WOMEN WHO ARE HIV POSITIVE IN THE LOWER MAINLAND: A SURVEY OF SOCIAL SUPPORT

by

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Abstract
This study examined whether women who were HIV positive perceived a lack of social support, and in what areas these perceived inadequacies existed. Women who were HIV positive (n=17) and living in the Lower Mainland were recruited by staff at three liaison service-providing organizations to provide a cross-sectional, non-random convenience sample. A survey questionnaire which included the Multidimensional Scale of Perceived Social Support (MSPSS) was either self-administered or conducted via a telephone interview. Statistical significance was found only for support scores crosstabulated with disclosure or non-disclosure of HIV status to friends, but not to family. Women who had HIV-related illnesses did not perceive less support than those who had been asymptomatic. Overall ratings of satisfaction with support were higher than anticipated. The results suggest that more exploratory research is necessary to clarify the meaning of social support for women living with HIV/AIDS.
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INTRODUCTION

In the AIDS crisis, women are most of the time completely invisible, face severe and sometimes insurmountable obstacles to coming out with a positive HIV status, have almost no research done about them, have little money, are rarely provided with adequate care, and have to take care of the most people. (Chris & Pearl, 1990, p. 241)

The needs of women who are infected with the human immunodeficiency virus (HIV) have largely been ignored in society. Women have not been recognized as a group affected by HIV, as has the male homosexual community, and therefore gaps in services for HIV positive women exist (Buckingham and Rehm, 1987; Novello, 1992). Until recently, the only publicity women received regarding acquired immunodeficiency syndrome (AIDS) and HIV was in being seen as "vectors of transmission" of HIV: blaming them for infecting men if they were prostitutes, or children if they were mothers (Lindhorst, 1988; Schneider, 1991). Even recent information about women living with HIV focuses solely on the natural history of the illness in women, or on its implications for reproduction (Hunter, 1992).

This study attempts to examine the extent to which women who are HIV positive and live in the Lower Mainland in British Columbia perceive they are supported. Although women throughout the world in numbers greater than three million
are living with HIV and AIDS (Hankins, 1990), this study will focus on the experiences of women in this one local area. The Lower Mainland encompasses the city of Vancouver, and the surrounding municipalities within the local telephone calling area of the city. This is by no means an effort to discount the issues of women living with HIV/AIDS elsewhere, as women from all walks of life are affected by HIV (Taylor, 1990).

Social support has been demonstrated to be an important factor in determining psychological and physical well-being (Ell, 1984). The psychosocial effect of HIV infection emphasizes the need for social support (Kaspar, 1989). The perception of social support from various sources will be examined. The components of the support, for example instrumental or emotional, will not be emphasized, in favour of assessing the women's perceptions. A particular type of support may offer more than one function of support (House & Kahn, 1985). For example, family members may provide instrumental support, but may also provide emotional support, and therefore questions focus on perceived support, or satisfaction with various types of support. The literature will be reviewed with regard to social support theory, and the importance of social support for people with chronic illness. The experiences of women living with HIV/AIDS will be examined, and the importance of social support for this population will be considered.

The measurement instrument in this study was a survey questionnaire, which was either self-administered, or
conducted via a telephone interview. Subjects were recruited for the study via professional staff at three liaison organizations in Vancouver which provide services for women living with HIV/AIDS. This cross-sectional convenience sample was non-random in order to preserve sample size (N=23).

The involvement of women who are HIV positive in the research process has been emphasized. Women living with HIV have been involved in generating the research question and developing and pretesting the questionnaire. A focus group had been planned in order to gain a richer interpretation of the results, although the number of women expressing interest in the group was too small to be feasible.

It was expected that women who are HIV positive would report low scores of perceived social support both on standardized and non-standardized scales. Women who had not disclosed their HIV status were hypothesized to have lower perceptions of support than those who had disclosed, and women who had experienced HIV-related illnesses or had AIDS were hypothesized to have lower perceptions of social support than women who were HIV positive and had not been ill. Income and services such as medical care and child care were predicted to be non-satisfactory or inadequate.

The results of the survey indicated much higher ratings of perceived support than anticipated. Variability in responses was also limited. The use of a descriptive level of research
will be discussed in light of the findings, and methodological considerations for further research suggested.

It can be said that AIDS and HIV infection are a social problem, and therefore require a social response. The social work profession is key in this response, in aiming to establish congruency between people and their community or environment. The importance of the social work response to AIDS has been well documented (Bourgon and Renaud, 1989; Furstenberg and Olson, 1984; Lindhorst, 1988). With a knowledge of the social support needs of women living with HIV, social workers can become involved, in cooperation with these women, in conducting meaningful research, developing and delivering accessible and adequate services, in advocating for support and services, and in educating against sexist, racist and classist stereotypes of these women (Shernoff, 1990).
BACKGROUND LITERATURE

Social Support

Social support literature has its origins in social science research of the 1970's (Cohen & Syme, 1985). Since then, many definitions of social support have been proposed, and conceptual clarification continues (Veiel & Baumann, 1992), often with little consensus (DiMatteo & Hays, 1981). Barrera (1986), and Heller and Swindle (1983) have criticized some social support research for failing to clearly define the social support concepts which are being investigated, and for using measurement instruments which are ambiguous. It is therefore necessary to examine the spectrum of social support conceptualization in order to facilitate its use as a research term.

Shumaker and Brownell (1984) broadly define social support as "an exchange of resources between at least two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient" (p. 13). More specifically, the domain of social support is used to refer to a number of different aspects of social relationships, such as: 1) the existence or quantity of social relationships (generally, or specifically, such as the presence of friends or a partner); 2) the structure of relationships (such as their range, or the presence of reciprocity); and 3) the functional content of relationships (such as emotional concern, instrumental or tangible aids, appraisal support,
and information) (House & Kahn, 1985). These last functional social support concepts have further been defined by House (1981) and are outlined by Rook (1984). Tangible, or instrumental aid includes material goods, money, labour, time and services, while emotional support deals with esteem, concern, affect, trust and listening. Appraisal support provides affirmation and feedback, and informational support offers advice, suggestions and information.

Kahn and Antonucci (1981) define social support in terms of interpersonal transactions which include

the expression of positive affect of one person toward another, the affirmation or endorsement of another person's behaviours, perceptions, or expressed views, and the giving of symbolic or material aid to another. (Kahn, 1979, p.85)

Cobb (1976) proposes three areas of support: emotional, esteem and network support, and Barrera (1986) conceptualizes social support as three broad categories. The first of these is social embeddedness, or the connections that people have to significant others in their social environment. This concept includes the presence of social ties (such as marital status), and social network analysis, in which individuals who have a relationship with the subject are identified. Barrera's second concept, enacted support, measures what individuals do when they provide support.

The third concept, perceived social support, draws upon the cognitive appraisal of connectedness to others. Caplan's
(1979) four variations of social support encompass the subjective appraisal of support in the form of "subjective tangible support" and "subjective psychological support", as opposed to the counterparts of "objective tangible support" and "objective psychological support", which are measured by an outside observer. Perceived availability and adequacy of social ties, and the perceived satisfaction with support are common measures of perceived social support (Sarason, Levine, Basham, & Sarason, 1983).

The literature suggests that perceived adequacy of social support more accurately measures adjustment to life stresses than do assessments of the number of people or the services used in an individual's support network (Cohen, 1988). In his review of numerous studies of social support and life stresses, Barrera (1986) found an inverse relationship between social support variables and perceived strain. Schonfeld (1991) notes that social network measures do not indicate responsivity to stressors, and therefore only indirectly provide evidence of support. Berkman's (1985) review of the literature concludes that "...it is necessary to move beyond measures of household composition, presence of kin, or group affiliation as adequate measures of social networks and support." (p.255). Additionally, measures of received support are often confounded by the need for support, or by the support offered being inappropriate for the person experiencing stress (Kessler, 1992).
Complications in measuring perceived support may stem from the measures being confounded by psychological symptoms (Schonfeld, 1991), as perceptions of support are likely influenced by an individual's psychological state, or even more basically, by personal characteristics such as social competency, personality, and usual coping style (DiMatteo & Hays, 1981; Heller & Swindle, 1983). Fischer, Nadler and Whitcher-Alagna (1982) report that requesting help may impact an individual's self-esteem, unfortunately resulting in those most in need of support being least likely to get it. Significant inverse relationships between quantitative measures of social support (such as size of social network) and personal characteristics such as level of depression and anxiety have been found (Sarason et al., 1983), although perceived social support has been found to be a better predictor of psychological state than objectively measured social support.

For the purposes of this study, social support will be broadly defined in two ways: firstly, as perceived support from specific persons; and secondly, as perceived support from services, or satisfaction with one's social conditions (such as housing). Palmer (1992) names these two categories as informal social support and extended social support. The actual functional properties of the support will not be the focus, as it may be possible for emotional support to be perceived as a result of having ones basic needs met, while
tangible or information support may be obtained from formal support services, as well as from friends and family.

Measures of perceived support are addressed in the Multidimensional Scale of Perceived Social Support (Dahlem, Zimet & Walker, 1991; Kazarian & McCabe, 1991; Zimet, Dahlem, Zimet & Farley, 1988; Zimet, Powell, Farley, Werkman & Berkoff, 1990). These include questions regarding perceived adequacy of support from friends, family and a significant other. The nature of this support appears to be mostly emotional, although the use of the word "help" in some of the questions could denote tangible support as well. Other variables of social support addressed in the study will be discussed shortly.

Social Support Theory

Lynch (1992) reports that social support "has been shown to facilitate adjustments to stressful life events and to decrease vulnerability to stress-related disorders" (p. 59). Social support has been demonstrated to be an important factor in contributing to psychological and physical well-being (Ell, 1984; Payne & Jones, 1987). Coping theorists have conceptualized social support as a form of coping assistance with stress (Thoits, 1986). One way in which social support accomplishes this is explained via the "buffering effect hypothesis", where support moderates the negative effects of stress on an individual's health and well-being (House & Kahn, 1985). This buffering effect might take the form of
increasing an individual's motivation to deal with a problem, provide necessary resources, or assist an individual in cognitively reappraising the stressor (Lynch, 1992).

A further hypothesis, the "direct-effects hypothesis" suggests that social support strengthens an individual in a direct manner, regardless of the presence of stressors (Lynch, 1992). Antonovsky (1979) proposes that the direct effects of social support on health provide resistance to "breakdown" (ie. impaired physical, psychological and social functioning) and enhance coping.

McGough (1990) cautions that both the buffering and direct-effects hypotheses are based on correlational studies; and that causality has yet to be determined between social support and health. Heller and Swindle (1983) also conclude that further research is required into the process of the support phenomenon's relation to health and well-being.

Negative aspects of social support must also be considered. Wortman and Conway (1985) provide a review of these, and report that individuals who experience negative interactions with others may perceive these interactions as additional stresses. Ell (1984) notes that very little attention has been given to the possible negative effects of support.

The mechanisms by which social support affect health are still relatively unclear (McGough, 1990), although research suggests a relationship between social support and immunity. As Green (1993) notes in a review article, social support has
been shown to be more associated with psychological rather
than physical well-being (Sarason et al., 1993), prompting
the question, "Does good social support promote psychological
well-being which in turn promotes good health, or does good
health ease psychological adaptation which in turn attracts a
wider support network?" (p. 91). Hormonal and biochemical
changes have been thought to be instrumental in altering the
vulnerability or susceptibility of an individual to illness,
via the components interacting in a balance (Lynch, 1992).
Stress theory proposes that stress can impair the immune
system, and therefore if positive social support mediates
stress effects, social support may modulate impairment of the
immune response (Jemmott & Locke, 1984).

Social Support and Chronic Illness

Due to the limited literature on social support and persons
living with HIV and AIDS, it is feasible to draw upon studies
examining the role of social support in chronic illness,
particularly in women, in order to gain further insight into
this phenomenon. High levels of distress have been found in
women with breast cancer who perceived a lack of social
support (Vachon, 1986), and there appears to be some evidence
that chronic illness may erode existing support (Bloom &
patients post-operatively and found that social and
professional support were significantly positively related to
psychological adjustment, and financial support to physical recovery. The importance of financial support, namely medical insurance, was cited in relation to ability to obtain a desired prosthesis or access treatment postoperatively. Northouse (1988), in her study of mastectomy patients, concluded that the quality of support, or perception of it, may be more important than the quantity of supportive services. In her review of previous research, she found that low levels of perceived support in mastectomy patients most likely resulted from support sources appearing inadequate to the patient, or family and friends avoiding the patient or providing inappropriate rather than useful forms of support.

Nelles, McCaffrey, Blanchard, and Ruckdeschel (1991) reviewed eleven studies relating to breast cancer patients and social support. Positive perceptions of social support from various sources appeared in turn to positively influence the study participants in numerous ways: perceiving self as more in control (Bloom, 1982); support in terms of social involvement was related to survival (Funch & Marshall, 1983); better adjustment to illness (Lichtman, Taylor & Wood, 1987); and mood improvement through participation in a support group (Spiegel, Bloom & Yalom, 1981). Primono, Yates, and Woods (1990), in their study of social support for women during chronic illness, found that the greater the woman's perception of affect and affirmation from her partner and family members, the greater was her self-reported marital quality and family functioning, and the lower her illness
demands and depression.

Women Living with HIV/AIDS

The links between social support, well-being, and immune function highlight the importance of social support for people who are HIV positive (McGough, 1990). Lynch (1992) notes that women in general may use more social support than men, and therefore women who are HIV positive may have even greater needs for support due to the presence of the additional stressor of HIV in their lives. This need for more social support may be due to the role of women in society, where they often find themselves in the role of caregiver, even when they themselves are ill (Kaspar, 1989; Smeltzer & Whipple, 1991). Henderson (1992) reports that positive women looking after an ill HIV positive partner did not themselves even realize how much they were doing, unless the partner was seriously ill and in hospital. Robinson (1988) found that women were more likely than men to be abandoned after the onset of chronic illness. Women infected with HIV are often poor, of colour and uneducated (Stuntzner-Gibson, 1991), and these factors may affect the women's access to support, if the supports are available to begin with.

Very little documentation exists on the experiences of women who are HIV positive (Stuntzner-Gibson, 1991). An extensive literature review reveals that virtually all
available literature focuses on the medical aspects of HIV, or on its implications for reproduction and childbearing (see also: Hunter, 1992; Kaspar, 1989). The few references to the social and psychological impact of HIV and AIDS on women's lives have thus far been presented in review articles, such as those by Kaspar, and Wiener (1991). Fortunately, composite works such as Canadian Women and AIDS: Beyond the Statistics (Manthorne, 1990), and Positive Women (Rudd & Taylor, 1992) have also become available. From first person accounts, review articles, and qualitative research, areas of social support having importance for women living with HIV and AIDS were identified. An extensive list drawn up by Palmer (1992) from a review of the literature was also utilized.

Social support, as broadly defined in this study, encompasses the functional aspects of emotional, tangible and informational aid from various sources, and the adequacy of these as perceived by women living with HIV/AIDS. Social support needs of these women were found to run the gamut from basic needs of money and shelter (Allen, 1994; Lindhorst, 1988; Manson Willms, Hayes & Hulchanski, 1991; Shayne & Kaplan, 1991), to the fear of rejection and isolation from family and friends (Manthorne, 1990; Zuckerman & Gordon, 1988), to the provision of adequate and appropriate services from health and helping professionals and service organizations (The ACT UP/New York Women and AIDS Book Group,
Deficiencies in social support provided by professionals and other people in a woman's social network may in turn increase the stress a woman who is living with HIV/AIDS might experience. Problems with social support may be due to support providers having misperceptions of the stressful life event, and consequently providing inappropriate and unsupportive aid (Wortman & Conway, 1985). Some women living with AIDS and HIV have reported that health professionals have refused them service (Henderson, 1992). Countertransference issues, such as overidentification with clients happens as potential supporters face relatively young people like themselves who are extremely ill or dying (Muth Evans, 1987; Roberts, Severinsen, Kuehn, Straker & Fritz, 1992) Inegalitarian or nonreciprocal relationships, due to increased contact with professionals during illness may leave a woman feeling less rather than more supported.

Illness might additionally provoke negative feelings in others, caregivers may feel overburdened, and mixed messages may be sent to the woman who is HIV positive. Women living with HIV and AIDS also may be experiencing many losses, both of instrumental and emotional value, such as the loss of a job due to illness, or the death of a partner or child due to AIDS (Kneisl, 1993).

AIDS and HIV infection additionally have a great deal of stigma attached to them, and Plummer (1988) writes that
segregation, discrimination and exclusion are the result. AIDS has generated fear, with its associations with already-stigmatized entities of sex, death, homosexuality and injection drug use, and further stigmatization results (Nera & Meltzer, 1989; Palmer, 1992). Fear of abandonment and the reactions of others are major stressors of persons living with HIV and AIDS (Miller, 1988; Sadovsky, 1991). In her own account of living with HIV, Fran Peavey (1990) writes:

This person doesn't even know what I am going through...I am sitting here looking like a normal person, yet I have a deep pain inside of me - and they don't even know...Am I doing a good job of covering up what I am really feeling and thinking? They can't tell. I don't want them to know. But then it would be a relief to share this with somebody...(p.126)

Accounts from other women living with HIV/AIDS range from:

If women test positive, they should try not to be scared to confide....because you can't do it alone....You have to have some kind of release, to talk to someone, to let it out somehow. (Roston, 1990a, p.64).

to that of "Dezarae", who says:

I feel my family has been drifting away from me,...because they're scared to bring their children around me or my daughter. (Roston, 1990b, p.168).

Women struggle with whom to disclose to, and when, and whether those whom they tell will be supportive. In the case of women with children, this can be an extremely difficult decision, as children may inadvertently reveal their mother's
HIV status to others (Reid, 1993). Hankin's (1993) review of presentations at the Berlin AIDS Conference included that of Pliskin who examined disclosure by women living with HIV to their non-infected children. Non-disclosure was influenced by women being concerned about their children's psychological well-being and fear of being rejected by their children. Forty percent of the women involved in the study said they would never tell their children.

Despite all of the external stigmatization, it is important to note that AIDS itself does not discriminate. Women have until recently, and still have not fully, been recognized as a group which is affected by AIDS, even though women are the fastest growing category of people with AIDS (Stuntzner-Gibson, 1991). Cumulative statistics released by the BC Centre for Disease Control (1993) which document provincial laboratory results from October 1985 to September 1993 show that 471 positive HIV antibody tests for women ages fifteen and over have been recorded, with 39 women of all ages having a diagnosis of AIDS in BC. The number of positive tests from women does not indicate the number of HIV positive individuals, as it is a count of the number of tests. Therefore, some of the tests may be retests. Dr. Robert Hogg of the BC Centre for Excellence in HIV/AIDS reports that 148 women from throughout BC have received drugs free of charge for antiretroviral therapy or for opportunistic infections through the Centre's HIV/AIDS Drug Program (Dr. Robert Hogg,
personal communication, March 1995). Of the 148 women enrolled in the program, 48 lived in Vancouver. Strathdee, Schechter, Hogg & O'Shaughnessy (1994) estimate that approximately 400 women may be HIV positive in British Columbia.

The HIV/AIDS Division of the Laboratory Centre for Disease Control (1994) received reports of 482 adult female AIDS cases of 8990 total adult cases in Canada, with 174 of these women still alive to December 31, 1993. Limitations of the Canadian statistics include the exclusion of women who are HIV positive. Sample (1992) cautions that women may be underrepresented in HIV/AIDS statistics due to "misdiagnosis and/or underdiagnosis" (p. 15).

Dr. Michael Rekart, director of the Sexually Transmitted Disease Control Branch, noted that 10 per cent of positive tests in British Columbia come from women (The Vancouver Courier, 1992). In British Columbia and in Canada the most common acquisition of HIV for women was through heterosexual contact, followed by intravenous drug use (BC Centre for Disease Control, 1993; HIV/AIDS Division, Laboratory Centre for Disease Control, 1994). Over three million women around the world are estimated to be infected with HIV (Hankins, 1990). AIDS is now expected to be one of the five leading causes of death among women (Levine & Neveloff Dubler, 1990), and deaths attributable to HIV/AIDS are believed to be underreported (Chu, Buehler & Berkelman, 1990). Worldwide, the number of AIDS cases among women is expected to equal the
number among men by the year 2000 (Hunter, 1992).

HIV infection manifestation in women, although in some ways similar to that in men, is different partially due to gynecological symptomatology. Only since July 1993 has the Canadian AIDS Case Definition included invasive cervical cancer to "assist in resolving the concerns of underestimating AIDS in women..." (p.24). Cohen (1993) asserts that a great deal of research is still required to fully understand the natural history and survival of women with AIDS, and that health professionals are still likely to overlook the possibility of HIV infection in women because of the assumption of lack of risk.

Since the beginning of the AIDS epidemic, the focus has largely been on the male homosexual community (Johnston, 1994), and women have been overlooked as being potentially at risk of contracting HIV, unless they belonged to so-called "risk groups" such as being homosexual or belonging to a minority group (Patton, 1993). Both women themselves and health professionals may incorrectly perceive women as not "at risk", because of this labelling and categorizing (Pearlberg, 1991). This has resulted in some cases of women not being tested for HIV, being diagnosed further along in their course of illness, and sometimes dying earlier because of inappropriate or non-existent medical care (Campbell, 1990; Cohen, 1993; Denenberg, 1990; Health and Welfare Canada, 1992).
The role of women in HIV infection has often been confined to women being portrayed as potential vectors of infection of men and children (Kurth & Hutchison, 1990; Lindhorst, 1988; Stuntzner-Gibson, 1991), rather than considering the risks of HIV for women themselves. Sherr's (1990) review of papers presented at the 1990 San Francisco AIDS Conference showed that there were 308 papers on children compared to 83 papers on women. Numerous authors have also written about the difficult reproductive decisions women living with HIV and AIDS are faced with: finding out about their positive status while pregnant, deciding whether to have a child in the midst of conflicting information, and facing pressure from health professionals to abort or not consider pregnancy an option because of risks to the fetus (Hunter & Rubenstein, 1992; Levine, 1990; Levine & Neveloff Dubler, 1990; Mitchell, 1988). Women's reproductive potential has also been used as justification for exclusion or underrepresentation in clinical AIDS drug trials, often at the expense of the overall health of infected women (Henderson, 1992; Pearlberg, 1991).

Wofsy (1988) makes the point that women living with HIV come from all walks of life, with issues crossing all boundaries of class, race and income. Taylor (1990) addresses this in her article reviewing her experiences in a support group for positive women in Toronto where she found that "HIV tends to bring women together but other
circumstances of women's lives can set them apart." (p.12).
It has been suggested that the focus turn from "risk groups" to "risk behaviours", as women from all kinds of demographic backgrounds can be engaged in unprotected intercourse or injection drug use, or have sexual partners who are. In Canada, more women who are testing HIV positive are injection drug users. In Montreal, these women made up 9% of women living with HIV, but by 1991, that percentage increased to 21% (Johnston, 1994).

HIV/AIDS and Social Support

Some studies were found in the literature which examine various forms of social support in relation to HIV and AIDS in men. Hogg et al. (1994) examined the relationship between socioeconomic status and survival in men living with HIV. Men with low incomes were found to have shorter survival times after HIV infection than men with high incomes. Donlou, Wolcott, Gottlieb and Landsverk (1985) found that mothers and close friends were identified as important sources of social support, but that social contacts overall were reduced in frequency. Reasons for this decrease included fear on the part of network members, as well as hesitancy on the part of respondents to disclose their health status. Social support was found to be negatively correlated with depression. Alexus (1989) studied the social network properties and their functional properties of ten HIV
positive men, and 13 men who had not been tested for HIV. She found the groups to be quite similar in terms of the social support properties, although there was more loss of network members for the men who were positive.

Zich and Temoshok (1990), in their study of gay men with AIDS and symptomatic HIV infection, found that decreased levels of social support were associated with increased levels of psychosomatic complaints. Individuals with worse prognoses were less likely to receive social support than their healthier counterparts. This may point to caregiver burnout, the stigmatization of AIDS, or the perception of those who are ill that they are unable to reciprocate the support they receive, and who therefore may feel unentitled to the assistance.

In a study of 181 people living with HIV/AIDS (of which only seven percent were women), the Hull-York Research Team (1993) examined disclosure of HIV status to family, friends and others. Seventeen people had told no one of their status and results indicated that HIV positive people "make careful decisions about who they inform of their HIV status - not only to avoid potentially hostile reactions but also to avoid causing distress to others." (p. 25).

Namir, Alumbaugh, Fawzy and Wolcott (1989) found that variables associated with good psychological and physical adaptation to AIDS include satisfaction with instrumental support and emotional support. These measures of satisfaction were relatively high, even though network size
was small. It has been noted that men who are HIV positive and belong to the gay community are much more likely to have support available to them, than are women who are HIV positive, who are often closeted and socially isolated because of the racist, classist and sexist stigmas associated with the illness (Kizer Bell, 1989). Baker and Seager (1991) found that social support in the form of contact with neighbours or friends received by male AIDS hospice patients was significantly less than that received by patients with other diagnoses in the same setting, perhaps alluding to the stigma associated with this illness. Hays, Chauncey and Tobey (1990) examined the social support networks of gay men with AIDS and found that network characteristics most highly correlated with psychological well-being included the amount of emotional and informational support they received, the number of close relationships they had, and the percentage of friends versus relatives in the men's network.

Green (1993) undertook a comprehensive review of social support literature in relation to HIV, and found a strong bias toward gay, white North American males. Major findings of reviewed literature included the correlation of positive psychological state with satisfaction with support and that emotional support tended to be rated as most desirable by HIV positive persons. Green concluded that research on HIV and social support was just in its infancy, particularly because the people affected by AIDS/HIV comprise a very heterogeneous
group by virtue of race, culture, socioeconomic status and gender. Also noted was an over-representation of persons with symptomatic HIV, which may not address support needs at various stages of illness.

The necessity to quantitatively document the experiences of women who are HIV positive is supported by the lack of information available in the literature. Where information is available, social support issues have been neglected in favour of a rigid biomedical focus. Reviews of the literature, and selected qualitative and quantitative studies of gay men with AIDS have generated a number of variables which can be tested in the present study as possible constructs of social support. The purpose of this study is therefore to address the questions: 1) Do women who are living with HIV and AIDS in the Lower Mainland perceive a lack of social support?, and 2) In what general areas, if any, do women who are HIV positive perceive a lack of social support?
METHOD

Study Design

A descriptive design was chosen to examine if women who are living with HIV/AIDS perceive a lack of social support, as suggested in literature reviews and some exploratory studies (Kaspar, 1989; Stuntzner-Gibson, 1991). This survey research was an attempt to begin to investigate whether social support is of importance in the experiences of these women. Descriptive design in the form of a self-administered or telephone interview questionnaire allowed for a maximum number of women to be involved in the study within the sampling frame stipulations.

Weaknesses of survey design have been well documented (Hessler, 1992). There is little control over independent variables, and contrary to experimental designs, control over the environment is not possible. Criticisms have also been made regarding whether the concepts presented in a survey will have the same meaning for all participants. Thus, survey research can be generally said to be strong on reliability and weak on validity, because of the artificiality in requesting a "rating" of opinions, feelings or experiences by subjects on predetermined scales (Rubin & Babbie, 1989). This study was designed with an awareness of the inherent weaknesses in survey design. However, of all possible designs, descriptive design was found to be the most
Sample

This study used a cross-sectional non-random convenience sample. At the descriptive level of design, this sampling method is most feasible, in order to survey a maximum number of participants in the sampling frame.

In the Third Quarter 1993 AIDS Update report published by the BC Centre for Disease Control (1993), 495 female tests of a total of 6,843 tests, were positive for the HIV antibody between October 7, 1985 and September 30, 1993 in BC. This number includes women under 15 years of age, and those whose age was unknown and represents 7.2% of all positive tests in the province. Seroprevalence studies estimated that 400 to 600 women may be HIV positive in the province of BC (Strathdee, Schechter, Hogg & O'Shaughnessy, 1994). Thirty-nine women have had AIDS in BC, and this number includes those women who have already died (BC Centre for Disease Control, 1993). The number of women testing positive is anticipated to increase, comprising an even greater percentage of positive tests.

The sampling frame for this study included women who are HIV positive and living in the Lower Mainland. The sampling frame was limited geographically in order to include women who may have access, or may be using services available to women living with HIV in this area. Further restrictions in
the sampling frame, such as sexual orientation and ethnicity were considered. However, these were ruled against in favour of obtaining a larger sample size.

This study included women who are HIV positive, who may or may not have AIDS, although a question determining this was included in the questionnaire to allow for a comparison of response variation to perceived support between these two groups. The number of women with HIV infection is significantly fewer than the number of men (BC Centre for Disease Control, 1993), and therefore it was decided that HIV positive status would be the recruitment criterion in order to include as many women as possible in the study.

Study participants were recruited via professional staff at three liaison organizations which provide services for women who are HIV positive (see Appendix A for copies of letters of organization approval and participation). These are: the Positive Women's Network, St. Paul's Hospital Infectious Disease Clinic, and BC's Children's Hospital HIV Care Unit, now the Oak Tree Clinic. Approval was also obtained from the Vancouver Persons with AIDS (PWA) Society, but survey distribution was not able to be arranged during the time of data collection. Subject recruitment took place following approval of the study by the University of British Columbia Behavioural Sciences Screening Committee for Research and Other Studies involving Human Subjects (see Appendix B).

The Positive Women's Network (PWN) has approximately 80
active members, with most of these women living in the Lower Mainland. A support group, which had previously been meeting on a weekly basis, was not being held at the time of the study, as attendance was very low. Instead, a peer phone system has been organized to provide support. Monthly events are scheduled, although it appears that it is a challenge for many women to come to these programmed events. Retreats, held once every three or four months, have better attendance. (Marcie Summers, PWN, personal communication, 1994).

The Infectious Disease Clinic (IDC) at St. Paul's Hospital is the only clinic treating people with HIV in BC, and drug trials are carried out as well. Approximately 95% of people who are HIV positive in the province are seen at least once in the IDC. On an ongoing basis, the IDC treats about 75% of people living with HIV in BC. During the course of the study, twenty women who were HIV positive were involved in a gynecological study in the IDC. Approximately 70 to 85 women who are HIV positive from all over the Lower Mainland are seen throughout St. Paul's Hospital at various times. The IDC social worker usually sees about eight positive women on an on-going basis at any time for counselling and support. These women are usually seen when they are first diagnosed with HIV. Recently, more positive women are being seen who are, or have been injection drug users, or who have partners with HIV disease. (Judy Krueckl, IDC, personal communication, 1994).

During the study, the HIV Care Unit at BC's Children's
Hospital became the Oak Tree Clinic at the Women and Family HIV Centre. The Oak Tree Clinic, as did the former HIV Care Unit, provides an outpatient consultative service. The women recruited for this study were all part of a support group for women who are HIV positive and have children. This support group is made up of a core group of approximately seven women who regularly attend. The actual number of women who have been seen at the Oak Tree Clinic was not available. Sixty-one adults have been seen at the Clinic, with at least one-third of these being men. (Lori Sheckter, Oak Tree Clinic, personal communication, 1994).

Situation-specific subject recruitment was adopted. Staff at the liaison organizations notified their clients of the study via telephone or face to face contact. The Positive Women's Network initially sent out a letter informing their clients about the study, asking them to send back a return section if they were interested in participating (Appendix C). Staff were given a list of points to cover when explaining the study to clients (see Appendix D). When the clients indicated interest in the study, a survey questionnaire was mailed or given to them. Written informed consent prior to receiving the study instrument as documented by Namir et al. (1989) was not necessary, as completion of the study instrument indicated consent. This was outlined in the survey covering letter (see Appendix E).

One of the participating organizations (BC's Children's
Hospital HIV Care Unit) offered clients the option of completing the survey via a telephone interview. The researcher then contacted the women at a time and day specified on a consent form completed by the subject (Appendix F). At St. Paul's Hospital, the IDC social worker contacted women whom she thought would participate in the study prior to sending or giving the questionnaire to them.

These methods of subject recruitment were elected because of the possible resistance which may have resulted from a direct mail-out questionnaire. Person to person contact, or prior information about the study provided the potential subjects with an opportunity to ask questions about the survey prior to receiving a copy of it. Receiving the questionnaire through a trusted person or organization was hoped to contribute to the response rate. Data collection took place from May through October 1993.

Using the methods described, 17 women were recruited for the study. Ten surveys were sent to clients of St. Paul's Hospital Infectious Disease Clinic by the social worker, and eight completed surveys were returned. Two surveys of six distributed by the Positive Women's Network were returned, and all seven clients of BC's Children's Hospital HIV Care Unit who gave consent to be interviewed by telephone completed the survey. The total sample size was 23, with 17 respondents, or a 73.9% response rate.

Liaison organization staff were asked to distribute the
survey only to those women who live in the Lower Mainland of British Columbia. Where staff did not know where a woman lived or did not ask, data received from women living outside of the Lower Mainland would be excluded from the study by virtue of a questionnaire question which asked whether the participant lived in or outside of the limited geographical area. Staff additionally only asked women who were known to them to be HIV positive to participate in the study. The investigators did not have access to subject names or phone numbers, except where a telephone interview was chosen and consented to. Completed self-administered questionnaires were mailed to the investigators in stamped, self-addressed envelopes included with the survey. Questionnaires were confidential, as no identifying names or numbers were included or requested.

Subjects were also recruited for a proposed focus group to discuss the results of the survey. In the survey package, a separate letter explaining the group (see Appendix G), and a separate stamped, self-addressed envelope were provided. The letter included a mail-back portion on which the participant is asked to give a name or initial(s) and a contact telephone number. In the case of subjects interviewed by telephone, they were given the same information regarding the focus group and were asked if they would like to be called at a later date. In order for the study participants to feel that they have control and ownership over the data collected, discussions of the results in small groups was proposed. A
richer interpretation of the results might be obtained through this. Seven study participants indicated interest in participating in a focus group.

A focus group was not held as planned because the anticipated turnout for the group was too low to conduct a focus group. This decision was based on the low number of women who indicated an interest in participating in the group. Instead, these women will be provided with a written summary of the results.

Although the use of a non-probability sample was most appropriate to the research question in order to obtain a maximum sample size, the results are less reliable, and are not be generalizable beyond the study population.

Measures

A survey was used in the study which included standardized and non-standardized measures (see Appendix G). The questionnaire was developed in consultation with professionals who work with women who are HIV positive from the three liaison organizations, as well as AIDS Vancouver, Vancouver Persons Living with AIDS (PWA) Society, and by women who are HIV positive, in order to improve validity. The questionnaire was pretested by these people as well. Only a limited number of women who were HIV positive pretested the questionnaire in order to allow for a maximum number to participate in the actual study. See Appendix H for
a discussion of the pretest.

The measure included questions about demographic information, experiences and perceptions of social support. Additionally, questions asking about the utilization of specific support services for HIV positive women were included.

The standardized measure used, the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet, Dahlem, Zimet and Farley, 1988) was developed to subjectively measure social support adequacy from three specific sources: family, friends and a significant other. The MSPSS was chosen for its brevity and its multidimensional focus on perceived support. It uses a seven-point Likert scale in responses to each of 12 questions. Other measures of perceived social support were considered, but judged less appropriate for the present study (Appendix I). Permission to use the MSPSS was obtained from one of its developers (see Appendix J).

The MSPSS has been tested on a number of occasions (Dahlem, Zimet and Walker, 1991; Kazarian and McCabe, 1991; Zimet, Powell, Farley, Werkman and Berkoff, 1990) and has been found to be a valid, reliable and easy to administer measure of perceived social support. Cronbach's coefficient alpha has been found to range from .84 to .92. This suggests that even when diverse subject samples are involved, reliable data are provided from an internal consistency viewpoint (Dahlem et al., 1991). Factor analysis confirmed the construct validity.
of the MSPSS, as it has been demonstrated that subjects clearly differentiate between sources of support.

The MSPSS may not adequately cover social support services under investigation in this study. Therefore, non-standardized measures were included in the survey to more clearly examine the subjects' satisfaction with social support in distinct areas such as housing and social services. These variables have been drawn from the literature by virtue of being postulated as being important factors of social support for women who are HIV positive, and appear to have face validity. If the MSPSS data from the present study are shown to be reliable and valid, this may suggest that data from the non-standardized questions may also have similar properties.

Reliability of the survey could be increased by ensuring that the questionnaires are done in the same way every time, with the same instructions and forms. The latter part of this is accounted for in the questionnaire covering letter and interview consent letter, but control over when, where and how the subject completes the form is not. It was noted which surveys were completed by telephone and which were self-administered, in order to compare the results between these two groups. Furthermore, one researcher completed all of the telephone interviews. The length of the study instrument was also considered in regard to reliability. Although the MSPSS is short, the questionnaire as a whole is
not. However, pretests did not reveal any negative feedback regarding the length of the questionnaire.

Data Analysis

Data were coded and entered into the UBC computer, and analyzed using the SPSSx program for Windows. Descriptive statistics were used to determine the central tendency of the perception of social support, and to describe the demographic data. The non-parametric statistic, Pearson's r, was calculated for some crosstabulations to examine if certain hypothesized variables covaried. Pearson's r is intended for use with interval level data, and for the purposes of this study, ordinal and nominal data were treated as interval level data to utilize this non-parametric test. Most of the data were collapsed prior to data analysis to ensure a cell size of at least five. Final result interpretation was to be aided by the input from survey participants in a focus group. However, this was decided against due to the results obtained, and the low number of women expressing an interest in the focus group.

Given the limitations of the survey design, the limited sampling frame, and the measures, this study remains feasible in light of current literature. Information is needed about the experiences of women who are HIV positive (Stuntzner-Gibson, 1991) and the role of social support is thought to be important in how these women cope with this stressor in their
lives (McGough, 1990). The results of the survey may be used to gain a better understanding of the social support needs of women living with HIV. The survey may prove to be a "pilot study" from which a larger-scale survey may be developed, which may address the particular difficulties in study methodology.
RESULTS

Sixteen women were given a self-administered survey and ten completed questionnaires were returned. Of the ten completed questionnaires, eight were from the ten distributed through St. Paul's Hospital; and two were from the six distributed by the Positive Women's Network. An additional seven women, who were recruited for the study through BC's Children's Hospital, completed the questionnaire in a telephone interview. Therefore the total sample size was 23, with 17 respondents, giving a 73.9% response rate.

Nine of the women were in the 30-39 age group, four were 20-29, four were 40-59 years of age. An overview of the demographic data can be found in Table 1. Four of the women had some college or university education, three had vocational or apprenticeship training, and ten had completed high school, or had some high school education.

Seven women reported an annual household income of $6,300 to $19,999; four had incomes ranging from $20,000 to $39,999, six women reported incomes over $40,000. The average number of people supported by the incomes was 2.5 people. Income sources were reported as (number of subjects indicating this in parentheses): income assistance (five), disability pension (six), employment (seven), savings (one), credit (one) and other (two). The two "other" sources were the "PWA Housing extraordinary assistance plan", and "pensions".
## Table 1:
Overview of Demographic Data

<table>
<thead>
<tr>
<th>Variable</th>
<th>Number of respondents:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age:</strong></td>
<td></td>
</tr>
<tr>
<td>20-29 years</td>
<td>4</td>
</tr>
<tr>
<td>30-39 years</td>
<td>9</td>
</tr>
<tr>
<td>40-59 years</td>
<td>4</td>
</tr>
<tr>
<td><strong>Household Income:</strong></td>
<td></td>
</tr>
<tr>
<td>$6,300-$19,999</td>
<td>7</td>
</tr>
<tr>
<td>$20,000-$39,999</td>
<td>4</td>
</tr>
<tr>
<td>over $40,000</td>
<td>6</td>
</tr>
<tr>
<td><strong>Ethnicity:</strong></td>
<td></td>
</tr>
<tr>
<td>White/Caucasian</td>
<td>16</td>
</tr>
<tr>
<td>Aboriginal</td>
<td>1</td>
</tr>
<tr>
<td><strong>Sexual Orientation:</strong></td>
<td></td>
</tr>
<tr>
<td>Heterosexual</td>
<td>16</td>
</tr>
<tr>
<td>Lesbian</td>
<td>1</td>
</tr>
<tr>
<td><strong>Previous injection drug use:</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3</td>
</tr>
<tr>
<td><strong>Current injection drug use:</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>0</td>
</tr>
<tr>
<td><strong>Have AIDS:</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4</td>
</tr>
<tr>
<td><strong>Symptomatic HIV infection:</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2</td>
</tr>
<tr>
<td><strong>Earlier HIV diagnosis possible:</strong></td>
<td></td>
</tr>
<tr>
<td>Reasons:</td>
<td></td>
</tr>
<tr>
<td>-Dr. not linking symptoms</td>
<td>5</td>
</tr>
<tr>
<td>-afraid might be HIV positive</td>
<td>2</td>
</tr>
<tr>
<td>-didn't think at risk</td>
<td>4</td>
</tr>
<tr>
<td>-not feeling sick</td>
<td>4</td>
</tr>
</tbody>
</table>


Income source categories were not mutually exclusive. Four of the seventeen survey participants worked outside of their homes. Ratings of income adequacy were collapsed from a seven to a three-point scale, with 1 representing inadequate income, 2 less than adequate income, and 3 adequate income. The majority of respondents (eleven) indicated that their income was less than adequate or inadequate. The mean rating for all seventeen respondents was 2.1 with a Standard Deviation of 0.76.

The majority of women (nine) reported that they had rental housing. Five women owned their homes, and three lived with parents.

Sixteen women identified themselves as white/caucasian and one as aboriginal. Sixteen women were heterosexual and one woman was a lesbian.

Three of the women reported they were injection drug users at the time they found out they were HIV positive. None of the survey participants indicated that they were currently injection drug users.

The relationship status of the respondents with regard to partners and children is shown in Table 2. Eleven women indicated that they had a partner or spouse at present. Of the eleven partners, four were described as HIV positive, and seven were described as HIV negative. Seven women had the same spouse or partner as they did when they were diagnosed as HIV positive, and five women reported they had
relationships end at the time or after they were diagnosed. In response to what happened to the five ended relationships, three women said that their partner/spouse had died, two reported that they had ended the relationship, and one said that her partner ended the relationship. The categories were not mutually exclusive.

Table 2: Relationship Status of Respondents

<table>
<thead>
<tr>
<th>Variable</th>
<th>Number of respondents:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have current partner/spouse:</td>
<td>11</td>
</tr>
<tr>
<td>Partner/spouse is HIV positive:</td>
<td>4</td>
</tr>
<tr>
<td>Same partner/spouse as when diagnosed HIV positive:</td>
<td>7</td>
</tr>
<tr>
<td>Relationship ended when diagnosed HIV positive:</td>
<td>5</td>
</tr>
<tr>
<td>Reasons:</td>
<td></td>
</tr>
<tr>
<td>-partner/spouse died</td>
<td>3</td>
</tr>
<tr>
<td>-respondent ended relationship</td>
<td>2</td>
</tr>
<tr>
<td>-partner ended relationship</td>
<td>1</td>
</tr>
<tr>
<td>Have children:</td>
<td>14</td>
</tr>
<tr>
<td>Children are HIV positive:</td>
<td>2</td>
</tr>
</tbody>
</table>

Fourteen of the women had children, with nine having one child each, three having three children, and two women having four children. The mean age of the children was twelve years
of age. The ages of four children are not included in this average because the respondent simply indicated that these children were "adults". Two women said that their children were HIV positive, and each had one positive child. Eleven women indicated that their children were not HIV positive, and one woman did not indicate the HIV status of her children.

Six women were diagnosed HIV positive from 1986 to 1988; four were diagnosed from 1989 to 1990, and seven were diagnosed between 1991 to 1993. None of the women indicated that they had told nobody of their HIV status. The eleven women with partners at present all reported that their partners knew of their HIV positive status. One additional woman reported that her partner/spouse knew, although she did not have a spouse at present.

Of the fourteen women with children, six reported that their children knew that they were HIV positive. Thirteen women indicated that their parents knew, fifteen women indicated that their siblings knew, fourteen women reported that their friends knew, and five women said that their coworkers were aware of their HIV positivity.

Mean scores for the three components of the Multidimensional Scale of Perceived Social Support (MSPSS) were calculated for the total group of women (n=16), with the exclusion of one subject due to an incomplete MSPSS. Scoring for the MSPSS is done on a seven-point Likert scale, with one
indicating "very strongly disagree", and seven, "very strongly agree". The scale was collapsed to three points in the following manner to accommodate the small number of respondents: scores of 1, 2 or 3 were converted to 1, to indicate a participant did not agree with the MSPSS statement they were asked to rate; a score of 4 was converted to 2 to indicate neutrality; and original scores of 5, 6, or 7 were converted to 3 to indicate agreement with the statement being rated. For comparison, the mean family score for the non-collapsed data was 5.34 (SD=2.12), while for the collapsed data was 2.56 (SD=0.81). The average friends score was 5.11 (SD=1.87) [non-collapsed], and 2.50 (SD=0.79) [collapsed], and the mean significant other score was 5.92 (SD=1.69) [non-collapsed], and 2.77 (SD=0.61) [collapsed]. The average MSPSS score for all categories was 5.46 (SD=1.93), or 2.61 (SD=0.75) using non-collapsed and collapsed data, respectively.

Table 3 shows mean scores for the three components of the Multidimensional Scale of Perceived Social Support (MSPSS) crosstabulated by related groups of persons to whom HIV status may or may not have been disclosed. It was hypothesized that if persons in a positive woman's network were aware of her HIV status, that the woman might perceive more support from them than from persons who did not have knowledge of her HIV status. The total "n" for the category of "children" was 13, and not 16 as for the other groupings, as only those women who indicated that they had children were
Table 3: MSPSS Score by HIV Status Disclosure

<table>
<thead>
<tr>
<th></th>
<th>Family</th>
<th>Friends</th>
<th>Significant Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents Know (n=12)</td>
<td>2.52</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents Don't Know (n=4)</td>
<td>2.69</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Siblings Know (n=14)</td>
<td>2.59</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Siblings Don't Know (n=2)</td>
<td>2.38</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children Know (n=6)</td>
<td>2.67</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children Don't Know (n=7)</td>
<td>2.57</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friends Know (n=13)</td>
<td></td>
<td>2.65</td>
<td></td>
</tr>
<tr>
<td>Friends Don't Know (n=3)</td>
<td></td>
<td>1.83</td>
<td></td>
</tr>
<tr>
<td>Partner Knows (n=11)</td>
<td></td>
<td></td>
<td>2.93</td>
</tr>
<tr>
<td>Partner Doesn't Know (n=5)</td>
<td></td>
<td></td>
<td>2.40</td>
</tr>
</tbody>
</table>

Subjects reporting that they had disclosed to their parents had a mean MSPSS family score of 2.52 (SD=0.84), while those who had not disclosed had a score of 2.69 (SD=0.68). Women reporting that their siblings were aware of their HIV status had a mean score of 2.58 (SD=0.80) on MSPSS items targeting support from family members, and women with siblings who were unaware of their HIV status had a mean score of 2.38 (SD=0.86) on the MSPSS family questions. It was not determined which subjects actually had parents or siblings.

Of the women with children, those who indicated that they
had disclosed their HIV status had a mean MSPSS score of 2.67 (SD=0.75), while those who did not indicate that they had disclosed scored a mean of 2.57 (SD=0.78).

Subjects reporting that they had disclosed their HIV status to friends had a mean score of 2.6 (SD=0.68) on MSPSS items dealing with friends, while women who had not disclosed to their friends had a mean score of 1.83 (SD=0.90). Women with partners who were aware of their HIV status scored an average of 2.93 (SD=0.25) on MSPSS items dealing with a significant other. This score is indicative of all of the women with partners, as all of these women reported that they had disclosed to their partners. The score for women whose partners do not know is therefore representative of women who reported that they did not have a partner or spouse at present. The mean MSPSS significant other score for these women was 2.40 (SD=0.92).

Pearson's r was calculated for the data in Table 3. Only two of the crosstabulations were found to have a statistically significant positive correlation between the two variables. The correlation between the independent and dependent variables for the disclosure/non-disclosure to friends and the MSPSS "friends" score was $r=0.4361, \ p<0.05$ for a one-tailed test. The crosstabulation of partner knows/doesn't know and the MSPSS "significant other" score had a correlation coefficient of $r=0.4692, \ p<0.05$ for a one-tailed test.
Ten subjects indicated that they thought that they could have been diagnosed HIV positive earlier than they were. Reasons for the failure of earlier diagnosis were not mutually exclusive, and included doctors not linking symptoms to HIV illness reported by five subjects, and the woman being afraid that she might be HIV positive reported by two subjects. Four subjects indicated that they did not think they were at risk for infection, and four subjects reported that they were not feeling sick as a reason for delayed diagnosis.

Four subjects reported that they had been diagnosed with AIDS. Of the remaining thirteen subjects, two indicated that they had experienced illnesses associated with HIV infection, and four subjects did not provide a response to this question. It was hypothesized that women who have AIDS or have been ill with HIV-related illnesses (symptomatic) may have had more difficult experiences than those women who are HIV positive but asymptomatic. Therefore, the symptomatic women may perceive less support than their asymptomatic counterparts. Table 4 displays MSPSS scores for these two groups of women, with the women with AIDS and the women who have had HIV-related illnesses grouped together.
Table 4: Health Status of Women by Mean MSPSS Score for each Category

<table>
<thead>
<tr>
<th></th>
<th>AIDS/HIV Illness n=6</th>
<th>No HIV Illness n=7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td>2.67</td>
<td>2.29</td>
</tr>
<tr>
<td>Friends</td>
<td>2.54</td>
<td>2.71</td>
</tr>
<tr>
<td>Significant Other</td>
<td>2.92</td>
<td>2.68</td>
</tr>
<tr>
<td>Total</td>
<td>2.71</td>
<td>2.56</td>
</tr>
</tbody>
</table>

Mean MSPSS family scores for the symptomatic (n=6) and asymptomatic (n=7) women were 2.67 (SD=0.75) and 2.29 (SD=0.92) respectively. Mean friends scores were 2.54 (SD=0.71) and 2.71 (SD=0.70). The women who had been ill or had AIDS had a mean significant other MSPSS score of 2.92 (SD=0.28), while those who had not been ill scored a mean of 2.68 (SD=0.71). The total mean MSPSS score for the symptomatic group was 2.71 (SD=0.63), and 2.56 (SD=0.81) for the asymptomatic group. Pearson’s r was calculated for the crosstabulations in Table 4. No statistically significant correlations were found.
The seven-point scale on which subjects rated how well they were feeling "today" was collapsed to a three-point scale, with 1 indicating "not well", 2 neutral, and 3 indicating "well". A mean score of 2.47 (SD=0.70) was obtained. This compares to a mean score of 5.1 (SD=1.69) for the non-collapsed data. The same mean score and SD were calculated for the question which asked how respondents felt one year ago. It was hypothesized that women who were not feeling well might perceive less support than those who indicated they were feeling well at present. Responses to this question were divided into two groups: 1) those women who responded they felt "not good/not bad" were grouped with those who reported they were on the "not well" side of the scale; 2) the women who rated themselves on the "well" end of the scale. The mean total MSPSS scores for the two groups were 2.58 (SD=0.76) for the "not well" group and 2.58 (SD=0.78) for the "well" group.

Scores on a seven point satisfaction scale for various types of support were collapsed into a three-point scale, with 1 indicating not satisfied, 2 indicating neutral, and 3 indicating satisfied. The means are shown in Figure 1. Counselling services (n=10), legal services (n=3) and alternative medicine (n=2) all had the highest mean score of 3.0 (SD=0).
Figure 1: Type of Support by Mean Scale Score of Satisfaction
Dental services (n=11) were rated an average of 2.73 (SD=0.62), and traditional medical services (n=15) were rated an average of 2.87 (SD=0.34). Childcare (n=10) had a mean rating of 2.80 (SD=0.60). Mean satisfaction with housing (n=16) was 2.75 (SD=0.43), mean satisfaction with transportation (n=17) was 2.65 (SD=0.76), and mean satisfaction with homemaking services (n=5) was 2.60 (SD=0.80).

A five-point scale asking respondents to indicate how often they had enough money to buy the food they needed was collapsed to a three-point scale. One indicated that a subject usually did not have enough money to buy food, two indicated that sometimes enough money was available, and 3 indicated that a subject usually had enough money. Twelve of the subjects reported that they usually had enough money to buy the food they needed. One respondent indicated she usually did not have enough money, and four women indicated a neutral rating, saying they "sometimes" had enough money for food. The mean score was 2.65 (SD=0.59), and is shown in Figure 1.

Of the five women who reported that they used the services of the Positive Women's Network, two reported that they used the support group for positive women, three utilized information services, one used the transportation allowance, and two participated in the telephone buddy program and one attended a retreat. Categories were not mutually exclusive.
Six women indicated that they used the services of the Vancouver Persons with AIDS (PWA) Society. One had received money for alternative medicine, one had received counselling, and one had received help finding housing. One woman used the PWA drop-in, three had used PWA for advocacy, and one had received legal aid. Four women reported they had used the services of AIDS Vancouver. One had used the food bank, one used information services, one utilized the buddy system, and one had used the emergency assistance fund. Service categories were not mutually exclusive.

Ten women included additional comments at the end of the questionnaire (Appendix K). A number of the participants mentioned something about people whom they turned to for support, such as friends or healthcare workers. A couple of women commented that homemaking services should be improved, and a few women made comments that they felt uncomfortable using AIDS social service organizations, and one women did not see the need for them because she received enough support from her friends. The need for more public and professional education and awareness of AIDS and HIV, and how women are affected by them, was indicated by some of the participants.

In the next section these findings will be discussed and reviewed in the context of the literature and the expected results from this research.
CONCLUSION

The results obtained from this study of women who are HIV positive were limited in the extent to which they could be tested for statistical significance because of the small number of participants (n=17). Variables tested for statistical significance will be discussed, and the descriptive statistics of the respondents' perceptions of social support will be reviewed. Study methodology will also be considered in its implications for future research regarding women living with HIV/AIDS.

Discussion of Results

Although the number of survey respondents was small (n=17), these women nonetheless represented 73.9% of the sample size, or 3.6% of the 495 HIV positive tests from women in BC to September 1993 (BC Centre for Disease Control, 1993). One hundred forty-eight women are enrolled in the HIV/AIDS Drug Program at the BC Centre for Excellence in HIV/AIDS (Dr. Robert Hogg, personal communication, 1995). The survey respondents would represent 11.5% of these women, although it was not determined whether participants were involved in the program. Since the drug program distributes drugs for antiretroviral therapy and for treatment of opportunistic infections, the women involved in the program are likely to be symptomatic. Six of the survey respondents indicated that they had AIDS or had experienced illnesses related to HIV
infection, and these women would comprise 4.1% of the women receiving treatment through the HIV/AIDS Drug Program. Survey research optimally has a sample size of at least 30. But given the relatively small number (400) of women who are estimated to be HIV positive in BC (Strathdee, Schechter, Hogg & O'Shaughnessy, 1994), and the lack of information about these women's experiences, the study remained feasible.

Seven of the women reported low income levels ($6,300 - $19,999), and six reported high levels (above $40,000), with the rest of the participants in between. Although some of the household incomes appeared to be relatively high, this did not necessarily mean that the women believed these incomes were adequate to meet their needs. Most of the study participants (eleven) indicated that their household incomes were less than adequate or inadequate. This requires further investigation into why incomes are falling short in meeting needs. This highlights the assertion in the literature that women who are HIV positive may have limited financial resources, and be unable to access needed support services, or provide for themselves and their families (Stuntzner-Gibson, 1991). Survival has been shown to be compromised for persons who are HIV positive with lower incomes, than those with higher incomes (Hogg et al., 1994).

Although a household income may be relatively high, a woman may not necessarily have access to this money, as noted by one of the participants in the open-ended comments (Appendix
K). This participant said that the household income was her husband's, and she was forced to ask other family members for money to buy the things she needed, such as nutritional supplements. High household incomes therefore do not mean access to this money for women, limiting their control over their lives.

With regard to food, the majority of the study participants indicated that they usually had enough money to buy the food they needed, with a mean of 2.65 on a three-point scale. Five women indicated that they usually did not have enough money, or sometimes had enough money for food. This requires further investigation, as nutrition, and the ability to meet changing nutritional requirements during HIV-related illnesses may play a role in maintaining health and preventing malnutrition (The ACT UP/New York Women and AIDS Book Group, 1990; Stine, 1993). Again, the issue of the control of monetary resources should be examined, as this may play a role in women's access to food and nutritional supplements.

Eleven of the study participants reported that they currently had a partner or spouse. Seven of these women said they had the same partner at the time they were diagnosed HIV positive. The literature suggests that upon diagnosis, persons may be abandoned by their partners or others in their social network (Kowalewski, 1988; Manthorne, 1990). Of the five women who had different partners or spouses at the time
of their diagnosis, only one indicated that her partner had ended the relationship. Three of the women reported that their partner or spouse at the time of diagnosis had died, but whether or not these were AIDS-related deaths was not determined in this study. More research is needed into the area of the dynamics of a positive woman's relationship with a partner, and what happens with this relationship upon HIV diagnosis, as the dissolution of this primary relationship may result in increased stress, and severe support needs.

Similar investigation is needed with respect to HIV positive women and their children. Of the 14 participants with children, six had told their children of their HIV status. The average age of all of the study participants' children was twelve years. The literature suggests that a woman's decisions to disclose to her children can be an excruciating one for numerous reasons. For example, women living with HIV/AIDS may be hesitant to disclose to younger children to avoid these children inadvertently telling others about their mother's HIV status (Manthorne, 1990; Rudd and Taylor, 1992).

In this study, it was hypothesized that women who had disclosed their HIV status to persons in their social network would perceive more support from these people than the women who had not disclosed. The literature suggests that revealing one's HIV status can be extremely frightening in terms of being abandoned, or causing so much distress to others that they are rendered incapable of offering support
(The Hull-York Research Team, 1993). However, Allen's (1994) study suggests that women found their relationships with family and friends, in time, became "deeper and more meaningful." (p. 15). Testing significance using Pearson's r for the crosstabulation between disclosure/nondisclosure and MSPSS scores revealed statistical significance only for the scores of disclosure/nondisclosure to friends and to a woman's partner. Both findings were moderate, with 44 and 47 percent of the variance being explained.

However, one limitation to the finding of statistical significance in the disclosure/nondisclosure to a partner is that all women with a partner or spouse at present reported that their partner knew of their HIV status. Thus, the mean MSPSS significant other score for the five women who did not have partners, at 2.40, was relatively high. This might suggest that someone other than a spouse or partner, such as a family member or friend is considered as a significant other. Former partners may be being referred to in this result.

Of the eleven women who had children, there was no significant difference in MSPSS scores for the women who had or had not disclosed to their children. MSPSS scores for disclosure and non-disclosure to parents or siblings had no significant differences. It should be noted that the present results do not indicate which women actually had parents or siblings.
The examination of the hypothesis that a woman might perceive more support from persons to whom she has disclosed her HIV status presents the possibility of a simultaneous equation. That is, disclosure may predict support: if a woman reveals her HIV status, it may present the opportunity for others to provide her with support appropriate to her needs. Conversely, the perception of a supportive relationship may predict disclosure of HIV status by the positive woman, as she would not fear abandonment or the inability of others to deal with her HIV status. These variables should be more closely investigated, and longitudinal and retrospective studies may be useful in discerning the relationship between perceived support and disclosure. Additionally, disclosure may not be a good predictor of support. In fact, some literature (Sample, 1992) suggests that if a woman discloses her HIV status and people in her social network do not respond as she hopes they will, the woman may feel just as isolated and misunderstood as she did prior to disclosure.

Women who reported that they had AIDS, or had experienced illnesses related to HIV infection did not perceive less support from their relationships than women who had not experienced HIV-related illnesses. This is contrary to the study hypothesis that symptomatic positive women, or women with AIDS, may experience more social support needs than asymptomatic women because of the stresses brought on by
illness. Zich and Temoshek (1990) found that gay men with AIDS and HIV-related illnesses perceived previous supports as inadequate. The results of the present study, while not examining the adequacy of support prior to HIV status, do not appear to support this. In fact, in most cases, women who were symptomatic had higher mean MSPSS scores than asymptomatic women. Perhaps the symptomatic women perceived more support because they have been unwell, and therefore other people may have been more available to the ill woman, or able to offer either more support, or support in various forms. By virtue of health problems becoming "visible", others may rally around a woman living with HIV/AIDS, and provide more assistance than previously.

The lack of higher MSPSS scores for asymptomatic women may also provide some insight into the experiences of these women. In terms of social services and community supports, the results may suggest that all women who are HIV positive have support requirements. A diagnosis of AIDS or the symptoms of HIV disease need not be present to include asymptomatic women as consumers in support service programs, which may previously have only targeted symptomatic women.

Mean MSPSS scores for all study participants were calculated, and all scores for the total scale and for the subscales of family, friends and significant other were at least 2.5 or higher. It was anticipated that the study participants would have reported lower perceptions of support, because of the many challenges faced by women living
with HIV/AIDS, as suggested in the literature (Manthorne, 1990; Stuntzner-Gibson, 1991). The high levels of perceived support indicated by subjects of other studies using the MSPSS as a measurement instrument has been noted (Zimet, Dahlem et al., 1988). Dahlem, Zimet and Walker (1991) investigated the possibility of a social desirability bias in the MSPSS, but this was not found. Therefore, other factors must account for the relatively high levels of social support perceived by study participants. Perhaps the MSPSS is not sensitive enough to discern when support is lacking for a positive woman.

Mean scores of satisfaction on non-standardized scales for support from other sources tended to be high as well, with no mean below 2.6 on a 3-point scale. Therefore, none of the mean scores indicated dissatisfaction with a resource or support source. Perception of support from all sources were higher than anticipated. Childcare, for example, had one of the highest mean ratings at 2.80. This may indicate that either women have very satisfactory childcare arrangements, or perhaps that the study participants themselves are the sole caregivers for their children, and therefore were not rating "external" sources of childcare.

The scales of satisfaction with supports may not be adequate to examine positive women's experiences. For example, traditional medical services rated a mean of 2.87, even though ten of the 17 study participants indicated that
they believed they could have been diagnosed HIV positive earlier than they were. Of these ten, five said that their
doctors had not linked their symptoms with HIV/AIDS. However, the satisfaction scales did not specify a time
restriction, and women may have been reporting on their
present experiences with traditional medicine, and not their
negative experiences of the past in terms of delay of
diagnosis. In addition, the majority of the study
participants were recruited through medical settings which
may offer a great deal of support to their clients, both in
maintenance of health, as well as emotional support through
counselling or support groups.

Implications for Research

The relatively consistent high levels of reported perceived
support and lack of response variability in this study call
into question the clinical significance of the data, in light
of the lack of statistical significance. The results appear
to be inconsistent with what is suggested about the
experiences of women living with HIV/AIDS in the literature
(Allen, 1994; Health and Welfare Canada, 1992; Manthorne,
1990), as well as with some of the comments made in response
to the open-ended question in the survey (see Appendix K).
Bearing this in mind, it could be suggested that the level of
analysis used, namely descriptive, is too far ahead of what
is required in the examination of the meaning of support for women who are HIV positive.

The variables of social support, as presented in the survey, may have little meaning for these women, and further investigation may be required at the exploratory level of research to determine what is really needed by these women in the way of support, and how it is defined by them. More exploratory work into this area may provide valuable new insights into the meaning of social support to women who are HIV positive. Definitions of social support might be obtained through case studies which at a later time may be tested via survey research.

The survey results were also confounded by the small number of respondents, and the necessity to collapse support scores, which further limited response variability. This, in turn, limited the ability to test for statistical significance, and rendered the proposal to hold a focus group of study respondents inappropriate. This is unfortunate, as the investigator intended to involve members of the study population in the analysis of results, to provide a richer interpretation.

Manson-Singer & Sullivan (1993) outline issues related to research involving persons living with HIV/AIDS. These include limitations in access to this population for reasons of confidentiality; the loss of community contacts through illness or death; and the need for continual adjustment and
sensitivity of social science research methods to the needs of this particular population. The importance of the inclusion of persons living with HIV/AIDS in research development and methodology in order to conduct studies which are meaningful is also discussed. Some of these issues are highlighted in this study of women living with HIV/AIDS.

The number of women recruited for this study was smaller than anticipated during study design. Limitations in the recruitment of subjects were due to the student researcher not being directly involved in any of the organizations through which the women were contacted, creating the necessity for liaison personnel. The liaisons were limited by the time which they could devote to the study, because recruitment of subjects was done in addition to their usual workloads. The Positive Women's Network was particularly limited in the amount of person-hours which could be committed to the study, as many of the staff are volunteers, and many of the women working for the Network are living with HIV/AIDS. Excerpts from the Network's pamphlet, "Why an HIV+ Woman is Not Here", are included in Appendix L, and outline many of the realities which women living with HIV/AIDS face daily which limit their activities. The strain of additional activities, such as involvement in external research, on non-governmental organizations such as the PWN has been made poignantly obvious in this study. Such a research burden is neither appropriate, nor efficacious in terms of results.

The best response rate (100%) was obtained through the
personal contacts with women via telephone interviews, following recruitment through a liaison organization (in this case, the HIV Care Unit). Consideration must be given as to the implications of such research for health care professionals, who have many other job responsibilities as well. Particularly for a larger scale project, the recruitment of subjects, as well as one-on-one interviewing is very time-intensive. This is an important methodological consideration, as response rate was vastly improved with personal contact. Although costly, this must be weighed against the value of obtaining the best response rate possible, particularly for a difficult-to-access population.

Despite the limitations of this study, it does contribute to what little is known about women who are living with HIV/AIDS. The number of respondents was small (17), but the number of women estimated to be HIV positive in BC (400-600), although growing, is still relatively small as well (Strathdee et al., 1994). The respondents could be seen to represent a significant proportion (11.5%) of those women receiving treatment for HIV (148) through the HIV/AIDS Drug Program (Dr. Robert Hogg, personal communication, 1995). If only respondents who have AIDS or are symptomatic are considered, they would still represent 4.1% of these women. The survey results also provide a starting point for understanding the experiences of women who are living with HIV/AIDS. Although most of the results were not
statistically significant in the examination of perception of more support from persons to whom a positive woman had disclosed her HIV status, the trendline for most of the data was in the direction of the hypothesis (see Table 3). This prompts the question of whether the level of significance for social science research may be too high. Despite a lack of statistical significance, the data should not be disregarded, but should be considered in light of clinical significance, and that women who are HIV positive have had very little research devoted to them.

This study points to the continuing need to identify and describe the experiences of women who are living with HIV/AIDS, as many questions still exist about their need for, and perception of support. The importance of use of appropriate research methodology with this population has been stressed. Since social workers are often in direct contact with these women, a unique opportunity is provided in which to cooperatively design and conduct meaningful research which may clarify the experiences of positive women. The research may then, in turn, be used as a lobbying tool to influence social policy, and to inform emotional/psychological and instrumental support services.
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Appendix A: Approval and Agreement from Liaison Organizations
Appendix B: Approval from UBC Behavioural Sciences Screening Committee
Appendix C: Initial Letter to Positive Women's Network Members
Dear Positive Women's Network Member:

This is to let you know about and ask for your participation in a research study looking at the social support needs of women who are HIV positive. Very little is known about the experiences of positive women, and this study will be one of the first to provide this type of information.

This letter has been sent to you by the Positive Women's Network on behalf of the University of BC researchers to let you know about the study. The researchers do not have access to your name, address or phone number. If you participate in the study, all information will be confidential.

Other HIV positive women have been involved in developing the questionnaire for this study, and the questionnaire will take about 30 minutes of your time to fill out.

The survey results will be written up in the Positive Women's Network and Vancouver PWA newsletters, and you will also be asked if you would like to participate in a small group to discuss the results with the researchers.

I, Iris Brendle Moczuk, am conducting the study, and I am a Social Work student at the University of BC, where my Masters degree work is focussing on women who are HIV positive. I will be using the results of the survey in my thesis work. Only I, and my research professor, Dr. Sharon Manson Singer, will have access to your completed questionnaire, and all questionnaires will be destroyed once your responses have been compiled.
I'm interested in participating in the study. Please check ONE of the options.

[ ] I would like to have the questionnaire sent to me. My address is:

Name: __________________________________________

Address: _______________________________________

_________________________________________________________________

_________________________________________________________________

[ ] I would like to have the student researcher, Iris Brendle Moczuk, call me to do the questionnaire by telephone.

Name or initials: ____________________________________________

Convenient days to call: ______________________________________

Convenient times to call: ______________________________________

PLEASE RETURN THIS PAGE IN THE SELF-ADDRESSED, STAMPED ENVELOPE PROVIDED. THANK YOU.
Appendix D: Explanation of Study

WOMEN WHO ARE HIV POSITIVE IN THE LOWER MAINLAND: A SURVEY OF SOCIAL SUPPORT NEEDS

Outline of points to cover with prospective study participants

-study being conducted by a Masters of Social Work student (Iris Brendle Moczuk) from the University of British Columbia

-survey questionnaire asks about the experiences of women who are HIV positive

-most of the questions deal with issues around support: from people and services

-very little is known about the experiences of women who are HIV positive, and therefore this type of information is important for organizations providing services for women who are positive in order to improve services, or gain funding for services

-questionnaire developed with input from women who are HIV positive, and the project is being conducted in cooperation with St. Paul's Hospital Infectious Disease Clinic, BC's Children's Hospital HIV Care Unit, and the Positive Women's Network (you can talk about your involvement if you have been involved)

-survey will take about 30 minutes to complete, and the results will be confidential

-Choices regarding survey completion:
  a) participant can be given/sent the questionnaire package, fill out the survey herself, and send it back to the researchers in a postage-paid envelope
  b) participant can give a name (or pseudonym), contact phone number and appropriate days and times to call, and the student researcher will call her and complete the questionnaire over the phone with her

-if potential participant has already been told about the study through another organization, or is already participating, they should not fill out the questionnaire again

-the researchers would like the participants to be involved in the analysis of the data. To facilitate this, the participants will be asked if they would like to be contacted to participate in a small focus group to discuss the results of the survey. If the participant expresses interest, the student researcher, Iris Brendle Moczuk, will contact the participant in June 1993, to arrange the focus group.

-participation in the study or the focus group is entirely voluntary, and participants can withdraw from the study at any time. Services and treatment the participant is currently receiving will not be affected.
Appendix E: Survey Cover Letter
Women Who are HIV Positive in the Lower Mainland: A Survey of Social Support Needs

Dear Survey Participant:

This survey asks about your experiences as a woman living with HIV. It focusses on the support you receive from people and services. This questionnaire has been developed with input from other women who are HIV positive. The questionnaire is being given out by people working with HIV positive women.

The survey will take about 30 minutes to fill out. The survey is confidential: there are no numbers or names on it to identify you. The researchers do not know who you are.

Some of the questions ask about personal or sensitive information. If you find that you need someone to talk to, the Positive Women's Network (893-2200) and the AIDS Vancouver Helpline (687-AIDS) are available.

If you complete the questionnaire and return it in the large postage-paid envelope, it will be assumed that you agree to participate in this study. Only myself, and my professor, Dr. Sharon Manson Singer will have access to your completed questionnaire.

The results of this survey may be used by organizations such as the Positive Women's Network and the Vancouver Persons with AIDS (PWA) Society to improve services to women who are HIV positive.

If you would like to discuss the results of the study with the researchers in a small group, please read and return the other letter in this package, in the other envelope provided. We hope to have the results by July 1993.
Appendix F: Consent for Telephone Interview
Women who are HIV Positive in the Lower Mainland: A Survey of Social Support Needs
CONSENT FORM

Dear Participant:

We are conducting a survey which asks about your experiences as a woman living with HIV. It focuses on the support you receive from people and services. The survey has been developed with input from other women who are HIV positive.

The survey will be done over the phone with you by the student researcher, at a time you find convenient. It will take about 30 minutes of your time.

You have the right not to participate in this study. You can refuse to answer questions, and can stop participating at any time without any consequences. The services you receive will not be affected.

Your answers will be kept confidential, and no names or numbers to identify you will be used. Only myself, and my professor, Dr. Sharon Manson Singer will have access to your completed questionnaire.

The results of the survey may be used by St. Paul's Hospital and BC's Children's Hospital, and organizations such as the Positive Women's Network to improve services to women who are HIV positive.

If you have any questions or comments about this study please feel free to call us at the numbers below.
Appendix G: Survey, and Focus Group Contact and Consent Forms
WOMEN WHO ARE HIV POSITIVE IN THE LOWER MAINLAND: A SURVEY OF SOCIAL SUPPORT NEEDS

A. Background Information

Your answers to these questions will help to understand your responses to other items in this questionnaire.

For each of the following questions, please CIRCLE your answers, and/or fill in the blanks provided.

1) Do you live in the Lower Mainland?

1. Yes
2. No

2) What is your age?

1. under 20 years
2. 20-29 years
3. 30-39 years
4. 40-49 years
5. 50-59 years
6. 60 years and older

3) What is your highest level of education?

1. some elementary school
2. completed elementary school
3. some high school
4. completed high school
5. vocational training / apprenticeship
6. some college or university
7. degree from college or university
4) What is your annual household income?

1. less than $6,300
2. $6,300 to less than $20,000
3. $20,000 to less than $30,000
4. $30,000 to less than $40,000
5. $40,000 to less than $50,000
6. $50,000 or more

5) How many people, including yourself, are supported by the income level above?


6) What are the sources of income in your household? (circle as many as needed)

1. income assistance
2. maintenance payments
3. disability pension
4. employment
5. savings
6. credit
7. other (please describe): 


7) Do you work outside of your home?

1. No
2. Yes
8) What type of housing do you have?
   1. own home
   2. rent home
   3. live in co-op housing
   4. live with parents
   5. other (please describe): ___________________________________________

9) On a scale of 1 to 7, how adequate is your income?

   
   1  2  3  4  5  6  7
   very neutral very
   inadequate adequate

10) What is your primary ethnic or cultural group?

   1. Aboriginal
   2. Chinese
   3. Korean
   4. Filipino
   5. Fijian
   6. Japanese
   7. Black
   8. Hispanic (Latina)
   9. South Asian
   10. Jewish
   11. White (Caucasian)
   12. Other (please describe): _______________________________________

11) What is your sexual orientation?

   1. Heterosexual (woman to man)
   2. Lesbian (woman to woman)
   3. Bisexual (woman to man or woman to woman)
12) Were you an injection drug user when you found out that you were HIV positive?

1. No
2. Yes

13) Are you an injection drug user now?

1. No
2. Yes

14) Do you have a partner/spouse now?

1. No (go to question 15)
2. Yes
   If yes, was this person your partner/spouse when you were diagnosed as being HIV positive?
   
   1. Yes (go to question 16)
   2. No (go to question 15)

15) When you were diagnosed as being HIV positive, did you have a partner/spouse?

1. No (go to question 16)
2. Yes
   If yes, what happened to your relationship with this person?
   
   1. I ended the relationship
   2. partner/spouse ended the relationship
   3. made decision together to end relationship
   4. partner/spouse died
   5. Other (please describe):
16) If you have a partner/spouse now, is your partner/spouse HIV positive?

1. No
2. I don't know
3. Yes

17) Do you have any children?

1. No (go to question 19)
2. Yes If yes, how many children do you have? ____________

What are the ages of your children? ______  ______  ______

18) Are any of your children HIV positive?

1. No
2. I don't know
3. Yes If yes, how many of your children are HIV positive? ____________

19) When were you diagnosed as being HIV positive? (fill in as much of the date as you know)

Year ________  Month ________
20) Who knows that you are HIV positive? (Circle as many as necessary)

1. Nobody
2. Partner/Spouse
3. Child(ren)
4. Parent(s)
5. Brother(s)/Sister(s)
6. Friend(s)
7. People I work with
8. Other people (please specify):

   

21) Do you think that you could have been diagnosed earlier than you were as being HIV positive?

1. No (go to question 22)
2. Yes If yes, for what reasons were you not diagnosed earlier? (circle as many responses as needed)

   1. My doctor(s) did not think my symptoms were related to HIV.
   2. I wasn't feeling sick.
   3. I was afraid to find out I might be HIV positive.
   4. I didn't think that I was at risk of being infected by HIV.
   5. Other (please describe):
22) Have you been diagnosed as having AIDS (acquired immunodeficiency syndrome)?

1. No  If no, have you had any illnesses related to HIV infection?
   1. No  (go to section B)
   2. Yes (go to section B)

2. Yes  If yes, when were you diagnosed as having AIDS?  (Fill in as much of the date as you know)

   Year __________   Month __________
B. Your Health

Please CIRCLE the number which corresponds to your answer for each question.

1) Please circle the number which best describes how you are feeling today:

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<td>not well</td>
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2) How well did you feel one year ago?

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3) Do you use any traditional types of medicine (for example: seeing medical doctors, using prescription drugs)?

1. No
2. Yes If yes, how satisfied are you with these traditional types of medicine you use?

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<tr>
<td>very unsatisfied</td>
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<td>very satisfied</td>
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4) Do you use any alternative types of medicine (for example: acupuncture, homeopathy, herbal therapies)?

1. No
2. Yes If yes, how satisfied are you with these alternative types of medicine you use?

1 2 3 4 5 6 7
very    neutral very
unsatisfied    satisfied

5) Do you use any dental services?

1. No
2. Yes If yes, how satisfied are you with these dental services?

1 2 3 4 5 6 7
very    neutral very
unsatisfied    satisfied
C. Social Support

The questions in this section ask about people and services, and how they support you.

Please CIRCLE your answers.

1) How satisfied are you with your housing situation?

1 2 3 4 5 6 7
very neutral very
unsatisfied satisfied

2) How satisfied are you with the transportation you use?

1 2 3 4 5 6 7
very neutral very
unsatisfied satisfied

3) Do you have any children?

1. No
2. Yes If yes, how satisfied are you with the child care you have for your children?

1 2 3 4 5 6 7
very neutral very
unsatisfied satisfied

4) Do you use any legal services?

1. No
2. Yes If yes, how satisfied are you with these legal services?

1 2 3 4 5 6 7
very neutral very
unsatisfied satisfied
5) Do you use any counselling services?

1. No
2. Yes  If yes, how satisfied are you with these counselling services?

1  2  3  4  5  6  7
very unsatisfied neutral very satisfied

6) Do you use any homemaker services?

1. No
2. Yes  If yes, how satisfied are you with these homemaker services?

1  2  3  4  5  6  7
very unsatisfied neutral very satisfied

7) Do you use any shopping services?

1. No
2. Yes  If yes, how satisfied are you with these shopping services?

1  2  3  4  5  6  7
very unsatisfied neutral very satisfied

8) Do you have enough money to buy the food you need?

1  2  3  4  5
never  seldom  sometimes  often  always
We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the 1 if you **Very Strongly Disagree**
Circle the 2 if you **Strongly Disagree**
Circle the 3 if you **Mildly Disagree**
Circle the 4 if you **are Neutral**
Circle the 5 if you **Mildly Agree**
Circle the 6 if you **Strongly Agree**
Circle the 7 if you **Very Strongly Agree**

1) There is a special person who is around when I am in need.

2) There is a special person with whom I can share my joys and sorrows.

3) My family really tries to help me.
4) I get the emotional help and support I need from my family.

1 2 3 4 5 6 7
very strongly mildly neutral mildly strongly very strongly
disagree disagree disagree agree agree strongly agree

5) I have a special person who is a real source of comfort to me.

1 2 3 4 5 6 7
very strongly mildly neutral mildly strongly very strongly
disagree disagree disagree agree agree strongly agree

6) My friends really try to help me.

1 2 3 4 5 6 7
very strongly mildly neutral mildly strongly very strongly
disagree disagree disagree agree agree strongly agree

7) I can count on my friends when things go wrong.

1 2 3 4 5 6 7
very strongly mildly neutral mildly strongly very strongly
disagree disagree disagree agree agree strongly agree

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8) I can talk about my problems with my family.

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9) I have friends with whom I can share my joys and sorrows.

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10) There is a special person in my life who cares about my feelings.

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11) My family is willing to help me make decisions.

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12) I can talk about my problems with my friends.

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We would like to know if you use any services provided by the organizations below. Please circle your answers and/or fill in the blanks.

1) Do you use any of the services provided by the Positive Women's Network?

1. No
2. Yes If yes, which services do you use? (circle all that you use)

1. Support group for positive women
2. Information services
3. Drop-In
4. Child care
5. Transportation Allowance
6. Telephone "Buddy"
7. Retreat
8. Other (please describe):

__________________________________________

__________________________________________

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2) Do you use any of the services provided by the Vancouver Persons with AIDS (PWA) Society?

1. No
2. Yes

If yes, which services have you used? (circle as many as you use)

1. Money for alternative medical care
2. Help in finding housing
3. Counselling services
4. Drop-In
5. Advocacy
6. Legal Aid
7. Food Bank
8. Other (please describe):

3) Do you use any of the services provided by AIDS Vancouver?

1. No
2. Yes

If yes, which services do you use? (circle as many as you use)

1. Food bank
2. Information services
3. Buddy system
4. Financial assistance
5. Speaker's Bureau/Education Services
6. Emergency Assistance Fund
7. Advocacy
8. Liaising with homecare services/Vancouver Meals Society
9. Other (please describe):
Appendix H: Summary of Pretest Results

The survey questionnaire was pretested by representatives from the three liaison organizations involved in the study, by representatives from Vancouver FWA, AIDS Vancouver, the Vancouver Health Department, by at least one woman who is HIV positive, and by the research professor.

The question arose whether the study should be limited to women who are HIV positive in the Lower Mainland. It was decided that this geographical limitation would remain in order to survey women who perhaps had somewhat similar experiences and had access to similar services in the Lower Mainland. If telephone calls were to become a part of the study, the cost of long-distance calls could not be covered by the student researcher, and therefore the study was limited to women living in the Lower Mainland.

An educational category of vocational training or apprenticeship was recommended and was included in the final draft of the questionnaire.

The fifth question in the "background" section was reworded as some pretesters found the wording ambiguous. Rather than using the word "household", the number of people living in a woman's home was worded as "supported by the income above".

A question asking if the woman was presently working was included, because this information was not necessarily clear from the question asking about sources of income. The type of housing a woman lived in was thought to be important, and
a question addressing this was added.

Under the ethnic/cultural group question, a category for Jewish women was suggested and added. One pretester suggested that a question asking if a woman's partner is an injection drug user be added, but this was not considered to add substantially to information about the woman. The day of diagnosis of being HIV positive was eliminated after one pretester informed the researchers that a person could, although with difficulty, be traced if this information was included. The day of AIDS diagnosis was also eliminated because this detail was considered unnecessary.

The question addressing a diagnosis of AIDS was problematic. Pretesters said that the definition of AIDS adopted by the CDC had recently been revised, and noted that women were often not diagnosed with AIDS because they did not experience the opportunistic infections included in its definition. In order to be able to differentiate between women who had and had not been given a diagnosis of AIDS, the question was retained. An additional section was included to target women who responded that they had not been diagnosed with AIDS. The added question asks whether a woman has had any illnesses associated with HIV infection. This would allow for a comparison of results between potentially "well" and "sick" women who are HIV positive. One pretester noted that the experiences of these two groups of women were often quite different and the study should be able to examine
these.

It was suggested that for each of the medical, dental and service questions requiring a rating that space be allowed for women to record the actual service or type of medicine they were using. It was decided that such information would complicate the questionnaire, possibly resulting in respondents skipping questions.

The questions about traditional types of medicine, dental services, homemaking and shopping services were suggested following the pretest. The wording of the questions was changed from asking about adequacy of the services to satisfaction with the services, in order to gain the most subjective opinion possible of social support.

The standardized questionnaire was moved from the beginning to the end of the social support section of the questionnaire after a few pretesters noted that it seemed abrupt and misplaced originally. Pretesters suggested that adequacy or satisfaction with diet was not the best way to phrase this question. It was changed, on the recommendation of one pretester to read: Do you have enough money to buy the food you need?, which provides greater clarification. The scale was changed to a five-point scale.

The lists of services provided by AIDS organizations were enhanced by representatives from the services to provide more complete lists. One pretester suggested that questions be included to ask why women might not access these services,
but it was decided that this was beyond the scope of the study.
Appendix I: Review of other Social Support Scales

The Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet, Dahlem, Zimet and Farley, 1988) was chosen as the standardized measure for the present study. This measure was chosen over others, such as the Social Support Questionnaire (Sarason, Levine, Basham and Sarason, 1983) and the Norbeck Social Support Questionnaire (Norbeck, Lindsey and Carrieri, 1983; Norbeck, Lindsey and Carrieri, 1981), because of its focus on perceived support, its simplicity, its short length, and its psychometric soundness. The other measures of social support examined required lengthy involvement of the subjects, and the actual listing of names or initials of persons in the support network. The MSPSS alternatively uses a seven-point Likert scale in response to each of 12 questions.

The Significant Others Scale (SOS) (Power, Champion, and Aris, 1988) and the Shortened Social Support (SSS) scale (Funch, Marshall, and Gebhardt, 1986) were also examined, and contained measures of perceptions of support. However, they were still largely in the developmental stages, and psychometric soundness has not been adequately established.
Appendix J: Permission for Use of MSPSS
Appendix K: Comments at End of Questionnaire

01 - homemaking service should be better. Before homemaking service implemented, no one wanted to come. Not set up properly. Three months of fighting with them. Still problems: no understanding of HIV. Need AIDS education.

02 - Would like to have homemaking services available when not feeling well. Same for childcare. Re: services (PWN, PWA, AIDS Vancouver): feel intimidated to ask for services. Even though in a higher income bracket, doesn't mean that spouse is willing to help pay for med's. Re: spouse. Feel no financial support for extras I need to keep me healthy. On food supplement - have to ask grandparents for money for these. When not well, spouse makes me feel guilty for not taking care of children. Re: HIV diagnosis: Doctor tested me without me knowing I was being tested. This should not happen.

03 - Would like something to happen in Surrey. If more people came forward, could set up a group. Then wouldn't have to plan whole day and travel. Difficult when looking after a family.

06 - PWA has not made me feel welcome or able to be involved and in fact PARC in general is viewed by myself and other straight women, men and certain gay friends to be an exclusive hostile environment where I am not comfortable or wanted.

08 - (participant indicated her name)

11 - would be useful if social services would provide a driver for 4 days per month on days when I know I have to do errands, eg. picking up AZT I talk about problems with nurses, doctor, and social workers even though I don't have much contact with family or friends Need more specialists (physicians) for children who are HIV positive.

12 - I am an AIDS Educator and do speaking engagements for PWA. I do phone counselling when asked to contact someone in my age group. I'm also involved in a HIV-T Support Group with the Hemo Society (CHS). I've gone public for PWA and AIDS Vancouver. I feel we all have to work together to get the stigma off this disease. It does not matter how we got it or where it came from. The past cannot be changed, but I'm not throwing away to-day!
13 - PWN building is not in a good location. I'm intimidated by shared space with PWA. All doctors should be more aware of HIV infection; 9 out of 10 doctors don't have pamphlets in their offices on AIDS/HIV. Need more openness among doctors to provide info. I believe that many more women are affected by HIV than we are aware of.

15 - It's not always necessary for people to use AIDS' services. I deal with it with my friends; those that know are supportive.

17 - People have to know we're out there; right next door. Then we wouldn't have to keep it a secret. It's not just gays and drug users; not just those.
WHY AN HIV POSITIVE WOMAN IS NOT HERE

Thank you again for your invitation for an HIV positive woman (HIVP) to participate in your event. The very reasons we are unable to attend or participate are typical issues for positive women, and we would like to take this opportunity to share some of these with you.

Women living with HIV or AIDS are enmeshed in a complex web of issues, each of which takes time and energy to accommodate. Dealing with the issues described below can leave women with few resources for community work. These issues explain why there are fewer than a dozen HIV+ women doing community work in the Lower Mainland, and why there are less than half a dozen willing to do public speaking in all of British Columbia.

- Women fear loss.
- Rural women fear discrimination and ostracism based on HIV status.
- We don't want to be stigmatized.
- Women with children have many more demands on their energy.
- Women are often caretakers.
- Living with a complicated medical regimen takes time and energy.
- Lack of community and the illness itself take a toll on HIV positive women.