

Positive Living and Quality of Life: A Program Evaluation

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Abstract

The literature suggests that the quality of life (QOL) of persons with HIV/AIDS tends to decline over time. A single-group, pre-test/post-test design was utilized to evaluate the QOL of participants of the Positive Living Conference, an educational/psychosocial conference for persons with HIV/AIDS. Results suggest a possible QOL maintenance effect and higher conference satisfaction was associated with greater increases in several quality of life scores. However, the absence of a control group limits conclusions.

Introduction

Despite significant treatment advances, HIV/AIDS remains a progressively debilitating disease affecting approximately 40,000 new persons annually in the U.S. Although life-extending highly active antiretroviral therapies (HAART) implemented over the past decade have offered numerous benefits, inadequate treatment response and side effects are not uncommon and attention to quality of life (QOL) has become important.

Research conducted prior to the advent of HAART indicated that QOL for persons with HIV/AIDS declined progressively over time (De Boer et al., 1995; Lubeck & Fries, 1992). While HAART has resulted in improvements in indicators of disease status, such as CD4 and viral load counts (Brecht et al., 2001), concomitant improvements in QOL have been less consistent. Some studies suggest initial improvements in QOL following the initiation of HAART (Mannheimer, et al., 2005; Nieuwkerk, et al., 2001) while others suggest minimal or no initial improvement (Brecht et al., 2001). Beyond the initiation of HAART, research suggests gradual declines in QOL (Pandya, et al., 2005; Nieuwkerk, et al., 2001; Swindells, et al., 2001; Burgoyne et al., 2004) although a few small studies have found relatively stable or even slightly improved QOL (Burgoyne et al., 2004; Saunders & Burgoyne, 2002). Given the trajectory of decline in physical health and QOL associated with HIV/AIDS, interventions that improve or maintain physical health and/or QOL have significant value.

The Positive Living Conference is one of the few consumer-oriented conferences remaining for persons with HIV/AIDS. The conference offers participants educational and psychosocial opportunities aimed at empowering patients to become active in their own treatment, hopefully helping patients maintain or improve their QOL. This study reports on an evaluation of the program.

Method

Participants

HIV-positive attendees of the 2004 and 2005 Positive Living Conference were eligible for participation. A sample of 70 participants with HIV or AIDS completed the study. Participants ranged in age from 21 to 62 years, with a mean of 43.7 years ($SD = 8.7$). The sample was predominantly male (75.7%) and evenly split among Caucasian/White participants (48.6%) and African American/Black participants (47.1%). Table 1 describes the sample in greater detail.

Measures

Participants completed demographic items at pre-test and conference satisfaction items at post-test. Participants completed the Functional Assessment of HIV Infection Scale (FAHI; Cella et al., 1996) at both pre-test and post-test. The FAHI measures QOL along the following dimensions: functional, social/family, emotional, relationship with doctor, and physical QOL; as well as HIV specific QOL and overall QOL. The FAHI has sufficient validity, sensitivity to change, and reliability, with an overall alpha level of 0.89, and test-retest correlation of 0.92 (Cella et al., 1996).

Method (continued)

Table 1: Demographic Characteristics of Sample (N = 70)

Demographic characteristic	n	%
Gender		
Male	53	75.7
Female	13	18.6
Transgender	3	4.3
Missing	1	1.4
Race/ethnicity		
Caucasian/White	34	48.6
African American/Black	33	47.1
Native American	2	2.9
Missing	1	1.4
Marital status		
Single/never married	36	51.4
Married/partnered	17	24.3
Divorced/separated	13	18.6
Widowed	3	4.3
Missing	1	1.4
Education		
Less than 12 years	6	8.5
12 years or equivalent	15	21.4
Some college	17	24.3
Two year degree	10	14.3
Four year degree	13	18.5
Advanced degree	5	7.1
missing	4	5.7
Monthly household income		
Less than \$500.	5	7.1
\$500. - \$999.	20	28.6
\$1,000. - \$1,499.	15	21.4
\$1,500. - \$1,999.	9	12.9
Greater than \$2,000.	20	28.6
Missing	1	1.4
Household size		
Living alone	29	41.4
Living with one person	26	37.1
Living with two or more persons	14	20.0
Missing	1	1.4

Procedure

A disclosure statement describing the nature of the project, as well as the risks and benefits of participation, was provided to each conference attendee. The disclosure statement indicated that participation was strictly confidential and voluntary. Participants completed pre-conference assessments of QOL administered during conference registration. Self-report measures of demographic variables and QOL were provided in conference registration packets, for completion and return at the very beginning of the conference. Post-conference QOL assessments were mailed two months later to participants who agreed to receive them via mail. Out of 149 participants who completed the pre-test, 70 (47%) also completed and returned the post-test by mail.

Results

Independent samples t-tests revealed no significant differences in pre-test QOL scores between 2004 and 2005 conference participants, therefore, the sample was pooled across the two years. Similarly, there were no significant differences in pre-test QOL scores between those who completed pre-test only and those who completed both pre- and post-tests.

QOL scores of participants, as listed in Table 2, were very similar to those of the normative sample used in the development of the measure, specifically 466 mixed cancer patients (Cella et al., 1996). All scores derived from this sample were within a half a standard deviation of the normative mean.

Paired samples t-tests were conducted to examine changes in scores from pre-test to post-test among the 70 participants who completed both. A small (1.2 points) but statistically significant decline of was found for functional QOL, $t(61) = 2.59, p = .01$ (two-tailed). All other QOL scores remained stable from pre-test to post-test. Table 2 presents the mean scores on QOL scales at pre-test and post-test, as well as the t-test findings.

Pearson's correlations were calculated to examine the relationship between change in QOL scores from pre-test to post-test and the number of workshops attended by the participants, in an effort to examine whether changes in QOL were associated with level of attendance and participation in conference activities. A significant positive association was found between level of attendance and emotional quality of life, such that greater participation in workshops was associated with greater improvement in emotional quality of life, $r(41) = .38, p = .01$. Spearman's correlations were calculated to examine the relationship between change in QOL scores and participant's overall satisfaction rating of the conference. Significant positive correlations were found between overall satisfaction ratings and social/family QOL, functional QOL, HIV symptoms, and overall QOL. These correlations indicated that greater satisfaction with the conference was associated with greater improvements in several areas of QOL. Table 3 displays the correlational findings.

Discussion

Findings of this program evaluation suggest that the Positive Living conference may have a positive QOL maintenance effect. Previous research suggests that QOL among patients with HIV often follows a downward trend over time. The findings of this research indicated that conference participants' QOL remained relatively stable over the two months following their participation (with the exception of functional QOL, which showed a statistically significant but not clinically significant decline). Unfortunately, the absence of a control group or comparison group severely limits conclusions about causality. Similarly, limited knowledge about factors influencing the longitudinal course of QOL among persons with HIV/AIDS also limits conclusions. While QOL appears to decline over time, it is unclear if the decline is more or less pronounced, or even stabilized or reversed, at different phases of medical treatment (e.g., individuals who have not yet initiated HAART, individuals on their initial course of HAART, individuals who have changed HAART treatments, individuals maintained on HAART, individuals who have repeatedly failed to respond to HAART, etc.).

The results of this evaluation suggest that psychosocial interventions such as the Positive Living Conference may assist in the maintenance of quality of life. Future research examining the longitudinal course of QOL among persons with HIV/AIDS at different phases of medical treatment would provide valuable information for comparison purposes. The data also suggest that the time, energy, and expense of conducting a controlled investigation of this type of intervention may be worthwhile.

Results (continued)

Table 2: Paired Samples t-tests of Mean Quality of Life Scores at Pre-Test and Post-Test

Quality of life score	Pre-test		Post-test		Change	t	df	p
	M	(SD)	M	(SD)				
Physical QOL	19.6	(5.7)	19.2	(6.3)	-0.4	0.94	63	.35
Social/family QOL	19.5	(6.6)	20.1	(6.4)	+0.6	-0.70	34	.49
Emotional QOL	17.5	(3.3)	16.9	(3.6)	-0.6	1.54	64	.13
Functional QOL	19.7	(6.5)	18.5	(7.6)	-1.2	2.59	61	.01 *
Relationship with doctor	6.5	(1.9)	6.1	(2.1)	-0.4	1.79	67	.08
HIV symptoms	51.1	(13.8)	50.6	(15.1)	-0.5	0.46	55	.65
Overall QOL	85.3	(18.6)	83.9	(21.9)	-1.4	0.83	30	.42

* $p < .05$

Table 3: Correlations Between Level of Conference Attendance, Conference Satisfaction Ratings, and Changes in Quality of Life from Pre-Test to Post-Test

Change in QOL score	Level of conference attendance			Conference satisfaction ratings		
	r	n	p	r	n	p
Physical QOL	-.23	42	.14	-.01	53	.97
Social/family QOL	-.04	24	.86	-.45	27	.02 *
Emotional QOL	.38	41	.01 *	-.02	51	.91
Functional QOL	-.16	40	.31	-.40	50	.00 **
Relationship with doctor	-.01	43	.96	-.02	54	.91
HIV symptoms	.06	40	.70	-.49	47	.00 **
Overall QOL	-.10	22	.66	-.70	24	.00 **

* $p < .05$

** $p < .01$

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