big hurdle is funding" (Focus Group (FG) 3 Respondent (R) 5; also FG 2 R 2 and Survey [Surv] Rs 12, 118, 120, 121, 127, 132). Much of the concern centred on adequate monies to cover the costs of the drug regimen as captured by this query from a pharmacist, "Who will fund the treatment?" (Surv R 59). A physician colleague, who declared himself to the "the last person that ever thinks about this kind of thing", worried that limited funding for "a very expensive treatment" (FG 1 R14) would make decisions to offer HIV PEP universally difficult as the program expanded:

There's not an endless amount of money available to give to the program, to give drugs to people and ... if you have a finite number of dollars ... with which to spend on a program like this and you had to start designating and being the one to make a decision, like who warrants the sum of money that's required for the treatment and who doesn't, it's very difficult for us as individuals to take that into consideration when the woman is sitting in front of you and you've got to decide whether she's worth \$1,500 or not for the treatment and yet if you are dealing with an infinitesimally small risk with someone who is not considered a high-risk person and you've

only got so much money ... is that something that you have to take into consideration? Maybe in the infancy of a program like this you're not really thinking that way, but as you get more involved in it, and the numbers will add up over the years and the available number of dollars is not going to get greater in all probability, you have to start thinking that way. (FG 1 R 14)

Without external funding for the drugs, many health care respondents believed that the hospitals would not be able to continue the program (FG 3 Rs 1, 6, FG 4 Rs 2, 3; Surv Rs 45, 58, 72, 97). A SANE stated that she "couldn't see clients using their own health plans to cover the cost of antivirals because of the lack of confidentiality" (Surv R 3). In any event, a program coordinator noted, "most of the clients don't have drug plans and if they do, they are very limited" (Surv R 79). This was seen as a particular problem by one program coordinator (SANE), whose program provided services to First Nation's communities:

One of the medications is covered for Aboriginal clients but the other one isn't so we'd have to look at funding for, I can't remember which one it is, but the second medication, so we're okay with about half of the treatments. (FG 3 R 3)

Still others were worried about the sustainability of the program in terms of compensation for existing staff and funds for new staff. A program coordinator (social worker) asked, "What kind of support is there going to be ... in terms of ... remuneration for those involved with it, because it is asking yet another thing for us to do?" (FG 1 R 1). This was seen as a particular problem for health care providers delivering the follow-up care as captured in the statement of another program coordinator (SANE):

With the nurses taking the lead as we have been the program can continue. However, staff funding resources for the follow-up nursing role will be a potential barrier that on a long-term basis would need to be addressed. (Surv R 79; also Surv Rs 38, 45, 100)

She felt that there "would be a need for more funds to increase the follow-up nursing positions to full time" (Surv R 79; also Surv R 3).

### ***Overworked and Unacknowledged Staff***

Several health care provider respondents with concerns about the sustainability of the HIV PEP Program cited overtaxed staff as an issue (Surv Rs 45, 86, 132). A pharmacist noted:

I would like to be more involved with counselling the patient, especially those on many drugs, but our hospital is down to less than a half-staff of pharmacists. It is therefore hard to cover all the programs we would wish. (Surv R 15)

A program coordinator (SANE) who had been involved also in providing direct HIV PEP care added that in her centre she had "heard from pharmacy it was added

workload" (Surv R 43). She continued by describing the additional burden the program created for her:

I did all the follow-ups – I do not have clerical support – calling, rebooking, etc. It is difficult when programs see 25 or less clients per year. Requires a lot of arranging each time through the emergency room where I am also manager. (Surv R 43)

According to another program coordinator (SANE), "it is a huge workload issue for tracking clients, organizing follow-up, and completing the paperwork" (Surv R 73). "It takes an extremely long time to go through all advantages and disadvantages of HIV PEP" (Surv R 26, SANE; also FG 1 R 5; Surv R 111). A program coordinator (social worker) explained:

To sustain a programme you need to ... acknowledge the time it takes to do this work, and often times a follow up is when patients will ... want to spend more time, exploring, getting more information ... so ... appointments aren't just ... here's your meds, go. It's about sitting down with someone, doing the blood work ... to make sure they're okay .... There could be some lessons learned. ... There's a lot of unseen work and unrecognized work. ... Without some kind of acknowledgment of this, the infrastructure that's required to offer a program, at the calibre I think we do, can't be sustained on an ongoing basis. (FG 1 R 1)

### **Expertise**

#### ***Insufficient External Supports***

Several health care provider respondents indicated that to maintain the program, external supports were necessary to ensure that the protocol (and accompanying forms and hand outs) was updated as required with current information about the optimal HIV PEP regimen that should be offered. A program coordinator (SANE) explained:

If we do continue the program without the study in place – the study has given us invaluable support and information and education – to keep us updated in all this stuff ..., we would be somewhat at a loss of where we would access that information. (FG 3, R 2)

Her colleague, a nurse, echoed this concern:

Yes, even keeping ... the latest information in the client booklets ..., I'm sort of saying we need someone to support us with the latest information so that we're able to ... provide a consistent program. (FG 3, R 4)

Several others also indicated that availability of HIV experts would be needed to continue to offer the program:

I would be interested in knowing ... if the HIV experts that are participating in this study will continue to give us consultation information if we require it (FG 3, R 1, program coordinator [SANE])

“That ...for sure”, her colleague added, is “one of our concerns” (FG 3 R 3, program coordinator [SANE]).

### ***Insufficiently Trained and Knowledgeable Staff***

A number of health care providers stated that inadequately trained and knowledgeable staff would be a barrier to an ongoing HIV PEP program, particularly with regard to participating physicians. A program coordinator (social worker) stated matter of factly, “emergency room physicians need to continue to be educated about HIV” (Surv R 42).

Several others health care providers agreed:

We have to talk to our Medical Director and if he’s not around ... which sometimes he’s not, we go to the emergency room physician and it’s a crapshoot.... Most of these guys – don’t know enough about HIV PEP to order it. It is kind of scary! You’re the emergency doctor. You should know. (FG 2 R 1, program coordinator [SANE])

I think a lot of physicians are just so set in their ways and so interested in not being proven wrong about something. ... Or not willing to take the chance that maybe they’re wrong. Because I know the one that we’ve had problems with, she keeps quoting statistics that she’s pulled off the internet. ... But when we try to counteract it, she says well, hers are right and ours are wrong. Well, at two o’clock in the morning, it’s a little difficult to deal with that. (FG 2 R 2, nurse; also Surv R 53)

One of the issues we’ve struggled with is certain doctors where you know they say, ‘Oh, it’s a partner assault, well, there’s no risk there. She’s been consenting to have sex with him for a long period of time.’ (FG 3 R 2, program coordinator [SANE])

An emergency room physician himself added that a too limited “knowledge of drugs and toxicities” would be a barrier to a sustainable HIV PEP program (Surv R 103). His colleague, also an emergency room physician, was additionally concerned that, “there is universal shortage of all health care providers; this is another ‘job’ to be done. The number of jobs, complexity, is rising and the number who can do this is falling” (Surv R 114).

### **Commitment**

#### ***Lack of Institutional Support***

Some health care provider respondents identified a lack of institutional support as a barrier to an ongoing HIV PEP Program. According to a program medical director, his “hospital would not cover 1/12 of the cost of medications” (Surv R 22). A program coordinator (SANE) emphatically stated that she had also experienced administrative resistance to the program, “from the hospital, big time” (FG 2 R1). She elaborated:

If the hospital wasn’t being reimbursed, I don’t think they’d do it any more. ... Because that’s

all we ever hear... They have told us, once this study is over, then we won’t be offering this. (FG 2 R1)

She also noted that specific hospital staff “were totally against it” (FG 2 R1):

Our pharmacy makes, I can’t remember, I mean, the way we pay for the medication is just absolutely ridiculous .... It was the Chief, the Head Pharmacist ... who disagreed with the protocol; who thinks the medications are unsafe. It’s just unbelievable! (FG 2 R1)

Another program coordinator (SANE) mentioned that she too “had a wee bit of hassle with the pharmacist at her hospital” (FG 4 R4):

She feels that it’s additional work for her to get the medications and she’s not getting financial compensation or whatnot for doing it. She thinks that it’s a bit of a hardship and I’ve had to go to pharmacy myself every time to get the follow-up drugs. They’ve never been brought up to the Emergency Department where we supply it. (FG 4 R4)

#### ***Physician Resistance to Offering HIV PEP***

Many health care provider respondents also stated that they “had a lot of problems with ... physicians” refusing to support the HIV PEP Program (FG 2 R1, program coordinator [SANE]; also Surv Rs 48, 72). Comments focussed on “on-going issues with some ... emergency room doctors” (Surv R 53, SANE) “just absolutely refusing to order” the medications (FG 2 R1, program coordinator [SANE]; also FG 2 R 2, FG 3 R 2; Surv Rs 42, 67, 75, 105):

Emergency room physicians who work with us feel the risk of therapy outweighs HIV seroconversion risk. They have frequently refused to order HIV PEP. (Surv R 44, SANE)

The majority ... of our ER doctors ... is great and accepts our recommendation. However, we have a couple who really give us a hard time. This certainly increases the stress level of our team. (Surv R 53, SANE)

It happens with our doctors all the time. ... The nurses who are on call will call me at home, and ask questions and I mean, it’s usually ... go ask the physician, but they’re not going to order it anyway. And most of the time they don’t. It surprises me when the ER doctors do order it. ... They have absolutely no interest whatsoever. (FG 2 R 1, program coordinator [SANE])

This latter program coordinator continued:

The only thing I don’t feel good about in offering to everyone is ... talking to these women, would you be interested in this medication? It’s very, very difficult when ... they answer “yes, I’d be interested”. So you take a history and then you go speak to a

physician who refuses to order the medication. (FG 2, R 1, program coordinator [SANE])

One SANE colleague noted a particularly upsetting incident with a physician at her centre:

We had one instance with one doctor – it wasn't the same one as usually gives us a hard time – she actually went in and told the patient that if it was her daughter she wouldn't recommend the medications because of the side effects. Anyway, we had quite a little to do about that. (FG 2 R2)

### **Accommodation**

#### ***Lack of Flexibility in Addressing Specific Client and Community Needs***

An important barrier to program sustainability was identified by several respondents as a lack of flexibility in the way in which the HIV PEP care itself was delivered. A program coordinator (SANE) whose centre serves a rural population was resolute, “it has to be something that becomes a flexible type of protocol or situation” (FG 4 R 2; also, FG 1 R 2, FG 4 R 1; Surv R 83).

Her colleague concurred:

Because something may happen or clients may be a no show and because of transportation reasons or whatever, in a rural area, they may not be able to get in for follow-up. (FG 4 R4, program coordinator [SANE])

This issue was identified as especially relevant to centres serving “remote Aboriginal communities” (FG 3 R 3, program coordinator [SANE]):

I think that we can keep the program going but I think that it needs a few modifications ... to make it sustainable. Because our clients are from the north, I think we have to involve the nursing stations more and I think we're going to have to look at not as much follow-up unfortunately and giving more medications out at each interview. (FG 3 R 3, program coordinator [SANE])

Some of the other barriers that we have locally are in dealing with First Nations persons being able to get in because some of the women are two and three hours away. And getting back and forth with the follow-up, that's something we've got to look at to come up with some better creative ways about dealing with it. (FG 4 R 2, program coordinator [SANE])

This latter health care provider mentioned attempts to connect with nurses on the reserve to support the implementation of the HIV PEP Program, but continued that they “were in a constant state of flux” and, therefore, “were very reluctant” to get involved. She emphasized that this would be an ongoing issue for offering HIV PEP medications and preventing unnecessary “drop offs” from the program (FG 4 R 2, program coordinator [SANE]).

### ***Inaccessibility and Lack of Clarity of Tools***

Certain study tools were also cited as problematic in sustaining the HIV PEP Program in an ongoing manner (Surv R 81). One issue raised by several health care providers was what they believed to be the inappropriate literacy level required to read client handouts:

I think that with working with different populations as well, not everyone is literate and not everyone can read English. ... So maybe making the material a little more user friendly so if they decide to go on the HIV PEP ... they have something ... with pictures or other things as opposed to the written booklet; it's a bit heavy. (FG 4 R 3, SANE; also FG 4 R 4)

A SANE colleague agreed, “I would like to see more ‘readable’ information – the average person reads at about a grade 6 level” (Surv R 37). A “need for more culturally sensitive food choice selections in the client information booklet” was also mentioned as important by another SANE who “had several Spanish only speaking clients on PEP” (Surv R 3).

There were also some concerns with the nursing tools. One nurse noted in referring to the documentation form for initial visits, “that white sheet is confusing. ... The one you tick off everything. ... I mean it just doesn't flow easily for me. It's really hard to concentrate at two o'clock in the morning” (FG 1 R 7). A program coordinator (SANE) stated, “I am hoping that ... separate documentation tools for HIV will be incorporated into our standard documentation tools...that sort of thing will help the staff considerably” (FG 3 R 2; also Surv R 37). Her colleague added, “If there is a reduction in paperwork. I think they're going to be excited to continue offering the medications to clients” (FG 3 R1, program coordinator [SANE]).

### **DISCUSSION**

Although the experienced health care providers surveyed and interviewed for this study for the most part believed that a program of universal offering of HIV PEP could be implemented, a substantial proportion identified important barriers to sustainability. Survey and focus group respondents felt that a lack of resources, expertise, commitment, and accommodation presented major obstacles to an ongoing and viable program of care. Among the particular challenges noted, a lack of funds to pay for HIV PEP medications and to hire new staff as well as to compensate appropriately those already employed, were seen as major impediments—perhaps not surprising given the economic climate at the time—as captured by one program coordinator (SANE), interviewed in one of the four focus groups:

We're in the midst of our balanced budget fiasco with cuts being announced in our regional health centre so at this point in time everything is in flux and everyone is trying to save their jobs and save money. ... In addition to just what's happening in the hospital – our program, where we are, at women's health care which gives us a lot of support, both

support staff wise and having a nurse practitioner, is going to change dramatically.

Other studies evaluating the use of PEP post sexual assault in countries with low prevalence rates of HIV have also noted that the cost of antiretroviral medications is “one of the greatest hurdles in implementing this type of protocol” (18: p.5, see also 41). One physician in our study projected that if the number of sexual assault survivors seeking HIV PEP increased over time, a lack of monies would lead to difficult decisions around “who really warrants” the expensive medications—an issue already the subject of wide-spread debate. Although the universal use of HIV PEP where the source is presumed unlikely to be HIV infected may not be cost-effective [11, 65-67], it is challenging to accurately identify those at high risk of HIV, thus making HIV PEP programs that target high risk victims only very difficult to implement.

Many of the other problems identified as barriers to sustaining an HIV PEP Program also have financial implications. The data indicated that if an HIV PEP Program offering universal care was to be implemented further external funding would be necessary, not just to accommodate the costs of the drugs and staff, but to hire outside supports such as HIV experts, who could consult on complex cases and ensure that the program client handouts and the protocol itself reflected the most current information available about HIV in the sexual assault context. These issues were of particular concern to staff at centres in smaller cities and towns in the north, where they stated there was a “need to ensure that all clients no matter where they live or seek treatment have the same resources” (Surv R 126). In these areas, health care providers also argued adamantly that any viable HIV PEP program of care would have to better accommodate unique community needs. This was stated to be of particular relevance to those serving the following: 1) multicultural clients for whom handouts would be needed in different languages, as well as redeveloped at lower literacy levels in English; and 2) Aboriginal persons, for whom follow-up was often difficult, due to travelling two or three hours to be seen. In the latter instance, this would seem crucial given that Aboriginal survivors may come from communities disproportionately affected by sexually transmitted infections and with limited access to health care services [68, 69]. Moreover, there is research that supports the “feasibility and practicality” of dispensing the full PEP regimen on the initial visit for those unable to return easily due to logistical reasons [70].

Another important barrier to sustaining an HIV PEP Program was identified as a lack of support from hospitals and certain groups of health care professionals working within them. Although some nurse respondents had experienced difficulties with some pharmacists who felt that they were not being adequately compensated for their time, most resistance was stated to have come from physicians who did not want to prescribe the PEP. Emergency room physicians sometimes disagreed with the program protocol believing that the side-effects outweighed the benefits of offering the medications universally and in cases of intimate partner sexual assault. This fact was attributed by nurses to a deficit in physician expertise and experience with use of HIV drugs in the sexual assault context. An emergency room

physician himself agreed that an inadequate knowledge about HIV medications and their possible side-effects would be a road block to province-wide implementation of an HIV PEP program. To be sure, physicians need to be familiar with various related HIV medications. However, at the same time, it must also be acknowledged that other health care providers have queried the value of a universal approach to offering HIV PEP to sexual assault survivors and in circumstances specifically in which there is ongoing exposure from an intimate assailant [11, 41, 50]. With regard to the latter, we agree with the World Health Organization that in these situations there must be a simultaneous focus on risk reduction and prevention [24].

This study had several limitations that warrant discussion. In regard to the survey, the low response rate – a characteristic of questionnaires generally of different types of health care provider groups [e.g., 71, 72-74] – may have resulted in self-selection bias. Administrators, nurses, physicians, social workers, and pharmacists who were most supportive of the HIV PEP Program may have been overrepresented in the sample, which may have compromised our ability to capture and later address the full range of barriers to the sustainability of such a program of care. A similar self-selection bias may have affected the results of the focus groups, where our findings also may not have fully reflected the opinions and experiences of all health care providers involved in offering the HIV PEP Program. However, despite these limitations, our study provides an opportunity for other jurisdictions to learn from the challenges that may arise in implementing and sustaining an HIV PEP program for survivors of sexual assault. It also allowed us to take steps systematically to address identified barriers to ensure that the offering of HIV PEP care could be successfully incorporated into standards of sexual assault care for Ontario.

### **Responding to Barriers to HIV PEP Program Implementation**

In February 2006, to address the most commonly noted barrier to an ongoing HIV PEP Program – the cost of medications – we approached the Ontario government for funding. Based on the recommendations arising from the HIV PEP Study data, the Ministry of Health and Long-term Care agreed to pay for a program of universally offering HIV PEP medications at all 34 provincial SA/DVTCs. Subsequently, we undertook a Knowledge-to-Action (KTA) Project [75] for the purpose of identifying strategies that might address the remaining threats to the viability of a long term program of HIV care. At the Network of SA/DVTC’s Annual Meeting in May 2006, and subsequently in several focus groups, health care providers were interviewed to aid in this process.

Almost all health care provider identified challenges/barriers to successful implementation of the HIV PEP Program were mapped to two tangible methods to address them: 1) adaptation and dissemination of, and training using revised, HIV PEP Study tools; and 2) establishment of an ongoing HIV PEP Expert Group. A KTA Project Advisory Committee comprised of HIV experts, SA/DVTC decision-makers and front-line staff, and community partners, was created to provide guidance on

revising and rolling out revised materials, and later formed the basis of the Expert Group.

### **Revision of the HIV PEP Study Tools**

Subsequent to the Network's Annual Meeting, a working group composed of select KTA Project Advisory Committee members was formed to assist with the actual adaptation of the tools and external consultations were held as needed with regard, in particular, to the client handout design and language simplification. Materials revised included: 1) Medical guidelines; 2) Initial visit flow sheet; 3) Follow-up flow sheet; 4) Client information handouts: a) HIV risk assessment pamphlet and b) HIV PEP information booklet; 5) Client scenarios for health care providers; 6) Fact sheets for physicians; 7) Fact sheets for pharmacists; 8) Fact sheets for other health care providers; 9) Fact sheets for clients; and 10) Orientation to HIV PEP Program power point presentation. These new materials were designed to provide updated, streamlined evidence-based guidelines and user-friendly information at appropriate literacy levels to support all health care providers involved in offering, and diverse clients in accepting, the HIV medications. Given problems that arose during the HIV PEP Study with some health care provider resistance to the protocol, their purpose was also to aid in enhancing interprofessional collaboration based on clarity of roles and responsibilities and improved communication within teams and between SA/DVTCs and other departments such as emergency medicine and pharmacy. Because a lack of flexibility in the delivery of the HIV PEP Program was also seen as a barrier to implementation, the revised tools were designed more generically – so that as a whole, they could function as a framework from which some processes could be tailored locally to address the specific needs of communities while maintaining a core protocol that would ensure quality of service delivery. The revised documents, which were reviewed by the entire Advisory Committee for clarity, conciseness, comprehensiveness, and utility of information and piloted at several SA/DVTCs, were favourably received. A website to house the final tools was created to ensure ease of access for health care providers and clients (available from [www.sadvreatmentcentres.net/HIVPEP](http://www.sadvreatmentcentres.net/HIVPEP)).

### **Rollout of the Revised HIV PEP Study Tools**

Beginning January 2007, orientation and training sessions, based on the revised tools, were developed, piloted at several SA/DVTCs, and delivered to health care providers and hospital policy makers across six regions of Ontario using a “train-the-trainer” model (SM). Following these sessions, nine interactive web-based modules were developed as a permanent reference guide (Background on HIV and HIV in Ontario, HIV PEP Study findings, The current HIV PEP Program, HIV PEP drug information, Initial visit and HIV risk assessment, Pre- and post-HIV test counselling, When to consult an HIV specialist, Follow-up visit and counselling, and HIV PEP side effects and management), which also contained the contact information of available local HIV experts for consultation. This online educational program, which addressed the issue of a lack of sufficient training and expertise among clinicians, also reduced the costs of in-person training, important given high staff turnover at SA/DVTCs [62]. Qualitative feedback in the

form of pre- and post-evaluation surveys indicated that the final online modules were successful in their deliverables and provided a comprehensive and sufficient core training program and a user-friendly interface on which to efficiently learn HIV PEP treatment and counselling protocols (available from [www.sadvreatmentcentres.net](http://www.sadvreatmentcentres.net)). The Network website, with these assessment and diagnostic/treatment tools, has become an important source for health care providers for continuous learning, ongoing skill upgrades, and HIV PEP awareness and competence, as well as for current information for community partner organizations, survivors of sexual violence, and the public.

### **Establishment of a Permanent HIV PEP Expert Group**

In January 2008, a permanent HIV PEP Expert Group was formed and continues to include three infectious disease specialists from across Ontario, one pharmacist with HIV expertise, one SA/DVTC program coordinator (SANE), one SA/DVTC follow-up nurse (SANE), and the provincial coordinator (SANE) of the Ontario Network of SA/DVTCs. The mandate of this Expert Group is to review the current HIV PEP drug regimen and the medical protocols and pamphlets used and to address other relevant medical issues on an annual basis. New data that are identified that could shape the ways in which the HIV PEP Program of care is offered are discussed and recommendations for changes made to the Network of SA/DVTCs. Establishment of this group has addressed concerns raised by health care provider respondents for the need for external experts for support to ensure the long-term sustainability and coordination of the HIV PEP Program as part of the standard of care for survivors of sexual assault in Ontario.

### **CONCLUSION**

This study revealed that multiple barriers can converge to prevent the implementation and sustainability of an HIV PEP Program of care to sexual assault survivors, including inadequate resources, expertise, commitment, and accommodation to unique community needs. However, identifying these challenges has led to efforts to address them: the creation of easy access web-based tools, the ability to self-assess knowledge and skills, and the access to local and centralized HIV experts. These measures have provided SA/DVTC staff with the capacity to effectively respond to the particular challenges that may arise in the future in their facilities as well as to the needs of individual survivors who may require HIV PEP and/or treatment. This has been particularly important for staff who have limited or infrequent experience in addressing HIV prophylactic care post sexual assault. Although addressing the need for more staff to better offer HIV PEP care specifically, and sexual assault care more generally, remains an ongoing issue for the Network, since the original HIV PEP Study, the universal offering of antiretroviral medications has become a standard of care at all 35 SA/DVTCs in Ontario and uptake and completion rates have increased by 8% (2003-2005: 32% v. 2008-2010: 40%). Based on this success, we continue to build the capacity of the Network to respond in an evidence-based manner to issues arising in providing sexual assault care by further enhancing research/clinical [e.g., 76, 77, 78] and hospital/stakeholder relationships (e.g., collaborations

with Ontario Women's Directorate and ECHO, an Agency of the Ontario Ministry of Health and Long-Term Care).

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