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Case Management and Health-Related Quality of Life Outcomes in a National Sample of Persons with HIV/AIDS

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Abstract

Objective—To examine whether having a case manager is associated with better physical and mental health scores (PH and MH).

Background—HIV/AIDS is a condition characterized by a variety of medical and social needs that vary between individuals and over time. Case-management has been advocated as a means to improve problems of access, cost and outcomes of HIV/AIDS care.

Methods—We analyzed data from a nationally representative sample of 2251 HIV positive persons receiving care in the in the HIV Costs and Services Utilization Study (HCSUS). Participants were interviewed at baseline and approximately 18 months later. Data were collected on use of case-management, sociodemographics, antiretroviral therapy, and health-related quality of life (HRQOL). We examined bivariate and multivariate associations of case-management at baseline with change in PH and MH at follow-up.

Results—We found that having contact with a case-manager at baseline significantly predicted improvement in PH (regression coefficient = 1.02, $p < 0.05$) among those not receiving HAART. We found no association of case management with MH among those not receiving HAART and those receiving HAART in multivariate analysis.

Conclusions—Our findings support a beneficial relationship between case managers and physical health for patients with HIV but only among those not already receiving recommended treatment with HAART.

Keywords

HIV/AIDS; case management; Quality of Life; HAART

Introduction

Case-management has been an important strategy for the federal Ryan White CARE Act to address growing disparities in the population with HIV in the U.S. HIV is a chronic infection with a wide range of medical and social manifestations.^{1–3} Extensive research has documented that persons with HIV often have myriad social needs, and that many of these needs often go unmet.^{2–6} Moreover, HIV disproportionately affects vulnerable populations, such as blacks and Hispanics, the poor, and substance users, who often have limited access to medical and social services^{7, 8} and consequently have difficulty receiving needed medical care early in the course of the disease.^{2, 9–19} For this reason, case management has been advocated as a strategy for vulnerable populations living with HIV/AIDS to improve access to care and health outcomes. In 2005, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act allocated 70.9 million dollars (12.3% of CARE Act funding) to case management services for Title I programs, and 66.1 million dollars (11.5% of CARE Act) for Title II programs.

A few studies have shown that having a case-manager predicts treatment with antiretroviral therapy.^{20, 21} Several other studies have also shown that case-management can assist in the delivery of important services to needy HIV positive populations.^{3, 22–24} Thus, we hypothesized that case management might also result in better health-related quality of life (HRQOL), or the ability to function in everyday activities and how one feels about their life. While many studies have demonstrated the beneficial impact of case management on the use of HIV care, very few have examined whether case-management is associated with improvement in physical or mental health.

To examine whether case-management is associated with better HRQOL, we analyzed data from HCSUS. HCSUS was a nationally representative cohort of 2267 persons with HIV infection who were receiving care at least every six months in the contiguous United States in 1996 and followed through 1998. The purpose of this study was to examine the effect of receiving case-management at baseline on HRQOL outcomes at follow-up.

Methods

Study Sample

Full details of the HCSUS sampling design are presented elsewhere.²⁵ In brief, the reference population was persons at least 18-years-old with known HIV infection who made at least one visit, in the context of regular or ongoing care, to a nonmilitary, nonprison medical provider (other than an emergency department) in the contiguous U.S., during the period January 5 to February 29, 1996. The HCSUS used a three stage sampling design, in which geographical areas, medical providers, and patients were sampled. In the first stage, we sampled 28 metropolitan areas and 25 clusters of rural counties within the U.S. In the second stage, we sampled a total of 148 urban and 51 rural providers. In the third stage, we sampled patients from de-identified lists of all eligible patients who visited participating providers during January and February of 1996. We constructed several weights to adjust for the differential selection probabilities across subgroups of the population, one to adjust for nonresponse, and one to adjust for the fact that some patients had more than one opportunity to enter the sample. Applying the weights permits inference to the population represented by the baseline sample.

We sampled 4042 eligible subjects, of whom 2864 (71%) completed full baseline interviews. After obtaining informed consent, all interviews were conducted using computer-assisted personal interviewing (CAPI) programs designed for this study. Baseline interviews were conducted between January of 1996 and April of 1997. The final follow-up interview was conducted between August of 1997 and January of 1998 (an average of approximately 18 months from baseline), with 2267, or 79% of initial respondents available for this interview.

In all, 16 (< 1%) people did not answer questions on HRQOL, and were excluded from this analysis for a final sample size of 2251. In all, 91% of the 2864 interviews were completed in person and the remainder over the telephone. Of 597 patients who did not complete all interviews, 236 (40%) were known to be deceased by follow-up. Case-management was not associated with mortality or being lost to follow-up.

HRQOL Measures

The main outcome was change in HRQOL from baseline to follow-up, using the 28-item HCSUS HRQOL measure (divided in 10 scales, see 43 Appendix 1).²⁶ The baseline and follow-up surveys included multi-item measures of physical functioning (9 items, alpha = 0.91), role functioning (2 items, alpha=0.85), pain (2 items, alpha = 0.84), general health perceptions (3 items, alpha = 0.80), emotional well-being (7 items, alpha = 0.90), social functioning (2 items, alpha = 0.82), and energy (2 items, alpha = 0.74). We also included a single item measure of disability days (days in bed for one-half day or more because of health). Using an oblique factor scoring solution involving all 10 scales, we derived physical (PH) and mental (MH) health summary scores from these measures, using an approach very similar to that used to score the RAND -36.²⁷⁻²⁹ Summary scores were transformed linearly to T-scores (mean = 50, SD = 10; higher scores represent better health).³⁰ The estimated reliabilities of these measures are 0.96 and 0.94, respectively, where 1.0 is the maximum and 0.70 is generally recognized as adequate.³¹

Case-management

The main independent variable in this analysis was having contact with a case manager. Participants were told that case manager meant “a social worker, nurse, AIDS services organization staff member, staff in other services organizations, or anyone else who is assigned to help you get and continue care.”^{3, 20} They were asked whether they had a case manager and if they had seen or spoken to the case manager within the last six months. If they had done so at least once they were considered to have had contact with a case manager.

Highly active antiretroviral therapy (HAART)

The working definition of HAART was based on the Centers for Disease Control and Prevention Guidelines for the use of antiretroviral agents in HIV-infected adults and adolescents.³² It was defined as taking combinations of nucleoside reverse transcriptase inhibitors (NRTI; e.g., zidovudine and lamivudine) plus certain protease inhibitors (PI; e.g., nelfinavir), combinations of PIs (e.g., ritonavir and saquinavir) or the combination of a PI plus a non nucleoside reverse transcriptase inhibitor (NNRTI; e.g., delavirdine). In each interview, participants were shown pictures of these drugs and asked if they had taken each individual antiretroviral medication at any time during the last 6 months. These data were used to derive a dichotomous indicator of HAART use, coded “1” if the person indicated taking a HAART combination any time during the last six months. We included use of HAART vs. any other regimen or no antiretrovirals as a stratifying variable (see below).

Control variables

In multivariate analyses, we adjusted for potential confounders, including age (18–34, 35–49, 50 and older), race/ethnicity (white, black/African American, Hispanic, other), gender, HIV risk exposure group (intravenous drug use, male-to-male sexual contact, heterosexual contact, other), educational attainment (less than high school degree, high school degree, some college, college degree or more), income (\$0–5,000, \$5,001 – 10,000, \$10,001–25,000, or greater than \$25,000), insurance status (private/fee-for-service, private/HMO, Medicare, Medicaid, and uninsured), U.S. geographic region (northeast, south, midwest, and west), and CD4 count (>=500, 200–499, 50–199, 0–49) all measured at baseline.

Analysis

First, we compared the characteristics of the sample among those who had versus did not have a case-manager at baseline (Table 1). Next, we examined the bivariate association of having a case-manager at baseline with change in physical and mental health from baseline to follow-up. We then stratified the sample into two groups: those who were receiving HAART at baseline versus those who were not. Finally, we used multiple linear regression (because the outcome was measured at the interval level) to estimate the association of having contact with a case-manager at baseline with change in physical and mental health at follow-up after controlling for covariates. Unstandardized regression coefficients and 95% CI's from the linear regression are presented for the effect of the independent variables at baseline on change in physical and mental health from baseline to follow-up. Inter-correlations among independent variables and the tolerance coefficient revealed no problems with multicollinearity in these models. Linearization methods in the survey analysis procedures of STATA 7.0 © were used in all models to account for clustering, stratification, and sampling weights, and to estimate model parameters and levels of significance.

Results

Those who did not have contact with a case-manager at baseline were significantly more likely to be older, nonwhite, female, have a history of drug use or be from a heterosexual risk group, low education, low income, uninsured or publicly insured, not living in the west, and low in CD4 count (Table 1). In bivariate analysis, having contact with a case-manager, compared with not having contact, predicted more positive change in PH at follow-up (mean increase in scores of 2.90 vs. 0.90, $p < 0.001$) and MH at follow-up (mean increase in scores of 2.80 vs. 1.80, $p < 0.01$; latter data not shown).

In multivariate analysis, we constructed parallel models for the two strata: being on HAART versus not being on HAART at baseline. For those who were not on HAART, we found that having contact with a case-manager at baseline predicted improvement in PH (regression coefficient = 1.02, $p < 0.05$; Table 2). This coefficient represents an average of about a 1-point improvement (on the 0–100 scale), which is a significant, but relatively small effect according to commonly used metrics.³³ Covariates that were significantly associated with improved PH were black race (1.5 points, $p < 0.05$), those reporting only heterosexual risk factors (1.5 points, $p < 0.05$), and those with CD4 count between 200 and 500 (1.3 points, $p < 0.05$). In contrast, women had significantly worse relative change in PH scores (−1.85 points, $p < 0.05$). For those who were on HAART, having contact with a case-manager was not associated with PH (Table 2). Those older than age 50 (−3.5 points, $p < 0.05$), blacks (−3.0 points, $p < 0.05$), and Hispanics (−2.34 points, $p < 0.05$) had significant worse change in PH; those with Medicaid (−2.94 points) or HMO insurance (2.69 points, $p < 0.05$), compared with private fee-for service insurance), those with incomes of \$0 – \$5,000 (3.23 points, $p < 0.05$), and those with incomes of \$10,000 – \$25,000 (1.7 points, $p < 0.05$), compared with greater than \$25,000) had relatively better PH at follow-up.

Contact with a case-manager was not associated with MH among those not on HAART (Table 3). However, blacks and those with other non-Hispanic race/ethnicities (compared to whites), women, and those with less than high school education or high school degree only (compared with college graduates) had relatively better MH scores. In the stratum that was initially on HAART, those older than age 50, blacks, injection drug users, and those with annual incomes more than \$5,000 – \$25,000 (compared with greater than \$25,000) showed relatively worse change in MH.

Conclusions

We found that case management for patients who were not on HAART at baseline was associated with relatively better changes in PH at follow-up, whereas case management had no impact on those who were already on HAART at baseline. We found no association of case management with MH scores in either group. The results suggest that the use of case management services may impact groups of persons with HIV/AIDS who are not receiving the most effective therapy differently than those already receiving potent antiretroviral treatment. There are few if any other published studies showing that case-management services have a positive impact on physical health. This finding is important because many vulnerable groups with HIV who are not receiving HAART might be reached by case-managers who are supported through Ryan White Care Act programs. Our findings suggest that case-managers efforts to serve those who are not yet on HAART are most likely to help them to improve their physical health.

Previous analyses of HCSUS data have shown that case management is associated with fewer unmet social needs and greater use of antiretroviral medications at follow-up.²⁰ Patients not on HAART at baseline appear more likely to gain access to HAART during the follow-up period because case managers helped them to receive HAART medications.²¹ However, we were not able to show that gaining access to HAART led to the improved physical health we observed among those not on HAART at baseline. Some of those on HAART at baseline had discontinued by follow-up due to adherence problems associated with early regimens in this sample.³⁴ No newer nationally representative studies have been conducted, so we don't know for sure how many HIV+ people who are eligible for HAART actually receive it. One 16-city study found that among those with CD4 counts < 350 cells/ml, fewer than 38% were receiving antiretrovirals, suggesting that many underserved person with HIV could benefit from getting case-management services early in the course of their disease.³⁵

There were several limitations to this analysis. Data were collected in the late 1990's more than 10 years ago. There have been improvements in treatment and supportive services since this time. Better and simpler antiretroviral regimens available now might result in better health outcomes than HCSUS data could demonstrate.³⁶ Although treatment with HAART is more common now than it was at the time of HCSUS, it is still likely that having a case manager is associated with better physical health outcomes at follow-up among those not receiving HAART, because having a case-manager at baseline was associated with gaining access to HAART at follow-up in HCSUS.²⁰ However, there have been no nationally representative studies on this topic since then. Another limitation of this study is that we could not randomize patients to receive case management and thus a causal link cannot be assumed. We also do not know the degree to which our definition of case management may have included nurses, social workers, outreach workers or other persons with similar community or cultural backgrounds to the patients studied, in addition to other potential forms of support service workers. Despite these limitations our analysis in a nationally representative sample demonstrated a prospective association of case management with improved physical health outcomes in some persons with HIV. Future studies that randomize participants to receive case management interventions compared with appropriate control conditions are needed to more definitively ascertain the impact of case-management. Unfortunately, previous randomized studies of case-management have not evaluated HRQOL outcomes, nor have they been conducted in large nationally representative samples.

This study also showed that blacks, heterosexuals, and those with CD4 counts between 200 and 500 improved most in physical health among those not initially on HAART. This finding is in contrast to one prior study in San Francisco, which found improvements in adherence and CD4 count associated with case-management, but did not find improvement in HRQOL.²¹

Among those initially on HAART by contrast, blacks, Hispanics, and older persons were most likely to decline in physical health. Blacks and Hispanics have been found to have lower adherence to ARV medication than whites in some studies, {Turner, 2001 #2032} although not in others. {Golin, 2002 #3194} In any case, outcomes appeared to depend sharply on whether or not patients were initially treated with HAART. It is important to acknowledge that some of these results might be due to regression toward the mean.

The analysis took advantage of the fact that data were collected soon after the advent of HAART between 1996 and 1999. Thus, many patients at that time were not on combination antiretroviral therapy. Today, most HIV-infected patients who are eligible for antiretrovirals probably are offered treatment with HAART. Given that no nationally representative studies have been conducted since HCSUS, it is not possible to know for certain. However, it would be very difficult to recruit large numbers of patients nationally who are not on HAART, as we were able to in the present study.

Previous studies of HIV case management have examined its impact without regard to whether or not patients are already receiving treatment with HAART. Our findings support a beneficial relationship between case managers and patients with HIV, but also highlight that this benefit may be limited to those who have not yet received treatment. Future evaluations of case-management interventions that pay close attention to current treatment status will help advance our understanding of this important component of care.

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Appendix A. The HCSUS 28-item HRQOL Measure

Physical Functioning

Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports

Climbing one flight of stairs

Walking more than a mile

Walking one block

Bathing or dressing yourself

Preparing meals or doing laundry

Shopping

Getting around inside your home

Feeding yourself

Role-functioning- physical

Working at a job, doing work around the house, or going to school

Doing certain kinds or amounts of work, housework, or schoolwork

Disability days

During the past four weeks, how many days did your health cause you to stay in bed for ½ a day or more?

Bodily Pain

During the past four weeks, how much did pain interfere with your normal work (including work outside the house and housework)?

How much bodily pain have you had during the past four weeks?

Social functioning

During the past four weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

During the past four weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

General health perceptions

In general, would you say your health in the past four weeks was

I seem to get sicker a little easier than other people

I have been feeling bad lately

Positive affect

Have you felt calm and peaceful?

Have you been a happy person?

Anxiety

Have you been a very nervous person?

Have you been anxious or worried?

Depressed affect

Have you felt downhearted and blue?

Have you felt so down in the dumps that nothing could cheer you up?

Have you felt depressed?

Energy/fatigue

Did you feel tired?

Did you have enough energy to do the things you wanted to do?

Table 1

Sample Characteristics by Case-Manager Status at Baseline in HCSUS

Characteristics	Contact with Case Manager N=1284 (56%)	No Contact with Case Manager N=967 (44%)
Age		
18–34	37	29*
35–49	52	59
50 & up	11	12
Race/Ethnicity		
White	38	63****
Black	41	21
Hispanic	17	13
Other	4	3
Gender		
Female	29	15****
Male	71	85
HIV risk group		
Male to Male contact	38	61****
Injecting Drug Use	30	18
Heterosexual contact	24	13
Other	8	8
Education		
No high school degree	30	17****
High school degree	31	23
Some college	27	30
College degree	12	30
Income		
0–\$5000	25	13****
\$5001–\$10,000	31	17
\$10,001–\$25,000	27	25
\$25,001+	17	45
Insurance status		
Private/fee-for-service	8	28****
Private HMO	8	25
Medicaid	38	17
Medicare	23	13
No insurance	23	17
Geographic region		
Northeast	30	19****
West	18	42
Midwest	13	7
South	39	32

Characteristics	Contact with Case Manager N=1284 (56%)	No Contact with Case Manager N=967 (44%)
Lowest CD4 count		
<50	23	15***
50–199	30	31
200–499	37	44
≥500	10	10

P-Values for Chi-square test of differences in proportions:

* $.01 \leq p < .05$;

** $.001 \leq p < .01$;

*** $.0001 \leq p < .001$;

**** $p < .0001$

Table 2

Multivariate Effect of Case Management at Baseline on Change in Physical Health After an Average of 18 Months of Follow-Up, HCSUS, January 1996–January 1998(**unstandardized regression coefficients, 95% CI**).

Baseline Characteristics	Not on HAART N=1655	On HAART at Baseline N=596
Have case-manager	1.02 (0.10, 1.93)*	-0.37 (-2.25, 1.52)
Age (18–34)		
35–49	-0.37 (-1.24, 0.49)	-0.43 (-2.29, 1.43)
50 & up	-1.39 (-2.90, 0.11)	-3.54 (-6.27, -0.82)*
Race/Ethnicity (White)		
Black	1.52 (0.24, 2.81)*	-2.97 (-5.64, -0.29)*
Hispanic	0.53 (-0.71, 1.77)	-2.34 (-4.68, -0.00)*
Other	1.09 (-1.23, 3.41)	-2.07 (-5.00, 0.86)
Gender (Male)		
Female	-1.85 (-2.66, -1.05)***	0.32 (-2.71, 3.36)
HIV Risk Group (MSM)		
Injecting Drug Use	0.90 (-0.34, 2.15)	-0.57 (-2.13, 0.98)
Heterosexual Contact	1.56 (0.25, 2.87)*	0.24 (-2.14, 2.63)
Education (Some College)		
No High School Degree	0.91 (-0.64, 2.46)	-1.06 (-5.12, 3.01)
High School Degree	1.09 (-0.56, 2.75)	-0.79 (-2.51, 0.93)
College Degree	1.02 (-0.34, 2.39)	-1.48 (-3.15, 0.20)
Income (>25k)		
0 – 5k	-0.33 (-1.58, 0.92)	3.23 (0.00, 6.46)*
>5 – 10k	0.63 (-0.83, 2.09)	1.85 (-0.63, 4.33)
>10 – 25k	-0.30 (-2.07, 1.48)	1.70 (0.69–3.33)*
Insurance Status (Private/fee-for-service)		
Private HMO	-0.24 (-2.02, 1.54)	2.69 (0.51, 4.87)*
Medicaid	-0.49 (2.96, 1.99)	2.94 (0.83, 5.06)**
Medicare	-0.59 (-3.03, 1.85)	2.03 (-0.38, 4.43)
No Insurance	-0.32 (-2.28, 1.63)	1.71 (-4.44, 7.87)
Geographic Region (West)		
Northeast	-0.38 (-1.63, 0.87)	0.63 (-1.64, 1.76)
Midwest	1.09 (-0.33, 2.52)	-1.56 (-3.24, 0.11)
South	0.59 (-0.68, 1.85)	0.86 (-1.02, 2.73)
Lowest CD4 Count (≥500)		
<50	0.89 (-0.42, 2.20)	1.97 (-0.57, 4.51)
50–199	1.12 (-0.42, 2.66)	2.07 (-1.52, 5.66)
200–499	1.32 (0.19, 2.44)*	1.27 (-0.82, 3.37)

P-Values:

* p<.05;

**
p<.01;

p<.001;

p<.0001

Table 3

Multivariate Effect of Case Management at Baseline on Change in Mental Health After an Average of 18 Months of Follow-Up, HCSUS, January 1996– January 1998 (**unstandardized regression coefficients, 95% CI**).

Baseline Characteristics	Not on HAART N=1652	On HAART at Baseline N=596
Have case-manager	0.35 (−0.54, 1.25)	0.41 (−1.23, 2.05)
Age (18–34)		
35–49	0.27 (−0.77, 1.30)	−0.63 (−2.12, 0.86)
50 & up	−0.80 (−2.76, 1.16)	−4.39 (−7.16, −1.63)**
Race/Ethnicity (White)		
Black	1.43 (0.29, 2.56)*	−2.74 (−5.00, −0.47)*
Hispanic	0.07 (−1.70, 1.84)	−0.75 (−3.73, 2.23)
Other	3.26 (1.22, 5.29)**	−1.50 (−3.89, 0.88)
Gender (Male)		
Female	−1.12 (−2.36, 0.02)*	1.99 (−0.75, 4.72)
HIV Risk Group (MSM)		
Injecting Drug Use	0.19 (−1.11, 1.48)	−3.00 (−5.19, −0.80)**
Heterosexual Contact	0.39 (−0.96, 1.74)	−1.22 (−2.99, 0.55)
Education (Some College)		
No High School Degree	1.87 (0.13, 3.61)*	1.53 (−1.75, 4.81)
High School Degree	1.41 (0.98, 2.73)*	−0.08 (−1.30, 1.13)
College Degree	1.07 (−0.43, 2.58)	−0.48 (−1.98, 1.02)
Income (>25k)		
0 – 5k	0.50 (−1.34, 2.33)	1.99 (−1.69, 5.67)
>5 – 10k	0.63 (−1.05, 2.32)	2.58 (0.54, 4.62)**
>10 – 25k	1.08 (−0.68, 2.84)	2.65 (1.17, 4.12)***
Insurance Status (Private/fee-for-service)		
Private HMO	−0.00 (−2.04, 2.03)	1.40 (−0.23, 3.03)
Medicaid	−0.78 (−2.88, 1.32)	0.49 (−1.56, 2.54)
Medicare	−0.85 (−3.27, 1.56)	−0.57 (−3.30, 2.17)
No Insurance	0.72 (−1.33, 2.78)	0.53 (−3.09, 4.14)
Geographic Region (West)		
Northeast	0.89 (−0.49, 2.26)	0.55 (−1.35, 2.46)
Midwest	1.94 (−0.10, 4.00)	−1.80 (−3.42, −0.18)*
South	0.47 (−1.25, 2.19)	0.91 (−1.04, 2.86)
Lowest CD4 Count (≥500)		
<50	0.12 (−2.04, 2.27)	1.21 (−2.34, 4.77)
50–199	0.34 (−1.78, 2.46)	1.97 (−2.64, 6.58)
200–499	0.61 (−0.68, 1.89)	1.25 (−3.27, 5.77)

P-Values:

* p<.05;

**
p<.01;

p<.001;

p<.0001