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**The Impact of Casey House Hospice
Community Programs on People Living
With HIV/AIDS**

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ABSTRACT

The Impact of Casey House Hospice Community Programs on People Living with HIV/AIDS

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- Background** Advances in clinical management of HIV/AIDS have transformed HIV infection from an acute illness to a chronic illness which now allows clients to receive treatment and support in the community. Home care is one of the major types of services in community-based care models. There is, however, a paucity of information about the effectiveness and costs of such services.
- Objectives** The purpose of this study was to compare the effectiveness of two differently funded Casey House Hospice Community Programs for people living with HIV/AIDS (PHAs). Admission to Casey House Community Programs is through their Home Hospice (HH) Program or the Community HIV/AIDS Partnership Program (CHAP), which provide a range of service funded through the local CCAC, directly or indirectly, with added services funded by Casey House.
- Methods** In this cross-sectional survey design, a consecutive sample of 60 consenting rostered clients were recruited over a 6 month period from the Greater Toronto Area and were assembled into 2 groups according to their source of funded services (HH or CHAP). A structured one hour interview was conducted to detail their needs related to the severity of their illness, quality of life, coping style, use of health and social services and satisfaction with the program services.
- Results** Study clients who received their home health care services through either HH or CHAP did not differ on any of the demographic, clinical, psychosocial, and satisfaction variables, or overall costs of health and social services. Twenty-three percent of the sample had impaired mental health function (largely depression) with overall poorer quality of life. The depressed clientele had more direct health and social services costs which were double that of the less depressed. These cost differences were accounted for by the crises use of more costly services (ER, ambulances, specialists, hospitalization), by depressed clients with less ability to anticipate or plan their response to adverse situations.

INTRODUCTION

People living with HIV/AIDS (PHAs) are living longer due to antiretroviral therapies and early prophylaxis for severe opportunistic infections (CDC, 1997). Support and advice during all stages of the disease process is necessary as PHAs adapt to their restrictive medication schedules and the often debilitating drug side effects. The challenge for those working with PHAs is to develop a comprehensive system of care that will provide high quality, in-home support. Such support involves a large network of formal and informal caregivers – family members, partners, care giving friends, homemakers and a variety of health care providers – who collaborate to provide holistic care. Thus, co-ordination, collaboration and communication are essential if this network is to meet all of the physical, psychological, social and spiritual needs of PHAs and their families (Linkewich et al., 1999).

BACKGROUND

Casey House is a Hospice in Toronto providing comprehensive and compassionate care for individuals living with HIV/AIDS and their families. The Hospice seeks to maximize the individual's quality of life by attending to their emotional, social and spiritual needs in addition to their physical health care requirements. The client with HIV/AIDS is valued as the central focus of the program of care and participates freely in the choice and direction of care. The Hospice opened in 1988 with 13 beds (1 for respite care and 12 for general or extended stay) in the residence and a continuing waiting list for admission. In response to the results of new treatments for HIV/AIDS, the Casey House Community Program was initiated in 1993 and currently offers care to approximately 120 PHAs in their own homes (Geraci, Flannery, Filman et al., 1997).

Casey House Hospice offers three care options for people living with HIV/AIDS at every stage of health: residential Hospice care, respite care, and Community Programs (in-home supportive and palliative care). The focus for this present study is the in-home supportive and palliative care, Casey House Community Programs option, with specific emphasis on documenting the effects on quality of life of these Community Programs to PHAs.

Admission to the Community Programs is through 1) the Casey House Assessment Nurse (referred to by health care providers, self or family); or 2) through Metro, Scarborough and East York Community Care Access Centres (CCAC); or 3) through these Community Care Access Centres to CHAP (Community HIV/AIDS Partnership Program) which is operated by Casey House in partnership with Comprehensive Rehabilitation and Mental Health Services (COTA), Central Neighbourhood House and Spectrum Health Care.

The model of care used in the Community Programs is the case management model with a Casey House registered nurse coordinating clinical services and collaborating with all other care providers. Those clients whose services are funded through the local CCAC or through the local CCAC to CHAP have the full range of CCAC coordinated services. CCAC services are policy driven by regulations regarding the type, maximum amount and frequency of services allowed. Services are added to CCAC services by Casey House personnel as determined by the primary care team, within Casey House budget allowances (Figure 1).

EVALUATION FRAMEWORK

Quality health care remains difficult to define in a concise, meaningful and generally applicable manner (Blumenthal, 1996). Maxwell (1984; 1992) among others identified six core components of quality which included effectiveness, acceptability, efficiency, access, equity and

relevance. To provide a more comprehensive assessment of quality, he combined the three elements of health care (structure, process and outcome) (Donabedian, 1980) in a matrix (Maxwell, 1984). Using this model of quality assessment, Armes and Higginson (1999) examined the quality of HIV palliative care services for PHAs in three London Health Authorities using a qualitative approach through semi-structured focus groups or individual interviews.

The results of the study showed that the indicators of quality services fit with the dimensions of the model as follows: competent skilled practitioners (effectiveness); confidential, non-discriminating and culturally competent care (acceptability); collaborative and coordinated care (efficiency); flexible and responsive care (access and relevance) and fair access for all clients (equity). In addition, the criteria used to judge the six dimensions of quality were influenced by clients' needs and personal circumstances further underscoring the importance of the client's perspective in the evaluation of quality care (Armes and Higginson, 1999).

Casey House's Community Program's primary goal is the alleviation of symptoms and suffering through their provision of high quality care at the most efficient cost. To evaluate how this purpose is being realized, the following study was designed. Maxwell's (1992) model of quality assessment was used to examine the quality of Community Programs for PHAs in the Greater Toronto Area and guided the following questions:

1. What is the comparative expense of clients served from two sources of funding arrangements in terms of types, amount and costs of health services used (accessibility; efficiency)?
2. What client characteristics combine to best explain a client's quality of life?

3. What client characteristics (disease, social, psychological, geographic) are associated with health and social services use?
4. What is client satisfaction with the Community Programs from two sources of funding arrangements (acceptability; relevance)?

The model variables and their measures are shown in Figure 2.

METHODS

Design

This cross-sectional analytic study was designed to compare the relationship between the funding source of managed services for Casey House Hospice Community Programs clients and the quality of care within a community caseload of approximately 120 clients over a 6 month period. Clients were classified into 2 groups according to their historic funded source of managed services: CHAP Program; Home Hospice Program and to their prior amount of community services for the relevant period of time (long/short). Quality of life, satisfaction and cost of care were compared between the 2 groups.

Clients on the roster of the Community Programs were advised about the study's purpose by their health care provider and a short, succinct description of the study was provided to the clients. Those clients who were approached were given the options to 1) indicate their willingness or not to participate directly to their health care provider who would then inform the project co-ordinator; or 2) call the project coordinator directly to confirm their willingness. Once verbal consent to have their name released to the project co-ordinator was obtained, the project co-ordinator contacted the client to obtain written consent and arranged an appointment to conduct the in-person or telephone interview at a mutually convenient time and place. This

process enabled the recruitment of people who were willing and able physically and emotionally to participate.

Participants were assured that confidentiality and anonymity would be maintained. Since the measurement was at one point in time, there was no need for names. Codes were used on data collection forms for sampling purposes. Interviews were conducted by telephone or in person. Ethics committee approval was obtained from McMaster University Research Ethics Board for the interviews, and participants signed an informed consent. Clients were assured that their participation or refusal to participate was confidential and would have no effect on their present or future health care.

Measurement

As outlined in the adaptation of Maxwell's (1984) model (Figure 2), structure, process and outcome variables were assessed at one point in time.

1. Structure Variables (Services Provided)
 - Source of funding for home care services; length of service use
2. Process Variables (Characteristics of Service Users)
 - Client coping; 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.

Measures

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 (Karnofsky, 1996), living arrangements, and current or previous occupation.

Health Related Quality of Life, Coping Ability and Depression

Research has shown that a person's ability to cope with HIV infection can be influenced by a multitude of psychosocial variables (Grassie et al, 1998) including depression and quality of life. We were interested in examining whether or not the clients' coping ability, the types of social support and /or the occurrence of depression were associated with the use of health and social services utilization.

Coping Ability

Ways of coping were measured using the Indices of Coping Responses questionnaire (Moos et al., 1984) which focuses on the cognitive and behavioural coping responses that individuals use when a stressful event has occurred. They are asked to rate their frequency of use of 33 different coping responses on a four-point scale of 0 to 3 with "0" indicating no use of the response and "3" indicating high use of the response. Responses are categorized into cognitive, behavioural and avoidance methods of coping and problem solving, logical analysis, emotional distress, affective regulation and information seeking foci of coping. Internal consistency has been demonstrated for the different scales with alpha scores ranging from .51 to .74. Construct validity has been demonstrated.

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 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 et al, 1989).

Depression

Client depression was assessed using the Mental Health Summary Scores, obtained from the administration of the MOS-HIV Health Survey questionnaire (see description below) (Wu et al, 1997). 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=.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, which we chose to use in this present study. Thus, those with scores less than 43 were considered depressed.

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 life (HRQoL) used extensively in diverse groups including human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) (Wu 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 measures 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 socioeconomic 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 end-points 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 Casey House Community Program was measured using the Client Satisfaction questionnaire (CSQ) (Attkisson et al., 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 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 and Demore, 1976, p. 1099). 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, 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 statistics using means, standard deviations, ranges and proportions were used to describe proportions of clients by funding source and exposed to different lengths of community program services.

Scores on psychosocial measures and health and social services expenditures were compared between the 2 groups from different funding sources, between those with different levels of functioning (Karnofsky Scale) and between those with high and low mental health function or depression. An alpha level of <0.05 was selected for statistical significance.

Sample Size Estimate

Given that CHAP Community Program services are hypothesized to be more effective than usual CCAC managed services through other provider agencies, a difference of 15 points in the MOS-HIV Mental Health Summary Scale, using the standardized mean score (out of 100) between CHAP and HH Community services, was thought to be an important clinical difference.

To detect this difference of 15 points between the two Community Program groups with a 2-tailed alpha of .05 and a beta of .20 (with 80% power), at least 17 subjects were required per group.

RESULTS

In this cross-sectional survey of PHAs using Casey House Hospice Community Programs, 60 of 139 listed clients (43%) agreed to participate in the survey and 59 completed the full interview (42%). The sampling results are shown in Figure 3. Consenting PHA clients were categorized according to the historical funding source of their Community Program services (Home Hospice versus CHAP) as well as their length of time on the Programs (> 1 year < 1 year). Home Hospice (n=37) and CHAP (n=23) were compared on their current status on all variables were short (n=24) and long term (n=36) users.

There were no statistically significant differences in personal and social demographics between the HH and CHAP funded groups. Approximately 90% of the clients in each group were male, between 40 and 49 years of age (47%), single (68%), of Canadian cultural background (70%) with English as their first language (78%) and 61% with some college or university education. Sixty percent of the total group lived in residential subsidized housing, with 95% of the sample living in the core of the city of Toronto, and 63% living alone while 20% lived with a spouse or partner. The results are shown in Table I.

In terms of their illness characterises, HH and CHAP funded groups were similar in their overall mean length of time since diagnosis (10.7 years) and in their length of time using the services of the Community Programs (22 months). While the two groups were similar in CD4 counts and viral load readings, both readings indicated a high risk of HIV disease progression.

Similarly the Karnofsky scale ratings were equivalent between the two groups and reflected significant performance disability in their scores. The results are shown in Table 2.

The funding source of Community Programs for client services did not distinguish between clients in terms of psychosocial variables including social support, mental health and quality of life. The groups did not differ in types and amount of social support (Table 4), their overall mental health (Table 5), or the 10 quality of life dimensions (Table 5). However in terms of coping style clients funded through HH engaged in more active behavioural coping ($t=2.08$, $p=.04$) and more information seeking ($t=2.77$, $p=.07$) than clients funded through CHAP. The results are shown in Table 3. The overall satisfaction rating about the services received by the two groups was similar with very high ratings with a mean score of 30 out of a possible 32. The total sample rated the quality of services received between good to excellent, 98% said they received the kind of services that they wanted and that they would recommend the programs to friends in need. The results are shown in Table 6.

In our next analysis, we sought to determine if more costly health resource utilization occurred in one of the differently funded groups compared to the other given that “topping up” services is a practice carried out on the advice of the resource team if needs are not being adequately met by the standard CCAC policies. Since the different funded sources of services might reflect different decisions regarding resource uses, we compared the health and social service expenditures between the two groups.

Table 7 contains a summary of the annual direct costs, out of pocket expenses and cash transfers per client, in both funded groups, in their use of every type of health service within two weeks to six months of the interview. Because the utilization data are skewed with variable standard deviations between the two groups, the Mann Whitney-U non-parametric statistical test

of difference was used. There were no statistically significant differences in overall per person annual direct expenditures ($p=0.9$) out of pocket expenses ($p=0.8$) or cash transfer effects ($p=0.9$); however, there were some interesting individual item differences between the two groups.

The HH group had more than double the expense for Emergency Room services and Voluntary Community Support Services, 5.7 times more for ambulance services, and 6.6 times more for hospital stays than the CHAP group. In contrast, the CHAP group had 4 times more expense for psychologists and twice the expense for diagnostic tests than the HH group and were the exclusive users of hospice services. While these costs accrue largely to the Ministry of Health and Long-Term Care, it is apparent that the HH group used the more expensive types of services (hospital, emergency, speciality practitioners such as PT, OT and Chiropractor) suggesting a more crisis or reactive type of utilization whereas the CHAP group appear to use more maintenance focussed services (hospice, counselling, complementary therapies). This difference in resource utilization may also reflect the HH group's different type of coping focus which was an active behavioural style. The HH funded group had more third party sources of support than the CHAP group including government insurance benefits and private investments and insurance. CHAP clients received 1.5 times more from ODSP whereas HH clients received 1.5 time more from Canada Pension and private insurance and more from investment income and long term disability.

Overall, it appears that the two funded community program types were able to serve and maintain the well being of this vulnerable group of clients. Both programs had clients with similar disease severity yet different types and amounts of self and Program selected services. They accomplished this with high satisfaction by the clients and with no difference in the clients

quality of life, including overall physical and mental health status, and with no greater cost in social and health services utilization.

Given the similarities between the two Community Program groups, we used the total group to examine the role that length of service use (less and more than 1 year) might play on adjustment to their condition as reflected in their psychosocial status and their use of health and social services. There were no statistically significant differences on the demographic (Table 8), clinical (Table 9), psychosocial (Table 10) or per person annual expenditures for health and social services utilization (Table 11) between the two groups with short and long-term community program service use. The shorter users of the Community Programs, however, had a different pattern of health services use with 3 ½ times more emergency services costs and 2-3 times other speciality clinicians costs (PT, OT, nutritionists, chiropractors, speech therapists), more use of support groups, more use of 911 services and ambulance services and 16 times the cost for hospitalization. Longer Community Program users, in contrast had higher costs for family physicians, psychologists, social workers and counselling services. This different pattern of use of types of services may reflect the different stages of adjustment to their symptomatic or deteriorating condition, with more reactive responses to the earlier threat their condition poses (call 911, get an ambulance, go to emergency). In contrast, for those with longer service use, the challenge to manage their condition may be reflected in the more health-promoting types of resource use such as mental health support (counselling, psychologists, social workers). Overall, it appears that the Community Programs are able to serve this group of clients with differing needs at different times in their treatment program with no greater overall expenditures for social and health services use.

Since these clients in this sample reflected a symptomatic and vulnerable total group as indicated by their CD4 count, viral loads and Karnofsky scale ratings (KRS), we wanted to understand the data from a clinical perspective. So we grouped clients according to their KRS scores (<80 versus > 80) (Revicki et al, 1998) with a score of > 80 considered to be better health and a score of < 80 to be worse health and then compared these two groups on their coping responses, quality of life and social support.

The two Karnofsky scale groups (low and high) did not differ in age or clinical severity but did differ statistically significantly on all the quality of life dimensions of the MOS-HIV Health Survey Scale. Those with poorer KRS performance ratings, indicating poorer health, had lower scores on all the physical and mental health scales including the physical and mental health summary scores. The groups did not differ, however, in coping methods or in types of social support. The results are summarized in Table 12.

It would appear that the Karnofsky scale is measuring similar concepts of health, i.e. level of performance or level of functioning, as the MOS-HIV Health Survey and is able to discriminate between poor and good health function. Given the importance of poor mental health and its association with decreased quality of life and poor adjustment, we sought to determine if more costly health resource utilization occurred within this group in their attempts to manage their circumstances. We grouped clients according to their mental health scores, with a score of under 43 on the MHSS, indicating “poor” mental health (comparable to a score of less than 20 on the CES-D scale), and scores of 43 and above indicating better mental health, and then compared the groups on demographic and clinical information, coping responses, physical health summary scores, social support and health services use.

Twenty-three percent of the sample (n=14) endorsed a low level of mental health (depressed) as indicated by their mental health summary score ($\bar{x}=39.87$, $SD=8.15$). They did not differ in the severity of their condition from the better mental health group, but did differ statistically significantly on the physical health summary scales with worse overall physical function related quality of life. This group of depressed PHAs used statistically significantly more avoidance coping and emotional discharge behaviours than their less depressed counterparts but did not differ from them in the types of social supports that they had or the severity or length of their disease. The results are shown in Table 13.

Table 14 contains a summary of the average annual direct costs, out of pocket expenses and cash transfer effects on illness per client. There was a statistically significant difference in direct and grand total (direct plus out of pocket) per person per annum expenditures wherein the depressed group of clients generated twice the expense of the “not depressed” group exceeding annually the not depressed by \$39, 804. This difference in health services expenditures is accounted for by the different pattern of health services use which is greater for the depressed in 9 of the more expensive types of health services including emergency room services, specialist physicians, physiotherapists, psychologists, social workers, 911calls, ambulance services, hospice and hospital stays. These expenditures accrue largely to the Ministry of Health and Long Term Care.

From the point of view of third party payers, there was a statistically significant difference between the two groups in total cash transfers with the depressed group receiving less in transfers. The “not depressed group” received more from company pensions, investment income, salary and long term disability whereas the depressed group received more from WSIB, family benefits, welfare and private insurance. These differences in cash transfers may reflect

the financial vulnerability of this group of depressed clients who do not appear to have the stable financial sources of the not depressed (e.g. LTD, investments, salaries) nor the variety.

SUMMARY

This cross-sectional survey of 60 PHA clients receiving one of two differently funded Casey House Community Programs, consisted of a comparative examination of the individual client's psychosocial and health status, his/her satisfaction with their home care services and use of health and social services. The two groups were similar in demographics, illness and psychosocial characteristics and were highly satisfied with the services provided by their respective Community Program. While they did not differ in their overall expenditures for health and social service use their pattern of use did differ. The Home Hospice funded group tended to use more expensive and more reactive services than the CHAP funded group. This difference in resource use may reflect differences in philosophy of the staff of the two programs with the CHAP program more oriented to more focussed and health promoting service use because of their Hospice affiliation whereas the CCAC staff may be more oriented to a reactive on demand type of decision making. Furthermore, this orientation coupled with clients who coped by action (active behavioural) and seeking guidance (information seeking) may provide a further explanation of the dynamics involved by considering the interactive effect of self selection of services in a national health care system where people will attempt to get what they think they need to achieve their well being (Browne et al, 1999).

Twenty-three percent of this total group of PHAs who had the same severity of illness suffered from depression which had a profound effect on their quality of life and their use of expensive health and social service costs in their help-seeking efforts. This may indicate the role

that depression, coupled with a severe chronic illness can play on the processes of adjustment. The severity of these PHAs illness was not associated with their depression but rather their depression was associated with difficulties in adjusting to the impact of their condition and circumstances in all aspects of their lives.

DISCUSSION

This study was conducted in the Greater Toronto Area (GTA) and the PHA client groups reflect similar circumstances and service options. The health and social service utilization data again 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; 1999). It is apparent that the type of service selected and the timing of that service can have a positive or negative impact on expenditures. Twenty-three percent of the clients suffered from depression which had significant influences on their ability to adjust to their condition. They used emergency room services and emergency services including 911 and ambulances, as well as physiotherapists, psychologists, social workers, hospice and hospitalization to cope. Conceivably efforts to treat depression could improve quality of life while reducing the use of expensive resources.

The prevalence of a high level of psychosocial challenges (poor quality of life and the presence of depression) suggests the need to train providers in the recognition of and appropriate referral for these states. The availability and use of multi model forms of supportive resources suggests that 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. Given the prevalence of depression in this total group of PHAs, supportive efforts may need to be further directed in two major areas. First the proper diagnosis and treatment of depression would be an important

step to take to reduce the distress and disability in significant areas of functioning to the sufferers. Raising the awareness of support workers and health care providers about those at risk suggests a need for ongoing, targeted measures that consider the psychological and social dimensions of client's lives.

Living with the stress and consequences of HIV/AIDS underscores the importance of social support and suggests the second focus of support for at risk 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.

More effective use of health services may be realized by directing services to those who would most benefit. If psychosocial function can be improved for some individuals, while reducing their use of health care services, such as costly hospitalization, then specific programs should be implemented that are tailored to these needs and characteristics.

Decision makers need to act on the lessons learned from research on community care program costs that have consistently demonstrated that it is more effective and less expensive to provide proactive health care services to the chronically ill than to provide services on demand in a piecemeal manner. These services not only pay for themselves in the same year but are associated with considerable savings (Browne et al, 1999).

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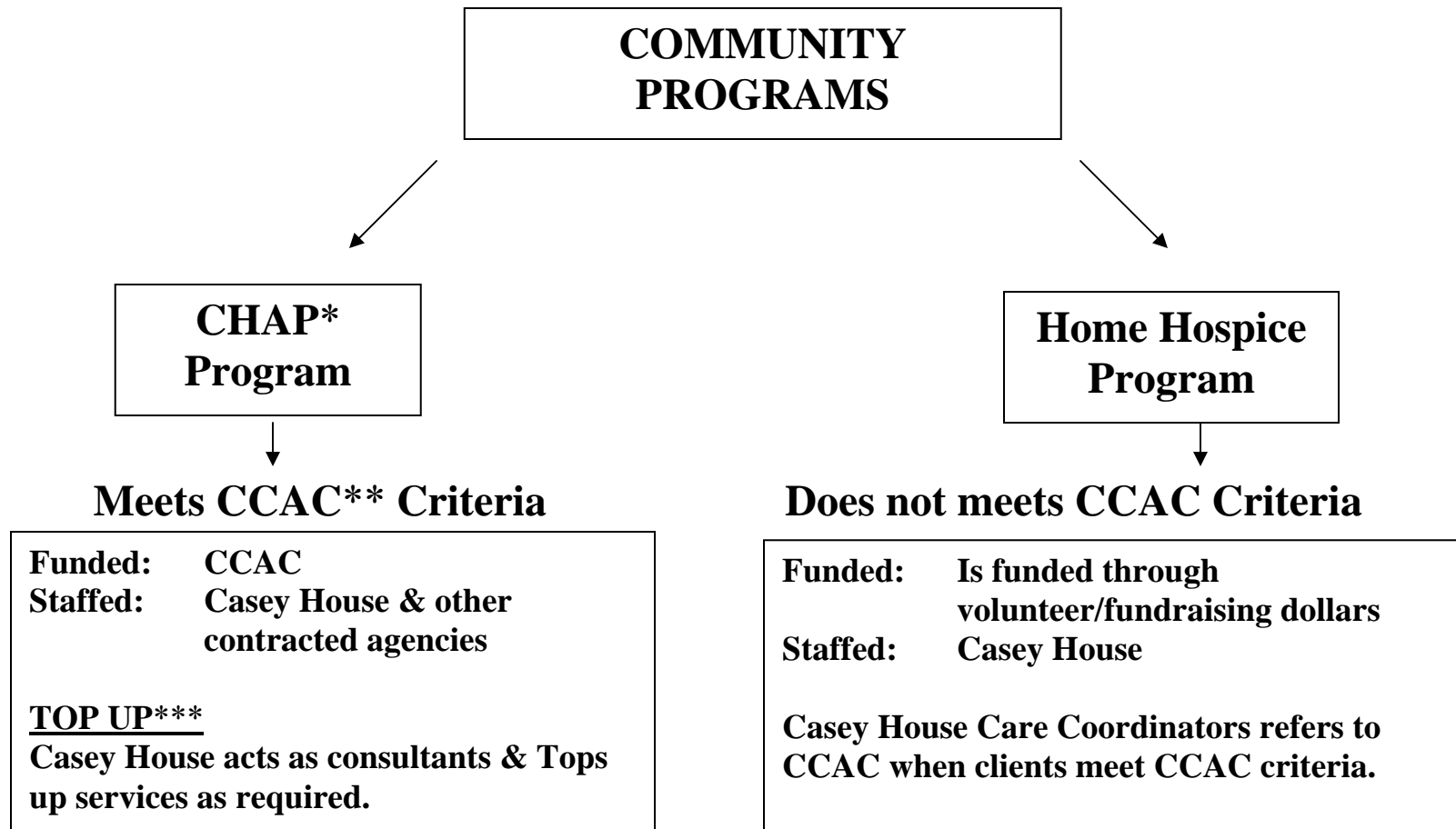
APPENDICES

APPENDIX A

Figures

Figure 1

Admission Flow to Casey House Community Programs



* CHAP – Community HIV/AIDS Partnership

** CCAC – Community Care Access Centre

*** TOP UP refers to addition of hours and/or services

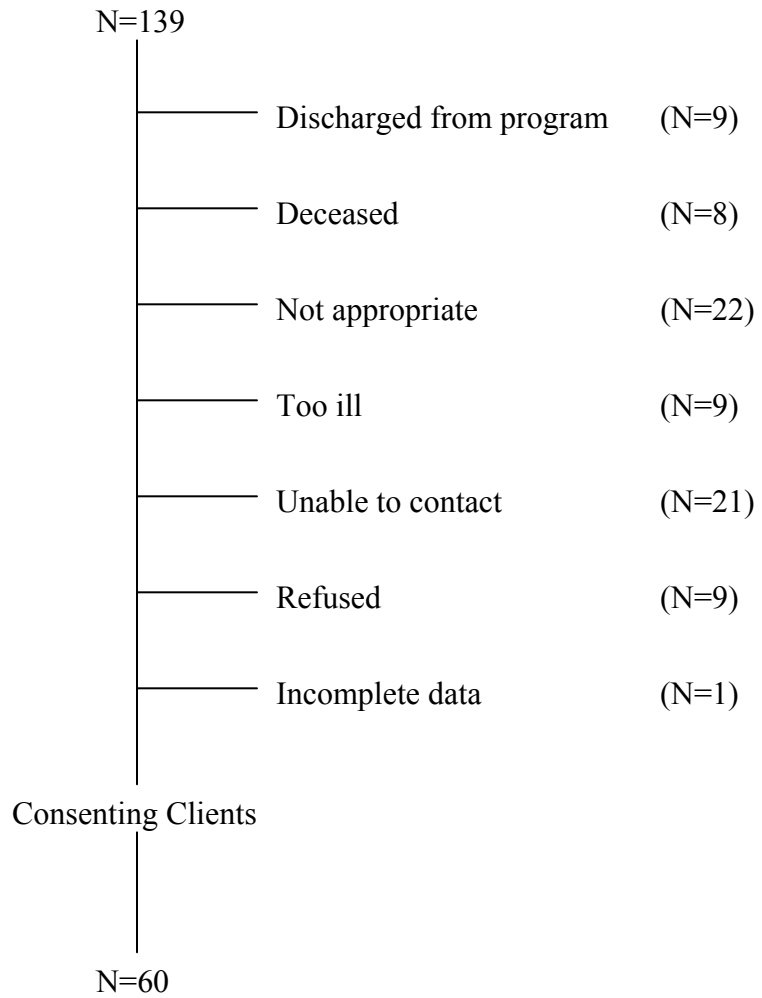
Figure 2
Quality of Care Variables and Their Measures*

	Structure	Process	Outcome	Measure
Effectiveness	Competence of service providers Support Services	Psychosocial, coping, disease severity	Quality of Life	<ul style="list-style-type: none"> • Karnofsky Disease Rating Scale • MOS-HIV Health Survey • Moos' Coping Scale • CSQ
Acceptability	Confidentiality	Continuity of care	Client Satisfaction	<ul style="list-style-type: none"> • CSQ
Efficiency	Type and mix of personnel	"Dose" of services	Costs of all service use	<ul style="list-style-type: none"> • long versus short service use • Health Services Inventory
Accessibility	<ul style="list-style-type: none"> • 24 hour care • use of community resources • types of funding source 	Amount of use of Health and Social Services	Expenditures for use of types of services	<ul style="list-style-type: none"> • Health Services Inventory
Equity	Non discriminatory practice	Client mix	Client Satisfaction	<ul style="list-style-type: none"> • Demographic data • CSQ
Relevance to Need	<ul style="list-style-type: none"> • Person centered • Service options • Flexible, responsive care 	Source of funded managed services <ul style="list-style-type: none"> • CCAC • CHAP 	Client Satisfaction	<ul style="list-style-type: none"> • Referral type • CSQ

*Adaptation of Maxwell, 1986

Figure 3
Sampling Process

Listed PHA Clients of Casey House
Community Programs (August 2001-February 2002)



APPENDIX B

Tables

Table 1
Comparison of Demographic Characteristics of PHA Clients from 2 Funding Sources For Community Programs

	GROUP				TEST STATISTICS	
	HH		CHAP		Chi-square	p-values
	Count	%	Count	%		
Gender						
Male	34	91.9%	20	87.0%	1.653	0.438
Female	3	8.1%	2	8.7%		
Transgender	0	0.0%	1	4.3%		
Age						
under 40	11	29.7%	10	43.5%	2.666	0.264
40-49	17	45.9%	11	47.8%		
50 & Up	9	24.3%	2	8.7%		
What is the highest level of education you have obtained?						
Grade School	4	11.8%	2	8.7%	2.465	0.482
High School or equivalent	10	29.4%	6	26.1%		
Some/complete College	7	20.6%	9	39.1%		
Some/complete University	13	38.0%	6	26.1%		
What is your current relationship status?						
Single	25	67.6%	16	69.6%	0.19	0.909
Divorced/Separated/Widow	1	2.7%	1	4.3%		
Married/Common-law/Partner	11	29.7%	6	26.1%		
How would you describe your ethno/cultural background?						
Canadian	23	62.2%	18	78.3%	3.505	0.320
British	2	5.4%	0	0.0%		
European	6	16.2%	1	4.3%		
Other	6	16.2%	4	17.2%		
What is your first language?						
English	29	78.4%	18	78.3%	1.313	0.519
French	1	2.7%	2	8.7%		
Other	7	18.9%	3	13.0%		
What are your current living arrangements?						
Your house/apartment	15	40.5%	8	34.8%	0.914	0.633
Residential housing subsidized	21	56.8%	15	65.2%		
Long Term Care Facility	1	2.7%	0	0.0%		
Geographic location						
City Core	34	91.9%	23	100.0%	0.627	0.428
City Suburbs	3	8.1%	0	0.0%		
Do you currently live with someone?						
Live Alone					0.011	0.917
Yes	23	62.2%	15	65.2%		
No	13	35.1%	8	34.8%		
Not Stated					0.61	0.435
Spouse or Partner						
Yes	9	24.3%	3	13.0%		
No	27	73.0%	20	87.0%		
Not Stated						
	1	2.7%	0	0.0%		

Table 2
Comparison of Clinical Characteristics of PHA Clients from 2 Funding Sources For Community Programs

Variable	GROUP				TEST STATISTICS	
	HH (N=37)		CHAP (N=23)		T-Test	p-values
	Mean	SD	Mean	SD		
Length of time since diagnosis (years)	10.91	4.49	10.28	5.49	0.48	0.6
Length of time using Community Programs (Months)	25.0	26.00	18.0	13.0	1.17	0.3
CD4% Count	271.0	215.0	245.0	186.0	0.48	0.6
Viral Load Count	43667	114623	49889	83874	-0.22	0.8
Karnofsky Scale Rating	69.0	16.0	69.0	15.0	-0.12	0.9

(Score of 70 indicates ability to care for self but unable to carry on normal activity or do active work.)

Table 3
Comparison of Types of Coping Responses of PHA Clients from 2 Funding Sources For Community Programs

Variable	GROUP				TEST STATISTICS	
	HH (N=37)		CHAP (N=23)		T-Test	p-values
	Mean	SD	Mean	SD		
Moos & Billing Coping Scale						
Cognitive Coping (0-33)	23.40	10.20	20.60	5.00	1.240	0.220
Active Behavioural Coping (0-39)	26.00	12.60	20.20	5.40	2.078	0.042*
Avoidance Coping (0-24)	8.10	8.90	7.10	3.00	0.516	0.608
Logical Analysis (0-12)	9.90	3.80	8.40	2.20	1.733	0.088
Information Seeking (0-21)	14.10	7.10	9.70	3.60	2.772	0.007*
Problem Solving (0-15)	10.30	5.10	9.00	2.60	1.158	0.252
Affective regulation (0-18)	11.60	6.40	9.40	3.70	1.443	0.154
Emotional Discharge (0-18)	6.50	6.60	6.00	2.40	0.346	0.731

*p<0.05

Table 4
Comparison of Types of Social Support of PHA Clients from 2 Funding Sources For Community Programs

Variable	GROUP				TEST STATISTICS	
	HH (N=37)		CHAP (N=23)		T-Test	p-values
	Mean	SD	Mean	SD		
Duke-UNC Social Support Scale *						
Confident Support (5-30)	13.54	9.44	14.30	6.04	-0.346	0.731
Affective Support (3-18)	8.14	5.84	6.78	3.09	1.024	0.310

Higher score = less social support

Table 5
Comparison of Health Related Quality of Life Dimensions of PHA Clients from 2 Funding Sources For Community Programs

Variable	GROUP				TEST STATISTICS	
	HH (N=37)		CHAP (N=23)		T-Test	p-values
	Mean	SD	Mean	SD		
HSF36 (Index scores)*(0-100)						
Overall Health Perception Index score	33.82	24.48	31.47	23.52	0.367	0.715
Physical Function index score	46.40	31.40	55.43	31.54	-1.082	0.284
Role Function index score	13.51	30.39	17.39	32.36	-0.469	0.641
Social Function index score	49.19	32.86	49.57	29.46	-0.045	0.964
Cognitive Function index score	62.16	24.71	59.78	21.77	0.379	0.706
Pain function index score	42.64	24.78	43.00	28.68	-0.050	0.960
Mental Health index score	63.57	20.02	60.87	18.41	0.523	0.603
Energy/Fatigue index score	39.19	22.50	36.96	23.10	0.370	0.713
Health Distress index score	60.95	26.40	59.13	24.89	0.265	0.792
Quality of Life index score	54.05	19.11	52.17	23.73	0.337	0.737
Health Transition index score	64.86	26.65	57.61	27.63	1.011	0.290
Physical Health summary T score (Mean=50, s.d.=10)	49.92	10.24	50.13	9.82	-0.078	0.938
Mental Health summary T score (Mean=50, s.d.=10)	50.48	10.70	49.23	8.93	0.469	0.640

Higher score = better health

Table 6
Comparison of PHAs' Satisfaction with Services from 2 Funding
Sources For Community Programs

Client Satisfaction Scale	GROUP				TEST STATISTICS			
	HH		CHAP		Chi-square	p-values		
	Count	%	Count	%				
How would you rate the quality of service you received?								
Good	9	24.3%	4	17.4%	0.097	0.755		
Excellent	28	75.7%	19	82.6%				
Did you get the kind of service you wanted?								
No, not really	1	2.7%	0	0.0%	4.875	0.087		
Yes, generally	7	18.9%	10	43.5%				
Yes, definitely	29	78.4%	13	56.5%				
To what extent has our program met your needs?								
Most of my needs have been met	13	35.1%	14	60.9%	3.795	0.051*		
Almost all of my needs have been met	24	64.9%	9	39.1%				
If a friend were in need of similar help, would you recommended the program?								
No, I don't think so	1	2.7%	0	0.0%	1.351	0.509		
Yes, I think so	3	8.1%	1	4.3%				
Yes, definitely	33	89.2%	22	95.7%				
How satisfied are you with the amount of help you received?								
Indifferent or mildly dissatisfied	2	5.4%	2	8.7%	0.876	0.645		
Mostly satisfied	10	27.0%	4	17.4%				
Very satisfied	25	67.6%	17	73.9%				
Have the services you received helped you to deal more effectively with your problems?								
Yes, they helped somewhat	12	32.4%	5	21.7%	0.359	0.549		
Yes, they helped a great deal	25	67.6%	18	78.3%				
In an overall, general sense, how satisfied are you with the service you received?								
Indifferent or mildly dissatisfied	1	2.7%	0	0.0%	2.190	0.334		
Mostly satisfied	6	16.2%	7	30.4%				
Very satisfied	30	81.1%	16	69.6%				
If you were to seek help again, would you come back to our program?								
Yes, I think so	3	8.1%	1	4.3%	0.004	0.950		
Yes, definitely	33	89.2%	22	95.7%				
Not stated	1	2.7%	0	0.0%				
Overall Satisfaction	N	̄	SD	N	̄	SD	t-test	p-value
	37	30.16%	2.15	23	29.83%	2.17	0.586	0.56

*p<0.05

Table 7
Comparison of Annual Expenditures of Health and Social Services Utilization of PHA
Clients from 2 Funding Sources For Community Programs

	GROUP				TEST STATISTICS		
	HH (N=36)		CHAP (N=23)		Mann-Whitney U	Z	p-values
	Mean	SD	Mean	SD			
Direct cost							
Family physicians (primary care)	392.53	384.95	583.68	653.23	357.00	-0.923	0.356
Emergency Room Service	652.53	3157.23	306.41	808.92	396.00	-0.534	0.593
Infectious diseases/HIV specialist	731.25	1031.18	635.09	994.07	354.50	-0.986	0.324
Psychiatrist	159.56	322.41	279.78	632.76	406.50	-0.161	0.872
Other Physician Specialists	1289.40	1643.30	1156.54	1718.70	371.00	-0.687	0.492
Nursing Cost	1101.29	1100.50	1402.82	1249.08	319.00	-1.479	0.139
Physiotherapist cost	671.70	2007.02	175.23	685.52	379.00	-0.914	0.361
Occupational Therapist cost	217.28	813.40	42.51	203.88	396.50	-0.624	0.533
Chiropractic cost	307.05	1209.07	67.38	263.62	380.00	-0.888	0.375
Nutritionist Cost	81.94	248.44	182.61	555.67	402.50	-0.318	0.750
Psychologist	123.33	740.00	482.61	1888.07	389.50	-1.000	0.317
Social Worker	803.84	1543.60	776.46	1564.05	403.50	-0.188	0.851
Counselling (family/pastoral/ addiction/legal)	160.31	840.81	256.39	1004.46	394.00	-0.593	0.553
Supporting groups (support/peer/ health education/ prevention/ recreation/financial/advocacy)	325.42	1319.46	266.53	638.47	392.00	-0.503	0.615
Speech Therapist	148.50	729.78	0.00	0.00	391.00	-1.140	0.254
Other health Professional (Naturopath/homeopath/ Chiropracist/ optometrist)	250.00	804.92	70.43	337.79	354.00	-1.567	0.117
Call 911 Service	85.51	394.73	12.17	58.35	408.00	-0.245	0.807
Ambulance Service	735.00	3936.59	127.83	613.03	408.50	-0.225	0.822
Meal on wheel	57.00	198.75	75.39	319.93	412.50	-0.048	0.962
ASO Food Bank	245.70	398.35	192.29	384.63	382.00	-0.639	0.523
Other community-based food bank	68.63	240.72	21.49	103.04	396.50	-0.624	0.533
General homemakers	535.34	1097.27	443.04	582.27	393.00	-0.374	0.708
House Cleaning only	0.00	0.00	380.87	1268.23	378.00	-1.784	0.074
Other Community support services	13.63	81.80	47.20	169.29	372.00	-1.498	0.134
Unpaid/Voluntary Community support services	3743.75	6474.41	1780.43	5530.07	288.00	-2.039	0.041*
Laboratory Cost	1352.79	1421.05	1740.93	1841.49	374.00	-0.628	0.530
Medical Procedure (IV, Vaccination, TPN, Radiotherapy, Blood transfusion, Injections)	268.15	453.82	260.83	410.35	403.00	-0.179	0.858
Blood Work Cost	801.66	795.00	519.76	748.25	329.50	-1.381	0.167
Other types of diagnostic tests	551.13	1252.67	1221.18	1715.59	301.00	-1.953	0.051
Medication cost	19979.31	12768.06	17027.17	8451.16	372.00	-0.653	0.514
Prescription drugs	19904.42	12735.32	16860.97	8466.44	370.00	-0.684	0.494
Non-prescription drugs	74.89	247.91	166.20	396.03	304.00	-1.849	0.064
Complementary Therapies	575.54	855.21	962.38	1427.51	360.00	-0.883	0.377
Supplies, aids or special devices	104.66	515.23	135.35	562.31	396.00	-0.533	0.594
Transportation cost	11.13	29.87	10.74	33.41	400.00	-0.348	0.728
Nursing Home stay cost	0.00	0.00	0.00	0.00	414.00	0.000	1.000

*p<0.05

Table 7
Comparison of Annual Expenditures of Health and Social Services Utilization of PHA
Clients from 2 Funding Sources For Community Programs

	GROUP				TEST STATISTICS		
	HH (N=36)		CHAP (N=23)		Mann-Whitney U	Z	p-values
	Mean	SD	Mean	SD			
Hospice Stay cost	0.00	0.00	8556.52	20168.65	342.00	-2.568	0.010*
Direct Cost excluding hospital cost	35192.08	17540.88	38459.08	23244.86	385.00	-0.451	0.652
Hospital Stay cost	14150.07	55684.41	2129.61	10213.24	396.00	-0.642	0.521
Direct cost including hospital cost	49342.15	56928.68	40588.68	26547.67	408.00	-0.093	0.926
Out of pocket							
Meals on wheels	14.17	85.00	52.17	250.22	407.00	-0.347	0.729
ASO Food Bank	0.00	0.00	0.00	0.00	414.00	0.000	1.000
Other community-based food bank	0.00	0.00	0.00	0.00	414.00	0.000	1.000
General homemakers	0.00	0.00	0.00	0.00	414.00	0.000	1.000
House Cleaning only	223.33	689.74	0.00	0.00	356.50	-1.850	0.064
Other Community support services	5.33	32.00	0.00	0.00	402.50	-0.799	0.424
Medication cost	511.81	1084.88	731.63	1110.68	351.50	-1.051	0.293
Prescription drugs	308.35	940.79	195.68	620.72	397.50	-0.377	0.706
Non-prescription drugs	203.46	647.90	535.95	943.16	363.00	-0.913	0.361
Supplies, aids or special devices	52.36	172.12	32.61	95.74	403.50	-0.261	0.794
Transportation cost	127.26	330.74	198.15	533.92	411.00	-0.048	0.962
Loss of pay due to health-related problem	0.00	0.00	147.83	591.51	378.00	-1.784	0.074
Total Out of pocket cost	934.26	1324.23	1014.57	1431.09	397.00	-0.265	0.791
Grand Total cost	50276.41	56905.26	41603.25	26376.15	412.00	-0.031	0.975
Cash Transfer							
Workplace Safety and Insurance Information Board	215.00	1290.00	0.00	0.00	402.50	-0.799	0.424
Ontario Disability Support Program (ODSP)	3543.61	4171.27	5660.88	4734.51	287.00	-2.035	0.042*
Canada Pension	4071.22	4250.99	2726.61	3624.29	340.50	-1.235	0.217
Company pension	1343.30	4151.48	949.45	3162.57	404.00	-0.296	0.767
Old Age Security	0.00	0.00	0.00	0.00	414.00	0.000	1.000
GAIN	0.00	0.00	0.00	0.00	414.00	0.000	1.000
Veterans' Benefit	0.00	0.00	0.00	0.00	414.00	0.000	1.000
Survivor Benefits	0.00	0.00	0.00	0.00	414.00	0.000	1.000
Family Benefits Allowance	0.00	0.00	336.52	1613.90	396.00	-1.251	0.211
Welfare or Social Assistance	226.67	1360.00	0.00	0.00	402.50	-0.799	0.424
Private Insurance (income replacement or annuities)	2368.67	8045.91	1520.87	5407.74	404.00	-0.296	0.767
Investment income	1688.89	9997.08	0.00	0.00	391.00	-1.140	0.254
Salary	1200.00	5304.88	1356.52	4508.96	401.50	-0.446	0.656
Cheque from Family	288.89	1429.84	86.96	417.03	408.50	-0.225	0.822
Long Term disability	1350.00	6300.00	0.00	0.00	391.00	-1.140	0.254
Grant For volunteering	0.00	0.00	52.17	250.22	396.00	-1.251	0.211
Cheque for Honorarium	100.00	600.00	0.00	0.00	402.50	-0.799	0.424
Cash Transfer Cost	16396.25	18301.22	12689.98	7173.72	402.00	-0.187	0.852

*p<0.05

Table 8
Comparison of Demographic Characteristics of PHA Clients with Less Than and More Than 1 Year Community Programs Services

	Received Services < 1 Year (N=24)		Received Services > 1 Year (N=36)		TEST STATISTICS	
	Count	%	Count	%	Chi-square	p-values
Group						
HH	15	62.5%	22	61.1%	0.012	0.914
CHAP	9	37.5%	14	38.9%		
Gender						
Male	20	83.3%	34	94.4%	2.531	0.282
Female	3	12.5%	2	5.6%		
Transgender	1	4.2%	0	0.0%		
Age						
under 40	6	25.0%	15	41.7%	4.034	0.133
40-49	15	62.5%	13	36.1%		
50 & Up	3	12.5%	8	22.2%		
What is the highest level of education you have obtained?						
Grade School	4	16.7%	2	6.1%	4.934	0.177
High School or equivalent	9	37.5%	7	21.2%		
Some/complete College	4	16.7%	12	36.4%		
Some/complete University	7	29.2%	12	36.4%		
What is your current relationship status?						
Single	16	66.7%	25	69.4%	3.173	0.205
Divorced/Separated Widow	2	8.3%	0	0.0%		
Married/Common-	6	25.0%	11	30.6%		
What are your current living arrangements?						
Your house/apartment	5	20.8%	18	50.0%	6.196	0.045*
Residential housing	18	75.0%	18	50.0%		
Long Term Care Facility	1	4.2%	0	0.0%		
Geographic location						
City Core	23	95.8%	34	94.4%	0.058	0.809
City Suburbs	1	4.2%	2	5.6%		
Do you currently live with someone?						
a) Live Alone						
Yes	16	66.7%	22	62.9%	0.090	0.764
No	8	33.3%	13	37.1%		
b) Spouse or Partner						
Yes	6	25.0%	6	17.1%	0.542	0.461
No	18	75.0%	29	82.9%		

*p<0.05

Table 9
Comparison of Clinical Characteristics of PHA Clients with Less Than and More Than 1 Year Community Programs Services

Variable	Received Services < 1 Year (N=24)		Received Services > 1 Year (N=36)		TEST STATISTICS	
	Mean	SD	Mean	SD	T-Test	p-values
Length of time since diagnosis (years)	10.6	5.75	10.7	4.25	-0.07	0.9
Length of time using Community Programs (Months)	6	3	32	24	-5.3	0.001*
CD4% Count	220	213	289	195	-1.3	0.2
Viral Load Count	69360	144629	29960	58924	1.26	0.2
Karnofsky Scale Rating	69	15	69	16	-0.03	0.97

*p<0.05

Table 10
Comparison of Psychosocial Variables (Coping Styles, Social Support and Quality of Life) of PHA
Clients with Less Than and More Than 1 Year Community Programs Services

Variable	Received Services < 1 Year (N=24)		Received Services > 1 Year (N=36)		TEST STATISTICS	
	Mean	SD	Mean	SD	T-Test	p-values
Cognitive Coping (0-33)	21.3	4.5	23.1	10.5	-0.776	0.441
Active Behavioural Coping (0-39)	21.0	7.3	25.6	12.4	-1.60	0.113
Avoidance Coping (0-24)	7.1	3.5	8.1	8.9	-0.538	0.593
Logical Analysis (0-12)	8.6	2.3	9.8	3.8	-1.33	0.190
Information Seeking (0-21)	11.2	4.2	13.3	7.4	-1.26	0.214
Problem Solving (15)	9.0	2.8	10.3	5.1	-1.20	0.236
Affective regulation (0-18)	9.8	4.4	11.4	6.3	-1.13	0.264
Emotional Discharge (0-18)	5.6	2.9	6.9	6.5	-0.900	0.372
Social Support Scores						
Confident support (5-30)	15.63	10.80	12.64	5.87	1.238	0.225
Affective Support (3-18)	8.71	6.84	6.89	3.11	1.222	0.231
HR Quality of Life Index Score (0-100)						
Overall Health Perception Index score	30.21	22.51	34.72	25.01	-0.712	0.479
Physical Function index score	46.18	31.94	52.31	31.41	-0.736	0.465
Role Function index score	14.58	31.20	15.28	31.21	-0.084	0.933
Social Function index score	40.83	29.18	55.00	31.85	-0.174	0.086
Cognitive Function index score	56.46	24.38	64.44	22.61	-1.30	0.199
Pain function index score	40.74	27.15	44.14	25.68	-0.490	0.626
Mental Health index score	62.33	20.77	62.67	18.57	-0.065	0.948
Energy/Fatigue index score	40.00	24.09	37.22	21.76	0.464	0.644
Health Distress index score	57.50	25.71	62.08	25.78	-0.675	0.502
Quality of Life index score	55.21	20.82	52.08	21.02	0.566	0.573
Health Transition index score	68.75	25.80	57.64	27.27	1.579	0.120
Physical Health summary T score (Mean=50, s.d.=10)	49.11	9.10	50.59	10.64	-0.559	0.578
Mental Health summary T score (Mean=50, s.d.=10)	48.93	9.75	50.71	10.24	-0.673	0.504

Table 11

Comparison of Annual Expenditures of Health and Social Services Utilization of PHA Clients with Less Than and More Than 1 Year Community Programs Services

	Received Services < 1 Year (N=24)		Received Services > 1 Year (N=36)		TEST STATISTICS		
	Mean	SD	Mean	SD	Mann-Whitney U	Z	p-values
Direct Cost							
Family physicians (primary care)	368.64	291.29	529.92	606.04	376.00	-0.615	0.538
Emergency Room Service	919.22	3926.94	261.01	748.73	406.00	-0.237	0.812
Infectious diseases/HIV specialist	788.48	1204.18	633.25	875.82	382.00	-0.530	0.596
Psychiatrist	148.01	349.15	243.75	530.20	383.00	-0.666	0.506
Other Physician Specialists	1207.38	1446.12	1256.92	1802.44	392.50	-0.343	0.731
Nursing Cost	1382.33	1257.15	1114.37	1098.20	376.50	-0.584	0.559
Physiotherapist cost	770.99	2152.95	291.07	1190.15	359	-1.437	0.151
Occupational Therapist cost	340.09	1004.45	27.16	162.96	370.5	-1.551	0.121
Chiropractic cost	323.39	1484.76	143.49	360.41	381.5	-0.849	0.396
Nutritionist Cost	206.51	556.82	66.67	239.05	375.5	-1.066	0.286
Psychologist	0.00	0.00	431.67	1662.94	379.5	-1.408	0.159
Social Worker	585.69	1322.79	925.72	1665.66	361	-0.950	0.342
Counselling (family/pastoral/addiction/legal)	15.90	76.24	313.96	1142.62	373	-1.215	0.224
Supporting groups (support/peer/health education/prevention/recreation/financial/advocacy)	497.31	1665.83	177.98	461.98	411.5	-0.057	0.954
Speech Therapist	185.95	891.77	29.70	178.20	407	-0.347	0.729
Other health Professional (Naturopath/homeopath/Chiropracist/ optometrist)	0.00	0.00	295.00	835.26	322	-2.403	0.016*
Call 911 Service	133.84	491.04	7.77	46.64	388.5	-1.041	0.298
Ambulance Service	1150.43	4914.70	81.67	490.00	389	-1.021	0.307
Meal on wheel	62.61	216.88	65.17	272.77	412.5	-0.048	0.962
ASO Food Bank	256.38	415.64	204.75	378.36	390	-0.479	0.632
Other community-based food bank	85.94	284.74	27.45	114.80	399	-0.535	0.593
General homemakers	751.24	1284.29	338.43	561.62	340.5	-1.309	0.191
House Cleaning only	0.00	0.00	243.33	1022.46	391	-1.140	0.254
Other Community support services	3.13	15.01	41.79	156.25	396	-0.642	0.521
Unpaid/Voluntary Community support services	2142.39	5580.59	3512.50	6508.30	359	-0.890	0.374
Laboratory Cost	1706.53	1716.82	1374.77	1521.35	385	-0.455	0.649
Medical Procedure (IV, Vaccination, TPN, Radiotherapy, Blood transfusion, Injections)	321.98	553.29	229.09	340.49	408.5	-0.090	0.929
Blood Work Cost	644.04	739.47	722.25	818.33	372	-0.687	0.492
Other types of diagnostic tests	1062.49	1573.48	652.52	1405.57	314	-1.728	0.084
Medication cost	16913.70	9360.50	20051.80	12344.56	365	-0.762	0.446
Prescription drugs	16833.15	9351.93	19922.19	12335.26	369	-0.699	0.484
Non-prescription drugs	80.55	288.29	129.61	331.94	407	-0.118	0.906
Complementary Therapies	753.54	1436.76	708.97	879.74	374	-0.654	0.513
Supplies, aids or special devices	271.61	832.03	17.60	59.78	390	-0.711	0.477
Transportation cost	11.97	29.84	10.34	32.14	375	-0.969	0.333
Nursing Home stay cost	0.00	0.00	0.00	0.00	414	0.000	1.000
Hospice Stay cost	3234.78	15513.47	3400.00	11565.27	399	-0.535	0.593
Direct Cost excluding hospital cost	35539.96	20419.03	37057.07	19712.85	411	-0.047	0.963
Hospital Stay cost	22147.93	68904.49	1360.58	8163.50	370	-1.569	0.117

*p<0.05

Table 11

Comparison of Annual Expenditures of Health and Social Services Utilization of PHA Clients with Less Than and More Than 1 Year Community Programs Services

	Received Services < 1 Year (N=24)		Received Services > 1 Year (N=36)		TEST STATISTICS		
	Mean	SD	Mean	SD	Mann-Whitney U	Z	p-values
Direct cost including hospital cost	57687.89	69871.89	38417.66	22292.80	367	-0.730	0.465
Out of pocket							
Meal on wheel	22.17	106.34	33.33	200.00	408	-0.297	0.766
ASO Food Bank	0.00	0.00	0.00	0.00	414	0.000	1.000
Other community-based food bank	0.00	0.00	0.00	0.00	414	0.000	1.000
General homemakers	0.00	0.00	0.00	0.00	414	0.000	1.000
House Cleaning only	213.91	787.69	86.67	315.03	410.5	-0.113	0.910
Other Community support services	8.35	40.03	0.00	0.00	396	-1.251	0.211
Medication cost	751.08	1279.32	499.39	957.91	414	0.000	1.000
Prescription drugs	536.11	1222.66	90.86	336.47	358.5	-1.270	0.204
Non-prescription drugs	214.96	616.91	408.53	876.93	359	-0.985	0.325
Supplies, aids or special devices	33.04	95.65	52.08	172.18	402.5	-0.286	0.775
Transportation cost	126.77	291.17	172.86	486.26	365.5	-0.768	0.442
Loss of pay due to health-related problem	121.74	583.84	16.67	100.00	407	-0.347	0.729
Total Out of pocket cost	1155.32	1472.12	844.34	1281.61	376	-0.591	0.554
Grand Total cost	58843.21	69728.52	39261.99	22265.93	365	-0.762	0.446
Cash Transfer							
Workplace Safety and Insurance Information Board	0.00	0.00	215.00	1290.00	402.5	-0.799	0.424
Ontario Disability Support Program (ODSP)	4627.21	4642.97	4204.02	4434.48	405.5	-0.136	0.892
Canada Pension	2571.37	3755.63	4170.40	4142.63	328	-1.446	0.148
Company pension	719.95	2420.16	1489.93	4434.47	400	-0.415	0.678
Old Age Security	0.00	0.00	0.00	0.00	414	0.000	1.000
GAIN	0.00	0.00	0.00	0.00	414	0.000	1.000
Veterans' Benefit	0.00	0.00	0.00	0.00	414	0.000	1.000
Survivor Benefits	0.00	0.00	0.00	0.00	414	0.000	1.000
Family Benefits Allowance	336.52	1613.90	0.00	0.00	396	-1.251	0.211
Welfare or Social Assistance	354.78	1701.48	0.00	0.00	396	-1.251	0.211
Private Insurance (income replacement or annuities)	2251.30	6260.37	1902.00	7663.06	395	-0.563	0.573
Investment income	2608.70	12510.86	22.22	133.33	407	-0.347	0.729
Salary	1356.52	4508.96	1200.00	5304.88	401.5	-0.446	0.656
Cheque from Family	452.17	1781.95	55.56	333.33	389	-1.021	0.307
Long Term disability	1565.22	7506.52	350.00	2100.00	407	-0.347	0.729
Grant For volunteering	0.00	0.00	33.33	200.00	402.5	-0.799	0.424
Cheque for Honorarium	156.52	750.65	0.00	0.00	396	-1.251	0.211
Cash transfer Cost	17000.27	21160.28	13642.46	9317.81	405	-0.140	0.889

Table 12
Comparison of Demographic, Clinical and Psychosocial Characteristics of PHAs With Better or Worse Performance Measured by Karnofsky Scale

	KRS \geq 80 (BETTER)		KRS $<$ 80 (WORSE)		TEST STATISTICS	
	Mean	SD	Mean	SD	T-Test	p-values
Demographic and Clinical Information						
Age	41.98	6.57	44.60	7.08	-1.431	0.158
Time using Community Programs services (months)	20	19	23	25	-0.486	0.629
Time diagnosed with HIV/AIDS (years)?	10.56	5.42	10.73	4.56	-0.135	0.893
CD4 Plus Lymphocyte Count	286	234	246	183	0.752	0.455
Viral Load Count	39658	76621	50031	118392	-0.373	0.711
HR quality of Life Index Score (0-100)						
Overall Health Perception Index score	53.59	22.97	20.07	13.21	6.373	0.001*
Physical Function index score	75.00	25.99	34.23	23.63	6.252	0.001*
Role Function index score	30.43	39.14	5.41	19.66	2.852	0.008*
Social Function index score	66.96	31.11	38.38	26.41	3.806	0.001*
Cognitive Function index score	76.30	17.98	51.89	21.68	4.517	0.001*
Paint function index score	57.97	29.39	33.33	18.70	3.594	0.001*
Mental Health index score	69.74	20.92	58.05	17.01	2.367	0.021*
Energy/Fatigue index score	55.22	21.77	27.84	15.79	5.236	0.001*
Health Distress index score	73.26	24.15	52.16	23.35	3.359	0.001*
Quality of Life index score	63.04	19.76	47.3	19.35	3.040	0.004*
Health Transition index score	67.39	28.64	58.78	25.83	1.204	0.234
Physical Health summary T score (Mean=50, s.d.=10)	59.18	8.11	44.29	6.02	7.60	0.001*
Mental Health summary T score (Mean=50, s.d.=10)	58.17	8.49	44.92	7.11	6.512	0.001*
Coping Scales						
Cognitive Coping (0-33)	22.0	4.2	22.6	10.6	-0.279	0.781
Active Behavioural Coping (0-39)	22.4	8.0	24.6	12.2	-0.741	0.462
Avoidance Coping (0-24)	7.1	3.7	8.1	8.7	-0.516	0.608
Logical Analysis (0-12)	8.9	2.4	9.6	3.8	-0.821	0.415
Information Seeking (0-21)	11.7	4.8	12.9	7.1	-0.735	0.465
Problem Solving (0-15)	9.0	3.0	10.3	5.0	-1.158	0.252
Affective regulation (0-18)	11.4	4.3	10.4	6.3	0.694	0.490
Emotional Discharge (0-18)	5.7	3.0	6.7	6.4	-0.691	0.492
Social Support Scales						
Confident Support (5-30)	12.43	8.75	14.70	7.92	-1.036	0.305
Affective Support (3-18)	7.74	5.63	7.54	4.61	0.149	0.882

*p<0.05

Table 13
Comparison of Demographic, Clinical and Psychosocial Characteristics of PHAs With Better or Worse Mental Health

	Mental Health (MHSS)*				TEST STATISTICS	
	Worse (<43) Mental Health (N=14)		Better (>43) Mental Health (N=46)		T-Test	p-values
	Mean	SD	Mean	SD		
Demographic and Clinical Information						
Age	42.87	8.70	43.82	6.43	-0.443	0.65
Time using Community Programs services (months)	22.00	24.00	22.00	22.00	-0.003	0.99
Time diagnosed with HIV/AIDS (years)?	11.02	4.79	10.56	4.93	0.306	0.76
KRS Scale Score	68.00	18.00	69.00	15.00	-0.268	0.78
CD4 Plus Lymphocyte Count	260.00	180.00	262.00	212.00	-0.026	0.98
Viral Load Count	89824	184621	33598	63279	1.080	0.30
HR Quality of Life Summary Scores (0-100)						
Physical Health summary T score (Mean=50, s.d.=10)	44.84	8.79	51.57	9.90	-2.282	0.026**
Mental Health summary T score (Mean=50, s.d.=10)	39.87	8.15	53.08	8.38	-5.195	0.000**
Coping Scales						
Cognitive Coping (0-33)	25.10	16.00	21.50	4.60	0.841	0.415
Active Behavioural Coping (0-39)	27.60	19.10	22.60	6.40	0.958	0.354
Avoidance Coping (0-24)	11.40	13.00	6.60	3.70	2.287	0.026**
Logical Analysis (0-12)	10.40	5.50	9.00	2.30	1.350	0.182
Information Seeking (0-21)	13.60	11.20	12.10	4.00	0.494	0.629
Problem Solving (0-15)	10.80	7.80	9.50	2.70	0.979	0.332
Affective regulation (0-18)	12.50	8.90	10.20	4.10	1.340	0.185
Emotional Discharge (0-18)	9.30	9.60	5.50	2.80	2.428	0.018**
Social Support Scales						
Confident Support (5-30)	15.50	7.05	13.33	8.59	0.861	0.393
Affective Support (3-18)	7.50	3.35	7.65	5.41	-0.099	0.921

*MHSS of <43 corresponds to a score of >20 on CES-D scale

**p<0.05

Table 14
Comparison of Annual Expenditures of Health and Social Services Utilizations of PHAs With Better or Worse Mental Health

	Mental Health (MHSS)**				TEST STATISTICS		
	Worse (<43) Mental Health (N=14)		Better (>43) Mental Health (N=46)				
	Mean	SD	Mean	SD	Mann-Whitney U	Z	p-values
Direct Cost							
Family physicians (primary care)	580.39	766.61	431.79	404.83	310.00	-0.093	0.926
Emergency Room Service	1510.15	5013.57	208.81	676.07	296.00	-0.646	0.518
Infectious diseases/HIV specialist	1126.93	1420.76	559.00	817.44	237.00	-1.482	0.138
Psychiatrist	208.93	632.86	205.65	411.28	286.50	-0.702	0.483
Other Physician Specialists	1177.56	1378.69	1256.29	1751.45	314.00	-0.018	0.985
Nursing Cost	1171.08	1238.68	1233.69	1148.13	281.50	-0.598	0.550
Physiotherapist cost	921.19	2661.29	340.33	1159.04	308.00	-0.210	0.834
Occupational Therapist cost	0.00	0.00	195.55	739.96	287.00	-1.145	0.252
Chiropractic cost	215.85	451.42	212.93	1075.03	281.00	-1.018	0.309
Nutritionist Cost	0.00	0.00	158.88	447.87	266.00	-1.555	0.120
Psychologist	634.29	2373.28	148.00	733.24	305.50	-0.445	0.657
Social Worker	1879.22	1998.55	455.28	1202.72	150.50	-3.380	0.001*
Counselling (family/pastoral/addiction/legal)	0.00	0.00	259.29	1026.38	273.00	-1.427	0.154
Supporting groups (support/peer/health education/prevention/recreation/financial/advocacy)	104.92	302.23	363.92	1243.59	295.00	-0.524	0.600
Speech Therapist	0.00	0.00	118.80	653.65	301.00	-0.796	0.426
Other health Professional (Naturopath/homeopath/Chiropodist/ optometrist)	115.71	432.96	200.00	724.98	291.00	-0.719	0.472
Call 911 Service	219.87	622.64	6.22	41.72	276.00	-1.825	0.068
Ambulance Service	1890.00	6274.64	65.33	438.27	276.50	-1.802	0.072
Meal on wheel	36.43	136.30	72.80	277.30	308.50	-0.240	0.811
ASO Food Bank	140.40	300.37	251.16	414.09	283.00	-0.732	0.464
Other community-based food bank	70.59	179.45	43.93	205.97	286.00	-1.186	0.236
General homemakers	775.32	1570.59	413.50	607.76	296.50	-0.378	0.706
House Cleaning only	342.86	1282.85	88.00	590.32	299.00	-0.909	0.363
Other Community support services	56.58	211.70	17.43	79.98	312.00	-0.123	0.902
Unpaid/Voluntary Community support services	4982.14	8774.27	2355.00	5044.08	257.00	-1.076	0.282
Laboratory Cost	2078.02	2265.77	1325.54	1302.21	279.00	-0.648	0.517
Medical Procedure (IV, Vaccination, TPN, Radiotherapy, Blood transfusion, Injections)	305.91	619.94	252.66	365.78	281.50	-0.625	0.532
Blood Work Cost	757.88	802.96	671.19	784.68	292.50	-0.422	0.673
Other types of diagnostic tests	1320.15	2256.02	654.35	1118.81	310.50	-0.089	0.929
Medication cost	16179.30	11421.51	19652.66	11256.03	243.00	-1.283	0.200
Prescription drugs	16010.92	11406.59	19560.19	11238.74	240.00	-1.336	0.181
Non-prescription drugs	168.39	384.37	92.47	291.41	280.00	-0.674	0.500
Complementary Therapies	1267.84	1685.63	557.87	828.61	214.00	-1.893	0.058
Supplies, aids or special devices	219.07	819.69	84.75	408.25	305.00	-0.340	0.734
Transportation cost	27.31	50.77	5.90	19.87	255.00	-1.709	0.088
Nursing Home stay cost	0.00	0.00	0.00	0.00	315.00	0.000	1.000
Hospice Stay cost	6342.86	16184.97	2400.00	12065.28	284.00	-1.267	0.205
Direct Cost excluding hospital cost	44580.73	25241.89	33940.97	17395.14	233.00	-1.461	0.144
Hospital Stay cost	31487.79	86447.58	2612.32	12426.47	282.00	-1.349	0.177

*p<0.05

**MHSS of <43 corresponds to a score of >20 on CES-D scale

Table 14
Comparison of Annual Expenditures of Health and Social Services Utilizations of PHAs With Better or Worse Mental Health

	Mental Health (MHSS)**				TEST STATISTICS		
	Worse (<43) Mental Health (N=14)		Better (>43) Mental Health (N=46)				
	Mean	SD	Mean	SD	Mann-Whitney U	Z	p-values
Direct cost including hospital cost	76068.52	83156.95	36553.29	23081.82	188.00	-2.263	0.024*
Out of pocket							
Meal on wheel	36.43	136.30	26.67	178.89	300.00	-0.852	0.394
ASO Food Bank	0.00	0.00	0.00	0.00	315.00	0.000	1.000
Other community-based food bank	0.00	0.00	0.00	0.00	315.00	0.000	1.000
General homemakers	0.00	0.00	0.00	0.00	315.00	0.000	1.000
House Cleaning only	85.71	320.71	152.00	602.40	308.50	-0.240	0.811
Other Community support services	0.00	0.00	4.27	28.62	308.00	-0.558	0.577
Medication cost	973.73	1339.52	480.46	989.57	296.50	-0.357	0.721
Prescription drugs	294.78	786.83	254.99	847.01	300.50	-0.380	0.704
Non-prescription drugs	678.95	1142.59	225.47	615.08	294.00	-0.431	0.666
Supplies, aids or special devices	72.14	179.58	36.11	135.76	287.50	-0.783	0.434
Transportation cost	17.98	20.38	197.49	472.45	243.00	-1.308	0.191
Loss of pay due to health-related problem	0.00	0.00	75.56	424.88	301.00	-0.796	0.426
Total Out of pocket cost	1185.99	1323.74	896.99	1372.22	295.00	-0.357	0.721
Grand Total cost	77254.51	82613.72	37450.28	23381.78	185.00	-2.316	0.021*
Cash Transfer							
Workplace Safety and Insurance Information Board	552.86	2068.60	0.00	0.00	292.50	-1.793	0.073
Ontario Disability Support Program (ODSP)	4326.27	4393.92	4382.28	4557.75	311.00	-0.073	0.941
Canada Pension	3137.66	3983.25	3674.42	4094.06	296.50	-0.356	0.721
Company pension	0.00	0.00	1559.92	4262.56	273.00	-1.427	0.154
Old Age Security	0.00	0.00	0.00	0.00	315.00	0.000	1.000
GAIN	0.00	0.00	0.00	0.00	315.00	0.000	1.000
Veterans' Benefit	0.00	0.00	0.00	0.00	315.00	0.000	1.000
Survivor Benefits	0.00	0.00	0.00	0.00	315.00	0.000	1.000
Family Benefits Allowance	552.86	2068.60	0.00	0.00	292.50	-1.793	0.073
Welfare or Social Assistance	582.86	2180.85	0.00	0.00	292.50	-1.793	0.073
Private Insurance (income replacement or annuities)	3000.00	11224.97	1738.93	5360.31	305.00	-0.340	0.734
Investment income	57.14	213.81	1333.33	8944.27	300.00	-0.852	0.394
Salary	0.00	0.00	1653.33	5647.59	287.00	-1.145	0.252
Cheque from Family	0.00	0.00	275.56	1306.83	294.00	-0.983	0.326
Long Term disability	0.00	0.00	1080.00	5645.34	301.00	-0.796	0.426
Grant For volunteering	0.00	0.00	26.67	178.89	308.00	-0.558	0.577
Cheque for Honorarium	0.00	0.00	80.00	536.66	308.00	-0.558	0.577
Cash transfer Cost	12209.64	12364.37	15804.44	15755.41	201.00	-2.032	0.042*

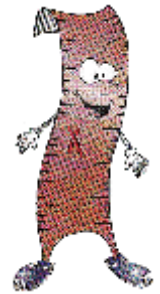
*p<0.05

**MHSS of <43 corresponds to a score of >20 on CES-D scale

APPENDIX C
Client Consent Form



CASEY HOUSE



CLEAR

THE IMPACT OF CASEY HOUSE HOSPICE COMMUNITY PROGRAM SERVICES ON PEOPLE LIVING WITH HIV/AIDS
Client Consent Form

I, _____, consent to be in a study conducted by researchers from Casey House Hospice and McMaster University, CLEAR Unit, to study ways of providing services to clients so they can live at home more effectively. The results will inform us of the success of Casey House Hospice Community Programs.

I have received an information sheet which describes the study. I have discussed the study with my Health Care Worker and the Research Project Co-ordinator and my questions have been answered to my satisfaction. I understand that my partner/family member/friend may assist me in answering questions in the interview if I would like.

I understand that I will take part in a 40-50 minute interview in my home at my convenience. This will be arranged with the Research Project Co-ordinator. The interviewer will ask questions related to my health and use of health care services.

There are no known risks or benefits from this study for myself, but it will advance the understanding of how to best serve clients receiving Casey House Community Hospice Services. I understand that my name will not be recorded with my answers and that I will not be personally identified in any discussion or written report. My name and any other identifying information will not be made available to anyone other than the investigators. I hereby authorize Casey House Community Hospice to release information from my Casey House Health Service Records to the researchers affiliated with this study.

I consent to take part in this study, knowing that I may withdraw from the study at any time even after signing this form. I understand that I am not obligated to take part in the study and that refusal to participate in the study will not affect the care I receive from Casey House Community Hospice now or in the future.

I have received a signed copy of this consent form. *If you wish additional information about this study, please call Lea Narciso, Casey House Hospice, 416-907-7180 ext. 24 or Karen Auld, McMaster University, Telephone Number (905) 525-9140 Ext. 27237.*

Client Signature

Date

Client Name (print)

Research Project Co-ordinator
Signature

Date

Research Project Co-ordinator
Name (print)