

**IMPROVING QUALITY OF LIFE
OF PEOPLE LIVING WITH HIV INFECTION THROUGH STRENGTHENING
SPIRITUAL ASPECT**

Kusman Ibrahim

Faculty of Nursing, Padjadjaran University

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ABSTRACT

The HIV/AIDS remains a major health problem among modern society though the incidence has shown a significant decrease in some parts of the world. The advance technology in Antiretroviral Therapy (ART) has dramatically lowered HIV-related morbidity and mortality. HIV/AIDS has changed from an acute fatality disease to a chronic manageable illness. Living with a chronic illness, people living with HIV infection (PLWH) are often deal with multiple hardships of life, such as physical impacts related to progression of the virus, stigma and discrimination, poor living condition, dependency on medication, and psychological and social and spiritual problems. As other chronically conditions, living with HIV infection require adequate coping and support to manage various problems that encountered by PLWH during their rest of lifetime. The complexities of living with HIV as a chronic illness also influence to the level of quality of life. There were growing literature explicating the quality of life of PLWH both qualitative and quantitative studies. Quality of life has become central issue to measure outcomes of health-related interventions, including nursing interventions. Thus, quality of life involves multidisiplinary term which in influenced by many factors, such as cultural, ethnic, and religious values. WHO (2004) defined quality of life as an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards, and concerns. Previous studies documented the relationships between religiousity and quality of life, since the religion could be as a source of coping to deal with particular life difficulties. Although there was a dispute regarding the similarity between religion and spirituality, generally understood that meaning of spirituality could be broader than religion. The linkage between spirituality and health has drawn significant attention among health researchers in attempt to improve quality of care. Taking into account of spirituality into nursing care is very relevant with the caring paradigm of holistic nursing. In the context of caring for PLWH, utilyzing spirituality is essential to achieve the goal of holistic and comprehensive nursing care. Strengthening spirituality is eventually expected to improve quality of life of PLWH.

Key words: quality of life, HIV infection, spirituality

INTRODUCTION

Number of people living with HIV/AIDS (PLWH) tend to decrease globally. However, it still shows increasing in some part of the world. The HIV pandemic remains a major problem and poses continual challenges to some countries, especially in developing and under developed countries (Fauci, 1999). Indonesia is a developing country which the the forth biggest population in the world. Population has been facing increasing numbers of People Living with HIV/AIDS (PLWH) since the first case was identified in 1987. Recently, the country has been noted as having the fastest growing HIV epidemic in Asia (UNAIDS, UNICEF, WHO, & ADB, 2008). The estimated number of PLWH in Indonesia were 380,000 at the end of 2012 (UNAIDS & WHO, 2012), and if prevention programs do not work effectively, it is predicted there may be 541,700 at the end of 2014 (National AIDS Commission., 2012).

The advancement of science and technology particularly in treatment for HIV/AIDS through invention of antiretroviral drugs had changed HIV/AIDS from an acute fatalistic disease into chronic manageable disease. Anti retrviral therapy (ART) has changed dramatically the life of PLWH to become healthier and longer life. However, some crucial issues of living with HIV/AIDS as a chronic disease are still prevalent. Adheren to ART is one of the major issue that may significantly effects to the health outcomes of PLWH. Low adheren to ART medication has been associated with the poor outcomes of viral suppression. This can cause poor physical condition of PLWH which also influence to their quality of life.

Quality of life has become a major consent in living with a particular chronic disease including HIV/AIDS. Quality of life reflects perception of patients toward the current health and well being condition as result from disease as well as its associated treatments. In health care sector, quality of life has been an acceptable indicator to evaluate the effect of health care interventions. Healthcare providers, including nurses, are expected to provide high quality of care to the patients regardless of their illness or disease (Smit, 2005). Various interventions have been developed to improve quality of life of care recipients. Since the concept of quality of life is holistic which involve physical, psychological, social and spiritual aspects, the interventions to improve quality of life may also cover these aspects. Spirituality has been known as having close relationship with the quality of life. Spirituality can be utilized as a source of coping to lessen the stress resulting from disease and other health problems. In addition, from the religious perspectives, spirituality has also been regarded as a connection between individuals and the God,

the source of supreme power which may give energy or power to human being for sustaining their life. This paper aims to review and discuss the various ways to improve quality of life of PLWH through strengthening spiritual aspect of PLWH.

CONCEPT OF QUALITY OF LIFE

Quality of life has been defined and measured in a number of different ways by nurse researchers. It is a multi-disciplinary term, not only used in everyday speech, but also in the context of research where it is linked to various specialized areas such as sociology, medicine, nursing, and psychology (Farquhar, 1995). It is difficult for people to agree on a definition of QoL, because the researchers in the various disciplines come from different perspectives. In addition, cultural, ethnic, and religious values may influence how quality of life is judged, and different people have different values (Ferrans & Powers, 1993).

Farquhar (1995) viewed three major types of definitions of QoL (1) global definitions, (2) component definitions, and (3) focused definitions. The global definitions (Type I) usually incorporate ideas of satisfaction or dissatisfaction, happiness or unhappiness, sense of well-being, the individual's own evaluation of life experiences, and achievement of a satisfactory social situation and physical capacity. The component definitions (Type II) are those which break quality of life down into a series of component parts or dimensions, or identify certain characteristics deemed essential to any evaluation of QoL. An example of component definitions was proposed by George and Bearon (as cited in Farquhar, 1995), who defined QoL in terms of four underlying dimensions, two of which are objective and two of which are reflected in the personal judgment of the individual. The objective dimensions are general health and functional status, and socio-economic status. The dimensions reflecting the personal judgment of the individual, or subjective evaluations, are life satisfaction and related measures, and self-esteem and related measures. Focused definitions (Type III) are those definitions, which refer to only one or a small number of components of health/functional ability (Farquhar, 1995).

Other researchers view quality of life as a multidimensional construct that encompasses perceptions of both positive and negative aspects of physical, emotional, social, and cognitive functions, as well as the negative aspects of somatic discomfort and other symptoms produced by a disease or its treatment (King, 1998). Similarly, Ferrans and Powers (1993) conceptualized quality of life as a multidimensional construct that consists of four major life domains: health

and functioning, social and economic, psychological/spiritual, and family. Although the researchers have different views in defining quality of life, commonly they agree that quality of life a multidimensional construct.

DIMENSIONS OF QUALITY OF LIFE

Despite controversies regarding the dimensions of quality of life, most experts agree that there are four to five generally accepted dimensions to QoL (King, 1998). These are (1) physical, (2) psychological, (3) social, (4) somatic/disease and treatment-related symptoms, and (5) spiritual. The physical dimension is the one that most closely approximates the outcome measures traditionally used, including functional abilities such as activity level, strength, energy, self-care, and fertility. The psychological dimension includes life satisfaction and achievement of life goals, affect, perceived stress, self-esteem, psychological defense mechanism, anxiety, depression, fear, and coping. The social dimension or social well-being refers to how individuals carry on relationships with family, friends, colleagues at work, and the general community, including sexual satisfaction. The somatic dimension refers to disease symptoms and treatment side effects. Spiritual well-being refers to one's life purpose and meaning (Aeroson, et al. as cited in King, 1998).

Based on analyses of the WHOQoL group, four dimensions or domains were considered most appropriate for the WHOQoL-BREF (World Health Organization Quality of Life Group, 1994). The four domains of the WHOQoL-BREF include physical, psychological, social relationships, and environment domains. Physical health includes pain and discomfort, dependence on medical treatment, energy and fatigue, mobility, sleep and rest, activities of daily living, and work capacity. Psychological health includes positive affects, spirituality, thinking, learning, memory and concentration, body image and appearance, self-esteem, and negative effect. Social relationships are comprised of personal relationships, sexual activity, and social support, and the environment dimension consists of physical safety and security, physical environment, financial resources, opportunities for acquiring new information and skills, participation in and opportunities for recreation/leisure activities, home environment, accessibility and quality of health and social care, and transportation.

MEASUREMENT OF QUALITY OF LIFE

Quality of life studies can provide comprehensive and sensitive methods for communicating information on the burden of disease and effectiveness of treatment if they are designed and implemented well. Experts haven't yet reached an agreement on a gold standard or best method of measuring QoL (Haberman & Bush, 1998). The focus of QoL measurement has shifted from measuring health alone to also measuring other aspects of a person's life such as spirituality and employment, thus becoming more comprehensive (Corless, Nicholas, & Nokes, 2001). Generally, measuring QoL may be divided in two ways, namely quantitative measurement and qualitative measurement.

The qualitative inquiry is a form of systematic measurement that is becoming increasingly popular (Haberman & Bush, 1998). A qualitative method may include a few open-ended questions at the end of a forced-choice questionnaire, or a short semi-structured interview. Some additional qualitative methods include participant observation, storytelling, interviewing key informants, or use of client diaries as a way to chronologically log symptoms or health behaviors. Commonly, investigators use multiple types of data collection in one study (King, 1998).

The quantitative measurement is another way to measure QoL, with the use of standardized questionnaires, either fixed-item or forced-choice (Haberman & Bush, 1998). The advantages of such standardized tools are that they usually have known reliability and validity, they ensure every participant is asked the same set of items, it is easy to administer and complete, and results can be compared across studies that use the same instruments. The disadvantages are limited responses addressing only the items contained in the questionnaire, so many important aspects in assessing QoL may be overlooked. For example, if the questionnaire focuses on physical functioning, participants will not be asked to identify problems related to social, emotional, or spiritual functioning. Several quality of life instruments already exist for measuring quality of life quantitatively.

In 1991, the Division of Mental Health of the WHO initiated World Health Organization Quality of Life (WHOQoL) project. The aim of this project was to develop an internationally applicable and cross-culturally comparable quality of life (QoL) assessment instrument. This WHOQoL instrument was developed collaboratively in a number of centers worldwide. After going through several stages, the final result was a 100-item version of the instrument, which is

known as the WHOQoL-100. The WHOQoL-100 assesses individuals' perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns. It is a 100-item instrument that currently exists in directly comparable forms in 29 language versions. In order to use the instrument outside of a clinical setting, the WHOQoL group also developed a short version named the WHOQoL-BREF containing 26 items (WHOQoL Group, 1994).

QUALITY OF LIFE OF PLWH

People living with HIV/AIDS confront many issues as a result from the disease as well as its treatment. These have been noted to have influence on their quality of life. Previous study reported that PLWH's QoL was severely compromised and limitations in mobility and usual activities, as well as pain/discomfort constituted major problems. There is also a high prevalence of anxiety and depression (Hughes, Jelsma, Maclean, Darder, & Tinise, 2004). Poverty/poor living condition and poor functional status were also associated to lower quality of life (Phaladze, et al., 2005).

On the other hand, the presence of ART medication has shown a positive impact on the health of PLWH. A greater length of time on ART medications showed fewer comorbid health problems, and greater social support had better physical functioning (McInerney, et al., 2008). PLWH have expressed their understanding and perception about the living with HIV/AIDS. Farber, Mirsalimi, Williams, and Stephenmcdaniel (2003) investigated the meaning of living HIV/AIDS from their perspective, its included as ability to maintain life functioning, describing QoL before getting sick and current hardships; isolation and the desire for connection with others, describing how perceived stigmatization, discrimination, and alienation affect QoL; anticipating the future, describing fears about future QoL; and reflection, describing the effect of vulnerable relationships and regrets on QoL. A study on quality of life of women infected by HIV in a Private Clinic in Bandung City found that more than 50% (n=45) of the respondents scored their quality of life as moderate (Figure 1), and their health status were perceived as average (Figure 2) (Dermawan, Ibrahim, & Nursiswati, 2013)

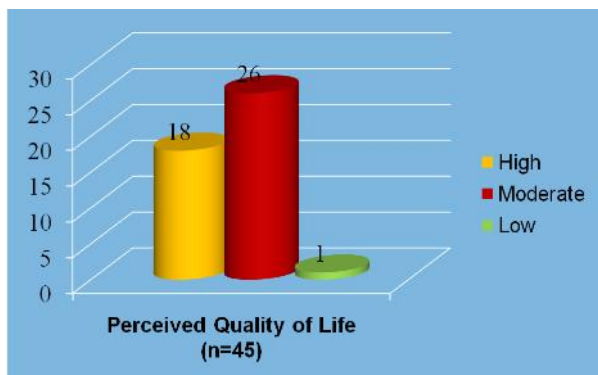


Figure 1. Quality of life

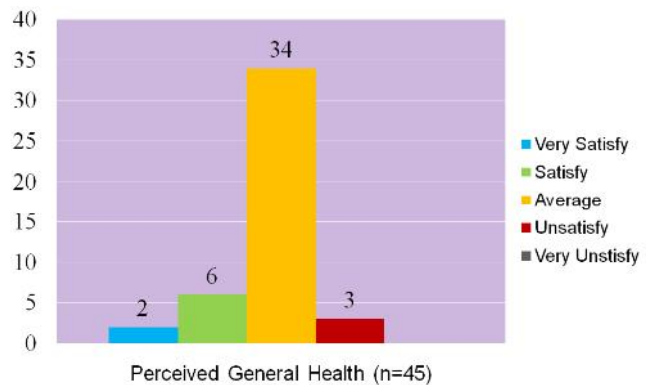


Figure 2. Perceived health status

CONCEPT OF SPIRITUALITY

For a long time, nursing literature concerning spiritual care was directed towards belief systems and religious practices. It was largely defined in a very narrow way as relating to religious functions and intervention, to calling the hospital chaplain. Regardless of that, nurses were often confronted with spiritual needs of the patients and recognized expressions such as "God must be punishing me" or questions like "Nurse do you think there is anything after death?" these expressions clearly indicated the need for spiritual care.

The term holistic care in nursing is one that many nurses who have trained or experienced will be familiar with (Harrison, 1993; Narayanasamy, 1996). In the present time, the nurses recognize the importance of considering the physical, psychological, social, cultural and spiritual aspects of patient's needs and care (Dossey & Dossey, 1998). There is evidence to suggest that the first four of these needs are recognized, taught and practiced in nursing care and curricular (Narayanasamy, 1996), but the aspect of spiritual care is one that is frequently overlooked and delegated to a religious leader (Govier, 2000).

Articles addressed to the concept of spirituality stress the difficulties in defining the term (McSherry & Draper, 1997; Oldnall, 1996; Ross, 1995). For example, McSherry (1998) points out that spirituality is poorly defined and understood by nurses. Oldnall (1996) concludes that the problem nurses have in arriving at a definition of spirituality is because of a lack of guidance from theorists and educationalists. The problem seems to be that while spiritual care is

considered to be a nursing responsibility, there is lack of clarity and agreement as to the meanings of spiritual, spiritual need and spiritual care (Greasley, 2001).

SPIRITUALITY AND HEALTH

The advancement of health technology tended to change the focus of health care from a caring, service oriented model to a technological and curative oriented model. As a consequence, health care providers give less attention to psychosocial and spiritual aspects of the patients than physical and technological aspects. In respond to this condition, nurses who believe in holistic care have attempted to balance their care by recognizing the linkage between spiritual and health. Nursing acknowledges spiritual care as an important and ethical obligation in holistic care (Ross, 1995). Yet, as medical advances make the nursing care more technological, the intent to provide spiritual care as part of holistic care is often not put into practice. Nurses who infrequently assess patients' spiritual needs may neglect spiritual care (Narayanasamy, 1996)

SPIRITUALITY OF PLWH

Spirituality and religion are often central issues for patients dealing with chronic illness. HIV/AIDS presents a unique set of existential challenges to patients as they confront issues of hope, death, grief, meaning/purpose, and loss. People with HIV/AIDS incorporate spirituality as a way to cope, to help reframe their lives, and to bring a sense of meaning and purpose to their lives in the face of devastating situation. Higher levels of spirituality have been associated with improvements in life satisfaction, functional health status, health-related quality of life (HRQoL), and overall well-being among PLWH (Cotton, et al., 2006). A study on meaning of living with, and caring for HIV /AIDS in Bandung City, using focused ethnographic approach (Ibrahim, Songwathana, & Bonyasopun, 2010). Two themes (meaning) reflected spirituality/religious belief of the informants:

1. Being tested of *iman* (faith) and *sabar* (patience) through the ups and downs of HIV-related suffering

“It is a great test from God, so I must receive it with patience. I actually do not want anyone to know about my story because it is such a sorrow to live with this illness...(tears are flowing down her eyes), my husband has gone already and left me with my little daughter in need of the necessities of life.” (K3)

2. Time for doing “*mawas diri*” (self-evaluation) and “*insyaf*” (repentance)

“I learned living with HIV is like being under the shadows of death. Many of my friends had died already. I thank God that He still granted me life though I am a sinful person. This time is the moment to “insyaf” back to the right way, and submit everything to God while striving to take benefits from this remaining life” (K10)

Whereas, caring was reflected in three themes below:

1. Accepting the reality of having HIV infection while “*pasrah*” (submitting self) to God

“Now, I couldn’t do much further, but accepting the reality as it is. This is my destiny as a consequence of my previous behavior. I don’t know how much of my life remains. Only one thing I care for myself by means of “pasrah” surrendering self to God and praying, I hope everything will be better.” (K9)

2. Striving to maintain health by performing optimum “*ikhtiar*” (effort) and “*do’a*” (supplication/prayer)

“I believe that everything is under the control of God, even our disease and our body, if God wish to heal our body, He has power to do so, we just follow His commands and pray for the best wish for us. So to me, care may imply optimizing “ikhtiar” (effort) to search for best treatment for maintaining health while offering “do’a”(prayer) to God.” (K2)

3. Gaining blessing of God by doing “*kebaikan*” (good deeds) and worshipping

“Thank God for allowing me to remain alive though I have done many mistakes in the past time. I observed many of my friends have already gone and they did not have time to ask forgiveness and doing “kebaikan”. So, to me caring could be meant as doing “kebaikan” and worship to compensate my previous mistakes and gain blessing of God. I believe that God is merciful and I hope He helps me.” (K1)

QUALITY OF LIFE AND SPIRITUALITY OF PLWH

A study on Quality of Life of Women Infected by HIV in a Private Clinic in Bandung City, using WHOQOL-HIV BREF Instrument (Dermawan, Ibrahim, Nursiswati, 2013) found that “meaningful life” was selected by respondents as the highest aspect of quality of life within spiritual dimension (Tabel 1).

Spiritual Dimension	Mean	SD
Meaningful life	3.27	0.86
Bothered of blamming HIV status	3.18	0.58
Worry about death	3.16	0.35
Fear the future	3.10	0.97

What can nurses do to improve QoL of PLWH through strengthening spiritual aspect?

Nurses' spirituality correlated with their understanding of spiritual care. Holistic care is possible only when the nurse is conscious about the self that is integrated and harmonious (Chung, Wong, & Chan, 2007). The level of spirituality/religion is associated, both directly and indirectly, with feeling that life is better now than previously (Szaflarski, 2006). Minimize the negative side of a patient's spirituality such as viewing misfortune as a divine curse, religious-based counseling, meditation, and forgiveness protocols may improve spirituality-based beliefs, practices, and coping strategies in positive ways (Cohen, 2006). Practise therapeutic communication that can create an opening for discussions with individuals about their spiritual beliefs and values;

Take into account the unique spiritual beliefs and values of individuals, families and communities during decision-making, treatment and care. Demonstrate sensitivity to and respect for diversity in spiritual beliefs, support of spiritual preferences and attention to spiritual needs as nursing competencies. Work collaboratively with other care providers to be attentive to the spiritual beliefs and values and the physical and psycho-social needs of individuals and families at all stages of life. Canadian Nurses Association (2010) recommended some strategies to improve quality of life through strengthening spiritual aspects as the following:

- Practise therapeutic communication that can create an opening for discussions with individuals about their spiritual beliefs and values;
- Take into account the unique spiritual beliefs and values of individuals, families and communities during decision-making, treatment and care
- Demonstrate sensitivity to and respect for diversity in spiritual beliefs, support of spiritual preferences and attention to spiritual needs as nursing competencies
- Work collaboratively with other health care providers to be attentive to the spiritual beliefs and values and the physical and psycho-social needs of individuals and families at all stages of life.

In addition, McEwen (2005) also proposed the strategies to improve quality of life through strengthening spiritual aspects which more focus on patient than provider as the following:

- Be accessible
- Discover a heal
- Provide support groups

- Reinforce current education
- Provide additional coping strategies
- Increase patient participation in decision making

Although, nurses have developed many interventions and strategies to improve patients' quality of life, barriers are often encountered. McEwen (2005) highlighted barriers to providing nursing care focused on quality of life:

- Lack of time
- Lack of valid tools
- Patient unwillingness to administer questionnaires
- Nurses not liking research
- Believing it could be invasion of patient's privacy

CONCLUSION

Quality of life has become important issue for people living HIV/AIDS as an indicator of health outcome after receiving treatment and care. Many ways engthening can be carried out to improve patients' quality of life. Nurses believe that patients are holistic with consisted of physical, psychosocial, and spiritual aspects. Spirituality has shown important role for patients who suffer from particular diseases especialy chronic diseases and life threatening diseases. Strengthening spirituality can be a strategic nursing intervention to improve patients' quality of life, since there were close association between spirituality and coping and feeling of satisfaction. Nurses need to understand deeply the concept of spirituality, and incorporate it into nursing care to improve patients' quality of life.

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