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AUTHOR Soule, Christine J.; Appleton, Valerie
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ABSTRACT

Diagnosis of HIV/AIDS promotes a fear of the unknown, of death, or annihilation of self, of being, and of identity. Individuals face this threat in unique and holistic ways. This experience of crisis reflects stages of shock, disorganization, reorganization and resolution. Crisis can become a turning point and result in a passage toward successful adjustment, however. This study of 14 persons diagnosed with HIV/AIDS 5 to 7 months previously, examines the emotional, physical and spiritual changes that resulted from the HIV/AIDS diagnosis in three areas: (1) relationships with the self, or self-care; (2) relationships with others; and (3) relationships with a Higher Power. The participants interviewed reported a period of self-destructive behavior lasting from 6 months to 2 years, followed by an improved physical, social, and spiritual life. Participants also reported an inclination toward becoming more fully functioning and more open to self-exploration. Education and psychological care--including mental health counseling and pastoral care--are essential to dealing with this overwhelming disease. Other recommendations include counseling approaches that better facilitate the transition from trauma toward resolution and generativity. Further studies of the psychosocial effects on persons diagnosed with HIV/AIDS are recommended. Contains 19 references. (KW)

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Life Quality Changes after HIV/AIDS
Diagnosis: Positive Directions

Christine J. Soule, MS
and
Valerie Appleton, Ed.D., ATR, MFCC*

**Address correspondence to this author:*

Assistant Professor
Department of Applied Psychology
MS #92
Eastern Washington University
Cheney, WA 99004

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Running Head: Life Quality Changes after HIV/AIDS Diagnosis

Abstract

This study explores perceived changes in the quality of life after the HIV/AIDS diagnosis. Three areas of relationships were considered: with the self or self-care, with others, and with a Higher Power. Interviews were conducted with fourteen volunteers at least six months after the HIV/AIDS diagnosis. The participants reported a period of self destructive behavior lasting from 6 months to two years, followed by improved physical, social, and spiritual life. The recommendations include counseling approaches that better facilitate the transition from trauma toward resolution and generativity.

Introduction

Diagnosis of a life-threatening illness promotes a fear of the unknown, of death, of annihilation of self, of being, of identity (Pattison, 1976). Individuals face this threat in unique and holistic ways. The experience of crisis reflects stages of shock, disorganization, reorganization, and resolution. Crisis can also become a turning point and result in a passage towards successful adjustment (Jillings, 1985). A larger goal of trauma intervention is improvement of functioning beyond the pre-crisis level (Aguilera & Messick, 1986).

This study encouraged HIV/AIDS patients/clients to "find voice" by reviewing and sharing the spiritual and psycho social responses to HIV/AIDS diagnosis. It explores what emotional, physical, and spiritual changes that result from the HIV/AIDS diagnosis in three areas: 1) self-care, 2) relationship with others, and 3) relationship with a Higher Power. The literature review reflects these areas.

Self-care

Receiving a positive HIV diagnosis often leads to the negative psychological consequences of depression, social isolation, unwanted dependency on others, and economic difficulties (Quinette, 1992). Self-care can be a struggle in the adjustment to living with AIDS, including diet problems (Kineer, 1992), weight loss (McCaffrey, 1987), and lack of exercise (LaPeriere, cited in Pfeiffer, 1992).

As Pfeiffer (1992) describes, good self care has an impact on the progress of the disease. Aerobic exercise, for example, can slow the advance of the HIV/AIDS virus and act as a buffer for the detrimental mood changes that typically accompany stress in people infected with HIV/AIDS. Individuals who regularly exercised experience less anxiety and depression after HIV-AIDS diagnosis than those patients who do not exercise. Practiced relaxation techniques decrease depression and anxiety, and increase the CD4 cells that are so important in fighting AIDS.

Encouraging the patient to develop an "attitude" about the disease and a relationship with their doctor promotes a pro-active stance in self care (Siegel, 1986). Education, questions, knowledge about each medication and treatment can build cooperation and respect. Good or bad health is more than a matter of chance, and responsibility for the decisions relating to one's health contribute to wellness (Spence, 1986). Spence recommends that self-care entails the end of self-abuse and the development of a relationship with oneself that provides a foundation for nourishing relationships with others.

Relationship with Others

Often the HIV/AIDS diagnosis causes an intense crisis as persons with AIDS reveal to families of origin a lifestyle that might not be seen as acceptable. The diagnosis often forces into the open unresolved issues in relationships with family members and the need to reconcile them (Boyd, 1990). Many lives are full of relationships built on

disappointment, misunderstanding or the inability to reach each other and really communicate (Spence, 1986).

Therapy, workshops and retreats for persons with HIV/AIDS offer a chance to reconcile disagreements so that one's life and death can proceed (Kubler-Ross, 1987). Individual counseling offers the person with HIV/AIDS opportunities to explore family issues with a focus on present relationships and potentially improve the quality of life. The best medicine is to examine patients' histories, learn how they have coped in the past, and work with them to cope better in the future no matter how foreshortened that future may be (Quinette, 1992).

Relationship with a Higher Power

Societal judgments, and poor support from family, congregation, or community may ostracize many persons with HIV/AIDS. The stigma causes several obstacles to the renewal of meaning and hope. When homophobic labels become internalized patients may interpret the diagnosis as a punishment from God and alienation from the self may result. Exploring the choices of both spirituality and religion facilitates a sense of inner well being and the freedom to love oneself and others (Dunphy, 1988). Spirituality may be seen as a journey of the soul; not to religion itself, but to the drive in humankind that gives rise to religion (Fortunato, 1987).

Lowered self-esteem and the isolation of persons with HIV/AIDS have an impact on the spiritual aspects of life such as:

meaning, hope, love, one's belief in a Higher Power, forgiveness, and reconciliation. Such issues are experienced with much greater intensity than before the morbid diagnosis (Dunphy, 1987). Guilt over the role that addictions or behaviors played in causing the illness can block the possibility of finding meaning and hope in life.

Methodology

Subjects

Fourteen persons, five to seven months post HIV/AIDS diagnosis, volunteered as participants for this qualitative study (twelve males and two females). All of the volunteers who were able to participate were included in the study. The sexual orientation of the participants included ten homosexual, two bi-sexual, and two heterosexual. The ages of the participants ranged from 28 to 49 years with a mean age of 33 years. The dates of HIV/AIDS diagnosis ranged from 2 to 8 years with a mean of 5.57 years. All fourteen participants were Caucasian, from a northwestern state; six were in the middle to upper socio-economic class, and the other eight were in the lower socio-economic class. The demographics of the participants were due to convenience sampling effects.

The local AIDS network, practicing physicians who specialize in HIV/AIDS treatment, a local campus chaplain, and a public health nurse located potential participants for the study. A letter was distributed to potential participants through these agencies and

institutions. Participation was voluntary and all material was protected as confidential.

Methods

Data were collected through an hour long, taped interview. The interviews included a set of open-ended questions designed to draw out the participants responses to the following questions: how is life different from before the diagnosis to the present in the areas of self-care, relationships with others, and relationship with a Higher Power. The research questions asked: will the quality of life show changes in self-care, relationships with others and relationship with a Higher Power since the HIV/AIDS diagnosis.

Assessment

The participants' statements were recorded and arranged according to three areas of relationship: 1) to self or self care, 2) with others, and 3) with a Higher Power. Three sub-areas: emotional, physical, and spiritual dimensions of the post diagnosis experience were considered in each of the relationship domains. This framework is used for the description of the findings.

Findings

The generosity and willingness of participants to contribute to this research was very moving. They wanted others to know and share their stories and the insights they experienced, as one individual called it, "An awakening." Each person felt that they were able to give something through the interview process.

Self-Care

A majority of the participants in this study had a shift in the emotional and physical aspects of self care typified by a time limited period denial and self-abuse lasting from six months to two years after the diagnosis. During this period they used alcohol, drugs and/or sex in an attempt to escape the reality of the disease. After this period, however, the majority have practiced better health care than before diagnosis. Ten have stopped using drugs and/or alcohol, while two of the subjects continue to use alcohol and/or drugs, and two subjects never used alcohol and/or drugs.

Insert Table 1 about here.

Statements about this self-abusive period included feelings of hopelessness such as, "I was waiting to die." Eight of the subjects had considered suicide since diagnosis. One participant stated, "I'd rather have my friends and family think that I committed suicide than that I had died from AIDS." Other statements reflected resolution of the initial denial, "I finally quit drugs because I was worried about what would happen to the children." Other comments suggested motivation towards change that express the dichotomy between life values and behaviors, such as, "I cannot have peace, harmony, and wholesomeness with drugs or alcohol."

Spontaneous changes occurred for two individuals. One quit using drugs, alcohol, and smoking upon diagnosis and said, "My head tapes said, get your act together." Another reported, "I discovered I was the caretaker in the family. I started therapy and then my family got into therapy too." HIV/AIDS diagnosis caused an improvement in eating, sleeping, exercise habits in twelve of the subjects, while all fourteen maintain safe sex. Sample statements include:

"My doctor said if I wanted to fight this disease I'd better give up the alcohol."

"In the past six months there's been a radical change in my eating habits, I'm more aware of eating enough food, lots of bananas, yogurt, apples."

"I got to the point where I couldn't ride my bike anymore when I was on marijuana. Now, I am building up my strength again."

"I'm careful to tell sex partners that I have HIV/AIDS and I practice safe sex."

Counseling was a major factor in reducing and maintaining mental and emotional health due to the stress of HIV/AIDS diagnosis, addictions, and family of origin problems for eleven participants. For example, one stated, "I'm not worried about going to heaven, I've already had hell here on earth. For years I was sexually abused by my father."

All fourteen participants had goals for the future ranging from further education to concerns about tying up loose ends in personal

relationships before facing death with statements such as: "I want to get my GED and then go to the community college and study business administration." And, "I can barely get up and get dressed. Deciding what to eat and cook is tough. My goal is one day at a time."

Spiritual self-care for twelve individuals included meditation, journaling and making a "home" for self. One mused, "Now I enjoy living alone, making a home for myself, with my fish (aquarium), plants that others have given me, and my cats."

Relationship With Others.

Despite partner or spousal relationships, loneliness was a prominent feature of life after the HIV/AIDS diagnosis. However, the majority of participants in this study also sought out social contacts and support systems. This domain included emotional and physical sub-areas, however no spiritual aspects were reported.

Isolation was a prominent theme in life since the HIV/AIDS diagnosis. Example statements include, "Without a partner, I wonder who will be there for me when I die." and, "I'm still the same person that I was before I had AIDS. People forget you because you are sick."

 Insert Table 2 about here.

Close friends of seven of the study members also have HIV/AIDS. Doctors included in the identification of "friends," were

described as persons who sometimes acted as a spiritual guide and counselor and the person whom they trusted the most with their life.

Activities with others enjoyed by ten included belonging to a men's chorus or speaking to schools, agencies and organizations about HIV/AIDS. However, thirteen of the subjects reported negative experiences in support groups and the development of a proactive attitude about the disease. For example:

"I get irritated when I go to groups because everyone is on the pitty-potty. I want to get on with life. This disease has to learn to live with me!"

Discontinued family relationships predominate among this sample of individuals. Statements include issues with parents, such as, "My Father denied my homosexuality. I live a long way from home now for my own peace of mind." and, "My Mom won't talk about the incest. My whole family denies the incest happened. I get crazy when I go home." Of the two who maintained family ties, one individual reconstructed connections upon receiving support from family members after the diagnosis stating, "I've learned that I can be minimally involved with family members now, I'm learning to stay out of family problems." The other had a positive relationship with family members that continued after diagnosis and remembers, "My family has always been accepting of my homosexuality and provided care and concern for me."

Relationships with partners and spouses are an active part of the lives of the study participants. These relationships offered a committed, caring, supportive environment. There was growth for each partner within the relationships, for example, "My partner and I both go to counseling separately and together." Through the HIV/AIDS diagnosis one participant reported that the partner, "has learned to be more honest and confrontational with himself and with me."

Partners or spouses for ten of the participants also have the HIV/AIDS diagnosis. Pain appears in the statement, "I don't know if I can watch another loved one die. I'd rather it be me." Of the four individuals who did not have relationships with partners or spouses, two felt losing a partner or spouse to death was too fearful to experience again. The other two were working on their own issues and were tentative about exploring a new relationship. One said, "I used to have destructive relationships and couldn't get out of them. I'm almost ready for a healthy relationship now."

Relationship with a Higher Power

Spirituality was sought by the majority of the study participants. The domains of emotion and spirituality were reported in the relationship with a Higher Power but no physical components. Ten reported having a relationship with a Higher Power; five participants had re-established a relationship with a Higher Power, while another

five had developed a new spiritual relationship with a Higher Power. Four reported an established, long term relationship with God.

Insert Table 3 about here.

The HIV/AIDS diagnosis was viewed by some as "God's punishment" and, "God is saying, I'd better get my life in order."

Another stated,

"I used to think the diagnosis was God's punishment. I don't anymore. I believe I'm setting an example for my children, friends and others. I'm connected to a Higher Power now who gives me faith and love."

The changing of church and theological affiliations brought acceptance and peace into lives, for example, "I changed to a church that was accepting of people with AIDS." Re-established relationships with a Higher Power were reflected in statements such as:

"I was raised a strict Catholic. When I was drugging and not eating there was no room for God. Now, I've come to peace with my body, with self spiritually. I'm reading the Bible again. I'm not a fanatic anymore."

The four who already had a firmly established spiritual tie made statements such as, "I've always had a strong spiritual relationship with God." One of these individuals was moved to leave a

professional occupation to attend seminary after the HIV/AIDS diagnosis.

Discussion

Several issues of note were manifested through the interviews. At least ten of the subjects interviewed were from alcoholic and physically abusive homes. They resorted to dangerous sex practices, alcohol, and drug abuse during the period following the HIV/AIDS diagnoses. Suicidal thoughts and self-blame were prevalent. The majority also cut off ties with their families.

However, despite familial and reactive patterns, these self-destructive behaviors were reported as temporary coping mechanisms. The majority of those interviewed discussed positive adaptations since the diagnosis and catalytic personal change toward life improvement. Relationships with others were actively sought. Professionals and doctors were seen as allies in helping with life stresses. All fourteen of the participants in this study now practice pro-active health care through safe sex, better eating, exercise, and regular sleep. They have developed or have continued a relationship with a Higher Power. One individual left his corporate job to join a seminary and others practice spiritual centering through prayer, journaling, and meditation.

The availability of counseling and pastoral care for persons with HIV/AIDS was also of concern for half of the individuals interviewed. Another participant said, "I had a good counselor but she moved away.

I haven't found a good counselor who understands the horrifying experience of living with AIDS. I've tried to find a counselor."

A sense of peace and forgiveness of the self and others were seen as important by the participants. Furthermore, the search for meaning in the face of death was of common concern. One individual finds meaning in the prayer that through her God finds a way to speak to others about the disease.

The quality of life for only one of the fourteen people interviewed in this study included having a good support system in place, being independent with highly paid professional occupation, and having a stable relationship with God. Diagnosis for this person caused only minor disruption in the previous quality of life.

Conclusions

A poignant example of a qualitative life change after the diagnosis of a life-threatening illness is offered by Graham:

"I realize that this diagnosis of AIDS presents me with a choice: the choice either to be a hopeless victim and die of AIDS, or to make my life right now what it always ought to have been"
(cited in Spence, 1986, page 1).

In this study, persons facing death reported an inclination toward becoming more fully functioning and more open to self-exploration. One spoke from the heart when saying, "I have been a much better person because of this disease, whether I'm cured or not. I'm sorry that the whole world can't have the awakening that AIDS

provides." Behavior change among the participants was the spontaneous product of the individuals' resolution of the conflicts between core values and self destructive behaviors (Prochaska & DiClemente, 1982).

Among the limitations of the study is the lack of pre-diagnosis interviews as well as an interview directly following the diagnosis. Participants may have over reported their adaptation, or those who volunteered may be those who typically seek counseling or are already pro-active in their lives. Additionally, hesitancy in the HIV/AIDS community towards participation due to fear of persecution may have affected the sample size. The impact of illness also was manifested in persons who volunteered for the study but became too ill to be interviewed.

Recommendations

Essential to dealing with this overwhelming disease is education, psychological care, including mental health counseling and pastoral care. Thirteen of the participants had negative experiences in support groups and yet felt they do not have enough resources to meet the fear of suffering and the stigma of having HIV/AIDS. They unanimously encourage providers to offer more and better counseling and pastoral care to persons with HIV/AIDS. A trusted professional who understands both the diagnosis and its sequel can mitigate the stresses of adaptation to HIV/AIDS.

The positive quality of life changes that may result from HIV/AIDS diagnosis warrant further study. Education of counselors that includes counseling approaches that focus on self-motivated change might offer alternatives for patients experiencing post-diagnosis defensiveness and self-abuse. Rather than classifying such behaviors as pathologic, denial of and resistance to change may be seen as an important part of an adaptive change response (Miller & Rollnick, 1991).

Traditional or standardized interventions may not meet idiosyncratic needs. There is need for further studies of the psychosocial effects on persons diagnosed with HIV/AIDS that include a consideration of personal spirituality and of the stories of the deeply symbolic journey to death. The idiosyncratic meanings of these symbols can be therapeutically externalized through art processes. Art therapy offers the clinician and the researcher new ways of seeing and facilitating the unique transitions that move individuals from the crises of life-threatening events through to their closure (Appleton, 1993). Creative, generative opportunities for self care, relationships with others, and spirituality are core to the resolution of trauma and need be considered in counselor training and service programs.

Table 1.

Self-care Issues After HIV/AIDS Diagnosis (n=14).

<u>Self Care Issues</u>	<u>No. of Participants</u>
<i>Emotional</i>	
Continue to use drug/alcohol to cope	2
Never used drugs/alcohol	2
Considered suicide	8
Stopped using drugs/alcohol for denial	10
Experienced a denial period (6 months - 2 years)	11
Used sex, drugs, & alcohol to escape reality	11
View counseling as major factor in mental health	11
<i>Physical</i>	
Improved health habits	12
Practice safe sex	14
<i>Spiritual</i>	
Have goals for the future	14
Practice spiritual self care	12

Table 2.

Relationships With Others After HIV/AIDS Diagnosis (n=14).

<u>Relationships with Others Issues</u>	<u>No. of Participants</u>
<i>Emotional / Physical</i>	
Have close friends with AIDS	7
See Doctor as friend	7
Engage in activities with others	10
Experience loneliness	13
Experienced support groups as negative	13
Families:	
Maintained family ties	2
Discontinued family ties	12
Partners:	
Without partners - lost to death	2
Without partners due to personal issues	2
Relationships with partners/spouses, and s/o	10
Partners with HIV/AIDS	10

 Note: No "spiritual" statements were categorized under the relationship area identified.

Table 3.

Relationship With a Higher Power (H. P.) After HIV/AIDS Diagnosis and Other Quality of Life Issues (n=14).

Relationship with (H. P.) Issues	No. of Participants
<i>Emotional/Spiritual</i>	
Joined a seminary after diagnosis for HIV/AIDS	1
Ongoing spiritual relationship with a H. P.	4
Re-established with a H. P.	5
Established a new relationship with a H. P	5
Has a relationship with a H. P.	10
Other Quality of Life Issues:	
<i>Emotional/Spiritual</i>	
Concerned about availability of pastoral care and counseling	6
HIV/AIDS diagnosis was catalyst for personal change	13
Encourage the development of better mental/emotional care	14
<i>Others</i>	
Had a good financial and emotional support system	1
Came from families with alcohol/substance abuse	10

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