

FAMILY RESILIENCY, UNCERTAINTY, OPTIMISM, AND THE
QUALITY OF LIFE OF INDIVIDUALS WITH HIV/AIDS

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The purpose of the study was to contribute to the understanding of quality of life as it is experienced by a community-based, non-clinical sample of individuals with HIV/AIDS, applying family resiliency theory and the cognitive appraisal concepts. More specifically, the following variables were examined as predictors of quality of life: disease progression; the family resiliency variables of family problem solving and coping ability, family resources, and family appraisal of the diagnosis; and the cognitive appraisal variables of uncertainty and optimism. Through the use of a Web-based survey, 147 individuals with HIV/AIDS completed an online questionnaire, defining family broadly and in their own way, and responding to instruments measuring disease progression and their perceptions of family resiliency, cognitive appraisal and quality of life.

Disease progression as measured by CD4 count, was not found to be related to quality of life. When considered separately, both the family resiliency variables and the cognitive appraisal variables were found to predict quality of life. However, when entered after disease progression and cognitive appraisal variables in a hierarchical regression equation, the family resiliency variables were not found to add significantly to the prediction of quality of life, due to the intercorrelations between the family resiliency and cognitive appraisal variables. One important consideration in interpreting the results is that a number of individuals who lived alone indicated that they were unable to respond to the family resiliency measures, and living situation may be an important factor in the influence of family resiliency variables in predicting quality of life. The overall prediction model, comprised of the three sets of predictor variables, was found to explain over 60% of the variance in quality of life. The results may be helpful in understanding the quality of life of individuals with HIV/AIDS and may be of assistance to professionals in identifying needed interventions and service delivery options.

Chapter IV

RESULTS AND DISCUSSION

The purpose of the present study was to investigate variables that may contribute to the quality of life of individuals with HIV/AIDS. A community-based, non-clinical sample was used, and variables investigated included those associated with family resiliency theory and cognitive appraisal, in addition to disease progression.

Descriptive Data for the Total Sample on Primary Measures Used in the Study

Primary measures were one measure of quality of life, the HIV/AIDS-Targeted Quality of Life Scale (HAT-QoL); two measures of cognitive appraisal, the Life Orientation Test-Revised (LOT-R) and the Mishel Uncertainty in Illness Scale (MUIS); three measures of family variables, the Family Inventory of Resources for Management (FIRM) Scales, the Family Oriented Personal Evaluation Scales (F-COPES), and the Family Coping Coherence Index (FCCI); and one measure of HIV/AIDS disease progression, CD4 count (along with viral load as a secondary disease progression measure).

A total of 73 participants failed to complete every survey item. For measures that had responses missing responses to fewer than 10% of the items, a replacement by means method was used to allow the computation of total scores for the measure. With replacement by mean, the missing item is assigned the mean value for other items on that particular scale for that participant. Thus, if an individual skipped one item on the LOT-R, and had a mean of 2.67 for the remaining items, the missing item would be assigned a value of 2.67. When a participant failed to complete more than 10% of the items on a particular measure, no total score was computed for that participant, and the participant was not included in any analysis involving that score. Therefore, the number of scores available varied for each measures. The majority of the measures had 124 participant

scores available, and the LOT-R had 125. The family measures were not completed by a number of participants, resulting in many unusable surveys, and the FIRM had the fewest scores available with 116.

Means and standard deviations for the total sample on total scores for all of the primary measures are reported in Table 4.1. In addition, means and standard deviations for subscale scores on three of the measures that have subscales defined, the HAT-QoL, F-COPES, and FIRM, are reported in Table 4.2, even though only total scores were used in the primary analyses in the present study.

Quality of Life

Quality of life was operationalized through the HIV-specific questionnaire, the HAT-QoL and, the mean total score for the sample was 119.97 (SD = 19.63), which converted to a mean of 71.75 (SD = 15.83) on the 1-100 standardized scale for the HAT-QoL (see Table 4.1). According to data reported by Holmes and Shea (1999) in the development of the instrument, the mean total score on overall function for their sample of seropositive individuals, including outpatients, was 61.9 (SD = 24.6). Thus, in comparison to the Holmes and Shea sample, the sample used in the present study appeared to be reporting an average to above average quality of life. In comparing the subscale scores for the present sample with those of the Holmes and Shea sample (see Table 4.2), the scores appeared to be generally comparable or higher for the present sample, with the possible exceptions of the Medication Worries and the Provider Trust subscales.

Table 4.1

Means and Standard Deviations for the Quality of Life, Cognitive Appraisal, Family, and Disease Progression Measures

Scale	n	M	SD
Quality of Life			
HAT-QoL	124	71.76	20.40
Cognitive Appraisal			
LOT	125	15.83	5.30
MUIS	124	112.99	18.48
Family			
FIRM	116	113.47	26.55
FCOPES	124	101.04	15.71
FCCI	124	15.34	2.73
HIV/AIDS Progression			
CD4Count	103	533.34	264.22
Viral Load	102	16074.22	57689.17
CD4 change	98	-55.49	183.91

Table 4.2

Mean and Standard Deviations for Subscale Scores on Family and Cognitive Variables

Subscale	Study Sample		Normative Samples	
	M	SD	M	SD
HAT-QoL (N = 125)				
Life Satisfaction	66.90	25.91	63.9	23.0
Health Worries	74.45	25.02	50.6	27.4
Financial Worries	64.99	29.01	53.0	30.4
Medication Worries	63.74	23.81	68.2	20.8
HIV Mastery	81.96	26.31	68.0	25.1
Disclosure Worries	71.25	26.86	62.9	26.9
Provider Trust	77.91	30.82	81.3	24.4
Sexual Function	77.95	18.08	51.1	28.4
FIRM (N = 116)				
Family Strengths I	33.41	7.30	35	6
Family Strengths II	41.66	11.91	39	9
Extended Family Social Support	8.15	2.89	9	2
Financial Well-Being	30.29	10.18	29	9
F-COPES (N = 124)				
Acquiring Social Support	27.56	6.79	26.66	6.48
Reframing	31.98	4.73	30.42	4.89
Seeking Spiritual Support	9.47	5.11	15.76	3.01
Mobilizing Family for Help	14.36	3.15	12.24	3.29
Passive Appraisal	14.70	3.03	8.33	3.01

Cognitive Appraisal

The MUIS is a measure of uncertainty/certainty in illness, and the instrument was scored in such a way in the present study that higher scores reflect greater certainty about the course of illness, while lower scores reflect greater uncertainty. Past research found mean scores for a sample of non-hospitalized individuals (i.e., people who were sick but being treated as outpatients) of 117 on the MUIS, while a sample of hospitalized individuals had a mean of 106, those waiting on surgery showed less certainty about the course of their illness as reflected in their lower mean score of 95, and the overall mean score for the total sample was 107 (Mishel, 1999). The sample in the present study had a mean of 112.99, between the mean scores of Mishel's samples of individuals who were hospitalized and those who were ill but were being treated on an outpatient basis.

HIV/AIDS is a disease which is often considered to be ambiguous in terms of progression and to have unexpected and unpredictable effects on individuals who are infected. A relatively high degree of certainty about the illness appeared to have been expressed by the participants in this study, given the uncertainties that are generally associated with HIV/AIDS. One factor may be the high educational attainment of participants and the extent of involvement that many appeared to have in the experience of their HIV/AIDS, as exemplified by their willingness to take the time to participate in the present study on HIV/AIDS, despite the lack of any incentives other than contributing to knowledge regarding the disease.

The other cognitive appraisal measure, the Life Orientation Test-Revised (LOT-R), quantifies an individual's overall optimism. The mean score on the LOT-R found for the sample used in developing the instrument by Scheier et al. (1994) was 14.33 (SD = 4.28),

and the participants in the present study had a mean score of 15.83 ($SD = 5.30$). A past study on 108 men positive for HIV had a mean score of 19.9 (Johnson, & Endler, 2002). Thus, participants in the present study appeared to score in the average to above average range compared to the Scheier et al. sample, but perhaps lower than the Johnson and Endler sample of men who were HIV positive. The studies using the LOT-R with people with HIV/AIDS, including the present study, suggest the possibility that people who are seropositive may be more optimistic than might generally be expected, due to the life-threatening illness that they are experiencing.

Family Variables

Participants were asked to think about the family that they defined in responding to the demographic items, which defined family very broadly, when responding to family measures, and the three family measures used were drawn from the McCubbin & McCubbin (1991) family resiliency model. Coping and problem solving were measured by means of the F-COPES. A mean total score of 94.37 was found for the original sample of undergraduate students used by McCubbin et al. (1981) in developing the instrument, and they suggested that scores below 81 indicate a weakness in coping and problem solving for a family, while scores above 107 indicate a strength. The mean score found for the sample in the present study was 101.04 ($SD = 15.71$), a score that appeared to be somewhat higher than the mean in the McCubbin et al. sample, and approaching the level where coping and problem solving could be viewed as a strength for a family. In addition, scores are similar to those found by McCubbin and McCubbin (1991) for a sample of single-parent black families ($M = 101.15$) and high conflict families with Myelomeningocele ($M = 103.11$). Results found in previous research and

in the present study would appear to suggest that families under stressful conditions may maintain strong coping and problem solving skills. Scores for the 6 subscales of the FCOPES were also analyzed and are summarized in Table 4.2. The subscale means suggest that the seeking of spiritual support may be lower for the participants in the present study, and the use of passive appraisal as a coping skill may be higher.

The second family measure was the FIRM, measuring the amount of available resources for a family, and the sample in the present study had a mean score of 113.47 (SD = 26.55). This mean score is similar the mean of 110 found by McCubbin et al. (1998) with their sample of families with chronic illnesses. This sample appears to fit into the average range of coping resources for the family system. McCubbin et al. suggest that scores below 92 indicate a depletion of resources, while scores above 124 indicate a better than average supply of resources. The high standard deviation of 26.55 indicates that this sample varies greatly in the resources available to the families. Means were also computed for the four subscales of the FIRM and are reported in Table 4.2, with all scores appearing to be comparable to the mean scores in the McCubbin et al. sample.

The third family measure was the FCCI, which measures family coherence and coping for this population also fell close to norm means that had previously been achieved. McCubbin, Larsen, and Olson (1981) found a mean of 16 in the sample used in developing the scale, and the mean of 15.71 found for the sample in the present study appeared comparable. Since ratings for the present sample appeared to be low on the FCOPES subscale regarding the seeking of spiritual support, the one item on the FCCI that concerned God was removed, to determine the impact of this item on the correlations

between the FCCI and other variables used in the present study. However, the analysis suggested that the presence or absence of this one item did not appear to affect any of the correlations between the FCCI and the other scores.

Overall the family scores would appear to indicate that the participants in this survey were generally in the average range relative to the various comparison groups with respect to the amount of resources available for them to utilize, their skill in utilizing these resources, and the appraisal of events in their lives. While finding means scores for this sample as “typical” in terms of their means scores on these measures, people with HIV/AIDS are rarely seen as typical. The families they described are usually not nuclear families, but generally families that include non-married partners, and they are also a part of a highly stigmatized group, being predominantly homosexual. Thus, while it may be expected that this group would have fewer resources, the finding that their resources and, thus, resiliency is in the average range with respect to comparison samples speaks to the ways in which individuals adapt when diagnosed with a chronic illness such as HIV.

Disease Progression

The CD4 count, along with viral load, indicates disease progression. As an individual’s CD4 count drops, the immune system’s ability to fight off disease also drops accordingly. A normal CD4 count would be between 500 and 1450, and 95 percent of people without HIV infection have counts in this range (Bartlett & Finkbeiner, 2001). Individuals who fall below 500 are considered symptomatic and often start medication at that time. When CD4 count falls below 200, an individual is considered to have AIDS. In the past, the CD4 count for individuals with HIV/AIDS would decrease as a function of time after contracting the virus. More recently, perhaps due to the advent of more

effective medications, some individuals now have CD4 counts that increase over time, perhaps as much as 100 percent in a year (Bartlett & Finkbeiner, 2001). CD4 counts can vary for an individual for many reasons, including the particular laboratory technician who conducts the test and, therefore, it is wise to think of the CD4 count in terms of a general range. Numerous medical studies have used CD4 count as a marker of disease progression (e.g., Weinfurt, Wilke, Glick, Freimuth, & Schulman, 2000), and CD4 count is often used in conjunction with viral load, the measure of virus in an individual, which increases as CD4 count decreases.

As may be seen in Table 4.1, the mean CD4 count for the sample was 533.34, close to the level where individuals begin to become symptomatic, with a large standard deviation, indicating considerable variability among participants. In addition, the mean change in CD4 count from one year ago to the time of the study was a small negative change of -55.49 , again with a large standard deviation. As expected, CD4 count was found to be negatively correlated with viral load, $r = -.272$, $p < .01$. CD4 count was used in the majority of analysis in this study due to it being the more recognized disease marker.

Intercorrelations Among Primary Measures

Pearson correlation coefficients were computed among the seven primary variables under study, and Table 4.3 displays the intercorrelations. Scores on the two cognitive variables, uncertainty and optimism, were correlated with quality of life, both at $p < .01$, as were the three family variables at $p < .01$. As expected, family coping and optimism were correlated, $r = .405$, $p < .01$, and the intercorrelations between every pair of the measured

Table 4.3

Correlations Among Six Predictor Measures and Quality of Life

Measures	1	2	3	4	5	6	7
1. HAT-QoL	---	.090	.716**	.688**	.611**	.396**	.275**
2. CD4 count		---	-.018	.238*	.098	.228*	.185
3. LOT			---	.695**	.667**	.405**	.350**
4. MUIS				---	.614**	.388**	.203*
5. FIRM					---	.605**	.443**
6. FCOPES						---	.645**
7. FCCI							---

Note. HAT-QoL = HIV/AIDS Targeted Quality of Life scale; LOT = Life Orientation Test; MUIS = Michel Uncertainty in Illness Scale; FIRM = Family Inventory of Resources for Management; FCOPES = Family Crisis Orientated Personal Evaluation Scales; FCCI = Family Coping Coherence Index

*p<.05, two tailed, **p<.01, two tailed.

cognitive and family variables were significant. Quality of life was seen to correlate with all the variables of interest except CD-4 count. In fact, CD-4 count was found to correlate significantly with only family coping and uncertainty. Thus, the measure of disease progression was the only measure that did not correlate consistently with the other measures used in the present study.

Regression Analysis in Predicting Quality of Life

Four regression analyses were conducted, first on the model as a whole and then on the three sets of individual variables - disease progression, cognitive appraisal, and family variables - regressed on quality of life (see Table 4.4). The first regression model used all six predictor variables, including CD4 count, the two cognitive appraisal variables, and the three family variables. The six variable model was found to have an adjusted R^2 value of .61, $F(6, 94) = 27.09$, $p < .01$. Thus 61% of the variance in QOL could be predicted on the basis of the all six variables in the model, which is considered to be a large effect size (Cohen & Cohen, 1983). The ANOVA table for Model 1 is presented in Table 4.5

In the second regression model, the disease progression marker of CD-4 count was regressed individually on quality of life and was found to account for an insignificant percent of the variance in quality of life scores. For the third regression model, using the two cognitive variables, uncertainty and optimism, as the predictors of quality of life, an adjusted R^2 of .58 was found, indicating that the two cognitive variables accounted for 58% of the variance in quality of life scores, with $F(2, 120) = 83.59$, $p < .01$. The final fourth regression model used the three family variables to predict quality of life, and

Table 4.4

Multiple Regression Analysis of the Study's Predictor Variables and Quality of Life

Predictor variable	R	R ²	AdjR ²	F	df	p
Regression Model 1						
All CD4 count Optimism Uncertainty Coping Resources Appraisal	.796	.634	.610	27.09	(6, 94)	.001
Regression Model 2						
CD4 count	.090	.008	-.002	0.81	(1, 100)	.371
Regression Model 3						
Cognitive Appraisal Optimism Uncertainty	.763	.582	.575	83.58	(2, 120)	.001
Regression Model 4						
Family Coping Resources Appraisal	.613	.376	.359	22.33	(3, 111)	.001

Table 4.5

Analysis of Variance for Model 1

Source	Sum of squares	df	Mean square	F	p
Model 1					
Regression	26919.27	6	4486.55	27.09	.001
Residual	15567.48	94	165.61		
Total	42486.75	100			

Predictors: Constant, CD4 count, Uncertainty, optimism, coping, resources, appraisal.

Dependent variable: Quality of Life

*p<.05. **p<.01

results yielded an R^2 of .36, indicating that 36% of the variance in quality of life scores could be predicted on the basis of the three family variables, $F(3,111) = 22.33, p < .01$.

The results of the regression analyses indicate that both the cognitive variables and the family variables, when regressed alone on quality of life, can predict a significant amount of the variance in quality of life scores. The overall adjusted R^2 of .58 for the model suggests that the six-variable model does not increase the ability to predict quality of life over and above the variance explained by the cognitive appraisal model variables alone, using just two predictor variables.

While there could be numerous reasons for the lack of improved prediction with the addition of the three family variables and the disease progression variables, over and above the prediction provided by the two cognitive variables alone, the most likely possibility would appear to be the amount of shared variance between the cognitive appraisal variables and the family variables, which was found in the intercorrelations among primary variables presented in Table 4.3. Thus, while both family variables and cognitive appraisal variables are good independent predictors of variance in quality of life, the portions of the variance explained appear to overlap with one another. That is, much of the variance explained by the family variables is also explained by the cognitive appraisal variables, and the cognitive variables appear to predict more of the variance. Some of this shared variance could be expected, as the literature describes the relationship between optimism and family resiliency, which the three family variables purport to measure (e.g., Scheier & Carver, 1987). From the correlational data it can be surmised that this is the case, as the LOT-R correlates highly with each of the three measures on family (see Table 4.3). It may be that optimism provides one way of coping,

and the FCOPES in the family variables is a measure of the family's coping ability. Maintaining optimism and hope has been seen to be an effective way of coping for families (Johnson & Endler, 2002).

Less has been theorized and studied concerning the connection between uncertainty in illness and family resiliency. Uncertainty scores were found to be positively correlated with both the family variables of problem solving/coping and social support, and were significantly correlated with the family's appraisal of the illness (see Table 4.3). This indicates that the individual's certainty about the illness increases in accord with family resiliency. It is likely that certainty/uncertainty is connected to the way an individual and family attempt to cope and solve the problems that come with disease. Indeed, family resiliency studies that considered uncertainty found that greater uncertainty lead to less family resilience (McCubbin & McCubbin, 1991).

Hierarchical Regression

A hierarchical regression was then conducted on quality of life, using the three sets of six predictors to examine the amount of variance accounted for by each variable in the model, and the results are displayed in Table 4.6, and the analysis of variance tables are displayed in Table 4.7. In hierarchical regression, variables entered first are given any shared variance they may have with variables entered later in the model. In this model family variables were entered last in order to most rigorously test their unique contributions to prediction. The disease progression variable, CD-4 count, was entered at Step 1 in the equation and failed to explain a significant amount of the variance in quality of life scores, $R^2_{\text{change}} = -.008$, $F_{\text{change}}(1,99) = .788$, ns. Thus, disease progression was not found to explain a significant amount of the variance in quality of life scores. The

Table 4.6

Hierarchical Regression Analysis of the Study's Predictor Variables and Quality of Life
(N = 100)

Variable	R	R2	AdjR2	R2change	Fchange	df	change sig
Step 1							
Disease progression CD4 count	.089	.008	-.002	.008	.788	(1, 99)	.377
Step 2							
Cognitive Appraisal Optimism Uncertainty	.791	.626	.614	.618	80.01	(2, 97)	.001
Step 3							
Family Variables Coping Resources Appraisal	.796	.634	.610	.008	.685	(3, 94)	.563

Table 4.7

Analysis of Variance for Hierarchical Regression

Model	Sum of squares	df	Mean square	F	p
1. Regression	335.48	1	335.48	.788	.377
Residual	42151.26	99	425.77		
Total	42486.75	100			
2. Regression	26578.74	3	8859.58	54.02**	.001
Residual	15908.00	97	164.00		
Total	42486.75	100			
3. Regression	26919.27	6	4486.55	27.09**	.001
Residual	15567.48	94	165.61		
Total	42486.75	100			

Model 1: CD4 count

Model 2: CD4 count, Optimism, Uncertainty

Model 3: CD4 count, Optimism, Uncertainty, Coping, Resources, Appraisal

*p < .05. **p < .01.

cognitive appraisal variables of uncertainty and optimism were entered together at Step 2 of the regression equation, and these two variables together were found to increase the variance in quality of life explained in Step 1 by 61.8%, $R^2_{\text{change}} = .61$, $F_{\text{change}}(1, 99) = 80.01$, $p < .01$. Finally, the three family variables, entered together in Step 3, uniquely added only about 1% in explanatory power over Step 2, $R^2_{\text{change}} = .008$, $F_{\text{change}}(3, 94) = 0.69$, ns. Therefore, in spite of explaining a significant amount of variance when regressed on QOL alone, the family variables were not found to contribute to explaining variance over and above that explained by the two cognitive appraisal variables. This would suggest that the variance explained by the family variables is also explained by the cognitive appraisal variables, with the family variables predicting very little unique variance of their own.

Following is the regression equation for predicting Quality of Life Scores from the six predictors:

$$\text{Quality of life} = 36.83 + [\text{LOT score } (1.66)] + [\text{MUIS score } (.38)] - [\text{FCCI score } (.22)] + [\text{FIRM score } (.04)] + [\text{FCOPES score } (.12)] - [\text{CD-4 count } (.001)]$$

The regression equation allows prediction of quality of life from the six predictors used in the present study. For example, an increase of 3 points in an individual's MUIS score would predict an increase in the participant's quality of life score of about 1 point. As can be seen in the equation, CD4 count has very little effect on overall QOL, as is also true for FCCI scores.

Chapter V

SUMMARY AND IMPLICATIONS

Purpose

The purpose of the present study was to examine the relationships of family variables, cognitive appraisal variables, and HIV disease progression to the quality of life (QOL) of individuals with HIV/AIDS. The review of the literature indicated that individuals with HIV/AIDS are living long with their chronic disease, and there is a need for a greater understanding of the factors that contribute to their quality of life. It is important to understand contributing factors in order to better serve the growing number of individuals who are living with HIV. This information could potentially enable medical and rehabilitation professionals to tailor intervention and education strategies after diagnosis in order to facilitate the overall quality of life of people with HIV. Through a Website questionnaire, a community-based sample of individuals with HIV were surveyed to obtain measures of disease progression, cognitive appraisal, and family resilience variables, in addition to quality of life.

The survey allowed the following research question to be addressed: What are the relationships of the following variables with each other and with quality of life?

- Appraisal of the diagnosis
- Problem solving and coping ability
- Support level
- Uncertainty
- Individual optimism
- Disease progression

Discussion of Findings

The regression equations indicate that quality of life for individuals with HIV/AIDS can be predicted from the six independent variables examined in this study. The overall model allows for prediction of 58 % of the variance in quality of life scores, and both cognitive appraisal and family resilience variables were found to explain significant amounts of variance in quality of life. However, when hierarchical regression was used, the disease progression variable of quality of life was not found to contribute significantly to explaining quality of life. The cognitive appraisal variables were then found to explain a significant amount of the variance in quality of life, but the addition of the family resilience predictors did not explain a significant amount of the variance that was not already explained at the previous steps in the analysis. Thus, the variance explained by the family resilience variables overlapped with that explained by the cognitive appraisal variables, and family resilience failed to make a unique contribution in predicting quality of life.

The two cognitive appraisal variables and the three family variables were all found to be significantly correlated with QOL. Again, the self-report measure of CD-4 count was not found to be significantly correlated with QOL, and was found to significantly correlate only with family coping and the cognitive appraisal variable of uncertainty. The two cognitive appraisal and three family variables were all found to be significantly correlated with one another.

The regression models indicate that disease progression may not be a substantial contributing factor to quality of life. This finding seems inconsistent with the general medical model and with other previous findings (e.g., Weinfurt, Willke, Glick, Freimuth,

& Schulman, 2000). One reason for this finding in the present study could be the generally healthy status of participants in this study. A total of 79% reported being asymptomatic, and the overall mean CD4 count was 533, above the level typically associated with symptoms. Thus, this sample of individuals was managing to maintain good health in spite of their HIV status. In addition, 39% of participants indicated that they had been diagnosed over 12 years previously, thus allowing them time to incorporate the chronic illness into their lives. Therefore, their quality of life may have become less connected to disease markers.

The relationship of the cognitive appraisal variables of uncertainty and optimism to quality of life that was found in the present study appears to be even stronger than in past studies (McCain & Cella, 1995). These cognitive appraisal variables appear to be highly correlated with the family resilience variables measured in this study. These findings suggest that education after diagnosis, and the opportunity to explore with medical professionals the course of treatment that is going to take place could potentially decrease the amount of uncertainty individuals with HIV/AIDS feel after diagnosis. This decrease in uncertainty might then contribute to a higher quality of life, as education is a common way of dealing with uncertainty (Weitz, 1989). Similarly, the encouragement of optimism in individuals with HIV/AIDS, through both educational programs and therapeutic interventions, could have additional positive effects on QOL for these individuals. It appears that family involvement is correlated with optimism and certainty about the course of HIV progression. Therefore, finding ways to involve the family in the educational process would appear to be beneficial to both reducing uncertainty and increasing optimism.

The lack of correlation of the disease progression markers of HIV/AIDS on quality of life is also informative. HIV/AIDS appears unique in the world of chronic illnesses. Other studies have indicated that the more progressed the chronic illness, measured by such things as general health or the number of disease factors present, the lower the quality of life experienced by the individual. The lack of relationship found here supports the belief of Loew and Rapin (1994) that researchers tend to view the life quality of individuals with chronic illnesses more negatively than do the affected individuals themselves. It appears people with HIV/AIDS may be more concerned about factors in their lives other than just the disease.

Implications

This study supports the significant relationship that amount and quality of social support brings to the quality of life of individuals with HIV. Social support remains an important need, and individuals with HIV should be treated in an integrated health care setting that focuses on the many important implications of the disease, including social aspects, education, and the provision of an optimistic atmosphere, along with the medical care that is needed. All of these factors could help individuals with HIV/AIDS not only to live longer but also to enjoy higher quality lives. With this in mind, HIV medical clinics can focus on quality of life by attempting to meet mental health needs and assist individuals in learning how to minimize the uncertainty of the disease, while working to build coping and problem solving skills, in an atmosphere that fosters positive outcome expectancies.

Rehabilitation professionals can also use this information to aid people with other chronic illnesses. The installation of optimism is a primary tenant of the rehabilitation

philosophy that encourages individuals to attain their highest potential. Uncertainty has been seen to be a deterrent to the goal of achieving potential for many individuals with disabilities. Often it is the rehabilitation professional that hinders this goal through being difficult for the consumer to work with (Kosciulek, 1991). Rehabilitation can take a needed step in trying to minimize uncertainty about chronic illness in order to help individuals in attaining the quality of life that they desire.

Future studies may wish to look into the shared variance of the cognitive appraisal and family resilience variables in order to better understand their interrelationships. Such research could help determine how optimism is developed by individuals and how to minimize uncertainty in managing and living with chronic illnesses. The finding that seripositive men may successfully maintain their optimism, despite their life-threatening disease, is also a topic that may be worthy of further study in order to determine the strategies that may be helpful in encouraging optimism. The use of longitudinal research designs could also be helpful in further clarifying the relationships of the predictor variables of cognitive appraisal and family resilience to quality of life.

Limitations

The present study had a number of limitations. First, in an attempt to allow anonymity, substantial missing data occurred, limiting the sample and necessitating interpolation in computing scores on the primary measures for some of the participants. Second, the collection of the data by means of the Internet makes it difficult to define the population from which the sample was drawn, and reduces generalizability. In addition, not all individuals with HIV/AIDS have Internet access, and the sample was likely biased in terms of education and financial resources. Third, the study did not reward

participants in any way, and the individuals who participated were likely more interested in issues related to HIV, and this may have influenced scores on some of the measures used in the study, such as uncertainty, as the participants may have had a greater knowledge base than others with HIV who did not choose to participate. Fourth, since self-report was used for all of the measures, including disease progression, the accuracy of self-report is open to question.

The variables measured also contribute to the limitations of the study. Quality of life is difficult to define and measure. There are over 300 scales designed to measure quality of life. Additionally, there is often disagreement over the dimensions that constitute quality of life and how they should be conceptualized and measured. The ability to compare the results of this study with other studies can be limited due to the different ways that QOL is defined and quantified in other studies.

Conclusion

Individuals such as Matt Johnson no longer have to face a death sentence after diagnosis with HIV. He can look forward to a longer life, and also a higher quality of life, if certain non-medical variables are positively in place.

The analyses in the present study lend support to the continuing exploration of aspects of quality of life that can be positively influenced for individuals with chronic illnesses and the most effective ways to influence them. As life with a chronic disease like HIV/AIDS is extended through medical advances, quality of life issues become even more important. The amount of time contributed and the passion demonstrated by a number of participants through their correspondence with the researcher were substantial and encouraging. There are apparently large numbers of individuals with HIV/AIDS

who wish to know more about this chronic illness and are willing to volunteer their time and energy into assisting researchers in developing an information base, and researchers should be equally passionate.