

Counting Pills or Counting What HIV+ Women Have to Say

BY JACQUELINE GAHAGAN AND CHARLOTTE LOPPIE

Despite the contextual complexity of women and HIV/AIDS, their lived experiences continue to be ignored in most HIV research, and prevention programs.

La possibilité pour les femmes séropositives d'adhérer à une thérapie antirétrovirale est très souvent entravée par des facteurs biopsychologiques dont le soin aux autres, les effets secondaires, la peur de révéler leur état et l'incertitude des effets à long terme. Les auteures suggèrent que des ressources additionnelles soient mises en place pour donner du support aux femmes séropositives qui désirent se soumettre à cette thérapie.

As the number of Canadian women infected with HIV continues to increase, we are faced with pressing health policy dilemmas. Not only do increasing infection

rates indicate a need to address myriad social, economic, and political contexts that enhance women's risk, but we must also determine effective means of preventing disease progression among women living with HIV infection.

Despite the obvious contextual complexity of women and HIV/AIDS, their lived experiences continue to be all but ignored in most HIV research, prevention programs, and medication compliance campaigns. In order to address the broad factors that enhance women's risk for HIV infection and consequently, women's access to, and utilization of, antiretroviral medications to prevent the disease progression, the complex social, cultural, and economic reality of women's lives must be considered.

This article outlines the lived experiences of a sample of Ontario women living with HIV. The purpose of this study is to explore women's perceptions of medication adherence, the factors that contribute to non-adherence, and to offer suggestions for programmatic changes in current practice to better meet the needs of women living with HIV (Gahagan).

Due to the overall lack of pre-existing research focusing specifically on issues faced by HIV positive women, a grounded theory approach was used to examine the issue of adherence. In grounded theory, interviewing and data analysis are closely connected and take place throughout the research process in a cyclical rather than linear manner (Strauss and Corbin).

Method

Women living with HIV infection were referred to this study through AIDS service organizations throughout the province of Ontario. Women over the age of 18 living with HIV in Ontario, who were taking antiretroviral therapy, or who had ceased taking it, were eligible to participate. Interviews took place from January 1999 through April 1999 at either the woman's home or at a local AIDS service organization. On average, eight participants from each of six regions across the province were interviewed for a total of 53 interviews.

The average age of the respondents was 35; 95 per cent self-identified as Caucasian; 47 per cent reported having less than high school education; 41.5 per cent reported being single. The majority (67.9 per cent) of the women interviewed reported government disability pension as their primary source of monthly income. Most (79 per cent) of the women reported becoming HIV infected through unprotected sexual intercourse with an HIV positive male partner. While there were a large number of women interviewed who reported having used drugs in their lifetime, the most commonly reported drug used was marijuana (82 per cent).

An in-depth interview data collection technique was used with each woman in order to gather detailed information regarding the factors that impact on the incorporation of the medication regimen into their daily lives, particularly in relation to adherence (Lofland). All interviews were audiotaped with the permission of each woman and all tapes were transcribed verbatim. The transcribed interviews were then subjected to thematic analysis, as described by Strauss, in order to determine the types of issues faced by women with HIV in relation to their medication.

Major Findings

Thematic analysis of the in-depth interviews identified five central themes emerging from the data: social support; family and childcare responsibilities; access to appropriate resources; substance use; and isolation. Each one of these central themes will be briefly discussed in the following sections.

The theme of social support emerged in most women's accounts of coping with their diagnosis and their treat-

on Pills?

About Antiretroviral Therapy

ment-related issues. In particular, three quarters (75 per cent) of the women interviewed expressed concerns about the lack of social support for even the most basic daily tasks such as food preparation, transportation to medical appointments, or reminders to take their medication.

When asked about family as a source of social support in her life, Rhoda, a 32-year-old respondent states:

Are you kidding, if I ask my family for help they say stuff like you did this to yourself and now you want us to clean up after you? I don't talk to them anymore.

Over one half of the women interviewed suggested that social support from family would be a welcome coping strategy. However, in many instances, once certain family members knew about their HIV status, these women were not able to rely on family for support. Twenty women interviewed described feeling overwhelmed with issues related to their HIV status but also felt unable to connect with support mechanisms in their area. This was especially true for women living in more rural areas of the province. Donna, a 35-year-old from rural Ontario explains:

My support system is me. I can't really talk to anyone. There needs to be more support for women, especially HIV positive women who can't talk to family about things, you know, no one in their life they can just count on to be there for help out here [rural Ontario].

The 18 women with live-in partners expressed concern over the amount of assistance they required to meet their family and childcare responsibilities. When feeling well, 22 of the 24 women with children discussed focusing their energy on their children's healthcare and emotional needs rather than on their own needs. This in turn, left three-quarters of these respondents feeling overwhelmed and exhausted, and in a number of cases, feeling quite guilty about not being able to provide for all of the needs of their family, particularly their children.

As Judy, a 33-year old living with her common-law husband and one of her three children, points out:

I feel bad that he has to do all the work and look after the kids. I just couldn't imagine going through this without him.

In addition to the strain of fulfilling their role as wife

and mother, many women discussed how they forfeited their own health needs for the sake of others. This included not going to scheduled doctor's appointments and not refilling their own medication prescriptions. This type of sacrifice was revealed by several women, who expressed the belief that as long as they were able to take care of their partner, they would remain a family. Rosie, a 36-year-old living with her two children and her HIV positive husband states:

I don't have much without him, I mean in terms of family. If he gets real sick and has to go to the hospital, I know I won't have anyone to talk to. I can't tell the kids what's going on so it's my choice I guess to take care of him so we can still be a family.

Access to gender appropriate resources¹, including medical information regarding treatment options generated much discussion and debate from the women. Thirty-eight of the women interviewed expressed concern over the lack of gender appropriate support and medical resources. In particular, they voiced concern regarding current information about the effects of drugs on their physical appearance and overall physical abilities. Fifteen of the women suggested a general lack of awareness or interest on the part of healthcare providers regarding the potentially debilitating side-effects of the medication, particularly in the first few weeks or months of therapy. When questioning their physicians about treatment options, twelve of the women interviewed expressed frustration and concern over a "wait and see" approach, which many women attributed to the physician's own lack of knowledge concerning the effect of the treatments on women's bodies. Insufficient information about medications led eight women to take "medication holidays" in order to manage side-effects. As Bridget, a 28-year-old married respondent with two children states:

When I found out I had HIV, all I got from the doctor was a pamphlet on men with AIDS. He didn't have a clue

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where to send me for more help. I had to search everywhere to find stuff related to women and these meds.

Twelve women remarked on the overall lack of gender sensitivity among healthcare providers regarding changes in women's bodies resulting from antiretroviral medication. Eight women reported frustration about continuing to take their medication under pressure from their physician, while two reported stopping their medication altogether as a result of changes in their physical appearance. Two additional women reported refusing to begin medication for fear of being thought of as unattractive due to potential changes in their appearance. Weight gain, changes in menstrual cycles, hair loss, or changes to the texture of hair, as well as lipodystrophy (the redistribution of body fat), were among the most commonly identified physical changes. Almost half of those interviewed felt they were not taken seriously and when they pressed their physician for answers, they reported feeling "talked down to." Karen, a single 28-year-old concerned with weight gain expressed her frustration as follows:

"I worry about having no control in my life.... When I was using my life was out of control, but not like now. I have no control over my health or the pills they tell me to take."

Oh yeah, but 80 pounds in a year and a half! That's craziness, I'm going to be at least 500 pounds if I continue on it [the medication]. I asked the doctor, like, does the weight gain stop? My doctor doesn't have any idea. He just says it's different for everyone so just keep taking them. What if I have a heart attack from all this weight? Will he answer me then?

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It is noteworthy that of those who disclosed a history of drug use, particularly injection drug use, felt they had been prescreened for antiretroviral therapy. In fact, the underlying assumption expressed by the women with a drug use history was that as a drug user, either past or current, they were not regarded as suitable candidates to manage a complex medication regimen.

Women with a drug use history also expressed frustration at the lack of integration of health services for those with HIV infection and other conditions such as Hepatitis C. Those seeking treatment options for both issues were required to negotiate their way from one specialist to another, often leaving them feeling overwhelmed and defeated. This was particularly the case for women living in smaller communities and those who were dependent on others for transportation to and from medical appointments. Kim, a 38-year-old divorced woman with a history of injection drug use, expressed the tension in meeting her

health care needs as follows:

Ya, the doc comes in and says to me, you knew you'd get this from sharing needles right? I asked him about treatment for my HIV and he said not until I got off the drugs. Like it didn't matter that I had this cuz I was a junkie to him.

For those with addiction issues as well as HIV infection, adhering to antiretroviral therapy was seen as an added burden, which took away from energy required to recover from their addiction. As well, women with addictions felt they faced a "one or the other" dilemma when it came to accessing services for their dual diagnoses. Several women commented on how their specialist did not seem to share important information with other specialists to ensure that nothing was overlooked in assessing their treatment needs.

Sam, a 28-year-old recovering injection drug user who lives with her female partner, expresses her concern about the lack of health services for those living with HIV and addiction issues in the following statement:

I worry about having no control in my life, I mean, when I was using [injection drugs] my life was out of control, but not like now. I have no control over my health or the pills they tell me to take and they wonder why I don't always take them like they say to. Maybe drugs did control my life but now my pills for HIV and the docs who tell me go here, go there, all that crazy being pushed from one doc to another controls my life.

The theme of isolation emerged as an issue for many of the women interviewed. Thirty-five of these women reported feeling some sense of isolation about telling others of their HIV status or in accessing mainstream AIDS service organizations (ASOs) and resources or in having others around to remind them about taking their medications. Fifteen of the women who had accessed local ASOs felt isolated by the lack of resources and services specific to women's needs and felt that men with HIV were the focus of the agency's resources, including staff makeup and time devoted to women's issues. Nine of the women expressed concern about the lack of other women in regular attendance at women's support group meetings at ASOs where such programs exist, which again served to increase the sense of isolation experienced by many of the women. This was particularly the case for the twelve women living in small rural areas, who had not disclosed their HIV status to friends and relatives due to personal safety concerns or concern for their children's safety in the community. Sherrie, a 43-year-old women living in a small city, described her sense of isolation as follows:

I live in a little bachelor unit and there's nobody there but me. I don't want anyone to know how sick I am so

I lay in bed for days and so I forget to take my meds. Finally I tried to get out of bed and fell flat on my face on the floor. All I kept thinking was I am going to die right here and nobody's going to know.

Most women who became HIV infected through sex with their long-term male partner or while married felt they were the only one to experience such circumstances. As a result, women who reported becoming infected within such relationships made a conscious decision not to disclose to family members, in several instances, including their children. Most reported feeling isolated and withdrawn as a result of learning their status in the context of what they understood to be a "monogamous, safe relationship." As Judy, a 32-year-old living with her common-law husband and one of her three children reports:

My ex-husband donated blood and found out that he was positive. I think he decided to donate because he knew. I couldn't believe it and just kept it all to myself. I couldn't talk to anyone and I didn't want anyone to know because of my kids. I thought I was the only woman to get this from her husband. We have been married for a long time and I just couldn't believe it and didn't think anyone else would understand what I was going through. And it was just like a broken ladder from there.

Based on the findings of this study, women's overall lack of social support, their family and child care responsibilities, the lack of accessible and appropriate resources, substance use, and isolation all represent barriers to achieving ideal adherence to antiretroviral therapy. Many women expressed frustration at not having social support and fear of disclosure of their HIV status. This overall lack of social support added to their sense of isolation and hopelessness. Many women with young children expressed sincere interest in adhering in an effort to prevent the progression of the disease in order to watch their children grow up and enter adulthood. Ironically, these were the same women who expressed feeling overwhelmed by their family and child care responsibilities and as a result, often simply forgot to take their medication. Of the women with children, many expressed feeling guilty if they missed taking their medication. However, they were also concerned about not spending quality time with their children due to illness as a side effect of the medication or to fatigue brought on by their HIV status.

Summary

A lack of adherence² to antiretroviral therapy has become recognized as a potential health threat to those living with HIV. The clinical literature suggests that less than optimal adherence can lead to drug resistance and thus, reduce the probability of securing an effective medication regimen that prevents the progression of HIV to full-blown

AIDS.³ As suggested by the findings of this study, adherence does not occur in a social vacuum and as such, appropriate support systems within the medical community and the community at large represent crucial factors in reducing the potential for disease progression among women living with HIV.

Issues related to social support, isolation, child care, and family responsibilities all served to constrain many women's ability to incorporate anti-retroviral medications into their lives. Many women expressed feeling both physically and emotionally overwhelmed by the general lack of social support available to them, particularly among those women who, due to fear of reprisal, losing custody of their children, or outright rejection, have decided not to disclose their status to family or friends.

Ironically, the structural inequalities women face, which may place them at enhanced risk of HIV infection, are the same factors that create barriers to full and equal access to HIV treatment, care, and support (Gorna). Although recommendations for the eradication of these inequalities transcend the scope of this paper, it is recognized that several health policy mechanisms, currently within our grasp, could begin to address issues of access to treatment.

Any standard of care for women living with HIV in Canada must recognize, at a minimum, the disparity between men's and women's socioeconomic status and how this impacts on access to healthcare services, including treatment for HIV.⁴ This standard of care must also recognize women's health in its own right and not simply as an adjunct to men's health. This standard of care must afford women with HIV the ability to make decisions about their sexual and reproductive lives in a non-judgmental and objective manner, and it must also take into consideration the treatment of women who have been dually diagnosed and are in need of either mental health care or addictions treatment.

In order to make treatment more accessible to women living with HIV, we must begin to regard HIV testing as part of an optimal standard of healthcare, afforded to all women, and not something dictated by pregnancy or left to the whim of fate. The reality is that many women discover their HIV status once their male partner has been tested and found to be HIV positive, or when they become pregnant, or when they are hospitalized for an opportunistic infection. Although not ideal, offering increased access to HIV testing for women may allow those who are found to be HIV positive an opportunity to seek out appropriate treatments early in their diagnosis, before

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facing hospitalization for treatment of previously undiagnosed or unrecognized opportunistic infections. Sadly, by increasing the visibility and acceptability of HIV testing for all women, we may also begin to see a more accurate picture of the magnitude of HIV infection among women in Canada.

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¹Gender appropriate resources include those that offer an understanding of the different sociocultural, economic, and political ways men and women are impacted by HIV, including gender-based risk factors for HIV infection, as well as care, treatment, and support for those living with HIV/AIDS.

²An editorial in *The Annals of Internal Medicine*, 15 September 1998, 129:503-505 suggested "Adherence, often used interchangeably with compliance, is the act, action, or quality of being consistent with administration of prescribed medication. Adherence is preferred [to compliance] because it affirms that the patients actively participate in choosing and maintaining a medication regimen." While much of the early studies on the antiretroviral therapies focused on achieving and maintaining high levels of adherence to the regimens, more recent studies have indicated that all is not necessarily lost when patients alter their medication regimens to cope with side-effects or food restrictions, etc. associated with the medications.

³Adherence, unlike compliance—the term compliance refers to the degree to which the patient follows the instructions of their healthcare provider in relation to recommendations for their medication regimen—takes into consideration the myriad of psychosocial, biomedical, political, and other factors that can impact on one's ability to take medications as prescribed, including one's decision to reduce or skip a dose or not take the medication at the prescribed frequencies or intervals. Several authors writing at the time of the release of these new HIV treatments were highly critical of the use of such terminology on the grounds that it was both paternalistic and disempowering for the patient (Crespo-Fierro; Lerner, Gulick, and Neveloff Dubler). The notion that patients must fully comply with their physician's requirements for treatment or "fail" treatment was regarded as a judgmental and inaccurate approach to determining the salient factors that impact on adherence, particularly among more socially disadvantaged populations (Steiner; Strathdee, Palepu, Cornelisse, Yip, O'Shaughnessy, Montaner, Schechter, and Hogg; Lyons). Many would argue that the use of the label non-compliant served to overemphasize

the role of the health care provider in determining who was a viable candidate for complex medication regimens as well as how their medication should be taken. Perhaps more importantly, the ability of health care providers to determine who will or will not remain compliant shortly following the release of antiretroviral therapies was over-emphasized and yet not well examined or understood (Dunbar-Jacob, Schlenk, Burke, and Mathews; Heath, Hogg, Singer, Schechter, O'Shaughnessy, and Montaner; Misener and Sowell; Rand and Weeks).

Clinical guidelines published following the release of the new antiretroviral therapies suggested that the ability of the patient to adhere to the medications was critical to achieving maximal benefit of treatment. A lack of adherence was seen as leading to treatment failure and drug resistance, mutant strains the virus, and the need for the physician to determine the best "salvage" regimens for patients who had "failed" treatment either virologically or clinically (Chaisson and Moore; Eldre, Wu, Chaisson, and Moore; Horowitz, Telzak, Sepowitz, and Wormser; Volberding and Deeks).

⁴At the time of this study in 1999 there were a number of intervention programs available to HIV positive women, largely through AIDS service organizations in Ontario. These included the London Regional AIDS Hospice and the John Gordon Supportive Housing Programme for people living with HIV/AIDS where a care plan is developed and staff are available 24 hours a day for support and assistance. They also offer respite and programs for caregiver relief or convalescing. Their programs offer support primarily to those living in southwestern region of Ontario with dual diagnosis including HIV and Hepatitis C. Other organizations include:

- Camp Chrysalis, which was run under the auspices of Families and Children Experiencing AIDS, provided support programs, information, and advocacy for families infected or affected by HIV/AIDS in the camp setting in Northern Ontario.

- Oasis, in Ottawa, Ontario, provides a wide range of health and social services for those living with HIV, including those living with mental illness, addictions, those who are homeless or involved in the sex trade.

- Fife House in Toronto, Ontario, offers safe and affordable housing and support services for people living with HIV/AIDS, including a residential program for women.

- PASAN, the Prisoners with HIV/AIDS Support Action Network, based in Toronto, Ontario, offers advocacy, education, and support for prisoners from across Canada through prison visits, as well as a toll free information and support line.

- Teresa Group, Toronto, Ontario, offers support to women, their children and other family members living with or affected by HIV/AIDS.

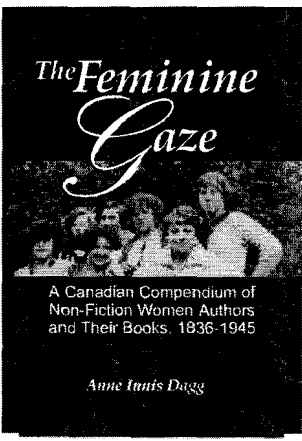
- Voices of Positive Women, located in Toronto, Ontario offers counselling, advocacy, financial assistance, treatment information, and support for women living

with HIV/AIDS. Voices is run by and for women living with HIV/AIDS in Ontario and is focused on empowering HIV positive women to represent the issues faced by HIV positive women to government and non-governmental organizations.

Many of the women interviewed for this study had used or were using these services, as well as other AIDS service organizations across Ontario not listed, at the time of the study in 1999. These types of programs tend to focus on systems of care and support for those living with HIV/AIDS rather than strictly on clinical or medical interventions.

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