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**The Impact of Support Services  
Provided by the AIDS Committee of Ottawa  
on Persons Infected by HIV/AIDS**

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## **EXECUTIVE SUMMARY**

### **Objective**

The purpose of this study was to compare the effects and expenses resulting from more and/or less use of AIDS Committee of Ottawa (ACO) Support Services for persons infected by HIV/AIDS. ACO Support Services include individual and/or group counselling, drop-in “Living Room” support and tangible aid (food, clothes, affiliation and/or income) alone or in some combination.

### **Design**

This was a historic cohort analytic study of a convenience sample of 50 Persons with HIV/AIDS (PHAs) measured after classifying them according to their prior receipt of more or less intense support services from ACO. Measures included sociodemographic information such as length and current severity of HIV/AIDS, living arrangements and prior occupations, social support, depression, Karnofsky Rating Scale (KRS), the Medical Outcomes – HIV Health Survey, and inventory about their use of ACO and all other health and social services and their satisfaction with ACO services.

### **Results**

A greater proportion of high users of ACO services were statistically significantly single, in poorer function, lived alone and reported less affective support. While not statistically significant, high users of ACO approached the depressed range ( $\geq 20$ ) of the Centre for Epidemiological Studies Depression (CES-D) Scale while low users did not ( $\bar{x} = 17.3$ ).

While there was no difference in the KRS current status of HIV illness, CD4, viral load, functional states, quality of life (MOS-HIV Score), income, employment status, high users of ACO Services had administratively lower total mean expenditures for the use of direct government funded expenditures largely due to less use of medication (\$14,706 vs. \$16,002). High users of ACO Services had greater per person, per annum expenditures for the use of direct services: family physician (\$300 vs. \$138); emergency room physician (\$215 vs. \$17); psychiatrists (\$234 vs. \$51); community funded dentists (\$1375 vs. \$133); ACO counsellors (\$347 vs. \$48) and food banks (\$222 vs. \$150).

Lower users of ACO services had higher per person, annum expenditures for HIV specialist (\$665 vs. \$255); other physician specialists (\$382 vs. \$183); chiropractors (\$261 vs. \$14); laboratory tests (\$1506 vs. \$933) than their high user counterparts.

Forty percent (40%) of clients of ACO were depressed (> 20 CES-D Score) and these depressed persons rated their health more poorly in every dimension. Depressed PHAs at ACO had less disability support, used fewer medications, yet consumed more social assistance, family physicians, psychiatrists, visiting nurses, psychologists, children's aid, 911 and hospital services, addictions counsellors, support groups, food bank services and had greater out-of-pocket expenditures for medications, complimentary therapy, supplies and devices.

## **Conclusion**

The ACO is providing most of its services to the more vulnerable group of PHAs who are single, with poorer function, live alone, with less support, more depressed and higher users of other government funded services and lower use of all medications. There is a need to train

ACO providers in the recognition, appropriate referral and compliance with treatment for depression.

## **PRESENT STATE OF THE KNOWLEDGE**

There has been a dramatic shift of the human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) epidemic into poor, marginalized and minority communities. At the same time, the availability of new highly active antiretroviral treatments has made it possible for a large number of individuals to live for a much longer time with their disease. A net result is that the community is faced with an increasing number of people who are living with HIV/AIDS and are dependent on publicly supported health care services (O'Neill, Marconi et al, 2000).

Also as a result of such changes, people living with HIV/AIDS now often require service over several years rather than months, as once was the case. As PHAs live longer, the emphasis has become directed toward living a better quality of life; “Traditional” staff and volunteer services, such as buddy supports, volunteer drivers, peer counselling, support groups and hospital visitation have expanded over time to include housing assistance, foodbanks, needle exchange, counselling regarding work or family issues, information about treatment options and new treatment effects, access to complementary therapies and alternative therapies or nutritional counselling to name a few (Cain, 1997).

Another result of the improved prognosis for people living with HIV/AIDS is the developing opportunity and emphasis for them to remain in the workforce or re-enter the workforce. This change in work potential has resulted in a growing emphasis on rehabilitation efforts to maximize active daily living within a chronic illness and develop the necessary skills for labour force participation.

The persons infected, affected and devastated by the HIV/AIDS epidemic initially were primarily the gay population and it was the gay community that rallied to provide support and

compassionate care to its own community. Though the gay population continue to be most affected by the epidemic (72.8%) both in terms of absolute number of HIV-infected persons and HIV prevalence rates, several other groups are growing in both relative and absolute importance (Remis, Wallace et al, 1999). For example, in Ontario persons from HIV-endemic countries constitute a growing proportion of AIDS cases (2.3%) and mother infant HIV transmissions. High rates of HIV infection in Intravenous Drug Users (IDUs) are reported. Persons infected by heterosexual contact represent a relatively smaller number of persons infected to date (8.5%) but Remis et al. (1999) report that this group is growing rapidly.

The prevalence and incidence rates of HIV are slightly different for the Ottawa area. An estimated 3.5/1000 HIV prevalence rates in the Ottawa population in 2000 (Anne Right & Associates Inc, 2003) are reported. An increasing incidence (new cases) of HIV is reported in the Ottawa area. (270 estimated in 2000 versus 195 in 1999). The number of AIDS cases is dropping (from 78 cases in 1991 to 11 cases in 2000). Case fatality is declining, therefore, the numbers living with HIV are increasing. MSM account for the highest prevalence and incidence. It is reported that the HIV prevalence rate in MSM is increasing faster in Ottawa than Toronto. The estimated prevalence among IDUs in Ottawa is reported to be 18% and co-infection with HEP-C is becoming a worrisome concern. Persons from HIV endemic countries in the Ottawa area have the highest rate of maternal transmission and a much higher rate of infection in men. Transmission occurs mainly through heterosexual contact in this group. The estimated incidence among heterosexuals in the Ottawa area is doubling with a higher infection rate among women. In addition, 18% infected MSM report also having sex with women. The higher rates of parents are also reflected in children exposed to HIV (of the 120 exposed, 25 children were infected).

The challenge for those working in the field is to develop a comprehensive system of support that accesses existing publicly funded services, which collaborate together and with the individual to provide holistic care. Thus, co-ordination, collaboration and communication are essential if this network is to meet the physical, psychological, social and spiritual needs of people now living with HIV/AIDS (Linkewich, Setliff et al, 1999).

Workers in ASOs need a wide range of practice skills and need to be knowledgeable about many issues including medical treatments and how to manage the effects of treatments, counselling about employment and related concerns, death/dying, bereavement, dealing with a culturally diverse clientele, accessing and co-ordinating community resources and accessing government entitlement (Cain, 1997) to name but a few. Quality health care remains difficult to define in a concise, meaningful and generally applicable way (Blumenthal, 1996).

Arnes and Higginson (1999) assessed the components of high-quality HIV care using the multidimensional model of quality assessment developed by Maxwell (1984, 1992) Maxwell's model identified the components of high-quality HIV care as competent, skilled practitioners (effectiveness); confidential, non-discriminatory and culturally sensitive care (acceptability); collaborative and co-ordinated care (efficiency); flexible and responsive care (access and relevance to need); and fair access for all clients (equity). Their results showed that the six dimensions of quality appeared to be inextricably linked from the client's point of view.

Each of these changes in the prevalence rates and the clinical course of HIV/AIDS places new demands on the support services required and how these services are delivered.

## **BACKGROUND**

The AIDS Committee of Ottawa (ACO) was established in 1985 in response to the HIV/AIDS crisis. As the ACO vision statement reflects, the organization exists to provide support, advocacy, prevention and research education for men, women and children living with or closely affected by HIV/AIDS. It does this by collaborating with other organizations and the PHA community to promote the well being and quality of life of persons living with or clearly affected by HIV/AIDS (mission statement).

The real interests of the AIDS Committee of Ottawa (ACO) are in documenting the need for and effects and expenses (costs minus costs averted) of their support services program to persons infected by HIV/AIDS. The function of support services is to address the psychosocial, coping and social issues of clients infected by HIV/AIDS. Other support services offered include tangible aid (food, clothes, affiliation, income).

The interest of ACO is to ensure that support services attend to the alleviation of symptoms and suffering through their provision of high quality care at the most efficient cost. A broader provision of supportive care for its clients will contribute to improving care for the disenfranchised.

## **OBJECTIVE**

The primary purpose of this study was to compare the effects and expenses resulting from more and/or less AIDS Committee of Ottawa support services for persons infected by HIV/AIDS. Support services of the AIDS Committee of Ottawa include individual and group counselling, and drop-in “Living Room” support.

## **Questions**

1. What was client satisfaction with AIDS Committee of Ottawa Support Services?
2. What was the effect (Medical Outcomes HIV Health Survey) and comparative expense of clients served more or less intensely with support services? Here, it is hypothesized that higher levels of support services result in better outcomes and pay for themselves by averting the use of other publicly funded services
3. What client variables (disease, social, health status) distinguished high and low users of support services?
4. What were the comparative client and health services utilization variables between those clients of ACO that are depressed and those that are not depressed?

## **Design**

This was a historic cohort analytic study of the AIDS Committee of Ottawa community caseload of 50 persons measured at one point in time and classified as to their prior receipt of intense or less intense support services at the AIDS Committee of Ottawa community services.

## **MEASUREMENT**

As outlined in an adaptation of Maxwell's (1984) model, structure process and outcome variables were assessed at one point in time.

1. Structure Variables (Services Provided)
  - Amount of service use.
2. Process Variables (Characteristics of Service Users)
  - Presence of depression; social support; Karnofsky Rating Scale (of disability).

➤ Client characteristics including disease severity (CD4 Count, Viral Load).

3. Outcome (Service Effectiveness) and Use of Health and Social Services

➤ Quality of life; client satisfaction with care; per person annual expenditures for all health and social services use.

4. Client narratives about:

- a. Services viewed as most helpful and/or useful and why
- b. Needs, wants, issues, predicaments not currently being addressed by existing services
- c. Ideas about refinements in services that could ameliorate these challenges, who (which agency) should provide these

At the completion of data collection, the data recorded at the time of the interviews were transferred to coding sheets.

## **Measures**

The specific measures that were used include:

### Demographic Questionnaire

Demographic information was obtained from clients and included age, gender, language, ethnic background, education, income, length of time diagnosed with HIV/AIDS, severity of disease rating (The Measurement Group, 1996), living arrangements, and current or previous occupation.

### Health Related Quality of Life and Depression

We were interested in examining whether or not the types of social support and/or the occurrence of depression were associated with the use of health and social services utilization.

## Social Support

Social Support has been proposed to serve as a buffer or modifier of the effects of psychosocial and physical stress on the emotional and physical health of the individual (Broadhead, Kaplan et al, 1983; Cohen and Wills, 1985). The Social Support Questionnaire measures two components of perceived emotional support: confidant support, reflecting a “confidant relationship where important matters in life are discussed and shared” and affective support, reflecting a more emotional form of support or caring. Construct validity, concurrent validity and discriminate validity have been demonstrated for the two scales (Broadhead, Gehlbach et al, 1989). The lower score of this 6-point scale reflects an assessment “as much as I would like”; the higher score reflects an assessment “much less than I would like”.

## Depression

Depression was assessed for clients using the Centre for Epidemiological Studies Depression Scale (CES-D Scale). This is a 20-item, four-point Likert summative scale, rated from zero (rarely) to three (most or all of the time), with a range of zero to 60. Clinically meaningful scores have been demonstrated with a score of 20 or higher indicative of dysthymia, and 40 signifying a major depression. Ratings are summed for a total score. The CES-D Scale has been widely used as a short, easily administered indicator of depression in non-psychiatric populations (Radloff, 1977). With a sample of 754 care givers, Given et al. (1992), reported a reliability value of .91 Coefficient Alpha. Time to complete the instruments is estimated to be approximately 15 minutes.

Client depression was also assessed using the Mental Health Summary Scores obtained from the administration of the MOS-HIV Health Survey questionnaire (see description below)

(Wu, 1996). The Mental Health Summary Score is composed of the summed scores of 5 scales including Mental Health, Health Distress, Quality of Life, Cognitive Function and Vitality. Means and standard deviations for the summary scores were used in the analysis. Revicki et al. (1998) reported that patients with more symptoms of depression, measured by the Centre for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977) with mean scores greater than 23 corresponded to scores of 36 (SD=0.07) on the Mental Health Summary Scale. In a survey of 26 PHAs using community AIDS support services, Lush et al, (2002) demonstrated that a CES-D score of 20 or higher (depressed) was associated with a clinical meaningful Mental Health Summary Score of less than 43.

#### The Karnofsky Rating Scale

This scale indicated the client's current performance status (or level of functioning) as indicated by the client's ability to perform common tasks. The scale ranges from 0-100% with a rating of 0% equal to the client being deceased and a rating of 100% to the client being normal and manifesting no signs of disease (The Measurement Group, 1996).

#### Quality of Life (MOS-HIV Health Survey)

The Medical Outcomes Study HIV-Health Survey is a brief, comprehensive measure of health-related quality of (HRQoL) used extensively in diverse groups including human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) (Wu, Revicki et al, 1997; Wu, Hays et al, 1997). The 35-item questionnaire assesses ten dimensions of health including general health perceptions (5 items), pain (2 items), physical functioning (6 items), role functioning (2 items), social functioning (1 item), cognitive functioning (4 items), mental health

(5 items), energy/fatigue (4 items), health distress (4 items), quality of life (1 item), and health distress (1 item). The questionnaire takes about 15 minutes to complete. Subscales are scored on a 0-100 scale (a higher score indicates better health) and physical and mental health summary scores can be generated. The MOS-HIV has been shown to be internally consistent, correlate with concurrent measure of health, discriminate between distinct groups, predict future outcomes and be responsive to changes over time. Limited experience suggests acceptable reliability and validity in women, injection drug users and African-Americans and lower socio-economic status patients. The MOS-HIV is available in 14 languages and has been included as a secondary measure in numerous clinical trials for all stages of disease. In several studies, it has detected significant differences between treatments, in some cases concordant with conventional endpoints and, in others, discordant. The interpretation of scores is facilitated by an explanation in terms meaningful to the intended audience.

#### Client Satisfaction with Services

Satisfaction with the services provided by AIDS Committee of Ottawa was measured using the Client Satisfaction questionnaire (CSQ) (Attkisson and Colleagues, 1992). This eight-item questionnaire is answered on a scale from one to four indicating dissatisfaction or satisfaction with global and specific aspects of the services being evaluated. The questionnaire can be given a total score. Content, construct and predictive validity have been reported as good and split-half reliability and internal consistency are high.

## Health and Social Service Utilization Questionnaire (HSSUQ)

The use of health and social services for each client was documented. The health and social service utilization variable was measured by an inventory developed by Browne, et al. (1990) based on Spitzer's methodology. It consists of questions about the respondent's use of categories of direct health services/primary care, emergency room, specialists, hospital episodes and days (irrespective of episode), use of other health and social professionals, and laboratory services. Inquiries are "*restricted to the reliable duration of recall span: six months for remembering a hospitalization, two weeks for a visit to a physician, and two days for the consumption of a prescription medication*" (Spitzer, Roberts et al, 1976). To calculate annual utilization measures, the various spans of time are extended to yield an annual rate of utilization per category of health and social service and multiplied by the dollar value of the service to yield a measure of costs of health service. Browne et al. (1990) added questions to the health service utilization inventory, designed to assess the direct out-of-pocket expenditures, indirect costs, cash transfer effects of illness and other social costs. The additional approaches to the measure of out-of-pocket expenditures and the assignment of dollar values for direct and indirect costs are described more fully elsewhere (Browne, Arpin et al, 1990). This measure has been tested previously and has demonstrated discriminant validity. High levels of observed agreement (.72-.99) between the patient and the clinic record have been reported (Browne et al, 1990).

### **Analysis**

Descriptive analysis using descriptive statistics of means, medians, SD's, proportions and confidence intervals were used to describe proportions of clients exposed to different intensities of services, mean sociodemographics, and depression scores, MOS-HIV survey scores, use of

health and social services, and satisfaction with services. T-tests were used to determine the differences in means between groups in CES-D, MOS-HIV scores and Kruskal Wallis tests for differences in utilization of services costs in dollar values. Stepwise regression models were developed to explain predictors of physical health, mental health and cost of services.

### **Sample Size**

In order to determine a difference of 15, with SD of 20 on the MOS-HIV scale, at least 29 subjects/group using  $\alpha = .05$  (2 tail) and  $\beta = .20$  were needed.

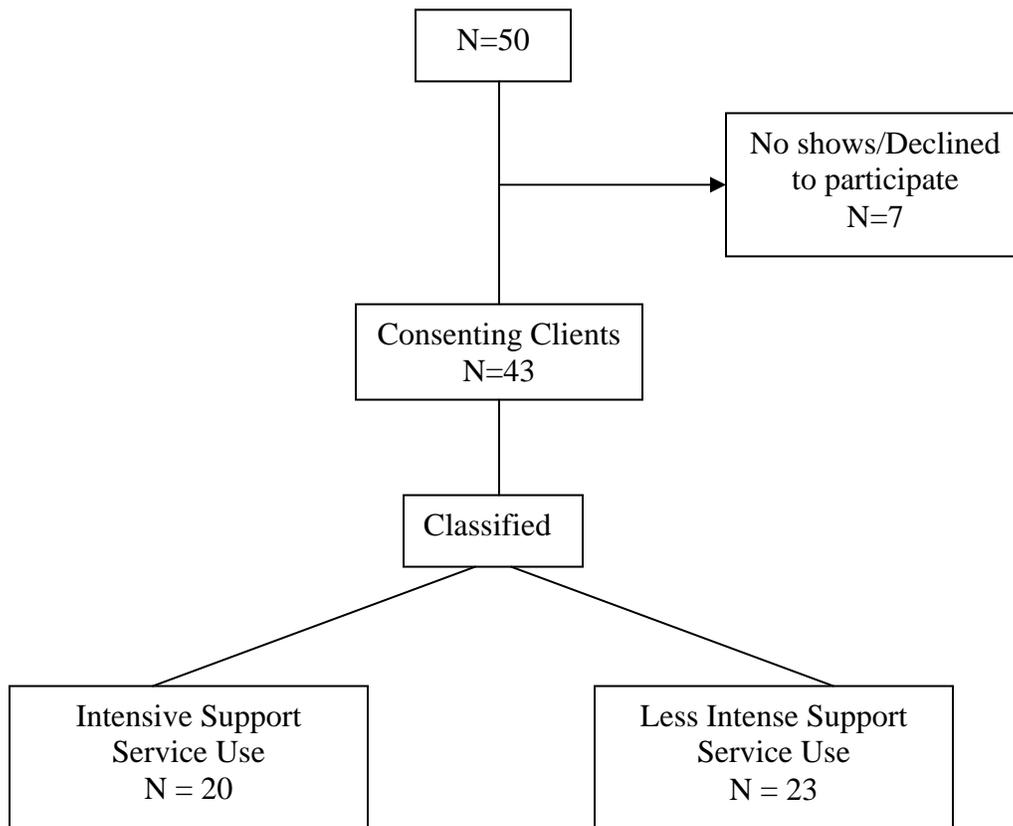
### **Ethics**

All clients had a choice of participating in the study which involved completing questionnaires. The test results were completely anonymous. The participants signed consent for the study. Clients had the choice of withdrawing or refusing the study at any time and this would not in any way affect their care or service. The medical ethics committee at McMaster University approved the study and the consent form.

## RESULTS

Fifty clients were approached to participate of whom 7 did not show for the interview or declined to participate. Twenty clients were high intensity users of ACO services; 23 were low intensity service users.

### Sampling Frame AIDS Committee of Ottawa Clientele



### Demographic Information of Respondents

There were 43 respondents to the study: 35 (81%) males and 8 (19%) females. All were Canadian (Table 1). Most respondents (51%) were 40 – 49 years of age with a mean age of 42 years (7+/- years). Most (58%) were single, 35 % reported being married, living common-law or in a partnership; and 7% were divorced, separated or widowed. Most reported that they had

some/or completed college or university education. The most common first language was English (65%) and French was the first language of 28%. French-Canadian was the most often reported (35%) ethno/cultural background; English Canadian was reported by 21%; Native by 7%.

Most respondents lived in their own house/apartment or subsidized housing (28%); 9% lived in transitional housing; 5% reported being homeless and 5% were living in someone else's house or apartment. 54% reported living alone; 23% with a spouse/partner; living with roommates was reported by 9%, with children by 12% and with other family members by 5% of the respondents. Most respondents lived in the city core. Respondents reported an average of 7 years in their present relationships. An average of 10 years (+/-6 years) was the reported length of time diagnosed with HIV/AIDS (Table 1). Partners, family members and friends (37%) were the greatest referral source to the services of the AIDS Committee of Ottawa (Table 2).

**Table 1**  
**Demographic Information of Respondents**

Variable	Total (N=43)	
	Count	%
<b>Gender</b>		
Males	35	81%
Females	8	19%
<b>Age</b>		
20-29 years old	4	9%
30-39 years old	10	23%
40-49 years old	22	51%
50 & over	7	16%
<b>What is the highest level of education you have obtained?</b>		
None	1	2%
Grade School	10	23%
High School or equivalent	5	12%
Some/complete college	15	35%
Some/complete university	12	28%
<b>What is your current relationship status?</b>		
Single	25	58%
Divorced/Separated/Widow	3	7%
Married/Common-law/Partner	15	35%
<b>Length of time in present relationship (years) if not single?</b>		
< 1 year	1	8%
one year to five years	4	31%
6 years to 10 years	5	38%
over 11 years	3	22%
<b>How would you describe your ethno/cultural background?</b>		
Canadian	9	21%
French-Canadian	15	35%
Native	3	7%
Other	16	41%
<b>What is your first language?</b>		
English speaking	28	65%
French speaking	12	28%
Other	3	7%
<b>What are your current living arrangements?</b>		
Your house/apartment	23	54%
Transitional housing	4	9%
Homeless/street	2	5%
Someone else's house/apartment	2	5%
Subsidized housing	12	28%
<b>Do you currently live with someone?</b>		
Live alone	23	54%
Spouse or partner	10	23%
Roommate	4	9%
Children	5	12%
Other Family member	2	5%
<b>Geographic location</b>		
City core	33	77%
City suburbs	10	23%

**Table 2**  
**Referral Source to the ACO**

<b>Source</b>	<b>Count</b>	<b>%</b>
Self	8	18.6%
Partner/family members/friends	16	37.2%
ASO	3	7.0%
Physicians/Hospital	5	11.7%
Other	14	32.6%

The respondents were asked to which particular group they felt they belonged. Multiple answers were permitted for this question (Table 3a). Fifty-five percent of the responses (24) identified male, and the same number identified gay; 23% identified themselves as heterosexuals. Twenty-one percent identified themselves as female. Sixteen percent identified themselves as Intravenous Drug Users (IDU). When asked which of the groups the respondent felt he/she most closely identified with and belonged to (Table 3b), 31% responded gay, 21% responded heterosexual and 17% responded male and 7% female.

**Table 3a**  
**Classifications Clients Identified With**

<b>Particular groups which clients felt they belonged to. (multiple answers)</b>		
<b>Group</b>	<b>N</b>	<b>%</b>
Male	24	55.8%
Female	9	20.9%
MSM	3	7.0%
IDU	7	16.3%
HIV endemic countries	2	4.7%
Heterosexual	10	23.3%
Bisexual	3	7.0%
Gay	24	55.8%
Aboriginal	3	7.0%
Ethno-Specific	2	4.7%
Street Involved	2	4.7%
Youth	3	7.1%
Other	10	23.3%

**Table 3b**  
**Classifications Clients Most Identified With**

<b>Groups the client felt he/she belonged to the most.</b>		
<b>Group</b>	<b>N</b>	<b>%</b>
Male	7	16.7%
Female	3	7.1%
Heterosexual	9	21.4%
Bisexual	2	4.8%
Gay	13	31.0%

Several indexes were used to assess health status, quality of life and current stage of illness of the respondents. The quality of life (MOS-HIV Health Survey) questionnaire is scored on a scale (0-100) with higher scores indicating better health (Table 4). The Physical Function (mean 67.8), Social Function (mean 68.4), Cognitive Function (mean 72.0) and the Health Distress (mean 70.2) Index mean scores suggest moderately good health in those aspects.

The Role Function index score reflects poor role function and problems with work or other daily activities. The overall Health Perception index score (mean 48.6), Pain Index score (mean 60.1), Energy/Fatigue index score (mean 47.8), Quality of Life index score (mean 57.0) and the Health Transition index score (mean 55.8) suggest moderate health.

The client scores of the HIV Health Survey reflect poorer health status than those of other studies (Burgess, Dayer et al, 1993; Revicki, Wu et al, 1995) of samples based on all stages of HIV status.

**Table 4**  
**Functional Health Status and Quality of Life Index Score (0-100)**  
**(MOS-HIV Health Survey)**

<b>Index Score</b>	<b>Mean</b>	<b>SD</b>
Overall Health Perception Index score	48.6	32.4
Physical Function index score	67.8	25.6
Role Function index score	26.7	39.9
Social Function index score	68.4	32.4
Cognitive Function index score	72.0	25.5
Pain function index score	54.8	28.5
Mental Health Index score	60.1	23.3
Energy/Fatigue index score	47.8	23.2
Health Distress index score	70.2	29.2
Quality of Life index score	57.0	25.8
Health Transition index score	55.8	27.7
Physical health summary index score	53.39	21.78
Mental Health Summary index score	60.04	21.29

Most respondents rated their overall health (KRS scale) as good (51%) to excellent (14%), although 32% rated their health as fair (28%) or very bad (4.7%); one person reported that he could not rate his overall health (Table 5). In their assessment of their current stage of illness (Table 6), most respondents reported that they were able to carry on normal activity with or without effort and with or without some signs or symptoms of disease. Nineteen percent of the respondents reported that they could care for themselves but were unable to carry on normal activity; 5% required occasional assistance and 5% reported they were disabled and required special care and assistance.

**Table 5**  
**Rating of Overall Health (KRS Scale)**

<b>Rating</b>	<b>Count</b>	<b>%</b>
1 Excellent	6	14.0%
2 Good	22	51.2%
3 Fair	12	27.9%
4 Very Bad	2	4.7%
5 Terrible	0	0.0%
6 Don't Know	1	2.3%

**Table 6**  
**Current Assessment of Stage of Illness**

<b>Rating</b>	<b>Definition</b>	<b>N</b>	<b>%</b>
100	= Normal; no complaints; no evidence of disease.	7	16.3
90	= Able to carry on normal activity; minor signs or symptoms of disease.	15	34.9
80	= Normal activity with effort; some signs or symptoms of disease.	9	20.9
70	= Cares for self; unable to carry on normal activity or to do active work.	8	18.6
60	= Requires occasional assistance but is able to care for most of own needs.	2	4.7
50	= Requires considerable assistance and frequent medical care.		
40	= Disabled; requires special care and assistance.	2	4.7
30	= Severely disabled; hospitalization indicated although death not imminent.		
20	= Very sick; hospitalization necessary; active, supportive treatment necessary.		
10	= Moribund, fatal processes progressing rapidly.		

**Table 7**  
**CD4 and Viral Load Counts**

	<b>X</b>	<b>SD</b>
CD4 Lymphocyte Count N=35	495	274
Viral Load Count N=36	19,216	41,703

**Table 8**  
**Social Support (Broadhead)**

	<b>Mean</b>	<b>SD</b>
Confidant Support (5-30) (higher = worse)	12.23	6.98
Affective Support (3-18) (higher = worse)	8.67	4.89

**Table 9**  
**Depression Status (CES-D)**

	<b>Mean</b>	<b>SD</b>
CES-D Score	18.63	13.49
<b>Depression Status</b>	<b>N</b>	<b>%</b>
Depressed (21-60)	17	39.5
Not Depressed (0-20)	26	60.5

Social support has been proposed to serve as a buffer of the effects of stress on the emotional and physical health of the individual. The mean  $12 \pm 7$  for confidant support suggests that respondents generally rated their support “as much as they would like”; this rating was similar for affective support (mean  $8.7 \pm 5$ ) (Table 8).

Forty percent of the respondents (N=17) endorsed symptoms of depression as indicated by their CES-D scores (Table 9).

**What is client satisfaction  
with the AIDS Committee of  
Ottawa Support Services?**

Support services of the AIDS Committee of Ottawa include individual and group counselling, support groups and drop-in “Living Room” support. Client satisfaction with each support service he/she used was probed using a 4-point rating scale indicating dissatisfaction or satisfaction with global and specific aspects of the service being evaluated (Nguyen et al, 1983). In addition, comments and suggestions were sought for each question.

Respondents were asked to only assess those services in which they participated. Ten clients had attended individual counselling, nine attended group counselling, and 40 clients used drop-in (Living Room) support services.

The global client satisfaction scores could range from 8 to 32; the higher the score, the greater the satisfaction. The average score for individual counselling was 26 from 10 clients; group counselling was 29 from 9 clients; and 23 for drop-in (Living Room Support) used by 40 clients. As the maximum score could be 32, most rated the services they used highly (average of 23 – 29) (Table 10).

**Table 10**  
**Global Satisfaction Scores**

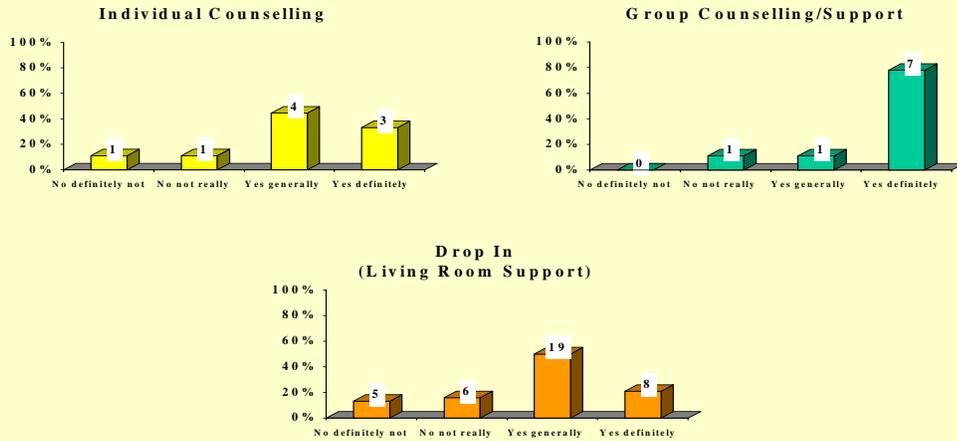
<b>Client Satisfaction Score (8-32)</b>	<b>N</b>	<b>Mean</b>	<b>SD</b>
Individual Counselling	10	26.3	6.3
Group/Support groups Counselling	9	28.76	4.51
Drop-In (Living Room Support)	40	22.9	5.4

The range of services provided by individual and group/support group counselling and drop-in (Living Room) support was generally considered to be what was wanted (Figure 1). The quality for individual and group counselling was rated good to excellent overall.

Figure 1

AIDS Committee of Ottawa  
Satisfaction with Services

Were these the ranges of services that you wanted?



The quality of the most used service, the drop-in Living Room support service, was rated good to excellent by 63% and poor to fair by 38% (Figure 2). Almost all or most needs were met for clients in individual and group counselling. There was more variability in the drop-in service with 55% of clients feeling that most or almost all their needs were met whereas 45% felt that none or few of their needs were met (Figure 3).

Figure 2

AIDS Committee of Ottawa  
Satisfaction with Services (Cont'd)

How would you rate the quality of service you received through?

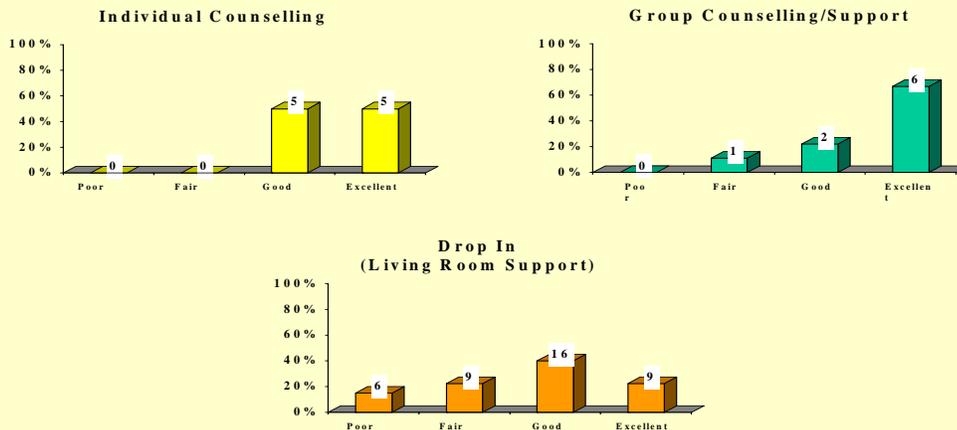
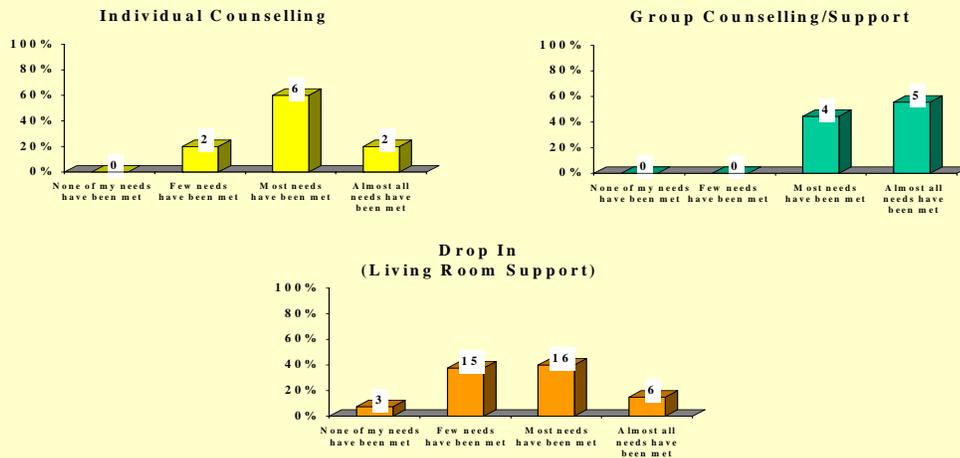


Figure 3

**AIDS Committee of Ottawa**  
Satisfaction with Services (Cont'd)

To what extent has the program met your needs?

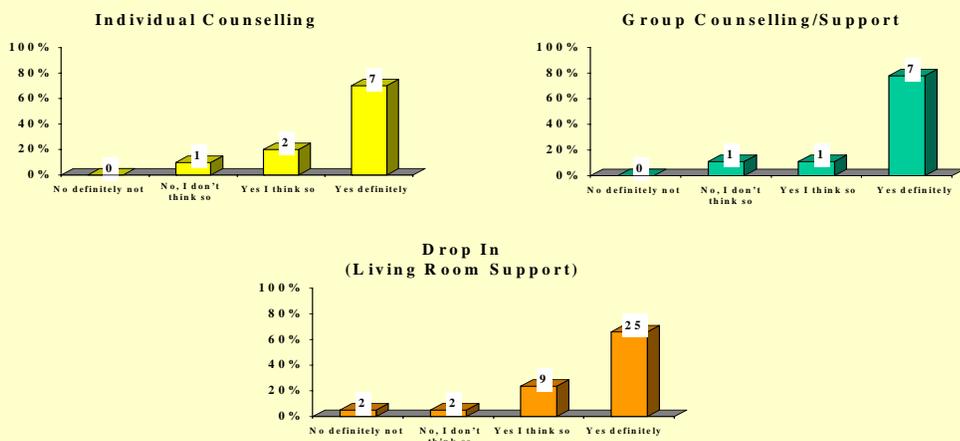


If a friend were in need of similar help, most clients thought they would recommend individual counselling to him/her; most clients who used group counselling would definitely do so; most clients who used the Living Room support thought they would recommend the service (Figure 4).

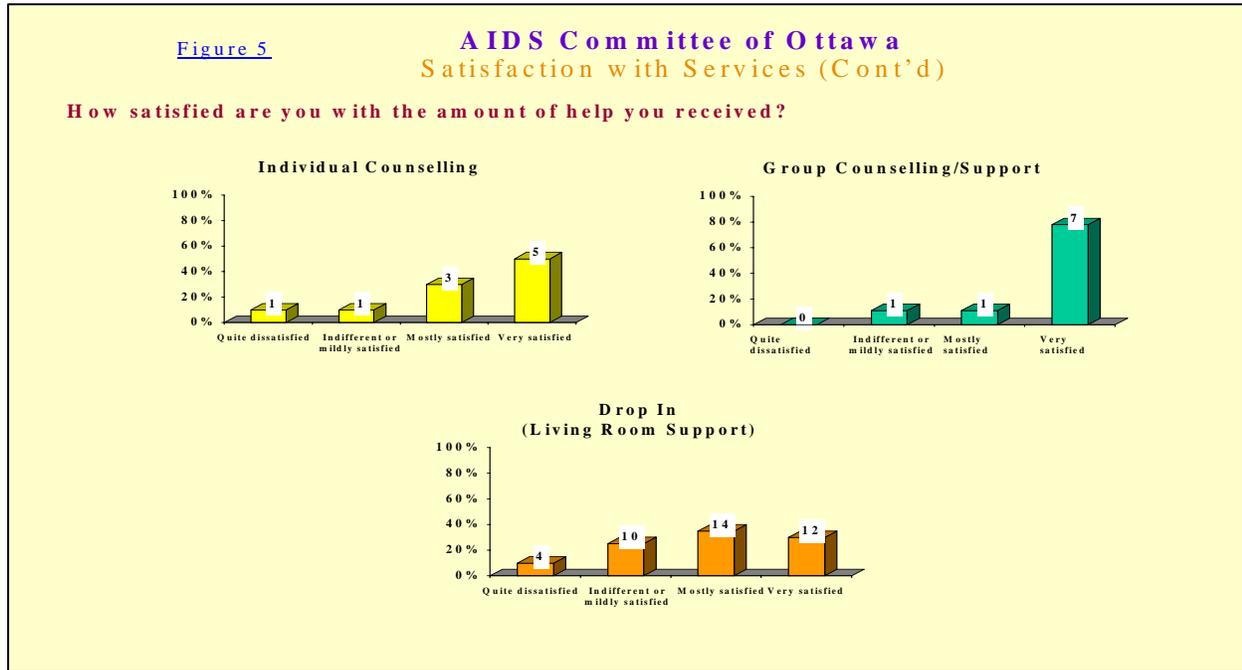
Figure 4

**AIDS Committee of Ottawa**  
Satisfaction with Services (Cont'd)

If a friend were in need of similar help, would you recommend the program to him/her?



Most clients (80%) were mostly satisfied or very satisfied with the amount of help they received in individual counselling; most clients were very satisfied with the amount of help they received in group counselling; 65% were mostly or very satisfied with the Living Room support with 35% dissatisfied or indifferent (Figure 5).

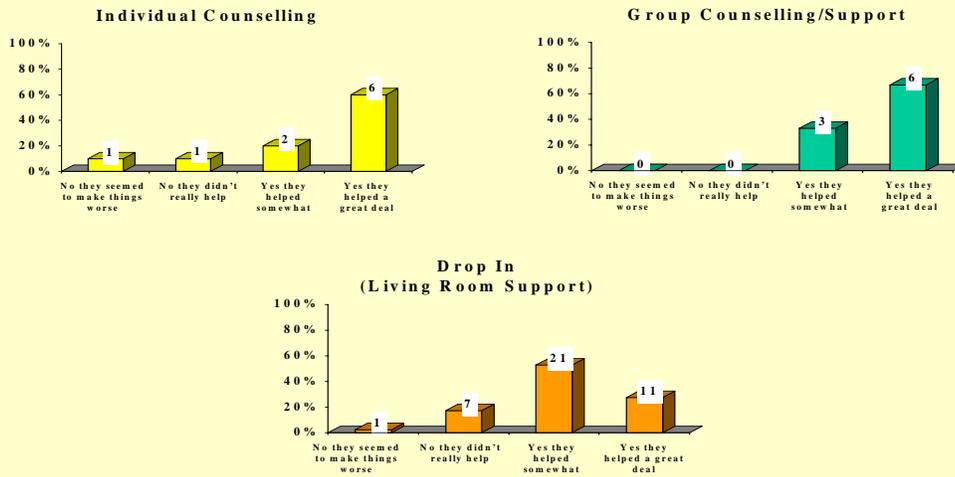


When asked about whether the service helped the client to deal more effectively with his/her problems, 80% responded that individual counselling helped somewhat or a great deal; 67% responded that group counselling helped somewhat or a great deal; 80% of the participants using the Living Room support felt that the service helped them somewhat or a great deal to deal more effectively with their problems (Figure 6).

Figure 6

AIDS Committee of Ottawa  
Satisfaction with Services (Cont'd)

Have the services helped you to deal more effectively with your problems?

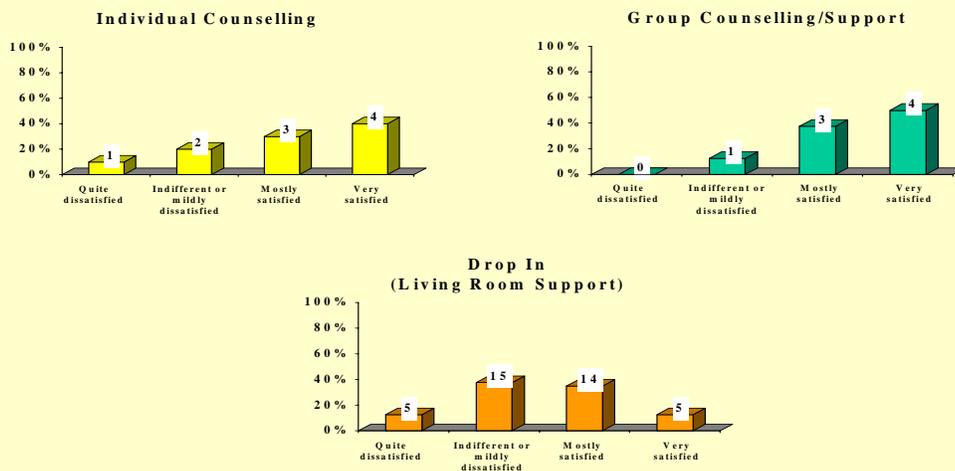


Clients were asked how satisfied they were with the services they received in an overall, general sense (Figure 7). Seventy (70)% were mostly or very satisfied with individual counselling; 88% were mostly or very satisfied with group counselling; half the clients were mostly or very satisfied with the Living Room support while half were quite or mildly dissatisfied.

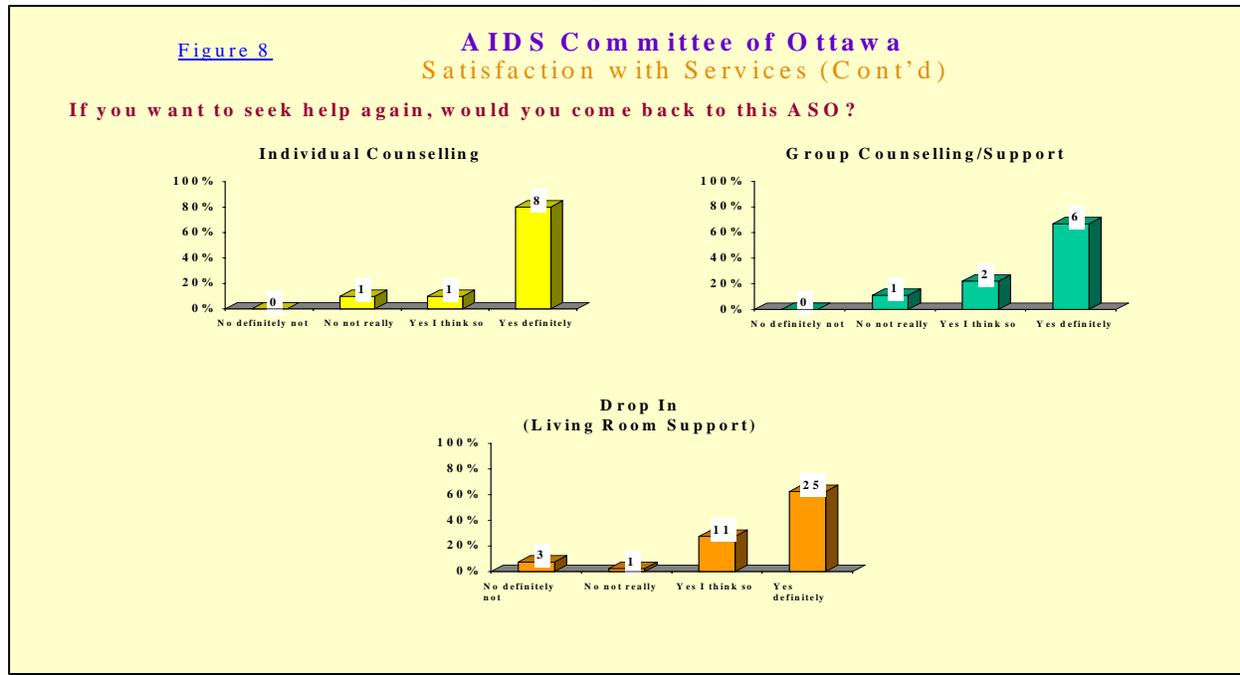
Figure 7

AIDS Committee of Ottawa  
Satisfaction with Services (Cont'd)

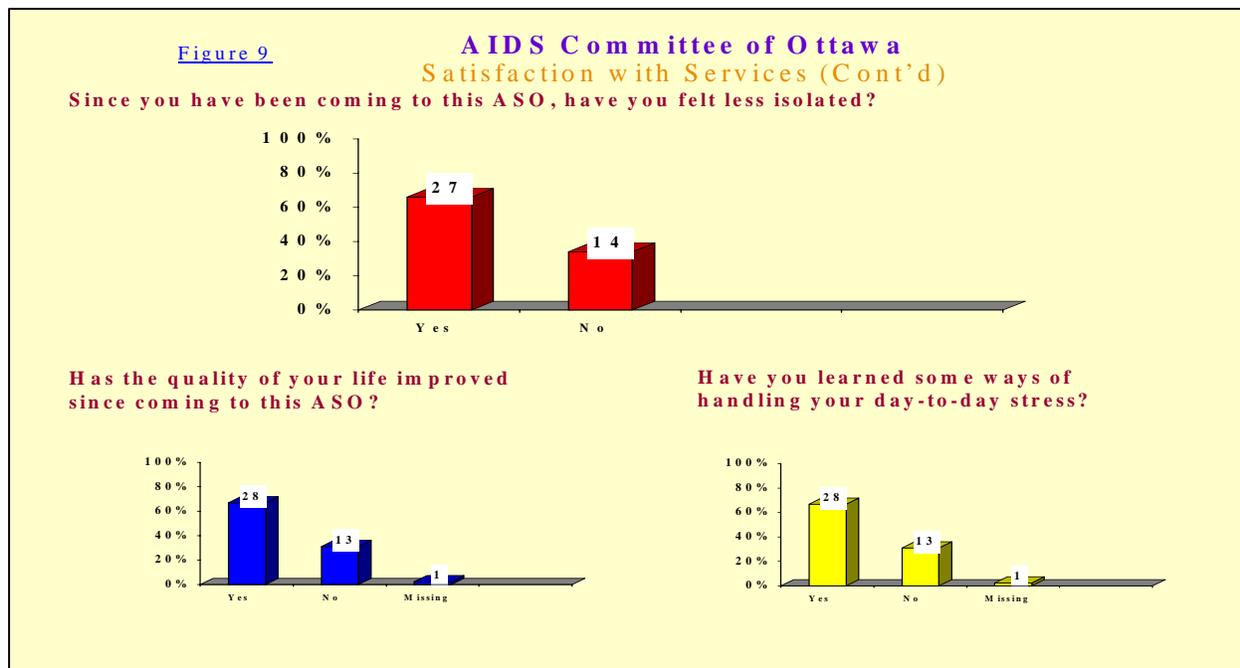
In an overall, general sense, how satisfied are you with the service(s) you received?



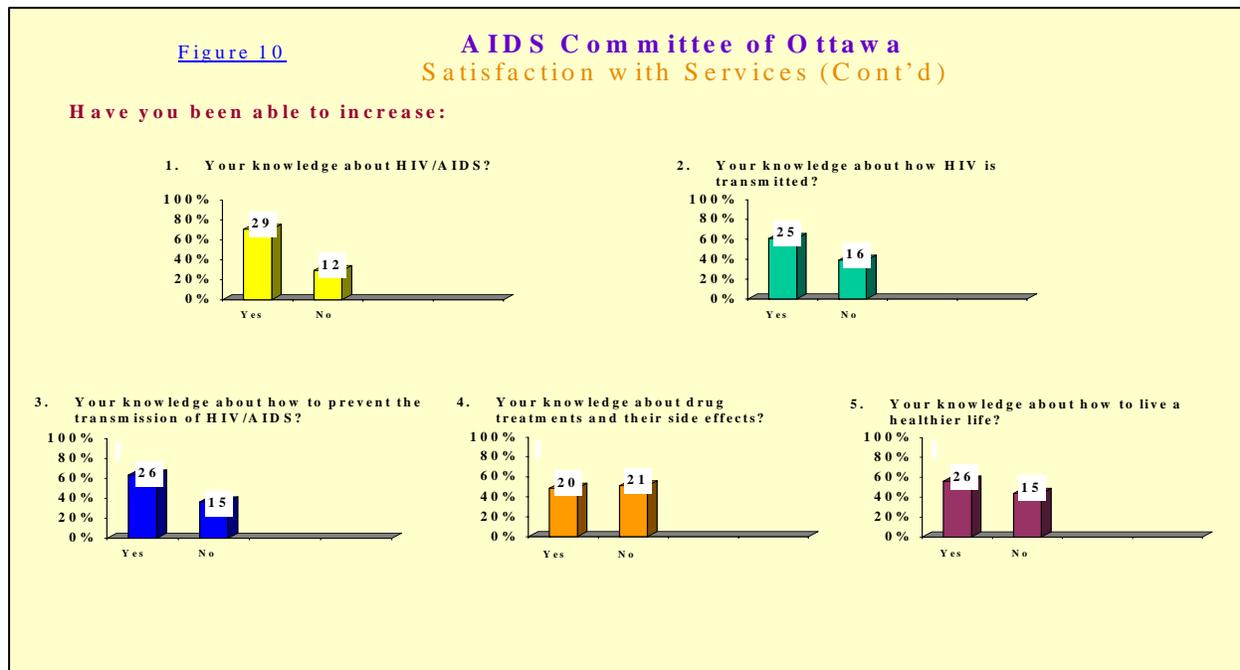
Most clients (80%) who used individual counselling service would come back to ACO for this service again; 67% would return to ACO for group counselling and most clients (90%) would use the Living Room support service again (Figure 8).



All the respondents were asked if they felt less isolated since coming to ACO and 66% responded yes. Sixty-four percent felt their quality of life improved since coming to the ACO and 67% felt they had learned some ways of handling their day-to-day stress (Figure 9).



Most clients (71%) responded that their knowledge about HIV/AIDS increased; their knowledge about how HIV is transmitted increased (61%); their knowledge about prevention increased (64%); about half the respondents (49%) reported that their knowledge about drug treatments and their side effects increased and about half (56%) the respondents reported that their knowledge about how to live a healthier life increased (Figure 10).



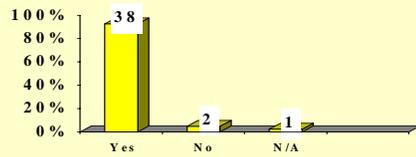
Ninety-three (93) percent of the respondents reported practicing safer sex and 93% tried to influence others to practice safer sex. Twenty-one clients responded to the question regarding use of clean needles and 81% reported doing so (Figure 11).

Figure 11

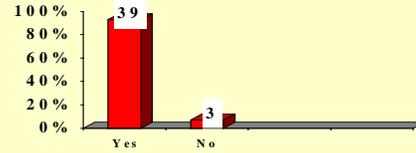
### AIDS Committee of Ottawa Satisfaction with Services (Cont'd)

Do you:

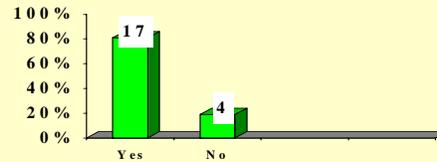
1. Practice safe sex?



2. Influence others to practice safe sex?



3. Use clean needles?



## Qualitative Report of Satisfaction With Services

Support services of the AIDS Committee of Ottawa include individual and group counselling, support groups and drop-in “Living Room” support. Comments and suggestions were sought for each question. The comments for all the questions were entered into Nvivo and the questions were used for coding. Nvivo is designed for use in qualitative data analysis. Emergent and recurring ideas from the data were generated. In using the questions for coding, all the comments from all the interviewees were compiled under each question. The Comments fall into two major categories: AIDS Committee of Ottawa Services and ACO Personnel. The results were subsequently summarized as following:

The staff at AIDS Committee of Ottawa (ACO) provide very good and helpful services to their clients. The services they provide have helped many PHAs emotionally and physically. For instance, some PHAs, in counselling and support groups have found comfort, a “realization of mortality to help me live my life today” and “hope in my life” and “gained the strength to go on”. Others were helped in disclosing their status and sharing “stories” with other PHAs. The

staff has also helped PHAs gain acceptance for what they can and cannot do. Staff provided hope when one PHA felt suicidal.

PHAs have not only physical needs, but also emotional, social and economical needs – for some, clothing exchange is an issue while others say, “a smoking room is needed”. In order for the ACO to address the multiple needs of PHAs, it was thought to be appropriate and a step in the right direction to include the thoughts and concerns of those infected. Moreover, it was also felt that the opportunity to provide suggestions would well enhance services that are given to clients.

PHAs have suggested that The Living Room is a place where they socialize, communicate, relax and get to know each other and share “stories and experiences” with others about the different challenges that exist in their lives. PHAs report that they are better able to cope with their emotional and social difficulties through sharing experiences with others who are in the same situation. Thus, it is a valuable tool for PHAs to have the “drop-in” Living Room support. Some PHAs asked that the “Living Room” hours of operation be longer and flexible, “since you can’t predict feeling down”. Activities like movie night, bowling could be added.

The clients reported feeling very emotionally vulnerable, thus, they want to be treated, connected and communicated with, in such a way that they feel socially, culturally and “economically” secure. Feeling welcome in the ACO is important to them. In the process of connecting with the PHAs, it is felt to be very important to minimize high staff turnover, as some report that it is vital for the PHAs to have staff that know about them and understand so that they can build a relationship with the staff for their emotional comfort (i.e., they don’t have to explain their story over and over again, as when there is a staff turnover). Therefore, in order for ACO to connect and make the PHAs feel welcome, the clients felt that it was important to train the

volunteers, outreach workers and counsellors so that they meet the PHAs needs, and also recruit French speaking staff. Clients entered into a relationship with ACO, at least in part, in order to satisfy the need for “relatedness” and a sense of belonging. This need can be nurtured by the organization. The ability to trust that staff would maintain confidences was seen as key to feeling safe and secure.

In addition to establishing a homelike environment within the ACO, suggestions were made to get the community involved with the ACO in issues like housing, food and volunteering. It was thought that these liaisons would contribute to creating awareness and educating the public about PHAs and their needs. Liaisons with other agencies are important if the service is not provided by the ACO. Outreach workers and counsellors also play an important role as well, in normalizing PHAs lives, whether it is providing PHAs with information on Hepatitis C and HIV or sharing experiences. These activities enhance their role in the organization enormously.

One PHA said, “I don’t agree with the way they ask if you have needles, drugs, weapons, etc. in front of children”. Thus, ACO should not only be a place where PHAs feel safe (i.e., “knives and needles should be carefully monitored), but also comfortable and most of all a place where they are neither judged nor exposed. Some clients reported being afraid of intravenous drug users (IUDs): “they make me feel scared and uncomfortable”.

Advances in monitoring HIV infection have improved the prognosis for persons living with HIV/AIDS. Now, HIV is coming to be seen as a chronic but manageable infection rather than a terminal illness. As a result of such changes, people living with HIV/AIDS now often require service over several years rather than several months, as once was the case. As PHAs live longer, the emphasis has become directed toward living a better quality of life. This is

reflected in the PHAs' suggestions to widen the range of services provided. Ideas such as providing those long time survivors with "workshops on positive sexuality, employment opportunity/preparation and information on new classes of drugs", to name but a few that were mentioned. Services such as Reiki, massage and reflexology were reported to be important to the quality of life of participants. Shoppers' certificates and clothing exchanges were well appreciated.

As reflected in the demographic characteristics of the clients at ACO, the persons infected, affected and devastated by the HIV/AIDS epidemic have changed. Initially, those infected were primarily MSM and it was the gay community that rallied to provide support and compassionate care to its own community. Though MSM continues to be most affected by the epidemic, several other groups are gaining in relative and absolute importance. Persons from HIV-endemic countries, mother-infant HIV transmissions, persons infected by heterosexual contact and IDUs all contribute to a growing proportion of HIV/AIDS cases. The cultural mix at ACO also puts increased demands for services to meet the diverse needs of this diverse population. Some PHAs also identified differences in financial levels. These differences again split the respondents into groups that reflect the lower income, homeless and middle income; each wanting a greater range of services. Each "group" requests different services that are group need-specific. Examples include activities and services for heterosexual men, women's groups, IDU groups, francophone groups, homeless groups and a request for peer support groups. More individual therapies that include Reiki, Massage, Reflexology and Energy Healing were requested. More at home services are needed; "a Buddy system would have helped".

**What client variables (disease,  
social and health status)  
distinguish high and low users  
of support services?**

Users of ACO services were classified into two groups. High intensity users were classified as such if they used ACO services at least once a week; low intensity users were those who used the services less than once a week.

High intensity users of ACO were similar to low intensity users in age (Table 11), gender, and educational level. There were no differences between the two groups in length of time in present relationship and length of time diagnosed with HIV/AIDS (Table 11).

There were significant differences between high intensity users and lower intensity users of the ACO in relationship status, living arrangements (Table 11), the Karnofsky scale measuring overall health and social support (Table 12). The high intensity users were more likely single, with poorer function as measured by the Karnofsky scale, more likely to live alone and reported less affective support.

**Table 11**  
**Comparison of the Measures by High and Low Intensity Users at the ACO on Demographic Variables**

	High Intensity Users (N=20)		Low Intensity Users (N=23)		Test Statistics	
	Mean	SD	Mean	SD	T-test	p-value
<b>Demographic</b>						
Age	40.38	6.78	43.1	8.36	-1.16	0.25
Length of time in present relationships (years)	4	5	7	4	-1.07	0.31
What is the length of time that you have been diagnosed with HIV/AIDS (in years)?	9.28	4.87	10.92	6.84	-0.89	0.38
How long have you been using the services of Ottawa ASO (years)	5.18	3.95	4.8	3.01	0.35	0.73
<b>Current Relationship Status</b>						
	<b>Count</b>	<b>%</b>	<b>Count</b>	<b>%</b>	<b>Chi Square</b>	<b>p-value</b>
Single	17	85.00%	8	34.80%	11.487	0.003*
Divorced/Separated/Widow	0	0.00%	3	13.00%		
Married/Common-law/Partner	3	15.00%	12	52.20%		
<b>Living Arrangements</b>						
Live alone	14	70.00%	9	39.10%	11.333	0.003*
Spouse or partner	0	0.00%	10	43.50%		
Others	6	30.00%	4	17.40%		

\*statistically significant difference

There were no differences between the groups using the physical and mental health summary scales of the HIV/AIDS (Table 12), functional health status or any of the subscales of the HIV/AIDS SF36 (Table 12). There were no significant differences in current stage of illness (Karnofsky), CD4 Plus Lymphocyte count or Viral Load count, other measures of physical health (Table 12).

**Table 12**  
**A Comparison of High Intensity Users of ACO to Low Intensity Users on Clinical Variables**

	High Intensity Users (N=20)		Low intensity users (N=23)		Test Statistics	
	Mean	SD	Mean	SD	T-test	p-value
<b>Clinical measure</b>						
KRS: Current stage of your illness	80	17	84	12	-0.88	0.39
CD4 Plus Lymphocyte Count	511	280	483	276	0.30	0.77
Viral Load Count	15722	38528	22012	44869	-0.44	0.66
<b>HSF36: Functional Health Status and Quality of Life Index Score (0-100)</b>						
Overall Health Perception Index score	46.5	30.09	50.43	34.83	-0.39	0.70
Physical Function	70.0	28.54	65.94	23.15	0.52	0.61
Role Function	17.5	33.54	34.78	43.78	-1.44	0.16
Social Function	63.0	35.11	73.04	29.91	-1.01	0.32
Cognitive Function	71.3	28.88	72.61	22.76	-0.17	0.86
Pain function	60.6	29.61	49.76	27.19	1.25	0.22
Mental Health	59.0	25.23	61.04	22.08	-0.28	0.78
Energy/Fatigue	48.2	27.4	47.46	19.53	0.10	0.92
Health Distress	71.0	31.06	69.57	28.08	0.16	0.87
Quality of Life	58.8	24.7	55.43	27.13	0.42	0.68
Health Transition	55.0	32.04	56.52	24.09	-0.18	0.86
Physical health summary	53.4	23.32	53.41	20.88	-0.01	0.99
Mental Health Summary	59.3	24.71	60.65	18.36	-0.20	0.84
<b>Depression Status (CESD)</b>						
CESD Score	20.2	15.62	17.26	11.5	0.71	0.48
<b>Social Support</b>						
Confidant Support (5-30)	12.85	6.75	11.70	7.28	0.537	0.59
Affective Support (3-18)	10.20	4.73	7.35	4.73	1.973	0.06
<b>KRS</b>						
	<b>Count</b>	<b>%</b>	<b>Count</b>	<b>%</b>	<b>Chi Square</b>	<b>p-value</b>
Excellent/Good	9	47.40%	19	82.60%	5.815	0.016*
Fair/Poor	10	52.60%	4	17.40%		

\*statistically significant difference

**Table 13**  
**Yearly Income and Employment Status of High and Low Users of ACO Services**

	User group				Test Statistics	
	High user		Low user		Chi Square	p-value
	Count	%	Count	%		
<b>Overall Yearly from all sources before tax deduction</b>						
\$5,000 - \$9,999	7	35.00%	6	26.10%	2.451	0.653
\$10,000 - \$19,999	9	45.00%	12	52.20%		
\$20,000 - \$29,999	3	15.00%	4	17.40%		
\$30,000 - \$39,999	1	5.00%	0	0.00%		
\$40,000 and Up	0	0.00%	1	4.30%		
<b>Employment</b>						
Employed Full Time	0	0.00%	1	4.30%	3.384	0.34
Employed Part Time	1	5.00%	2	8.70%		
Unemployed - Unable to work	2	10.00%	0	0.00%		
On Disability - Long term	17	85.00%	20	87.00%		

There were no statistically significant differences between those who were high users of ACO service and those low users on overall yearly income and employment status. Eighty percent (80%) of the high user group and 78% of the low user group had incomes below \$19,999.00. Eighty five percent (85%) of high users and 87% of low users were on long-term disability (Table 13).

The annual per person expenditures for use of health and social services by the high user group of ACO services compared to the low user group are presented in Table 14. PHAs who are high users of ACO services receive more Employment Insurance ( $\bar{x}$ =\$117 vs. \$0), Ontario Disability support ( $\bar{x}$ =\$7216 vs. \$6137), other government funds ( $\bar{x}$ =\$380 vs. \$0) and Family Benefit Allowance ( $\bar{x}$ =\$130 vs. \$31). Low users of ACO services received more from Canada Pension ( $\bar{x}$ =\$3248 vs. \$2351) and private disability insurance ( $\bar{x}$ =\$2160 vs. \$1207) for a total cash transfer of \$11,832 for the high users compared to \$11,975 for the low users. Thus, overall there were no differences in total money for cash transfer

High users of ACO services on average consumed administratively less per person, per annum of total direct government costs (\$14,706 vs. \$16,002) (largely due to less use of medication) although not statistically significant due to large standard deviations. Nevertheless, the per person, per annum expenditures for use of family physician were greater ( $\bar{x}$ =\$300 vs. \$138), as were per person, per annum expenditures for Emergency Room physicians ( $\bar{x}$ =\$215 vs. \$17,  $p=.02$ ), psychiatrist services ( $\bar{x}$ =\$234 vs. \$51), psychologist services ( $\bar{x}$ =\$666 vs. \$261) and physiotherapist services ( $\bar{x}$ =\$343 vs. \$0). High users of ACO services had a pattern of greater use of other community organization expenses that included dentists ( $\bar{x}$ =\$1375 vs. \$133,  $p=.03$ ), ASO counsellors ( $\bar{x}$ =\$347 vs. \$48), food bank ( $\bar{x}$ =\$222 vs. \$150) and use of complementary therapy. The total community-funded costs of high users of ACO services was \$6221 compared to \$4003 for low users. Out of pocket costs for high users of ACO services more often went toward the use of complementary therapy.

Low users of ACO services, on the other hand, had higher per person, per annum expenditures for HIV specialists ( $\bar{x}$ =\$665 vs. \$255,  $p=.008$ ) and other physician specialists ( $\bar{x}$ =\$382 vs. \$183), chiropractors ( $\bar{x}$ =\$261 vs. \$14) and laboratory out patient tests ( $\bar{x}$ =\$1506 vs. \$933), then their high user counterparts. The cost of medication for the low users was greater than for the high users group by approximately \$1500 ( $\bar{x}$ =\$12,211 vs. \$10,728), suggesting either a greater number of drugs prescribed, or a higher adherence to medication by these low users of ACO.

The direct government-funded cost including hospital cost resulted in the cost of services provided to low ACO users to be more ( $\bar{x}$ =\$16,002 vs. \$14,706), due to the greater expenditure for medications.

The low users of ACO services used community services that primarily included support groups ( $\bar{x}$ =\$677 vs. \$347). Low users also spent more on “out of pocket” expenditure on medications ( $\bar{x}$ =\$976 vs. \$666).

**Table 14**  
**Comparison of High and Low Intensity Users on Annual Expenditures of**  
**Health and Social Services at ACO**

	User group				Test Statistics		
	High user (N=20)		Low user (N=23)		Mann-Whitney U	Z	p-value
	Mean	SD	Mean	SD			
<b>Government Expenses</b>							
Family physician (primary care)	300.29	309.15	138.24	205.97	161.5	-1.86	0.063
Infectious disease/HIV specialist	255.09	457.12	665.45	658.74	129.5	-2.647	0.008*
Emergency department physicians	215.34	430.30	17.02	81.64	170	-2.277	0.023*
Physician Specialist	182.89	338.68	381.89	795.03	206	-0.719	0.472
Psychiatrist	234.00	791.71	50.87	168.54	214.5	-0.679	0.497
Optometrist	99.00	266.57	43.04	154.26	214.5	-0.678	0.498
Chiropractor	13.92	62.25	260.87	1251.09	229	-0.067	0.947
Visiting nurse (Home care/PH/VON/SEN)	46.39	207.47	0.00	0.00	218.5	-1.072	0.284
Homemaker	76.80	343.46	78.26	375.33	229	-0.067	0.947
Physiotherapy	342.89	1533.44	0.00	0.00	218.5	-1.072	0.284
Psychologist	666.00	1847.78	260.87	1251.09	206	-1.16	0.246
Social Worker	340.98	1072.58	237.20	669.72	225.5	-0.197	0.844
Children's Aid Worker	36.13	161.59	0.00	0.00	218.5	-1.072	0.284
Laboratory outpatient tests	933.10	1155.74	1506.47	943.13	163.5	-1.648	0.099
911 call	4.66	20.86	0.00	0.00	218.5	-1.072	0.284
Medication cost	10728.41	8776.05	12211.02	10185.55	205.5	-0.597	0.551
Supplies, aids or special device	148.80	665.45	80.29	385.06	228	-0.133	0.894
Direct government Funded cost excluding hospital cost	14624.69	10627.40	15931.51	10934.35	199	-0.755	0.45
Hospital cost	81.64	365.08	70.99	340.44	228.5	-0.1	0.92
Direct government Funded cost including hospital cost	14706.32	10630.58	16002.49	10970.87	202	-0.682	0.495
<b>Other Community Organization Expenses</b>							
Dentist	1374.52	2885.00	132.80	440.00	165.5	-2.212	0.027*
ASO counsellor	347.36	644.05	47.97	126.64	195	-1.256	0.209
Addiction counsellor	240.00	738.70	260.87	1251.09	218	-0.662	0.508
Support groups / peer support	346.50	777.71	677.48	2018.70	217.5	-0.385	0.7
Health education / prevention talks	21.90	97.94	0.00	0.00	218.5	-1.072	0.284
Meals on wheel/ Soup kitchen	0.00	0.00	15.52	47.23	200	-1.654	0.098
Food bank	221.78	517.51	149.99	376.94	222	-0.287	0.774
Use of Complementary Therapy	1273.65	1846.61	270.57	590.17	155.5	-2.091	0.037*
Other Transportation	46.80	161.93	5.22	25.02	216	-0.772	0.44
Total Use of Unpaid/voluntary community support services	2348.82	3578.48	2442.10	5537.26	212	-0.471	0.638
Total community Funded Cost	6221.32	5542.99	4002.52	6370.43	132	-2.388	0.017

**Table 14**  
**Comparison of High and Low Intensity Users on Annual Expenditures of**  
**Health and Social Services at ACO**

	User group				Test Statistics		
	High user (N=20)		Low user (N=23)		Mann-Whitney U	Z	p-value
	Mean	SD	Mean	SD			
<b>Out of Pocket Cost</b>							
Medication cost	665.52	1336.67	975.80	1632.39	207.5	-0.57	0.569
Use of Complementary Therapy	568.23	876.95	255.72	607.08	188	-1.111	0.266
Supplies, aids or special device	0.00	0.00	13.04	62.55	220	-0.933	0.351
Parking	0.00	0.00	39.13	153.09	210	-1.334	0.182
Mileage	0.00	0.00	39.26	123.79	200	-1.654	0.098
Other Transportation	78.60	173.31	102.37	115.55	175.5	-1.504	0.133
Out of pocket cost	3661.17	3807.66	3867.42	6078.54	226.5	-0.085	0.932
Grand cost excluding hospital cost	22158.36	12755.90	21359.34	10975.38	226	-0.097	0.922
Grand cost including hospital cost	22240.00	12734.72	21430.33	11008.11	228	-0.049	0.961
<b>Cash Transfer Cost</b>							
Employment Insurance	117.20	524.13	0.00	0.00	218.5	-1.072	0.284
Canada Pension	2350.87	3900.16	3248.35	5480.76	213	-0.486	0.627
Ontario Disability Support Program	7216.20	5659.36	6136.70	6471.59	200.5	-0.728	0.466
Welfare or Social Assistance	430.80	1435.12	400.17	1919.17	218	-0.662	0.508
Family Benefit Allowance	129.60	579.59	30.57	146.63	228	-0.133	0.894
Private Insurance on Disability	1207.20	4088.31	2160.00	7255.42	229	-0.048	0.961
Others government cheques	380.40	1359.54	0.00	0.00	195.5	-1.902	0.057
<b>Total Cash transfer</b>	11832.27	5648.54	11975.79	7061.80	216	-0.341	0.733

\*statistically significant difference

**What are the comparative  
client and Health Service  
Utilization variables between  
those clients of ACO that are  
depressed and those that are  
not depressed?**

Forty percent of the clients of the AIDS Committee of Ottawa were depressed (based on the CES-D Scale score of 21 to 60). Comparing those who were depressed with those not depressed was an important dimension to consider, given the importance of depression and its association with decreased quality of life.

The depressed group were significantly younger (Table 15) than the non-depressed group and the reported length of time that they had been diagnosed with HIV/AIDS was also shorter (7.8 years +/- 5 years) compared to the non-depressed group (11.7 years +/- 6 years). There were no other significant differences between the groups on demographic variables.

**Table 15**  
**Comparison of Depressed and Non-Depressed Clients on Demographic Variables**

Variable	Depressed		Not Depressed		Test Statistics	
	N	%	N	%	Chi Square	Sig
<b>Age</b>						
20-29 years old	3	17.60%	1	3.80%	2.610	0.46
30-39 years old	3	17.60%	7	26.90%		
40-49 years old	8	47.10%	14	53.80%		
50 & Up	3	17.60%	4	15.40%		
<b>Length of time</b>	<b>Mean</b>	<b>SD</b>	<b>Mean</b>	<b>SD</b>	<b>T-test</b>	<b>p-value</b>
What is the length of time that you have been diagnosed with HIV/AIDS (in years)?	7.84	4.75	11.67	6.31	-2.134	0.04*
<b>Functional Health Status</b>	<b>Mean</b>	<b>SD</b>	<b>Mean</b>	<b>SD</b>	<b>T-test</b>	<b>p-value</b>
Overall Health Perception Index score	34.4	35.0	57.9	27.4	-2.459	0.02*
Physical Function	59.3	24.6	73.4	25.1	-1.821	0.08
Role Function	11.8	28.1	36.5	43.7	-2.261	0.03*
Social Function	52.9	33.1	78.5	28.2	-2.706	0.01*
Cognitive Function	51.8	26.2	85.2	13.9	-5.464	0.00*
Pain function	46.4	24.0	60.3	30.3	-1.585	0.12
Mental Health	38.8	17.1	74.0	14.8	-7.170	0.00*
Energy/Fatigue	30.1	17.8	59.4	18.8	-5.104	0.00*
Health Distress	48.2	29.1	84.6	18.5	-4.585	0.00*
Quality of Life	42.7	29.0	66.4	18.6	-2.990	0.01*
Health Transition	45.6	33.4	62.5	21.5	-2.026	0.05*
Physical health summary	39.82	19.87	62.25	18.37	-3.792	0.00*
Mental Health Summary	41.2	18.08	72.36	12.36	-6.725	0.00*
<b>KRS Scale – Overall Health</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>Chi Square</b>	<b>Sig</b>
Excellent/Good	8	47.1%	20	80.0%	4.941	0.03*
Fair/Poor	9	53.0%	5	20.0%		
<b>Social Support</b>	<b>Mean</b>	<b>SD</b>	<b>Mean</b>	<b>SD</b>	<b>T-test</b>	<b>p-value</b>
Confidant Support (5-30)	15.18	7.24	10.31	6.20	2.356	0.02*
Affective Support (3-18)	11.29	4.44	6.96	4.45	3.124	0.00*

\*statistically significant difference

In terms of their illness characteristics, the depressed group rated their health more poorly on almost every subscale of the MOS-HIV functional Health Status scale except physical function and pain function (Table 15). Depressed PHAs (Table 15) had consistently poorer health perceptions, role function, social function, cognitive function, mental health function, energy/fatigue, health distress, quality of life, and health transition. The depressed group rated

their overall physical and mental health more poorly than their non-depressed counterparts (Table 15).

Similarly, the Karnofsky scale ratings of overall health reflected statistically significant differences with 53% of the depressed group rating their health as fair/poor.

The depressed group reported that they had significantly more confidant support (mean 16.2) and affective support (mean 11.3) than they would like compared to the non-depressed group, who reported confidant support (mean 10.3) and affective support (mean 7.0) as much as they would like (the higher the score, the less support).

The comparison between the depressed and not depressed client groups revealed that the depressed group experienced statistically significant poorer physical health ( $\bar{x}$  39.8 SD 19.9) and mental health ( $\bar{x}$  41.2, SD 18.1) overall than the non-depressed group (Table 16) ( $\bar{x}$  62.3, SD 18.37 and  $\bar{x}$  72.4, SD 12.4) respectively. The non-depressed physical and mental health scores are 10 – 20 points lower (poorer) than SF-36 norms for the general population.

**Table 16**  
**Comparison of Depressed and Non-Depressed Clients on Physical and Mental Health Summary Index**

	Depressed (N=17)	Not Depressed (N=26)	t-test	p-value
<b>Physical Health Summary Index score</b>				
Mean	39.82	62.25	-3.792	<0.001*
SD	19.87	18.37		
<b>Mental Health Summary Index score</b>				
Mean	41.19	72.36	-6.725	<0.001*
SD	18.08	12.36		

\*statistically significant difference

There were no statistically significant differences between those who were depressed and those not depressed on overall yearly income and employment status. All of the depressed group had income below \$29,999 as did 92% of the non-depressed group (Table 17).

**Table 17**  
**Yearly Income and Employment Status:**  
**Comparison Between the Depressed Clients and Those Not Depressed**

	Depressed 21-60		Not Depressed 0-20		Test Statistics	
	Count	%	Count	%	Chi Square	p-value
<b>Overall Yearly Income from all sources before tax deduction</b>						
\$5,000 - \$9,999	6	35.30%	7	26.90%	1.596	0.81 NS
\$10,000 - \$19,999	8	47.10%	13	50.00%		
\$20,000 - \$29,999	3	17.60%	4	15.40%		
\$30,000 - \$39,999	0	0.00%	1	3.80%		
\$40,000 and Up	0	0.00%	1	3.80%		
<b>Employment</b>						
Employed Full Time	0	0.00%	1	3.80%	1.647	0.65 NS
Employed Part Time	2	11.80%	1	3.80%		
Unemployed - Unable to work	1	5.90%	1	3.80%		
On Disability - Long term	14	82.40%	23	88.50%		

Table 18 examines the income characteristics and annual per person expenditures for use of health and social services by the group of depressed PHAs compared to the non-depressed group. PHAs with depression have less Ontario Disability Support ( $\bar{x}$  = \$5548 vs. \$7351) less Canada Pension ( $\bar{x}$  = \$2542 vs \$3019) yet receive more social assistance and family benefit allowance ( $\bar{x}$  = \$658 vs \$381). Although there were no statistically significant differences between the depressed vs non-depressed groups, the patterns of use might provide some insight into the service use.

The depressed PHAs on average consumed administratively more per person per annum direct government costs that included Family Physician ( $\bar{x}$  = \$291 vs \$163), psychiatrist ( $\bar{x}$  = \$241 vs \$68), visiting nurse ( $\bar{x}$  = \$55 vs \$0), psychologist ( $\bar{x}$  = \$706 vs \$282), Children's Aid worker ( $\bar{x}$  = \$43 vs \$0), supplies, aids or special devices ( $\bar{x}$  = \$175 vs \$71), and 911 services ( $\bar{x}$  = \$5 vs \$0). The depressed group also incurred slightly higher hospital costs ( $\bar{x}$  = \$96 vs \$63), than the non-depressed group.

The depressed PHAs consumed more of an array of comprehensive community services that included addictions counsellors ( $\bar{x}$  = \$494 vs \$92), support groups ( $\bar{x}$  = \$930 vs \$258) and food bank services ( $\bar{x}$  = \$232 vs \$152) for a greater total use of unpaid/voluntary community support services ( $\bar{x}$  = \$3576 vs \$1629).

The depressed PHAs also reported greater “out of pocket” expenditures ( $\bar{x}$  = \$5336 vs \$2749) than the non-depressed group. These “out of pocket” expenses included costs for medications ( $\bar{x}$  = \$999 vs \$722), use of complimentary therapy ( $\bar{x}$  = \$637 vs \$247) and supplies, aid or special devices ( $\bar{x}$  = \$18 vs \$0).

PHAs without depression received more income from Canada Pension ( $\bar{x}$  = \$3019 vs \$2542) and the Ontario Disability Program ( $\bar{x}$  = \$7351 vs \$5548) and other government cheques ( $\bar{x}$  = \$284 vs \$12) for a total cash transfer of \$12,406 vs \$11,147 for the depressed group.

The non-depressed group had more visits with HIV specialists ( $\bar{x}$  = \$582 vs \$309) and other physician specialists ( $\bar{x}$  = \$321 vs \$240), chiropractors ( $\bar{x}$  = \$230 vs \$16), physiotherapists ( $\bar{x}$  = \$263 vs \$0) and social workers ( $\bar{x}$  = \$367 vs \$160) more frequently than their depressed counterparts.

The cost of medication for the non-depressed group was greater than for the depressed group ( $\bar{x}$  = \$12,758 vs \$9629) and the direct government funded costs including hospital cost was also greater for the non-depressed group ( $\bar{x}$  = \$16,631 vs \$13,322), due to the greater medication costs.

The non-depressed group reported spending less on “out of pocket” expenditures ( $\bar{x}$  = \$2748 vs \$5335).

**Table 18**  
**Comparison of Depressed and Non-Depressed Clients on Annual Expenditures of**  
**Health and Social Services at ACO**

	User group				Test Statistics		
	Depressed 21-60		Not Depressed 0-20		Mann-Whitney U	Z	P-value
	Mean	SD	Mean	SD			
<b>Government Expenses</b>							
Family physician (primary care)	290.94	285.79	163.05	249.42	160.50	-1.68	0.09
Infectious disease/HIV specialist	309.71	419.70	582.39	685.15	169.00	-1.40	0.16
Emergency department physicians	92.12	294.60	120.47	327.93	205.50	-0.60	0.55
Physician Specialist	240.68	359.84	321.14	758.16	209.00	-0.37	0.71
Psychiatrist	240.88	854.25	67.50	190.60	219.00	-0.09	0.93
Optometrist	40.59	167.35	87.69	239.69	200.50	-0.92	0.36
Chiropractor	16.38	67.52	230.77	1176.70	217.00	-0.27	0.79
Visiting nurse (Home care/PH/VON/SEN)	54.58	225.03	0.00	0.00	208.00	-1.24	0.22
Homemaker	90.35	372.53	69.23	353.01	217.00	-0.27	0.79
Physiotherapy	0.00	0.00	263.76	1344.92	212.50	-0.81	0.42
Psychologist	705.88	1992.63	281.54	1194.68	211.00	-0.49	0.62
Social Worker	160.46	661.60	367.21	987.89	200.50	-0.92	0.36
Children's Aid Worker	42.51	175.27	0.00	0.00	208.00	-1.24	0.22
Laboratory outpatient tests	1227.78	916.11	1247.64	1183.76	213.00	-0.20	0.84
911 call	5.49	22.62	0.00	0.00	208.00	-1.24	0.22
Medication cost	9629.45	10371.23	12758.50	8826.42	160.00	-1.52	0.13
Supplies, aids or special device	175.06	721.79	71.03	362.16	216.00	-0.34	0.73
Direct government Funded cost excluding hospital cost	13322.84	12192.80	16631.93	9598.52	162.00	-1.47	0.14
Hospital cost	96.04	395.99	62.80	320.20	216.50	-0.31	0.76
Direct government Funded cost including hospital cost	13418.88	12206.93	16694.72	9630.41	166.00	-1.37	0.17
<b>Other Community Organization Expenses</b>							
Dentist	359.35	858.76	939.84	2558.37	206.50	-0.51	0.61
ASO counsellor	86.41	206.14	253.14	573.66	212.50	-0.31	0.76
Addiction counsellor	494.12	1533.16	92.31	470.68	203.00	-1.01	0.31
Support groups / peer support	930.35	2389.59	257.54	502.07	208.00	-0.41	0.68
Health education / prevention talks	0.00	0.00	16.85	85.90	212.50	-0.81	0.42
Meals on wheel/ Soup kitchen	21.00	54.27	0.00	0.00	182.00	-2.19	0.03*
Food bank	231.92	464.87	151.64	435.69	202.00	-0.70	0.49
Use of Complementary Therapy	428.35	736.33	939.00	1695.41	187.50	-0.96	0.34
Other Transportation	48.00	169.49	9.23	47.07	203.50	-0.98	0.33
Total Use of Unpaid/voluntary community support services	3575.96	6253.78	1628.98	3182.60	166.50	-1.46	0.15
Total community Funded Cost	6175.47	6881.54	4288.52	5422.03	170.00	-1.27	0.21

**Table 18**  
**Comparison of Depressed and Non-Depressed Clients on Annual Expenditures of**  
**Health and Social Services at ACO**

	User group				Test Statistics		
	Depressed 21-60		Not Depressed 0-20		Mann-Whitney U	Z	P-value
	Mean	SD	Mean	SD			
<b>Out of Pocket Cost</b>							
Medication cost	999.36	1567.07	721.72	1463.11	165.00	-1.45	0.15
Use of Complementary Therapy	636.82	952.87	246.93	554.07	146.00	-2.03	0.04*
Supplies, aids or special device	17.65	72.76	0.00	0.00	208.00	-1.24	0.22
Parking	10.59	43.66	27.69	141.20	217.00	-0.27	0.79
Mileage	2.80	11.53	32.90	117.00	216.00	-0.28	0.78
Other Transportation	92.61	153.44	90.46	140.53	211.50	-0.27	0.79
Out of pocket cost	5335.78	6912.05	2748.68	3197.30	164.50	-1.40	0.16
Grand cost excluding hospital cost	21258.13	13788.43	22040.15	10392.80	199.00	-0.55	0.59
Grand cost including hospital cost	21354.17	13771.78	22102.95	10418.97	203.00	-0.45	0.66
<b>Cash Transfer Cost</b>							
Employment Insurance	137.88	568.50	0.00	0.00	208.00	-1.24	0.22
Canada Pension	2542.27	3766.44	3019.64	5400.60	220.50	-0.02	0.99
Ontario Disability Support Program	5548.94	5299.07	7351.38	6510.68	186.50	-0.87	0.39
Welfare or Social Assistance	506.82	1550.74	354.00	1805.05	204.50	-0.93	0.35
Family Benefit Allowance	152.47	628.65	27.05	137.91	216.00	-0.34	0.73
Private Insurance on Disability	2247.53	6375.54	1369.85	5751.90	212.00	-0.44	0.66
Others government cheques	12.00	49.48	284.77	1197.71	216.00	-0.28	0.78
<b>Total Cash transfer</b>	<b>11147.92</b>	<b>6404.02</b>	<b>12406.69</b>	<b>6422.10</b>	<b>172.00</b>	<b>-1.22</b>	<b>0.22</b>

\*statistically significant difference

**What are the client factors  
that predict the Mental  
Health Status and Physical  
Health Status?**

We were interested in understanding the factors that explained (predicted) the Mental Health Summary Index Score of the MOS/HIV Health Status Scale. Several variables were entered into the equation: single, live alone, length of time diagnosed with HIV/AIDS, overall rating of health, current stage of illness, confidant support, affective support and age (Table 19).

**Table 19**  
**Predictors of the Mental Health Summary Score**

<b>Variable</b>	<b>Beta</b>	<b>R</b>	<b>R Square</b>	<b>R<sup>2</sup> Change</b>	<b>Sig F Change</b>
Affective Support	-0.347	0.495	0.245	0.245	0.001
Length of time since diagnosis	0.311	0.565	0.320	0.075	0.024

Two variables, affective support and length of time since diagnosis, explained 32% of the Mental Health Summary Score. Affective support contributed most of the variation (24.5%) and positively affected the Mental Health Score i.e. the more affective support, the greater the mental health. The longer the time since diagnosis contributed 7.5% to explain the Mental Health Summary Score, that is, the longer the time since diagnosis, the better the mental health.

We were also interested in understanding which variables explained the Physical Health Summary Index Score. The same variables were entered into the regression equation and included single, live alone, length of time since diagnosis, rating of overall health, current stage of illness, confidant support, affective support and age. In this model, we also included CES Depression score. Four variables explained 68% of the dependent variable: Physical Health Summary Index Score (Table 20).

**Table 20**  
**Predictors of the Physical Health Summary Score**

<b>Variable</b>	<b>Beta</b>	<b>R</b>	<b>R Square</b>	<b>R<sup>2</sup> Change</b>	<b>Sig F Change</b>
CES-Depression	-.474	.598	.358	.358	.000
Current stage of illness	.354	.742	.551	.193	.000
Length of time since diagnosis	.306	.794	.630	.079	.006
Live alone	.229	.822	.676	.046	.026
Constant					

Depression contributed 36% toward explaining the physical health summary score; current stage of illness 19%; length of time since diagnosis 8% and living alone contributed another 5%. Those clients who were not depressed, whose reported stage of illness was good, who had HIV for a longer period of time and who lived alone reported better physical health.

A regression analysis was done on total costs. The following variables were entered into the stepwise regression model: single, live alone, length of time diagnosed with HIV/AIDS, overall rating of health, current stage of illness, CES-Depression, confidant and affective support. No variables entered the equation to explain total health service costs.

# **DISCUSSION**

This cross sectional survey of 43 PHA clients receiving support services from the AIDS Committee of Ottawa (ACO) consisted of a comparative examination of the psychosocial and health status of the participants, his/her satisfaction with the services they received and their use of health and social services.

Supportive care is defined as the provision of necessary services determined by those living with or affected by HIV/AIDS, to meet their physical, social, emotional, informational, spiritual and practical needs throughout the spectrum of the illness experience (Doll, 1997). Supportive care is a continuum and consists of services aimed at all things that determine health. Canadian evidence documents that supportive care for vulnerable populations pays for itself during the same year of receipt (Browne, Roberts et al, 1995; Browne, Robinson et al, 1999a; Browne, Roberts et al, 1999b; Browne, Roberts et al, 2001).

The ACO is providing support services to a diverse group of clients. While the PHA clients reported satisfaction with the services provided, this diverse population is requesting more services that are group need-specific. Examples included requests for specific services for gay men, heterosexual men, women's groups, IDU groups, francophone groups, peer support groups and homeless groups, to name a few.

The ACO clients also reflect the changes brought about by the effectiveness of antiretroviral treatments that have made it possible for HIV infected individuals to live for a much longer time with their disease. As PHAs live longer, the emphasis has become directed toward living a better quality of life. Services have expanded within the ACO to maximize active daily living within a long-term illness and more of these services are being requested. Suggestions such as workshops on positive sexuality, employment preparation, information on

new classes of drugs and services such as massage, reflexology and Reiki were made. Recreational activities such as movie nights and bowling as examples were requested.

Of course, a demand for more services has implications for resources. Some ideas were generated in the interviews. Suggestions were made to get the community more involved in providing services (e.g. massage) and supplies (e.g. Shopper's Drug certificates, food bank). The respondents recognized that these efforts are already in place but again would like more. They also thought that recruiting more volunteers would contribute toward creating awareness and educating the public about PHAs and their needs. Liaisons with other agencies and referral sources are important particularly if the service is not provided by the ACO.

There is a great deal of variability among the health care services clients used. Some used a lot of services, some did not so that there is a large variation among costs.

The effect of self-selection of services in a national health care system is that people will attempt to use the services that they think they need to achieve their well-being (Browne et al, 1999a). This effort was demonstrated in the two comparative analyses that were done, that is, the comparison of high and low users of ACO services, and a comparison of those who were depressed with a non-depressed group.

The AIDS Committee of Ottawa is playing a particularly important role of providing support for those clients who are more likely single, with poorer function, live alone and report less affective support, the high user group of ACO services.

This high user group did not differ on their functional health status or in their reports of depression. It appears that ACO is able to serve this group of clients and help them maintain their quality of life and provide a supportive social network.

A significant proportion (40%) of the clients of the AIDS Committee of Ottawa were depressed. As noted in the literature, there is a greater likelihood of depression in those who have significant health problems (Wells et al 1991; Kessler et al, 1994; Croghan et al, 1998). Depression is associated with diminished health status and substantially lower health related quality of life persisting over time. Depression is associated with a high rate of health care utilizations and severe limitations in daily functioning (Manning & Wells, 1992; Simon, Ormel, VonVorff et al, 1995).

In addition, it was noted in a recent review of the literature that depressed patients were 3 times as likely as non-depressed patients to be non-compliant of their medical treatment (DiMatteo, Lepper & Croghan, 2000) although the reasons are not known. Some suggested hypotheses included:

1. compliance might be difficult for the depressed person who holds little optimism that any action will be worthwhile;
2. social isolation from those who would provide support and assistance and the presence of barriers such as adverse effects and financial constraints.

The comparative analysis of the depressed clients of ACO with the non-depressed clients demonstrates that depression negatively affects both the mental and physical health of depressed clients. Depressed PHAs reported consistently poorer perceptions of their health, poorer role, social, cognitive and mental health function; less energy, less quality of life, more health distress and a perception that their health is getting worse.

The health and social service utilization data confirms the lesson that people in a national health care system will use the services they think they need to achieve well being (Browne et al, 1995; Browne et al, 1999a; Browne et al, 1999b). However, the effect of self-selection of

services used by the depressed clients of ACO suggests that their pattern of use might not reflect the most effective resource options or, as the literature suggests, these clients may not be complying with their medical regimen. The depressed clients, for example, are spending less on government-funded services, particularly medication, but using more “out of pocket” costs to themselves for “over the counter” medications and complementary therapies.

It does appear from the health service utilization data, that the depressed clients are using psychological services (psychologists, psychiatrists, counselling) more frequently while HIV related services (HIV specialists, other specialists, government-funded medication) are being used less frequently.

The availability and use of multimodal forms of community and ACO supportive resources suggests at the very least the “not-depressed” group is receiving the right resource options and is documentation of the efforts and value of the community programs.

The prevalence of a high level of depression suggests the need to train ACO providers in the recognition of and appropriate referral for this depression. One suggestion for ACO and other health professionals treating HIV infected persons is that recognizing and treating depression might improve adherence to the medical and prevention regimen and subsequently reduce disability, enhance functioning, improve health care outcomes and decrease the spread of HIV.

Raising the awareness of support workers and other health care providers about those at risk suggests a need for on-going targeted measures that consider the psychological and social dimensions of clients’ lives. The importance of social support is underscored. A second focus of support for clients would be to assist them to develop social networks to assist families and significant others to deal with the total impact of the illness and treatments.

This study has implications for ACO service. More support and training for ASO staff in the care and treatment of a more impaired group of PHAs including care of depression could be beneficial. Experienced mental health professionals could provide ASO staff and volunteers to

- recognize depression and other mental health problems
- enable PHAs to take up referral to HIV/AIDS clinics/specialists for appropriate and adequate doses of medication
- assist clients to comply with their pharmacotherapy and prevention regimens
- provide basic interpersonal or cognitive behaviour counselling strategies once PHAs have begun to respond to their medication
- serve the hard to reach PHAs

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