

HIV/AIDS and Palliative Care in the Atlantic Region



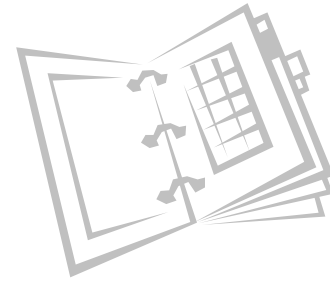
FINAL REPORT

Needs of Persons Living With
HIV/AIDS and Their Caregivers

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Canadian Palliative Care Association, January 24, 2000

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i EXECUTIVE SUMMARY

An HIV/AIDS and palliative care needs assessment study of persons living with HIV/AIDS and their caregivers (i.e., partners, family members and friends) in the Atlantic Region was conducted. The study was aimed at assessing the awareness, experiences, as well as current and anticipated needs of persons living with HIV/AIDS and their caregivers in relation to palliative care services in the four Atlantic provinces (i.e., New Brunswick, Nova Scotia, PEI, and Newfoundland & Labrador). It was designed to assist the Canadian Palliative Care Association in its planning and advocacy efforts for services meeting the needs of persons affected by HIV/AIDS in the region.

Two separate questionnaires were developed and distributed through the region's HIV/AIDS Clinics and AIDS Service Organizations. A total of 103 persons living with HIV/AIDS (PLWHIV/AIDS) at various stages of HIV disease and 67 caregivers (previously, presently, or potentially involved in a loved-one's HIV-related care) from across the four Atlantic provinces responded to the *HIV/AIDS and Palliative Care in the Atlantic Region Survey*.

Despite advancements in HIV/AIDS-related treatments and improvements in the health of many PLWHIV/AIDS, the findings highlighted the multitude of challenges and complexities of HIV disease and related caregiving, as well as the need to address various psychosocial, financial, informational, and service needs. The data also point to the essential role of informal caregivers in meeting the current and potential care needs of PLWHIV/AIDS. The anticipated need and preference for home health care services emerged repeatedly, as did the projected need for a number of other HIV-related services (e.g., volunteer support; homemaker/home support; transportation services; other alternatives to hospitalization; legal services; palliative care education; grief/bereavement counselling; and, respite care).

Most PLWHIV/AIDS and caregivers had not received any information related to HIV/AIDS and palliative care; many expressed inadequate levels of knowledge and comfort; and a significant proportion perceived palliative care as an approach to be used in the final stage of illness, rather than as an integral aspect of care throughout HIV disease.

In sum, the data underscore the need to mobilize toward six main objectives : (1) To increase overall knowledge and comfort levels around various palliative care issues; (2) To address a variety of HIV-related information needs; (3) To decrease various HIV-related financial stressors; (4) To increase the availability and accessibility of quality home care and palliative care services; (5) To decrease certain HIV-related psychosocial stressors; and (6) To further explore strategies for best meeting PLWHIV/AIDS and caregivers' greatest anticipated HIV-related service needs.

In total, 12 main strategies are recommended for meeting the above objectives. These encompass several educational and support strategies (e.g., written materials; workshops/educational sessions); lobbying and advocacy; and the establishment of an Atlantic Canada HIV/AIDS and Palliative Care Committee. In addition, it is noted that the timely implementation of recommendations related to the needs of formal caregivers is also an integral component of meeting the various current and anticipated needs of persons living with HIV/AIDS and their partners, family members, and friends.

1.0 PURPOSE AND METHODOLOGY

1.1 Background and Rationale

Over the past few years, there have been substantial advancements related to the health of many persons living with HIV/AIDS. Although not effective for all, the arrival of protease inhibitors and combination therapy has enabled many to live longer, healthier lives. Because of this change, the emphasis of HIV/AIDS palliative care has also shifted from improving the quality of life for persons who are dying or are bereaved to a continuum of services aimed at improving the quality of life of persons **LIVING** with HIV/AIDS and their loved-ones.

The present study comprises the second phase of related research funded by Health Canada (AIDS Care, Treatment and Support Program) and conducted by the Canadian Palliative Care Association (CPCA) toward its planing and advocacy efforts for services meeting the needs of persons affected by HIV/AIDS in Atlantic Canada. The first phase consisted of an assessment of the HIV-related experience and educational needs of professional caregivers. It was the first study of its kind to assess the HIV-related experience and educational needs of formal caregivers involved specifically in the provision of in-patient and home-based palliative care across the four Atlantic Provinces. Data on types of services and clientele, HIV/AIDS experience and training, HIV-related challenges, comfort and knowledge levels, specific informational needs, as well as recommended strategies for meeting the identified needs were gathered. A total of 69 formal caregivers, representing a diversity of in-patient and home-based programs, responded to the mailed questionnaire and provided much useful information pertaining to the HIV/AIDS-related experience and needs of personnel in various facilities.

While valuable insight into HIV-related palliative care experiences and needs had been gained, it was recognized that very little was known about the current or anticipated HIV-related palliative care needs of individuals personally affected by HIV/AIDS, and that the information gathered comprised only a fraction of that required to assist CPCA in their planning and advocacy efforts toward meeting the needs of persons affected by HIV/AIDS in Atlantic Canada. Completing the equation required assessing the experiences and needs of persons living with HIV/AIDS and their informal caregivers, such as family members, partners and friends.

1.2 Project Objective

➤ To assess the awareness, experiences, and needs of persons living with HIV/AIDS and their caregivers in relation to palliative care services in the Atlantic Region (i.e., New Brunswick, Nova Scotia, PEI and Newfoundland). More specifically, the study was aimed at assessing:

- Awareness of palliative care services in the Atlantic Region
- Experiences with HIV-related palliative care services/programs
- Current and anticipated needs in relation to HIV/AIDS palliative care.

1.3 Project Outline

The Project was carried out in four main phases over a six-month period (July 20, 1999 - January 20, 2000). A total of 29 days over the six months were allotted for the project's completion. The approximate time frames for each of the project's main phases are outlined in Table 1 below.

Table 1. Project Outline: Phases and Main Components	
I. Environmental Scan (2 days)	<ul style="list-style-type: none"> Review of the literature and research relating to palliative care needs assessments of persons living with HIV/AIDS and their caregivers. Telephone consultations with Atlantic Region AIDS Service Organizations and HIV/AIDS Clinics regarding the project design and methodology.
II. Research Design and Methodology (8 days)	<ul style="list-style-type: none"> Refinement of sampling strategy. Development of two cover letters and questionnaires to assess: <ul style="list-style-type: none"> Awareness of palliative care services in the Atlantic Region; Experiences with HIV-related palliative care services/programs; Current and anticipated needs in relation to HIV/AIDS palliative care. Consultation with CPCA toward the revision and finalization of the needs assessment questionnaires.
III. Data Collection, Entry & Analysis (14 days)	<ul style="list-style-type: none"> Translation and printing of questionnaires. Preparation of mail-out to ASO's and HIV/AIDS Clinics. Development of database and data analyses programs. Data entry (170 questionnaires). Follow-up with intermediaries regarding return of questionnaires. Data analyses and compilation.
IV. Final Report (5 days)	<ul style="list-style-type: none"> Preparation of a report summarizing the findings of the needs assessment, and incorporating recommendations for future direction in relation to meeting the information and service-related palliative care needs of persons living with HIV/AIDS and their caregivers in the Atlantic Canada.

1.4 Sampling Strategy

Sampling procedures were developed in consultation with each of the AIDS Service Organizations and HIV/AIDS Clinics in the Atlantic Region and were guided by the objective of attaining a large and representative sample of persons affected by HIV/AIDS across the four Atlantic provinces. Three major considerations played a role in the design of the sampling strategy: (1) Resources (e.g., financial, human); (2) Need for maintaining anonymity; and (3) An estimated 500-600 known cases of HIV/AIDS across the region. In short, choice of sample size was based on the need to reduce sampling error, while accounting for the possible 40%-70% rate of non-response in mail surveys.

In order to ensure a representative sample, an attempt was made to reach as many persons living with HIV/AIDS and informal caregivers as possible. As shown in Table 2, questionnaires were distributed through a combination of AIDS Service Organizations and the three HIV/AIDS Clinics in the Atlantic Region. A total of 320 questionnaires designed for persons living with HIV/AIDS were distributed solely through the region's HIV/AIDS Clinics. That is, all HIV/AIDS Clinics agreed to send the written surveys to the patients on their mailing lists. All mail-outs were done directly through the clinics; neither the researcher nor CPCA had access to any of the mailing lists or contact information.

It should be noted that only approximately one-third of the questionnaires initially provided to the Moncton HIV/AIDS Clinic for distribution to their clients in New Brunswick and Prince Edward Island were actually disseminated. Problems occurred early on in their mail-out, and they opted to proceed by distributing questionnaires over a two-month period during patient visits. With additional time and resources, larger and more representative samples of PLWHIV/AIDS from New Brunswick and PEI could have been attained.

AIDS Service Organizations (ASO's) in all four provinces were involved in the distribution of approximately 55 Informal Caregiver questionnaires (see Table 2). These organizations had agreed to distribute the surveys to their clients who were previously, presently, or potentially involved in a loved-one's HIV/AIDS-related care. ASO's were not asked to distribute questionnaires to persons living with HIV/AIDS since the vast majority of these individuals were accessing one of the region's HIV/AIDS Clinics. To ensure a larger and more representative sample of informal caregivers, each package of questionnaires for persons living with HIV/AIDS also included a copy of the Caregiver questionnaire that could be given to a loved-one if so desired.

	PLWHIV/AIDS (# distributed)		Caregivers (# distributed)*	
Newfoundland & Labrador	• HIV/AIDS Clinic - St. Clare's Hospital	82	• Newfoundland & Labrador AIDS Committee	15
PEI	• Moncton HIV/AIDS Clinic- The Moncton Hospital	5	• AIDS PEI	5
Nova Scotia	• HIV/AIDS Clinic - QE-II Health Science Centre	188	• Atlantic First Nations AIDS Task Force • AIDS Coalition of Cape Breton	15
New Brunswick	• Moncton HIV/AIDS Clinic- The Moncton Hospital	45	• AIDS New Brunswick • AIDS Saint John • SIDA AIDS Moncton	20
Total	320		55	
* This table excludes the number of Caregiver questionnaires included in the packages distributed to persons living with HIV/AIDS. The methodology did not permit a calculation of the number of surveys that actually reached caregivers through the efforts of their loved-ones.				

1.5 Questionnaires

1.5.1 Overview. Two separate questionnaires were designed to respectively assess the needs of persons living with HIV/AIDS and their informal caregivers (i.e., family members, partners, and friends). As shown in the Appendix, several items were applicable to both PLWHIV/AIDS and caregivers (e.g., demographic items) and were included in both questionnaires. The surveys were available in English and French, and required approximately 20 minutes to complete. The majority of questions were close-ended - i.e., asking respondents to choose from several specified response categories or an “other” response option. Various open-ended questions were also included to provide participants with the opportunity to clarify or expand on certain issues. Six key informants, including individuals personally affected by HIV/AIDS, were involved in the questionnaires’ development and editing.

A cover letter, explaining the purpose of the needs assessment study, accompanied each questionnaire. It also indicated that participation was entirely voluntary, all questions were optional, and that all questionnaires would remain completely anonymous. To maximize participation rates, individuals who were interested in taking part in the study but did not wish to complete the written survey were provided with the option of an anonymous telephone interview. Self-addressed stamped envelopes accompanied all questionnaires.

The *PLWHIV/AIDS Needs Assessment Survey* consisted of 37 questions, divided into four sections: (a) *Background Information* - meant to gather basic demographic data (e.g., sex, age, ethnicity, sexual orientation, place of residence); (b) *HIV-Related Health Information* - designed to gather data pertaining to health status (e.g., year of diagnosis/infection, CD4 and viral load counts, hospitalization, quality of care, and activities of daily living); (c) *HIV/AIDS and Palliative Care* - assessing attitudes, knowledge, comfort, and fears surrounding various HIV-related palliative care issues, as well as current and anticipated sources of HIV-related information, support and care; and (d) *Information and Support Services/Needs* - gathering information on the various potential challenges and experiences related to living with HIV/AIDS, as well as, employment, financial, informational, and service needs.

As shown in Appendix, the questionnaire designed to assess the needs of caregivers included 25 questions, divided into five sections. (a) *Background Information* - assessing much of the same basic demographic data as the PLWHIV/AIDS questionnaire; (b) *Loved-one(s) with HIV/AIDS* - meant to gather general and health status information regarding the loved-one(s) in whose HIV/AIDS-related care they are/were involved; (c) *Involvement in HIV/AIDS-Related Care* - designed to more specifically assess the quality and quantity of HIV/AIDS-related caregiving; (d) *Experiences and Feelings* - assessing the prevalence and intensity of various HIV-related caregiving experiences and challenges; and (e) *Information and Support Services/Needs* - examining caregivers’ HIV-related knowledge and comfort, as well as need for various sources of support, information and services.

1.5.2 Data Analyses. All data gathered over the course of the present study were coded and entered into a computer database (Microsoft Access 97). Following the completion of data entry, the information was exported into Microsoft Excel 97 for data tabulations and analyses.

1.6 Participant Rate and Sample Size

A total of 170 individuals personally affected by HIV/AIDS participated in this phase of the *HIV/AIDS and Palliative Care in the Atlantic Region* study. More specifically, a total of 103 persons living with HIV/AIDS (32% response rate) and 67 caregivers across the four Atlantic provinces completed and returned the questionnaires. It should be noted that the number of questionnaires returned from caregivers exceeds the total distributed through ASO's. As previously mentioned, the return rate for the caregiver surveys could not be precisely calculated, since a copy of the questionnaire was included in each mail-out to persons living with HIV/AIDS.

As illustrated in Figure 1, the number of respondents by province varied considerably. The greatest number of questionnaires were returned from Nova Scotia (91), followed by Newfoundland and Labrador (42), and New Brunswick (32). Very few (5) were received from PEI residents. The provincial representations of the total PLWHIV/AIDS and caregiver samples are presented in Table 2. It is important to keep in mind that, given the challenges encountered in the distribution of questionnaires to persons living with HIV/AIDS, New Brunswick and PEI samples are somewhat under represented. Nonetheless, all response rates are acceptable within the guidelines of survey methodology.

Figure 1

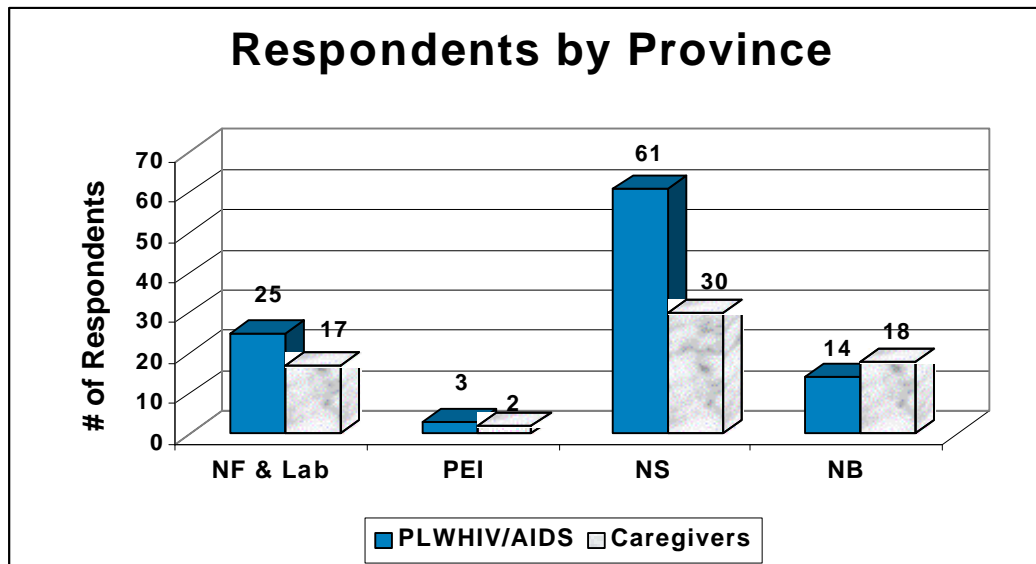


Table 3. Provincial Representation of Total Samples

	PLWHIV/AIDS	Caregivers
Newfoundland and Labrador	24%	25%
Prince Edward Island	3%	3%
Nova Scotia	59%	45%
New Brunswick	14%	27%
Total Respondents	103	67

2.0 FINDINGS - PERSONS LIVING WITH HIV/AIDS

2.1 Demographic Information

Of the 103 PLWHIV/AIDS respondents, 84 (82%) were male and 17 (17%) were female. As shown in Figure 2, two individuals did not indicate their gender, and more than 80% of the entire female sample were from Newfoundland. In terms of sexual orientation, 61% identified themselves as gay, 27% as heterosexual, 6% as bisexual. The remainder were either “unsure” (1%) or opted not to respond (5%).

Participants ranged in age categories encompassing 25 through 64 years, with approximately three-quarters of the sample between the ages of 25 and 44, and an additional 20% ranging in age from 45-54 years. Relatively few (6%) PLWHIV/AIDS reported being 55 years of age or older. The vast majority (93%) of the sample self-identified as Caucasian. Other ethnic/cultural groups - Black (2%); Aboriginal/First Nation (1%); Middle Eastern (1%) - were mentioned by a small minority, and 3% self-identified as “inter-racial”.

While individuals from both rural and urban areas were represented, more than one-half (59%) reported living in a city, 26% in a town, and 15% in a village or rural area. In terms of accommodations, the majority were either renting an apartment/house (45%) or were living in their own home/condo (39%); a smaller but substantial number (14%) were staying at the home of friends or family. Two participants were living in either a rooming/boarding house or a special care home. No one reported residing in a nursing home or shelter. As displayed in Figure 3, a diversity of living arrangements were represented by PLWHIV/AIDS, with most living alone (39%) or with their partner/spouse (36%). An additional 23% were living with their parents or with their children. Relatively few other living arrangements were reported.

Figure 2

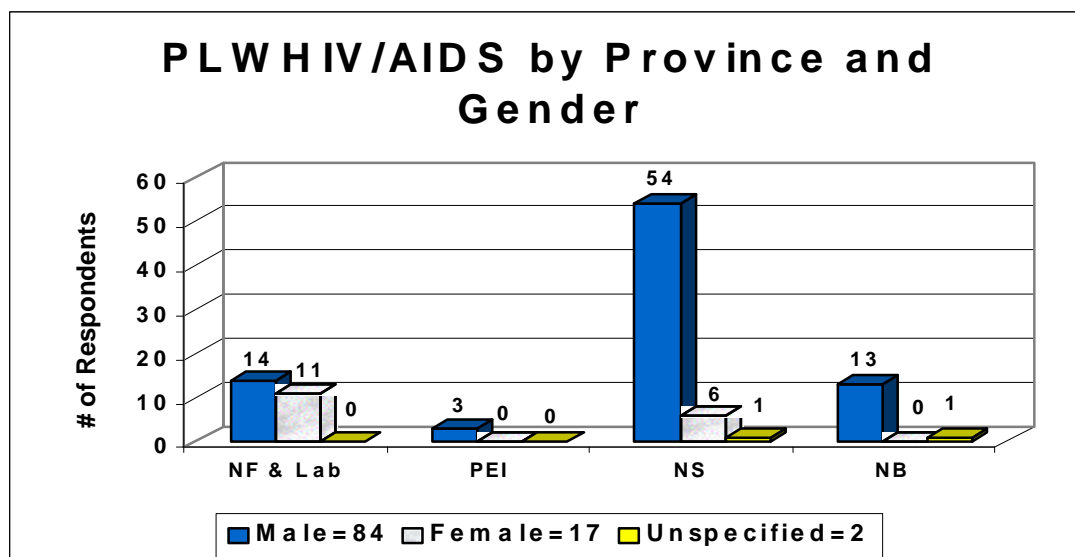
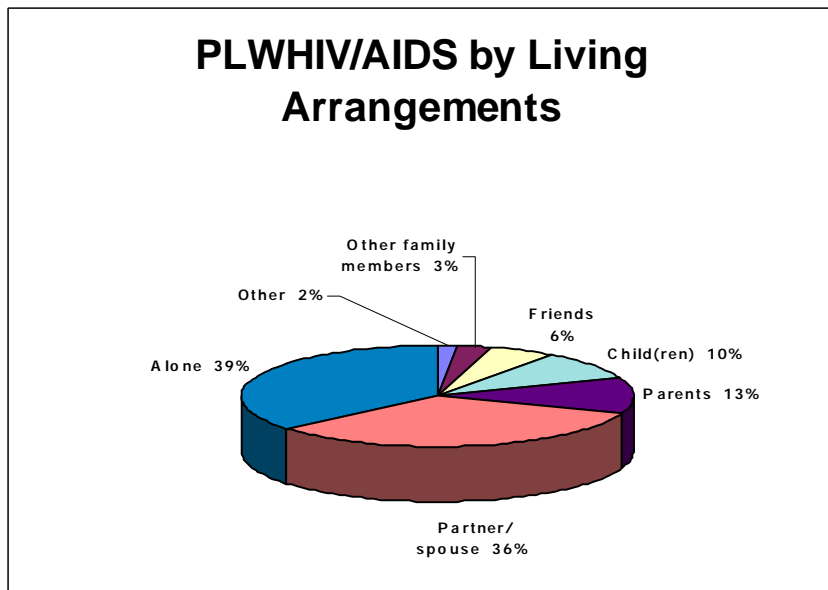


Figure 3

2.2 HIV-Related Health Information

2.2.1 Overview of Health Status. To assess the length of time individuals had been living with HIV/AIDS, they were asked to indicate the year of their HIV+ diagnosis, as well as the year they believe they were infected. As shown in Figure 4, the number of years participants had been living with HIV/AIDS varied greatly, ranging from less than one year to approximately 20 years. On average, however, individuals reported having been infected for approximately 11 years ($M = 1988$; $SD = 5$) and diagnosed for seven years ($M = 1992$; $SD = 4$).

While participants at all stages of HIV disease were represented, the overall sample reported being in relatively good health (see Figure 5). That is, three-quarters were either not experiencing any HIV-related symptoms (39%) or experiencing such symptoms “some of the time” (35%). Smaller proportions were chronically experiencing symptoms (7%) or living with advanced HIV disease (17%). Further, more than one-half of all PLWHIV/AIDS had never been hospitalized due to an HIV-related illness (57%), while only 17% had been so within the last year.

2.2.2 Approximate CD4 and Viral Load Counts. Figures 6 and 7 provide additional insight into the current state of participants’ health status. As shown, more than one-half reported current CD4 lymphocyte cell counts (per mm^3) ranging from a low of 200 to more than 750, while approximately one-third of the sample indicated CD4 counts below 200. In addition, exactly one-half of the sample reported an undetectable viral load (see Figure 7). It should be noted, however, that several of the participants’ health status had improved over time, a finding likely attributed to the arrival of combination therapy. For instance, more than three-quarters had previously received results indicating CD4 cell counts of 200 or less, and/or a viral load of 10,000 copies/ml or more.

Figure 4

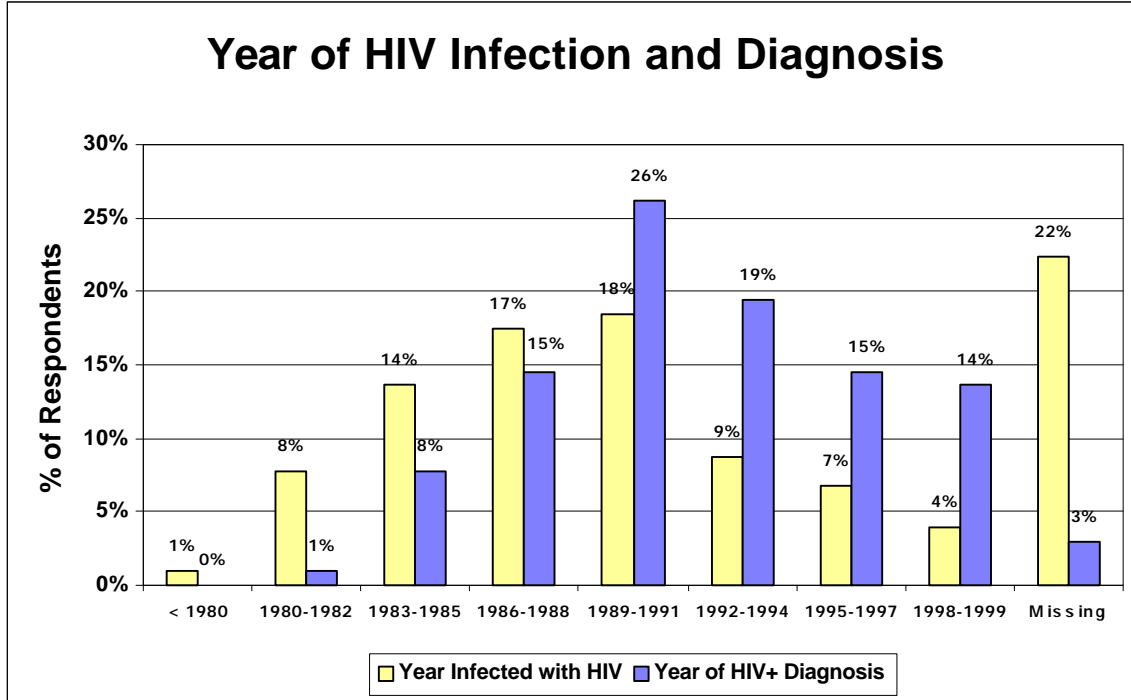


Figure 5

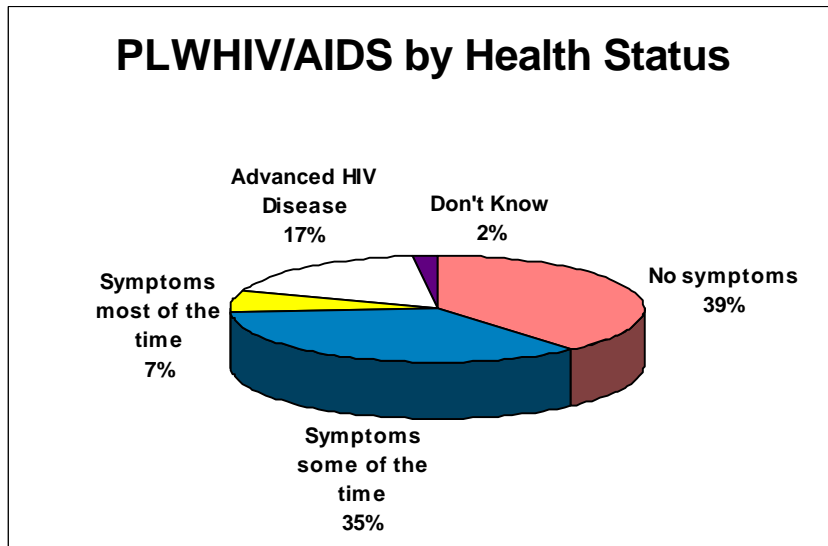


Figure 6

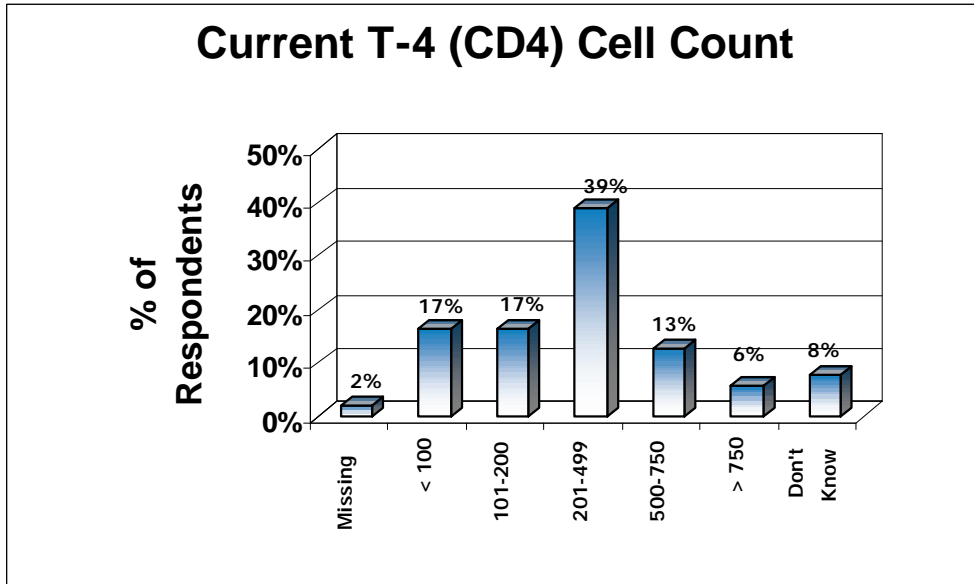
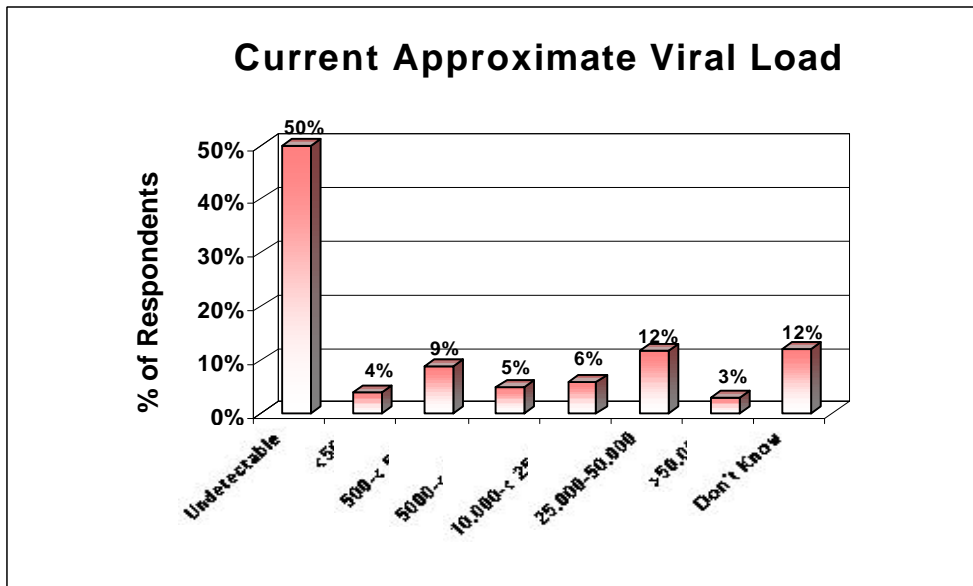


Figure 7



2.2.3 Impact on Activities of Daily Living. As a very general indicator of HIV-related impact on the sample’s activities of daily living, participants were asked to indicate on a scale ranging from 1 (“not at all”) to 5 (“a lot”) the extent to which their current health limited their ability or enjoyment in everyday activities. An open-ended question also asked them to qualify their response. While responses spanned the entire scale, close to three quarters of all PLWHIV/AIDS reported some limitations (see Figure 8). On average, these respondents noted that their health was posing “moderate” limitations on their ability or enjoyment of everyday activities ($M = 3.0$; $SD = 1.1$).

Qualitative analyses of participants' responses to the open-ended question asking them to clarify the limitations posed by their current health revealed several main themes. As outlined in Table 4, the most commonly identified limitations were related to physical and psychosocial concerns, and/or a combination thereof.

Figure 8

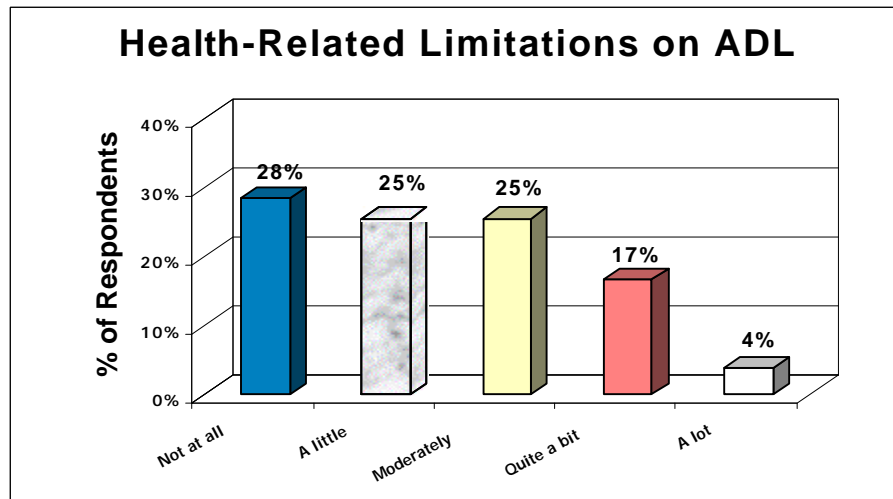
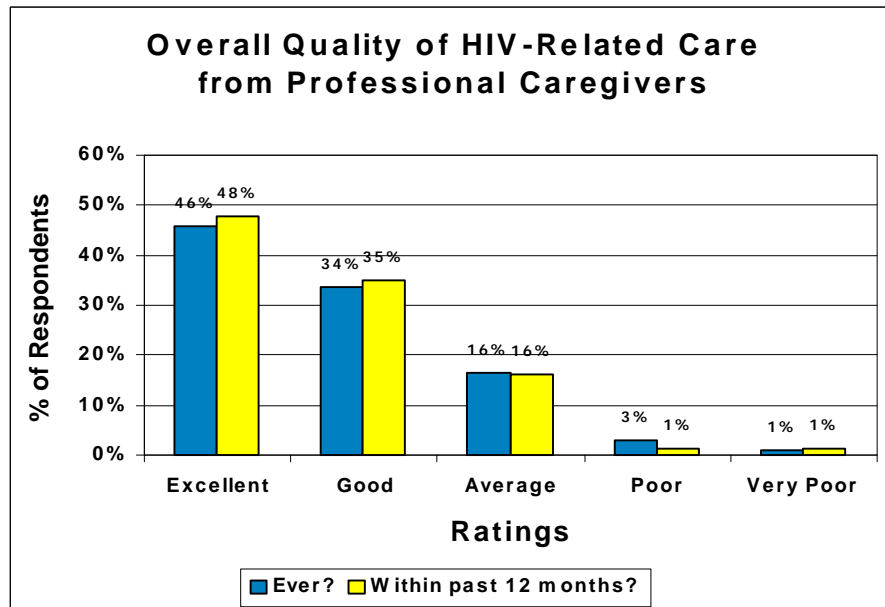


Table 4. Current Health-Related Limitations on Everyday Activities (n = 68)

"Not at all"	<ul style="list-style-type: none"> • <i>As a result of living with no symptoms, I have no limits at this time.</i> • <i>Feeling healthy/I feel fine/I feel good/I'm in good health (4).</i> • <i>I am very active. Lots of energy.</i> • <i>I do everything I want and I enjoy life to the utmost.</i> • <i>I enjoy going to social activities like bingo, card games and walking.</i> • <i>I have been very lucky about my health, no problems so far.</i> • <i>I try not to think about it, or not dwell on it.</i> • <i>My answer explains it all. I feel I am able and can enjoy all activities.</i> • <i>I work and do what I want to. Energy level is great, etc.</i>
"A little"	<p><u>Physical Concerns</u></p> <ul style="list-style-type: none"> • <i>I tend to tire easily (2).</i> • <i>Concerns around health-HIV+ for 8 years - now showing symptoms; recent illness, etc.</i> • <i>Drug requirements; eating and bowel problems (minor).</i> • <i>Drug side effects sometimes slow me down.</i> • <i>Drug side effects; general malaise/tiredness.</i> • <i>Drugs sometimes interfere with my quality of life. Some infections orally can make me sick.</i> • <i>Find that I'm not as strong and tire and also bruise easier; my bones get sore.</i> • <i>Need rest.</i> • <i>Still have occasional diarrhea and numbness around mouth and penis (medication related).</i> • <i>Neuropathy and weather affect mobility sometimes</i> • <i>Some days just feel too tired to do anything-even routine household tasks</i> <p><u>Psychosocial Concerns</u></p> <ul style="list-style-type: none"> • <i>Chronic depression/Depression (2).</i> • <i>One seems more likely to question lifestyle, diet, etc. which limits freedom of the person.</i> • <i>Tired all the time. People that know I'm HIV don't visit or socialize with me.</i>

	<p><u>Miscellaneous</u></p> <ul style="list-style-type: none"> • Coming home to take pills, with food. • Hearing impaired. • Got approved for Canada Pension. Seeking retraining for new job. • It's always a factor in any decision or daily function. • Often I will not have a drink if in the mood. • Time table of taking medication. Otherwise, not at all.
"Moderately"	<p><u>Physical Concerns</u></p> <ul style="list-style-type: none"> • A lot of fatigue. • After starting treatment I developed irritable bowel syndrome and am cramped with diarrhea daily. • Fatigue, drugs and complications affect daily activities. Subsides in the afternoon. • Fatigue; partially blind. • I find I can't or don't have the energy to do much/Lack of energy. • Lots of leg/joint pain, nausea, diarrhea. • Memory loss, digesting problems, lots of diarrhea making it hard to be mobile and outside the apartment. • Pancreatitis-Diabetes. • Tired, playing less sports. • Walking and balance. <p><u>Multiple Concerns</u></p> <ul style="list-style-type: none"> • (1) Need rest, reduced stress; (2) Affected work/salary expectations; (3) Affected social life. • Fatigue, anxiety, isolated (physical and spiritual); stress and expense of travel to Halifax. • I get tired easily and have a lot of little infections. Also get depressed a lot due to this illness. • Tiredness, timing of medications, fear of infections and other people. <p><u>Miscellaneous</u></p> <ul style="list-style-type: none"> • I have to schedule/balance each day carefully. Get to bed by 8:30 PM - 6:00 am each day. • Because of med (price) I've been forced on to disability. • Good days, bad days.
"Quite a bit"	<p><u>Physical Concerns</u></p> <ul style="list-style-type: none"> • Always "sick". Low energy, very fatigued • Right now, I'm having trouble with low platelets so I'm tired and have low energy quite a bit. • Severe fatigue, diarrhea, staph infections. • Shakes, diarrhea, sweats, neuropathy, stress, weight loss. • Side effects of med and general malaise. • Some fatigue, low energy, some numbness in legs and feet, and so on. • Tired a lot, and I get sick (vomit) a lot due to the drugs. <p><u>Multiple Concerns</u></p> <ul style="list-style-type: none"> • Anxiety, depression/side effects of drugs/loss of friends. • Fatigue, nausea, weak, depression. • I am very fatigued and depressed most times. • Not being self supportive/unable to work anymore because of fatigue and nausea due to meds. <p><u>Miscellaneous</u></p> <ul style="list-style-type: none"> • Currently on short-term disability. • Je dois me préoccuper régulièrement de mon état de santé. [I always have to think about my state of health]- translation.
"A lot"	<p><u>Multiple Concerns</u></p> <ul style="list-style-type: none"> • I don't sleep well, worry about welfare of my pets should something happen to me. Decidedly "need" marijuana and have used often (when needed & I have it) for past 3 yrs. Used moderately before, use medicinally now. • Very tired. Sleep a minimum 15 hours a day and severe depression.

Figure 9

2.2.4 Quality of Care Received From Professionals. On a 5-point scale, ranging from “excellent” to “very poor”, participants were asked to rate the overall quality of HIV-related care that they had received from paid caregivers (e.g., doctors, nurses, counsellors). As illustrated in Figure 9 above, there was no significant difference in participant ratings in relation to the care that they had “ever” received versus the care received within the past year. This may be related to the earlier finding that participants had, on average, only been diagnosed for seven years. On the whole, most PLWHIV/AIDS (80%) rated their care as either “excellent” or “good”. A relatively smaller proportion rated their care as “average”, and very few considered their HIV-related care to be poor. Participants’ responses to the open-ended question asking them to explain their respective ratings are presented verbatim in order of themes in Table 5.

Table 5. Over all Quality of HIV-Related Care Received (n=52)

"Excellent"	<p><u>Informative and Client-Centred</u></p> <ul style="list-style-type: none"> • <i>Always attentive, caring and compassionate.</i> • <i>I always feel at ease with Dr. Nguyen. Consie (nurse) keeps me informed and I can talk openly with her. Annette (NLAC) is always ready and willing to listen and I feel comfortable and at ease by the end of the conversation.</i> • <i>Everyone at ID clinic is very kind, understanding, not judgmental/helpful.</i> • <i>Doctor has been there to explain any questions I have and to keep me updated on things.</i> • <i>Friendly, competent, timely, well explained, compassionate, flexible.</i> • <i>Medical staff in St. John's and in my hometown very supportive.</i> • <i>My specialist and nurse have always been very attentive to my personal and health care needs.</i> • <i>Prompt and caring service; they have lots of time for me; they show genuine concern for my well being.</i> • <i>Regular appointments-available to answer questions-knowledgeable-pleasant-concerned individuals-non-judgmental.</i> • <i>Regular interview & examinations; available to reach by phone. Referrals to specialists quickly.</i> • <i>The doctors I have had always been kind and caring. Also the nurses, especially Consie Campbell. I have a number I can call at anytime.</i> • <i>They keep me well informed; are understanding, and I have no problem with getting medication.</i> • <i>All questions were answered and I was well looked after.</i>
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	<p><u>General</u></p> <ul style="list-style-type: none"> • <i>Whether at home (doctors) or at clinic-wonderful.</i> • <i>Great people in Clinic</i> • <i>I am very fortunate to have a great family physician, psychiatrist and nurses.</i> • <i>I have an excellent doctor.</i> • <i>[I live in] a special care home Halifax. Dr. Dow's treatment great.</i> • <i>The Doctor and nurses are the best I have ever met. Just great.</i> • <i>The doctors and nurses are excellent to me on my visits for check-ups.</i> • <i>They all have been very understanding and very helpful.</i> • <i>They are kind and caring people.</i> • <i>They care...they try.</i> • <i>Very informative.</i>
"Good"	<p><u>Need for Increased Access to Care and Information</u></p> <ul style="list-style-type: none"> • <i>The visit at the hospital was good except not enough staff.</i> • <i>I feel that a lot more could be done if we had more people to take care of persons with HIV/AIDS.</i> • <i>ID specialist too overworked. His attitude is deteriorating.</i> • <i>Clinic workers are reluctant to give information on drug side effects even when asked.</i> • <i>They don't tell you what to expect. It's like a need to know basis-this should change.</i> • <i>Had difficulty finding doctors that knew and understood HIV. Great doctors I have now!</i> • <i>Issues around poor communication, poor "team" approach to my care</i> • <i>First off, I had a poor GP. Not able to talk with anyone who could help me understand how this would affect me.</i> • <i>Not all doctors are aware of HIV. It's sometimes necessary to go to a walk-in clinic (& not family Dr.)</i> • <i>A number of caregivers are scared to contract the disease from patients. Therefore, they don't check us properly.</i> • <i>Got a positive diagnosis of KS/later changed and wasn't notified until about a year after!!</i> <p><u>General</u></p> <ul style="list-style-type: none"> • <i>Family doctor-very good. Clinic-average.</i> • <i>They treat me nice. I like the nurses out there.</i> • <i>My visits to clinic are infrequent and therefore I'll save "excellent" for a future survey.</i> • <i>Had some trouble with my Gynecologist- changed doctors. Overall-fairly good.</i> <p><u>Miscellaneous</u></p> <ul style="list-style-type: none"> • <i>Ontario has better care given when told one is HIV upon entering Emergency Room and are more thorough. The doctors and caregivers are pretty good (must say).</i> • <i>Distance is a factor in my case.</i>
"Average"	<p><u>Various</u></p> <ul style="list-style-type: none"> • <i>I worry sometimes about the long periods between clinic visits.</i> • <i>In relation to physical care, the nurses etc. treat the disease not the patient. Since I'm not particularly needy, I don't avail many of the services.</i> • <i>Moved from Vancouver in July 1999. Rural care (Cape Breton) is poor, long way to Halifax</i> • <i>Not educated enough.</i> • <i>Not enough people there to help you.</i> • <i>Nurses overburdened with work; things not explained well.</i> • <i>Very positive with HIV team & medical specialists. Some negative experiences re. hospitalizations.</i>
"Poor"	<p><u>Various</u></p> <ul style="list-style-type: none"> • <i>I had a drug-induced seizure and had to fly to Toronto for that diagnosis/staff very ignorant of HIV illness.</i> • <i>Very impersonal, bordering on cold. Felt like a unit, not a human.</i> • <i>In the past year I feel I have been reduced to no more than an object for medical students to prod, study and humiliate. Care was better and more personal 10 years ago.</i> • <i>My first doctor was judgemental! Presently I have an honorable and outstanding doctor!</i>

2.3 HIV/AIDS and Palliative Care

2.3.1 Attitudes Related to HIV/AIDS and Palliative Care. Several items were designed to gain a greater understanding of participants' views toward HIV/AIDS and palliative care, within the context of combination therapy and the enhanced wellness/survival of many persons living with HIV/AIDS. To ensure consistency in individuals' interpretation of the term "palliative care", the following definitions and descriptions were provided:

Palliative Care has been described as "... aimed at relief of suffering and improving the quality of life for persons who are living with or dying from advanced illness or are bereaved."

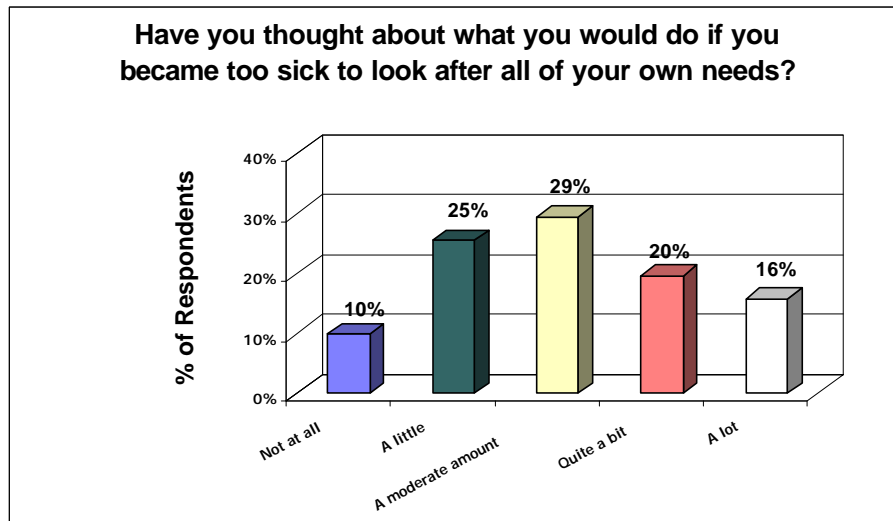
With improvements in HIV/AIDS therapies over the past few years, many persons living with HIV/AIDS are feeling healthy and surviving long-term with HIV-infection.

"HIV/AIDS palliative care is not viewed as an approach in the final stage of illness but an integral aspect of care which begins early and becomes increasingly important as the disease progresses."

Participants were asked to indicate to what extent they had thought about what they would do in the event that they became too ill to look after all of their own needs. As shown in Figure 10, responses varied considerably, although the vast majority (90%) had given at least some thought to the issue. On average, participants had given "a moderate amount" of thought to what they would do in the event of illness ($M = 3.1$; $SD = 1.2$, on a 5-point scale).

The results also indicate that combination therapy has impacted on the HIV/AIDS-related palliative care views of many PLWHIV/AIDS. That is, more than one-half (51%) of individuals diagnosed prior to the availability of combination therapy indicated that their thinking about HIV/AIDS and palliative care had since changed. As highlighted in Table 6, the majority of individuals who reported that their thinking had changed commented on their improved health status and the fact that they no longer perceived palliative care as a priority or current need. In contrast, those who did not report a change in thinking about palliative care indicated that they either had never given palliative care much thought in the first place, or continued to see it as relevant because they perceived limitations in the long-term efficacy of combination therapy. A few participants also commented that their thinking about palliative care had not changed since they had not responded well to treatment.

Views toward palliative care were further assessed by asking individuals whether they felt that the issues of HIV/AIDS and Palliative Care applied to them. In total, close to two-thirds (61%) of all respondents indicated that such issues applied. The results indicate, however, that a significant number of persons living with HIV/AIDS perceive palliative care as an approach to be used in the final stage of illness, rather than as an integral aspect of care throughout HIV disease. For instance, more than one-third (35%) of persons living with HIV/AIDS indicated that the issues of HIV/AIDS and palliative care were not applicable to them because they were not living with advanced HIV disease.

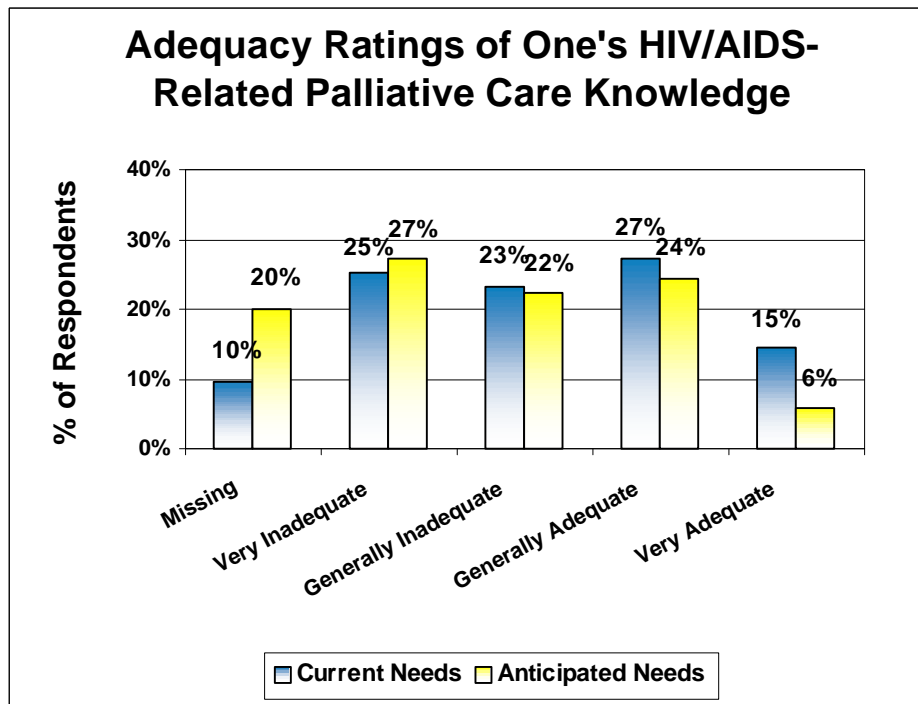
Figure 10**Table 6. Change in Thinking about Palliative Care Since the Arrival of Combination Therapy (n = 45)**

"Yes"	<p><u>Palliative Care No Longer Seen as a Priority/Current Need</u></p> <ul style="list-style-type: none"> • <i>Because I have been healthy since combination therapy. I don't think about what I would do if I got sick anymore; before I did.</i> • <i>Because I have remained in relatively good health for many years, I have remained complacent and do not feel rushed to make plans for palliative care.</i> • <i>Palliative care is most important to people with advanced HIV/AIDS.</i> • <i>I now see palliative care as further off in the future.</i> • <i>I see less need for care due to the success of the new therapies.</i> • <i>I was really sick and needed palliative care when first diagnosed. Now with the PI's, I am much stronger and can care for myself.</i> • <i>I feel it will be longer before I will need 24-hour care.</i> • <i>Not as immediate a need.</i> • <i>I will only wonder about it whenever I do get sick, but that's not for a while, I hope?</i> • <i>Not as pressing a concern with better treatment.</i> • <i>Possibility of living independently, longer deferral of thinking of Q-15.</i> <p><u>General Comments Regarding Improved Health/Hope</u></p> <ul style="list-style-type: none"> • <i>My first experience with medication was with AZT and I found I could not tolerate it at all. Protease Inhibitors have led to a dramatic improvement in my health.</i> • <i>Living better, longer, more activity, not so concerned about dying, etc.</i> • <i>I believe combination therapy has greatly improved my health.</i> • <i>I feel that, because of combination therapy, my quality and length of life is very much improved.</i> • <i>I feel that with the new drugs, a lot of people are living longer and this gives me hope for the future.</i> • <i>Felt I would need the care much sooner.</i> • <i>I'm able to live on my own.</i> • <i>It has changed because of all the new drugs that have been developed.</i> • <i>Oui, je vis d'espoir. [Yes, I am living with hope]-translation.</i> • <i>Paradigm shift from helping people die comfortably to helping people live comfortably.</i> • <i>Because I am getting better, not sicker.</i>
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	<p><u>Miscellaneous</u></p> <ul style="list-style-type: none"> • <i>Realize the side effects/symptoms are going to cause long-term care needs at some point.</i> • <i>The possibility of a longer, healthier life has made me be more concerned with my long-term financial health.</i> • <i>I have a longer life span expectation and yet know I will deal with a long slow decline instead of a rapid one.</i> • <i>Visited Casey House in Toronto and have become more aware of palliative care and won't have someone to look after me so I'm more concerned about it.</i> • <i>Yes because I have travelled somewhat and seen many different HIV palliative care/hospice programs.</i>
"No"	<p><u>Have Never Given Palliative Care Much Thought</u></p> <ul style="list-style-type: none"> • <i>I haven't thought about palliative care because I don't know much about it.</i> • <i>Never heard of it.</i> • <i>Never need any.</i> • <i>Don't think about it.</i> • <i>Not enough knowledge-information available to making any kind of a decision.</i> • <i>I have not ever considered palliative care as an option.</i> • <i>I was lucky enough to stay so healthy that I did not consider the need for palliative care.</i> • <i>Try not to think about it.</i> • <i>Well read of info on being well</i> • <i>Have not given it much thought.</i> <p><u>Perceived Limitations of Combination Therapy</u></p> <ul style="list-style-type: none"> • <i>As part of my reality, I have long accepted this virus as incurable and far from chronic but manageable. To the best of my knowledge, AIDS will still be killing me. Not without a fight though.</i> • <i>Recently, I have little faith in combo therapy.</i> • <i>Combination therapy is not a cure. It merely prolongs the inevitable.</i> • <i>Have tried four therapies without success.</i> • <i>I don't see how the care would change. The length of time before I require such care has changed.</i> • <i>I realize I still need to make some long-term plans.</i> <p><u>Miscellaneous</u></p> <ul style="list-style-type: none"> • <i>I worry about lack of support from the Government (disability etc.).</i>

2.3.2 HIV/AIDS and Palliative Care-Related Knowledge. The results indicate that close to two-thirds (63%) of PLWHIV/AIDS in the Atlantic Region have not received any information about HIV/AIDS and palliative care. Of the minority of respondents who had received related information, the two most commonly cited sources were AIDS Service Organizations (50%) and HIV/AIDS Clinics (24%). Not surprisingly, when asked to rate their overall level of knowledge about HIV/AIDS and palliative care, 28% reported knowing “nothing at all”, while fewer than 8% of participants reported knowing “a lot”.

The need for HIV/AIDS and palliative care education is further highlighted in Figure 11, which presents the results of a question asking participants to describe the adequacy of their HIV/AIDS and palliative care knowledge in relation to both their current and anticipated needs. As shown, less than one-half rated their knowledge as “generally” (27%) or “very” (15%) adequate in terms of their current needs, and less than one-third rated their knowledge as “generally” (24%) or “very” (6%) adequate in terms of their anticipated needs.

Figure 11

2.3.3 Comfort Level and Fears. Participants were also asked about their comfort level and fears related to HIV/AIDS and palliative care. Results point to a substantial amount of discomfort and fear surrounding HIV/AIDS and palliative care. For instance, more than one-third (36%) of participants reported that they were either “very uncomfortable” or “generally uncomfortable with HIV/AIDS and palliative care issues, and 41% reported related fears. Individuals indicating such fears were asked to explain their response. As outlined in Table 7, the qualitative analyses of these open-end responses revealed that the majority of fears are related to concerns about the availability/accessibility of adequate palliative care services and/or the loss of control/independence.

2.3.4 Sources of HIV-Related Information, Support and Care. Figure 12 illustrates the organizations from which participants had ever received information, support or services related to their HIV-related care or needs. While 69% cited at least one source, close to one-third of the entire sample reported never having had such contact with any of the organizations/programs listed. As shown, AIDS Service Organizations were by far the most commonly cited sources of HIV-related information and support (58%). In contrast, very few participants (i.e., 1% - 6%) had received related services from any of the other potential providers, including: Hospital-based Palliative Care Programs; Home Health Care Services/Agencies; Provincial Palliative Care or Home Care Associations; Local Hospice Palliative Care Programs; the Canadian Palliative Care Association; or the National Home Care Association.

Although the results indicate that persons living with HIV/AIDS are currently relying on few outside sources of HIV-related information and support, the data also underscore the importance of partners, family members,

Table 7. Fears About HIV/AIDS and Palliative Care (n =34)**Availability/Accessibility of Palliative Care Services**

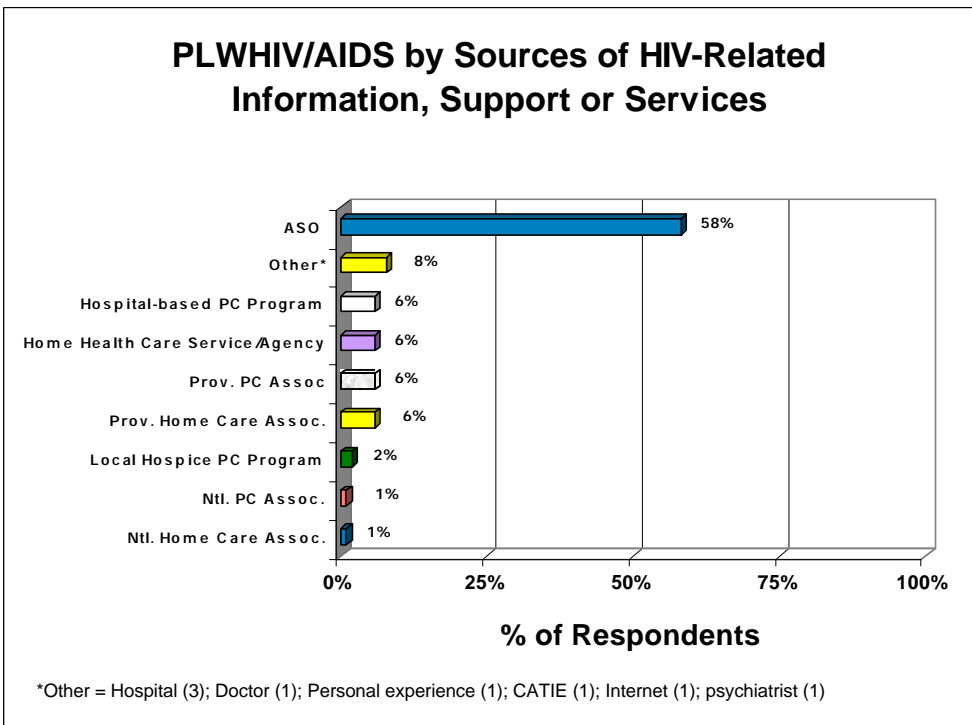
- *There aren't enough facilities for people in the final stages.*
- *Availability and confidentiality in a rural area.*
- *Services are not readily available in my area!*
- *Knowledgeable caregivers.*
- *A lot here living in Newfoundland. There is nothing in place for PHA's from province.*
- *Most of the time, I worry about whether I will really be taken care of when I get too ill to care for myself.*
- *Good care.*
- *My ASO (ACNS) is unable to provide such care (funding; human resources).*
- *Family on West Coast; few friends here.*
- *Fear the government may stop paying for my medications.*
- *If it will be there when I need it.*
- *Currently no, but concerned that care may diminish.*
- *I fear that NS does not have a good care program.*

Loss of Control/Independence

- *Loss of independence to "the system".*
- *I am very independent and fear being in a position to be cared for.*
- *I find that one is expected to go along with the doctor's decision without discussion or patient input.*
- *Freedom, working, dignity.*
- *Respect and dignity.*
- *Being included in decisions regarding my care.*
- *Fear of not being in control of my life.*
- *Being judged by health care professionals and the right/the need to die in dignity!*
- *I am concerned as to my loss of mobility and ability to care for myself.*

Miscellaneous

- *Just the concern wondering where the funds are going to come from.*
- *The pressure and care would be put on family and friends.*
- *Of course.*
- *What do you think?*
- *I don't know much about it.*
- *Being from a small town and confidentiality.*
- *The term "Palliative Care" seems so Final.*
- *Need to know as an individual how the system would work for me.*
- *When I hear palliative care, I think of death.*
- *Spent a lot of time with friends in palliative care.*
- *How much burden I will be.*
- *In general, reaching that level of HIV/AIDS when I would need care.*

Figure 12

and friends in terms of current and potential care needs. For instance, participants were asked to rate the overall level of support and care they had received to date from their loved-ones in helping them deal with HIV/AIDS. A total of 71% of all PLWHIV/AIDS rated the support as excellent (43%) or “good” (28%). In contrast, only 4% rated the support in the “poor” to “very poor” range. An additional 10% felt the support they had received was moderate, while 14% indicated that the question was not applicable since their loved-one(s) were not aware of their HIV/AIDS diagnosis.

As shown in Figure 13, the majority of persons living with HIV/AIDS also anticipate a high level of involvement from their loved-ones should they ever need assistance or basic care due to HIV-related illness. For instance, 63% of all PLWHIV/AIDS indicated that their loved-one(s) would be “very much” or “quite” involved, and an additional 18% said that their loved-one(s) would at least be “a little” or “moderately” involved. Respondents anticipated that a number of their loved-ones would be involved in their HIV-related care, most commonly including their: friends (48%), parents (45%), and partner/spouse (42%). “Other family members” were also commonly cited as caregivers (48%), and 12% indicated that their child/children would be involved. A total of 10 individuals (10%) felt that they would have no loved-one(s) involved in their HIV-related care.

2.3.5 Perceived Usefulness of Various Health Care Settings. Figure 14 depicts the results of a question asking participants to indicate which health care settings would potentially be of use to them in the event that they needed assistance or nursing care but did not need to be hospitalized. The data clearly highlight the preference individuals have for receiving health care in their own homes (e.g., visiting nurse,

paid caregivers). That is, almost all PLWHIV/AIDS (94%) indicated that home health care would be useful to them if they ever needed assistance or nursing care. A smaller but substantial proportion (39%) of individuals also perceive an HIV/AIDS special care home or hospice as potentially useful alternatives to hospitalization. It should be noted that neither of these options is currently available in the Atlantic Region. Other alternative health care settings - i.e., non HIV-specific special care home/hospice (19%) and nursing home (9%) - were less frequently cited as potentially helpful environments. In addition to being perceived as a potentially useful alternative to hospitalization, home health care was also ranked as the first choice by 90% of PLWHIV/AIDS. In contrast, an HIV/AIDS special care home/hospice was rated as the preferred alternative to hospitalization by only 8% of participants.

A separate item asked individuals whether they would ever consider living in a hospice/special care home for persons with AIDS. A total of 45% of all individuals reported that they would never consider such an option, and 23% indicated that they would possibly consider it. As evident in Table 8, the most commonly cited reasons against ever considering this setting were related to the desire/preference to stay at home and to be close to loved-ones. A number of participants also indicated intentions toward suicide/euthanasia in the event of advanced illness necessitating hospice/special care home services. Several others noted that this type of setting was not a consideration for them, given their discomfort around the illness of others. As also shown in Table 8, the majority of individuals who indicated that they would possibly consider this option explained that their decision would be based on a variety of circumstances (e.g., finances, lack of informal caregivers, state of health, qualifications of the facility). A few others emphasized that they would consider a hospice/special care facility only as a last resort.

Figure 13

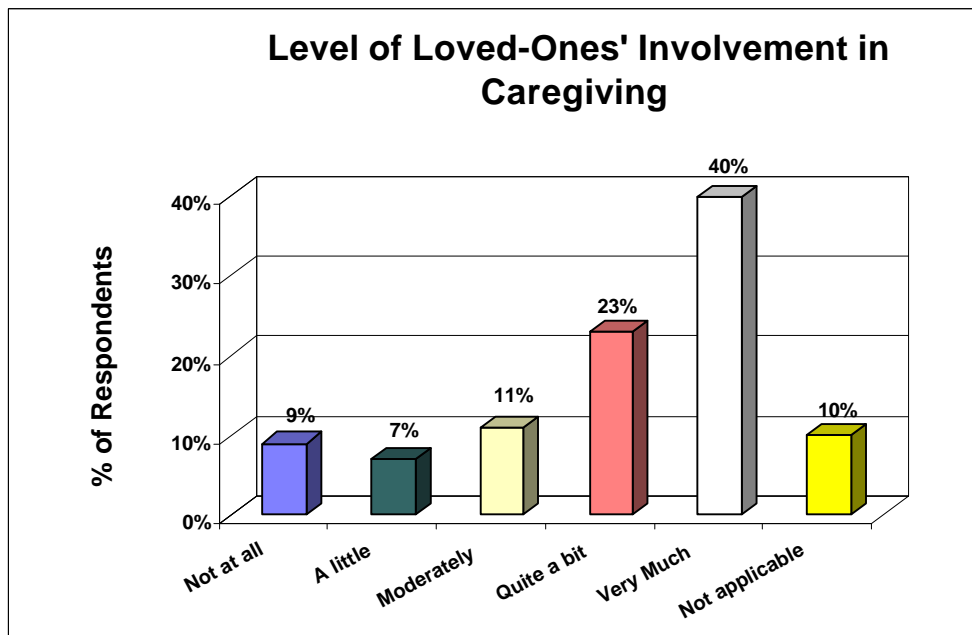
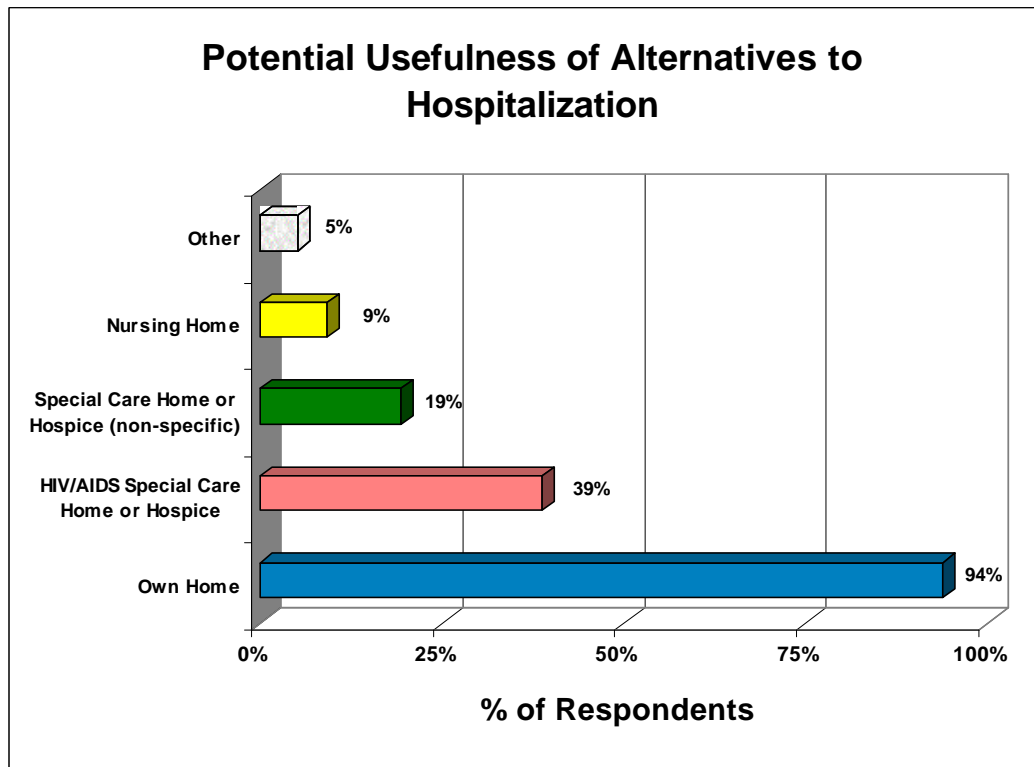


Figure 14**Table 8. Reasons Against Considering a Hospice/Special Care Home**! **Desire/Preference to Stay at Home (18)**

- e.g., *"I am more comfortable at home."*
"I would like to stay at home with loved ones/pets"
"I do not wish to live away from husband and child."
"I rather be taken care of in my own home."
"My wife and family would want to care for me at home."
"No, I wish to die in my own home."

! **Would Consider Suicide/Euthanasia If Hospice/Special Care Home Services Required (7)**

- e.g., *"Advanced to that degree, suicide is option I'd take first."*
"If I'm that sick, it's time to die."
"If it comes to that, I don't think I want to continue with living."
"If it ever appears that I'll be unable to care for myself, I'll end everything."
"If my health is that poor I believe that I would take my life. Being in that position is not a quality of life."
"When my ability for independence is gone to that point, I believe in euthanasia not wanting to be a burden."

! **Discomfort Around Others' Illness (5)**

- e.g., *"It would be difficult if I were ill to see other people every day in a much more advanced stage of illness".*
"Too "needy" a group."
"I would not want to see people suffer."

<p>! <u>Miscellaneous (8)</u></p> <p>e.g., <i>“I don't care to even consider the situation arising. At this point, I am independent.”</i> <i>“I have enough people in my life. I don't think I would have to worry about it.”</i> <i>“Uncomfortable around too much illness, sickness and depressed people. I'm a very private person, always have been.”</i> <i>“Nothing available here.”</i> <i>“Would be totally uncomfortable for numerous reasons!!!”</i></p>
<p>! <u>Might Consider, Depending on Circumstances (12)</u></p> <p>e.g., <i>“As long as my parents are alive, I don't need a hospice.”</i> <i>“Depending on how ill I was and circumstances.”</i> <i>“Depending on several factors, close to friends and certain family members, distance for them to travel, visit, etc.”</i> <i>“Depends on reputation and knowledge of persons involved.”</i> <i>“I'm not sure at this time in my life so I can't give a final answer. If my family and home care wasn't enough or I was a burden on my family, I would consider it. It wouldn't be my 1st choice.”</i> <i>“If financially unable to meet my own needs.”</i> <i>“If there was no one around at the time (i.e., no partner/friends).”</i> <i>“If I get too ill for my family to take care of me I would want them to place me somewhere where they have the training/knowledge.”</i> <i>“Only if I couldn't get someone in to help out every so often.”</i></p> <p>! <u>Might Consider, But Only as a Last Resort (3)</u></p> <p><i>“Only as a last resort.”</i> <i>“Respectfully, I would hope to avoid if possible.”</i> <i>“Last resort. Only if I had no other option and would be very sick. I would tend to consider this a <mouvoir>.”</i></p>

2.4 Experiences and Feelings

Participants were asked to rate on a 4-point scale, ranging from 1 (not at all) to 4 (a lot), the extent to which they were facing each of 10 different experiences or feelings. Figure 15 depicts the percentage of individuals who indicated that they were currently experiencing a given challenge/positive situation on a scale encompassing the ratings “a little” through to “a lot”. This figure does not reflect the intensity of particular experiences; however, it does provide insight into their prevalence. For instance, 8/10 experiences or feelings were being faced to some extent by 55%-85% of all respondents. While certain challenges are evident, the findings also underscore some positive experiences. That is, the two most commonly cited experiences were “feeling loved and supported by family and friends” and “feeling that my life has quality and meaning”. In terms of challenges, the findings highlight the prevalence of: Emotional/ psychological difficulties; feelings of being alone/isolated; HIV/AIDS-related symptoms; lack of accessible HIV/AIDS services; lack of accessible home care/palliative care services; and, physical pain/discomfort (i.e., all cited by 55%-74% of all respondents).

The intensity of these various experiences is presented in Table 9 in terms of means ratings, as well as in the percentage of PLWHIV/AIDS who provided ratings of 3 (“Quite a bit”) or 4 (“A lot”). Mean ratings ranged from a low of 1.4 (i.e., professionals unwilling to provide HIV/AIDS care) to a high of 2.9 (i.e., feeling loved and supported by family/friends). As shown, several challenges were being faced with relative intensity by more than one-quarter to almost two-thirds of all PLWHIV/AIDS: HIV-related symptoms; lack of home care/palliative care services; emotional/psychological difficulties; as well as, feeling alone/isolated. Despite

these challenges, approximately two-thirds of all participants also rated the positive feelings with relatively intensity - i.e., “my life has quality/meaning” and “feeling loved and supported by family/friends”.

Figure 15

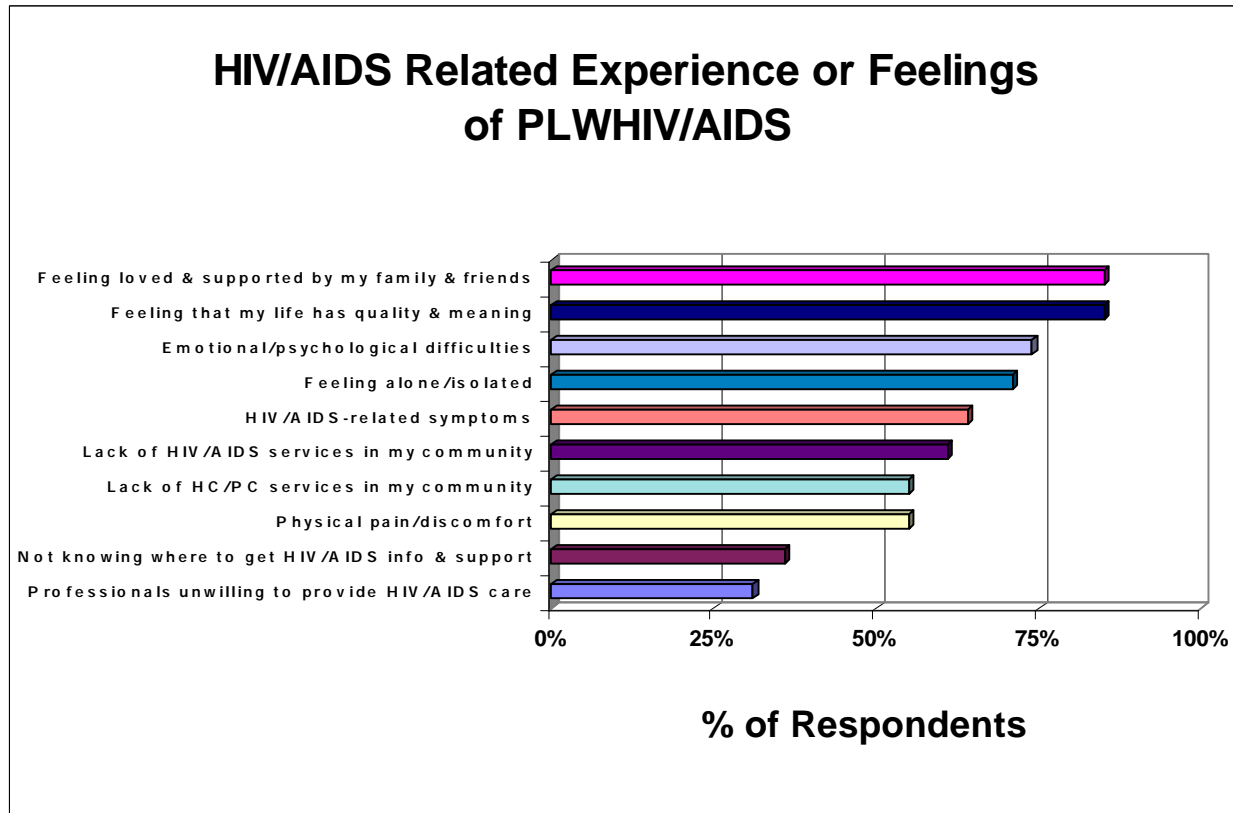


Table 9. HIV/AIDS Experiences and Feelings of Persons Living with HIV/AIDS

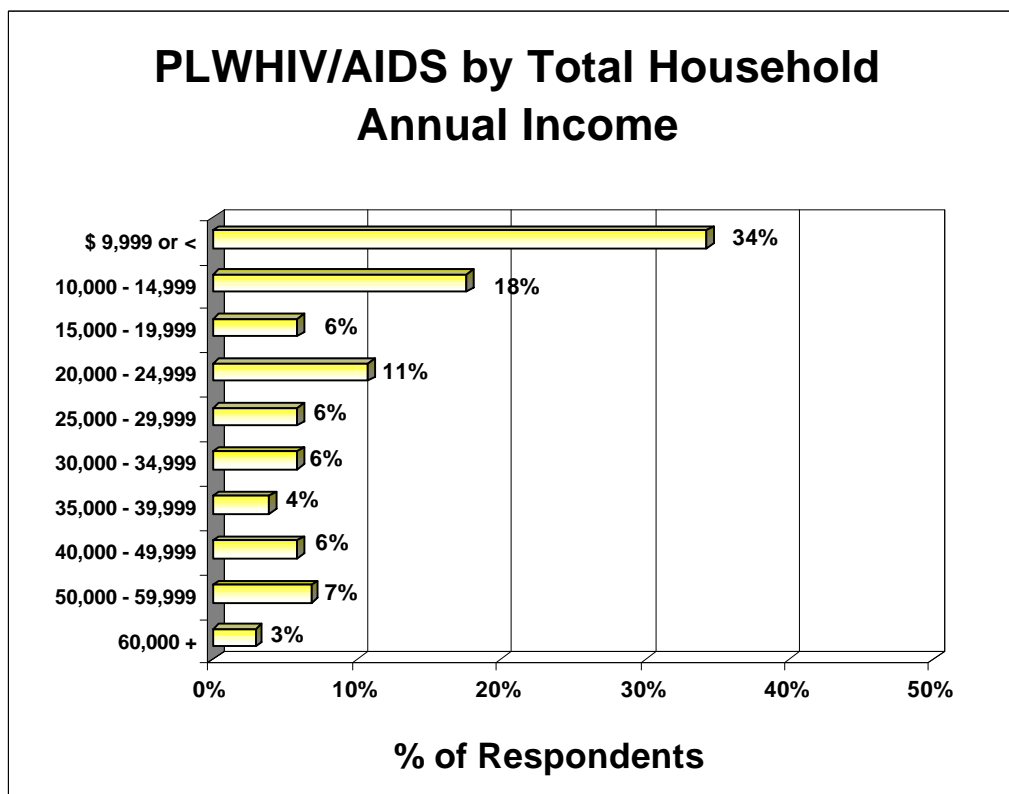
	Mean ratings	% Reporting 3 or 4
Professionals unwilling to provide me with HIV/AIDS care	1.4	10%
Not knowing where to get HIV-related information & support	1.5	15%
Physical pain/discomfort	1.8	21%
HIV/AIDS-related symptoms	1.9	29%
Lack of home care/palliative care services in my community	2	34%
Lack of HIV/AIDS services in my community	2.1	21%
Emotional/psychological difficulties	2.3	41%
Feeling alone/isolated	2.3	41%
Feeling that my life has quality and meaning	2.7	60%
Feeling loved and support by my family and friends	2.9	63%

2.5 Information and Support Services/Needs

2.5.1 Employment and Financial Situation. Since an individual's financial situation can impact significantly on the HIV-related care and services that can be accessed, several items were designed to assess the employment and financial status of PLWHIV/AIDS. While a diversity of employment situations were represented by participants, more than one-half reported that they were disabled (51%). The next two most frequently cited employment situations were "working with full-time salary" and "volunteer work", reported by 21% and 12% of participants, respectively. Other employment scenarios (e.g., self-employed, student, unemployed, part-time salary, full-time homemaker, and retired) were cited by only 2%-9% of all participants

The data underscore substantial financial need among the sample of persons living with HIV/AIDS. First, as shown in Figure 16, more than one-third of participants reported total annual household incomes (i.e., from all sources and before deductions) of less than \$10,000. Second, the median household income fell within the category encompassing \$10,000 - \$14,999, revealing that only one-half of the PLWHIV/AIDS households had incomes above \$15,000. All incomes were supporting a range of one through four individuals ($M = 1.3$).

Figure 16

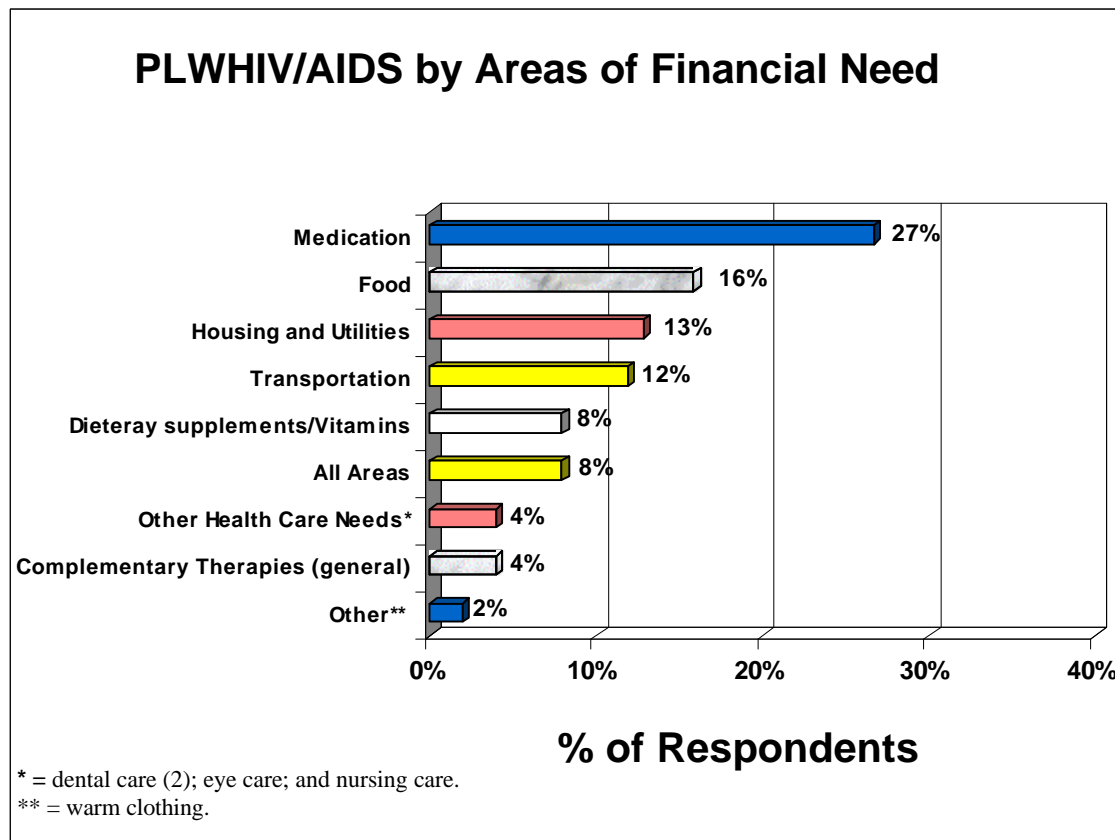


Clearly, a substantial proportion of PLWHIV/AIDS in Atlantic Canada are living below the poverty line. According to data published by Statistics Canada¹, the low-income cut-off in 1997 for a single person household in the Atlantic Region approximated \$12,000 - \$15,000, while that for a two-person household was approximately \$15,000 - \$19,000 (i.e., based on the size of the community in which one resides).

The majority of individuals (61%) responded that they were currently experiencing financial difficulties meeting their HIV/AIDS-related care needs. Qualitative analyses of the open-ended question asking participants to indicate the areas in which they currently needed financial assistance revealed a need in a variety of domains, most commonly including: medication/drug costs (27%), food (16%), housing and utilities (13%), as well as transportation (12%). A substantial proportion of PLWHIV/AIDS (12%) also mentioned a need for dietary supplements, vitamins, and other complementary therapies. A total 8% of the entire sample stated that they needed help in all areas (see Figure 17). As stated by one participant:

“Given that after I pay for housing and utilities, I have only \$300 per month to cover food, clothes, maintain my vehicle and cover all other expenses, I could use help in a number of areas.”

Figure 17



¹ Statistics Canada (1999). *Income Distribution by Size in Canada, 1997*. Cat. No. 13-207-XPB, April 1999.

2.5.2 HIV-Related Service Utilization. This section asked respondents to indicate which of 16 services they: (1) Were currently using; and (2) Were not currently using but anticipated needing or using in the future. As shown in Table 10, the vast majority (83%) of all PLWHIV/AIDS were currently using antiretroviral therapies. Other most commonly utilized services included: prophylactic medications; AIDS Service Organizations; complementary/alternative therapies; and financial assistance (i.e., cited by 40%-53% of all respondents). None of the other services were reported by more than one-quarter of participants.

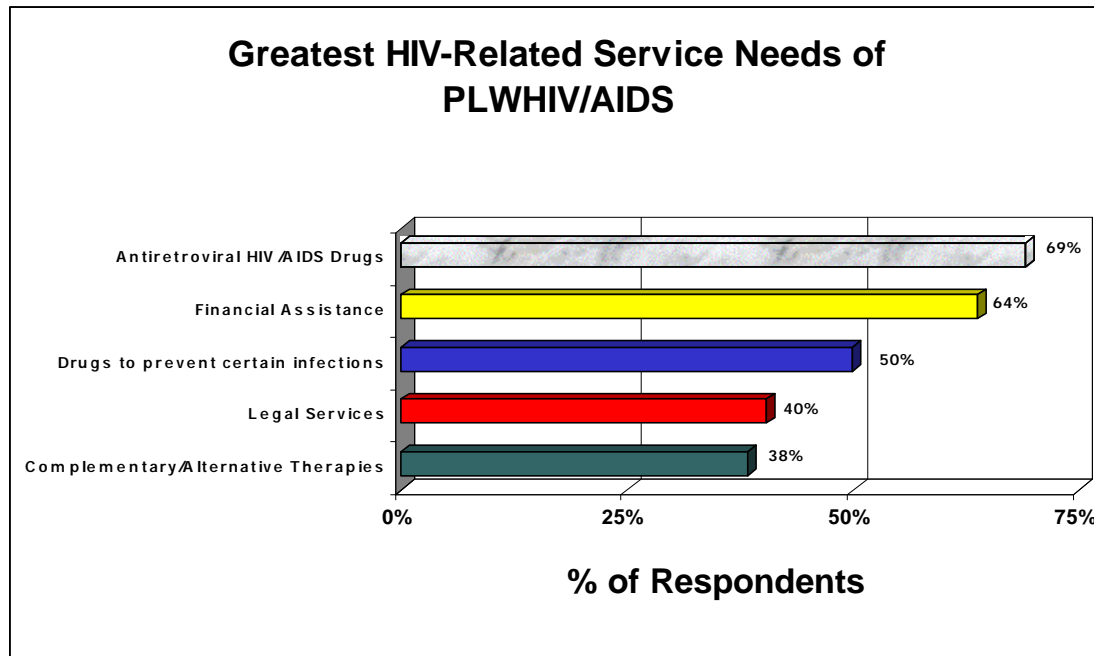
A significant percentage of respondents indicated that there were various HIV-related services that they were not currently using but may use or need in the future. In fact, two-thirds or more of all participants indicated that they anticipated needing or using six of the services listed: Home health care (77%); volunteer support (73%); homemaker/home support (69%); transportation services (68%); other alternatives to hospitalization (67%); and legal services (66%). Although less frequently cited, it is important to note that the remaining services - with the exception of addiction treatment/counselling - were identified as potential future needs by approximately 37% - 58% of individuals.

Participants were also asked to indicate their five greatest current HIV-related service needs. These data are presented in Figure 18. Only items that were ranked in the top five by more than one-quarter of all participants are listed. As shown, antiretroviral drugs, financial assistance, prophylactic medications, legal services, and complementary/alternative therapies were most commonly cited by PLWHIV/AIDS (i.e., 38%-69%) as the services they most needed/needed more of .

Table 10. HIV/AIDS-Related Service Utilization (PLWHIV/AIDS)

	Currently Using	Not Currently Using But May Use/Need in Future
Antiretroviral HIV/AIDS Drugs	83%	17%
Drugs to prevent certain infections	53%	47%
ASO	47%	37%
Complementary/Alternative Therapies	46%	44%
Financial Assistance	40%	50%
Nutritional Counselling	25%	53%
Emotional/Psychological Counselling	24%	59%
HIV/AIDS Peer Support	20%	54%
Transportation Services	13%	68%
Spiritual/Pastoral Support	13%	58%
Homemaker/Home Support	10%	69%
Legal Services	9%	66%
Home Health Care	6%	77%
Addiction Treatment/Counselling	5%	15%
Volunteer Support	4%	73%
Other	2%	7%
Other Alternatives to Hospitalization	1%	67%

Figure 18



2.5.3 HIV-Related Information Needs. A total of 80% of all participants indicated that they were interested in receiving some or more information about HIV/AIDS and Palliative Care. On the basis of the list discussed above (i.e., Section 2.5.2), they were asked to rank order the five services about which they most needed additional information. The results pertaining to participants' greatest informational needs are presented in Figure 19. Again, only the services which received top five rankings by a minimum of one-quarter of participants are listed. As shown, information on financial assistance was most commonly cited (53%). However, one-quarter to more than two-thirds of all participants also reported a highly ranked need for information pertaining to: complementary/alternative therapies, home health care, emotional/psychological counselling, other alternatives to hospitalization, antiretroviral HIV/AIDS drugs, legal services, homemaker/ home support, and prophylactic medications.

To determine which strategies would be most useful in meeting the informational needs of persons living with HIV/AIDS, participants were asked to rank order their top three choices out of a possible 11 educational approaches. As illustrated in Figure 20, written materials, consultations with experienced Palliative Care providers, local workshops and self-help discussion groups received the highest ratings, and were ranked as top choices by 33%-55% of all PLWHIV/AIDS. Provincial workshops and consultations with experienced home care providers also received relatively high rankings by approximately one-quarter of the sample, whereas the other possible approaches (i.e., Atlantic Regional Workshop, audiovisual materials, consultations with AIDS organizations) were selected by only 13%-16% of all participants. The vast majority (94%) of the respondents cited English as their preferred language for receiving information, 5% reported being equally comfortable in English and French, while 1% indicated French as a preference.

Figure 19

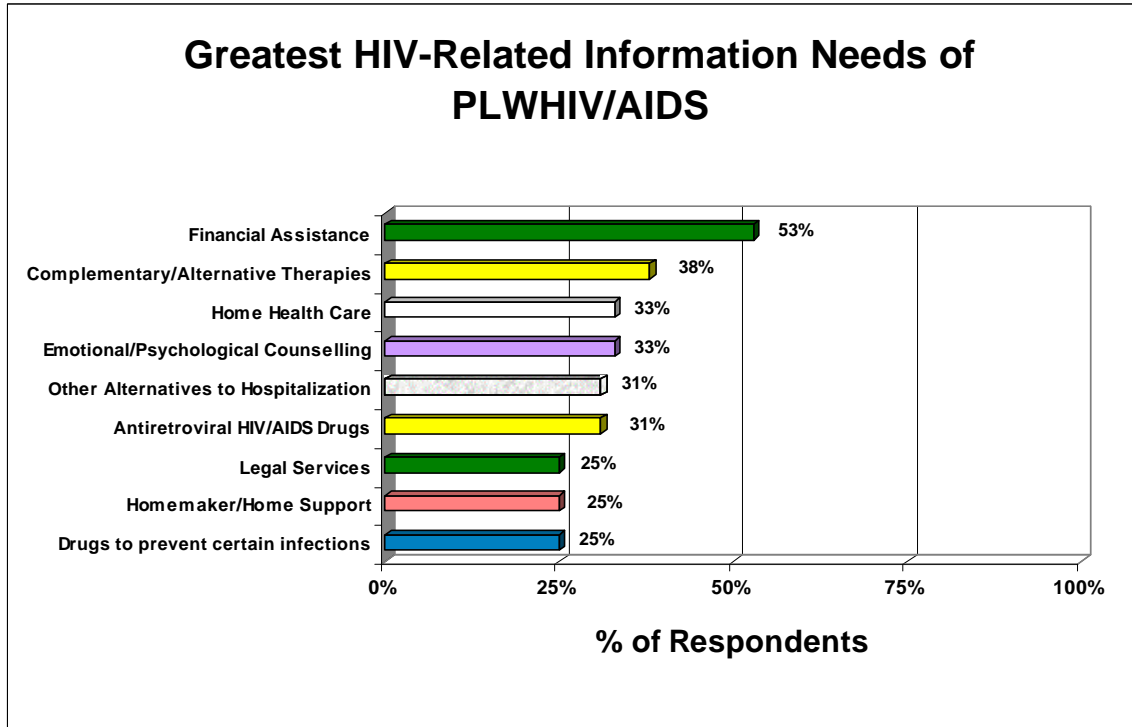
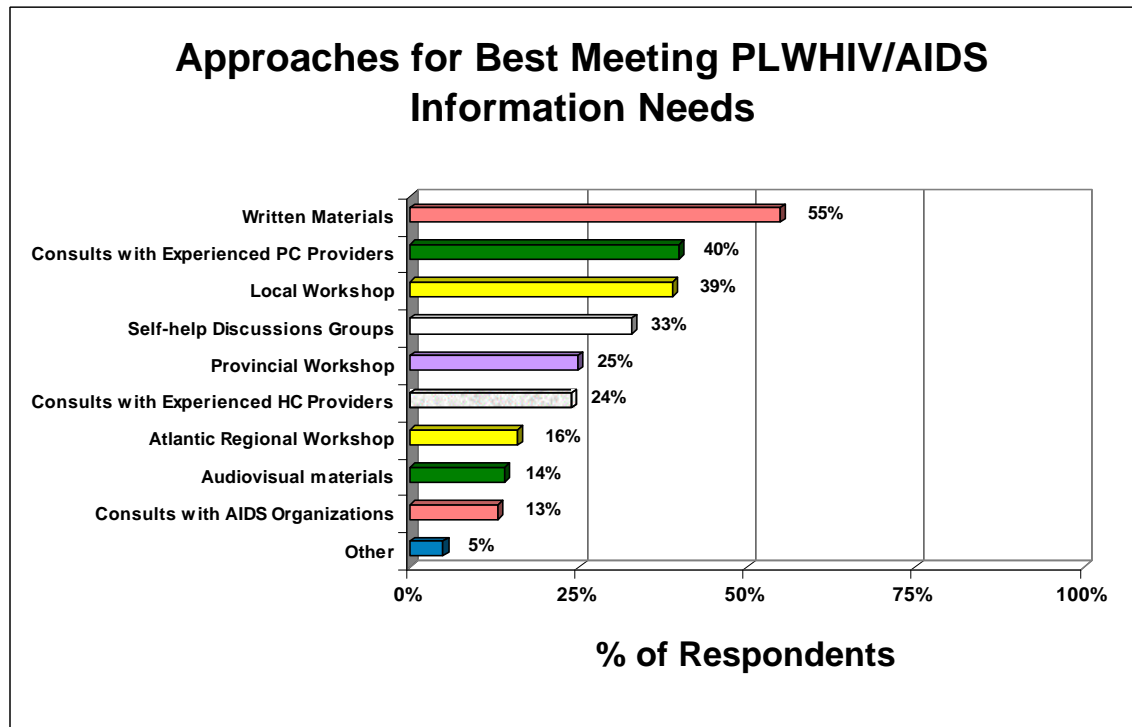


Figure 20



2.6 Additional Comments

A total of 39 persons living with HIV/AIDS (38%) responded to the open-ended question asking them whether they had any additional comments about any aspect of the survey. Table 11 presents a verbatim sample of the additional comments and attempts to capture the essence of the many invaluable messages made by persons living with HIV/AIDS. As shown, the most commonly mentioned comments related to the lack of HIV/AIDS-related services (e.g., medical, psychosocial, financial, palliative care, home care) in many areas of the Atlantic Region. Several individuals also took the opportunity to share additional thoughts regarding palliative care (e.g., fears, concerns, impact of protease inhibitors, euthanasia), while others provided specific feedback about the contents of the questionnaire. Issues that arose rarely and could not be classified under one of the four main themes are listed in the “miscellaneous” category.

Table 11. Additional Comments - Persons Living with HIV/AIDS (n=39)

! **Lack of HIV/AIDS-Related Services (11)**

e.g., *“With the rapid deterioration of NS's health care system, the exodus of doctors and hospital closures in the last 1-2 years, I dread the thought of being in a Palliative situation here. Home care is talked about, but is almost non-existent. In this town, we once had a fully functional hospital. Now we have on-call doctors. If you're HIV+, you can't even have blood drawn here. So, I don't think I would ever be desperate enough to go into a palliative care ward in this province to hold onto life. Should ask about euthanasia. For those of us who have cared for our partners and others at the end of life (no Palliative Care available, Home Care sometimes not covered in certain situations or provided by inexperienced volunteers) we may not wish upon our friends or elderly parents the physical/emotional/monetary responsibility/burden of caring for us. I believe we should all have the right/opportunity to die in the warm cocoon of our own homes.”*

Male, Nova Scotia

“Living with this illness for the past 8 ½ years has been extremely trying. There are not many services available in industrial Cape Breton - no HIV clinic, no trained HIV specialist, no psychologist really understanding this illness. There is stigma attached to this disease; lack of funding for individuals living on a very tight budget, etc.”

Gender Unspecified, Nova Scotia

“There is absolutely very little or no support systems in the province (NF). Monies from Ottawa are used to pay for the employees of the AIDS Committee. There is no input from Provincial Government. Social Services pay \$139 bi-weekly. Not too much!”

Male, Newfoundland

“I've been sick off and on the last 10 years, but with new drugs and experimental ones, I feel better physically. But I think the biggest need is to try and retrain or introduce PLWHIV back into the work force, so we can start to feel better about ourselves, but any attempt to do so on our own puts us at risk of losing what little financial assistance and drug coverage we are receiving. If there was a way around this, so that PLWHIV are not penalized, we would feel better emotionally and mentally which would in turn give us a better "Quality" of life.”

Male, Nova Scotia

“I worry about my future and what will happen when I get sick because my parents are both deceased and the rest of my family have their own personal battles. I would feel a lot better knowing that there were other alternatives for persons with HIV and AIDS.”

Male, Nova Scotia

“I need low income housing to meet my needs. I need help (like a NB health card to cover cost of secondary drugs). I believe I will soon move from New Brunswick!”

Male, New Brunswick

“I think anyone living with HIV/AIDS should be receiving some kind of money monthly... it would help to buy extra groceries (ex. fruits & juices)”

Female, Newfoundland

“It’s tough to think about the future, especially as a mature woman who has been independent all my life. I didn’t expect to live this long. My life is pretty good by some standards. But my money has run out before my life! Financial dependence is more frightening than death. I have also cared for an infected spouse to his death - been there, done it for someone else, so I know about the scenario, but I do not have the luxury of a loving spouse to look after me. At this point, I try not to get too involved about the future, but it underpins my entire life. In the end, it would be nice to know that services etc. would be available for me but I know too well that they are not. Thanks for the survey.”

Female, Nova Scotia

! **Attitudes Toward Palliative Care (9)**

e.g., *“The whole situation is overwhelming to me, and being very healthy except for my KS makes me want to put this on the back burner. The only family member that knows is my sister. I know I’ll have to deal with it down the road, I just hope down the road is a long way.”*

Male, Nova Scotia

“With the protease inhibitors, my concerns have shifted from life’s final years to employment and financial coping with extended life span. Survival was much simpler when the expected life span was shorter. Now I have lost my LTD and been thrown out to my own resources as I no longer have a company plan.”

Male, Nova Scotia

“Having been self sufficient since the age of 18, I worry about being dependent on others. It’s difficult for me to think about palliative care at this time as this disease has not limited any of my activities or life.”

Male, New Brunswick

“We must talk about end of life issues, the right to die.”

Male, Nova Scotia

“I have very little knowledge about the subject. I don’t feel a need to think about it. I would expect to go to the hospital to die. I would feel safe with the care and pain control, etc. I would want the doctors to keep me alive as much as possible.”

Male, Nova Scotia

“I don’t know much about Palliative Care but I don’t think I’d have any trouble getting the info if I needed it. I usually don’t go looking for information and I’m not involved in any groups or anything because my HIV is secret and has been since I’ve been diagnosed. Only my parents know and a couple of very close friends but I think these surveys are good and I try to help whenever I can.”

Female, Newfoundland

“This survey has not been easy to fill out because honestly I have not given palliative care too much thought, as I do not like to think ahead to that stage of my illness, while I remain in relatively good health. I do realize this is not the best way of thinking of my future, by not thinking at all. Perhaps this will give me an awakening.”

Male, Nova Scotia

! **Comments About the Survey (9)**

e.g., *“I wish you luck with this assessment. I have been involved with others before and really haven’t seen or heard about the outcome of it. I do feel there should have been other questions asked about the children of the infected parents. Thanks!”*

Female, Nova Scotia

“Questions about need for self-induced euthanasia or assisted suicide would be useful to those who don't know the difference between morals and legalities and those who feel they may have the right to decide their own time of death.”

Male, Nova Scotia

“Why was I not asked: Are you overall: 1) happy 2) unhappy 3) comfortable 4) eating enough 5) getting any socializing 6) do you have enough \$ to live adequately? 7) Have ways to do your shopping? Get around the city? 8) Like your current environment?”

Male, New Brunswick

“Over all, a thorough survey, but there are some areas that are unclear how to answer and need more explanation. Also need an area of counselling on relationships-how to have one, to tell someone that you are HIV+ and not be shunned because you are.”

Male, Nova Scotia

! **Miscellaneous (10)**

“I lost my partner almost 1 yr. ago and feel very aware of what is currently available. I always felt (as did he) that his care was excellent! The staff at the HIV Clinic and the hospital were very good. Fortunately we also were relatively financially stable. That made an enormous difference all the way around.”

Male, Nova Scotia

“Please tell the professionals to start treating HIV/AIDS patients with some dignity. We know that the disease does not choose black, white, yellow, brown or otherwise. It is the nature we live in. Therefore, lets cope together.”

Male, Nova Scotia

“There needs to be public education on HIV/AIDS. People need not to be judged (because they're positive) or harassed in public. We have the right to be accepted as human beings!”

Male, Nova Scotia

“I feel I am being shunned by the ID Department for treatment because I want to refuse medication to lower my viral load. I don't want to take any medication except to treat infections etc. I think I should be able to still attend this clinic. My Doctor just died and my new doctor is not well versed in AIDS treatment.”

Male, Nova Scotia

“Thank you for the opportunity to express my worries. I hope palliative care information will be made available.”

Female, Nova Scotia

“At this point in time, I feel great, thanks to doctors, clinic and friends. I carry on feeling positive about life and hope for each day to be good. I teach, have lots of interest, friends, maintain a beautiful home. I feel fortunate and blessed that I can do all these things and think in a positive way about the future”.

Male, Nova Scotia

“If any workshops are to be done (I assume funding would come from NAS III) I would suggest they be done at a local/community level to foster understanding and community involvement in AIDS care.”

Female, Nova Scotia

“Many people with HIV/AIDS related diseases spend many dollars on care and expenses. Also, many people like myself spend a lot of time and money to try and cover up the disease because of fear from friends and family of their attitude towards us.”

Female, Newfoundland

3.0 FINDINGS- INFORMAL CAREGIVERS

3.1 Demographic Information

A total of 67 caregivers across the four Atlantic Provinces participated in the survey. As shown in Figure 21, an equal number of men (48%) and women (48%) were represented, while three individuals (4%) did not specify their gender. More than one-half of caregivers (57%) self-identified as heterosexual, 36% as gay men, and 4% as bisexual. Two participants chose not to respond. Caregivers ranged in age categories encompassing 25 through 65 or more years (see Figure 22). However, almost two-thirds (64%) of the sample were between 25 and 44 years of age. A total of 19 caregivers (29%) indicated that they were also living with HIV/AIDS.

As was similarly indicated by the sample of persons living with HIV/AIDS, more than one-half of caregivers (55%) were residing in a city, 28% in a town, and 16% in a village or rural area. The majority of participants identified as Caucasian (87%). Only six participants reported other ethnic/cultural groups: Aboriginal/First Nation (2); Black (1); Middle Eastern (1); Inuit (1); and “Other” (1). Two caregivers preferred not to indicate their ethnicity.

The sample reported a diversity of employment situations: Employed full-time (37%); disabled (18%); full-time homemaker (13%); employed part-time (12%); and self-employed (7%). In addition, a number of caregivers were retired, involved in volunteer work, unemployed, or students (i.e., 3% - 10%).

Figure 21

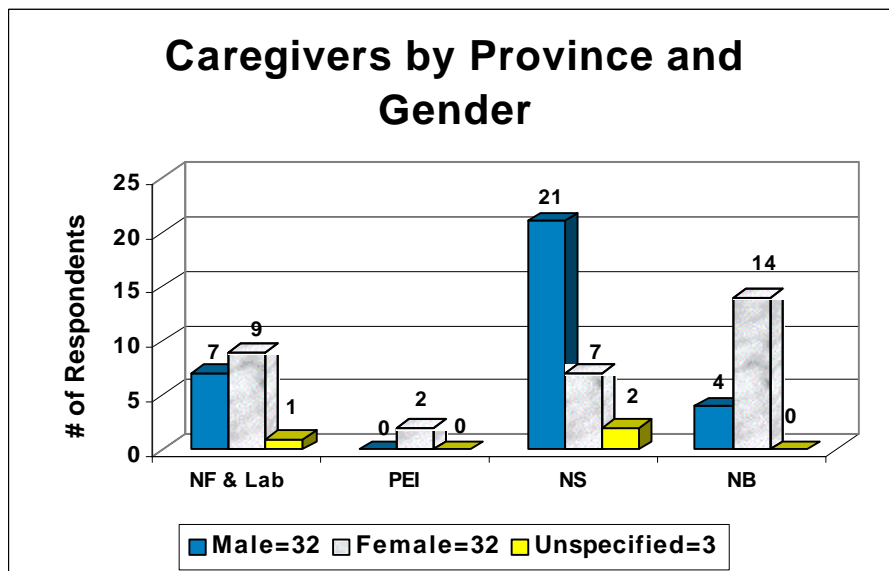
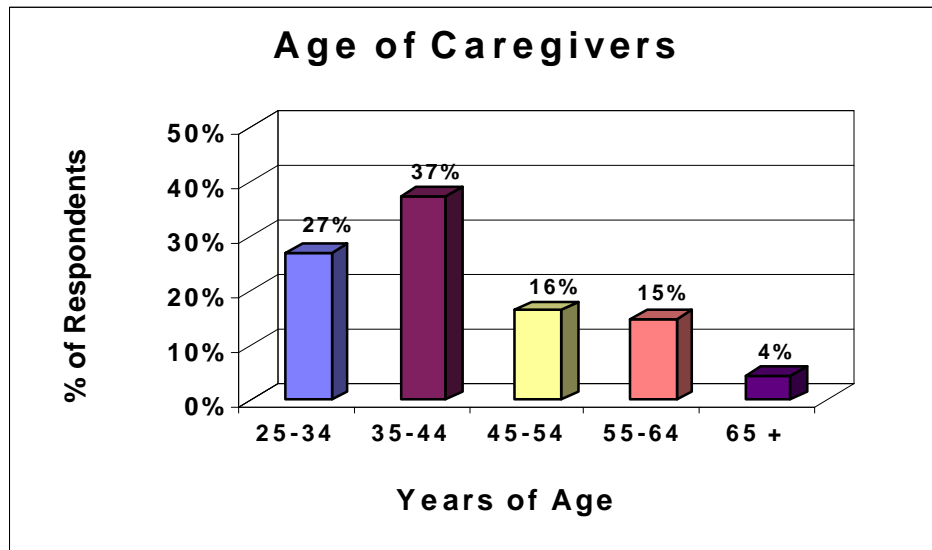


Figure 22

3.2 Loved-One(s) with HIV/AIDS

3.2.1 Overview. Caregivers were asked to indicate the year in which they first found out that a loved-one was living with HIV/AIDS. As depicted in Figure 23, the amount of time caregivers had known about a loved-one's diagnosis varied significantly, ranging from less than one year to approximately 20 years. However, the majority (70%) had been informed of a loved-one's diagnosis in the nine years between 1989 and 1997 ($M = 1992$; $SD = 4$).

While participants reported having provided HIV/AIDS-related care to a range of one to 50 persons living with HIV/AIDS ($M = 2.1$; $SD = 6.2$), more than three-quarters of the sample had provided such care to one loved-one. An additional 14% had provided HIV/AIDS-related care to two loved-ones, and 8% had provided care to three to six loved-ones. Participants identified a diversity of relationships to these loved-ones, which included their: partner/spouse (53%), child (23%), friends (23%), other relative (17%), and parent (3%).

3.2.2 Most Significant Caregiving Involvement. For the remainder of the questions in this section, participants were asked to respond by focussing on their loved-one in whose care they were most significantly involved. Items were designed to assess their relationship with this loved-one, his/her current health status, frequency of contact, as well as the level of HIV/AIDS-related care their loved-one required from both formal and informal caregivers. These data are presented in Figures 24-26.

As shown in Figure 24, approximately one-half of the present sample had provided/were providing HIV/AIDS-related care to their partner/spouse, and close to one-quarter were caregivers to their child. Several participants were caregivers to another relative (e.g., sibling, in-law) or to a friend, while two reported being most significantly involved in the HIV/AIDS-related care of a parent.

Figure 23

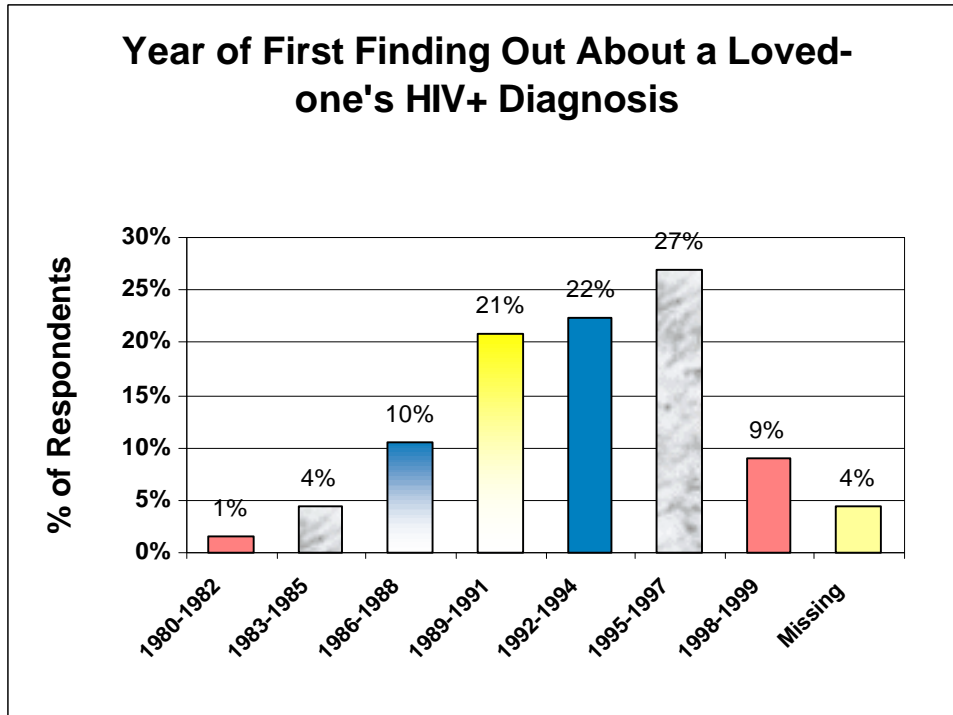
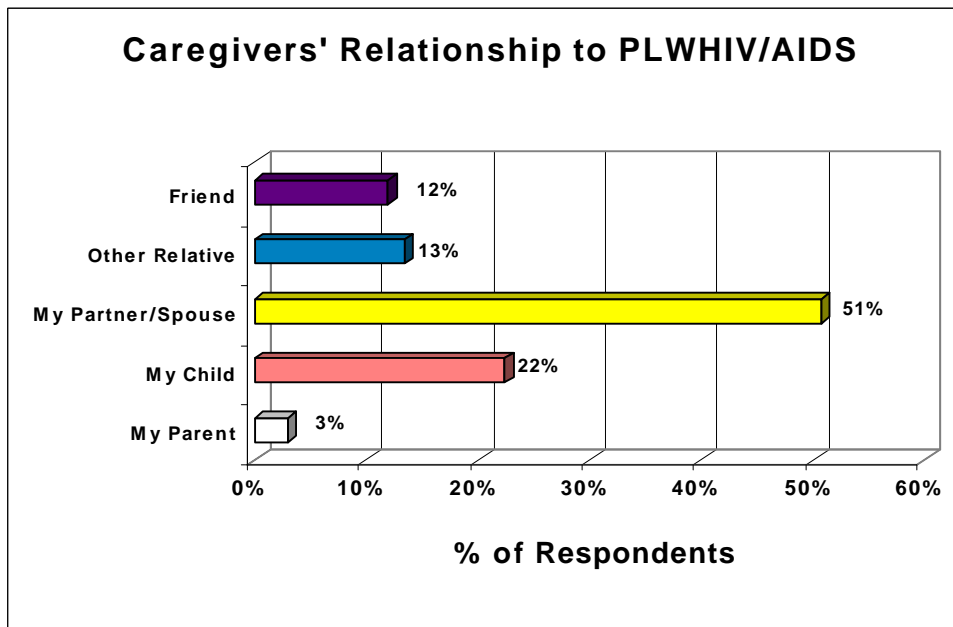


Figure 24



Thirty percent of caregivers reported that their loved-one in whose care they were most involved was deceased. As depicted in Figure 25, loved-ones living with HIV/AIDS were at various stages of HIV disease. However, the majority were in relatively good health, either experiencing symptoms “some of the time” or asymptomatic (i.e. 33/47, or 70% of the PLWHIV/AIDS). A total of 23% of caregivers reported that their loved-one was at an advanced stage of HIV disease, and approximately 6% indicated that they were chronically experiencing symptoms.

More than 80% of caregivers reported that their loved-one had lived with them at some point since their HIV diagnosis (see Figure 26). Approximately one-half of all caregivers were currently living with this person (not surprisingly, since 51% indicated that their most significant HIV/AIDS-related caregiving relationship was with their spouse or partner). It should also be noted that 40% of all caregivers reported that their loved-one was living in another province or country when first diagnosed with HIV/AIDS, and that 60% of the parents indicated that their child had moved home since being diagnosed. These data indicate that many persons living with HIV/AIDS in the Atlantic Region are infected elsewhere, and eventually return home to be close to family.

Figure 25

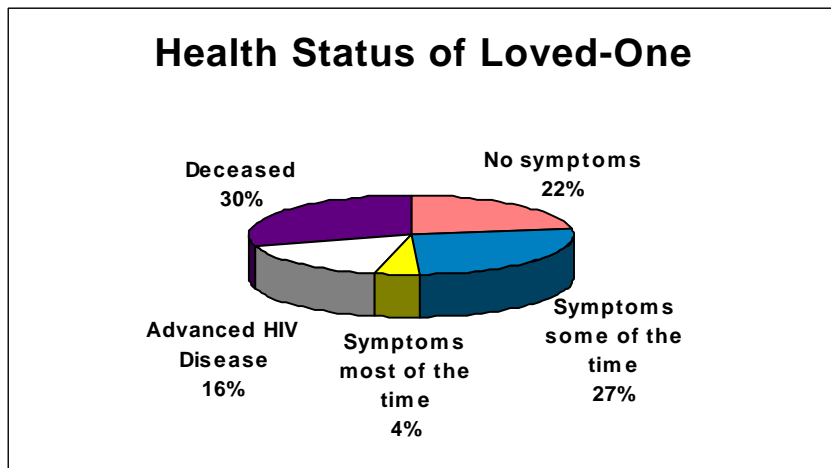
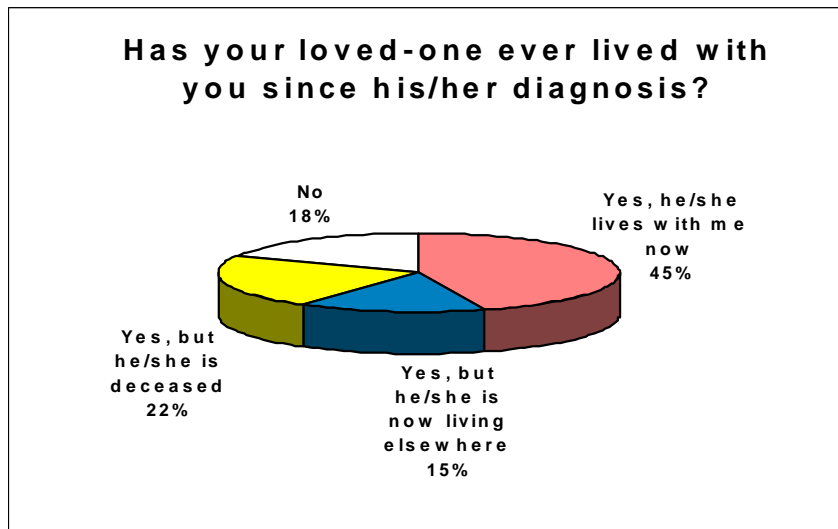


Figure 26



On a 5-point scale, ranging from “none” to “very much”, participants were asked to indicate to what extent they believed their loved-one currently required HIV-related care from both formal (e.g., physician, nurse, social worker) and informal (e.g., family members, partner and/or friends) caregivers. As depicted in Figure 27, the ratings related to the care needed from both types of caregivers were generally very similar, and underscore the importance of both in HIV-related care. Excluding the responses from the caregivers whose loved-one was deceased, most respondents indicated that their loved-one required “a little” through to “a moderate” extent of HIV-related care ($M = 2.8$ and 2.7 out of 5 for formal and informal caregivers, respectively).

3.3 Involvement in HIV/AIDS-Related Palliative Care

Figure 28 illustrates the type of HIV/AIDS-related care provided by the informal caregivers. Participants whose loved-ones were deceased were asked to indicate their previous caregiving involvement. As shown, the vast majority of caregivers reported providing emotional support to their loved-one. Approximately one-half of the caregivers who had lost their loved-one to HIV/AIDS had provided support in various other health-related and practical domains, including: Help with errands (55%); nursing care (50%); basic care (45%), housework (45%). Examples of nursing care included giving medications, injections, changing dressings, while basic care included help with such tasks as bathing, grooming and toileting. In contrast, relatively fewer present-day HIV/AIDS-related caregivers were currently involved in basic or nursing care - i.e., an expected finding, given that the majority (70%) of caregivers reported that their loved-one was in relatively good health (i.e., asymptomatic or sporadic symptoms). Approximately one-half of these participants were, however, providing practical support (e.g., help with errands and housework), and 83% reported that they were in daily contact with their loved-one.

Figure 27

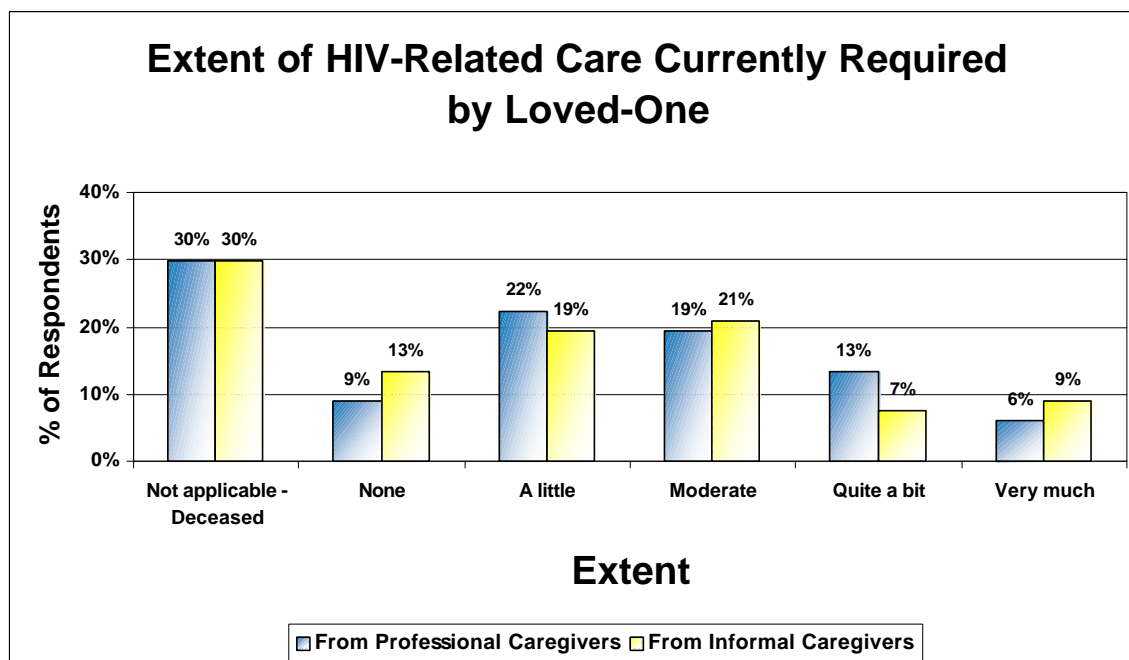


Figure 28

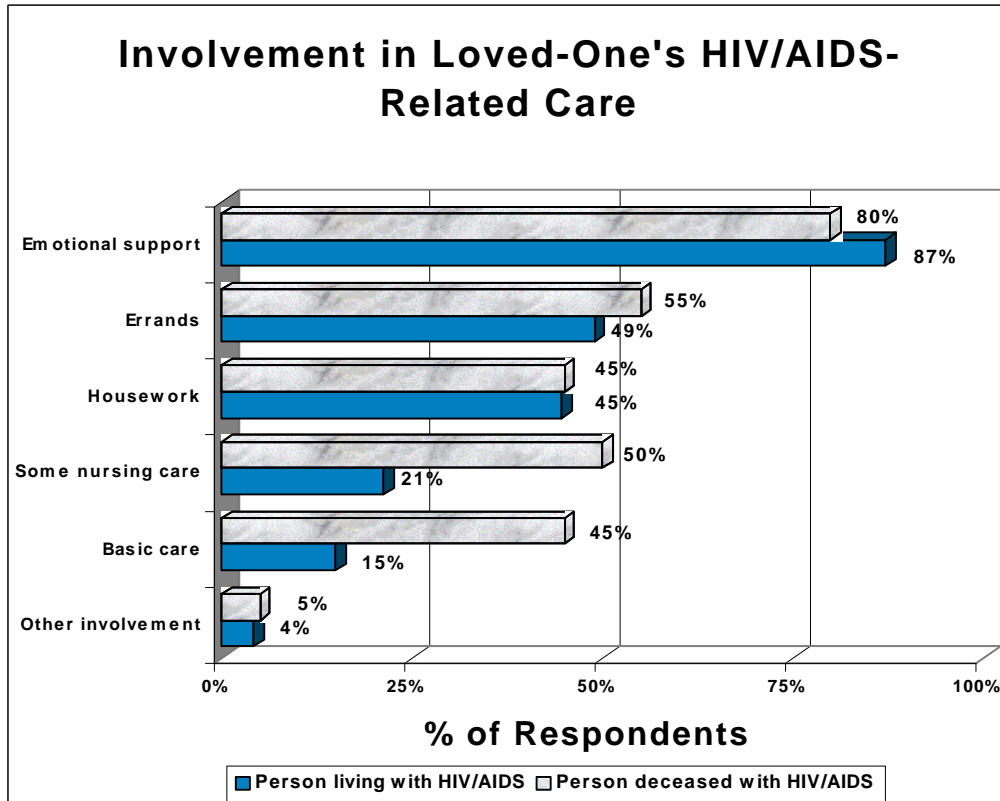
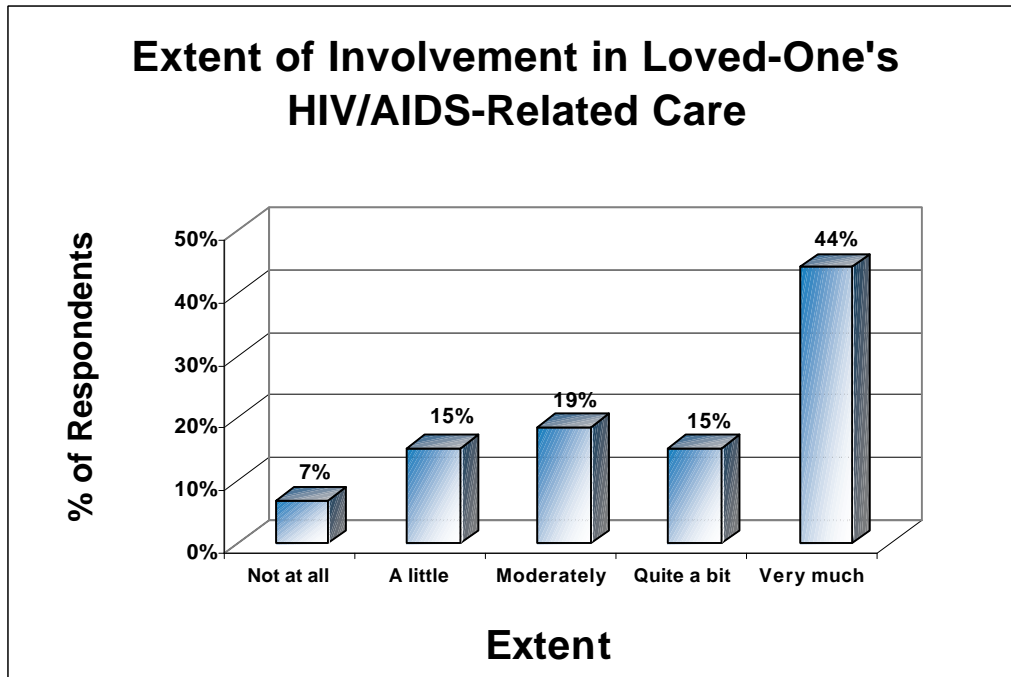


Figure 29



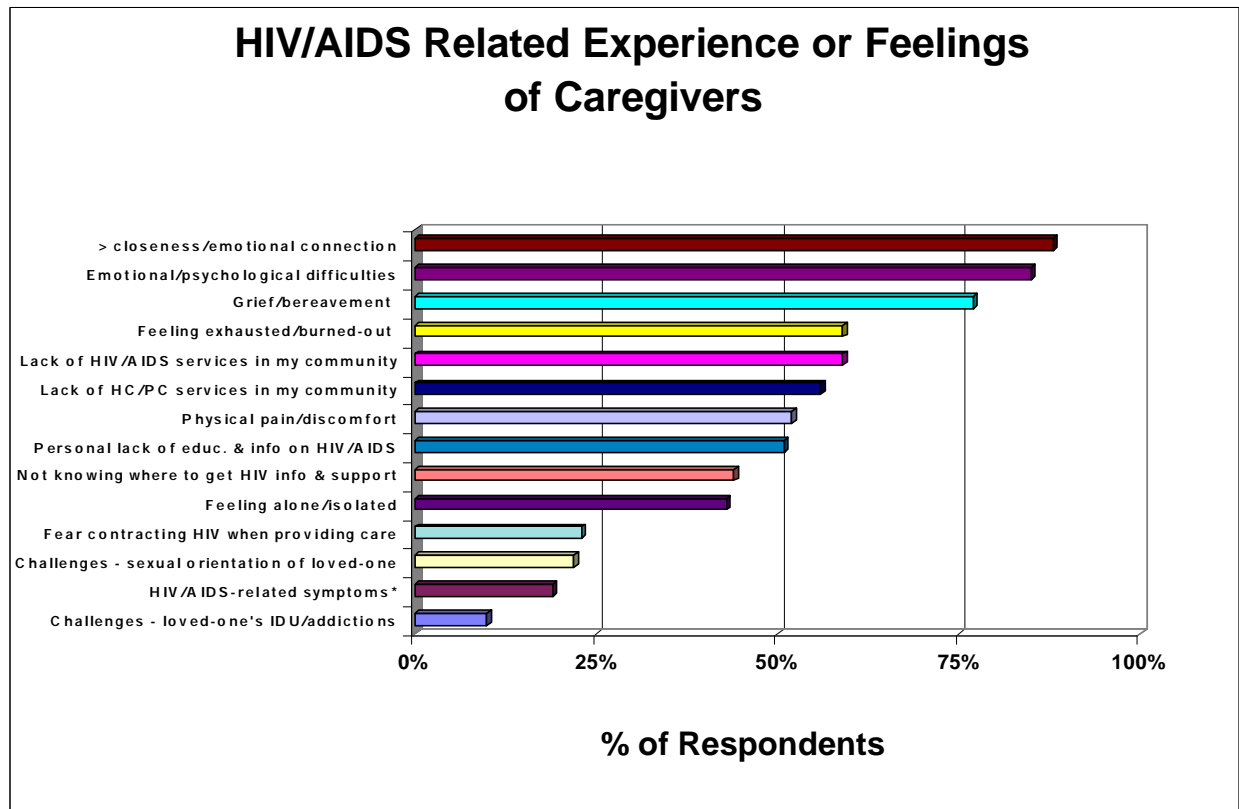
To gain greater insight into caregivers' level of involvement in a loved-one's HIV-related care, participants were asked to rate the overall extent of their involvement on a scale ranging from 1 ("not at all") to 5 ("very much"). As illustrated in Figure 29 above, 44% indicated that they were/had been "very much" involved in their living/ deceased loved-one's care. Other caregivers provided varied ratings, ranging from "not at all" to "quite a bit" (7%-19% of the total sample). A separate item also inquired about the involvement of other formal and informal caregivers in their loved-one's HIV/AIDS-related care. Approximately one-half reported the involvement of other informal caregivers and 12% cited the support of trained volunteers, while approximately one-quarter of participants indicated that they were the only ones providing their loved-one with HIV-related care.

3.4 Experiences and Feelings

Caregivers were also asked to rate on a 4-point scale the extent to which they were currently experiencing each of 14 different challenges or feelings. The data pertaining to the percentage of the total sample who were experiencing each of these situations at least to some extent (i.e., ratings of "a little" through to "a lot") are provided in Figure 30.

As shown, while the majority of caregivers reported feeling a greater closeness and emotional connection to their loved-one since finding out about his/her diagnosis, the findings also point to the prevalence of certain challenges and stressors. For instance, HIV/AIDS-related grief/ bereavement and emotional/psychological difficulties were the two most commonly cited experiences, and were reported by 77% - 85% of caregivers, respectively. In addition, more than one-half of caregivers reported: exhaustion/burn-out; lack of HIV/AIDS services in their community; lack of home care/palliative care services in their community; physical pain or discomfort; as well as, a personal lack of education and information on HIV/AIDS. A significant proportion (more than 40%) were also feeling alone, isolated and/or unsupported in their HIV/AIDS-related caregiving and did not know where to obtain HIV-related information and support.

Mean ratings for each of these experiences are included in Table 12, as are the percentages of caregivers who reported relatively intense ratings [i.e., 3 ("quite a bit") or 4 ("a lot") out of 4]. As shown, average ratings ranged from a low of 1.2 (i.e., challenges related to their loved-one's injection drug use/addictions) to a high of 3.1 (i.e., feeling a greater closeness and emotional connection to their loved-one since finding out about his/her diagnosis). Several challenges were reported as relatively intensive by approximately one-quarter to one-half of all caregivers: exhaustion/burn-out; feeling alone, isolated, and/or unsupported in HIV/AIDS-related caregiving; lack of HIV/AIDS-related, home care, and palliative care services; emotional/psychological difficulties; and, most notably, HIV/AIDS-related grief/bereavement. Also evident in Table 12 is the finding that a substantial proportion of caregivers who were also diagnosed with HIV/AIDS were experiencing a relatively high level of related symptoms.

Figure 30**Table 12. HIV/AIDS Experiences and Feelings of Caregivers**

	Mean ratings	% Reporting 3 or 4
Challenges re. loved-ones injection drug use/addictions	1.2	5%
Fear contracting HIV when providing care	1.3	8%
HIV/AIDS-related symptoms*	2.3	11%
Challenges re. sexual orientation of loved-one	1.2	12%
Not knowing where to get HIV/AIDS info & support	1.6	13%
Personal lack of education & information on HIV/AIDS	1.7	14%
Physical pain/discomfort	1.8	21%
Feeling exhausted/burned-out in HIV/AIDS caregiving	2	26%
Feeling alone/isolated	2.1	33%
Lack of HIV/AIDS services in my community	2.1	35%
Lack of home care/palliative care services in my community	2.2	37%
Emotional/psychological difficulties	2.4	40%
HIV/AIDS-related symptoms*	2.3	44%
Grief/bereavement around HIV/AIDS	2.5	50%
Feeling a greater closeness/emotional connection to loved-one	3.1	70%

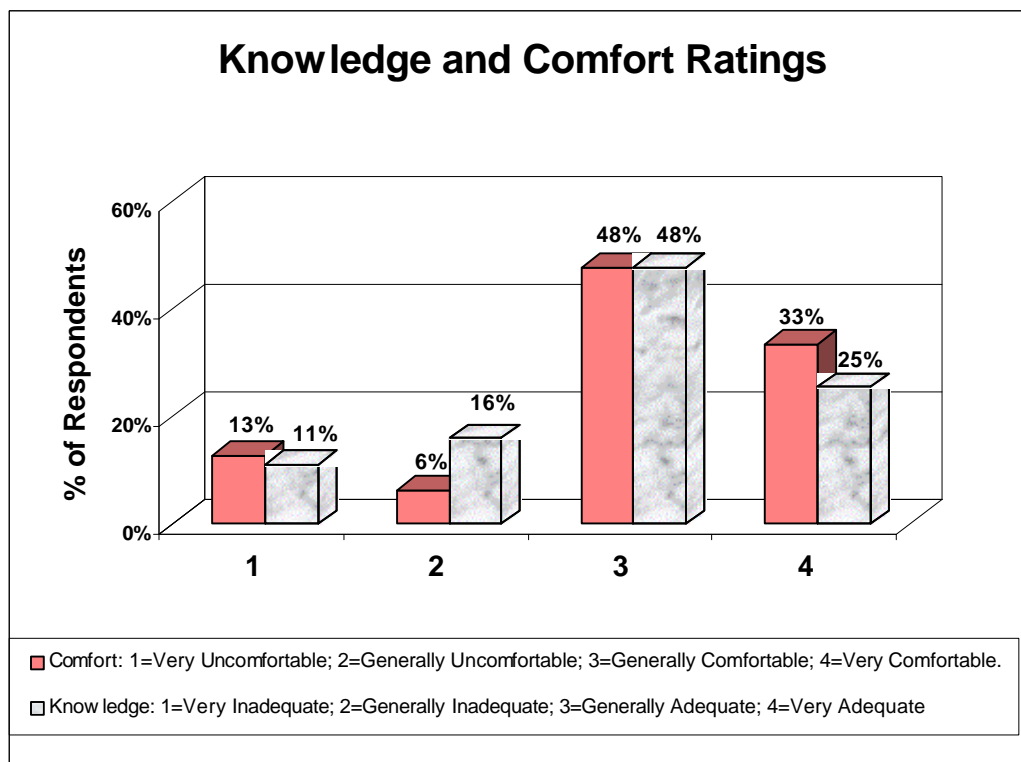
* Based only on the responses provided by the 19 caregivers who were also living with HIV/AIDS.

3.5 Information and Support Services/Needs

3.5.1 HIV-Related Knowledge and Comfort Ratings. Figure 31 illustrates caregivers' self-ratings regarding their: (a) Level of comfort providing (or potentially providing) HIV/AIDS care to their loved one; and (b) Level of knowledge necessary for providing (or potentially providing) such care (see Figure 31).

As shown, top knowledge and comfort ratings were provided by one-quarter and one-third of all caregivers, respectively; approximately one-half considered their knowledge and comfort levels to be generally adequate. Nonetheless, the results do highlight the need for education/training for a number of caregivers. That is, 27% of all participants indicated that their knowledge was either very or generally inadequate, and 19% rated themselves as very or generally uncomfortable in the provision of HIV/AIDS care. In addition, more than one-half of all caregivers reported that they had never received any information about HIV/AIDS and palliative care (e.g., what it is; services available; issues). The questionnaire described Palliative Care as: "... aimed at relief of suffering and improving the quality of life for persons who are living with or dying from advanced illness or are bereaved."

Figure 31



3.5.2 HIV-Related Support. The vast majority of caregivers (90%) identified at least one person or organization as a source of support to help them deal with having a loved-one with HIV/AIDS. As shown in Figure 32, the most common sources of support included: Medical professionals, friends, and other family members (i.e., cited by 52%-55% of caregivers), as well as partners/spouses and AIDS organizations (i.e., 42%-43%). Persons living with HIV/AIDS were also cited as a relatively common source of support for the caregivers. In contrast, other potential support resources, including mental health professionals, Chaplain/Clergy members, Palliative Care organizations, local hospice/palliative care programs, and home care organizations were seldom identified (i.e., 4% - 16%).

The results underscore the need for providing HIV/AIDS-related caregivers with additional emotional support (see Figure 33). For instance, approximately two-thirds of caregivers indicated that there were various sources of support that they needed but were not receiving or receiving sufficiently. As their five greatest unmet HIV-related support needs, participants most commonly identified: Medical professionals, AIDS Service Organizations, other family members, their partner/spouse, and mental health professionals (i.e., cited in the top five by 24%-39% of caregivers).

Figure 32

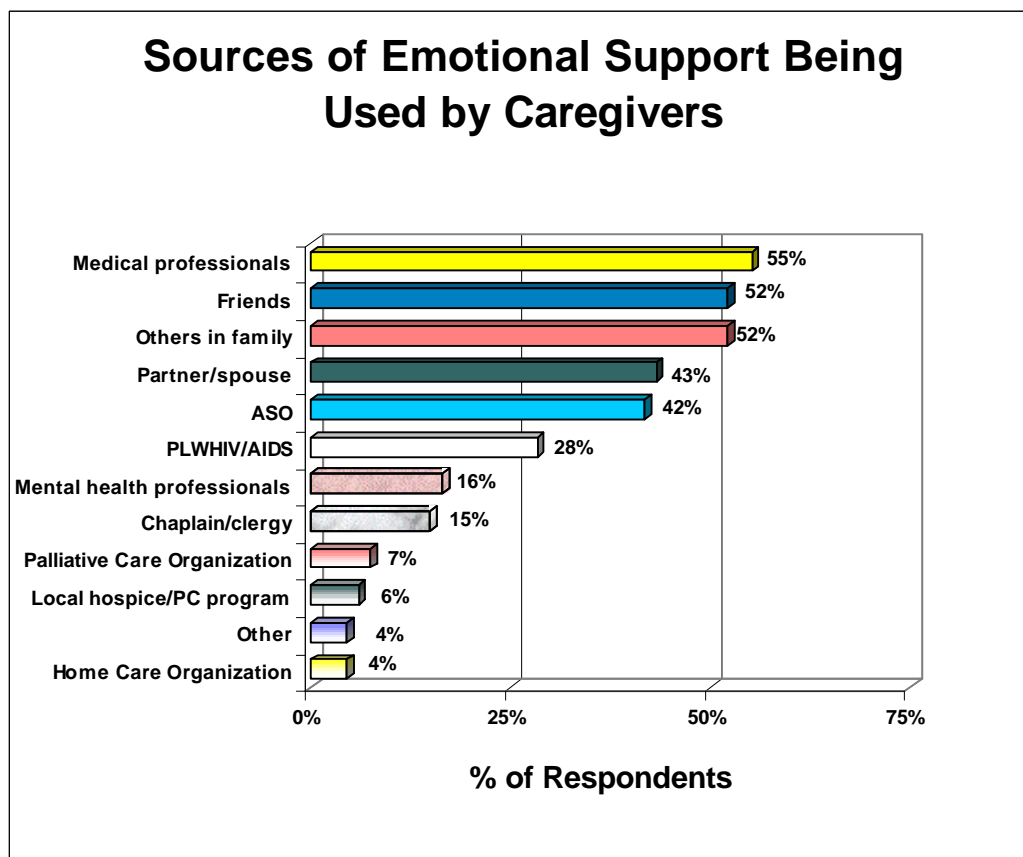
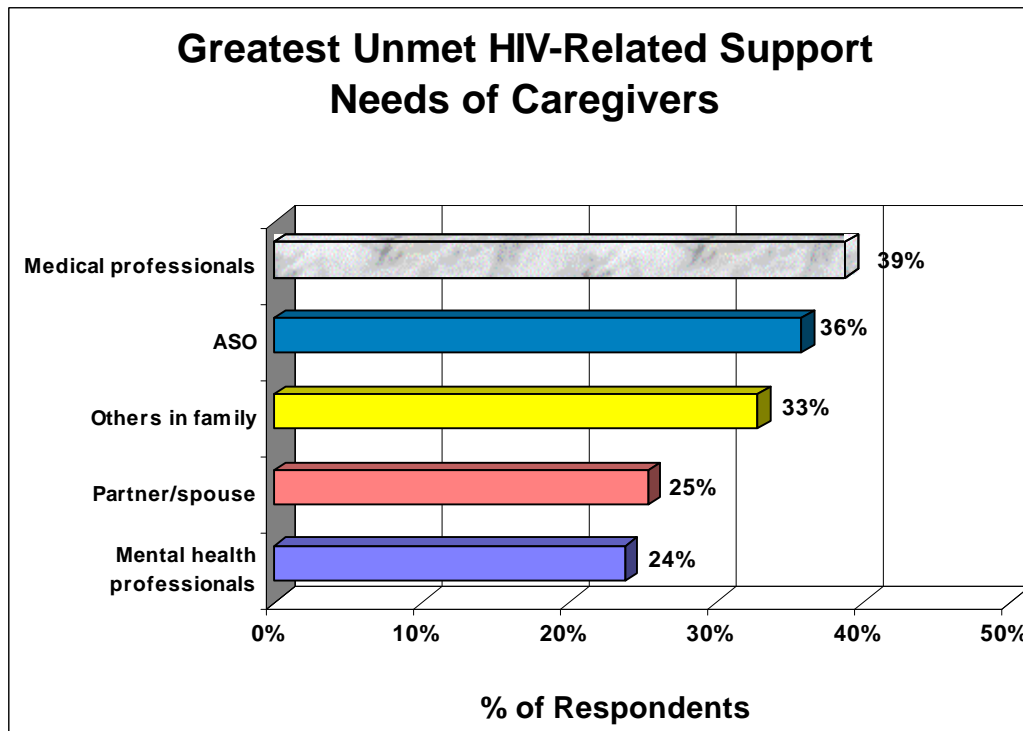


Figure 33

3.5.3 HIV-Related Services. Participants were asked to indicate whether they had ever received any HIV-related information or support services related to their loved-one's care or needs from any of eight different potential sources. As shown in Figure 34, almost one-third of caregivers stated that they had never received any such services. Although 58% of participants had received some type of service from ASO's, caregivers had received HIV-related information or support from relatively few other sources. That is, only 3% - 15% of caregivers had ever received related services from the following: National Home/Palliative Care Associations; Provincial Home/Palliative Care Associations; Home Health Care Services/Agencies; Local Hospice Palliative Care Programs; and Hospital-based Palliative Care Programs.

Table 13 presents the results of the item asking caregivers to indicate which of eight services they were: (1) Currently using; and, (2) Not currently using but anticipated needing or using in the future. It should be noted that, with the exception of AIDS organizations (i.e., being utilized by 39% of caregivers), relatively few caregivers were using HIV/AIDS-related services. That is, only 5%-18% of all caregivers respectively reported the current use of: Respite care, palliative care education, grief/bereavement counselling, emotional/psychological counselling, peer support, and spiritual/pastoral support.

While relatively few services are currently being accessed, it is important to recognize that a substantial proportion of caregivers do anticipate using or needing many of these services. For instance, approximately one-half to two-thirds of all caregivers reported an anticipated need for: Peer support/counselling, spiritual/pastoral support, respite care, emotional/psychological counselling, grief/bereavement counselling, and palliative care education (See Table 13).

Table 13. HIV/AIDS-Related Service Utilization (Caregivers)		
	Currently Using	Not Currently Using But May Need/Use in Future
Respite Care	5%	55%
Palliative Care Education	9%	67%
Other	9%	6%
Grief/Bereavement Counselling	13%	66%
Emotional/Psychological Counselling	15%	63%
Peer Support/Counseling	18%	46%
Spiritual/Pastoral Support	18%	51%
AIDS Organization	39%	31%

3.5.4 HIV-Related Information Needs. The vast majority of participants (93%) indicated that there were several types of information that would be useful to them as HIV/AIDS-related caregivers. In order to get a sense of caregivers' priority needs, they were asked to rank order their five greatest informational needs. Figure 34 includes only the types of information which were assigned top five rankings by a minimum of one-quarter of all participants. As shown, information pertaining to the basics of palliative care was the most frequently cited greatest informational need (61%). However, ten other types of information, ranging from HIV/AIDS-related symptoms and illnesses to emotional/psychological support for informal caregivers were also highly ranked by 25% to 41% of participants, respectively.

Caregivers were asked to indicate which of 11 different educational approaches would be useful to them in terms of meeting their need for information on HIV/AIDS and palliative care. Written materials, support groups/consultations with other informal caregivers, local workshops, as well as consultations with: experienced palliative care providers, experienced home care providers, persons living with HIV/AIDS and AIDS organizations were most frequently cited as useful (i.e., 34%-56%). Participants were also asked to rank order their top three choices for best meeting their HIV/AIDS and palliative care needs. As shown in Figure 35, support groups/consultations with other informal caregivers, consultations with experienced palliative care and home care providers, local workshops, and written materials received top rankings by 27% - 34% of caregivers. None of the other educational approaches received top rankings by more than one-quarter of all participants.

Figure 34

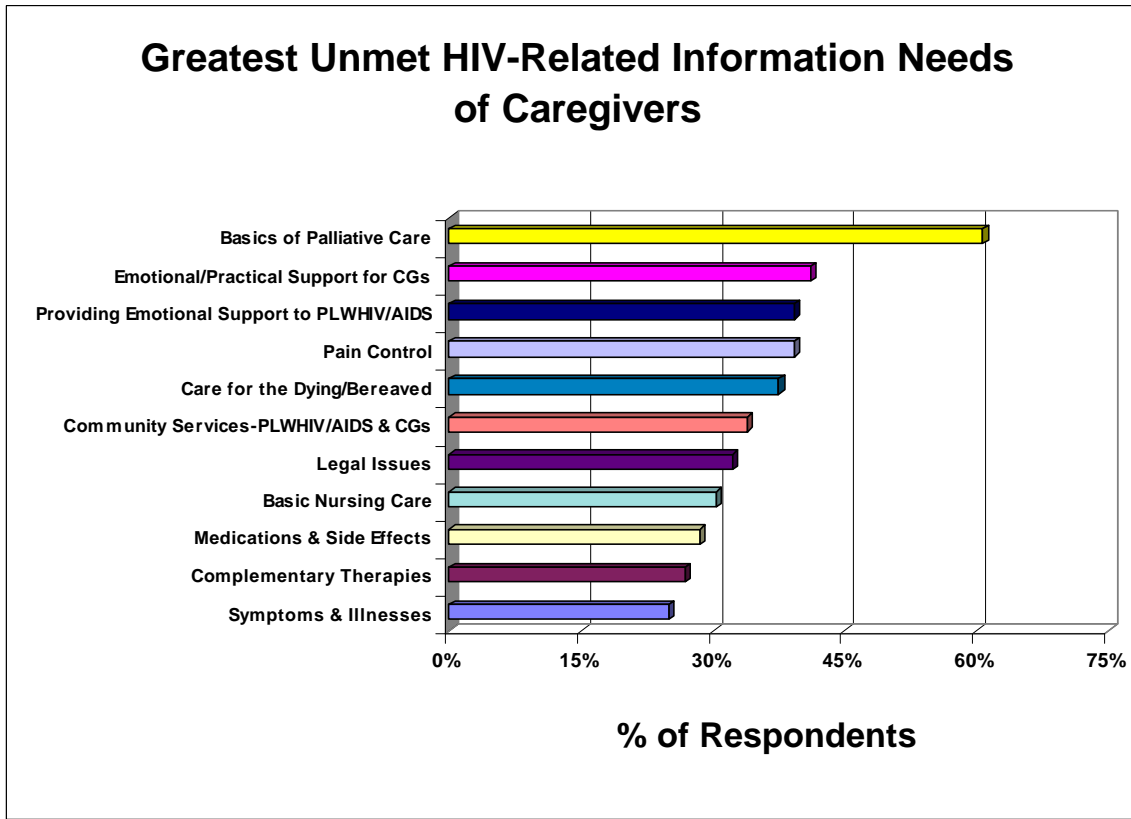
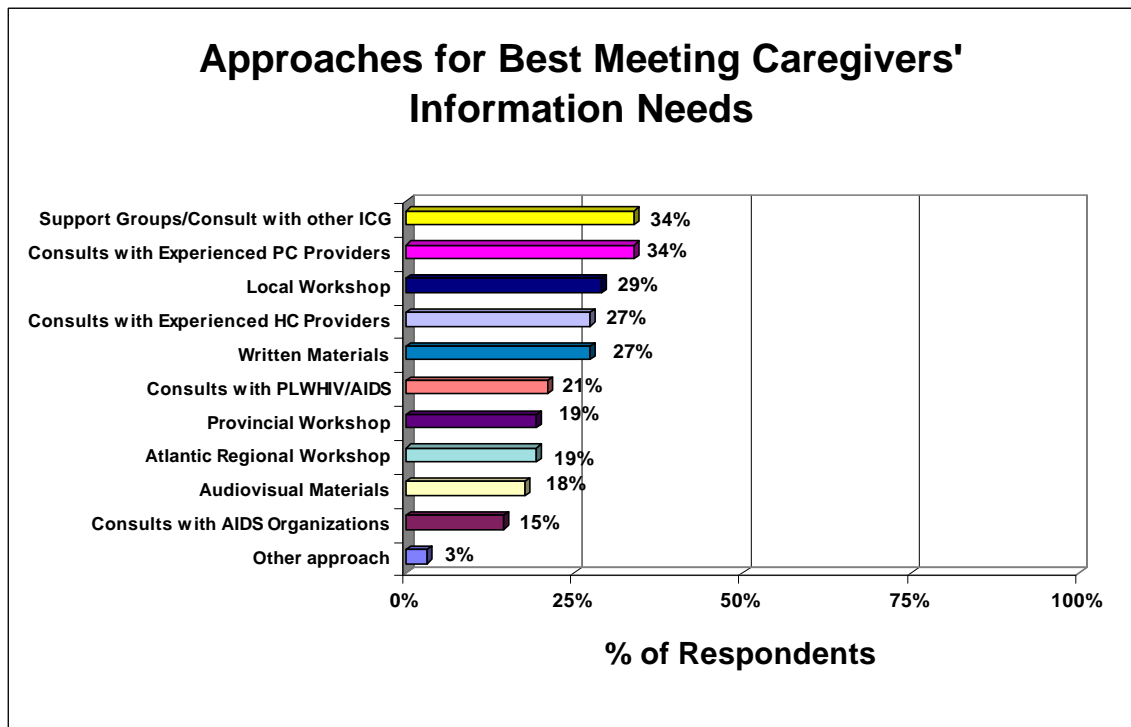


Figure 35



3.6 Additional Comments

A total of 15 caregivers (22%) provided additional comments regarding the present survey. As outlined in Table 14, qualitative analyses of the responses revealed two main themes: (1) A need for specific HIV/AIDS-related services; and (2) Challenges of HIV/AIDS-related caregiving. All of these responses, as well as those listed under a “miscellaneous” category are present below.

Table 14. Additional Comments -Caregivers (n=15)

! Need for HIV/AIDS-Related Services

There is a need for a hospice in the Atlantic. Persons are going to Spirit World in closed boxes (hospitals)!!! Should be at home or supportive environment (hospice).

Male, Partner, Nova Scotia

My partner and I need many services. We have no information on these services!! Low income housing etc. I have no health card for drugs. No help to cope with needs!! NB is not a place to live with HIV/AIDS. It's better to move elsewhere. I believe Quebec is a better place for all needs of HIV/AIDS.

Male, Partner, New Brunswick

I've had the privilege of being with friends at the moment of death. Some were at St. Paul's (Vancouver) which I found to be a warm, loving place staffed by gentle, compassionate men and women. However, it's an exception, not the norm. Palliative and home care has a long way to go outside of major Canadian cities before I'd want to entrust myself to it.

Male, Partner, Nova Scotia

After losing a brother to AIDS, I have spent a good deal of time thinking about what would have helped. Definitely - if we would have had access to quality home palliative care - we would have been able to keep him at home until he died and would not have had him in the hospital for 3 months.

Female, Sister, New Brunswick

I was pleased to fill this out. I would like to have a workshop set up for the people who are helping or caring for HIV/AIDS patients. Nothing too big, maybe a couple of hours a weekend. Thank God my sister is not as bad as she was when we first found out. She is just as healthy as me. But there is still that possibility that her health could fail. I would like to speak to others in my position. Thank you.

Female, Sister, Newfoundland

My partner was infected around 1980, diagnosed in 1988, and passed away in 1994. Throughout that time we kept his status info to ourselves, and in the last 6 months I told his family - hoping for support, etc. This did not happen, and only compounded the problems day to day. Because of the closeness of this community, information was leaked from the medical field, which had a negative result in my life, and approx. 5 years after the fact, I am still treated as a "leper" even though I am not HIV+. There needs to be more care, help and understanding publicly, not only of the disease, but of the strain and stress on the patient as well as the caregiver.

Male, Partner, New Brunswick

Some sort of hospice is needed in Newfoundland or greater emphasis on palliative care at home with support. There are not enough connected services in NF and too many social services Roadblocks!!!

Male, Partner, Newfoundland

! **Challenges of HIV/AIDS-Related Caregiving**

The most difficult part of caring for a person who has HIV/AIDS is dealing with their expression of anger, frustration, hopelessness/helplessness. As the caregiver, I tend to be bearing the load of both of us-DENIAL. The conscience of the caregiver seems to raise the emotional, mental, physical and spiritual right until exhaustion or breakdown. Not wanting to give up hope is hard to deal with when someone else has the keys!!!!

Female, Partner, Nova Scotia

Our son is in reasonably good health. Sometimes we forget that, when he is having a bad day that he has HIV/AIDS. Then we wonder how he will be next week, next month and next year and how we will deal with it all. When he is sicker and down in the dumps, we wonder what we can do and say.

Female, Parent, PEI

! **Miscellaneous**

Excellent.

Male, Partner, Newfoundland

I don't know what a Palliative Care Provider is.

Female, Parent, Newfoundland

Hoping the confidentiality is respected.

Female, Partner, Newfoundland

Thanks for caring enough to assist us with providing information to better assist our communities. Great survey.

Male, Friend, Nova Scotia

Other than the loss of his sight, my brother had a relatively good 10 years. There were lots of trips to doctors and blood tests but he refused to take all the new drugs to prolong his life. He didn't want any of the side effects. He did not waste away to nothing and when the end came he was in hospital for 3 weeks. He didn't get to palliative care. He just slipped away. Sister Nicky from AIDS Saint John is a joy and was a great source of comfort.

Female, Sister, New Brunswick

4.0 MAIN FINDINGS AND RECOMMENDATIONS

A total of 103 persons living with HIV/AIDS and 67 caregivers from across the four Atlantic provinces participated in this second phase of the *HIV/AIDS and Palliative Care in the Atlantic Region Survey*. The main findings are summarized respectively in the present section, and are followed by a list of recommendations intended to provide the Canadian Palliative Care Association with some direction in meeting the needs of persons affected by HIV/AIDS in the Atlantic Region.

4.1 Summary of Main Findings - Persons Living with HIV/AIDS

① HIV-Related Health Information

Overview

! Respondents included 84 men, 17 women, and two individuals who did not specify their gender. The number of years participants had been living with HIV/AIDS varied greatly (i.e., less than one year to approximately 20 years). On average, however, individuals reported having been infected for approximately 11 years and diagnosed for 7 years. While participants at all stages of HIV disease were represented, the majority of respondents reported being in relatively good health:

- Approximately three-quarters of the sample reported being asymptomatic or symptomatic “sometimes”. Smaller proportions were chronically experiencing symptoms or living with advanced HIV disease.
- More than one-half of all PLWHIV/AIDS had never been hospitalized due to an HIV-related illness, while only 17% had been hospitalized within the last year.
- Approximately two-thirds of the sample reported CD4 counts above 200; one-half noted that their viral load was currently undetectable.

! While corroborating the research indicating that combination therapy is not effective for everyone - e.g., “*I have tried four therapies without success*” - the findings also highlight related improvements in the health of many persons living with HIV/AIDS. For instance, more than three-quarters had previously received results indicating CD4 cell counts of 200 or less, and/or a viral load of 10,000 or more copies/ml.

“My first experience with medication was with AZT and I found I could not tolerate it at all. Protease Inhibitors have led to dramatic improvement in my health.”

Limitations on Everyday Activities

- ! Despite advancements in HIV/AIDS-related treatments, living with HIV/AIDS remains challenging for most. For instance, close to three-quarters of all PLWHIV/AIDS reported that their current health was posing certain limitations on their ability or enjoyment in everyday activities. On average, these participants cited “moderate” limitations in terms of their daily activities. The majority explained that these limitations were related primarily to physical and/or psychosocial concerns. Examples of physical limitations included: fatigue, weakness, neuropathy, diarrhea, weight loss, miscellaneous infections, and various challenges related to HIV-related medications (e.g., side effects, time table). Psychosocial concerns included: depression, anxiety, fear, stress, isolation, lack of social supports, and financial limitations.

Overall Quality of HIV-Related Care Received from Professionals

- ! On the whole, the majority of persons living with HIV/AIDS were satisfied with the quality of the care that they had received from professional caregivers (e.g., doctors, nurses, counsellors). For instance, more than 80% rated the overall quality of their HIV-related care as either “excellent” or “good”. An additional 16% of respondents rated it as “average”, and very few ranked it as “poor” or “very poor”.

In general, the majority of participants who provided top ratings (“excellent”) to the care received from professionals focused on the informative and client-centred qualities of their care. In short, the adjectives used to describe their caregivers included: attentive, caring, kind, compassionate, supportive, genuinely concerned, helpful, and knowledgeable. The main theme to emerge from the comments made by the participants who considered their care to be “good” was the need for increased access to care and information (e.g., insufficient number of trained caregivers, insufficient sharing of information regarding disease progression and/or side effects of medications). Explanations provided by the PLWHIV/AIDS who provided lower ratings (“average” - “very poor”) varied substantially. Several participants mentioned that they felt that their care was very impersonal, some focused on the lack of training provided to professionals, and others commented on the inadequate access that they had to HIV-related care.

② HIV/AIDS and Palliative Care

Attitudes and Fears

- ! Approximately two-thirds of all persons living with HIV/AIDS contended that the issues of HIV/AIDS and Palliative Care were personally applicable. However, the data indicate that a significant number of individuals perceive palliative care as an approach to be used in the final stage of illness, rather than as an integral aspect of care throughout HIV disease. For instance, more than one-third of PLWHIV/AIDS noted that the issues of HIV/AIDS and palliative care were not applicable to them because they were not living with advanced HIV disease.

! Combination therapy has impacted on the HIV/AIDS-related palliative care views of many PLWHIV/AIDS.

- Approximately one-half of all individuals diagnosed prior to the availability of combination therapy indicated that their thinking about HIV/AIDS and palliative care had since changed. Most commented on their improved health status and the fact that they no longer perceived palliative care as a priority or current need.
- The majority of participants who did not report a change in thinking about palliative care explained that had never given palliative care much thought in the first place. A smaller number indicated that palliative care issues continued to be relevant since they questioned the long-term efficacy of combination therapy, or had not responded well to treatment.

! Many PLWHIV/AIDS expressed discomfort and fear surrounding HIV/AIDS and palliative care.

- More than one-third of participants reported that they were either “very” or “generally” uncomfortable with HIV/AIDS and palliative care issues, and 41% reported related fears. Participants’ comments revealed the majority of fears are related to concerns about the availability/accessibility of adequate palliative care services and/or the loss of control and independence.

e.g., “Most of the time, I worry about whether I will really be taken care of when I get too ill to care for myself.”; “I am very independent and fear being in a position to be cared for.”

Knowledge and Comfort Levels

! The findings point to a need for providing HIV/AIDS and palliative care education for PLWHIV/AIDS in the Atlantic Region.

- Close to two-thirds of participants reported that they had not received any information about HIV/AIDS and palliative care.
- Approximately one-third reported knowing “nothing at all” about the issue, while fewer than 8% of participants reported knowing “a lot”.
- Less than one-half of participants rated their knowledge about HIV/AIDS and palliative care as “generally” or “very” adequate in terms of their current needs; less than one-third rated their knowledge as “generally” or “very” adequate in terms of their anticipated needs.

Sources of HIV-Related Information and Support

! A total of 69% of PLWHIV/AIDS reported having received some HIV-related information, support or services related to their needs. AIDS Service Organizations were by far the most commonly cited sources of HIV-related information and support (58%). In contrast, very few participants (i.e., 1% - 6%) had received related services from any of the other potential providers, including: Hospital-based Palliative Care Programs; Home Health Care Services/Agencies; Provincial Palliative Care or Home Care Associations; Local Hospice Palliative Care Programs; the Canadian Palliative Care Association; or the National Home Care Association.

! While persons living with HIV/AIDS are currently relying on few outside sources of HIV-related information and support, the data underscore the importance of partners, family members, and friends in terms of current and potential care needs.

- Almost three-quarters of all PLWHIV/AIDS rated the support and care that they had received to date from their loved-ones in helping them to deal with HIV/AIDS as excellent (43%) or “good” (28%). In contrast, only 4% rated the support in the “poor” to “very poor” range.
- The majority of persons living with HIV/AIDS anticipate a high level of involvement from their loved-ones should they ever need assistance or basic care due to HIV-related illness. For instance, 63% of all PLWHIV/AIDS indicated that their loved-one(s) would be “very much” or “quite” involved, and an additional 18% said that their loved-one(s) would at least be “a little” or “moderately” involved. A total of 10 individuals felt that none of their loved-ones would be involved in their HIV-related care.

Respondents anticipated that a number of their loved-ones would be involved in their HIV-related care, most commonly including their: friends, parents, partner/spouse, and other family members. A few indicated that their child/children would be involved.

Alternatives to Hospitalization

! Perceptions regarding the potential usefulness of various health care settings in the event that participants ever needed assistance or nursing care but did not require hospitalization were assessed.

- The vast majority of persons living with HIV/AIDS (94%) emphasized the potential importance of receiving health care in their own homes (e.g., visiting nurse, paid caregivers).
- A smaller, but substantial proportion (39%) of individuals also perceived an HIV/AIDS special care home/hospice - i.e., not currently available in Atlantic Canada - as a potentially useful alternative to hospitalization.
- Other alternative health care settings - i.e., nursing home and non HIV-specific special care home/hospice were rarely cited (i.e., 9%-19%) by PLWHIV/AIDS as potentially helpful environments.

- ! The results also emphasize the definite preference most PLWHIV/AIDS have for home health care. That is, in addition to being widely perceived as a potentially useful alternative to hospitalization, home health care was also ranked as the first choice by 90% of all respondents. Although seen as potentially beneficial, an HIV-special care home/hospice was rated as the preferred alternative to hospitalization by only 8% of individuals.

- ! A separate question revealed a range of attitudes toward hospices/special care homes for persons with AIDS - i.e., 45% indicated that they would never consider living in such a setting, while 55% indicated that they would or would possibly consider the option.

The most commonly mentioned reasons for never considering an AIDS-related hospice/special care home were related to the desire/preference to stay at home and to be close to loved-ones. The next most frequently cited reasons were related to: (1) Intentions to consider suicide/euthanasia in the event of advanced illness; and (2) A discomfort around the illness of others. The majority of participants who indicated that they would possibly consider a hospice/special care home explained that their decision would be based on a variety of circumstances (e.g., finances, lack of informal caregivers, state of health, qualifications of the facility). A few others emphasized that they would consider such a facility only as a last resort.

③ Experiences and Feelings

- ! Participants were asked to rate on a 4-point scale, ranging from 1 (not at all) to 4 (a lot), the extent to which they were facing each of 10 different experiences or feelings. The relevance of various issues to the lives of PLWHIV/AIDS was evident. That is, 8/10 experiences listed were being faced to some extent by 55%-85% of all respondents.

While certain challenges are evident, the findings also underscored some positive experiences. For instance, the two most commonly and intensely (i.e., ratings of 3 or 4) identified experiences were: “*Feeling loved and supported by family and friends*” (63%) and “*Feeling that my life has quality and meaning*” (60%). The following challenges were intensely reported by 29%-41% of PLWHIV/AIDS:

- Emotional/ psychological difficulties;
- Feeling alone/isolated;
- Lack of accessible HIV/AIDS services;
- Lack of accessible home care/palliative care services; and
- HIV/AIDS-related symptoms

④ Information and Support Services/Needs

Financial Status

- ! The data highlight substantial financial need among the sample of persons living with HIV/AIDS. Many PLWHIV/AIDS in Atlantic Canada are living below the poverty line.
- More than one-third of participants reported total annual household incomes of less than \$10,000; only one-half of all PLWHIV/AIDS reported household incomes above \$15,000.
 - Almost two-thirds of individuals cited financial difficulties meeting their current HIV-related care needs. The need for financial assistance in various domains was expressed, and most commonly included: medication/drug costs, food, housing and utilities, as well as transportation, dietary supplements, vitamins, and other complementary therapies.

Current and Anticipated HIV-Related Service Needs

- ! HIV/AIDS-related service utilization was assessed in relation to both current and anticipated needs.
- The vast majority (83%) of all PLWHIV/AIDS were currently using antiretroviral therapies. Other commonly utilized services included: Prophylactic medications, AIDS Service Organizations, complementary/alternative therapies, and financial assistance (i.e., cited by close to one-half of all respondents). None of the other services were being used by more than one-quarter of the participants.
 - A significant percentage of respondents indicated that there were various HIV-related services that they were not currently using but may use or need in the future. Two-thirds or more of all participants indicated that they anticipated needing or using six of the services listed (i.e., Home health care (77%); volunteer support (73%); homemaker/home support (69%); transportation services (68%); other alternatives to hospitalization (67%); and legal services (66%). Although less frequently cited, all remaining services - with the exception of addiction treatment/counselling- were identified as potential future needs by approximately 37% - 58% of individuals.

HIV-Relation Informational Needs

- ! The majority of respondents (80%) indicated that they were interested in receiving information about HIV/AIDS and Palliative Care, and cited a diversity of informational needs. Most commonly identified as one of participants' five greatest needs was information on financial assistance (53%).
- One-quarter to more than two-thirds of all participants also reported a highly ranked need for information pertaining to: Complementary/alternative therapies, home health care, emotional/psychological counselling, other alternatives to hospitalization, antiretroviral HIV/AIDS drugs, legal services, homemaker/home support, and prophylactic medications.

! Persons living with HIV/AIDS noted that their information needs would best be met through various educational approaches. The following were ranked as one of the top three approaches by roughly one-third to one-half of all respondents:

- Written materials (55%)
- Consultations with experienced Palliative Care providers (40%)
- Local workshops (39%)
- Self-help discussion groups (33%)

Provincial workshops and consultations with experienced home care providers also received relatively high rankings (24%-25%). Relatively few individuals reported a preference for other possible approaches (i.e., Atlantic Regional Workshop, audiovisual materials, consultations with AIDS organizations).

4.2 Summary of Main Findings - Informal Caregivers

① Loved-One(s) with HIV/AIDS

Overview

! Caregivers included an equal number of male (32) and female (32) respondents, as well as three individuals who did not indicate their gender. A total of 19 caregivers (29%) indicated that they were also living with HIV/AIDS.

! While the amount of time caregivers had known about a loved-one's diagnosis varied significantly (i.e., less than one year to approximately 20 years), the majority (70%) had been informed of a loved-one's diagnosis in the nine years between 1989 and 1997. On average, respondents had provided HIV/AIDS-related care to two loved-ones (Range: 1 - 50).

Most Significant Caregiving Involvement

! The majority of caregivers reported that their loved-one in whose care they were most involved was either their partner/spouse (51%) or their child (22%). Fewer indicated being most significantly involved in the HIV-related care of an "other" relative, a friend, or a parent (3% - 13%). A total of 30% of all caregivers reported that this loved-one was deceased.

! Caregivers whose loved-ones were living with HIV/AIDS were at various stages of HIV disease. However, the majority were in relatively good health, either experiencing symptoms "some of the time" or asymptomatic (i.e. 70% of the PLWHIV/AIDS). Approximately one-quarter of the caregivers noted that their loved-one was at an advanced stage of HIV disease, and less than 10% indicated that they were chronically experiencing symptoms.

- ! Most caregivers reported that their loved one currently required “a little” through to “a moderate” extent of HIV-related care from both formal (e.g., physician, nurse, social worker) and informal (e.g., family members, partner and/or friends) caregivers. The ratings assigned to both were virtually identical and underscore the importance of both professionals and loved-ones in HIV-related care.

② Involvement in HIV/AIDS-Related Palliative Care

- ! Various types of involvement in HIV/AIDS-related care were cited by the informal caregivers. First, the provision of emotional support was noted by the vast majority of caregivers whose loved-ones were living with HIV/AIDS as well as by those whose loved-ones were deceased.
- ! Approximately one-half of the caregivers who had lost their loved-one to HIV/AIDS had provided support in various other health-related and practical domains, including: Help with errands, nursing care (e.g., medications, changing dressings), basic care (e.g., bathing, grooming), and housework.
- ! While relatively fewer present-day HIV/AIDS-related caregivers were involved in either basic care (15%) or nursing care (21%), close to one-half were providing practical support (e.g., help with errands and housework), and 83% reported that they were in daily contact with their loved-one.
- ! Approximately one-half of all respondents indicated that other informal caregivers were also involved in their loved-one’s HIV-related care; 12% cited the involvement of trained volunteers; and approximately one-quarter said that they were alone in the provision of their loved-one’s care.

③ Experiences and Feelings

- ! While the majority of caregivers reported feeling a greater closeness and emotional connection to their loved-one since finding out about his/her diagnosis, the findings also point to the current prevalence of certain HIV-related caregiving challenges and stressors- e.g., emotional/psychological difficulties and AIDS-related grief/bereavement were the two most commonly cited experiences, and were reported by 77% - 85% of caregivers.
- ! Several challenges were reported as relatively intense - i.e., ratings of 3 or 4 on the 4-point scale - by approximately one-quarter to one-half of all caregivers. These respectively included:
 - Exhaustion/burn-out;
 - Feeling alone, isolated, and/or unsupported in HIV/AIDS-related caregiving;
 - Lack of accessible HIV/AIDS-related services;
 - Lack of accessible home care and palliative care services;
 - Emotional/psychological difficulties; and
 - HIV/AIDS-related grief/bereavement.

Further, 44% of the caregivers who were also diagnosed with HIV/AIDS were experiencing a relatively high level of related symptoms.

④ Information and Support Services/Needs

HIV-Related Knowledge and Comfort Ratings

- ! More than one-half of all caregivers reported that they had never received any information about HIV/AIDS and palliative care (e.g., what it is; services available; issues).

- ! Participants' self-ratings of their knowledge and comfort levels related to providing (or potentially providing) HIV/AIDS care to their loved-one also indicate the need for education/training for a significant proportion of caregivers in the Atlantic Region.
 - Ratings of “very adequate” and “very comfortable” were provided by only 25% and 33% of respondents, respectively.
 - In total, 27% of all caregivers rated their knowledge was either very or generally inadequate, and 19% rated themselves as very or generally uncomfortable in the provision of HIV/AIDS care.

Sources of HIV/AIDS-Related Support and Information

- ! While the vast majority of caregivers identified at least one person or organization as a source of support to help them deal with having a loved-one with HIV/AIDS, the results underscore the need for providing HIV/AIDS-related caregivers with additional emotional support.
 - Approximately two-thirds of caregivers indicated that there were various sources of support that they needed but were not receiving or receiving sufficiently. The five most needed sources of support were: Medical professionals; AIDS Service Organizations; other family members; one's partner or spouse; and, mental health professionals. Each of these received top five rankings by 24%-39% of caregivers as their greatest unmet HIV-related support needs.

- ! Almost one-third of caregivers stated that they had never received any HIV-related information or support services related to their loved-one's care or needs. Although 58% of participants had received some type of service from ASO's, they had received HIV-related information or support from relatively few other sources.

e.g., only 3% - 15% of caregivers had ever received related services from National or Provincial Palliative Care or Home Care Associations; Home Health Care Agencies; Local Hospices; and Hospital-based Palliative Care Programs.

Current and Anticipated HIV-Related Service Needs

- ! With the exception of AIDS organizations (i.e., being utilized by 39% of caregivers), relatively few caregivers were currently using HIV/AIDS-related services. For instance, respite care, palliative care education, grief/bereavement counselling, emotional/psychological counselling, peer support, and spiritual/pastoral support were only being accessed by 5%-18% of all caregivers, respectively.

- ! As was found with the sample of persons living with HIV/AIDS, however, a substantial proportion of caregivers anticipated using or needing many of these services. For example, approximately one-half to two-thirds of all caregivers anticipated a need for: Peer support/counselling, spiritual/pastoral support, respite care, emotional/psychological counselling, grief/bereavement counselling, and palliative care education.

HIV-Related Information Needs

- ! The vast majority of participants (93%) indicated that there were several types of information that would be useful to them as HIV/AIDS-related caregivers.
 - Information pertaining to the basics of palliative care was the most frequently cited greatest need (i.e., ranked in the top 5 by 61% of caregivers). However, a number of other types of information also received high rankings by 25% - 41% of participants. These respectively included information on:
 - HIV/AIDS symptoms and illness
 - Complementary therapies
 - HIV/AIDS medications and their side effects
 - Basic nursing care (e.g., giving medications, injections, changing dressings)
 - Legal issues and services (e.g., wills, living wills, power of attorney)
 - Community services available to persons living with HIV/AIDS & their family and friends
 - Care for the dying and the bereaved (e.g., the last hours, funerals, memorials)
 - Pain control
 - Providing emotional support to persons living with HIV/AIDS
 - Emotional and practical support for HIV/AIDS caregivers

- ! Caregivers provided top three rankings to the following as the educational approaches to best meet their informational needs:
 - Support groups/consultations with other informal caregivers (34%)
 - Consultations with experienced palliative care providers (34%)
 - Local workshops (29%)
 - Consultations with experienced home care providers (27%).
 - Written materials (27%)

4.3 Recommendations and Conclusions

The following is a listing of the recommendations based on the main findings pertaining to the HIV-related experiences and needs of persons living with HIV/AIDS and their informal caregivers in the Atlantic Region. It should be noted that the information contained in this section is meant to complement, not replace, the recommendations stemming from the earlier assessment regarding the HIV-related educational needs of formal caregivers involved in the provision of in-patient and home-based palliative care. In fact, as outlined in Table 15, meeting the various current and anticipated HIV-related palliative care needs of persons living with HIV/AIDS and their caregivers will also necessitate the timely implementation of recommendations stemming from the needs assessment survey of professional caregivers.

It is recommended that the Canadian Palliative Care Association strive toward six main objectives in its planning and advocacy efforts toward meeting the needs of persons affected by HIV/AIDS in the Atlantic Region. These are applicable to the needs of both persons living with HIV/AIDS and to their caregivers. It should be noted that the objectives and recommended strategies are neither exhaustive nor arranged in order of priority. However, they are intended primarily to spark additional discussion and mobilization toward the fulfilment of various HIV-related palliative care needs.

- ❶ To increase overall knowledge and comfort levels around various palliative care issues;
- ❷ To address greatest HIV-related information needs;
- ❸ To decrease HIV-related financial stressors;
- ❹ To increase the availability and accessibility of quality home care and palliative care services;
- ❺ To decrease certain HIV-related psychosocial stressors; and
- ❻ To further explore strategies for best meeting PLWHIV/AIDS and caregivers' greatest anticipated HIV-related service needs.

5.0 APPENDICES

(not available in PDF version)

- Cover Letters
- Questionnaires