

HEALTH RELATED QUALITY OF LIFE OF
PEOPLE LIVING WITH HIV/AIDS WHO
USE COMMUNITY-BASED SUPPORT AND
SERVICES: IMPLICATIONS FOR
SERVICE PROVIDERS

BY

A RESEARCH PARTNERSHIP WITH:
ONTARIO AIDS NETWORK
OAN PHA CAUCUS
CLEAR UNIT, MCMASTER UNIVERSITY

FUNDED BY

THE COMMUNITY-LINKED EVALUATION AIDS
RESOURCE (CLEAR) UNIT
MCMASTER UNIVERSITY, HAMILTON ONTARIO
2001 - 2003

BACKGROUND

- Community-based AIDS service organizations, funded by Ontario Government in early 1980s to serve estimated 21,000 PHAs – majority concentrated in Toronto
- Some US research evidence (2002) that supportive services (drug treatment, case management, housing assistance, mental health treatment) were associated with early entry into and retention in HIV care
- No Canadian study that examined characteristics of PHAs who use these CBAO services and/or the impact of such services use on the nature of use of the formal health and social services system

STUDY OBJECTIVES

1. To determine the characteristics, health related quality of life, and service utilization patterns of PHAs who used ASOs compared with PHAs who did not
2. To determine the relationship of ASO use with the use of other health and social service utilization
3. To discuss the implications of the findings for ASO services

METHODS

Research Setting:

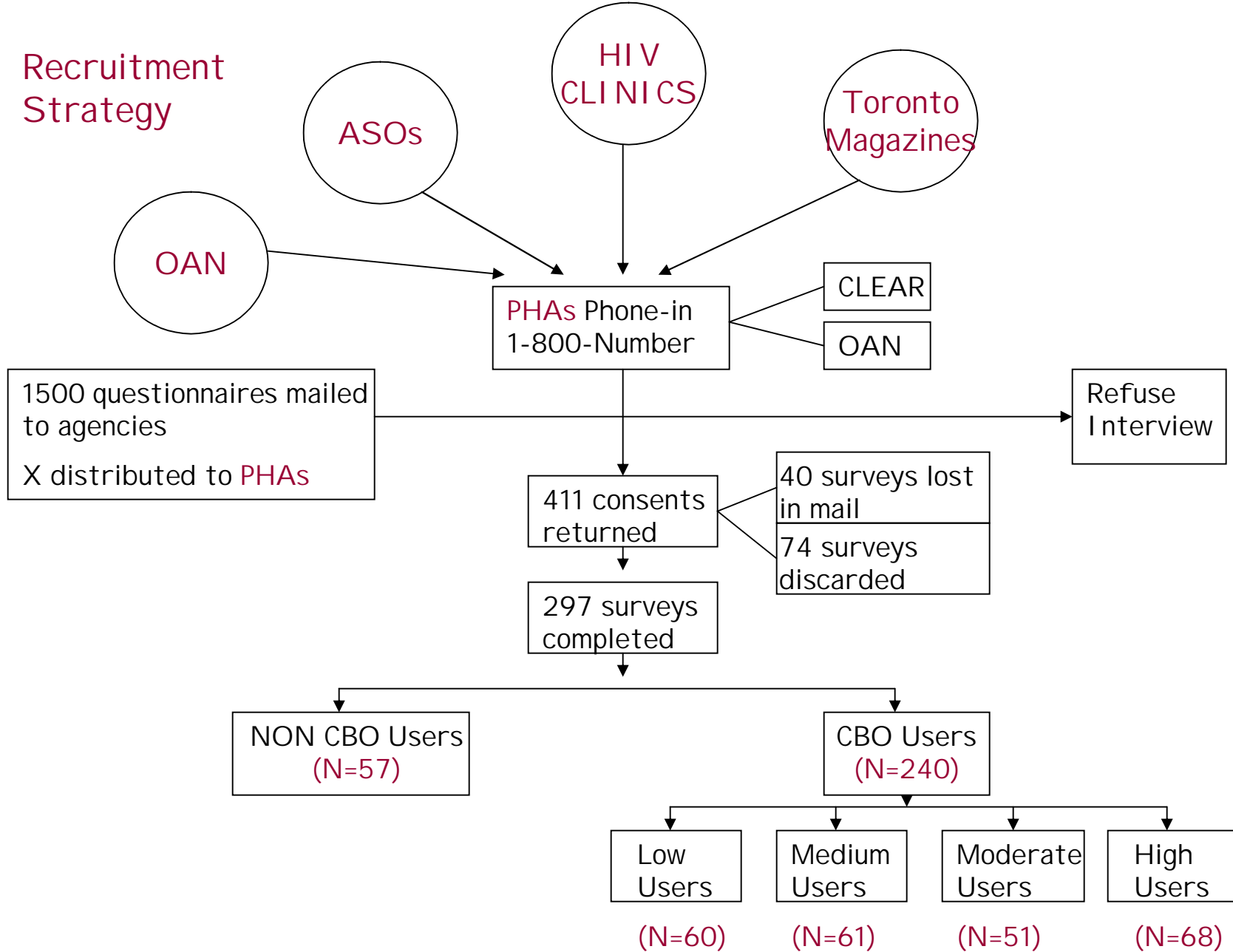
PHAs who used:

- AIDS Service Organizations (ASOs) in the Ontario AIDS Network (OAN)
- Other community based health and social services

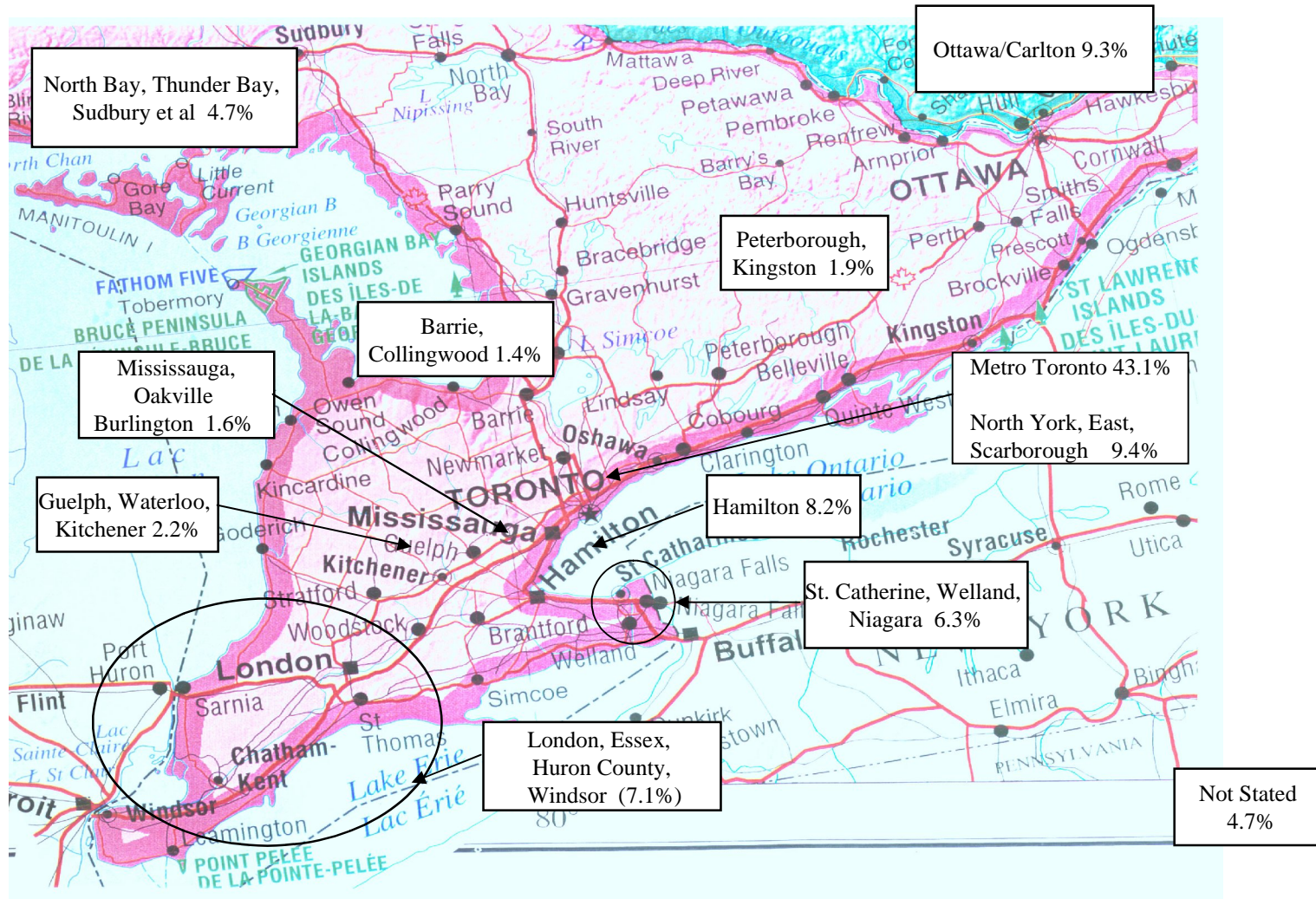
Study Design:

- Cross-sectional survey between October 2001 – August 2002 of 297 PHAs
- PHAs were recruited using:
 - 1500 questionnaires mailed to ASOs
 - Public notices posted in ASOs, HIV clinics, newspapers
- Interested PHAs:
 - Called toll free number
 - Consenters completed telephone, mail out or in-person interviews
 - Participation voluntary/anonymous
 - Honorarium of \$25 for completing interview

Study Flow Diagram



GEOGRAPHIC LOCATION OF RESPONDENTS



MEASURES

- **Demographic information** (age, gender, language, ethnic background, education, income, type of living arrangement, employment status, geographic location and background of exposure group)
- **Use of CBAOs** (participants were asked what services they used and whether they used CBAOs [largely ASOs] during the past year and, if so, how many times)

MEASURES

Health Related Quality of Life and Depression

- **Quality of Life - MOS-HIV** (Wu et al., 1997) 36-item questionnaire scored on a 0-100 scale includes 10 dimensions (health perception, pain, physical, role, social and cognitive functioning, mental health, energy, health distress and quality of life)
- **Centre for Epidemiological Studies Depression Scale (CES-D Scale)**, 20-item, 4 point Likert summative scale, rated from zero (rarely) to four (most or all of the time) is used for assessing depression among **PHAs**. Scores greater than 21 suggest depression

MEASURES

Health Related Quality of Life and Depression (Cont'd)

- **Karnofsky Rating Scale** (The Measurement Group, 1996) is used to assess the client's current performance status as indicated by the client's ability to perform common tasks. The scale ranges from 0-100% with a rate of 0% equal to the client being dead and rating of 100% to the client being normal and manifesting no signs of disease
- **Health and Social Service Utilization Questionnaire (HSSUQ)** consists of questions about 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 professional and laboratory services

RESULTS

RESULTS

Characteristics

Use of CBAOs

81% CBAO users (N = 240)

19% Non CBAO Users (N = 57)

Frequency of Use

28% of users (N = 68) 52 + times/year (high intensity)

21% of users (N = 51) 30-51 times/year (moderate intensity)

25% of users (N = 61) 11 - 29 times/year (modest intensity)

25% of users (N = 60) 1 - 10 times/year (low intensity)

RESULTS

Demographic Characteristics

Similarities

CBAO users and non-users were demographically similar in:

- age (76% between 30-49 years of age)
- gender (79% were male)
- marital status (51% were single)
- education (65% had some post secondary education)
- living location (78% lived in city core)
- living arrangement (71% lived in own house/apartment)
- living circumstances (49% lived alone)

Small proportions in both groups were:

- living with a caregiver (10%)
- street involved (6%)
- identified with a mental health community (16%)
- were injection drug users (6%)

RESULTS

Demographic Characteristics (Cont'd)

Differences

Groups did differ in:

- income (CBAO users had lower annual income)
- gender identify (CBAO users heterosexual 26% vs 12%, gay 33% vs 19%)
- physical disability (CBAO users 23% vs 9%)

RESULTS

Health Characteristics

Similarities

CBAO users and non users had similar health characteristics:

- length of illness (8.7 years; SD=5.0)
- stage of illness (Karnofsky score 80.5; SD=15.4)
- CD 4 plus lymphocyte counts (531.2; SD=576.8)
- CD 4 counts (263.1; SD=258.8)
- Self rated overall health (41.8% reporting fair to poor health)

Differences

CBAO users and non users differed in:

- ability to carry on normal activity (29% of users unable vs 17.5%)
- symptom free (12.9% users vs 22.8%)
- presence of depression (58.3% users vs 37.8%)
- use of antidepressants (28.8% of users vs 15.8%)

RESULTS

Health Related Quality of Life

Similarities

CBAO users and non users were similar in health related quality of life in:

- physical, social, and cognitive function
- in their health distress
- quality of life
- overall health perception

Differences

CBAO users differed from non users in scoring significantly lower in:

- role function, managing pain and energy
- their overall physical health summary score (52.5 vs 59.3)
- the overall mental health summary score (60 vs 66.8)

RESULTS

Use of Health and Social Services

CBAO users had:

- higher per person per annum direct costs for use of health and social services including:
 - higher costs for hospital stays
 - more family physician care
 - more naturopathic care
 - more unpaid voluntary community support services
 - more food bank services
- higher out of pocket costs
- higher cash transfers from government and private insurance particularly from ODSP

SUMMARY

Given the high prevalence of depression in the CBAO users important to determine links between depression and quality of life and patterns of health and social service utilization.

RESULTS

Health Related Quality of Life of Depressed and Non Depressed PHAs

Depressed PHAs (N = 161), 54.2% of the sample

- scored greater than 20 on the CES-D scale ($p < .001$)
- reported statistically significantly poorer quality of life than non depressed PHAs on all dimensions of the MOS-HIV Health Survey including the general health perception index, the physical health summary index and the mental health summary index ($p < .001$)
- used ASO services more (87%) than non depressed PHAs (74%)
- most ASO users were depressed (58%)
- ASO users were more depressed ($X = 23.9$) than non ASO users ($X = 19.2$)

RESULTS

Annual Expenditures on Use of Health and Social Services

Similarities

- total annualized costs for health and social services for depressed and non depressed were similar

Differences

- depressed PHAs used significantly more crisis health care and related services (Emergency department, 911, family counselors, food bank services)
- non depressed PHAs used significantly more "other" direct services explained mostly by greater medication use
- use of HIV/AIDS medication was higher (80%) in non depressed PHAs than depressed PHAs (65%)
- use of antidepressant medication was higher in depressed PHAs (29%) compared to 23% of non depressed PHAs

DISCUSSION

Study Findings:

CBAOs appear to be serving Ontario's most vulnerable PHAs and fostering their access to other supportive community services and mainstream medical care

Appears the range and mix of CBAO services are appropriate to the needs of PHAs and that CBAOs are fulfilling their mandate to facilitate PHA links to formal HIV/AIDS Services

Affirm the importance of recognizing and treating depression in PHAs: to improve their quality of life; to reduce their use of emergency, crisis oriented publicly funded services; to improve HIV/AIDS treatment effectiveness by improving ability of PHA to stay on medication

IMPLICATIONS FOR SERVICE PROVIDERS

Results Suggest:

1. Enhance existing and develop new programs and services
 - CBAOs need to reach other vulnerable people to living with HIV to enhance quality of life by appropriate referral and use of health promotion and social services
2. Increase knowledge, skills and tools
 - with increased training and support from experienced mental health professionals, CBAO staff and volunteers
 - could more effectively recognize depression and other mental health distress
 - help PHAs stay on prescribed medication through support and counseling
3. Establish strategic partnerships and collaborations
 - could link PHAs with HIV clinics offering appropriate medication