

# **NURSE**

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*Some people walk in the rain. Others just get wet.*  
- Roger Miller

## **“Quality of Life” – What is it Really?**

David J. Sterken MN, CNS, CPNP

Quality of life – we see this ever-popular phrase in nursing articles describing the lives of people infected with HIV. Yet, I believe that there is a danger in trying to quantify “quality of life” for the purpose of research. Although I would agree that the “quality of life” research has identified many key issues important to those living with HIV, we must never forget that “quality” is defined differently by each and every individual.

“Quality” is defined by Webster as “peculiar and essential character” and “the identifying character.” The very definition of the term “quality” takes on a personal nature demanding a level of intimacy between practitioner and patient. Intimacy is seeing more than a physical presence and lab values when you interact with your patient. Intimacy demands that we “know” one another on a deeply physical, emotional, mental, and spiritual level.

The nature of our health care system does not foster intimacy and as a result often the “quality of life” agenda is lost in the discovery of a “new combination of drugs.” All too often I have seen my fellow sojourners suffer in silence simply because very little time is allotted to develop intimate relationships and thus discover the essential character (quality) of our patients.

I believe that as HIV+ nurses/patients we are in a unique position to not only add to the sustenance of research that looks at quality of life in the HIV+ population, but to promote patient/practitioner relationships that look at HIV more holistically. I am more than my CD4 count and viral load! My life is impacted by relationships, job issues, planning for the future, and everyday stressors, all of which impact quality of life. Sharing with your health care practitioner how psychosocial variables impact your relationships and your ability to live with the disease will enable them to better understand quality of life issues in the HIV population.

## **Getting Down To The Nuts & Bolts: “Living” with HIV**

David J. Sterken MN, CNS, CPNP

Why is it that the nursing literature in regard to care of the person living with HIV is littered with article about “quality of life?” Just where did the concept originate and why has there been such a big

push to discover the impact that HIV has on an individual’s ability to function in life?

The concept of quality of life originated from care of oncology patients (Grimes & Cole, 1996, p. 691). It developed from the idea that while treatment of disease is often a necessity a delicate balance must be maintained allowing one to continue to live a life filled with meaning and purpose. As the result of a national agenda, initiated by the National Institute for Nursing Research, seeking to identify critical nursing

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## Getting Down To The Nuts & Bolts: “Living” with HIV,

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research areas, Larson and Ropka (1990) identified as a priority the need to re-research the multidimensional problems faced by persons living with HIV infection. Further discussion served to narrow the focus toward “identification of psychosocial variables and the relationship of these variables as they influence persons with HIV infection, their families, and their loved ones” (Nunes, Raymond, Nicholas, Leuner, & Webster, 1995).

Over the past decade nursing researchers have worked hard to identify how HIV impacts quality of life. The following is a list of factors that impact life quality in persons with HIV.

- **Ability to function in life activities and roles** (Grimes & Cole, 1996). Reliance on others to perform daily activities of living is a disruptive force, which can be mediated by one’s enabling skills. Enabling skills are behaviors and skills that are learned as a response to aversive and disruptive events. Thus, the more an individual with HIV disease is involved in self-care, personal, family, and social roles, the greater the perceived level of well being.
- **Self-Transcendence** (Mellors, Riley, & Erlen, 1997). Self-transcendence is a developmental characteristic that expands one’s boundaries of self to take on broader life perspectives, activities, and purposes that help one discover or make meaning of one’s life. Faced with the irreversible fact of their terminal illness, PWHIV are able to transform this information from despair to challenge, from psychological crisis to personal growth, from a death sentence to a new meaning and quality of life
- **Balance** (Murdaugh, 1998). Achieving a balance is a process in which persons with HIV disease strive to maintain quality as they learn to live with a disease that has a slow, pro-

gressive downhill trajectory. Bedell (1999) found that those who worked to find and maintain balance in their lives refused to let the clinical aspects of AIDS take control of their daily lives and define how they viewed themselves, or others viewed them, as individuals.

- **Psychosocial counseling and stress management** (Lutgendorf, Antoni, Schneiderman, & Fletcher, 1994). Psychosocial interventions which enhance an individual’s sense of control, teach adaptive coping strategies, improve ability to elicit social support, and modify ways that individuals think about stressors, may enhance psychological adjustment in HIV-infected individuals, thereby improving the quality of their lives.
- **Comorbid psychiatric conditions** (Sherbourne, Hays, Fleishman, Vitello, Magruder, Bing, McCaffrey, Burnam, Longshore, Eggan, Bozzette, Shapiro, 2000). Comorbid mood disorders (depression, anxiety/panic attacks) and other psychiatric conditions, such as alcohol abuse and substance dependence, may result in poorer prognosis and response to treatment for persons with HIV.
- **Symptom progression** (Lubeck & Fries, 1992). The trends in this study suggest that there is a significant impact on an individual’s quality of life when he or she has progressed to the stage of having one or more serious opportunistic infections. Cunningham et al, (1998), defined symptom progression in terms of “constitutional symptoms” like fever, night sweats, myalgias, fatigue, anorexia (sometimes with nausea and vomiting), and weight loss. Recommendation is made that clinicians should screen HIV infected patient regularly for these symptoms so that efforts can be made to treat such complaints before they become detrimental to quality of life.
- **Will to Live** (Tsevat, Sherman, McElwee, Mandell, Simbartl, Sonnenberg, Fowler, 1999). This study found that half of the patient interviewed indicated that their life

### Contact us...

One of the main goals of the HIV-Positive Nursing Committee and **+ Nurse** is to reach out to all HIV-Positive nurses, regardless of practice setting or organizational affiliation. You do not have to be a member of ANAC or an AIDS nurse to benefit from **+ Nurse**.

You can contact us at **+ Nurse**, c/o Association of Nurses in AIDS Care, 80 S. Summit Street, 500 Courtyard Square, Akron Ohio 44308; **Phone:** 330-762-5739 or 800-260-6780; **Fax:** 330-762-5813; **E-Mail:** [anac@anacnet.org](mailto:anac@anacnet.org); **Web site:** [www.anacnet.org](http://www.anacnet.org)

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**We are all on a spiral path. No growth takes place in a straight line. There will be setbacks along the way... There will be shadows, but they will be balanced by patches of light and fountains of joy as we grow and progress. Awareness of the pattern is all you need to sustain you along the way...**  
**- Kristin Zambucka**

Getting Down To The Nuts & Bolts:  
 "Living" with HIV,  
 Continued from page 2

with HIV is better than it was before they contracted HIV. Factors unrelated to health that contributed to health values included spirituality and concern and love for one's children.

- **Social support** (Friedland, Renwick, & McColl, 1996). Relationships that provide emotional as well as physical intimacy improve quality of life.

*This by far is not a comprehensive list but provides insight into factors that contribute to quality of life in people living with HIV. As people infected with HIV live longer issues related to quality of life will continue to unfold and prove paramount in the medical management of the disease.*

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## Self-Transcendence – Finding Meaning and Purpose

David J. Sterken MN, CNS, CPNP

Self-transcendence and quality of life are concepts that are intimately linked to one another. Self-transcendence is the ability to feel that life has balance even though one might experience significant symptoms associated with an illness (Mellors, Riley, & Erlen, 1997). In short, it is a developmental progression toward quality of life, which permits less emotional disruption despite events that heighten one's sense of mortality (Lewis & Galliston, 1989; Reed, 1991b).

During the course of research for this particular edition of +Nurse I came across an article entitled "Meaning and Purpose in the Lives of Persons with AIDS", by Doris Coward. In this article, Coward (1994) examined the concept of self-transcendence from the perspective of both men and women with AIDS. I believe her findings demonstrate the need to incorporate gender and individual difference when seeking to discover experiences from which our patients, and we ourselves as HIV+ nurses, may derive meaning and emotional well being. The results of the study are as follows:

### *Men's Themes*

- **Experiencing Fear:** Rejection from others, process of dying, loss of connections, opportunity to be known by others when they died
- **Taking Care of Themselves:** Took an active and assertive role in their health care, would not give up the control to someone else
- **Seeking Out Challenge:** Challenge was a way to prove self and to bolster self-confidence
- **Creating a Legacy:** The need to be known by others

- **Accepting That Which Cannot Be Changed:** Accepting all parts of themselves including the part with AIDS
- **Connecting with Others:** Participating in support groups, sharing their knowledge and experience with AIDS, keeping in touch with friends and family
- **Letting Go:** Meaningless activities, work
- **Accepting Help:** Asking for and accepting help was not always easy
- **Having Hope:** Seeking ways to live longer, maintaining meaningful personal relationships, continuing to find reason for being through participation in community events

### *Women's Themes*

- **Experiencing Fear and Aloneness:** Overwhelming sense of isolation and abandonment from caring others as well as from God
- **Experiencing Uncertainty:** Could not predict the behavior of others related to their diagnosis, could not predict periods of their own illness or wellness.
- **Using Others as Role Models:** Motivated by the everyday struggles of others who lived with AIDS
- **Finding Inner Strength:** Therapy, journaling
- **Reaching Out To Receive and To Give:** Shared their experience in support groups, and individually with other women who had AIDS.
- **Making a Difference, Having Purpose:** Increased sense of self worth from believing that their sense of purpose and self-worth from believing that their own unique experience could make a difference
- **Viewing AIDS as an Opportunity:** AIDS had provided an opportunity for personal growth
- **Having Hope:** Expressed hope for living with people who loved them and to whom they could give their love.

In this study these men and women found meaning in reaching out to relieve their fear and aloneness and in maintaining hope for a cure. Purpose and meaning for the individuals in this study was primarily based on the development

*Nothing can hurt you unless you give it the power to do so.  
- A Course in Miracles*

*Change and growth take place when a person has risked himself, and dares to become involved in experimenting with his own life.  
- Herbert Otto*

**What would it be like if you lived each day, each breath, as a work of art in progress? Imagine that you are a Master-piece unfolding, every second of every day a work of art taking form with every breath.**  
**- Thomas Crum**

*Self-Transcendence – Finding Meaning and Purpose,*  
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and continued maintenance of human relationships rather than the presence or absence of physical symptoms.

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