Spirituality in coping with HIV/AIDS

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This article creates a general framework for spirituality and HIV/AIDS as a chronic illness using a health care perspective. Spirituality provides an important function of helping people to find meaning and purpose in their lives. Various research findings that support the use of spirituality for coping with HIV/AIDS will be provided. Having been defined as one of the coping means with HIV/AIDS, spirituality is argued in this paper as an empowering resource in both well-being of the individuals with such a life threatening illness and their adaptation to the illness process. It has been observed in many researches held in varying research designs with various patient groups that as the functioning of spirituality in the patients with HIV/AIDS increases, depression, hopelessness and level of anxiety decrease; and adaptation, life satisfaction and quality of life proliferate. This paper argues it is extremely important that the professionals in the field of health support the patients who try to cope with especially the psychological and emotional effects of the illness process not only psycho-socially but also in forming meaning and goals about life as well as empower them spiritually.

Spirituality, HIV/AIDS, coping, medical social work

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INTRODUCTION

"Death could be born only where the meaning and purpose of life, and ultimately hope is exhausted."

Health is defined in recent years as a multi-dimensional concept which foresees a complete wellbeing not only physically, psychologically, mentally and socially, but also spiritually. Within this framework, besides some philosophers, many behavioral and social science academicians define health on philosophical grounds as the wholeness and especially harmony of mind, body and spirit, in which while the spirit controls the mind the latter controls the body. They even go further and describe the individual philosophically not as "a human being who bears spiritual experiences", but as "a spiritual being who bears human experiences" [1,2]. Therefore, it is considered that the spiritual area takes place among the high priority components in forming the wellbeing of the individual.

Apparently, embracing the individual's biopsychosocial environment, spirituality has begun to be included among the scales which are used to determine the variables such as quality of life and life satisfaction in various illnesses including mental disorders [3,4,5,6]. At this point the concept of spirituality needs to be clarified. One definition of spirituality puts it as the power beyond the individual himself/herself and his/her existence. Another defines it as the personal awareness covering both the physical and the metaphysical [7]. A more comprehensive definition of Elkins et al. (1988) includes such components as transcendental dimension, goal and meaning of life, basic mission in life, sacredness of life, material values, altruism, and idealism, etc. [8].

Naming spirituality and the spiritual arena of the individual as a phenomenon and restricting those with certain limits is quite difficult due to the vague and complicated nature of the concept. This difficulty results from the fact that spirituality is mostly individual based, subjective, unique and mysterious [9]. Moreover, what is common in all the definitions of the concept is to perceive life as "meaning" and "purpose".

Spirituality from the health perspective is defined as the individual's intrapersonal and interpersonal connectedness and his/her connectedness with transcendental purposes [10,11,12]; and defining the term in this way also includes the dimensions of spirituality. Built upon a three-dimensional scope, spirituality explains the very meaning of the individual's existence. Therefore, the point at which the individual grasps the meaning and purpose of life is his/her spiritual arena which may be either the subjective and esoteric relationship with God or a Higher Power, or a relationship of value and belief with nature, arts, music, family, and social environment, etc. [13]. Undoubtedly, aggregate of all those may be seen as the components which help the individual give meaning to his/her own life.

To put these dimensions into more concrete terms with the context of HIV/AIDS patients, intrapersonal connectedness is related to the individual's feelings on their own self. While the individual's love, acceptance and awareness of his/her own self increase, his/her spiritual wellbeing advances. The individual's following states of mind address the power of his/her connectedness with the self: (i) I feel myself peaceful, (ii) I have reasons to live, (iii) I have certain goals in my life, and (iv) I am satisfied with life.

Interpersonal connectedness refers primarily to the individual's family, and social and cultural environment including also peer groups and health professionals. Tolerant attitudes towards and strong links with the views, values and beliefs of these environmental factors strengthen the wellbeing of the individual in his/her spiritual area.

Transcendental connectedness, on the other hand, implies practices towards the believed Higher Power. These practices may appear as pray for "getting closer to the superior power" and reaching peace, religious rituals as worshipping, and/or inclination towards some spiritual endeavor with a strong bond of love (such as nature, arts, music, stars, and meditation, etc.).

The notion of connectedness is often encountered in the scientific literature on spirituality. Connectedness helps one set up links with sources stronger than him/her [14]. Connectedness within chronic illnesses in general and HIV/AIDS in particular creates opportunities for the individuals to get motivated and strengthened in coping with the illness. The search for meaning, on the other hand, is to form a goal and meaning about life within the context of the illness [14,15]. Attributing meaning to the illness process is also a quite effective coping mean for the individual; providing him/her with the possibility of a close and profound relationship with his/her own self, the Higher Power, and the environment, it helps him/her value life and construct an intellectual control on what is happening.

Connectedness and the search for meaning make up the fundamental components of spirituality in the HIV/AIDS context. What is at stake in this point is the fact that the individual both inclines towards either his/her deeps or a sacred power through the belief systems, and involves in a closer communication with his/her environment. Such tendencies facilitate the control of the illness for the individuals who are confronted with a dangerous life event as HIV/AIDS.

Elkins et al. (1988) developed a conceptual design on spirituality and included four assumptions in it: firstly, spirituality is a human phenomenon and located in every person potentially. Secondly, spirituality could be defined and explained by phenomenological approaches. Thirdly, spirituality is a human experience which includes values, attitudes, perspectives, beliefs and feelings. Finally, spirituality is not the same as religion [8]. In this phase, we need to clarify the structural differences between religion and spirituality.

RELATIONSHIP BETWEEN RELIGION AND SPIRITUALITY

Religion and spirituality is usually a matter of heated discussion. The literature often witnesses interchangeable uses of the two. The reason why spirituality had not long been included among the basics of the health paradigm (including physical, psychological, mental, cultural, and social aspects) is the fact that it is seen as analogous to theology's main subject, religion. However it should be noted that there is a conceptual difference between spirituality and religion, and the former is a broader concept which embraces the later [16,17].

Religion implies an institutional and complex structure comprised of beliefs, rules, rituals, and practices. It is essentially a moral institution and what lies in its essence is the faith in and submission to God who has the power to create. In addition, while religious beliefs and practices are based on sacredness to a greatest extent, spirituality focuses on the image of self [18].
Having a composition which also includes religion, spirituality refers to the entire individual experiences, thoughts and feelings. In this respect, it appears in all societies and different belief systems, and bears a universal characteristic. Nevertheless, it is possible to find some elements of religion in spirituality, and vice versa, which obviously addresses the fact that the two complete each other. Spirituality includes subjective experiences, thoughts and feelings on the mystery (and metaphysics) in human life. It is concerned with the individual's search for meaning and emotions about the dealings around him/her. Existentally speaking, spirituality both explains any life experience of the individual, and implies his/her search for and subjective relationship with God or higher power [19].

Having a quality beyond any religious belonging, spirituality includes even nonbelievers, and serves for the individual to attribute meaning to and set goals for life [20]. On the other hand, should spirituality have been defined as restricted and/or analogous to the faith in God or religion, it would not have been possible to witness the "spiritual" support of atheists, agnostics, humanists, and hedonists in forming their coping strategies [21]. Therefore, spirituality embraces all believers and nonbelievers.

Some spiritual enterprise include leisure activities in nature and strengthening of ties with the beloved, and lays stress on the individual's feelings of compassion, mercy, love, and altruism [22]. Another aspect of spirituality is its ability to explain the suffering and challenging situation via the individual's belief, and reach the conviction that it is ultimately not harmful [23,24]. At this point, suffering is considered as a valuable part of human life and real as much as joy, and happiness and pleasure are believed to be the gifts of physical and psychological pains.

In the last analysis, the following joint discourse of three celestial religions of the earth – Judaism, Christianity and Islam – as well as Buddhism and even Hinduism is extremely effective in re-explaining life and setting a spiritual wholeness by establishing belief, adaptation and inner peace in cases of HIV/AIDS and many threatening chronic illnesses: "human life is aggregate of sorrow, pain, challenges as well as gladness, happiness and peace."

**HIV/AIDS as a Chronic Illness**

Previously perceived as a fatal disease, HIV/AIDS has been included in the scope of chronic illnesses thanks to availability of protease inhibitors and the powerful combination of antiretroviral therapies [25]. Hence, the illnesses such as diabetes mellitus, cancer and HIV/AIDS, which create vital threats for individuals, require long run observation and protection, cause pathological transformations in physical appearance and physiological structure, and cannot be thoroughly cured but managed are by now classified within chronic illnesses. These illnesses profoundly influence the basic functions of the individual's life, and due to their unpredictable nature, inflame strong psychological, physical, sexual, social and economic pressures [26]. Having been confronted with physical and functional losses because of the illness, the individuals start evaluating their lives through a brand new perspective.

Besides, HIV/AIDS and other chronic illnesses may make the individual depend on others by impairing some of his/her functions, and this reveals an anxiety for the loss of self-control on life. Patients experience a fear of losing their economic independence and refrain from being a burden on the shoulders of their families [27]. They often suffer several psychological problems, too. Besides the pain of the illness itself, they face with some stressors as the anxiety of uncertainty and the change in the body image. Naturally, majority of these illnesses cannot be treated, but only managed. Such stressors cause a change in the patients' wellbeing and elicit an existential search for meaning and purpose which appears out in the form of the question, "what is the meaning and purpose of life for me?" [12,17].

Confronting a life threatening chronic illness whose treatment is not explored yet is perhaps the most distressful life experience. Researches have shown that individuals with HIV/AIDS suffer serious psychiatric disorders as well as various biological and psychosocial problems. Despite developments in antiretroviral treatments; mood, anxiety and substance abuse disorders in the patients with HIV/AIDS appear often among psychiatric disorders [28]. Furthermore, the stressors linked with the nature of the illness rigorously influence patients. Illness related stressors may include cognitive and motor decline, hospitalizations, invasive treatments, pain, fatigue, loss of mobility, sexual dysfunction and disinterest, body disfigurement, numerous unpleasant side effects from complicated medication regimens, financial burden, and the stress that accompanies facing one's own mortality [29].

Great majority of the patients who are hospitalized after a certain diagnosis experience an intense anxiety. This is a fear against their unknown and vague future caused by the illness. Furthermore, their existence in all senses is under threat [30,31,32]. This state pessimistically accelerates the progress of the illness.

Furthermore, HIV/AIDS greatly impacts populations that may already experience social stigma and discrimination [33]. Beyond the likelihood of facing multiple stigmatized identities due to race, gender, sexual orientation, and disability, many patients infected with HIV live in urban environments and may concurrently experience the stressors of poverty, unemployment, and exposure to violence and crime [29].

According to Sidell (1997), for an individual who suffers a chronic illness such as HIV/AIDS, the ultimate goal is to adapt to it, which is perhaps the most effective of all the coping struggles. On the other hand, the process of adaptation is quite complicated and covers multi-dimensional variables because every individual is influenced by his/her illness at varying levels [34]. However, universally speaking, what play an important role throughout the coping process are the support of the socio-cultural environment in the context of family and society as well as re-explaining the illness and the individual's self perception and evaluation.

It is observed after the diagnosis that some phases of general quality are achieved in the process of adaptation. The first phase is crisis which may also be described as the phase of loss. "Loss" means the loss of capacity, some functions, economic resources, and quality of life [35,36]. The second phase of the adaptation process comprises of the individual's confrontation with depression and emotional turmoil. Besides depression, fear, disappointment and anger are among the most intense feelings. The next phase addresses some changes in life style, everyday activities, and nourishment habits [35]. These changes indicate the fact that the illness is well managed and a process of adaptation has started. In the last phase, individuals are involved in a struggle for keeping control of their lives, and a process of empowerment starts for the individuals with HIV/AIDS [37]. Empowerment may become possible either via relationship with the environment through social support, or
with God or another Higher Power which is attributed sacredness through spiritual links.

**ROLE OF SPIRITUALITY IN COPING WITH HIV/AIDS**

In a longitudinal research by Szafarski, et al. (2006) direct or indirect effects of spirituality on the perceptions of living of 450 patients with HIV/AIDS were examined. The research in which extensive demographic data were collected and various instruments of measurement were used revealed that having learned that they carried HIV virus, one third of the participants first experienced a deep anxiety against this vital threat, then started adapting to this pressing life event by changing their style of behavior and thinking as the acceptance and especially spiritual inclinations increased. It was determined that re-explaining life, forming goals, and keeping hope play important roles in realizing this [38]. Therefore, when the individual confronts with intensive emotional distress, somatic illness or death, the spiritual dimension appears out as a coping strategy. In another research which is qualitatively designed by Pierson, Randall-Curtis and Patrick (2002) with 35 advanced AIDS patients, spirituality and various spiritual rituals were highlighted as a very important dimension [39]. Still another research consolidated the fact that greater spiritual or religious faith follows the diagnosis of HIV/AIDS [40].

Coping is defined as the prevailing cognitive and behavioral endeavor to meet certain external and/or internal demands caused by mostly psychological and emotional pressures [41]. It is possible to classify the coping behaviors and attitudes into two, namely, the solution oriented and emotionally motivated. The former constitutes the coping behaviors and attitudes on the main source of the problem and the latter constitutes the coping attitudes on the emotional effects of the main source [41]. In other words, coping attitudes are classified as active and passive. The active ones comprise of behavioral or psychological reactions aimed at either changing the stressor itself or demolishing it; and the passive ones include the acts which help avoiding the stressors. In coping with HIV/AIDS, as demanding direct assistance from the environment means active coping, adaptation to the physical and psychological change refers to the emotionally motivated coping.

Despite the fact that research literature covers a vast number of works on coping, majority of all are illness or stress based. The work on the role of religion and spirituality in coping with the illness, on the other hand, seems limited [42].

Two assumptions have quite dominantly triggered the neglect of spiritual dimension in researches. First is to argue that spirituality cannot be worked through scientific glasses. The second is the common belief that spirituality cannot be studied in a scientific frame because it is the very subject of theology. Here, the corner stone of the discussion is how to do the measurement [43]. Nevertheless, spirituality has been welcomed in scientific realm especially since the 1970’s following the changes in social science paradigm, the increase in the inclination of drawing a picture of the whole instead of generalizing the results, and assignment of the individuals not as the object, but as the subject of the research.

A considerable number of both qualitative and quantitative research with various patient groups show that an increase in the functioning of spirituality in the individuals with HIV/AIDS decreases depression, hopelessness, level of anxiety, suicidal thoughts, and expectation for a quick death, and stimulates psychological functions, adaptation to the illness process, life satisfaction, and quality of life [25,38,44,45,46,47]. Moreover, even the chronic patients who proclaim the negation of any higher power may raise a hope for survival via coping with the illness in his/her subconscious, and an expectation for a divine miracle.

In a quantitative research held on 201 patients with various chronic illnesses by Rowe and Allen (2004), the relationship between spirituality and coping was analyzed. A positive correlation was identified between the increase in the intrapersonal, interpersonal and transcendental connectedness of the patients and their psychological well-being and functions [17]. In another quantitative research by Cotton, et al. (2006), 450 patients with HIV/AIDS were followed 18 months and implemented various scales periodically. It was identified as a result that three-fourth of all thought “HIV/AIDS would strengthen their belief.” It was observed that majority of the participants experienced an increase in their hope for life, self-esteem and life satisfaction owing to spiritual coping strategies. In addition, rather low use of alcohol and substance was noticed among them. Finally, a negative correlation was found between the patients’ spiritual functions and their levels of depression and hopelessness [44], Sowell et al. (1997) carried a qualitative research with 27 women who were diagnosed as HIV/AIDS. It was affirmed in this research which is based on focus group interviews that the connectedness with primarily God or a Higher Power and their relatives is quite efficient in coping with the psychological effects of the illness, and by doing so, they re-explain their lives. Furthermore, it was also asserted that spiritual arenas of the patients are a quite useful and strong resource in protecting against social stigmas stemming from the nature of their illness and developing goals for future [45]. Therefore, it should be noted that spirituality exists in all patients regardless of the type of illness, the population group to be influenced, ethnicity, or religious orientation. All these studies prove that spirituality is a quite efficient instrument in coping with especially the psychological and emotional effects of HIV/AIDS.

Spiritual acts contain tolerant and pardonning attitudes, religious practices (worship, pray, etc.), and being bounded to primary relatives, other environmental actors, and every single living organism. These are quite strong coping resources for patients with chronic illnesses. In this sense, it is of assistance that physicians, nurses, social workers, psychologists, and other health professionals support patients in establishing stronger ties with these empowering sources.

Hafen et al. (1996) argue that threatening states of chronic illnesses such as HIV/AIDS provide a natural effect for the individual in re-interpreting his/her life and so experiencing changes in his/her spiritual arena [48]. On the other hand, individual reactions may differ in cases of crisis; the patient may not cooperate a harmony of mind, body and spirit, and achieve a positive development [49]. In this regard, it is mandatory for re-establishing the spiritual ties that the patients feel as if they keep control of their own lives instead of submitting to the illness process, which is only possible through spiritual development.

Hall (1998) explained the indicators of spiritual development. Individuals may devote themselves to God or Higher Power; and they may involve in intensive communication and relation with the environment. Consequently, individuals may form structural changes in their lives and
re-organize their personal values by capturing meaning and purpose in their illnesses [46].

Individuals may get tied up more with their religions which they think as a source of hope and power for the purpose of finding help in a chronic illness case even though they do not attribute much significance to it in their lives. Such a process was encountered in Ironson and the others’ longitudinal research (2006) on 100 patients with HIV/AIDS. This four year research revealed that the participants worshipped more after the diagnosis in order to get support of the belief in God [47]. Wulff (1997) describes the reasons behind the increasing inclination in religious practices, rituals and worshipping in two dimensions: communicating with a supra-natural power and setting up a personal relief and internal peace by this communication. Therefore, a reasonable form of coping with the illness will appear as a possibility [50]. In addition, the ones who do not believe may meet their spiritual needs by concentrating on their selves and inclining towards nature, arts, music, and their close relationships. To put it into more concrete terms, what comes to the fore is to hang more on to life and get satisfied more.

CONCLUSIONS

Some theorists conceptualize spirituality as an aspect to be measured in three dimensions: practices, beliefs and life experiences [43]. Practice refers to the observable behaviors such as praying, fasting, worshipping, and meditation, etc. Beliefs are the constructs in the transcendental dimension beyond intellectual knowledge and senses changing from culture to culture. Life experiences, on the other hand, address to the field which is the most difficult to measure and assumed sacredness to the greatest extent. In this scope, regardless of being religiously based or not, spirituality could possibly be explored in every system of thought or incidence.

Coping spiritually with HIV/AIDS has a universal worth for all humanity regardless of any religious criterion. In this sense, spirituality exists neither only in synagogue, church, mosque, and temple, nor in stars, music, dance, beauty of nature and any love relationship, but every single sphere of ordinary life.

In the final analysis, confronting with HIV/AIDS whose treatment is not completely known yet, but could only be managed keeps all individuals regardless of belonging to any one religion under strain by a feeling of losing the control in their lives. In this point, stimulating spiritual coping strategies help the individual empower himself/herself and form a personal wholeness by combining “biopsychosocial-spiritual” perspectives.

Therefore, being an indispensable part of one’s identity and world view, spirituality gives inspiring and empowering answers to the following existential questions for the individuals with life threatening illnesses such as HIV/AIDS: “What is the meaning of life for me?”, “what is my purpose in life?”, etc. Researches focused directly on the spiritual area and conducted on patients from different age groups with quite various illness types, mostly with the ones with HIV/AIDS show that spirituality is effective in perception of life as worth living.

While the professionals in the health field know the ultimate goals on how to improve the wellbeing of the individuals with HIV/AIDS intellectually, physically, psychologically, socially, culturally, and spiritually, the spiritual dimension among these is mostly neglected. Hence, spirituality needs to be re-built by using a scientific perspective without being restricted only by theological area, and become a proper instrument to be used effectively in professional implementation of the professionals in the health field. In order to realize this, it will be of great use to notice the support patients receive from the spiritual area in coping with the psychological and emotional effects of the illness, and including spirituality to the empowering process besides family and friends, etc.

References