

AN ASSESSMENT OF THE PERCEIVED NEEDS
OF WOMEN LIVING WITH HIV/AIDS IN SASKATCHEWAN

by

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Abstract

This study explores and describes the perceived needs of women living with HIV/AIDS in Saskatchewan. A purposive sample was used to recruit women to participate in three focus groups. A total of eleven women from urban and rural areas of Saskatchewan participated. Based on seroprevalence estimates this number may represent one third to one half of all expected cases of women with HIV/AIDS in Saskatchewan. Recursive analysis was used to validate the themes identified in the first two focus groups with participants in a third focus group. Content analysis of the data identified four themes from the women's experiences: 1) medical needs, 2) economic needs, 3) mental health needs, and 4) service needs. The results support previous studies which indicate that women with HIV have a number of unmet needs. Women from rural areas were found to have more unmet needs and limited access to appropriate services and supports than urban women. Three types of coping strategies were found to be used by the women in getting their needs met: avoidance, maintenance, and mastery. Those who utilized a mastery coping strategy were more successful in having their needs met than those who did not. A number of individual, organizational, systemic, and policy interventions are identified to assist women in moving towards mastery coping strategies. Social workers can work at the clinical, family group, and policy levels to improve the situation for women living with HIV/AIDS in Saskatchewan.

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CHAPTER 1 - INTRODUCTION

The medical effect is only a small part of having AIDS, it's the social part that is difficult. I'm not sick now but if I do get sick I can go to a hospital and get medication for it, but there isn't anything for the effects of the way people blame you for getting it and think that you're a slut or druggy. They don't treat you like a normal person. So you have to deal with the medical effects, the social effects and the psychological effects. In helping women to deal with having AIDS all of these have to be dealt with together because they all affect the person. They are all connected. Like I said I'm not sick but I'm still affected by it. It's a part of my life, a part of everything that I do now.

In Canada women are the fastest growing category of people with AIDS, yet there is only limited information available on women with HIV/AIDS (Stuntzner-Gibson, 1991; Easton, 1992). While women and men face many of the same issues in dealing with HIV/AIDS: denial, shame, fear, depression, loss, isolation (Macks, 1988; Stuntzner-Gibson, 1991), the degree to which these affect women, as well as the lack of available resources and supports, makes the experience of women with HIV/AIDS very different from that of men with HIV/AIDS.

The purpose of this study is to identify and describe the perceived needs of women living with HIV/AIDS in Saskatchewan. The results of this study will provide information upon which social workers and other service

agencies and professionals can build a more responsive system to help women with HIV/AIDS in Saskatchewan. It will identify perceived needs, and service gaps in the systems of support service delivery for women with HIV/AIDS in Saskatchewan.

Chapter two examines relevant literature. A review of the social support literature is presented as it has been shown to be an important factor in maintaining psychological and physiological well-being when people are exposed to stressors. The stress and coping literature is reviewed to identify the role that social support can play in ameliorating the negative effects of diseases such as those associated with HIV. The importance of the perception of an individual being the most significant indicator of support is proposed. Studies are reviewed to explore the role that social support plays in coping with and in the progression of chronic illnesses. Literature and studies on HIV/AIDS are examined to identify links between chronic illness, HIV/AIDS, and the role of social support. The etiology of HIV and AIDS, including both physical and emotional effects are noted. The issue of women and HIV/AIDS is then reviewed to provide insight into the differences between women with HIV/AIDS and men with HIV/AIDS. Finally, previous studies on the needs of those living with HIV/AIDS are reviewed to provide a perspective on what has been done and the need for this study.

Chapter three provides an outline of the study design. A qualitative approach was undertaken in this study. A purposive sample was used to obtain the participation of women living with HIV/AIDS in all of the three focus groups that were conducted. The focus groups were audio-recorded and then transcribed. Following the first two focus groups, data derived therefrom were subjected to content analysis and the results were presented to a third focus group and they were asked to comment on the validity of the themes identified. Participants provided feedback and further data that were then analyzed. Limitations to the study are also discussed in this chapter.

Chapter four presents the findings from the three focus groups within a framework of four general categories of needs: medical, mental health, informational, and service delivery. Within each group, medical needs were discussed in relation to accessibility (to doctors, health care facilities, and drug trials), information (that was accessible, relevant and understandable), and experiences with health professionals (personal experiences with doctors and hospital/health staff, and the treatment of their children by health professionals). Economic needs were discussed in relation to having enough money (for food, transportation, child care, legal services, housing, clothing) and getting money (gaining access to services that

provide assistance and receiving benefits to which they are entitled. Mental health needs were discussed in relation to pressures and stressors (isolation, family relationships, social discrimination) and service providers (accessibility, competency, types). Service needs were discussed in relation to information (options, resources, relevancy), access (use of, crisis response, and bureaucracy), adequacy (income assistance, provisions), and experiences with service providers (insensitivity, personal agendas).

Chapter five presents a discussion of the findings. A model outlining three coping strategies that the participants used in getting their needs met is presented and discussed. Suggestions for interventions on a personal, organizational, system and policy levels are presented. Suggestions for future research are also presented.

The literature has shown that HIV-infected women are affected by a combination of physiological, psychological, sociological and political forces. Factors such as age, socio-economic class, ethnicity, having children and/or a partner, social supports, geographic location, coping style and ability, individual perceptions, and progression of diseases associated with HIV all play an integral role in the effect HIV/AIDS has on an individual. An understanding of the needs of women with HIV//AIDS in Saskatchewan and how these needs are and are not being met will provide

information that could enable service providers to develop more appropriate services and policies. It is therefore important that women with HIV/AIDS be asked what they perceive their needs to be.

CHAPTER 2 - LITERATURE REVIEW

This chapter reviews the current literature pertaining to the value of perceived social support in contributing to a greater sense of physical and emotional well-being in the lives of women with HIV/AIDS. Social support is explored as an important factor in maintaining psychological and physiological well-being when exposed to stressors. Stress and coping literature is reviewed to identify the impact that stress can have on an individual as well as the role of coping in moderating stress. Studies are reviewed to explore the important role that social support plays in the coping with and progression of chronic illnesses. Literature and studies on HIV/AIDS are reviewed to provide links between chronic illness, HIV/AIDS, and the role of social support. Specific psychosocial factors and losses associated with HIV/AIDS and their effect on the individual are discussed. Literature concerning women and HIV/AIDS is reviewed to provide insight into the differences between women and men with HIV/AIDS. Finally, previous studies on the needs of those living with HIV/AIDS are reviewed to provide a perspective on their results and the need for this study relative to other studies.

Social Support

Social support is a multi-dimensional construct that has no constant definition. There have been many attempts to define social support. Shumaker & Brownell (1984) define support as "an exchange of resources between two individuals perceived by the provider or recipient to be intended to enhance the well being of the recipient" (p.13). This definition suggests that one must consider the perceptions of the recipient and the giver of support to determine the influence of the exchange. This definition implies that there may be different perceptions of social support. For example, what one perceives as social support might not be so perceived by another.

Reis (1983) proposes a definition of social support that focuses on the perception of the recipient in determining whether social support exists. Reis describes social support as "the perception that one feels cared for, esteemed, or otherwise closely involved with other people" (p.24).

Types of Social Support

Several different classification schemes have been developed to distinguish between different types of social support (Pattison, 1977; Cobbs, 1976; House, 1981).

Pattison provides the most basic classification system. He

identifies two types; instrumental and affective.

Instrumental support addresses the tangible forms, such as material aid and financial assistance, whereas affective support includes such things as emotional, social reinforcement, recognition, and esteem building. Cobbs defines three basic types of social support: tangible (money, food); informational (about available resources); and emotional (acceptance, acknowledgement, love). House adds to these by defining social support as "an interpersonal transaction involving one or more of the following; (1)emotional concern (liking, love, empathy), (2)instrumental aid (goods or services), (3)information (about the environment), or (4)appraisal (information relevant to self-evaluation)" (House, 1981, p.39).

Other researchers offer extensive conceptualizations of different types of support. Barrera and Ainley (1983, pp.135-136), for example, describe six categories of social support: material aid (providing tangible materials in the form of money and other physical objects), behavioral assistance (sharing of tasks through physical labour), intimate interaction (traditional nondirective counselling behaviours such as listening, caring, expressing understanding), guidance (offering advice, information or instruction), feedback (proving individuals with feedback about their behaviours, thoughts, or feelings), and positive

social interactions (engaging in social interactions for fun and relaxation).

As more studies on social support are undertaken, there appears to be an increase in the number of classification schemes. Although there are numerous definitions of support, the basic premise underlying all models is that those who perceive themselves as having social support are physically and emotionally healthier than those who do not. Unfortunately no model has been shown to accurately indicate how social support promotes physical and psychological well being (Thoits, 1982). One step toward understanding the process of how social support works to promote the well-being of an individual may be found in the stress and coping literature. The work in this area attempts to explain what effect social support may have on helping individuals to cope with life events, regardless of whether they are perceived as being stressful.

Stress and Coping

Stress occurs when an event is perceived to be of threat or harm to an individual, or when it exceeds the individual's ability to effectively manage the event (Lazarus & Folkman, 1984; Hymovich & Hagopian, 1992). When one perceives oneself to be under stress, one seeks different ways of dealing with the perceived stressor

(Thoits, 1986). This process, known as coping, involves "efforts, both action-oriented and intrapsychic, to manage environmental and internal demands, and conflicts among them, which tax or exceed a person's resources" (Lazarus & Launier, 1978, p.311).

Cohen & Wills (1985) and Thoits (1986) hypothesize that coping works to moderate the negative effect of a stressful situation. In the coping process, social support works by changing the situation, altering the meaning it has, and/or changing the individual's affective response to the stressor. Others have proposed that social support is instrumental in the coping process by enhancing one's self esteem and sense of self-control over one's environment (mastery), engendering positive emotional experiences, thereby reducing the negative effects of stress (Pearlin, Lieberman, Menaghan, & Mullan, 1981).

Pearlin and Schooler (1978) propose that the level of mastery influences the ability to successfully cope with stress. They hold that women who have high mastery are able to cope more successfully with stress than those with low mastery. Mastery is a personal resource that is central to self-concept and a powerful determinant of stress outcomes (Pearlin & Schooler, 1978). Mastery is defined as the extent to which life chances are perceived to be under an individual's control. It includes both an internal sense of

control and a feeling of successful manipulation of the environment. Research suggests that those high in mastery are likely to have the ability to successfully manipulate social aspects of their environment (Hobfoll & Lerman, 1989; Thoits, 1987). Women with high mastery are more likely than those with low mastery to be able to cope effectively with life challenges and to seek help only when needed (Hanson, Jones, & Carpenter, 1984; Kobasa & Puccetti, 1983). In contrast women with low mastery lack these competencies (Hanson et al., 1984).

Because of their internal resources, high mastery women are more likely to acquire and use social supports more effectively than low mastery women. As a result they are more successful in coping with stress (Kobasa & Puccetti, 1983; Hobfoll, Nadler, & Leiberian, 1986).

Lazarus' transactional model of stress (Lazarus, 1981) further explains the connection between the presentation of a stressful event and the use of social support. Lazarus proposes that when an event occurs, the individual's perception of that event plays a vital role in the potential effect it may have. The basic premise of this model is that an individual's reaction to a situation depends upon the assessment of that situation as a threat. This assessment or cognitive appraisal has been divided into two components: primary and secondary (Lazarus & Launier, 1978).

Primary appraisal refers to the interpretation that an individual gives to a situation or potential stressor. It involves the individual assessing an event in relation to his/her well-being (Folkman, Lazarus, Gruen, & DeLongis, 1986). During the stage of primary appraisal or initial assessment, supportive exchanges can broaden the individual's interpretation of the event and help the individual to clarify his/her understanding of the situation. If a situation is irrelevant, it is viewed as having no effect, or a positive effect upon a person. If the situation is appraised as a threat, and stress inducing, secondary appraisal occurs.

Secondary appraisal refers to an individual's assessment of available coping resources. It is during this stage where coping or "the strategies for dealing with threat" become relevant (Lazarus & Launier, 1978). Support can be useful at this stage by increasing the number of coping options or resources that the individual perceives to be available (Schilling, 1987). Social support may also be influential during this stage by providing the individual with the direct resources that he/she needs to cope with the stressor (Cohen & McKay, 1984). This is useful in that it may decrease or limit the period of exposure to a threat. This limits the potentially deleterious physical and psychological effects that a stressor may induce.

According to Lazarus et al. (1974) "All coping and emotion flow from these mediating appraisals, and it has been our position that we must understand the appraisal process and the conditions that influence it in order to understand coping and emotion" (p.260). Central to this and related models is the role of the perceived meaning of the stressor and the response or coping alternatives that individuals perceive to be available to them (Schachter, 1966). The success of social support as a coping resource depends on how well the resources exchanged meet the recipient's stress-related needs (House, 1981).

Taylor (1983) provides further details of the operationalization of the evaluation processes (primary and secondary). He hypothesizes that an individual goes through a series of processes to cognitively cope with a presenting situation; a search for the meaning of the event, an attempt to regain mastery, and the enhancement of self esteem. Taylor hypothesizes that social support can play an important role in each of these processes by providing the individual with resources that influence one's frame of mind during the appraisal of an event. For example, if the individual perceives a situation as a threat, the perception of having available social support may function to provide an increased sense of self-esteem and self-control in secondary appraisal. In this way the individual is likely

to respond to the situation in a manner that does not negatively affect his/her physical or mental health. This may be achieved through having the feeling that a situation can be successfully managed through the use of personal skills or through securing help from friends, family, peers or professionals. The individual is therefore less likely to feel out of control, or incompetent and less likely to have psychological or physical residual effects from this situation (Heller & Swindle, 1983).

To better understand how social support operates in primary and secondary appraisal it is useful to look at two hypotheses that have been proposed to explain its effect on assisting the individual to cope: direct-effect, and buffering-effect. The direct-effect hypothesis proposes that social support influences health by strengthening the individual in some direct manner regardless of the presence of stressors (Broadhead, Kaplan, James, Wagner, Schoenbach, Grimson, Heyden, Tibblin, & Gehlbach, 1983). In this hypothesis social support provides the individual with a healthy sense of self and personal resources even in the absence of perceived stress. In this way a repertoire of coping mechanisms and resources is constructed that allows an individual to make sense and feel in control of situations (mastery) regardless of the presence of a perceived stressor (Heller & Swindle, 1983). Aaron

Antonovsky (1979) in a comprehensive study of vulnerability and immunity provides evidence that supports this.

Antonovsky found social support to be a more general resistance factor that reduces "breakdown" (ie. impaired physical, psychological, and social functioning) and enhances coping throughout the life cycle.

Other investigators have found that social support acts more as a buffer that protects individuals from the harmful effects of stress (Cohen & McKay, 1984; Gore, 1981; House, 1981). According to this buffering-effect hypothesis, social support acts as a reserve and a resource to blunt the effects of stress or to enable an individual to cope with stress more effectively when it is at high levels.

John Cassel (1974) provides evidence that social support buffers physical and psychological distress. In his analysis of social support and health and illness, Cassel found that social support is capable of moderating stressful life events and therefore is a major factor in distinguishing individual vulnerability to illness. He found that when an individual undergoes change, especially if it is unwanted or unexpected, the buffering effect of support is greatest.

The link between social support and stress has been supported by Rook (1984). His study provides evidence for the belief that social support facilitates adjustment to

stressful life events and decreases vulnerability to stress related disorders. He found that social support aided in the adaptation to a stressor, decreasing the likelihood or severity of adverse physiological or emotional effects of the stressor on the individual (Rook, 1984).

Measurements of Social Support

One of the problems in studying the effects of social support is that there are no constant measures for assessing the presence of social support. The literature identifies three approaches for study: social embeddedness, enacted support, and perceived social support (Barrera, 1986).

Social embeddedness refers to the connections that individuals have to significant others. A social network, direct and indirect linkages that connects an individual to family, friends and peers has been the instrument used to measure social embeddedness (d'Abbs, 1982; Mitchell & Trickett, 1980; Wellman, 1981). These connections are viewed as indicators of social resources that might function as a support in time of crisis. Social embeddedness is believed to be associated with one's sense of belonging to the community and implies a lack of alienation and social isolation (Gottlieb, 1983; Sarason, 1974). A shortcoming of social embeddedness measures is that they often list numbers of people within a network but do not necessarily assess the

quality of support offered to the individual (Barrera, 1981).

Enacted support refers to the specific behaviours or actions that others perform in providing assistance to an individual. Tardy (1985) refers to behavioral descriptions of support (listening, giving advice, showing affection, lending money, providing information), as "enacted" support to separate it from support that is potentially available (social embeddedness) and support that is useful to the recipient (perceived support). Measures of enacted support complement other measures by assessing what individuals do when they provide support (Cowen, 1980; Gottlieb, 1978). Measures of enacted social support measure "perceived-received" support. A shortcoming of enacted support measures is that they list actions that others perform with the intention of being supportive but which may not be viewed by the recipient as being helpful. In many cases, the actions of others may be more harmful than helpful. There are many examples of incongruent social support in which providers feel they are being helpful, while the recipients feel they are not. For example, the bereaved are often recipients of well-meaning but inappropriate remarks from friends and relatives (Kushner, 1983; Schiff, 1977). Comments such as, "It's probably for the best", or "You'll get over it", do little to alleviate and may actually

exacerbate the pain of someone who has suffered the death of a loved one (Schilling, 1987).

Perceived social support is characterized as a cognitive appraisal of one's connections to others. Many measures of perceived social support involve perceived availability and adequacy of support (Cohen & Hoberman, 1983; Holahan & Moos, 1981; Procidano & Heller, 1983; Turner, Franklin, & Levin, 1983). Measures of perceived support recognize that not all linkages between individuals and their environment result in social support. It recognizes that while the potential for social support may exist, it must be perceived as available or adequate to meet the need (Cohen & Hoberman, 1983; Procidano & Heller, 1983; Turner, Frankel, & Levin, 1983). Measures of perceived social support uses the cognitive appraisal of an individual to the environment and confidence in the availability and adequacy of support (Tracy, 1990; Barrera, 1981; Henderson, Byrne, & Duncan-Jones, 1981).

Perceived adequacy of support has been found to be more predictive of a positive outcome than availability of support (Turner, 1981). Wethington and Kessler (1986) suggest that the difference between received support and perceived support is important in stress and coping research. They found that the perception that suitable supports are available provides increased self esteem that

better enables an individual to cope with presenting situations.

Cohen and McKay (1984) agree that perceived support is the most effective measurement of social support. They found that social support is only effective as a stress buffer if the resources provided match the demands posed by the stressor. Thus, emotional support will not be effective if tangible assistance is needed and vice versa.

Studies have also shown that the perception that one has available resources to draw upon to provide emotional or active assistance in times of need can be beneficial for one's mental health (Wethington & Kessler, 1986).

Individuals who report high levels of perceived support report fewer psychological symptoms and appear to be more resistant to the adverse effects of stressors than do individuals who report relatively low levels (Cohen & Wills, 1985).

Social Support and Illness

The exact link between social support and the likelihood of illness is not clearly understood. Studies in this area have concluded that the presence of social support can reduce many of the negative consequences of stress, including symptom reporting, health-related restrictive activity and depression (Elliot & Eisdorfer, 1982; McKinlay

et al., 1988; Cohen & Will, 1985; Gottlieb, 1981; Sarason & Sarason, 1985; Cohen & Syme, 1985; Duck & Silver, 1990; Gottlieb, 1987; Sarason, Sarason & Pierce, 1990; Rook, 1984).

Other studies suggest that individuals with high levels of support are less likely to develop serious illnesses due to positive changes in the immune system (Jemmott & Locke, 1984; Levy & Krueger, 1985).

Plaut & Friedman (1981) found, in a review of literature on the ways psychosocial factors influence the disease process, that mechanisms underlying these effects include hormonal and biochemical changes which are instrumental in altering the vulnerability or susceptibility of an individual to disease. Of the studies reviewed, results generally supported the belief that the actual stressor or event was less important than the perception of the individual's ability to cope with that stressor.

Cohen & Syme (1985) suggest that perceived social support has a positive effect on disease etiology and recovery from illness. They propose that social support is instrumental by enhancing self-esteem and positive feelings. These are thought to indirectly strengthen the immune system, thereby speeding recovery from illness and reducing susceptibility to disease.

Studies in the areas of cancer have also reported a positive relationship between social support and both psychological and physiological well-being (Bloom, 1982; Lichtman & Taylor, 1986; Taylor, Falke, Shoptaw & Lichtman, 1986). Individuals who reported receiving support from others at the time of a cancer diagnosis were found to experience less emotional distress and survive longer (Funch & Marshall, 1983; Weisman & Wordon, 1975).

There is extensive literature on the role of social support at different stages of dying and variations in levels of social support according to the chronicity of illness (Glaser & Strauss, 1968; Anderson & Bury, 1988; Corbin & Strauss, 1988). Research into the role of social support in the management of long term and/or terminal illness has generally found a positive link between social support, the individual's ability to cope with illness, and the promotion of recovery (Wortman & Dunkel-Schetter, 1979; DiMatteo & Hays, 1981; Wortman, 1984; Madge & Marmot, 1987). Studies with both humans and animals have provided evidence that psychosocial factors may greatly influence the functioning of the immune system (Jemmot & Lock, 1984; Levy & Krueger, 1985). Kiecolt, Glaser and Glaser (1988) have shown that stress is an important factor in the development of the herpes virus and in susceptibility to the common cold.

The study of social support and HIV/AIDS is fairly new. Solomon (1987) hypothesizes that stress and psychosocial factors can influence the replication of HIV and the progression of AIDS. Antoni, LaPerriere, Schneiderman, and Fletcher (1991) suggest that stressors related to HIV/AIDS such as receiving a positive diagnosis may trigger numerous psychological and physiological events that impair cellular immune functioning.

Social support has been shown to play a vital role in influencing disease etiology and progression in chronic illness. The provision of instrumental and emotional supports has been shown to be important in limiting the psychological effects of stressors (Cohen & Wills, 1985; Wethington & Kessler, 1986). Studies have also shown that stress and the resulting psychological factors play a role in immune functioning and virus replication (Jemmott & Lock, 1984; Levy & Krueger, 1985; Kiecolt, Glaser and Glaser, 1988). Drawing upon these studies, it would follow that social support may play a key role in helping limit the effects of stressors faced by those infected with HIV.

Social Support and HIV/AIDS

Definition and History

Acquired Immune Deficiency Syndrome (AIDS) is a group of illnesses that may occur after infection with the Human Immunodeficiency Virus (HIV), a slow-acting retrovirus that attacks the immune system. When the immune system is impaired the body becomes vulnerable to infections and cancers typically warded off by people with healthy immune systems. These illnesses are called opportunistic infections, and they may or may not be fatal (Haley, 1993).

In the beginning HIV/AIDS was viewed as a disease that affected only gay men. This disease, or GRID (Gay Related Immune Deficiency Syndrome) as it was initially called, received little attention in the popular media because it was believed to affect only a marginalized segment of the population. Even when GRID, or AIDS as it was later renamed, was found to infect intravenous drug users, hemophiliacs, and members of the Haitian community, there was still little interest in the disease. It was not until AIDS began to affect non-marginalized members of society (i.e. heterosexual men) that public attention was directed toward addressing this disease (Treicher, 1987).

The fact that HIV/AIDS was first discovered in members of a marginalized community, has been an important factor in how HIV/AIDS is viewed. It has also influenced the

treatment of those with HIV/AIDS in society, the availability of resources to help those with HIV/AIDS, and ultimately the number and degree of stressors that an individual with HIV/AIDS must confront. At first research focused more on transmission routes of HIV and effective methods of prevention. Not until recently have the physiological and psychological effects of HIV/AIDS on infected individuals been studied. The result of the lack of information that focuses on the socio-psychological aspects of HIV/AIDS, coupled with the fact that it has been associated with gay men and that it is fatal and sexually transmissible, has led to those with HIV/AIDS being stigmatized, feared, blamed, ostracized, and discriminated against by society at large. These factors and the nature of the infection/disease which simultaneously increases the need for support and makes the provision of support less likely, leave people with HIV-infection vulnerable, thus increasing the need for social support (Green, 1993). Any examination of HIV/AIDS must always be considered within this larger social context, because it is within this context that people with HIV/AIDS attempt to cope with their illness.

Psychosocial Needs and Issues of People with HIV/AIDS

People with HIV-infection face a complex set of psychosocial needs and issues as they confront HIV-infection. Many of the psychological responses and coping mechanisms for dealing with HIV infection are similar to those of other life-threatening illnesses. However the social and political nature of HIV/AIDS may limit the coping resources and/or exacerbate the effects of stressors.

Numerous researchers have written on a number of losses and psychosocial changes that one faces in coping with HIV/AIDS (Ahmed, 1992; Manson Willms, 1992, Kneisl, 1993, Hamilton, 1993; Cambridge, 1993, Green, 1993). These include loss of: health; finances, job or former lifestyle; stigmatization, rejection, isolation; support from peers, family or friends; self esteem; physical contact, intimacy and sexual capability; a sense of stability, predictability or feelings of control; future hopes and dreams; and multiple death losses.

Loss of Employment and Income

HIV/AIDS usually strikes people "in the prime of life". With the onset of symptoms, individuals with HIV/AIDS may find themselves unable to perform the duties of their jobs. Changes such as decreased strength and energy, limited mobility and difficulty in concentration may require

individuals to work less or quit their jobs. The consequences of a decrease in income not only includes the loss of ability to provide for oneself and one's significant others, but also the sense of a loss of self-worth, identity and pride. Individuals are often forced to rely on family, friends and social agencies for financial support during a period in their lives when they should be focusing on establishing independence. They may also perceive themselves as being a drain on the system at precisely the time that they should be making maximum contributions to the system. For those individuals who have no replacement for loss of employment, feelings of depression, anger, boredom and isolation are exacerbated by empty days (Macks & Turner, 1986). With the loss of employment and the personal and social identity that is attached to work, individuals with HIV experience a loss of self-identity and social connectedness. Without supports that provide a sense of worth, purpose and identity, individuals with HIV may experience a decline in mental and physical health.

Stigmatization: Rejection and Isolation

Individuals with HIV-infection may also be stigmatized and ostracized. Because of the history and nature of the disease, people with HIV/AIDS have been viewed as guilty and deserving of their infections. The social perception of

those with HIV/AIDS has led to internalized guilt, self-blame and a lower sense of self-worth. The feelings that result from internalized self-blame, inferiority and inadequacy, can seriously impair one's ability to cope (Namir, 1986).

The actual occurrence as well as the fear associated with the possibility of being blamed and rejected may lead to increased isolation and alienation. Consequently, when diagnosed with HIV/AIDS an individual faces the dilemma of who to tell. An individual must decide whether to reveal his/her status and open up opportunities to receive support (Taylor, 1990). There are many factors that influence this decision: perceived support, perceived rejection, and the effects on the individual's family, especially children.

Those who perceive that their disclosure will be met with a negative response are not likely to reveal their status to others. This lack of social support combined with the need to hide their status may increase a sense of isolation and reinforce self-blame. Those who are able to selectively disclose may also experience these feelings if they have to hide their status from friends, family, peers, and cohorts.

Individuals whose disclosures are met with negative responses may also face additional stressors. A negative response may confirm an individual's sense of self-blame and

worthlessness. Dealing with overt negative reactions may be compounded if the individual has no other sources of support.

The decision to reveal one's status is also influenced by the presence of family and children. This is particularly true for women who are typically the caregivers of the family. Women, concerned with the potential negative impact on their children of revealing their status often choose to keep it secret, even from family (Cambridge, 1993).

Loss of Self-Esteem

Loss of self-esteem and pride may be common among individuals with an HIV-infection. In a society that values attractiveness and independence, body disfigurement and/or loss of control over bodily functions may increase one's sense of undesirability and dependence. These factors can reinforce a low sense of self and increase isolation and depression (Manson-Willms, 1992).

Loss of self-esteem has been linked to helplessness and the ability of the individual to effectively cope with stressors. Leserman, Perkins, & Evans (1991) found that those individuals who reported a high sense of self-esteem were more positive and had a more healthy adaptation to HIV-infection.

Loss of Physical Contact/Intimacy/Sexual Capability

Individuals with HIV-infection often experience a number of changes in the area of physical closeness. Fear of contagion on the part of the individual or others may result in decreased physical contact. Many of these feelings may be intensified by the irrational use of procedures (gloves, masks, separate dishes) in situations that do not require such precautions.

The physical manifestations of HIV-infection can result in weight loss, body disfigurement and lack of energy. Because of these changes, people with HIV may feel that they are physically unable to be intimate or sexual. They may feel dirty or contaminated and uneasy or unsure of how to adopt new sexual patterns and may feel reluctant about becoming intimate or sexual (Macks, 1989). They may avoid forming new relationships or withdraw from existing ones for fear of being rejected and experiencing more loss (Anderson, 1992).

Loss of Future

The loss of a sense of future hopes and dreams is common among people with chronic illnesses. Most HIV-infected persons are adults between 20 and 40 years of age (Shaw, 1988). They are young, previously healthy and in the prime of their lives. Most people during these years are

focusing on personal goals, relationships, starting or raising a family, and aspirations of the future. HIV infection forces individuals to refocus their thoughts on their mortality. Individuals' lives may be thrown into a tailspin leaving them with feelings of anger and despair. These feelings may be intensified as an individual's physical strength and energy decrease. The optimistic view of opportunity and growth is replaced with thoughts of morbidity and mortality.

Loss of Control and Stability

HIV-infection may bring with it an increased sense of loss of control and stability. The limited information that exists on HIV/AIDS, the course of illness, and the remissions which often occur may have a great effect on the individual's ability to cope with illness. Not being able to predict the course of illness will affect the individual's ability to prepare for future situations. The effect of this on an individual's sense of self may greatly affect his/her ability to acquire and access the resources/supports needed to effectively assess and cope with stressors.

Multiple Deaths

Many individuals with HIV-infection who are faced with their own mortality may also be dealing with the deaths or potential deaths of people around them. Those who access the support of others with HIV/AIDS may experience the deaths of a many in their support system. Others whose partners or children are also infected may experience even greater loss.

Social Support Requirements

HIV infection has an asymptomatic phase that may last as long as 10-15 years (Monoz et al., 1988). HIV illness has come to be viewed along a continuum that includes at one end the asymptomatic stage of HIV infection and at the other end full-blown AIDS marked by life threatening, opportunistic illnesses (Melbye, 1986; Patton, 1990). As HIV disease progresses, a number of different crises occur. They include the time of initial diagnosis, the initial onset and recurrence of a particular symptom or infection, a loss of mobility, failure of treatment, rejection by others or the terminal stage of illness (Manson Willms, 1992; Reidy & Taggart, 1992). As with other serious illnesses such as cancer (Haney, 1984), the social support needed to cope with HIV illness can be expected to vary at different points in the progression of the illness (Christ & Weiner, 1985;

Forstein, 1984). Similarly the type and number of coping strategies and psychosocial resources needed may vary at different points along the continuum (Lazarus & Folkman, 1984). For example, an individual who is recently diagnosed may value information and emotional support more than the direct physical care valued by one who is restricted to his/her bed with an opportunistic infection.

Individuals with HIV-illness must face a number of situations that have the potential to be very stressful. These include stigmatization, alienation, abandonment by family and friends, fear, disease progression and numerous losses (Flaskerud, 1989). The literature shows that social support can be instrumental in providing a buffer against severe stress, which can be crucial in maintaining well-being. It is important that the types of support that are most effective in buffering HIV-related stress be identified so that appropriate support resources can be developed and made available to help those with HIV-infection (Hays, Turner, & Coates, 1992). A review of the research literature provides an insight into which types of support have been most effective for people with HIV-infection.

Namir et al. (1989), Wolcott, Namir, Fawzy, Gottlieb, and Mitsuyasu (1986), Zich & Temoshok et al. (1987) all found that emotionally-sustaining types of support (listening, acceptance), tended to be viewed by people with

HIV disease as the most desirable, even though they are not significantly correlated to physical or psychological well-being.

Namir et al. (1989) and Wolcott, Namir, Fawzy, Gottlieb, and Mitsuyasu (1986) also reported that gay men who were satisfied with their social support network and who participated in the AIDS community displayed healthier coping strategies than those who did not.

Chuang, Devins, Hunsley, and Gill (1989) found that gay men who reported absence of confidants had more depression and other types of psychological distress. The researchers hypothesized that perceived physical symptoms may add psychological distress, particularly among those with inadequate social supports.

Namir, Alumbaugh, Fawzy, and Wolcott (1989) found that satisfaction with instrumental and emotional support was a variable associated with good psychological and physical adaptation to AIDS. In their study of gay men they found that satisfaction measures were high even with a small network.

The importance of perception of support on health was also confirmed in a number of other studies. Hays, Turner, & Coates (1992) in a study using gay men, found that as the number of HIV symptoms increased, the men with low information support satisfaction were more depressed than

men with high information support satisfaction. They concluded that satisfaction with informational support can buffer the psychological distress associated with experiencing HIV symptoms.

Hays, Turner & Coates (1992) provide evidence that links information to a positive sense of well-being. In their study they found that information and advice from others was useful in helping individuals gain a realistic perspective of their situation and develop effective coping strategies. They found that the sharing of similar experiences was beneficial in increasing the ability to cope effectively. Also, gathering information about AIDS may be stress reducing as it contributes to a sense of control and predictability (Glaser & Singer, 1972).

Zich & Temoshok's (1987) study of individuals with AIDS found that increased physical distress was associated with lower perceived availability of social support. They suggest that this may be due to physical symptoms being an expression of psychological distress rather than a direct reflection of one's medical state. The perception that one has a strong availability of social support is linked with decreased hopelessness and depression. Donlou, Wolcott, Gottlieb and Landsver (1985) verify these findings in their study which found social support to be negatively correlated with depression. They also reported that support from a

spouse-lover in particular was strongly correlated with a positive self esteem.

Existing research on social support, chronic illness and AIDS supports the belief that social support plays an instrumental role in helping an individual to maintain well-being. The research notes the importance that the perception of support can play in both physical and mental health. In order to understand this role in promoting well-being, it is also important to note the variables that might be associated with individual perception. Studies on the personal traits and perceived social support conclude that recipients of social support have characteristics that enhance or detract from their ability or motivation to access support. Variables, such as age, gender, socio-economic class, race, sexual orientation and ethnicity and socio-psychological factors also play a vital role in one's ability to access and make sense of available support (Conn & Peterson, 1989; Nadler, 1993).

The literature has shown that, as a group, women may be affected by social support differently than men (Flaherty & Richman, 1989). These differences may have implications for HIV-positive women who use support services. Women in general have been shown to use more social support than men (Rosario, Shinn, Morch & Huekabee, 1988), and use support that is more intimate and of a more self-disclosing nature.

As a result of this it is important that the social support needs of women be examined more closely to provide a better understanding of their needs.

Women and HIV/AIDS

AIDS is considered to be one of the leading causes of death among women in the U.S. (Levine & Neveloff Dubler, 1990). Women who are poor, visible minorities or are from pattern II countries are more likely to be infected (Levine & Neveloff Dubler, 1990). World wide it is estimated that there are over three million women infected with HIV (Hankins, 1990). By the year 2000 it is believed that the total number of women with AIDS will equal that of men. In Canada the incidence of HIV infection and AIDS is increasing dramatically in women (Hankins, 1991). As of December 1993, of the 11,192 reported cases of AIDS in adults, 673 cases were reported in women (Health Canada, 1995). In Saskatchewan, of the 89 reported cases of AIDS in adults, 10 were reported in women (Health Canada, 1995). It is estimated that the number of women with HIV/AIDS in the province could be between 20 and 30 (Robert Remis, September 13, 1995).

History of Women and AIDS

The extent of the effect that HIV/AIDS has on women is still largely unknown. This is due in part to how women with HIV/AIDS have been addressed. During the early years of the HIV/AIDS epidemic, most of what was written and discussed about AIDS and its implications was drawn from the experiences of men who had sex with men. Women were either overlooked or discussed as potential vectors of transmission to men and children (Lindhorst, 1988; Stuntzner-Gibson, 1991). The result is that there is little information available about the effect of HIV/AIDS on women. The literature which does exist usually has been extrapolated from the male situation. Only recently has information focusing specifically on women and HIV/AIDS been published. Much of this information is presented in the form of review articles or first person accounts, but there continues to be a large gap in research that qualitatively and quantitatively examines the effect of HIV/AIDS on women.

Psychosocial Needs of Women with HIV/AIDS

Women with HIV/AIDS experience many of the same issues and losses that men with HIV/AIDS experience in dealing with their disease. But the degree to which these affect women, as well as the lack of available resources and support, makes the experience of women with HIV/AIDS very different

from that of men with HIV/AIDS.

A review of the current literature reveals some of the differences that a women with HIV/AIDS must face. Stuntzner-Gibson (1991, p.22) states that "many of the emotions experienced by women with HIV disease such as denial, panic, shame, fear, depression, and anger are common to all HIV-infected people". Others report that women with HIV/AIDS are affected by the denial of AIDS in women, sexism and sex-role stereotyping, poverty, stigma, blame, isolation, alienation, and loss (Easton, 1992: Chin, 1990; National Health and Welfare Canada, 1991; NAPWA, 1992).

Halpern (1989) reports that for many women who are infected and affected, their position is characterized by financial and emotional dependence which is reinforced by the legal system, the health care system and social services. Issues concerning women, particularly in respect to reproduction and sexuality are regarded as specialized, marginal and less significant. Implicit in the fact that less attention is paid to the manifestations and effects of AIDS in women is the assumption that women's illnesses, and indeed women themselves, are less important than men (Richardson, 1988; Schneider & Jenness, 1995).

Denial of HIV/AIDS in Women

Within the AIDS epidemic, women have been ignored because of the perception that they are not at risk (Denenberg, 1990). There has been little attention given to the physical or psychological effects of HIV infection on women. Some of the results of such a view of women with HIV/AIDS are that women who do not perceive themselves to be at risk are not tested for HIV. The lack of research also means that appropriate definitions or indicators of AIDS in women are not available or considered relevant to health professionals. This has led to many women being misdiagnosed or being diagnosed late in their illness (Cohen, 1993; Health and Welfare Canada, 1992). Recent steps have been taken to recognize the difference in HIV infection manifestation in women from that of men. In July 1993 the Canadian AIDS Case Definition included cervical cancer as a gynaecological symptom that denoted an AIDS diagnosis.

Sexism and Sex-Role Stereotyping

The effect of HIV-infection on women is magnified by gender-based oppression and stereotyping of women in roles such as caregiver (Macks, 1988; Patton, 1990; Kitzinger, 1994). Stuntzner-Gibson (1991), in her review of a statement made to the Fourth International AIDS Conference

by the International Working Group on Women and AIDS (1988, pp.1-2), presents a litany of gender-based discrimination of women with HIV:

...deeply ingrained societal racism, sexism and discrimination by economic status; inadequate quality and inaccessibility of primary health care and of holistic, hospice, and respite care alternatives; absence of appropriate, affordable housing, particularly for female-headed households, the impoverished and the poor; insufficient child care facilities and support services for child rearing of both HIV-infected and non-HIV-infected infants and children; unequal educational opportunities and illiteracy; unemployment and low-paying jobs, which enforce dependency on social service agencies; the suppression, distortion, and devaluation of female sexuality through cultural insensitivity and overt discrimination, leading to a lack of appropriate women's health care; discrimination toward lesbians and violence against women resulting in sexual assault-physical attacks-and murder of lesbians, women, and gay men and those thought to be lesbian and gay; and the exclusion of women's and children's issues from the funding and design of research, treatment, and experimental protocols (p.23).

Because of sex-role stereotyping and socialization, women often find themselves in the role of caregiver. Women with HIV continue to carry out this role even in the presence of personal, severe illness (Kaspar, 1989). The effect of this can be great on women who, in putting the needs of others ahead of their own, will allow themselves to become run-down and will ignore receiving treatment in order to fulfil these duties. For women who have children or partners who are also positive, the physical and emotional

demands placed upon them may be far greater, increasing as others progress in their illnesses.

Most women with HIV-infection (79%) are in their childbearing years (13-39) (Shaw, 1988). The reproductive capacity of women places additional demands and stressors upon women with HIV-infection. This is important when we consider that many women identify their sense of worth with their ability to have and care for children and that many women's diagnoses of HIV-infection are made during pregnancy. Women must address the question of whether to have children. This decision often involves dealing with public pressure to not have children, the possibility of infecting their child, and the fact that they may not live to raise their children.

Economic Status of Women

Women with HIV-infection are often economically disadvantaged, and are poorer than men infected with HIV (Stuntzner-Gibson, 1991). These women often have a forced dependency upon social institutions including income assistance and health care. The effect of being poor also means that they may not be able to provide for their own and their family's basic needs. They are less likely to be able to afford alternative therapies and relaxation activities that might reduce stress. They may not be able to afford

the transportation or childcare which might enable them to attend those appointments and services that could be beneficial to receiving proper medical care and social support.

The effect of being poor may also play an important role in the progression of illness. Hogg, Strathdee, Craib, O'Shaughnessy, Montaner and Schechter (1994) found that men with low incomes have shorter survival times after HIV infection than men with high incomes. Parkes (1972) reported low socio-economic status to be a predictor of poor outcome in coping with grief. From these studies it may be logically posited that women would have shorter survival times after HIV infection than their male counterparts given their comparative economic status.

Stigmatization

A number of articles, (Macks, 1988; Stuntzner-Gibson, 1991, Lindhorst, 1988) have examined the effect on women of the societal stigma attached to HIV/AIDS. Korniewisch, O'Brien and Larson (1990) report that the stigma one faces "reflects both the individual's perception of self and others' perception of self" (p.15). Women who are diagnosed with HIV/AIDS must immediately contend with the stigma associated with lifestyles of marginalized members of society. Women with HIV/AIDS must deal with the

psychological strains of living with HIV/AIDS, the oppression that they face as women, and the stigma and blame that they and society place upon them for having HIV/AIDS.

Isolation

Isolation is perhaps one of the biggest and most destructive stressors (Hamilton, 1993). For women, increased isolation can result from caregiver duties, the fear of having their status revealed and the resulting discrimination, and the lack of available resources. In most major centres women may not seek out existing AIDS service organizations because of their perception that such organizations are dominated by gay men and would therefore not provide services appropriate for them as women (Kitzinger, 1994).

Women with children have an additional factor that may increase their isolation. Because of the safety and acceptance of their children both at school and within the family, they may choose not to reveal their status and seek support. In many cases, family members who might serve as support are the last to know of the woman's diagnosis, and may not be informed until a medical crisis arises (Cambridge, 1993).

Community Resources

Community based resources were, from the first recorded cases of HIV/AIDS, founded by and for gay men. Because of the lack of attention paid to HIV/AIDS, resources for those who are not gay have been slow to develop. This has meant that women wanting to obtain community support have had to do so within the networks of gay men. HIV disease among women is framed within a different set of psychosocial roles and boundaries than it is for gay men (Cochran & Mays, 1991). Many of the community based resources may not be psycho-socially appropriate for helping women and so they have been left to deal with their disease without the support of community resources. Women with HIV come from diverse backgrounds. Factors such as culture, socio-economic class, ethnicity and lack of family and community support have been found to contribute to social isolation (Taylor, 1990).

Because of a lack of attention given to women with HIV/AIDS, the medical and psychological needs of women with HIV disease remain largely undocumented. The absence of a common social group identification, invisibility within the larger HIV community, and inadequate research and service delivery focusing on women's specific needs has compounded the isolation, denial and ultimately the premature death of these women (Kitzinger, 1994).

Previous Needs Assessment Studies

A number of studies and reviews have outlined some of the instrumental and psychological/emotional needs of people living with HIV/AIDS (Palmer, 1991; Lamping et al, 1990; Nova Scotia PWA Coalition, 1990; SIDA AIDS Moncton, 1990; SIDA AIDS New Brunswick, 1992). Emotional/psychological considerations that have been identified include: counselling; support groups; confidentiality; anxiety/depression; self esteem; intimacy and affection; shame and guilt; coping ability; relaxation/recreation; role change adjustment; sexual dysfunction or disinterest; pastoral care and spiritual support. Instrumental needs have been identified as: housing; financial assistance; access to medicines; legal assistance; transportation; employment; education; child care; palliative care/hospice; access to social services; and long term care facility.

Studies of the needs of people living with HIV/AIDS have focused primarily on urban men. They have provided little gender specific information on women with the exception of Brendle-Moczuk (1995) who provided a quantitative survey of social support needs of 17 women with HIV in the Vancouver lower mainland area of British Columbia.

The benefits of social support on the physiological and psychological well-being of an individual have been well

documented. Social support can only be effective if the resources provided match the demands posed by the stressor (Cohen & McKay, 1984). Identifying the needs and the type of support required to help an individual meet those needs is essential in developing resources and services that will be effective and efficient in confronting the AIDS crisis (Hays, Turner, & Coates, 1992).

This literature review has demonstrated that women with HIV/AIDS have a number of specific needs. It has also demonstrated that these needs are significantly different from those of men. While some of the studies do address women's needs, few take into account the potential differences in the geographical structure, cultural make-up, and lifestyle of women in Saskatchewan. Available information may not be applicable to women with HIV/AIDS in Saskatchewan.

Saskatchewan

Saskatchewan is a province located in the middle of Western Canada. Its area is 651,900 square kilometres. It has a population of nearly one million people. The two most populated cities in the province are Regina and Saskatoon, each of which has a population of about 200,000. Sixty-two percent of the population lives in urban areas and thirty-eight percent lives in rural areas. The climate of

Saskatchewan can, in one year, be one of extremes. January temperatures below -50C and July temperatures of +40C have been recorded. The primary resources in the province are agriculture and mining.

In Saskatchewan at present there are four community-based organizations (People Living With AIDS Network, AIDS Saskatoon, AIDS Regina and AIDS Moose Jaw) which exist to assist people living with HIV/AIDS. Although some services are currently being offered by these groups, there are no services offered specifically for women. There has been no formal effort to determine the needs of these women. The purpose of this study is therefore to: 1) Define the needs of women living with HIV/AIDS in Saskatchewan, 2) Identify gaps in the existing services, and 3) Provide information to be used in assessing and/or developing services for women with HIV/AIDS in Saskatchewan.

CHAPTER 3 - STUDY DESIGN AND EXECUTION

This chapter provides an outline of the research design and sample for the study. It describes the procedures followed in recruiting subjects and collecting and analyzing data. Limitations of the study are also discussed.

METHOD

Introduction

Type of Research

A qualitative, exploratory approach was selected as the method of research for this study. A qualitative approach allows for the examination of multiple angles in the lives of women with HIV/AIDS in Saskatchewan and may provide a more detailed picture of the needs of the participants (Bullock & Millham, 1987). As little is known about the specific needs of women with HIV/AIDS in Saskatchewan, an exploratory design is appropriate.

Rationale

In Canada, women are the fastest growing category of people with AIDS, yet there is only limited information on women with HIV/AIDS. Much of the existing literature has been extrapolated from the male situation to that of the female. As a result there are no well defined variables

which outline the needs of women living with HIV/AIDS and the obstacles which prevent them from having those needs met. The rationale behind this study is to provide information on the needs of women with HIV/AIDS for use by service providers in all fields to better enable them to develop services and policies that could help these women to have their needs met. This study will also allow some women to come together and share their experiences with each other.

Ethics

A review of the proposed research study was presented for ethical approval to the University of British Columbia's Ethical Review Board (see Appendix A). Maintaining confidentiality is essential when working with subjects who are HIV infected, given the stigma associated with the disease. In reporting information the decision was made to not present any demographics or examples of experiences that could identify the participants. Participants also agreed not to share what was said by others outside of the focus group.

Sample

Population

As of April 1995, there have been 10 women in Saskatchewan diagnosed with AIDS (Health Canada, 1995). Using seroprevalence rates provided by Dr. Robert Remis, Epidemiologist at the Centre for AIDS Studies at McGill University, it is estimated that the number of women with HIV/AIDS in the province could be between 20 and 30 (Robert Remis, September 13, 1995).

Health Canada (1995) reports that as of April 1995 there were 673 cases of AIDS reported in women in Canada of which 10 cases were in women from Saskatchewan. In April of 1993 Health and Welfare Canada reported 448 cases of AIDS in women in Canada of which 4 cases were in women from Saskatchewan. For Canadian women this is an increase of 66% in two years, but for Saskatchewan women this is an increase of 250%. These statistics compare to a 36% increase of AIDS cases in men in Canada during the same two years, and a 42% increase of AIDS cases in men in Saskatchewan (Robert Remis, September 13, 1995).

If we were to use the percentage of change that was reported among women with AIDS in Canada between 1993 and 1995 (66%) and apply this same percentage increase to the number of cases of AIDS in women in Saskatchewan over the same time period (1.66×4) statistics show that we could

expect between 6 and 7 cases of AIDS in women in Saskatchewan. The difference is between three and four cases or (250% - 66%) 184%.

The question that might be asked is whether the rather large increase in the percentage of cases reported in women in Saskatchewan is a trend or just an anomaly due to a small number of cases? To determine the actual gradient more data points are required. However the trend is troubling if the gradient between 1993 and 1995 is as steep as the difference between these two years indicates.

Sampling Frame

This study used a purposive sample. Purposive sampling was undertaken in an attempt to include as many women with HIV/AIDS in Saskatchewan as possible. Due to limitations in reporting and public access to HIV/AIDS results, there was no random means of selection from the women with HIV/AIDS population.

Only women who had contact and were on the mailing list of the three provincial AIDS service organizations (AIDS Saskatoon, The Persons Living With AIDS Network of Saskatchewan, and AIDS Regina) or the two hospitals with HIV specialists (The Royal University Hospital, and The Plains Hospital), were contacted for participation in this study.

Recruitment Techniques

Three provincial community AIDS organizations (AIDS Saskatoon, AIDS Regina, Persons Living With AIDS Network) and two provincial hospitals with HIV specialists (Infectious Disease Control Units at the Royal University Hospital in Saskatoon and the Plains Hospital in Regina), were contacted to obtain their cooperation in mailing out letters inviting those women who had contact with their agencies to the focus group (see Appendix B). The agencies cooperated by mailing out to those women on their mailing lists letters inviting them to participate in a focus group (see Appendix C). The focus group was at a preset time and place and participants were so advised. These five resources were chosen because the researcher believed that they would have the widest contact with women living with HIV/AIDS in Saskatchewan.

Sample Population

There were a total of eleven women who participated in the study. Of this eleven, one was a member of a First Nation and the other ten were from other non-First Nation backgrounds. The participants ranged in age from mid-20's to mid-60's. Seven of the women had children, and two of these seven also had grandchildren. Four of the women were married or in long term relationships. Eight of the women

were from urban areas and three were from rural areas. Eight of the women received financial assistance in some form from the government. Two of the women reported contracting HIV from blood transfusions. The remaining participants were unsure as to the transmission route of their infection. Two of the women reported finding out about their infection during pregnancy. Three women reported being diagnosed after long periods of reoccurring yeast infections. Two women were diagnosed when they went into the hospital for surgery. One woman was diagnosed after her partner was diagnosed with HIV-infection. The disease stage of the participants is not known.

Measures

A qualitative interview schedule for the focus groups was designed to elicit information about the needs of women living with HIV/AIDS in Saskatchewan (see Appendix D). Subject areas, questions and probes were derived from the literature on the psycho-social and social support needs of women living with HIV/AIDS.

A pretest of the interview schedule was completed to determine whether the wording of the questions and probes could be understood, and whether the questions would elicit discussion. This schedule was used for focus groups one and two. During the third focus group an analysis of the data

was presented to the participants for their feedback. Subject areas, questions and probes for this session were derived from the analysis of the data and from the interview schedule used in the first two focus groups.

Reliability and Validity

Several steps were taken by the researcher to increase reliability. The same questions and probes were presented using the same sentence structure to the first two focus groups. During the focus group session, questions were placed upon a chart and presented to the participants. Each of the probes was introduced to both groups in the same order. Face validity was assumed as all participants stated that they were able to understand the questions and the probes that were presented.

Limitations of the Measure

The measures are limited in that the questions and probes used in the interview schedule may have guided group discussions in a different direction than it might have taken using other more open ended measures.

Data collection Techniques

A focus group was used as the tool for collecting data. Focus group methods were selected because it was time and cost efficient, it allowed the women to compare experiences and encourage each other to discuss concerns, and it provided them the opportunity to engage in dialogue on matters and areas that they felt were important. Moreover, it did not limit them to answering specific questions and it allowed for greater exploration of the issues that the women identified as the most important. The first focus group was held in Saskatoon in early 1994, the second focus group was held in Regina in spring of 1994. These sites were chosen because they are the two largest cities in the province and are centrally located in the south and central part of the province. The researcher felt that providing focus groups in two different centrally located cities would make it easier for women to attend. Each focus group was held in an AIDS organization meeting place. This was chosen because it was provided without cost and was believed to be a location that the women might already know. At the beginning of the focus group session, participants were presented with a consent form to read and sign (see Appendix E). Each focus group lasted for two and one-half hours. Participants were provided with lunch. Expenses incurred by the women to attend the group were

reimbursed and a small honorarium (\$20) was provided.

The third focus group was held in the summer of 1994 in Saskatoon and lasted for two hours. Participants were provided with an analysis of the findings from the first two groups, invited to provide feedback and add further comments about their experiences.

Focus group sessions were audio recorded to allow for the transcription of the data. All identifying information was stripped from the transcripts to maintain the confidentiality of the participants. The transcription allowed the researcher to verify what was said and the context.

Data Analysis

A grounded theory approach outlined by Glaser & Strauss (1967) was used to analyze the data. The focus group audio-recordings were transcribed and a system of open coding (content analysis) was used to identify the topics, issues and possible themes emerging from the data. The tape of the focus group was listened to and the transcripts read several times to obtain a general impression of the content. The transcripts were then reviewed for pertinent ideas, themes and issues, coding the substance of the content in the margins. Many of the codes reflected respondents' own words or were related to constructs found in the literature on

social support. These open codes were then taken from the original transcripts and recorded on separate pieces of paper. The open codes were then reviewed repeatedly to identify common themes. The themes were reviewed to identify core categories by clustering general common themes. Core categories are central themes that appear repeatedly throughout the data, relate easily to other categories and have clear implications for more general theory (Strauss, 1987). The open codes were then highlighted according to the conceptual categories identified. The process of linking open codes to themes and deriving core categories was then organized in a chart to reveal the connection between open codes, themes and categories (For an example see Appendix E).

Limitations of the Method

The methodology used in the study has several limitations including research strategy, a sampling bias and the use of focus groups. The strategy only invited those women with HIV/AIDS in Saskatchewan who had contact with one or more of the five agencies.

The recruitment technique had several limitations. It did not allow women who do not have contact with one of the five services or whose mailing address was not available to the services to participate in the study.

Use of a focus group to collect data for the study had several limitations. It limited the participants to only those who felt comfortable participating in a group discussion with the researcher and who were able to attend the focus group at the time and place pre-set by the researcher. Women who may have been excluded were those who: did not feel comfortable participating in group discussions; did not want to attend a group that was located in the selected agencies; or were unable to attend due to geographical distance, limited mobility, lack of transportation or childcare, and/or conflicting schedules.

Having a male social work student as the group facilitator could have affected the process of data collection and interpretation. Because of this, some women may not have been willing to participate. It could also have affected the participants' abilities to express their experiences and feelings of being a woman with HIV/AIDS. Attempts were made to limit the potential effect that this might have had through letters of introduction to the participants, the letters explained the nature of the study, who the researcher was, and encouraged the women to contact either the researcher, one of the five agencies used to distribute the letters, or the primary researcher for further information. Participants were also asked to provide feedback on whether the gender and status of the

researcher had an effect on their ability or comfort level to share in the group.

Using a focus group method influenced the information that was obtained. The participants were affected by the experiences of the other participants. While the focus group interview schedule and probes provided a structure for the session, women were free to talk about any experience that they felt they wanted to share.

A number of methods used in this study added to the reliability and validity of the findings. The first method which contributed to the validity of the study was the use of recursive analysis. The researcher's interpretations of the data were taken back to the participants to allow them to provide feedback and input into the analysis and presentation of the data. This assisted in ensuring that what was reported was representative of what was said by the participants.

The second method used to enhance the internal reliability of the study was the use of systematic procedures throughout the collection and analysis of data. The process of audio recording and analysis for themes and categories ensured that the interpretation of the researcher could be validated by reviewing the data.

Strengths of the Method

Despite the limitations of the methodology, this approach was chosen as it was a feasible method to increase knowledge in an area where little was known about the needs of women living with HIV.

The method was respectful to the women in that it allowed them to share their experiences with each other in a relatively unstructured format. It also allowed them to contribute to a process that will hopefully improve the situation for women living with HIV/AIDS in Saskatchewan. Their voices tell the stories of their experiences.

Results

This chapter outlines the findings using thick description based on a model of constructivist inquiry as advocated by Guba and Lincoln (1989). The quotes have been taken from verbatim transcripts in order to present concise representations of the responses. During the data analysis, data were organized into a number of broad categories and themes that were derived from the interview schedule. These categories were used to create an outline for presenting the results.

The analysis of the focus group data identified four categories of needs: medical, economic, mental health and service. These four categories were then linked to form a larger framework in which all the data could be interpreted and understood. The framework that emerged from the data describes the experiences of women living with HIV/AIDS in Saskatchewan.

Data were presented using these four categories to preserve the context in which women experience needs and attempt to have their needs met. It was felt that categorizing the experiences of the women into those outlined in the social support literature (instrumental, emotional, informational) would not allow for the contextualization of the factors salient in the experiences of the women as they tried to have their needs met.

In presenting the experiences of the women some of the themes were repeated within one or more of the categories. This was necessary as many of the needs of women occurred within separate contexts. Presenting a need within the context in which it occurred is important to providing a full understanding of the need.

The women were asked to comment on all of their experiences as women living with HIV/AIDS. Some of the women had experiences outside of Saskatchewan which may also be reflected in the results.

Experiences of Women Living with HIV/AIDS in Saskatchewan

Living with HIV/AIDS in Saskatchewan for women can best be described as living in "isolation", being "scared" and being "powerless". Understanding the daily experiences of women as they attempt to get their needs met requires an understanding of how it feels to have "no control". Understanding the women's perceptions of their needs means having to know what it is like to "be treated like second class citizens" and "ignored".

Knowing the physical, mental, financial and service needs of women living with HIV/AIDS in Saskatchewan means little if it is not put into the context in which they attempt to get these needs met. Only by placing the needs of women living with HIV/AIDS into a wider context of the

treatment of women in society, can one begin to understand the experiences of these women.

Medical Needs

The category of medical needs was of great concern. This is not surprising considering that HIV/AIDS is a condition that is linked to one's physiology and that the medical system has been historically male dominated. Within this category, the themes of accessibility, information and experiences with medical health professionals were drawn out.

Accessibility of Medical Services

Accessibility, or the lack thereof, was raised in a number of different areas. Of concern was the inaccessibility of appropriate medical services in rural areas. One respondent noted that the hospital closest to her would not accept people with HIV/AIDS because they did not have the facilities or knowledge to treat someone with HIV/AIDS.

We can't get any help from there [hospital], like we live in [rural town 1] so the closest hospital is in [rural town 2]. But [rural town 2] won't take you. They'll refuse you. So that means in an emergency you got to come all the way to Saskatoon. Well it's like the hospital in [rural town 2] is not geared for, I guess dealing with that [HIV/AIDS] at all. They don't have the facilities for it or whatever.

For this woman and others who live in various parts of rural Saskatchewan, having to travel long distances to receive medical treatment was not only inconvenient but could be potentially deadly. To receive appropriate medical treatment a woman had to travel to one of the major centres. If she had a family, she often had to leave her family behind; perhaps for an extended period of time if extended medical care was required. For a woman who was the primary caregiver in the family, this caused further stress. If no childcare was available, some women reported foregoing needed treatment in order to fulfil their role as caregiver.

They need to make the services more accessible because if they don't then who's going to go? I can't drive in to town all the time, especially if I'm sick, it's too far.

If you have a family and kids, driving into the city to a hospital is not practical. If I get sick I have to decide if I have the time to go into the city to go to the hospital. I have to decide if I can find someone to take care of the kids after school and if I can find a ride into the city. And if I had to go into the hospital or anything like stay overnight I couldn't do it because there's no one to take care of my family. So I don't go. That's what I do. And if I don't go then I could become sick and it puts my health at risk.

Not seeking treatment due to family care responsibilities was also common among women who lived in urban centres.

Having children really is limiting. Like if I get sick I can't always go to the doctor or the hospital. I have to pack them up and take them with me to sit in the waiting room. They get frustrated with having to wait and start whining and then it gets on my nerves and I'm more stressed out than I was before I went.

I'm always worried about getting sick and then what's going to happen. If I can't take care of my kids then can they take them away from me? I am afraid sometimes to go to the doctor because he might say that I have to go into the hospital and then who will take care of my kids? There's no way that nobody's taking my kids from me. I just won't go into Dr. xxx if I get too sick.

Women in rural areas reported being unable to gain access to medical services due to lack of availability of adequate services, and not having transportation and/or available funds to get to a major centre for treatment. In cases of accidents and emergencies where time was of the utmost importance, having to travel the extra distance to receive treatment meant a greater likelihood of increased illness.

In Saskatoon and Regina, medical services are more accessible than they are in the rural areas, but accessibility, or the lack thereof, is still a major issue. For many of the participants the inaccessibility of doctors was an important factor in them not receiving medical-care.

We phoned the office and then we got the damned machine and then we wait and think we should phone again. And it's maybe a week later that they phone us...

It's almost impossible to get a hold of a doctor. If I want to see him I have to call and book an appointment way ahead. How am I supposed to know what I'm going to be feeling like a week ahead. Sometimes it just hits me. You know one minute you're doing okay and the next you're feeling like shit.

When the focus groups were held, there were only two HIV/AIDS specialists in Saskatchewan: one in Regina and one in Saskatoon. There is now one other specialist in Saskatoon who works for nine months of the year. While there are many other doctors, primary care is still frequently given by the specialist. The women reported that this lack of medical resources when they were "ill", "in crisis", or "waiting to get test results back" and waiting to see a doctor was "stressful and increases anxiety".

Women's lack of access to drug trials was a concern to a high majority of the participants. In the past, women have been excluded from many drug trials because of potential damage to their reproductive systems, or because researchers feared a pregnancy during the trial. When women were allowed to participate they were required to be on birth control pills. The result has been that there is little information on the effect of drugs on women. For the participants, this lack of information meant that they had little faith in receiving proper diagnosis and treatment.

As a result of the lack of access to drug trials women are being treated based on studies done on men, which has potentially negative effects for women with HIV/AIDS because the virus affects men and women completely differently. I know from past experiences that doctors don't know what the hell is going on with HIV. They don't know what to look for, what the symptoms are, or how to treat a woman that is positive.

The participants felt that they should be given the opportunity to participate in the studies and to decide whether to take birth control pills. The participants felt that not allowing them this choice was a "violation of their rights" and another way in which "women are seen for only [their] ability to have babies". They felt that allowing all women to participate in drug trials would "increase the information that is available about the effects of drugs on women's bodies". As some of the participants pointed out, having information about the effect of drugs on women can be lifesaving.

It is important that women are given the chance to go into trials if they are on the pill or not because everyone deserves the right to treatment. All they do is violate our rights. I think that by keeping us out of drug trials they increase the chance of us being misdiagnosed or receiving treatment that could be harmful. Like when I was on AZT I was depressed and suicidal but I didn't know that it was because of the AZT because it wasn't listed as a side effect because the tests were done on the men. But a friend found an article on AZT and women that said that sometimes women who took AZT were suicidal. That was enough for me. I went off the AZT and within a day I was okay. I wouldn't have known that if there hadn't have been any tests done on women.

I think that by not giving women access to drug trials they are increasing the chances that we won't be helped and will continue to die faster than the men. By not recognizing women in the drug trials they are saying that we don't count, but we are the fastest growing group with HIV. When are they going to start doing tests, after we are already dying?

The issue of access to drug trials raised a number of issues. It involved the control of reproductive rights of women and the value that society places on the freedom to choose what they do with their bodies. It also reflected the view that women are valued only for their reproductive capacities.

Information - Health and Treatment

All of the participants reported that information played an important role in helping them better maintain their health. Without information, they were not able to gain access to services that may have been helpful to them, and they were not able to make informed choices about their health. As noted in the previous example of the effects of AZT on women, available information is often based on studies that have been done on men. For the participants, gender bias in available HIV/AIDS information has resulted in misdiagnosis.

If we can't get to the doctors then we can't help take care of our health. Even in some areas they say that there are adequate hospitals and doctors

but there isn't. Just look at where I am, I wouldn't go to the hospital there because they don't know anything. I had been going to the doctor on and off for over a year. I was run down and tired and kept having an infection. He just said that I needed to get more rest or said that I mustn't have been taking the medication that he had given me right or it would have cleared up. But I was and I kept telling him that it wasn't working but he didn't believe me. No one thought to check for HIV. I didn't know about it then. It wasn't until I got pregnant and they did a routine test that I found out that I was HIV positive. I told my doctor and he didn't believe it. He said that they must have done the test wrong. I could have died before they would have figured out what was really wrong.

A few of the participants were concerned about the limited information that they were given about their health status and about the side effects of the medications they were given.

And I hate getting medication with only a little warning on it or a little pamphlet that goes with it. I have a book at home that helps, because you don't get the info that you need. What it might not work with, or what could be dangerous, or sun exposure, or sun sensitivity or whatever. And what are the signs of overdoses or so forth. I mean not everybody's the same. And that's not given out either. Like every time I get a new drug I was given, you might get headaches, and upset stomach duh, duh. Not everybody's the same. But here's a list this long of a certain little percentages of people that have this symptom or there down the line of up to 15%. What if I'm one of the 15%, that information is not given along with these heavy duty medications. It should be. You don't get that and it should be. If there is a long list give us the list we can handle it, but we'd like to know. I hate putting something in me that I don't know what it's going to do, except for what the 99% have.

I would like more information on medical things. My doctor doesn't tell me what is happening, like when he is doing tests and what they mean and stuff like that. It is really important that I know what is happening with my body so that I can make the best decisions for me. I know my body better than anyone else but I need to be given all of the information. When I don't know what is happening I tend to get worried about what is happening. I think that if I was given the information I could better prepare myself for what is happening.

The majority of the women felt that this information was required for women to be able to make informed decisions about their health. Denying women information means that they are either making uninformed and potentially harmful decisions or that they must be dependent upon someone to make decisions for them. Being informed about their health status and what their options are helped reduce the women's stress levels and made them "feel more in control" of their lives.

Not having information causes you to worry. You don't know what is going on. It takes the control away from me and puts it into the hands of other people who make decisions about me without me knowing. I think that information is important but the person has to be consulted with to make a decision. If you don't then she ends up feeling useless and a burden.

I think that information is important because it puts control into the person. They are able to make a decision with all of the information. That way they aren't making a decision on only part of the information and being hurt by not knowing about something. Women can choose what she feels is right for her. It's important in the mental health of a woman. I feel better when I know what

is happening even if it isn't good news. At least I can make decisions that I feel [are] right for me and I can work on changing things, but if I don't know then how am I supposed to change.

Without the information we may do something that is hazardous to our health because we didn't know. I think that knowing what is happening is better than not knowing. Sure it may be scary to know that my count is going down but at least I know and can prepare myself for it. If I don't know and then all of a sudden find out it is worse because of the shock.

All of the participants agreed that having information gave them a sense of personal control. Regardless of whether the information was good or bad, it was still viewed as beneficial. The women felt that being included in decisions that affect them gave them a sense of power and control over their lives.

It is important for women to receive information that is understandable and relevant so that they can make informed choices. All of the participants stated that information was often printed in "medical jargon terms" that they could not understand, or that the information was "outdated or contradictory". Being presented with information that they were not able to understand or relate to often left participants feeling "confused and frightened".

Have you ever found that pamphlets are used for everything. When I was diagnosed I was given so many pamphlets. And if they weren't saying the same thing they were contradicting each other.

And I didn't know where to turn so I got rid of all of it and now I'm only doing it on experience. Because that frightened me more.

Information needs to be available in simple people terms. I don't have lots of school and so I can't understand all those words in the books but I would like to. I figure that if it is about me then I should be able to know about it. But I can't understand it and I can't go running to friends every time I don't understand something. How are you even supposed to know that it is something that you might need to know or [that it] is important if you can't understand it. I think that an important part in helping people to take control of their lives and health is to give them choices by letting them have information.

For the participants, making informed decisions allowed them to feel "a part of what is happening" to them and to feel "more in control". Having control was viewed as a necessary precursor for maintaining a sense of worth and in turn for feeling physically and mentally healthier.

Experiences with Health Professionals

The experiences of women with health professionals were mixed. Most of the women reported at some time feeling, "judged" and treated like "second class citizens" by those within the health care system. A majority of the participants felt that they were at some time "not taken seriously" and that they were seen as being a "nuisance" and "whiners".

I think that the men get better services that the women do. I think we're disqualified and the men get what they want. We're whiners and nobody pays attention and I feel that with Dr. xxx. I know my body better than he does but he keeps telling me what it is that I need. I say to him, "You only work with me once every three months, but I know my body." I know how each drug affects me. And he said, "Well you can't." But I do, listen to me.

Many participants felt that they were not listened to when they went to their doctors. They found that their opinions of their health were frequently dismissed and/or treated with pills. Most of the participants often felt "powerless" in their relationship with their doctor, that the doctors were in control and told them how they felt.

I can't believe these medical staff. You'd think that they know about things and act like professionals with their patients, but they don't. They sit there and when you tell them something about how you know you're feeling they don't listen. They say we'll just wait for the doctor or tests or that it's not really what I'm feeling. How the hell do they know what I'm feeling?

These feelings of "not being listened to", "ignored" and "devalued" left some of the participants not wanting to go back to the doctor.

Doctors and medical staff think that they are better than us. We go to them for help and they don't do anything for us. I have gone into see Dr. xxx because I had a problem with my medications and [was] feeling tired and dizzy. I told him that I thought it was because of the drug dosage and he said it was probably just something else. He told me to go home and relax and come back next week if it was still there and he would

look into it. So what did I get out of going there and sitting for two hours to see him? Nothing. I was so angry that I went and changed my dosage on my own and didn't tell him. I don't really want to go back to him because I really don't think that he takes you seriously. But who else is there? No one.

The women felt that they were left with the decision of returning for medical attention to a health professional where they did not feel "valued", "heard" or "respected", or doing without getting help.

The perceived imbalance of power between patient and health professional was also noted in the way that women felt they were treated in the health care system. Women were often not informed of their rights and had their rights violated. A few of the participants reported that they were tested without their prior consent and were not notified of the results of these tests.

I looked in my file and found tests that I didn't know that were done had turned out positive. Like I was Hepatitis C positive. I was never told. I was tested for Hepatitis B and tested positive too. That too I was never told.

It happens all the time that we aren't given results of tests that are done without our permission. It is important that we be given the results of the tests so that we can decide what we should be doing. If my T4 count is 300 or 50 I want to know so that I can do whatever it is that I think is necessary, even if the doctor doesn't think that it is important that I know. I may do the same thing, but at least I'm doing what I want based on all of the information.

The women felt that not being informed of tests being performed and of the results was not only a "violation of rights" but it also withheld information that they could have used in making informed decisions for themselves.

I think that it is important that we are given the full information on our health status so that we can decide what is best for us. What's the sense of having information if we aren't given it. I think that it is really important that we be given information because it is our lives that are concerned. If there are tests that are being done on us we should know because it is a violation of rights if we aren't told. I think we should also be told what the results are if there are tests that are done.

Women felt that they were not always given all of the information about their health status. In one case, a participant commented on the importance of having information so that she could make changes to ensure better health.

That's like me when my count went down to 50 I did not have a clue. It went down to 50 [and] nobody bothered telling me. And then I bounced back to...What is it now? 260. I should have been told so that I could have started this work earlier, but nobody bothered. What's the point in keeping a file if we aren't given the information anyway?

Some of the other participants reported that they had learned to "take control", which enabled them to obtain the information that they required. They offered anecdotes to the other participants as helpful suggestions of what they could do to ensure that they received the information that

they wanted.

I use to have that problem [not being given needed information], but not anymore. I learned that if you want to know anything you have to take control and get it. Now if I have any questions I keep asking until I get an answer that I can understand. If one person doesn't have it then ask another; someone will eventually know.

When I go to see Dr. xxx I have a list of questions that I want answered before I leave. And I don't go until I get them. It's a matter of standing up for your rights. It's easier that way, because I know that I'm getting the answers to what I want to know.

Whatever education or reading I have, I have obtained on my own. I went to seminars and lectures. I even went as far as getting a single issue of a publication for physicians. There were big words in there that for us normal people are not easy to understand, but you eventually learn. Once you get into reading and figuring out what words mean it's a lot better information than I've gotten from anywhere else.

These women reported that being prepared and standing up for themselves allowed them to obtain the information that led them to feel more in control. The other participants agreed that this would have made good use of their doctors' appointments, but they did not all feel that they could be assertive enough to get the information that they wanted.

The lack of knowledge that doctors have about HIV/AIDS infections in women was an area of concern for the most of the participants. As a result of this lack of knowledge many women were not diagnosed properly. The women felt that

they "missed out" on receiving treatment that may have helped them because they were not diagnosed when they first displayed signs of HIV infection. A high majority of the women stated that some doctors all too often operated on assumptions:

I had first symptoms appear in '84, '85 but I just went in and out of hospital. Nobody ever thought nothing. That's also another thing that I think that doctors aren't doing [testing], they're seeing people coming in with all these repeated infections and by now they've got secondary infections. If there is nothing that comes out of it fine, but they should pay closer attention to what is happening with their patients. Because when something keeps coming back it might be indicative of something. Suggesting counselling in pursuit of testing might be in order. They're so afraid to scare people.

Before I got diagnosed I always had problems with my white cell count. It ran for years before I came down with a yeast infection in my mouth. Physicians should become a little more aware. They don't know everything and the chart doesn't tell you everything. No one knows what HIV means, it keeps changing. They keep adding more and more different infections and the doctors don't keep up.

Working on assumptions about who is likely to have HIV/AIDS and who is not prevented many women from receiving tests that could have helped inform them about the state of their health. It also prevented them from receiving early treatment that could have played a part in maintaining their health longer.

A few of the women felt that the assumptions of doctors prohibited women from receiving the medication or amount of medication that they required. One of the participants reported having to make several trips to her doctor for medication because he would not give her ample dosages. She believed that this was because he thought she might overdose. Another woman was often denied medication. She believed this was because the doctors were operating under the assumption that because she had once been a drug addict she would abuse the medication.

I have a problem with my medication. My doctor won't give me any medication because I use to use drugs. I've been off of drugs and straight for over two years, but yet I have to argue like hell to get Tylenol 3. I know I'm dying but he says, that's because of [your] past abusive behaviour so you're not entitled to anything that's going to get you high or whatever. I can take Tylenol 3 for headaches, but sometimes my headaches don't go away. But I can't get anything more than that because I'm a druggie. Even though it doesn't matter if you've been off for 20 years you're still looked at as a junkie. They're not sure if I have cancer or not and I can't get any medication for that. There are times that I literally have to crawl out of bed because of the pain. And I don't get nothing because it's like you're a junkie you should be able to endure it more or something.

These women felt that the assumptions of the doctors worked to the detriment of their health. Not receiving medication caused one woman "physical pain" and "emotional suffering" because she felt that the doctors were holding

her past drug use "against" her. She also worried that she might not be informed of medications or would be denied access to medication that might help her to stay healthy longer.

A majority of the women reported that some health care professionals were "insensitive", and "lacked empathy" needed to deal with the emotional side of HIV/AIDS. The participants reported cases where they had not experienced professional treatment from the doctors.

I really don't think that Dr. xxx is very professional. I remember him bawling me out. I came home and was really upset. One time I missed my appointment and he literally gave me shit over the phone. He doesn't have any right giving me shit. I don't need to be yelled down by a doctor just because he had a bad day. And there are days when he's had a bad day and he takes it out on us, literally. Or he ignores me totally. I was in tears one day when he got in to me, I didn't need that.

The woman who did not receive professional treatment from her doctors felt that it sometimes "causes more stress to go and see him [the doctor] than he can help me with".

The women felt that part of the reason they may not have received the "personalized" service that they required is because doctors are overworked. They felt that with only two specialists in the province there was not time for the doctors to keep up on HIV/AIDS information or to spend time dealing with all aspects of the person living with HIV/AIDS.

Doctor xxx doesn't have the time to give his patients too much. There is not enough people specializing in AIDS to deal with the number of people that need help, so people are not getting the care and attention that they need. Like I haven't been feeling well for the past few weeks, I'm probably dealing with stress, but I really needed to see a doctor but they didn't have time to fit me in because they are too busy. Like it takes time to discuss the problem you may be having and get to a solution.

I'm just totally discouraged with the medical profession that I don't want to go back. I think that the medical people are over-worked. They have too many patients and not enough staff, not enough doctors. I also think that they are too afraid to get involved with the patient and treat them as a person.

The doctors don't tell us about what is going on. I don't think that they know themselves. They can't really have the time to know about it all. With so few doctors who take care of all of the infectious diseases there isn't any way that he can keep up on what's happening out there. If we were living in a bigger place then we might have specialized doctors just for HIV who know about what there is. But because we live here it's like it's not as important because there is less of us. It's like it really only matters if there is a high number of you. If there isn't a high number of you then it doesn't matter as much. So we would be better off living in a bigger city or being gay, but then we would have to leave everything we know here. I don't think they respect the quality of life that we should have.

Many of the women reported that physicians knowledgeable of HIV/AIDS were overbooked and had little time to spend with their patients.

Dr. xxx is so overbooked with patients that he's totally unaware of who is who and what is happening in people's lives.

You phone the front desk and they say he's busy, they'll page him. He's got too many cases that he can't handle them all by himself. He's the only one doing that here. What do you think he's got for support? We're whining that we don't got any. Like he has [X] people that are all dying.

The women suggested that doctors should be given more information about HIV/AIDS when they go to school and that attending seminars on HIV/AIDS should be mandatory for those working in the health field.

Dr. xxx has something for family doctors and stuff but it's always the same people who go. I think that they should make other GPs get out and learn about it [HIV/AIDS]. If they don't make it mandatory then no one will come because they don't want to be bothered because there is so much to learn. It's easier for them to just say, "Sorry I don't have experience working with AIDS so you should go to someone else".

The women felt that what was of primary importance was having a doctor who treated them with respect, listened to their concerns, provided them with information and consulted with them before making a decision and who recognized and valued them as a "person, not just a number".

It's a matter of being respected. I go to him and it's like he's doing me this big favour and I should shut up and do whatever he says. But it's not like that. Everyone is different and has different needs and has different problems and reactions. You have to listen to your patients to find out who they are and what's worrying them. I think that the mental affects your physical state and vice versa and so you have to deal with them both together to really help. But Dr. xxx and health people only want to treat you like you're an illness and that's it. That only helps some of

the time. It really doesn't cure you or help you as much as it could.

It's simple, all we want is to be treated civil. It has a big effect. For starters, if a doctor doesn't respect me or lies to me I don't want to go back to him. If I don't want to go back to him then I don't get the treatment that I need.

What good is it having a doctor or nurse if they aren't respecting you? I'm not going to them. I would rather do it myself. At least I know that I'm not being disrespected.

Those who do not feel respected and valued were less likely to seek needed treatment. Some of the women reported positive interactions with a number of doctors.

My doctor is pretty good. He doesn't know everything there is to know about HIV or whatever, but he is really friendly and he tries. He listens to what I am saying and talks to me. I think that that is as helpful as being given drugs.

I think it's a matter of shopping around. There are some doctors that are good and there are doctors that are bad. Everyone has their day. You have to check around and see who is seeing who. They may not have all of the information, but as long as they are willing to learn. I find that I'm the one who is educating my doctor, but that's okay because he's learning so he can help others.

A few of the participants also spoke of the need for formal medicine to recognize the value in holistic approaches to treating them.

I find that there is no support for people who go for the holistic approach. You go on your vitamins and herbs and there is no support. Like he [doctor] will not shoot it straight down but

once in a while he will come out with a comment like, "Oh yeah herbs, well it's whatever turns you on." Give me a little more support. Tell me that maybe it is doing me some good.

More support on that [holistic approaches] would be nice. I have seen friends die. I have known a lot of people that are now dead and gone and I have hung on with kids and stress. And I seriously attribute a lot of that to some of the things that I have taken in the way of herbs and stuff. And reflexology, I didn't believe in that but I've learned. There are a lot of different things that can work, especially if you believe in them. I think that there needs to be more of a connection between alternative medicine and medicine. They should do more research into it and see if they can work together.

Participants felt penalized because the number of people, most particularly women with HIV/AIDS in Saskatchewan, is so small. They were left feeling that they were "second class citizens" who society thinks "should be grateful for what [they] get". The treatment that they received from the health care system did little to meet their physical needs and even less to meet their psychological needs.

A majority of the women reported that some of the nurses who worked with the specialists were very sensitive and instrumental in helping them. A high majority of the women felt that within the limited services that were available to them through the health care system, a female doctor would better understand their needs and would therefore be better suited to helping them cope with their

HIV/AIDS status.

Well I think that the doctors should be more sensitive to us being women. Like don't just come in and say why aren't you doing this or that. Or take off your clothes and let's look at you. I mean we are different. We can't get to appointments or take medications, or eat right all the time because we have other responsibilities. We have kids that need to be taken care of first, and they don't see that. All they see is the person in front of them and they don't think about what that person is like outside of that room. Like they don't know what it means to have kids, or to be a woman.

I would like to have a woman doctor because I feel more comfortable. I mean I can't just rip off my cloths and be examined in front of a man doctor. It is embarrassing. I feel like I'm being violated and used. It's not comfortable having a man paw all over you, even if he is a doctor. We come with a lot of stuff that's happened to us before with men and it all comes up again when you have to go and see a doctor. Especially if you have to stand naked in front of him and let him paw all over you and you can't do nothing. It's embarrassing and not right. They should have someone who knows about the effects on our needs. I think that it would help to have a women. I mean when you are diagnosed it is hard to understand what is happening and accept it. There is a lot of confusion, anger , guilt and shame that you are feeling. It is embarrassing and leaves you without any power. It's like no one will want you now, you are good for nothing, and often times it is a man who gave it to you. It's a man too that won't want you any more, like for a relationship. It's like a man has all this emotion over you and then to have to deal with it with a man, like a doctor isn't right. It doesn't feel right. That's why I think that a woman would be better because she knows what you might be dealing with emotionally and she also knows a woman's body.

I think that we need doctors that know how to work with women. I want someone who is going to be able to relate to me as a person. AIDS is not just about having a virus and getting sick

medically it is about being a human being and how being sick effects me as a person. I don't think that you can separate the physical part and the psychological or personal part. When I go to see a doctor I want to be dealt with as a person. I want to talk about how this or that makes me feel inside not just physically. My doctor can't do that. I think that if it takes a woman doctor to be able to do that then that's what we need. I'm a whole person, so treat me like one.

For the participants, the issue of wanting a female doctor was linked to the perception that as a woman, the doctor would better understand and address the needs of another woman. It was also linked to feeling more comfortable being examined by a woman.

Women felt "violated", "mistreated", "judged" and "disrespected" most in the area of their reproductive systems. Numerous cases were recounted of being counselled to have an abortion or to have their tubes tied. The extreme but not uncommon case told by two women was of having or being threatened of having their tubes tied while under sedation.

When I was in the hospital...the [doctor] there advised me to have an abortion and to have my tubes tied so I couldn't have no more. And then when I continued with the pregnancy they said, Well we're going to tie your tubes as soon as the baby's born." It's like what if I want to have more children or what if there is a cure in a few years, what then.

Stay away from Demerol, trust me. They brought me in for a headache and tied my tubes right off.

Women felt that they were judged on the basis of their HIV status. They felt that health professionals reacted to them based on their own personal beliefs and not on what was best for the women.

I don't think that the doctors are really practical with what they tell us. My doctor when I found I was positive told me that I should avoid sex, use condoms and never have children. That's what they say, never have children. I don't think that's right, because who's to say that the children will be positive. I read that only less than 40% of babies born to positive women turn out to be positive.

I think that it is a judgement that they make against us. Like if you are positive you cannot be a good mother, but who are they to judge us? How do they know what sort of mother we are. Yeah we may die early but then so can anyone. I could walk out of here and get hit by a bus and die today and it's not due to being positive. I think that they are just short sighted and don't really think about what we are thinking 'cause if they did they wouldn't be saying things like that.

That's what they told me [to have an abortion]. My doctor said that I would be infecting my baby and that the baby would die. I almost had one but then I read that not all babies keep being positive. But he didn't give me that option.

Some of the participants described hospital staff as being "insensitive" and "judgemental". They felt that the staff blamed them for infecting themselves and potentially others. They were very concerned with the lack of professionalism and confidentiality in the hospitals. Two of the participants commented on the negligent treatment they received in the hospital after giving birth. One woman

was separated from her child and was not able to see him because she was not breast-feeding him.

Everybody else was feeding but they wouldn't bring me my child because I wasn't breast feeding because I was HIV positive. So they said there was no need.

Another woman and her child were isolated from those on the maternity ward. In both cases the women were discharged early due to the hospital's fear that their presence might cause a scene if others were to find out about their status. They felt that being sent home exhausted and with a newborn put their health at risk. Not being able to rest and recover meant that they had to push themselves and further weaken their immune system.

I had her on Friday and I spent Saturday, and Sunday in the hospital. They did not take her into the nursery, she had to stay in my room. And then finally they got the guts up to walk into the room and say that because it might cause some kind of panic. Other moms might find out that I was HIV positive and it might cause panic, plus the press might get a hold of it so could I pack up my bags and leave on Monday. And that's when hospitals made you stay seven days. I got so sick, I laid there, I wasn't ready for this. I never got any sleep because they had her in my room. I was just as wiped out two days later when they released me as the day I had her.

Participants were concerned with the unprofessional treatment that they received from staff in the health profession. The women described incidents where confidentiality of their status was breached:

Some people aren't open with their status and they [hospital staff] are standing in the hallways whispering telling people who have nothing really to do with your care that you're positive. And they're looking in. It is really ridiculous you shouldn't have to go through that, especially when you're sick. Especially in a hospital, you think that they should know better.

Living in small towns it's harder to find good health professionals. There aren't any that know much about HIV and AIDS. Those that do don't want to deal with you because you're a risk to them, or they can't keep anything private and everyone finds out. They need to have a law or something that forces people to be confidential. They are supposed to be professionals but they are the biggest gossipers in town.

To the participants, especially those living in rural areas the issue of confidentiality was seen as being crucial to living a "normal life".

If other people found out about my HIV I would be ostracized. No one would want to be around me. I've seen it before. It happens. And then I would have nothing and then where would I be? Worse off.

Almost all of the participants reported that treatment by health care professionals had improved over the past few years.

I think that they [hospital staff] have gotten better than they used to be. They don't have the red tape outside the door when we're in there. Remember? Now they have experience and most of them treat you just like you're any other patient.

Treatment of Children

Participants expressed concern that they and their children were treated like "guinea pigs":

I don't know, they're so cruel. I mean I can't take it 'cause I feel guilty if I don't go in when they're drawing his blood. It looks like they're torturing him or something because they have him strapped down to the table and they have a nurse on each side sticking needles in him. And he's screaming. They keep telling me that they don't have to do it again and then they go, "Oh yeah we have to do it again". They tested him at four months and he was negative, which is rare. They tested him at nine months, he was negative. At a year they did the antibody test with the antigen yet they still want to keep doing more tests, more tests, more tests. It's like I don't want my son to be a guinea pig you know. I don't think it's a necessity to be pricking him all the time. Like I don't even know what the hell they're doing with it or why they keep doing tests.

The women with children report they are affected by the treatment their children receive by health professionals.

If they're [doctors] abusing my kids I sure the hell don't want to be seeing them. It also makes you feel guilty because you know that they are treating your kids that way because of you. If you weren't HIV positive then they wouldn't be treating them like guinea pigs, but like normal kids.

For some of the women, the affect of this treatment not only increased their stress levels but reinforced the belief that it "is [their] fault that [their] child has to suffer." Most of the women with children did not want to return to their doctors for treatment because they felt "judged" and

"forced to bring [their] children back in for more abuse".

Economic Needs

The category of economic needs was central to many of the participants. The ability to meet the demands of day-to-day living was based on having the financial means to do so. The themes that emerged from the participants in this category were based on having enough money and on getting money.

Having Enough Money

Having enough money was a part of almost every facet of the women's lives, from meeting the basic costs of daily expenditures, taking care of their health, to planning for the care of their children after their death. It is an area that the women stated caused much "stress and fear" in their lives. For the women not having money meant "dependency upon others" and making "sacrifices at the cost of [their] health".

I think that having money is really important to have your needs met. Without money I can't afford to do a lot of things that I need to. Like I can't afford housing, food, clothing or medicine. If I don't have that then I can't worry about getting my other needs met because these come first.

If you are worrying about not having the basic necessities then it is going to affect your health. Or if you don't have food you can't eat so you're going to get sick. And if you can't afford housing then you could be out on the street, which is going to effect your health.

Not having money causes a lot of stress that adds to the difficulty of coping with being HIV positive. Stress makes me tired and runs me down. When I get run down I get sicker faster. And if I get sick I can't do the things that I need to do, like take care of my kids, pick up food or do the house.

For the participants who live on limited incomes, money was linked not only to having their basic needs met but to being able to maintain their physical and mental health so that they could better cope with living with HIV/AIDS.

Food

Participants commented on the various areas in which not having money affected their lives. Participants stated that they almost always did not have enough money to get through the month. Often they would run out of food before the month's end.

I find we run out of money. Like I have not gone back once for any free vouchers, but we run out of money. With the two kids I'm supposed to buy everything on a limited amount, and they're both growing. It can't be done. I go to Value Village for clothes, I don't by new. At the end of the month we're scrounging around the house for food. It's a good thing that the school's have built-in lunches for the kids.

There isn't enough money for food even when you're a single person. I could use more. I don't have enough money to keep me going, yet my doctor looks at me and goes, "How come you're not gaining weight?" Well I told the worker that I need more money for food, but..

Not having enough food affected all parts of their lives. Not having sufficient and suitable food often meant that they were not getting the vitamins and nutrients that their bodies needed to stay healthy. The women felt that this meant that they would get "tired and run down faster" and were more likely to get sick. When they were run down they were not as "useful" to their families. Not being able to have enough food for the family or the energy to meet the needs of their families led many of the women to see themselves as "unfit" and "failures".

I know that money is big for me. I'm on social assistance and it doesn't cover much. I don't have enough for food, clothing or to do anything. I usually do without so that I can give them [children] things and then I get run down and sick and I'm no use to them then.

Definitely more money. You need to be able to live. It's connected to everything. To be able to keep my health up I have to have food and medicine. But I have to buy my kids clothes, have money for transportation, pay the bills and have a life. I don't have enough money to do that. I have to make priorities and cut things out. If it comes down to me and my kids then I do without the high protein foods or the vitamins. I have to think of them. I may not be here for much longer but they will. They shouldn't have to suffer because I have this disease.

When you can't even feed your kids it doesn't make you feel very good. All their friends are eating meat and stuff and all that I can give them is canned soup or whatever we got from the food bank. It effects me because I know they're suffering because of me. And it effects me because I get upset and then don't want to eat. I get stressed and then I don't take care of my health and it gets worse from there. It's the physical but it effects how I feel to. It's cyclical like

The feelings of failing as a mother added to the emotional stress that the women experienced. The women often experienced decreased health when they were not able to provide sufficient food to their families.

Legal Aid

The participants spoke of the lack of affordable and accessible legal aid. The participants required legal information and help in writing wills and for formalizing adoption and custody matters when they became sick or died. Not being able to afford legal help meant that the women did not have the security of knowing what would happen to their children. For the participants this uncertainty was stressful and ultimately affected their well-being.

I don't have no wills or nothing and that worries me. Like I don't know what is going to happen to my kids when I die. I don't know if my family will take them or if they'd be split up or the government would get them. It worries me that I could die tomorrow and they would be left out in the cold. I would like to give them some security before I die so that they know what will happen to them when I die. But I don't know what I can do.

I can't go to a lawyer because they only deal with criminal stuff for free and I don't have the money to pay them. I'd like to have some advice so I don't have to worry all the time. It's stressful when I have to worry. If I could get this out of the way it would be one less thing that I would have to worry about and I could use my energy to get better.

Transportation

Not being able to afford transportation was a concern of some of the participants. Without money for transportation, participants stated that they were not able to attend health-related appointments that they required. They were also not able to attend meetings that might have served as a support to them. For women in rural areas, not being able to afford transportation often meant that they could not travel into the cities to receive medical care or support.

I can't afford to buy a car, it costs too much for what I have. Without a car I am stuck here unless someone comes to pick me up. But I am too far away from people that I know. There are people that could drive me but then they might know that I am positive and that would make things worse. So I just try and forget it all. If it's pain I try to ignore it. It doesn't always work but it hasn't killed me yet. I can live. Today I came here on the bus and I'll go home early and no one will know. I can use the bus but it costs a lot of money and in winter I have to stand out in the cold for so long. If the bus breaks down then what. It's okay today they'll think I went into the city to do some shopping.

Housing

Being able to afford adequate housing was a concern raised by the participants. One of the participants stated that as a result of not being able to afford the adequate housing that she was occupying, she might have to move to housing that was not adequate.

Under housing, I don't know exactly how to say it but those of us who own our own homes or are paying mortgages, or who are living in adequate housing are being forced out because there's no way to pay for it. So we're going to be stuck out there like everybody else trying to find apartments that are unsuitable for our kids and our pets. Why are they forcing us to move to unsuitable places. Why don't they just give \$100 a month? It's not that much money.

Not being able to afford adequate accommodation meant participants had to "give up a quality of life". One of the participants stated that her "surroundings and environment are important in how [she] looks at things". She felt that having to move to inadequate housing would affect her mental and physical health.

I like where I am living now but Social Services says that it costs more than they have allowable, so I have to find another place. But I have lived here for a long time. I know my neighbours and the people around the neighbourhood. They are good for me and help me out if I need something. I have to move now to some place that I don't know and there won't be the people there to help me. I think that they should consider that. I'm going to be stuck in a place I don't know and will be all alone. I'm trying to fight it but I dread the move. It's stressful, I can feel it. I don't think that it is healthy to put someone's health

at risk just to save some money. I think that they need to look at the quality of life not just if they can save a few dollars. Anyway, if I move and am sick it will cost them more with medical help and all of that. It doesn't make sense.

Counselling

The participants commented on the effects of not being able to afford counselling services. Participants stated that they experienced difficulties both in their personal and family lives for which they required counselling.

I want something done with there being more services, or not having us having to pay any money for counselling because I'm having personal problems. I want to get them sorted out. There's no damn way that the little money that I get from them is enough to go out and be paying for services that I need. I don't want to end up in the psych ward or grabbing a gun and blowing someone's head off.

Your children, my marriage which is in big trouble, I mean they're all tied together. They're all because of the same thing. Like I mean this is a direct cause. You're changing a lot of things about our lives to start. I could use someone to help sort some things out.

Not being able to afford counselling meant that they did not receive the help that they needed in order to access mental health services which had long waiting lists. Not having support in working through psychosocial concerns left many of the women in a state of "anxiety and stress". It meant that the women had to cope with added stress during a time when their immune systems were already overworked.

Childcare

Not having money meant that the women could not afford childcare. Taking care of children was viewed by the women as an incredible stressor in their lives. They stated that they were often "exhausted" from running around and meeting the needs of their family. Many of the women felt that while a break would be useful in relieving stress and recovering from exhaustion, they could not afford it.

Know what I'd like to see...is a child care drop off centre at least maybe once a week so I can get the hell out of the house. I can bring the kids there and they can play together and I can get away and I don't have to come back until six o'clock. It would be a godsend to be able to drop my kids off and do whatever the hell I bloody well please and know I don't have to be somewhere in one hour two hours. It's a whole day thing where I don't have to worry about my kids or being somewhere. This is part of mental health. Spend the money here and they would save it from my not having to go to the hospital because I couldn't take time for myself and got sick. I need a break. Sometimes I'm ready to choke them. Why should they pay for my being uptight? They're living their lives and it's not their fault that I can't do all the chauffeuring, cooking, laundry and so on. It would be nice to have that for one day. Let the husband fend for himself and I'm out of there. Kids are a major stress, they get on your nerves after a while.

In the lives of the women, the role of caregiver was described as "demanding". It requires great "physical and mental" expenditure. Not being able to have a break from these demands and expectations meant that women are constantly under pressure to fulfil their roles. The effect

of this is that the women frequently "ran themselves down" trying to meet the needs of their families and experienced increased illness because they had to "keep going for the family's sake".

Money plays a central role in being able to live with HIV/AIDS. Having money is not only about "being able to afford to go out to a movie" but it is also linked with having the time and energy to take care of oneself.

That's it, you have to have money. Everyone has to have money to live on first. Then you can start worrying about how does my doctor treat me? How do I feel? Can I go to the support group? All of the problems that are about having HIV are secondary to having enough money first.

Getting Money

Not having money negatively affected the participants physical and mental health. The process of getting money proved to be as much, if not more, of a stress on them. The theme of getting money includes a look at some of the systems and systems personnel with whom women must deal in order to get enough money to provide for the basic necessities.

The main source of income for the participants was income assistance. In all cases, the amount of money received was deemed to be "insufficient", and "hard to get". The women felt that the Department of Income Assistance did

not fully recognize the cost of living with HIV/AIDS.

The women stated that their experiences with the Department of Income Assistance were filled with "bureaucratic hassles," that required "filling out thousands of forms" that they "did not understand". The women felt that the effect of such "administrative hassles" was to delay receipt of needed money. They felt that the department did not respond to the crises that they faced daily.

A lot of times Social Services doesn't see the need for a phone. They want all these letters from different doctors. You shouldn't have to run around to doctors to get letters for things like that because it is a necessity. Especially if you have kids. I mean emergencies happen with kids, you have to be able to call somebody.

The women felt that they were not being given their full entitlement. Through their discussions, it appeared to the women that what they received for assistance was often related to which financial aid worker they had. The result was that many of the women received different amounts of income assistance. In all cases, when the money provided did not cover the costs of a necessity, they had to either take money from another area or do without. For the participants, "when one has to choose between eating and having clothes or shelter to keep you warm, it is not much of a choice".

I have nothing for emergency stuff so I worry about something coming up because there isn't money for it. If the kids need clothes or a bill is extra I have to worry about how to pay it. That is stressful and I get sick from worrying about it. I don't want handouts from anyone. I'm not like that. But because I am sick I need help with the extra costs. And if they want me to do something for them I will if I can. I don't mind doing that at all.

When extra money was given to cover emergency costs of necessities, this amount was often deducted from the next cheque. This meant that the "insufficient amount" that the women received in one month would be even less for the next month. The women felt that this left them with a feeling of "hopelessness of never getting out of not having enough". As the participants described it, they were going "further into debt".

And Social Services thinks that you shouldn't run out of money with what they give you. And if you do they think you're wasting it. I've had flack when I ran out of diapers. My sons had the flu a couple of times and you run through the diapers like that. If I need money for diapers it gets deducted off my next months cheque and then I get told that, "You should have all your food for the whole month." It costs more to buy in the small towns, lots more sometimes. And I can't get by the next month with less money than they gave me this month which wasn't even enough. You keep going further and further down and can't get out. I don't think that's right.

Some of the participants stated concern over the lack of accessibility to the designated worker. Having only one worker to deal with the HIV/AIDS clientele often meant that

accessibility was limited when they required assistance.

Now there are those days when I have an emergency and I need to get a hold of a worker, and there isn't anyone to replace [them].

While the women reported that the system which delivers income assistance "on the whole was not effective" in responding to their crisis needs, they felt that they were likely getting more than others who did not see the Saskatoon designated HIV/AIDS income assistance worker. The women stated that the designated worker provided them with "better treatment and more aid" than other workers in the system did.

I think there are advantages to having a designated worker. He is able to learn about AIDS because those are most of the cases. And he doesn't judge you or make you feel guilty for being on assistance. It's more private.

Having just one worker for us all means that we are all going to get the same thing. Like other people I know get different things because their worker doesn't know about special amounts or won't tell you. It's important. Our needs change so fast that you need to have a worker that knows what can happen with illness and that believes you.

The women who did not have contact with the designated worker reported that the inconsistency they experienced often left them to have to "fend for [themselves] against a bureaucracy that [they] don't know anything about", and which "[they] don't feel that [they] should say anything

[to] because [they] might get cut off".

The women reported that the attitudes and actions of income assistance personnel left them feeling that they were being "blamed for running out of money" and for "draining the system". The effect of this weighed heavy on the women. In many cases because of the "hassles and blaming treatment" that they received in obtaining income assistance, they often accepted what they were given, even though they may have been entitled to more.

The only time that I see my worker is at review, that's every once a year. She will make calls back but I don't know how to explain to her. I don't have the right information right. That's probably why it's like, "Well that's all your getting." But I don't know what I'm supposed to be getting if she don't tell me. I can't tell her that I should be getting this because I don't know.

I think that there needs to be a system like where they have a list of what we are entitled to so that we can check it to see if we are getting what we are entitled to. Otherwise the social worker can discriminate because he doesn't like one of us or he thinks we deserve to get HIV. There is just too much difference in what people are getting. People are not always given what they should be getting because the worker doesn't know, or the worker doesn't want to give it to you because he doesn't think you deserve it anyway. Especially where there isn't a designated worker. A list of entitlements would be useful so that people could check to see if they are getting what they are entitled to. How else are you supposed to know unless you start talking to other people who are getting it.

The participants commented on other sources of income. The women were "confused about entitlement qualifications" to such programs as CPP and disability tax credit. They were unsure as to whether they qualified for benefits and how to find out if they did qualify. They found that this "lack of information around financial programs" caused frustration and anxiety.

Mental Health Needs

The category of mental health needs was an area that the women viewed as central to their ability to cope with their HIV/AIDS status. The stress of daily expectations and lack of support was reiterated throughout the focus group. The themes that emerged from the participants' discussions in the category of mental health were based on pressures and stressors and on service providers.

Pressures and Stressors

The participants stated that they experienced many of the same stresses as other people who did not have HIV/AIDS, but because of their HIV/AIDS status these stresses were magnified. HIV/AIDS was seen to exacerbate other life events. It magnified marital problems, financial problems, caregiver problems, and compounded a woman's sense of guilt at not "being able to do it all". Dealing with these

stresses without adequate support had negative effects on the mental and physical states of the participants.

I think that we go through a lot of the same things that other women do. You know, having to take care of families, dealing with male doctors, not having enough money or food, and then the hormonal changes but I think because we have HIV it makes it bigger. I mean we still have to deal with all of the same things but we also have to worry about taking extra care of our health, planning for the family when [we] die and we have to do it all in isolation. There isn't anyone to talk to that will understand what we are going through. There are other women out there, like here, but it's not so easy to get together because of once again the family and money and travelling. You add all of that up and it's hard to deal with alone. I don't think anyone could deal with it, even if they were healthy. And we're not"

I think that the mental health is compounded by having HIV. I mean people get depressed or have to deal with not having money or things like that but when there's HIV it adds to it. You throw in the fact that your health is deteriorating and that you will die. It's different from how cancer is because that's more accepted and you can talk about it and get sympathy. But with AIDS it is something that you have to keep in secret and worry about others finding out because it will make it more difficult. Like not having enough money is hard but when it affects your health to the point of being life-threatening then it's a bit different than just not having enough money anymore. Or when not having money means that you can't go out on the weekend it is different than meaning that you can't afford medicine or that you have to stay in with your kids who are whining because you are too sick to go out.

Isolation

The difficulty in coping with pressures and stressors placed upon them was a key issue for all participants. A high majority of the participants frequently stated that they felt physically or emotionally "isolated". The isolation seemed to be greater for those women in the rural areas, but its effects were similar for all the women. The feeling of being "isolated" left the women feeling "alone", "frustrated" and without the support that they felt that they needed.

Being isolated has a big effect on how you are and how you deal with things. When there is no one to turn to I have no one for support. When I feel down because of being sick or having down thoughts and have no one to turn to it makes it more difficult.

Living in rural areas you're really alienated. You feel that way because... Like I have friends in the town I live in but they're not the kind of people you can feel open enough to say, "Well hey I'm HIV positive". It's too much of a risk.

Family and Relationships

Family and relationships were viewed as one of the main causes of stress for the participants. Many of the participants stated that while their families did serve as a "source of support" they did not provide enough support.

People handle stress differently. That can be a problem if you don't have anyone to help you through it. In my case my family is in denial, so they haven't been that supportive because they don't want to talk about it. They say that I

shouldn't worry, that they'll find a cure soon and that I only get my self upset by worrying. I don't think that they understand. I have my parents but it is really hard on them right now. I mean it's hard to watch your daughter die, it's not supposed to happen in that order. So I can't talk with them much because then my mom gets upset. She says that she can handle it but I know that she hurts and cries. And that makes me feel bad for putting her through this and I end up feeling worse. It's like I'm the one who's sick and with all this stress and need support and I have to support them.

My family tries to be there for me when I get sick. They will ask me how I'm doing and bring me stuff if I'm too sick to get up, but it's not enough. It's not like I can tell my 10 year old that I am scared of dying or having pains in my vagina. He wouldn't be able to understand that and my husband can't either. It's hard to always have to be explaining what is going on to them. It's like I have to be reminded again of it all. It's too hard on them too. They don't need all this stuff. It's just easier saying that things are okay and I'm just a bit tired. But I'm scared. I think that having someone to talk to that knows what I'm going through and [who] can give me support and information on how to deal with it would be helpful.

For one woman, her husband's "denial" meant that she had to always "put on a happy face", even when she was sick, so that her illness would not become an issue.

He needs help he does. I can see it and I can feel it, and it's interfering a lot. And I get hurt as a result because I constantly follow this I'm so healthy image, I can do it all, I can take care of the kids, I can do everything. I can't. But if I don't then you see him going around the house and there's tension. So rather than that I put on a nice little face and I carry on. And I can't do that, I can't, I just can't.

Caregiver Expectations

The role and expectations of being the caregiver was a great source of stress in the participants' lives. All women with children feared not being able to "do it all" for their families. When they were sick they pushed themselves to meet the expectations of care giving and would experience "implied guilt" if they were not able to keep up.

You get the looks, and the kind of you know... I feel guilty for being sick. It's there, it's implied guilt because you aren't up doing what it is you should be doing, or what you think they think you should be doing. I've gone through illnesses and infections where I should have been in the hospital but I couldn't go because I felt too guilty to go. So I just kind of walk it off. I mean I treated myself at home and worked through it.

I think having to deal with being a caregiver is really important in being able to cope with being HIV positive. It takes up a lot of energy to have to deal with my husband and the kids that I don't have time for myself. If my kids needs something I'm the one who has to go running around and get it for them. The gay men don't have to worry about that because if they get tired they just lie down, but I have to keep going because if I don't do it then it doesn't get done and it's worse to have my husband ragging on me because the house isn't clean or supper isn't ready. So I just forget how I'm feeling and do it so I don't have to listen to them complaining. So I get run down and get sick because I have to take care of my caregiver things.

For a high majority of the participants their role as caregivers was synonymous for being "at the bottom of the list" when it came to the distribution of resources.

Woman are always limited by their role as caregiver. If there is 'X' amount of money in the family then the child should come first, no problem. But then the man gets next and the woman gets at the bottom. That really is stupid. Especially in the world of HIV where you need your health. Maybe things can change.

One of the participants who had a spouse with HIV/AIDS also dealt with the stress of worrying about her partner's health. She worried about the effect that his death would have on the family unit and feared that when he died the income she lost would further prevent her from being able to afford the "low quality of life" that they now had. The increased needs of her partner as he came more ill also took away from the time and energy that she needed to care for her own health.

Women are more of the caregivers and often forgotten. Having to deal with family and HIV is really stressful. There isn't time to take for yourself so you get run down. If my partner gets sick I'm the one that has to take care of him, but if I get sick there is no one to take care of me. I have to do it myself. You don't have time to worry about your health and then you become run down and sick.

Children

Children played a central role in many of the participants' lives. Many of the women felt worried about not being able to be a 'good mother' to their children. Many of their concerns centred on the need to prepare their children for their deaths. They felt that they were "not

equipped to tell [their] children" and could not find resources to help them do so.

We need to have something to teach kids about it. My kids are getting to the point where they suspect something is happening but they're not sure what. I don't know how to tell them. I'm not skilled in this. I need a childcare worker to come and help me tell them when they're ready. To sit there with me, make it a little easier, because who's to say that if I try to talk about it that I wouldn't flip out and what's the kid going to get out of it but a lot of anxiety and be scared and wonder what the hell is this all about. And I might get it across totally wrong.

Stigmatization

For a large majority of the participants, society's "blaming" and often hostile attitudes toward people living with HIV/AIDS caused them great stress and kept them from getting support. For one of the women, her isolation was linked to her fear of going out because of possibly experiencing discrimination. "I'm scared to go out and that's one of my needs that I'm getting really scared about". For many of the participants, the lack of acceptance of persons living with HIV/AIDS meant that they must keep their status a secret and had not gained access to needed support. One participant lied to those in her community about her spouse's AIDS status because she feared that her "family would be ostracized by the community if they were to find out". The participants agreed that this was a common experience for many people with HIV/AIDS.

I have only told two people other than my family in eight years. I have seen the way that people have responded to HIV and it hasn't been good. I don't want people to think that I walk the streets or shoot up, but that's how they think you got it and you can't change their minds because they don't listen to you. Their mind's are already made up.

There are lots of people who are positive out there who need support but don't get it because they are more afraid of the results of having people finding out. So if your choices are to tell someone and maybe be discriminated against or be ostracized or beaten and dealing with it on your own, I think that most people would just deal with it on their own because then they know what they are getting.

I know for myself that I would like to talk to people about how I'm feeling. I sometimes get really confused and down when I start thinking about being positive. I get scared because I don't know what is going to happen to me, if there will be a cure or if I will die in pain and alone. I get really lonely because I have friends but not ones that I can tell. I mean maybe I could but I don't think that they would accept it very well and if they don't then I'm left with no one and that's worse. So I know that having to deal with it all is really hard and stressful. I know that when I get scared and down that I have to watch because it's easy to start getting more down. I start being more depressed and more hurt and then I don't take care of myself and I get sick, and then I get more down because I'm sick and I keep getting worse.

Because of the negative and often hostile treatment toward people living with HIV/AIDS, some of the participants lived in constant fear of one day having others find out about her HIV status. For those women in the rural communities, this fear was magnified due to the small size

of the area, the intrusiveness, and the "lack of acceptance of difference" in these communities.

People that live in small towns are scared. People that live in small towns have to hide it. Where are they supposed to get help? The towns don't know anything about HIV. They don't want to know they have it.

Even when they know that it's in their community they don't accept it. Some people might say that they don't have a problem with it but they do. I knew someone who lived in a rural community in Saskatchewan. The community said that they were all supportive but then would say things like, "AIDS is God's punishment", "If you wouldn't have been immoral you wouldn't have gotten it". That's not acceptance, that's being hypocritical. They can tell you that there is all of the support out there but if you live there you now it's not there.

Service Providers

The women stated that because they constantly faced life stressors that were compounded by their positive status they were often in need of support, be it professional counselling, family support, peer support or information.

I think that one of the things that we need is more support. Like we have to deal with a lot of things that add a lot of stress to our lives. Having HIV is just another stressor that makes everything else that more difficult to deal with.

We need to have support groups for women. I need someone that I can turn to who isn't going to judge me. I know people that I can talk to but I can't talk to them about having HIV because they wouldn't take it too well. It's limiting. I can't talk to them about personal stuff. I mean almost everything we do is affected by our having HIV. You can't separate them. I need to talk with people about problems that I have and be able to talk about HIV.

Competency

A majority of the participants felt that there was a need for competent supportive counselling. In the past their experience has been that they were given "pills" but had not had their concerns heard.

I want psychiatric services. I want a qualified university degree type person to go to for help. Somebody that knows how to work with the HIV people. Someone who does not deal in more pills. What we needs is someone to sit down, keep their mouth shut and listen. I can do it a whole lot better than them and I'm not even a professional at this. All they can stress is pills, pills, pills, pills. That messes you up more.

For many of the participants, the effect of not having competent help in dealing with issues such as relationships left them feeling "isolated" and with problems that become increasingly more severe and stressful. For some, this added pressure and stress resulted in a weakened immune system that left them open to becoming ill. Becoming ill only increased the stress and pressure in their lives.

I think there needs to be something because when I get down about something it affects my health. I mean if I start getting depressed about being positive, about my kids or about being alone, I get more depressed and then it affects me health wise. I start to feel worse and get tired and have suicide thoughts and there's nothing I can do about it 'cause I don't have anyone or no way to help me deal with it all.

I think that there should be some more support for us because if they are trying to deal with our health they need to look at all of us not just our bodies. They need to look at what we feel and think and help us to deal with that.

Some of the participants felt that professionals only listened to them because they "were being paid". They stated that the professionals were too "detached" from what the participants were telling them and lacked "empathy". Participants found that in these situations talking with them did not help as it only added to their sense that they were "alone" and "messed up".

I don't like going to psychologists because it's too uncomfortable. You sit in their office and tell them your problems and they go, "Yes, tell me more." I don't think that they are really even listening.

They [professionals] don't understand because they aren't going through it. I think that it would be okay to go to someone who has gone through it maybe themselves or in their family or friends. Someone who has experiences in life in dealing with it one on one.

Other participants noted the value of seeing a professional when dealing with "private family issues" or where "objectivity" was desired but felt that "peer support is more helpful" because it did not place them in an unbalanced power relationship.

Having professional help is useful sometimes in helping, to have someone to talk with who isn't attached. You can tell them things and not worry about being judged. It helps sometimes but I think that having peer support is more helpful because it is less 'them' and 'us'. Having peer support has us all on the same level. You are able to get to know each other better and don't have to worry about getting too close.

Accessibility

For a high majority of the participants the issue of access to professional counselling also involved cost and availability at moments of crisis. The participants did not feel that they could gain access to professional help because "good counsellors usually cost money or are booked up, and mental health counsellors are only available from Monday to Friday from 9 to 5".

Mental health services you have to book an appointment 'way ahead of time. By the time your appointment comes around that particular crisis is over or you're dead. If you are alive usually it has taken a toll on your mental and physical health to get through it.

In rural areas, the issue of finding appropriate counselling support was linked to the issue of confidentiality. The women in the rural areas feared that if they sought support or counselling in their area, everyone else in the community would find out about their status. The participants felt that this would create, and for some had created, great difficulties because the "people were AIDS-phobic". Having their status revealed had led to "ostracism" and "violence against [them] and [their] children".

Peer Support

All of the participants felt that there was a need for women to come together, share their experiences and be supportive of one another. The women felt that they had experiences and needs that could only be understood by another woman with HIV/AIDS. Having a linking or connecting service was seen as a healthy method of dealing with pressures and stress. The women felt that many of their issues could be met through peer support. Sharing, being heard and understood are components that the women were looking for from supportive counselling. The sharing of experiences by other women who had or were going through similar situations was seen as being beneficial in coping by the participants.

I find that talking to people helps to be able to cope with life's problems. When I am feeling crazy because of all of the pressure in life, taking care of my kids, doing the house, bills, my husband, I would like to be able to have someone over for coffee or talk to someone who I know that I can open up to and who accepts me for what I am. I need to be able to talk openly and know that I'm not being judged or that someone else will find out about what I've said or whatever.

Service Needs

The category of service needs is one that is closely linked to the participants' ability to manage their lives while living with HIV/AIDS. Knowing what services are available, being able to gain access to those services,

receiving sufficient services and being treated respectfully while utilizing services are key components in this category. The themes drawn out in this category are information, access to services, adequacy of service and experiences with service providers.

Information and Referral

All of the women felt that having information provided them with the knowledge necessary to make informed choices. Having information allowed the women to feel that they had "control" of their lives. Central to receiving support was knowing where to find it. For many of the participants not knowing what was out there, or who was out there was a block to obtaining support. For example, two of the participants were not aware that The Persons Living with AIDS Network also provided services for people living with HIV.

It was funny because I didn't know nothing about the PLWA, my worker didn't tell me about it, my doctor didn't tell me about it, my dermatologist didn't tell me about it and when I went in there and asked something, they all knew about it. And the only one I heard about it from was her [one of the participants].

Information is pretty important because if you don't know that something exists then you can't make use of it. Like for the longest time I didn't know that [AIDS Service Organization] was here. That meant that I had to deal with things on my own. I didn't have the support that they give to you here or to get some of the money that they also have available to help you deal with extra costs for things. Without knowing that this

was here I had a harder time in dealing with things, so knowing about what there is is useful in dealing with HIV.

The participants felt that this lack of information prohibited women from gaining access to services and obtaining information. While information is important, the women also felt that the format and how women were treated during the delivery of the information also played an important part in helping them to cope with their HIV/AIDS.

A large majority of the women found that they received the most helpful information from other women who had gone or were going through similar experiences.

I think that first-hand experience is most helpful. Talking with people that are positive helps because they know what I'm going through and can relate to me. They don't judge me like it's my fault or anything. They know how AIDS affects the body and the psychological part of me better than someone who isn't infected. And they can help with knowing where to go for help with different things like, money, food, medicine and that. It's different getting help from someone you know who is positive because they will get me the services that I need not what others think that I need. There's a big difference.

Unfortunately not knowing how to connect up with other women with HIV/AIDS, or not being given the opportunity to do so left the women in a state of "confusion", "depression" and "isolation".

I've had a really hard time dealing with everything. I mean when I first got diagnosed I had no one to turn to for help. I thought that I was the only one with this disease. I felt like a freak. I used to get really depressed then because I didn't know that there was support available. I used to sit around all day wondering when I was going to die, like it was going to happen right away. I didn't know better then. And that was really bad because I didn't care about nothing. I didn't eat the proper foods or get rest or medicine. Nothing. I just wanted to get it over with so that I didn't have to fear when it would happen. Meeting other people with this has helped me because they have gone through it already. They can tell me what to expect and I can talk with them about things like when I get depressed.

Geographical Isolation

All of the women commented on the difficulty that living in Saskatchewan brought to getting together with other women who have HIV. Their discussions focused on the geographic distances between women and on the lack of power that women had in the field of HIV/AIDS to be able to develop services for women.

The problem is that we don't know who is out there for women.

Women are not able to come together to form the groups that are needed. Either we can't get to them or they're too scared to come out or the service isn't available. You know if we don't have a place where we can all go out or have a way of coming together then we won't get anything. And because it is men that control the money and what services are usually provided then of course what we need or want isn't going to be met because it just isn't important to them or they don't understand.

There aren't enough women in Saskatchewan to always get together to have a support group. There aren't enough women and we are all separated out. They need to have some groups every once and a while but they need something for when you leave the group.

Another problem because we are in Saskatchewan and everybody is so diverse and spread out and it's hard getting together. It's good that there are support services here, but it's not the same as being with another woman who has the same problems because they are the one's who can only really understand what you're going through. But to be able to reach these women and see them is a problem

Society and Information

All of the women felt that there was a lack of information being given to society about HIV/AIDS and about the people who are living with HIV/AIDS. One of the potential effects of this is that many people are continuing to put themselves at risk for contracting HIV because they do not think that they can become infected. This lack of knowledge also may affect the treatment that women receive from all members of society. The women felt that the lack of "personalizing" the individual with HIV/AIDS by the media and in AIDS seminars has meant that women continually are open to discrimination and insensitive treatment.

They need to help the public to understand about AIDS. They need to make sure that people know how HIV is spread so that they don't think that they can get it from just being around people who are infected. I would like to see more personalizing the person with AIDS. I think that it would be helpful if people realize that we are like the

people next door. We're not freaks, or prostitutes, or druggies. We are the same as them but we were unlucky and got infected.

They need to start educating people when they are young so that they don't grow up being discriminatory to people. If they understand and see that people with AIDS don't want to infect everyone and that they should be accepted as human beings and not judged maybe they won't be so cruel to people with AIDS. I think that if the public were more understanding and accepting that it would make things a lot easier for us.

Access to Services

Most of the women found that even when they were aware of services and options that were available they had difficulty gaining access to them. The women felt many services did not respond to their crisis needs. Agencies were often not open, or individuals were not available when they needed their service most.

On the weekend or after 5 when I need help there's nothing. You just have to tough it out I guess, work it out somehow. I walk or exercise. Go to the park, just try and clear my mind. There really isn't anyone else to talk to. Like I mean I've told a couple of people recently but I still don't like putting my burdens on other people so...

I think we need more 24 hour services. Like I need help sometimes to deal with things and there is no one around. I have a buddy and I will try and call her but she isn't around. It's hard. Especially when my son is going, "What's wrong mom?" And I can't explain, like all these emotions and depressions. Kids go through anger and frustration, "Why is my mommy like this? Why won't she talk to me?" But I can't...it's hard. I then get more depressed, and I can't get like that because it affects him.

Other components in deciding whether the women were able to avail themselves of services were proximity to the services, accessibility by public transport and availability of childcare. Many of the women noted that while services may be available, if childcare cannot be found then the service is still inaccessible to them. Of specific concern was availability of childcare to allow them to attend appointments with their doctors.

Services aren't practical. Like if I have to go to see a doctor or to the counsellors I can't be dragging along my kids. There's no way that they can sit there for hours waiting for me. It's not fair to them. So I just don't go. It's less stressful sometimes to deal with the pain than to deal with the kids nagging at you for hours while they're waiting.

All of the participants felt that prohibitive policies often prevented them from utilizing a service; ie. drug trials. They felt that while women were now being admitted to some trials, having to take birth control pills limited this accessibility. The women felt having to give up control of aspects of their body should not be a requirement for participating in trials. They felt that not being able to participate in drug trials was another way of "being controlled" by the "people with the power".

Give us the option of taking it. What's it going to hurt that they haven't already done damage to. It's like, "We'll tell you when to take drugs and we'll tell you what drugs to take."

A majority of the women were concerned about not gaining access to legal aid, counselling services, child care, or home care services because of lack of financial means. While services may be available they were often not accessible due to the cost associated with using them.

It costs money to do anything. To go to an appointment it costs money to get there and for child care. And if you want something that is any good then it costs extra; a good lawyer, therapist, baby sitter even to come down to a place like this for support. There might be good services out there but they are few and far between. And either I don't know about them or they are booked up so I can't use them anyway.

The participants felt that their ability to utilize services was often impeded by bureaucracy. This was apparent most when dealing with income assistance. The women felt that having documentation from doctors before receiving many benefits did not recognize the fact that they had limited time and energy in which to run around the city trying to get letters and specific documentation. They found that this process also was not conducive to meeting their crisis needs.

They want all these letters from different doctors. You shouldn't have to run around to doctors to get letters for things like that because it is a necessity. Especially if you have kids.

Many of the women found that "fighting between" different AIDS service organizations made it "difficult and uncomfortable" to take advantage of one service over another.

The way it is set up here is that if I go to [one of the AIDS service organizations] then [the other AIDS service organization] gets down on me. They go, "So what are they doing over there? What did they offer you? Was anyone else there?". It's like they grill me over with questions. And then if you get close or involved with one place then the other thinks that you're betraying them. It doesn't make it very comfortable for me. I thought that they should be working to help us but they don't. They are more worried about their personal fighting with people in the other place.

It's been like that for as long as I can remember and no one does anything. I heard that they were to be moving in together but it hasn't happened. I think that they are so worried about losing power that they sacrifice helping us.

Adequacy of Services

The participants felt that even when they know about and are able to gain access to services, what they receive is not adequate. For example several participants commented on the lack and poor quality of food that they received when they went to the food bank. The participants felt that the food given to them was of little use and was often obtained at risk to their health.

I find that I don't [get] my needs met. Like I can go in there and 20 people that go in ahead of me can walk out of there with food. I mean literally people are walking out of there with 2 boxes of food. I go in and I'm a family of four,

I get one box of food and the majority of it consists of donuts, muffins, cakes, bread and I get no good food. The last three times I've not gotten milk, but everybody else has walked out of there with two, three cartons of milk and fresh vegetables. The vegetable they're given me are rotten. The potatoes are dripping wet and the onions have brown rotten spots. Like I don't want to cut it up and feed that stuff to my family. And that's all they give me. I get two cans of food and that's it.

I've noticed that it's always the men that get everything first. They push their way to the front and take all of the good stuff. It's not fair. They are healthier and stronger than we are. Why can't we go first instead of having to wait out in minus 40 weather with our kids to get rotten food. I get sick because I have to stand outside and end up with nothing while they are healthy and walk away with all of the food. They should let the women with children in first.

The main area where the participants felt that they were not receiving adequate services was around income assistance. The women felt that the cost of living and having HIV/AIDS was not recognized by the system or by individual assistance workers. They found that the amount of money that was given to them did not meet the basic requirements for living (housing, transportation, food, clothing etc.).

The adequacy of services was often linked to the pragmatic practicality of a service. For example, for one of the participants fighting for her rights for confidentiality meant that she had to go public with her HIV status. It set up a situation within the system where women

were prevented from fighting against injustice, lest they leave themselves open for further abuse.

Confidentiality, yeah, it gets broken just a little too much. You have to fight any of these injustices through the Human Rights. There is a big hitch in there too because if you try it's got to go public. So you can't win. Your life story and status gets known by everyone and then you get discrimination. It has to be released and become public basically. You have just one option. If you want to fight confidentiality being broken then you have to go public, which is the thing you're fighting against in the first place; people knowing your status. You lose both ways.

The women commented on services in which they felt they could have some of their needs met. Some of these services included: a women's support group, a telephone support line, daycare, organized activities with others who have HIV and a hospice.

Support group:

I think that a women's group is a great thing. We did have one a few years ago and to me it was just a waste of time. It didn't meet any of my needs. You met people that were there but it was not like sharing information. It wasn't learning anything new. I don't think a lot of people had contact after. There needs to be more structure.

They were supposed to continue with the group but they never did. I haven't heard anything about it. I guess it's because we don't make enough noise or are high up in the priorities.

We need to have some sort of base that we can go back to so that we don't lose contact. It would be nice to have another group with a little more structure and some kind of base so we knew why we were there. You just can't throw different people together and expect them to get all their needs

met 'cause having someone to talk with is only part of what is needed. You still need to have the information about medication, sicknesses, how to get money and what to expect and how to deal with things. You need to have them all to meet your needs.

We need to be consulted with when they develop the group. You can't just decide to have a group for women and not involve them in setting it up. Everyone needs to be consulted because we all have different things that we want from a group.

Telephone support line:

Workshops are great but they aren't always going to meet the crisis needs. I think that we also need a telephone line. It's not always possible to make a group if you live out of town or have kids. There are things that happen and I need to talk with someone now. I can't afford to be calling long distance because it costs too much, and then I'd have that stress.

Daycare:

I could see a daycare facility so that people when they have to go to appointments or they just want to get out for a walk can drop their children off know that they are cared for properly. I also see more of a living room setting. More of a place to drop in and relax. Not just a volunteer agency. Like not involving you in having to work. You can just come in and relax for a while and have someone to talk to, not sit in the room yourself.

Organized activities with others who have HIV:

Activities and events that people can gather and go to. A car pool to pick up PLWAs that don't have transportation and have difficulties getting around. I see getting together for suppers so people can get together and talk about what they need or what they like on a regular basis.

Hospice:

I think that a hospice would be pretty good, especially for people who don't have any family, who don't have any place to go and who need care. You need care and to be with other people especially when you're ill. That has got to be the worst time to be alone. It would also be good because they don't treat you the best in the hospitals and this would allow for people to be with others who know what they're going through and to be supportive.

Experiences with Service Providers

A majority of the participants commented on the lack of information that was given to them by people who were supposed to be helping them.

We hardly ever find out about the drugs that are available. Either the government doesn't tell us or we never hear about it. Like Dr. xxx, and [AIDS organizations] get a bunch of up to date information on new drugs but they don't tell us because it's not important to them. Or they don't agree with it. It should be available for people to see and make their own decisions. They should realize that, that is something important.

Most reports of interactions with AIDS Service Organizations found them to be of limited use. Many of the women felt that providers were serving their own agendas and not helping them.

It's like they don't give you anything or share anything because they want to keep you coming here, but no one does anyway so what do they have to lose. Come on help the people you are supposed to be helping the way they want you to, not the way you want to.

To have a say in an agency you have to be a member of the board or on a committee, otherwise you're not taken seriously. They think that all you are is a whiner. There needs to be something where the opinions of the people are heard and something is done. Quite often I tell them a complaint and I don't know what they do about it because nothing changes. So I think, why should I bother and I just stop going because they don't care about what I think anyway.

When the women did access an AIDS organization, many reported experiencing feelings of "guilt" about betraying the other AIDS organization. The women felt that they were caught between two of the AIDS service agencies. The agencies were using them as pawns in their competition, instead of attempting to work together to help the people they were set up to help.

I've always thought that it would be nice to see a joining of the two agencies. Why does there need to be a feud, and the need to have two separate ones? Why can't it just all go together? Negotiate, sit down, choose a board of directors and pull together. Not one this way and one another way, and they got what we don't got and they don't got what we got. There's jealousy involved. Why? There's not supposed to be. They're supposed to have the interest of the people yet they're both going in opposite directions. And if you go to one you feels disloyal to the other. This is bullshit. I feel bad about it. You know, why should it work like that? You shouldn't feel that way. You should feel good about that you've gone to them.

Summary

The majority of the women felt that they needed the same things that other people needed but, because of their HIV-infection, they needed more of it.

We all basically need the same things. We need to have doctors that will respect us and listen to us when we say that we know our bodies. And like money and everything that goes with it. All of the food, and being able to have a normal life; have a quality of life. We have to have some support to help us with all that we are going through. It's a lot that's changing all at once, and we need some support in dealing with all of that. That is really important to have support. If there isn't any then you can feel really isolated and give up hope so easy.

What we need is to be respected. I don't know everything but I shouldn't be made to feel that I'm dumb. I need information, lots of information. I don't need to feel dumb about asking for it. It's what I need to help make decisions. That's why I find get togethers like this helpful. We have been talking about our problems and there is already someone here that's gone through it. I wouldn't know half the things that I do if it hadn't of been for [some of the participants].

The experiences of the women demonstrate that understanding their needs requires more than simply knowing what need they have (substantive instrumental issues). It also involves an understanding of the context within which they experience the need and within which they attempt to have their need met (process issues).

CHAPTER 5 - Conclusion and Discussion

This study has four important conclusions: First, many of the needs of women with HIV/AIDS in Saskatchewan are not being met. Second, women face a number of social and systemic obstacles in their attempts to have their needs met. Third, women who used mastery coping strategies were more successful in having their needs met than women who used maintenance and avoidance coping strategies. Fourth, social supports can play an important role in the success of a coping strategy. These findings offer valuable insights to understanding the needs of women with HIV/AIDS and have important practical implications for designing services to meet those needs.

Social Support and the Needs of Women with HIV/AIDS

The previous chapter presented the needs of women with HIV/AIDS within thematic categories that allowed for the substantive instrumental issues and process issues of the needs of the women to be explored. This provided a context within which the needs of the women could be understood. The exploration of the experiences of the women also provided a greater analysis of what the specific needs of the women are. Table 2 provides a listing of the needs of women using Cobbs' (1976) framework of three types of social

support (instrumental, emotional, informational). This framework is useful in that it provides a social support structure from which social support interventions can be made. For example, if a tangible need is presented then a point of intervention might include presenting tangible support.

This study confirms previous findings that document the specific needs of women with HIV/AIDS: money and shelter (Lindhorst, 1988; Manson Willms, Hayes & Hulchanski, 1991); acceptance (Manthorne, 1990; Zucker & Gordon, 1988); provision of adequate and appropriate health services, helping and service organizations (Allen, 1994; Richardson, 1994).

The findings are also consistent with the literature which suggests that factors such as denial of HIV/AIDS in women, sexism, sex-role stereotyping, poverty, stigma, isolation, alienation, blame and loss play a crucial role in magnifying the extent to which women experience stress and their ability to gain access to supports to cope effectively. Women who reported that these factors greatly affected them reported higher levels of stress, lower levels of support and fewer resources upon which to draw.

TABLE 2

SOCIAL SUPPORT NEEDS OF WOMEN WITH HIV/AIDS IN SASKATCHEWAN

INSTRUMENTAL NEEDS

- Money
- Food
- Housing
- Clothing
- Transportation
- Legal Assistance
- Counselling
- Medical Aid
- Medicine
- Childcare
- Alternative Therapies
- Relaxation/Recreation
- Access to Drug Trials
- Information

INFORMATION

- Financial entitlements
- Medical tests that are conducted on them and the results of tests when they are taken
- The effect of drugs on women
- The effect of HIV/AIDS on women
- Legal issues: human rights, wills, child?
- What services/resources are available?

EMOTIONAL

- Counselling
- Family and Relationships
- Confidentiality
- Peer Support
- Support Groups
- Discrimination
- Isolation
- Caregiver Expectations
- Self Imposed Guilt and Blame
- Depression
- Suicidal Ideation
- Respect and Consideration
- Options and Choice

While all women reported being affected by these factors, women living in rural areas were found to experience greater degrees of isolation, stigma, poverty and sexism. They had fewer accessible and appropriate services and supports than women in urban areas. Women in rural areas were also more likely to experience or fear social rejection and discrimination. One reason reported for this finding is that small towns have a 'mentality' that supports conforming to the norm. Also, due to the nature of rural areas, it was harder to maintain confidentiality as everyone knows each other's business. Perhaps as a result of these factors, women from rural areas reported needing greater support to meet their needs than did women from urban areas. Women from rural areas also reported lower satisfaction with their existing supports.

A Model of Coping Strategies used by Women with HIV/AIDS to Meet Needs

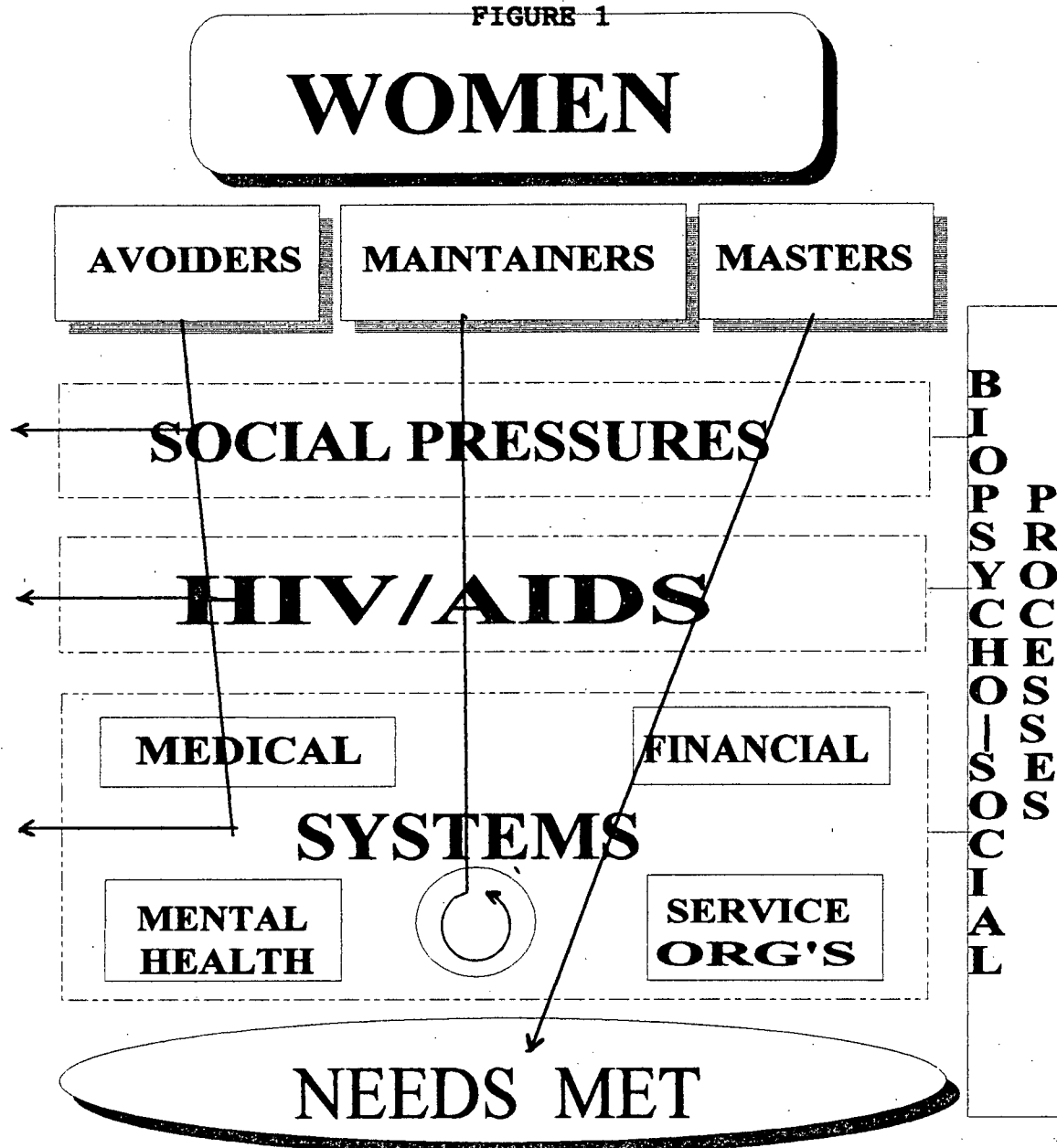
For women with HIV/AIDS, getting their needs met involves a process of encountering and successfully overcoming a number of obstacles. These obstacles include the social pressures that keep women in a position of powerlessness in society, the effects of the stigma that has been attached to HIV/AIDS, and organizational systems that reinforce dependency. This study identifies three coping patterns or

strategies used by the women in their attempts to go through the process of getting their needs met: avoidance, maintenance, and mastery. A model outlining the effect of the three coping strategies is presented for reference and discussion (see Figure 1).

The Process

The ability of the women to move through the obstacles may be effected by a number of social, psychological and biological factors. Social factors such as geographic location, cultural background, socio-economic status, education, information, social roles, availability and accessibility of services, and perceived support may play an important role in determining whether a woman can cope with presenting obstacles. Psychological factors which may effect the ability of a woman to move through presenting obstacles include low self-esteem, internalized blame and devaluing of self, and overall mental state. As well biological factors such as age, and stage of illness may also play a vital role in coping with obstacles. All of these factors alone or in interaction with one another may greatly influence how successful one is at moving through the obstacles.

FIGURE 1



Model of Coping Strategies used by
Women with HIV/AIDS to Meet Needs

The first obstacle that women with HIV/AIDS face in getting their needs met is the pressure from society which tells them that their needs are not important or are not as important as those of men and children. Gender-based oppression and stereotyping of women in dependency or controlled roles (caregiver, wife, prostitute), has meant that women have little economic or political power and few resources upon which to draw (Macks, 1988; Patton, 1990; Kitzinger, 1994; International Working Group on Women and AIDS, 1988).

The second obstacle is the stigma that has become attached to HIV/AIDS. Social denial of HIV/AIDS in women, blaming the victim, and acts of discrimination have left women with internalized blame and few resources.

The third obstacle involves the structures of the systems which they utilize for support including medical, mental health, financial, and service organizations. Many of these systems reinforce all of the social norms and values that are found in the first two obstacles. These systems are often impersonal, bureaucratic, fiscally-oriented (as opposed to client centred) and operate from a position of power. If a woman is able to work through these obstacles and make the system work for her, many of the services may provide a support function.

All three obstacles build upon and reinforce one another. Having one's needs effectively met requires a woman to cope with all three obstacles without the process costing her more (financially, emotionally) than she puts in.

Avoidance

In the study, the coping strategy that was based on avoidance proved to be least effective. Within the avoidance coping pattern, there were three different levels reached. First, there were women who in the past had chosen to avoid or withdraw from challenging the view that they were not as important as those around them. An internalized devaluing of self, isolation, knowledge of HIV-status, stage of illness, age and cultural background were important factors in their choice of coping strategy.

I was always told that the only thing that a woman is good for is having kids and taking care of the home. I didn't know better.

Second, there were women who had not internalized or been kept down by social misconceptions about the value and worth of women but were caught up in the stigma that is attached to their HIV-infection. These women had high levels of self blame and worthlessness. They often were isolated, lacked supports and lacked information about HIV/AIDS. Other factors that were important in their choice

of coping pattern were stage of illness, the presence of children, and the reaction of the person who notified them of their infection.

I used to think that this was my punishment for something. That's what everybody says. You're not going to get very far if you keep thinking like that. You'll just sit at home and die. There won't be nobody there for support. And women are living like that. That's the sad part.

Third, there were women who eventually encountered the system's obstacles either because they had moved through the first two obstacles or because a crisis situation (physical, psychological or economic) had brought them into the system. The women who used avoidance coping usually did not stay in the system but left it without being successful in meeting their needs. For some of these women their departure from the system resulted from negative or unfulfilled experiences. Their departure was often a way of stopping the feeling of being used and losing power. For example, a woman who attends a doctor's appointment and leaves feeling that she has been mistreated or that the emotional costs involved in going outweighed the benefits might decide to discontinue involvement with part or all of the medical system. In leaving the system the woman is able to keep from losing personal self-worth or power. She may also be missing out on receiving valuable support and medical services from part or all of the system. These women are

usually able to make the choice to leave the system because they have external supports and resources and are not suffering from illness.

What good is it having a doctor or nurse if they weren't respecting you. I'm not going to them. I would rather do it myself. At least I know I'm not being disrespected.

Maintenance

The second coping strategy that was used was one of maintenance. These women either were able to move through the first two obstacles and enter into the third, or entered the system due to crisis (financial, illness, mental or physical breakdown). These women usually utilized components of the system but did not get enough from the system to allow them to feel successful enough to move through it. For example a woman may utilize the mental health system for counselling. During her sessions with the counsellor she is able to work through some of her concerns but she leaves the office feeling that she is useless because she can't deal with things.

I think counselling is really helpful, but it also makes things more worse. I go and end up leaving [counsellors] office feeling like he's doing me a big favour and that he wonders why I can't deal with my life.

These women often felt that they were not given what they needed, that they were not listened to, were ignored and lacked a sense of self worth. While they may have received benefits from the system, the personal cost was also great. For women who are maintainers, after the benefits and costs are weighed out, they are left with a net zero effect. They tended to experience so few successes that they could not get control. Unlike those women who entered the system and then left without having their needs met, these women usually lacked external supports and became system dependent. An example of a this is:

I really don't want to go back to him [doctor] because I really don't think that he takes me seriously. But who else is there. No one.

If left in this state they would likely not move out of the system, but would become more dependent as they became ill and fewer of their needs were met. Examples of statements made by women who used this coping strategy are:

If I need money for diapers it gets deducted off my cheque and then I get told that, "you should have all your food for the whole month"...I can't get by the next month with less money than they gave me which wasn't even enough for this month. You keep going further and further down and can't get out. And Social Services thinks that you shouldn't run out of money with what you have.

They make you have a form for everything. To get extra money I need to get a letter from the doctor, and then maybe he won't give it to me so I have to find another doctor who will. It takes a lot of time and energy that we don't have. You

end up getting stressed and sick. They don't think of that. All they say is, "we need that letter, can't help you if you don't have it". Your damned if you do and damned if you don't.

Mastery

The third coping strategy that was identified was one of self-determination and mastery. These women were able to pass through all three obstacles and successfully have their needs met. These women differ from the other women in their ability to take control of their lives and make the system work for them. They were more likely to be assertive in dealing with system providers about what their needs were and how they could be met. Examples of statements made by mastery women include:

I used to have that problem [not being given needed information], but not anymore. I learned that if you want to know anything you have to take control and get it. Now if I have any questions I keep asking until I get an answer that I can understand. If one person doesn't have it then ask another, someone will eventually know.

When I go to see Dr. xxx I have a list of questions that I want answered before I leave. And I don't go until I get them. It's a matter of standing up for your rights. It's easier that way, because I know that I'm getting the answers to what I want to know.

These women were more likely to have strong support networks, have a healthier sense of self, were optimistic, vocal, informed, from urban areas, and chose to seek access to supportive services and avoided those services which they

perceived as costing more than they could provide. Whether these women were able to successfully move through the obstacles as a result of having these traits or whether successfully moving through the obstacles promoted the development of these traits is not certain. It does appear that the more success the women experienced in working through a system to have their needs met, the more likely they were to be able to move through other parts of the system. In these cases success promoted increased self-worth, motivation and ability to get a system to work for them. The women who used a mastery strategy did not always have their needs met or always make the system work for them, but the frequency with which they were able to do so was far above that of those who used other coping strategies.

These findings are consistent with the literature which hypothesizes that high mastery women are more likely to have stronger internal and external support structures and are able to successfully manipulate social aspects of their environment (Hobfoll & Lerman, 1989; Thoits, 1987). High mastery women are more likely to cope with life challenges and seek appropriate levels of support when it is needed (Hanson, Jones, & Carpenter, 1984; Kobasa & Puccetti, 1983). The literature also suggests that because of their sense of optimism and ability to cope with challenges, high mastery

women are deemed to be more attractive and better received by support providers (Gotlib & Hooley, 1988).

It is also believed that high mastery women will receive less support than others in low stress times because they are able to cope with the stress through the utilization of internal skills or minor external supports. When under high stress, mastery women will receive greater aid than others because of their ability to utilize necessary resources (Kobasa & Puccetti, 1983; Hobfoll, Nadler, & Leiberman, 1986). Those who use different coping strategies are likely to require high amounts of support even during low stress situations because they do not have a well developed system of internal and external support. During periods of high stress, these women will receive less support than mastery women because of their inappropriate handling of supportive interactions and by the poor quality of support available to them (Hanson et al., 1984).

Because of their effective coping style and positive outlook, mastery women are more likely to have better stress outcomes and to be more satisfied with the support they receive under both high and low stress situations than those with other coping strategies (Hobfoll, Nadler, & Leiberman, 1986). In contrast, those with other coping strategies are more likely to be dissatisfied with support regardless of levels of stress. Because they do not have the skills

necessary to effectively cope with both low and high levels of stress, they must turn to others. Having to depend upon others, especially when one is ill, may lead to increased feelings of vulnerability and dissatisfaction with what is received (Coyne, Aldwin & Lazarus, 1981; Hobfoll et al., 1986).

This model highlights some of the differences that coping strategies play in helping women with HIV/AIDS to get their needs met. Exploring the differences that exist between those women who have been able to get their needs met and are satisfied (masters) and those who cannot and are dissatisfied (maintainers, avoiders) may provide insight into possible interventions that can help women move toward mastery.

Implications for Service Delivery for Isolated Women with HIV/AIDS

Throughout the study the theme of isolation has been magnified. Women with HIV/AIDS in Saskatchewan have been isolated not only by geography, but by prejudice and lack of specific support services. From the experiences of women with HIV/AIDS in Saskatchewan it is possible to generalize that other women with HIV/AIDS who live in similar environments might have similar experiences and needs as the women in this study. This would include women who live in

the Maritimes, outside of Montreal in the Province of Quebec, Northern Ontario, Manitoba, outside of Calgary in Alberta, outside of Vancouver and Victoria in British Columbia, and in the North West Territories and the Yukon. Drawing from this connection it would be reasonable to assume that recommendations and interventions that would serve to help women with HIV/AIDS in Saskatchewan would also be of benefit to those in all of the other similar regions.

Interventions and Social Support

To move women toward a mastery coping strategy it is important that women acquire the skills and support necessary for them to take control over their lives. In doing so, women will experience greater success in having their needs met and become less dependent upon systems which reinforce dependency and powerlessness. Interventions to achieve such change need to focus on the mechanisms by which change can occur on an individual, community, and public policy level. Mechanisms for change can include provision of peer support and counselling, education, information and referral, advocacy, and personal practice.

While the following interventions are made in reference to women with HIV/AIDS, due to the small number and geographical distances between such women in Saskatchewan providing extensive changes and services for

only these women would not be cost effective. Interventions taken would be more effective if made with all women with disabilities in mind. In this way women with disabilities, including those with HIV/AIDS, would receive benefit from the development of appropriate and effective services and policies.

Peer Support and Counselling

The support from peers and others can play an important role in the lives of women with HIV/AIDS, their significant others, and those service providers who work with and for them. The provision of instrumental, informational and emotional supports from peers and professionals can help individuals to develop the skills needed to cope with stress and to successfully gain access to needed services.

Peer support for women with HIV/AIDS can play a vital role in helping women validate their experiences. Peers can serve as a source of emotional, informational, and instrumental support for women. They may be able to relate more easily to one another's experience. Knowing that there is someone who understands what they are going through may be very beneficial. Acceptance and compassion that come from peer support may help women to develop stronger self-esteem.

Peers can also provide informational support. Valuable information includes such things as clear and unambiguous indication of what services are available and how to utilize them successfully, and indicators of what to expect during stages of illness or depression.

The provision of social support from peers in the form of such things as childcare, information, advice, and listening can be important to women. They will likely be more able to engage in reciprocal exchanges with peers thus decreasing the feelings of failure and dependency that often accompany the need to utilize outside help. The support that peers provide may also decrease the need of women to seek out formal services which leave them with feelings of failure and dependency. In developing and providing peer support groups or networks it is important that the women have control over the group. In developing peer support groups or networks, consideration should be given to addressing the specific needs of women with HIV/AIDS. These include, among others, childcare requirements, transportation issues, and profound differences in geographic distance from major centres.

It is also important that support be available to the children and families of women with HIV/AIDS. They too may need help in coping with the infection of the woman who is their mother, wife, daughter, sister, aunt, or grandmother.

Providing support groups and space in AIDS organizations for children and families is an important part of helping women with HIV/AIDS. Childcare, individual and family counselling, education, and respite care would be useful in helping families obtain the skills and support needed to cope with the changes that HIV-infection brings.

Peer support structures are also needed among those service providers who care for women with HIV/AIDS. Providing peer support to these individuals is important as the emotional expenditure required to help those with HIV/AIDS may be great. Peer support would not only provide emotional support but would also be useful in increasing levels of networking and information exchange. The healthier and more informed service providers are the better they will be able to help those with whom they work.

Education

Education plays a critical role in assisting women to take control of their lives. Education provides women with the knowledge and skills needed for greater success in coping with stress, using services, and managing their health and relationships. Education may also be useful in providing social environments that are more conducive to getting needs met.

Providing workshops on coping and stress management for women with HIV/AIDS can serve to provide women with the necessary skills for managing periods of stress in a more effective manner. Developing the skills to effectively manage periods of stress enables women to obtain a greater sense of control over their physical environment. Learning how to effectively use supports to deal with stress helps ensure that supports are not over-taxed. This limits dependency on others and increases the likelihood that supports are available when needed. Women who are able to assert themselves are also likely to have greater success in dealing with systems. Being successful reinforces a sense of self and increases the likelihood that women can be more successful in having their needs met in other areas.

Part of the process of helping women to be more successful is teaching them how to effectively seek out and utilize services. This might include having women who have been successful in utilizing services guide other women through the process. This would provide practical information and non-judgemental support. Other techniques for helping women gain access to services include having a worker advocate, or representative from a service teach women the process of effectively getting what they need from the service. Successful utilization of such services as income assistance, legal aid and medical care is especially

important for women.

Education is also needed for women in areas related to their bodies and sexuality. Women with HIV/AIDS need to be taught how to care for themselves through proper diet, stress management, and other holistic practices. This would provide women with the knowledge and skills necessary for making choices to better care for themselves. This may increase the control that they have over their health and allow them to become less dependent upon others. Women, their families, and service providers may require assistance in becoming with expressions of intimacy and in providing palliative care.

Prevention education for women can play a vital role in helping women in the AIDS epidemic. Providing women with basic information on the transmission of the virus and helping them to make choices that are realistic for them can limit the number of women who become infected. The literature suggests that presenting this information in general health programs for women would increase the number of women who receive this information.

Part of the process of helping women with HIV/AIDS to get their needs met involves providing an environment that is accepting and receptive of them. Public education geared toward 'normalizing' women with HIV/AIDS and that focuses on the psychosocial needs of these women can be instrumental in

promoting a more accepting social climate. It is important that education programs take a holistic approach. It is not enough to present only the facts on HIV/AIDS but the accompanying fears and prejudices also need to be addressed. Challenging public homophobia and fear about AIDS is especially important in rural areas where there is a lack of support and services. Educational programs need to involve the community and address the social issues that exist in that community which promote hostile or unsupportive environments. Education also needs to be targeted toward those individuals who work with women with HIV/AIDS. Health professionals, AIDS service organization workers, social workers and social work students could benefit from education on the needs and psycho-social issues specific to women with HIV/AIDS. Their beliefs and practices should be examined and perhaps challenged. Practices which are respectful and sensitive to the needs of women should be adopted and taught.

Information and Referral

Information can play an important role in being able to control one's life. Being able to predict what is going to happen provides women with HIV/AIDS with the opportunity to make adjustments so that they are better able to cope with a situation. Having information also provides women with a

greater number of coping options from which to choose.

Information needs to be relevant and understandable if it is to be of any value to women. This is especially important in the field of medicine and law where the terms and language used are often very technical. Service providers can play an important role in helping women by providing them with up to date, relevant, and easily understood information. Service providers can rewrite information so that it is in plain language or can provide access to a resource person who is able to explain the information. It is not only important that understandable information exists but that a system exists which would ensure that women are provided with all relevant information.

Helping women to gain more control also entails providing them with the knowledge of and access to all available services and resources. Service providers can be instrumental in this process by compiling lists of available services and resources that the women may need and distributing this list to all women. This would allow the women to gain access to needed services without having to rely upon others for referral information. Creating a listing of available resources and services would also be useful as it would identify those areas where there is duplication in services and those areas where there are

gaps. Of specific interest to many women with HIV/AIDS is information regarding income assistance. A listing of financial entitlements would ensure that the women know what the allowable maximum is thus providing them with some incentive to fight for that as an entitlement.

Information about what services and resources are available would also be important for those who work with women with HIV/AIDS. Having a listing could help service providers who are looking for a referral. It would also be useful in helping them to forge linkages with other service providers for information exchange or support.

Advocacy

Advocacy can play an important role in helping women to obtain control over their environments. Service providers can work toward changes in procedures and policies that would help to increase women's access to services, their inclusion in drug trials, personal control over their reproductive systems, and environments free of AIDS-related discrimination.

Advocacy is needed to increase the availability and access of HIV-related services for women. Worker advocates can be instrumental in helping women to locate and gain access to existing services. They can work with and on behalf of women to obtain increased financial assistance for

such items as childcare, transportation and coverage of alternative therapies. Worker advocates and women can also approach AIDS service organizations, community groups, and funding agencies for money or assistance in developing new services that would allow women with HIV/AIDS and their families to receive needed support. Services such as childcare programs, support groups for women, children and other family members, workshops on assertiveness training, sexuality and health and self esteem building are all very much needed by women.

Advocacy in the field of education would also be useful. Agencies and policy makers should work to ensure that the public receives education in the areas of prevention, homophobia, and the psycho-social issues of those with HIV/AIDS. This would not only be instrumental in limiting the number of women who become infected but would provide a more supportive environment for women with HIV/AIDS.

Advocacy for changes in policies and practices that limit women's access to drug trials is needed to provide women with information that is necessary for them to receive the best treatment possible. There is also a need for advocacy to promote research which is specific to infected females. Information that can be obtained from needs assessments and research that is woman-specific would be

useful in providing an understanding of HIV/AIDS in women so that the development of appropriate services and inclusion of women-specific illnesses in the definition of AIDS may occur.

Advocacy is needed to help support women in their attempts to gain control over their reproductive systems. Promoting policies and practices which support a woman's right to choose whether she has children or takes birth control while participating in drug trials is important in giving control to women.

Summary

It is important that women are consulted at all levels of planning and implementation. Women with HIV/AIDS are the experts. They are the people who know what they need, and what barriers they face. In developing interventions for women, those who work with and for women must be respectful of and sensitive to the needs and psycho-social issues of women. If service providers begin to view and treat women as the experts, perhaps in which the way they interact with women will change. Understanding the needs and experiences of women with HIV/AIDS is a step toward better service for women with HIV/AIDS.

Implications for Future Research

The research did not differentiate between the needs of women on the basis of class, ethnic background, socio-economic status, or health status. Because only one person of First Nations background attended the focus group, the research may not adequately reflect the perspectives of those of other ethnic origins. Further, all of the women who attended were from lower-middle to middle class families. The research did not contain any information from women who were from other socio-economic backgrounds. The research did not focus on the needs of women at specific stages of illness. These are areas that could, and should, be examined in future studies.

In order to fully understand some of the factors that have prevented women from being able to satisfy their needs, it is important that those who work with and for women be consulted. Health and social service providers' perceptions of the women's needs and the barriers which prevent them from assisting the women should be examined .

This study has demonstrated the importance of the voices of women with HIV/AIDS. The women are the one's who know what it is that they want and do not want, what is working and what is not working. It is not enough to know how many services there are or how many people utilize a service as the number of services and frequency of contacts

is not necessarily a proxy for the quality of service. It is important to know whether the services that are provided are meeting the needs of those who use them. It will only be through qualitative research such as this study that we will learn to effectively and efficiently help women with HIV/AIDS to meet their needs.

This research has provided valuable insights into the plights of Saskatchewan women living with HIV/AIDS. It is to be hoped that it will provide the basis for further research in this area and that, together, the research will be used to inform decisions by all affected parties which will lead to an improved quality of life for such women.

BIBLIOGRAPHY

- Ahmed, P. (Ed.). (1992). Living and Dying with AIDS. New York: Plenum Press.
- Allen, J. (1994). Women and HIV/AIDS in Nova Scotia, Needs Assessment Report. Halifax: Nova Scotia and Women and AIDS Project.
- Anderson, R. & Bury, M. (1988). Living With Chronic Illness: The Experience of Patients and Their Families. London: Unwin Hymann Ltd.
- Antoni, M.H., LaPerriere, A., Schneiderman, N. & Fletcher, M.A. (1991). Stress and Immunity in Individuals at Risk for AIDS. Stress Medicine, 7, 35-44.
- Antonovsky, A. (1979). Health, Stress and Coping. San Francisco: Jossey-Bass
- Barnsley, Jan & Diana Ellis (1992). Research for Change: Participatory Action Research for Community Groups.
- Barrera, M., Jr. (1986). Distinctions between Social Support Concepts, Measures, and Models. American Journal of Community Psychology, 14(4), 413-445.
- Barrera, M. (1981). Social Support in the Adjustment of Pregnant Adolescents: Assessment Issues. In B.H. Gottlieb (Ed.), Social Networks and Social Support (pp. 69-96). California: Sage.
- Barrera, M. & Ainley, S.L. (1983). The Structure of Social Support: A Conceptual and Empirical Analysis. Journal of Community Psychology, 11, 133-143.
- Bloom, J. (1982). Social Support, Accommodation to Stress and Adjustment to Breast Cancer. Social Science and Medicine, 16, 1329-1338.
- Brendle-Moczuk, I. (1995). Women who are HIV Positive in the Lower Mainland: A Survey of Social Support. Vancouver: The University of British Columbia.

- Broadhead, W.E., Kaplan, B.H., Jones, S.A., Wagner, E.H., Shoenbach, V.J., Grimson, R., Heyden, S., Tibblin, G. & Gehlbach, S. (1983). The Epidemiologic Evidence for a Relationship Between Social Support and Health. American Journal of Epidemiology, 1(7), 521-537.
- Bullock, R. & Millham, S. (1987). A Holistic Approach To the Evaluation of Residential Institutions. Child and Youth Services, 8(3/4), 5-18.
- Cambridge, B. (1993) Women and HIV Disease. In T. Edison (Ed.), The AIDS Caregiver's Handbook (pp. 280-293). New York: St. Martin's Press.
- Cassel, J. (1976). The Contributions to the Social Environment to Host Resistance. American Journal of Epidemiology, 104, 107-123.
- Cassens, B.J. (1985). Social Consequences of Acquired Immunodeficiency Syndrome. Annals of Internal Medicine, 103(11), 761-771.
- Chin, James (1990). Current and Future Dimensions of the HIV/AIDS Pandemic in Women and Children. Lancet, 336, 221-224.
- Christ, G.H., & Weiner, L.S. (1985). Psychosocial Issues in AIDS. In T. DeVita, S. Hellman, & S.A. Rosenberg (Eds.), AIDS: Etiology, Diagnosis, Treatment and Prevention (pp. 275-297). Philadelphia: Lippincott
- Chu, S., Buehler, J. L Berelman, R. (1990). Impact of the Human Immunodeficiency Virus Epidemic on Mortality in Women of Reproductive Age, United States. Journal of the American Medical Association, 264(2), 225-229.
- Chuang, H.T., Devins, G.M., Hunsley, J., & Gill, M.J. (1989). Psychosocial Distress and Well-Being Among Gay and Bisexual Men With Human Immunodeficiency Virus Infection. American Journal of Psychiatry, 126, 568-577.
- Cobb, S. (1976). Social Support as a Moderator of Life Stress. Psychosomatic Medicine, 38, 300-314.
- Cochran, S.D., & Mays, V.M. (1989). Women and AIDS-Related Concerns: Roles for Psychologists in Helping the Worried Well. American Psychologist, 44, 529-535.

- Cohen, F.L. (1993). Clinical Manifestations and Treatment of HIV Infection and AIDS in Women. In F.L. Cohen and J.D. Durham (Ed.'s), Women, Children, and HIV/AIDS (pp. 83-103). New York: Springer Publishing Company.
- Cohen, S. (1988). Psychosocial Models of the Role of Social Support in the Etiology of Physical Disease. Health Psychology, 7, 269-297.
- Cohen, S. (1993). Stress, Social Support, and Disorder. In H.O.F. Veiel & V. Baumann (Eds.), The Meaning and Measurement of Social Support (pp. 109-120). New York: Hemisphere.
- Cohen, S., Tyrell, A.J., & Smith, A.P. (1991). Psychological Stress and Susceptibility to the Common Cold. New England Journal of Medicine, 29, 606-612.
- Cohen, S., & Hoberman, H. (1983). Positive Events and Social Supports as Buffers of Life Change Stress. Journal of Applied Social Psychology, 13, 99-125.
- Cohen, S. & Wills, T.A. (1985). Stress, Social Support and the Buffering Hypothesis. Psychological Bulletin, 90, 310-357.
- Cohen, S., & Syme, S.L. (1985). Issues in the Study and Application of Social Support. In S. Cohen & S.L. Syme (Eds.), Social Support and Health, (pp.3-22). Orlando: Academic.
- Cohen, S. & McKay, G. (1984). Social Support, Stress and the Buffering Hypothesis: A Theoretical Analysis. In A. Baum, J.E. Singer & S.E. Taylor (Eds.), Handbook of Psychology and Health (pp. 253-267). New Jersey: Erlbaum.
- Communications Division of Stats Canada (Ed.), (1994). Canada Year Book: 1994. Manitoba: D.W. Friesen & Sons Ltd.
- Conn, M., & Peterson, C. (1989). Social Support: Seek and Ye Shall Find. Journal of Social and Personal Relationships, 6, 345-358.
- Corbin, J.M. & Strauss, A. (1988). Unending Work and Care: Managing Chronic Illness at Home. San Francisco: Jossey-Bass.

- Cowen, E.L. (1980). The Wooing of Primary Prevention. American Journal of Community Psychology, 8, 258-284.
- Coyne, J.C., Aldwin, C., & Lazarus, R.S. (1981). Depression and Coping in Stressful Episodes. Journal of Abnormal Psychology, 90, 439-447.
- d'Abbs, P. (1982). Social Support Networks: A Critical Review of Models and Findings. Melbourne: Institute of Family Studies.
- Denenberg, R. (1990). Unique Aspects of HIV Infection in Women. In ACT UP (NY Women & AIDS Book Group), Women, AIDS & Activism (pp. 31-44). Toronto: Between The Lines.
- DiMatteo, M.R. & Hays, R. (1981). Social Support and Serious Illness. In B.H. Gottlieb (Ed.), Social Networks and Social Support (pp- 117-148). California: Sage Publications.
- Donlou, J., Wolcott, D., Gottlieb, M. L Landsver, J. (1985). Psychosocial Aspects of AIDS and AIDS-related Complex: A Pilot Study. Journal of Psychosocial Oncology, 3, 39-55.
- Douglas, P., & Pinsky, L. (1992). The Essential AIDS Fact Book. New York: Pocket Books.
- Duck, S., & Silver, R.C. (Eds.), (1990). Personal Relationships and Social Support. California: Sage.
- Easton, Beth. (1992). Women & AIDS. Healthsharing, 24(2), 12-19.
- Elliot, G. & Eisdorfer, C. (Eds.), (1982). Stress and Human Health. New York: Springer.
- Flaherty, J., & Richman, J. (1989). Gender Differences in the Perception and Utilization of Social Support: Theoretical Perspectives and an Empirical Test. Social Science and Medicine, 28, 1221-1228.
- Flaskerud, J.H., & Rush, C.E. (1989). AIDS and Traditional Health Beliefs and Practices of Black Women. Nursing Research, 38, 210-215.
- Folkman, S., Lazarus, R., Gwèn, R., & Delongis, A. (1986). Appraisal, Coping, Health Status, and Psychological Symptoms. Journal of Personality and Social Psychology, 50(3), 571-579

- Forstein, M. (1984). Psychological Impact of the Acquired Immune Deficiency Syndrome. Seminars in Oncology, 11, 77-82.
- Funch, D.P. & Marshall, J. (1983). The Role of Stress, Social Support and Age in Survival from Breast Cancer. Journal of Psychosomatic Research, 27(1), 77-83.
- Glaser, B. & Strauss, A. (1967). The Discovery of Grounded Theory. Chicago: Aldine.
- Glaser, B. & Strauss, A. (1968). Time for Dying. Chicago: Aldine.
- Gore, S. (1981). Stress-Buffering Functions of Social Supports: An Appraisal and Clarification of Research Models. In B.S. Dohrenwend & B.P. Dohrenwend (Eds.), Stressful Life Events and Their Contexts (pp. 202-222). New York: Prodist.
- Gotlib, I.H., & Hooley, J.M. (1988). Depression and Marital Distress: Current Status and Future Directions. In S. Duck, F. Hay, S.E. Hobfoll, W. Ickes, & B.M. Montgomery (Eds.), Handbook of Personal Relationships: Theory, Research, and Interventions (pp. 519-541). New York: Wiley.
- Gottlieb, B. (1978). The Development and Application of a Classification Scheme of Informal Helping Behaviors. Canadian Journal of Behavioral Sciences, 10, 105-115.
- Gottlieb, B. (1983). Social Support Strategies: Guidelines for Mental Health Practice. California: Sage.
- Gottlieb, B. (1987). Marshalling Social Support: Formats, Processes, and Effects. California: Sage.
- Green, G. (1993). Editorial Review: Social Support and HIV. AIDS Care, 5(1), 87-104.
- Guba, E., & Lincoln, Y. (1989). Fourth Generation Evaluation. Newbury Park: Sage Publications.
- Haley, C. (1993). AIDS 101. In T. Edison (Ed.), The AIDS Caregiver's Handbook (pp. 3-12). New York: St. Martin's Press.
- Halpren, Sue (1989). AIDS: Rethinking the Risk. MS., 17(11), 80-82.

- Hamilton, J.M., & Morris, V.L. (1993). The Psychosocial Aspects of AIDS. In T. Edison (Ed.), The AIDS Caregiver's Handbook (pp.81-99). New York: St. Martin's Press.
- Hamilton, J. (1993). The Psychosocial Aspects of AIDS. In T. Edison (Ed.), The AIDS Caregiver's Handbook (pp. 81-99). New York: St. Martin's Press.
- Haney, C.A. (1984). Psychosocial Factors in the Management of Patients With Cancer. In C.L. Cooper (Ed.), Psychosocial Stress and Cancer (pp. 201-227). New York: Wiley.
- Hankins, Catherine (1990). An Overview of Women and AIDS in Canada. In Jacquie Manthorne (Ed.), Canadian Women and AIDS: Beyond the Statistics. Montreal: Les Editions Communiqu'Elles.
- Hanson, R.O., Jones, W.H., & Carpenter, B.N. (1984). Relationship Competence and Social Support. In P. Shaver (Ed.), Review of Personality and Social Psychology (265-284). California: Sage.
- Hays, R., Turner, H., & Coates, T. (1992). Social Support, AIDS-Related Symptoms, and Depression Among Gay Men. Journal of Consulting and Clinical Psychology, 60, 463-469.
- Health and Welfare Canada (1992). Ending the Isolation: HIV Disease and Mental Health in the Second Decade. Ottawa: Minister of Supply and Services Canada.
- Health and Welfare Canada (1983). AIDS Community Action Program: Funding Guidelines. Ottawa: Ministry of Supply and Services.
- Health and Welfare Canada (1991). Meeting the Income Support Needs of Persons Living with HIV and AIDS. Ottawa: National Health and Welfare Canada.
- Health and Welfare Canada (1992). Chronic Diseases in Canada. Ottawa: Minister of Supply and Services Canada.
- Health and Welfare Canada (1993). Surveillance Update: AIDS in Canada. Ottawa: National Health and Welfare.
- Health Canada (1995). Surveillance Update: AIDS in Canada. Ottawa: Division of HIV/AIDS Epidemiology: Bureau of Communicable Disease Epidemiology.

- Heller, K. & Swindle, R.W. (1983). Social Networks, Perceived Social Support and Coping with Stress. In R.D. Felner, L.A. Jason, J. Moritsugu & S.S. Farber (Ed.'s), Preventative Psychology. Research and Practice in Community Intervention (pp. 87-103). New York: Pergamon.
- Henderson, S., Byrne, D.G., & Duncan-Jones, P. (1981). Neurosis and Social Environment. Sydney: Academic Press.
- Hobfoll, S.E., & Lerman, M. (1988). Personal Relationships, Personal Attributes, and Stress Resistance: Mothers' Reactions to their Child's Illness. American Journal of Community Psychology, 16, 565-589.
- Hobfoll, S.E., Nadler, A., & Leiberman, J. (1986). Satisfaction with Social Support During Crisis: Intimacy and Self-Esteem as Critical Determinants. Journal of Personality and Social Psychology, 51, 296-304.
- Hogg, R.S., Strathdee, S.A., Craib, K.J.P., O'Shaughnessy, M.V., Montaner, J.S.G. & Schechter, M.T. (1994, October 22). Lower Socioeconomic Status and Shorter Survival following HIV Infection. The Lancet, 344, 1120-1124.
- Holahan, C.J., & Moos, R.H. (1981). Social Support and Psychological Distress: A Longitudinal Analysis. Journal of Abnormal Psychology, 90, 365-370.
- Honey, E. (1988). AIDS and the Inner City: Critical Issues. Social Casework, 69, 365-370.
- House, J.S. (1981). Work. Stress. and Social Support. Reading: Addison- Wesley.
- House, J. and Rahn, R. (1985). Measures and Concepts of Social Support. In S. Cohen & S. Syme (Ed.'s), Social Support and Health, (pp. 83-108). Orlando: Academic Press.
- Hymovich, D. & Hagopian, G. (1992). Chronic Illness in Children and Adults. Philadelphia: W.B. Saunders.
- International Working Group on Women and AIDS (1988, June). Women, Children and AIDS. A Statement to the 1988 4th International AIDS Conference, Stockholm, Sweden. In D. Stuntzner-Gibson (1991). Women and HIV Disease: An Emerging Social Crisis. Social Work, 36, 5-8.

- Jemmot, J. & Locke, S. (1984). Psychosocial Factors, Immunological Mediation, and Human Susceptibility to Infectious Diseases: How much do we know? Psychology Bulletin, 95(1), 78-108.
- Kaspar, B. (1989). Women and AIDS: A Psychosocial Perspective. Affilia, 4(4), 7-22.
- Kiecolt-Glaser, J.K.K. & Glaser, R. (1988). Psychological Influences on Immunity: Implications for AIDS. American Psychologist, 43, 892-898.
- Kitzinger, J. (1994). Visible and Invisible Women in AIDS Discourses. In L. Doyal, J. Naidoo, & T. Wilton (Eds.), AIDS: Setting a Feminist Agenda (pp. 95-112). London: Taylor & Francis.
- Kneisl, C.R. (1993). Psychosocial and Economic Concerns of Women Affected by HIV Infection. In F.L. Cohen and J.D. Durham (Ed.'s), Women, Children, and HIV/AIDS (pp. 241-250). New York: Springer Publishing Company.
- Kobasa, S.C., & Puccetti, M.C. (1983). Personality and Social Resources in Stress Resistance. Journal of Personality and Social Psychology, 45, 839-850.
- Kushner, H.S. (1983). When Bad Things Happen to Good People. New York: Avon Books.
- Lazarus, P. (1981). The Stress and Coping Paradigm. In C. Eisdorfer, D. Cohen, A. Kleinman, & P. Maxim (Eds.), Models for Clinical Psychopathology (pp. 177-214). New York: SP Medical and Scientific Books.
- Lazarus, R. & Folkman, S. (1984). Coping and Adaptation. In W.D. Gentry (Ed.), The Handbook of Behavioral Medicine (pp. 282-325). New York: Guilford.
- Lazarus, R. & Folkman, S. (1984). Stress, Appraisal, and Coping. New York: Springer.
- Lazarus, R. & Launier, R. (1978). Stress-Related Transactions Between Person and Environment. In L. Pervin & M. Lewis (Eds.), Perspectives in International Psychology (pp. 287-327). New York: Plenum.

- Lazarus, R.S., Ovarial, J.R., & Opton, E.M. (1974). The Psychology of Coping: Issues of Research and Assessment. In G.V. Coelho, D.A. Hamburg, & J.E. Adams (Eds.), Coping and Adaptation. New York: Basic Books.
- Lesserman, J., Perkins, D.O., & Evans, D.L. (1992). Coping with the Threat of AIDS: The Role of Social Support. In R. Bor, & J. Elford (Eds.), The Family and HIV (pp. 98-109). Great Britain: Redwood Books.
- Levine, C. (1990). Women and HIV/AIDS Research, The Barriers to Equity. Evaluation Review, 14(5), 447-463.
- Levine, C. & Neveloff Dubler, N. (1990). Uncertain Risks and Bitter Realities: The Reproductive Choices of HIV-infected Women. The Milkbank Quarterly, 68(3), 321-351.
- Levy, S., Herberman, R., Maluish, A., Schlien, B., & Lippman, M. (1985). Prognostic Risk Assessment in Primary Breast Cancer by Behavioral and Immunological Parameters. Health Psychology, 4(2), 99-113.
- Lichtman, R.R., & Taylor, S.E., & Wood, J.V. (1987). Social Support of Marital Adjustment after Breast Cancer. Journal of Psychosocial Oncology, 5(3), 47-74.
- Lindhorst, Taryn. (1988). Women and AIDS: Scapegoats or a Social Problem. Affilia, 3(4), 51-59.
- Macks, J. (1989). The Psychological Needs of People with AIDS. In J. Dilley, C. Pies, & M. Helquist (Eds.), Face to Face: A Guide to AIDS Counselling (pp. 2-14). Berkeley, CA: AIDS Health Project.
- Macks, J. & Turner, D. (1986). Mental Health Issues of Persons with AIDS. In L. McKusick (Ed.), What To Do About AIDS (pp. 111-124). Berkeley: University of California Press.
- Macks, J. (1988). Women and AIDS: Countertransference Issues. Social Casework, 69, 340-347.
- Madge, N. & Marmot, M. (1987). Psychosocial Factors and Health. Quarterly Journal of Social Affairs, 3, 81-134.

- Manson Willms, S. (1992). Housing for Persons with HIV Infection in Canada: Health, Culture and Context. In M. Hayes, L. Foster, & H. Foster (Eds.), Community, Environment and Health: Geographic Perspectives (pp.257-278). Victoria: The University of Victoria.
- Manson Willms, S., Hayes, M.V. & Hulchanski, J.D. (1991). Choice, Voice, and Dignity: Housing Issues and Options for Persons with HIV Infection in Canada, A National Study. Ottawa: Health and Welfare Canada.
- Melbye, M. (1986). The Natural History of Human T Lymphotropic Virus-III: The Causes of AIDS. British Medical Journal, 292, 5-12.
- Mitchell, R., & Trickett, E. (1980). Task Force Report: Social Networks as Mediators of Social Support: An Analysis of the Effects and Determinants of Social Networks. Community Mental Health Journal, 16- 27-44.
- Monoz, A., Wang, M.C., Good, R., Detels, H., Ginsberg, L., Kingsley, J., Phair, J., & Polk, B.F. (1988). Mothers With AIDS. In P. Ahmed (Ed.), Living and Dying With AIDS (47-85). New York: Plenum Press.
- Nadler, A., & Mayseless, O. (1983). Recipients' Self-Esteem and Reaction to Help. In J. Fisher, A. Nadler, & B.M. De Paulo (Eds.), New Directions in Helping (pp. 167-188). California: Academic Press.
- Nadler, N. (1983). Personal Characteristics and Help Seeking. In B.M. DePaulo,, A. Nadler, & J. Fisher (Eds.), New Directions in Helping: Help Seeking (pp. 303-340). New York: Academic Press.
- Namir, S. (1986). Treatment Issues Concerning Persons with AIDS. In L. McKusick (Ed.), What To Do About AIDS (pp. 87-94). Berkeley, CA: University of California Press.
- Namir, S., Wolcott, D., Fawzy, F., & Alumbaugh, M. (1987). Coping with AIDS: Psychological and Health Implications. Journal of Applied Social Psychology, 17(3), 309-328.
- Namir, S., Alumbaugh, M.J., Fawzy, F., & Wolcott, D. (1989). The Relationship of Social Support to Physical and Psychological Aspects of AIDS. Psychology and Health, 3, 77-86.

- Nova Scotia PWA Coalition(1990). Holding our own: An Assessment of the Needs of Persons Living with HIV in Nova Scotia.
- Palmer, D. (1992). HIV/AIDS Policy: Everyone's Concern. Vancouver: University of British Columbia.
- Parkes, C.M. (1972). Bereavement: Studies of Grief in Adult Life. England: Penguin Books.
- Pattison, E.M. (1977). A Theoretical-Empirical Base for Social System Therapy. In E.F. Foulks, R.M. Wintrob, J. Westermeyer, & A.R. Favazza (Eds.), Current Perspectives in Cultural Psychiatry (pp. 217-253). New York: Spectrum.
- Patton, C. (1990). Inventing AIDS. New York: Routledge.
- Patton, M.Q. (1980). Qualitative Evaluation Methods. California: Sage Publications
- Patton, M. (1990). Qualitative Evaluation and Research Methods (2nd ed.). Newbury Park, CA: Sage.
- Pearlin, L.I., Lieberman, M.A., Menaghan, E.G., & Mullan, J.T. (1981). The Stress Process. Journal of Health and Social Behavior, 22, 337-356.
- Plaut, S.M., & Friedman, S.B. (1981). Psychosocial Factors in Infectious Diseases. In R. Ader (Ed.), Psychoneuroimmunology (pp. 3-33).
- Procidano, M.E. & Heller, K. (1983). Measures of Perceived Social Support from Friends and From Family: Three Validation Studies. American Journal of Community Psychology, 1, 1-24.
- Reidy, M., Taggart, M.E., & Asselin, L. (1994). Psychosocial Needs Expressed by the Natural Care-Givers of HIV-Infected Children. In R. Bor and J. Elford (Eds.), The Family and HIV (169-183). England: Redwood Books.
- Reis, H. (1983). Social Interaction and Well-Being. In S. Duck (Ed.), Repairing Personal Relationships (pp.24-32). London: Academic Press.
- Remis, R. (September, 13, 1995). Personal communication from Dr. Robert Remis, Epidemiologist, Centre for AIDS Studies, McGill University.

- Richardson, D. (1988). Women and the AIDS Crisis. London: Pandora.
- Rieder, I. and Ruppelt, P. (Eds.), (1989). Matters of Life and Death: Women Speak About Aids. London: Virago.
- Rook, R. (1984). The Negative Side of Social Interactions: Impact on Psychological Well-being. Journal of Personality and Social Psychology, 46, 1097-1108.
- Rosario, M., Shinn, M., Morch, H., & Huekabee, C. (1988). Gender Differences in Coping and Social Supports: Testing Socialization and Role Constraint Theories. Journal of Community Psychology, 16(1), 55-69.
- Sarason, S.B. (1974). The Psychological Sense of Community: Prospects for Community Psychology. San Francisco: Jossey-Bass.
- Sarason, B.R., Pierce, G.R., & Sarason, I.G. (1990). Social Support: The Sense of Acceptance and the Role of Relationships. In B.R. Sarason, G.R. Pierce, & I.G. Sarason (Eds.), Social Support: An Interactional View (pp. 95-128).
- Sarason, I.G. & Sarason, B.R. (Eds.). (1985). Social Support: Theory, Research and Applications. The Netherlands: Martinus Nijhoff.
- Schachter, S. (1966). The Interaction of Cognitive and Psychological Determinants of Emotional State. In C.D. Spielberger (Ed.), Anxiety and Behavior. New York: Academic Press.
- Schiff, H.S. (1977). The Bereaved Parent. New York: Crown.
- Schilling, R.F. (1987). Limitations of Social Support. Social Service Review, March 1987, 19-31.
- Schneider, B., & Jenness, V. (1995). Social Control, Civil Liberties, and Women's Sexuality. In B. Schneider & N. Stoller (Eds.), Women Resisting Change (pp. 74-96). Philadelphia: Temple University Press.
- Shaw, N.S. (1988). Preventing AIDS Among Women: The Role of Community Organizing. Socialist Review, 100, 76-92.

- Shumaker, S.A. & Brownell, A. (1984). Toward a Theory of Social Support: Closing Conceptual Gaps. Journal of Social Issues, 40(4), 11-36.
- SIDA AIDS New Brunswick (1992). A Needs Assessment of Persons Affected by HIV/AIDS in New Brunswick.
- SIDA AIDS Moncton (1990). Needs Evaluation Client Questionnaire.
- Solomon, G.F. (1987). Psychoneuroimmunologic Approaches to Research on AIDS. Annals of the New York Academy of Sciences, 496, 628-636.
- Stanley, Liz & Wise, Sue. (1983). Breaking out: Feminist Consciousness and Feminist Research. London: Routledge.
- Stuntzner-Gibson, D. (1991). Women and HIV Disease: An Emerging Social Crisis. Social Work, 36, 5-8.
- Swigonski, Mary. (1993). Feminist Standpoint Theory and the Questions of Social Work Research. Affilia, 3(4), 170-183.
- Tardy, C.H. (1985). Social Support Measurements. American Journal of Community Psychology, 13, 187-202.
- Taylor, S.E., Falke, R.L., Shoptaw, S.J., & Lightman, R.R. (1986). Social Support, Support Groups and the Cancer Patient. Journal of Clinical Psychology, 54, 608-615.
- Taylor, D. (1990). Testing Positive. Healthsharing, Spring, 1990, 9-13.
- Taylor, S.E., Falke, R.L., Shoptaw, S.J. & Lichtman, R.R. (1986). Social Support, Social Groups, and the Cancer Patient. Journal of Consulting and Clinical Psychology, 54, 608-615.
- Taylor, S. (1983). Adjustment to Threatening Events: A Theory of Cognitive Adaptation. American Psychologist, 38, 1161-1173.
- Thoits, P. (1986). Social Support as Coping Assistance. Journal of Consulting and Clinical Psychology, 54, 416-423.

- Thoits, P. (1982). Conceptual, Methodological and Theoretical Problems in Studying Social Support as a Buffer Against Life Stress. Journal of Health and Social Behavior, 23, 145-159.
- Thoits, P.A. (1987). Gender and Marital Status Differences in Control and Distress: Common Stress Virus Unique Stress Explanations. Journal of Health and Social Behavior, 28, 7-22.
- Tracy, E. (1990). Identifying Social Support Resources of At-Risk Families. Social Work, 35, 252-258.
- Treicher, P. (1987). AIDS, Homophobia, and Biomedical Discourse: An Epidemic of Signification. Cultural Studies, 1(3), pp. 263-305.
- Treicher, P. (1987). An Epidemic of Signification. In D. Crimp (Ed.), AIDS: Cultural Analysis, Cultural Activism (pp.31-70). London: The MIT Press.
- Treicher, P. (1988). AIDS, Gender and Biomedical Discourse: Current Contests for Meaning. In Elizabeth Fee & Daniel M. Fox, (Eds.), AIDS: The Burdens of History (pp.190-225). Berkley: University of California Press.
- Turner, R.J. (1981). Social Support as a Contingency in Psychological Well-Being. Journal of Health and Social Behavior, 22, 357-367.
- Turner, R.J., Frankl, G., & Levin, D. (1983). Social Support: Conceptualization, Measurement, and Implications for Mental Health. In J. Greenley (Ed.), Research in Community and Mental Health (pp.67-111). CT: JAI Press.
- Weisman, A. & Wordon, J. (1975). Psychosocial Analysis of Cancer Deaths. Omega, 6(1), 61-75.
- Wellman, B. (1981). Applying Network Analysis to the Study of Support. In B.H. Gottlieb (Ed.), Social Networks and Social Support (pp 171-200). California: Page Publications.
- Wethington, E. & Kessler, R.C. (1986). Perceived Support, Received Support, and Adjustment to Stressful Life Events. Journal of Health and Social Behavior, 27, 78-89.

- Wolcott, D., Namir, S., Fawzy, F., Gottlieb, M., & Mitsuyasu, R. (1986). Illness Concerns, Attitudes Towards Homosexuality, and Social Support in Gay Men with AIDS. General Hospital Psychiatry, 8(6), 395-403.
- Wortman, C.B. (1984). Social Support and the Cancer Patient: Conceptual and Methodological Issues. Cancer, 53, 2339-2359.
- Wortman C.B. & Dunkel-Schetter (1979). Interpersonal Relationships and Cancer: A Theoretical Analysis. Journal of Social Issues, 35, 120-155.
- Zich, J. & Temoshok, L. (1987). Perceptions of Social Support in Men with AIDS and ARC: Relationships with Distress and Hardiness. Journal of Applied Social Psychology, 17, 193-215.

APPENDICES

APPENDIX B - SAMPLE OF THE LETTER SENT TO AGENCIES
REQUESTING PARTICIPATION IN STUDY PROCESS

THE UNIVERSITY OF BRITISH COLUMBIA



School of Social Work
2080 West Mall
Vancouver, B.C. Canada V6T 1Z2
Tel: (604) 822-2255 Fax: (604) 822-8656

Dear

I am presently enrolled in the Masters of Social Work at the University of British Columbia. As part of the requirements for my degree I am interested in undertaking a project that will be of benefit to women with HIV/AIDS in Saskatchewan. The proposed project involves an assessment of the perceived needs of women living with HIV/AIDS in Saskatchewan. Further details of the study are provided below. I wish to ask for your help in reaching as many of these women as possible for the study. I would like for you to distribute an introductory letter and invitation to participate in the study to those women with HIV/AIDS who you are in contact with. This would allow for as many women as possible to have the chance to add their opinions, concerns and stories to a project that will hopefully be of significant benefit to providing appropriate services to women with HIV/AIDS in Saskatchewan.

Summary of Project

In Canada women are the fastest growing category of people with AIDS, yet little attention has been paid to the needs of women who are affected by this disease. In Saskatchewan there are no services offered specifically for women. There has been no formal effort undertaken to determine the needs of these women. The purpose of this study is to obtain this information. Women with HIV/AIDS in Saskatchewan will participate in this study to define the perceived needs of women living with HIV/AIDS in Saskatchewan. Participatory action research will be used as the methodological framework. This exploratory study will use a focus group to obtain information from the participants. A purposive and snowball sampling of participants will be used to contact participants. The content of the obtained data will be analyzed for emerging themes. The interpretation of these themes will then be taken back to those who participated in the focus group to ensure the

APPENDIX D - SAMPLE OF INTERVIEW SCHEDULE

FOCUS GROUP INTERVIEW SCHEDULE

1. What do you perceive your needs to be as a women living with HIV/AIDS in Saskatchewan?

Probes: Medical
Mental Health
Emotional Support
Rural
Support

Financial
Family/Children
Information
Services

2. Can you tell me about how these needs are being met or are not being met?
3. Can you tell me about how you feel your needs could be met?
4. Do you feel that being a woman affects the services, or range of services that you have available to you?
5. How would you describe your experience as a woman living with HIV/AIDS in Saskatchewan?

RAW DATA

CODES

CATEGORIES

This is an awful thing to say but okay, with women that have their menstrual periods and everything, I don't have mine because I had a hysterectomy. You guys suffer with a lot more yeast infections, where I don't get them.

Women with menstrual periods suffer from a number of yeast infections.

Medical- gender differences.

Not only that but it really drains me. By the time you're in the middle of your menstruation it's like, it feels like all the blood from your system is just gone and like, you just lay there.

Menstruation drains the energy from women.

Medical- gender differences.

It's hard enough when some healthy women go through their PMS and everything. It's hard enough on them, never mind when you have other things to deal with.

PMS affects magnified by additional stressors that participants deal with.

Medical- gender and stress.

But this is something these guys would have in common where I don't have in common anymore and I know with my family doctor, she is so afraid to take blood more than once a month because even just with the few tubes of blood she says that can make you get so low.

Women differ in body changes.

Women- Experience. with doctors.

Doctor. afraid taking blood more than once a month. Taking a few tubes of blood a month can make them low.

Medical-Experience with doctors.

I get twelve tubes taken every time.

Has more blood taken than another women's doctor has suggested be taken.

Medical-Experience with health professionals..

Mine used to be every month and I just couldn't keep up with that. I go from one month with headaches to another one and too many blood samples. Now it's every three months.

Headaches occur when blood was taken every month. Adjustment made to every three months.

Medical-Experience with Health professionals.

Then I have to go for biopsies every few months. They don't tell me what it is. They said that I came back CMV positive and my PAP test is normal, but we don't know what it is but it's not cancer right now. But it's suspicious cells that cause cancer, but we're not going to do anything for you. We're just going to take a chunk out of you every time you come for a biopsy, and then we'll see if it changes. So we'll watch it.

Has biopsies performed but not told what biopsy is.

Told that biopsies will continue to be performed.

Medical-Experience with health professionals

So we're built-in fucking guinea pigs and it's like if it's not our bodies either get rid of it. But it's just like they just want to have that knife there and they got us on so damn many pills that there's times that I have such a hard time swallowing pills.

Woman feels like a built in guinea pigs

Women controlled by the knife and pills.

I get severe abdominal pains from so many pills.

Pains from taking so many

You have to fight the federal government for what I want, trials for women. Trials for women, it's pissing me off. Because maybe we're willing, maybe we want to try something once given enough information on it. But it's always been men, men, men. And I know the fact that they use us as guinea pigs anyway. We seem to get far too many blood tests and we try all these pills and everything yet when something comes around it's like there's not enough proof about how this might work on you. We don't have enough research on women. You know we don't do trials. They aren't even offered.

Have you heard about the D14 or something, that the have out. What is this D14? What does it have for side effects? These are things that nobody has no answers.

I don't know what the side effects are but they say this new drug stops the HIV from going any further. But they won't give it to HIV people unless you're on your death bed.

pills

Have to fight for access for women to drug trials.

Women used as quinea pigs.

Too many blood tests given.

Need access to trials for women.

Women not given option to participate in drug trials.

Woman not given answers on the side effects of new available drug.

Conflicting information about availability and access to new drug.

Medical- Access to drug trials.

Medical- Experience with health professionals..

Medical -Access to drug trials.

Medical-information.

Women-Accessibility to drugs.

No, they will give it to you if you have taken AZT, DDI, DDC. So the three of them and then that's your last one. So that's what I am working for is that D14.

Women with information works toward obtaining access to new drug.

Medical-Access to trials.

So why don't they give it to people who are HIV positive instead of waiting until you progress so far first. Give us the option of taking it. What's it going to hurt that they haven't already done damage to. It's like we'll tell you when to take drugs and we'll tell you what drugs you take.

Want option to take drugs before government completes all of its studies. Others have control.

Told when and what drugs to take.

I think that's one of the things with the government is that things that do work, I don't think that they will give it to you until they find a way to tax you for it. Or to get one kind of something for it. They won't just give it to you, they've got to make money off it. It shouldn't be used to make money off of. You shouldn't make money off of people's death.

Medical -Information

Government controls drugs and will not make them accessible unless they profit.

Services-Information sharing.

We hardly ever find out about the drugs that are available. Either the government doesn't tell us or we never hear about it. Like Dr. xxx, [AIDS service organizations] get a bunch of up to date information on new drugs but they don't tell us because it's not important to them. Or they don't agree with it. I was at the [AIDS service organization] and saw this important study that was signed by thirty or so physicians and they should have taken note of that. And XXX goes that he didn't print it because he couldn't understand it. I don't care if he couldn't understand it. I've done a little more reading than you and I can, it's incredible, print it. Some may be interested in it. It should be available for people to see and make their own decisions. They should realize that, that is something important.

Another question that I have is does being a woman effect the services that you have available to you or the type of services that you get?

Not given information about available drugs.

Government, Doctors. and AIDS Service organizations don't share information

Personal bias used to decide if information is disbursed.

Information should be available for people to make to make their own decisions.

Information-Availability.

Medical-Information.

Information-Not shared

Medical-Experience with health professionals.

I think that the men get better services that the women do. I think we're disqualified and the men get what they want. We're whiners and nobody pays attention and I feel that with Dr. xxx I know my body better than he does but he keeps telling me what it is that I need. I say to him you only works with me once every three months, but I know my body. I know how each drug effects me. And he said well you can't. But I do, listen to me.

Men get better services.
Men get what they want.

Medical-Experience
with health
professionals.

Women are whiners and ignored.

Medical- Experience
with health
professionals.

Women's input on their body/health is ignored by Doctors. Told what they need.

But they don't think that we're qualified, but I am. I'm more qualified than he is. So don't tell me that I don't know my own body because I do.

Women told they are not qualified to know their bodies.

Medical-Experience
with health
professionals.

On one side its like you couldn't possibly have an infection and these headaches they got to be psychological, but on the other hand it's, "We don't know we don't have enough research done on women." So which is it, it couldn't be happening or it could be but you don't know why because there isn't enough research.

Illnesses said to be psychological.

Medical-Experience
with health professional.

Then stop the men's research and start working for the women for once.

Lack of information and research into women's illnesses.

Medical-Information.

Have you ever had any experience like for yeast infections or anything, anytime. I went to a doctor for it. I guess because I'm HIV positive or something they automatically assume that I'm promiscuous because all of a sudden I had gonorrhea, I had herpes, I had syphilis. I had, like every time I went and I had an infection it was, Oh you must have this and that.

Woman feels judged (based on assumptions) by doctor as being promiscuous..

Medical-Experience with health professionals

You can develop it on your own. All it is, is a variation of the chickenpox virus. It remains in your nerve endings if you've had chickenpox. Lots of stress, lack of proper diet and it can suddenly pop up. You don't have to sleep with someone to have got it. I would say stress is a major problem.

Medical-Information.

Stress is a major problem that affects health.

Mental Health- Stress

I definitely say that women get different treatment in a hospital. I whine a lot, did you know that? That's what they keep telling me.

Women get different treatment in hospitals.

Woman seen as a whiner by hospital staff.

Medical- Experience with health professionals.

We need more people that open their mouths and aren't afraid to speak up to the doctors. And we have to speak up to the doctors.

Women need to speak up to doctors.