

# *HIV/AIDS Women and Spirituality*

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**ABSTRACT:** The article highlights the care of women living with HIV/AIDS (WLHA) from a spiritual perspective. It focuses on the types of spiritual care received by the WLHA from caregivers especially from family members, health caregivers and faith community. Spiritual care integrates all aspects of a human being and it is not limited to activities emphasizing religion. It is any activity that “touches the spirit of another.” Spiritual care promotes connectedness with self, others, nature and the sacred. The article shows that prayer and trust in God/Divine are the two aspects of the spiritual support that the WLHA have acknowledged as having received from the health caregivers. Care for women’s spiritual needs could, therefore, be considered as an important component of overall healthcare quality.

**KEYWORDS:** Women, HIV/AIDS, caregivers, spirituality, prayer, God

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*“I hope for a day when every [c]hurch engages in open dialogue on issues of sexuality and gender difference. I hope for a day when every synagogue will mobilize as advocates for a global response to fight AIDS; when every temple will fully welcome people living with HIV, when every mosque is a place where young people will learn about the facts of HIV and AIDS. When that will have happen, I am convinced that nothing will stop our success in the fight against AIDS” (Piot 2004, 1).*

## Introduction

Today, the burden of living with human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) epidemic is a great challenge especially to the poorest—those who lack the power, resources, and knowledge to control their exposure to infection. The most vulnerable groups in human society subjected to HIV/AIDS are women and children. The experiences of discrimination and disempowerment, deprivation and dispossession, stigma and rejection provide the breeding ground for the spread of HIV/AIDS among women. Despite increased HIV/AIDS awareness and medical treatment, the horror surrounding this disease persists. The complexity of the illness shows that medical care alone is insufficient in coping with this condition. The nature of this illness, its development and the consequences require integral care and support.

The need of responding to ever growing multivariate caring context of women living with HIV/AIDS (WLHA) makes us ask: What is the significance of the word 'care'? What is the meaning of spirituality? What is the spiritual care provided by caregivers especially the family members, health caregivers and faith community to the WLHA? The reflection on the spiritual perspective of the care dealt with in this article is mainly based on a research done on the role of spiritual care of 600 WLHA in various HIV/AIDS care centres in Chennai, India.

## The Significance of "Care"

The word 'care' has different meanings, dimensions and values attached to it. Care is the term frequently used to explicate a number of meanings, such as affection, love, duty, well-being, responsibility and reciprocity. It is demonstrated through touch, action, emotion and bodily expression. Care is fundamental to an individual's identity as this is expressed in social relationships. Care can be part of formal, loving, and professional relationships. It is often based on a relationship, not only within a family context but also with others outside the family, in a healthcare or social setting. Although in

many ways it seems a vague and ambiguous concept, as a part of everyday life, often care is taken for granted (Philip 2007, 1).

The nouns *caregiver* and *care-recipient* are also loaded with meanings that entitle the former as powerful and the latter as powerless. As Harington Meyer, Heard, and Michel (2000, 2) suggest, the word caregiver implies "a free and willing service based on choice." According to Judith Philip (2007, 6), care involves tasks, roles and relationships. It is a disposition as well as practice. Care may also be reciprocal and interdependent rather than one-way. Care viewed over a lifetime will be different if it is periodic or continuous, or if it involves intense periods of time. The concept of care is also shaped by cultural values.

The concept of care is multifaceted. It includes philosophical, ideological, political, sociological, economic and spiritual aspects. It is difficult to set boundaries to care. Care can also be seen as a holistic notion pervading all human relationships and activities. It is the central part of life, binding together families, friends and communities. It is embedded in social relations. It is described as 'the engine of family life'. In other words, to have concern for the other would mean to experience a genuine feeling for the same. It is a kind of movement that touches the fiber of one's soul in which a person honestly feels honored and respected (Philip 2007, 16).

Therefore, care is an action undertaken on behalf of the one cared for, which aims at achieving optimal quality of life for the person through medical, psychological, social, and spiritual care and support. This care is given by various agents such as family members, healthcare givers, social workers, and faith community members throughout the entire course of HIV infection.

## Spirituality and Spiritual Care

In this article, the author treats 'spirituality' as a conscious relating of life issues/events to a supernatural reality. This conscious relating refers to the development of attitudes, moods, visions, motivations which animate people's lives and help them to reach out to increasing levels of experiences

of transcendence and freedom. This freedom encompasses all of physical, emotional, and mental experiences, and establishes relationships to something beyond (or greater) than oneself.

Spiritual care is a care that focuses on the spiritual dimensions of an individual. It is not limited to activities/practices emphasizing religion but is any activity that "touches the spirit of another." It is a transpersonal care and a pattern of evolving consciousness that increases levels of experiences of transcendence and freedom.

Spirituality has become a more and more widespread topic in contemporary models of healthcare. In fact, in the West more medical schools teach topics related to spirituality and health, and hospitals have started to develop spirituality programs to increase the delivery of compassionate care (Sloan, Bagiella and Powell 1999, 664-667). According to C.M. Puchalski et al. (2009, 885-904), spirituality could be defined as "the aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature and to the significant or sacred."

The patient's spirituality and religiosity have been shown to be correlated with reduced morbidity and mortality, better physical and mental health, healthier lifestyles, fewer required health services, improved coping skills, enhanced well-being, reduced stress, and illness prevention (Post, Pulchalski, and Larson 2000, 578-583; Koenig 2000, 1708). Many of these studies have been criticized, yet most physicians believe spirituality has a positive effect on the physical and mental well-being of patients (Sloan et al. 2000, 1913-1916; Larimore, Parker and Crowther 2002, 69-73). However, illness, especially terminal illness like cancer and HIV/AIDS, could trigger profound existential questions for the patient and family, as well as for healthcare professionals. Questions about why people suffer and die, or why people have to deal with unbearable stress are raised.

Some studies have shown that spirituality and religious beliefs and practices have an impact on how people cope with serious illness and mental/psychological stresses (Koenig, McCullough and Larson 2001). Spirituality

has given people a sense of well-being, improved quality of life, provided social support (Burgener 1999, 433-446) and has also affected healthcare decision-making (Silvestri et al. 2003, 1379-1382).

There are surveys indicating that patients want their doctors and caregivers to talk with them about their spiritual needs and integrate spirituality into their treatment procedures (McCord et al. 2004, 356-361).

HIV/AIDS Palliative Care Guidance states that spiritual care addresses the major life events that cause people to question themselves, their purpose and their meaning in life. Therefore, the interventions of the caregivers should be sensitive to the culture, religions, and rituals of the individual and community, and can include (but are not limited to) the following: Life review and assessment; counselling related to hopes and fears, meaning and purpose, guilt and forgiveness; and life-completion tasks (US Global AIDS Coordinator 2006). Spiritual care is defined within the contexts of religious practice, holistic care, and healing practices. It means incorporating religious practices or beliefs into the provision of care. Both patients and caregivers describe spiritual care as interventions that promote connectedness, a sense of feeling known and understood, as well as a search for finding meaning (Davis 2009).

According to Johanna Olson (2004, 7), spiritual care is to devote presence, attention and respectful assistance to helping people discern what is the meaning of life now, in this new environment of destruction and pain; and how they seek to live out that meaning as the recovery unfolds. Taylor (2002) has defined spiritual care as an approach used to integrate all aspects of a human being. According to McSherry (2007), spiritual care is similar to holistic care where the physical, psychological, social and spiritual dimensions of an individual are considered as a whole. For V. Carson (1989, viii) spiritual care is not limited to activities emphasizing religion but is any activity that "touches the spirit of another."

Furthermore, spiritual care could be defined as a care or intervention that promotes connectedness with self, others, nature and to the significant or sacred, as noted earlier. It is the way or the means through which individuals become capable of finding meaning and purpose in life. As a result, the quality of their life and relationships is improved.

With this brief understanding of spiritual care, we shall focus on the types of spiritual care received by the WLHA from the caregivers especially from family members, health caregivers and the faith community.

### Types of Spiritual Care Received by HIV/AIDS Women

#### *Family members*

Many women who become ill with HIV/AIDS will not be able to stay in hospitals, hospices or other institutions for a variety of reasons. Hence, the home-based care is to be given and the family members have a responsibility to take care of them. Home-based care is defined as the provision of health services by formal or informal caregivers in the home to promote, restore, or maintain the maximum level of comfort, functioning and health of WLHA, including care toward a dignified death. It can include preventive, promotive, therapeutic, rehabilitative, long-term maintenance and palliative care. Home-based care will also help remove stigma and discrimination.

One aspect of home-based care, largely neglected by most researchers, is spiritual care and support that are as important as physical care. Religious/spiritual activities undertaken by the caregivers on behalf of the one cared for could help boost their morale especially the morale of the persons living with HIV/AIDS. This kind of spiritual care and support could be best provided by the family members who are close to those living with HIV/AIDS (Limanonda 2003, 18). It is often family members that individuals with HIV/AIDS turn to for help and support, especially when the healthcare system cannot meet all their needs (D'Cruz 2004, 413-434). Bhassorn Limanonda says that it is important to understand the introduction of family-based care into the existing healthcare system. It does not mean totally transferring all responsibilities or imposing the burden of care to families. Rather, it involves attempts by the government to create more involvement of the family in the caring process and to provide moral support for people living with HIV/AIDS (PLHAs) (Limanonda 2003, 14).

As per the results of this research, there are different aspects of the spiritual care that the family members provided to the WLHA. Studies on the influence of religious health intervention, such as the patient's own prayers (Wilson et al. 2000, 817-822), other people's prayers (Masters et al. 2006, 21-26), multireligious healing services related to the hospital (Dann et al. 2005, 230-235), the importance of participation in faith-related support groups and psycho-analytic support groups with religious support (Breitbart 2002, 272-280), and conversations with chaplaincy health team members (Iler 2001, 5-11) have been made.

In healthcare, prayer is increasingly used in approaches to healing. Studies showed that the use of prayer is related to specific health outcomes and is acceptable within the medical practice (Duckro and Magaletta 1994, 211-219; McCullough 1995, 15-29). Prayer was perceived as a helpful, direct-action coping mechanism and was independent of whether individuals believed that their lives were controlled by themselves or a powerful other. The importance of the study was that it emphasized the direct action of prayer that the individual used as a coping strategy.

With respect to this research, the responses of the research participants highlight the following as the spiritual support of the family members given to the WLHA. Majority (65.8 percent) of the respondents interviewed agreed that *making vows* and *doing pooja* and *undertaking pilgrimages* (64.5 percent) and *praying* (72.2 percent) for healing of the WLHA are the spiritual supports that the family members offered to the WLHA. Thus, among the above four spiritual support provided for by the family members, prayer is the most valued spiritual support provided to the WLHA. This result can be substantiated by a paragraph taken from one of the in-depth interviews:

*"It's my mother who taught me to keep prayer as a part of my daily life;"*

*"It is in the family I learnt to pray daily and I do it much more in difficult times;"*

*"I have seen some very tough moments in my life; it was my mother's prayer for me that got me through those times;"*

*"I am a Christian, I would like to pray with my family members, but often those moments of prayer were moments where I could shed a lot of tears silently and once the prayers were over, I felt relaxed;"*

*"I consider the loving acts of my mother in giving me medicine and food at the right time, as acts of God [H]imself working through her. When I am depressed and become moody she encourages me, too."*

From the description by the participants, it clearly emerges that the spiritual support given by their family members are, indeed, integral to their lives. Besides, it is noted that some of the patients strive to make the care given by their family members as the central part of their lives, while others try to find balance. However, there is no doubt that the spiritual support of the family members is clearly an important determinant of the well-being of WLHA.

#### ***Health caregivers***

Researchers claim that a relationship is the pivotal point around which spiritual care needs to be given to terminally ill patients. However, they have also called attention to a mismatch between patients' expectations and understanding when it comes to spirituality, and what medical and family caregivers offer. There is a need for spiritual care, as many patients report about insufficient understanding of existential and religious issues when in contact with healthcare professionals (Manohar 2010).

Physicians also view religion and spirituality as a barrier when it impedes medical recommendations as a bridge in helping families answer questions that medicine cannot (Sreeraman 2009). A 'spirit to spirit' framework for spiritual caregiving respects individual personhood. This was achieved in the way physical care was given by focusing on presence, journeying together, listening, connecting, creating openings, and engaging in reciprocal sharing. When the health caregivers of this research were asked what type of spiritual care was given to the WLHA, they have listed the following.

Studies show that emotional and spiritual needs have a profound effect on patients' health outcomes, therefore deserving the attention of healthcare

professionals (Clark, Drain and Malone 2003, 5). Prayer has been classified as a spiritual treatment modality in the category of mind and body control by the National Centre for Complementary and Alternative Medicine (NCCAM) and is frequently used as an intervention in holistic nursing practice (Dossey, Keegan and Guzzetta 2000). Besides, prayer is the most universally recognized religious practice (Levin and Taylor 1997, 75-88). According to Hughes (1997, 318-326), individuals do strongly believe in a supreme being who is willing to listen to supplications from a pure heart and may also be inclined to grant favorable outcomes to those who pray.

With regard to the spiritual support of the health caregivers to the WLHA, the research showed that more than half of the research population agreed that praying for healing (69.3 percent) and teaching to trust in God/Divine (57.8 percent) are the two aspects of the spiritual support that the WLHA have acknowledged as having received from the health caregivers. Actually, a participant of an in-depth interview spoke about the spiritual support that she had received from her healthcare provider in the following words:

*"My nurse would always talk to me with kindness and enquire of me how I'm doing; she's somebody who cares. She teaches me how to manage with illness. She kindles in me a positive outlook on my life. I know that she is praying for me and supporting me always."*

Here, too, prayer seemed to be one of the most provided spiritual supports of the caregivers to the WLHA. Also here, one can find that the care the WLHA received from the health caregivers is an important spiritual care.

#### ***Faith and religious community***

Religion is an important part of the daily lives of most people in India. There were a couple of advocacy efforts at the national and regional level to increase the involvement of faith leaders and faith-based organizations (FBO) through conferences and round table discussions (RTDs). The majority of them address advocacy and HIV prevention with training and sensitization of religious leaders, awareness generation and working with orphans and other vulnerable children. The progress report on the Declaration of Commitment

on HIV/AIDS at the United Nations (UN) General Assembly Special Session on HIV/AIDS held in New Delhi states that there has been a mixed response from the FBOs (Ungass India Report 2005, 27). On the part of the Hindu religion, a work entitled *HIV/AIDS—The human dimensions: Voices from the Hindu world* is one of the earliest initiatives to look at the human (religious) dimension of HIV/AIDS (World Conference of Religion and Peace, n.d).

The Catholic Church in India developed the Catholic HIV/AIDS Policy in 2005 (Catholic Bishops' Conference in India, 2005). The policy strongly advocates nondiscrimination, compassion and a proactive role for church-based organizations in addressing issues around HIV/AIDS with a focus on care and support services for people living with AIDS. The National Spiritual Assembly of Baha'i (NSAB) India implemented a comprehensive adolescent skillbuilding program that includes HIV/AIDS in Delhi (The Baha'i Community of India and HIV and AIDS Prevention 2009).

The Christian AIDS Network Alliance (CANA) and other FBOs which had worked on HIV prevention served as a resource center and now conducted training, advocacy and action research. The National Council of Churches in India (NCCI) organized programs on HIV/AIDS prevention and education targeting different audiences, ranging from followers, to pastors, school children and PLHAs. The Emmanuel Hospitals Association's (EHA) work on HIV/AIDS focused its attention on the northeastern states of India, implementing services to drug addicts, truckers, and sex workers (National Council of Churches in India 2009).

With regard to Islam, it is said that the Islamic scholars and priests in the Himalayan State of Kashmir have come at the forefront to combat HIV/AIDS. Through their sermons, they now build awareness about HIV/AIDS (Ungass India Report 2005, 25). It is also stated that Mata Amritananthamayi Math is initiating a hospice for people living with AIDS near Trivandrum, Kerala. So, too, is the health network of Rama Krishna Mission in Tamil Nadu (Ungass India Report 2005, 27). Thus, there is a response on the part of the faith community to combat HIV/AIDS. At this juncture, it must be pointed out that the research, done in response to the care given by the faith groups to the WLHA, has come up with the following results.

HIV epidemic is an “exceptional” public health emergency requiring an “exceptional” response from all sections of society, including that of the faith communities. While significant progress has been made with the provision of life-prolonging and life-enhancing combination of antiretroviral therapy to those who need it, even in low- and middle-income countries, the annual HIV incidence far outstrips the reduction in HIV-related morbidity and mortality in such places. The action of FBOs in this field is often misunderstood and undervalued (Vitillo 2009, 77-84).

An article by Vitillo (2009) attempts to demonstrate the key contributive response by people of faith to the global HIV pandemic. Independent evaluations and statistical data regarding the level and quality of faith-based engagement in this field are presented in order to demonstrate that FBOs are lending exceptional energy, expertise, and experience in order to achieve the international commitment to advance universal access to HIV prevention, treatment, care, and support (Vitillo 2009, 77-84).

However, the WLHA of this research have said that the members of the faith community *do not pay regular visits* (74.5 percent) to their families. The WLHA have been *accepted into the community place of worship, prayer and celebration* because their HIV/AIDS status are not known; had their identities been revealed, probably they would not have been accepted (77.2 percent). Thus, the responses of the WLHA reveal the inadequate interventions of the faith community to the spiritual needs of the WLHA.

From all this, the author makes a clear conclusion that the spiritual support of the faith community to the WLHA is not at all sufficient.

## Conclusion

Evidently, there is a link between spiritual needs and spiritual care. The care that women received from the caregivers, especially from the family members and the health caregivers, revealed that spiritual care and support are two of the important aspects of care. However, the research has shown that the response of the faith/religious community to the care of WLHA is inadequate. This calls for an undaunted effort on the part of the faith-based community.

This effort will be made possible only if the expression used in South Africa called *ubuntu* translated as 'a universal bond of sharing that connects all humanity' becomes true; "You are my sisters and brothers, whether you consider yourself a Buddhist, Christian, Hindu, Jew, Muslim, or agnostic, man or woman and we must treat each other as such... We must stand shoulder to shoulder, heart to heart, in the fight against HIV/AIDS" (The Global Health Council 2005); if the words of Blessed Teresa of Calcutta: "A person infected by HIV/AIDS is Jesus among us. How can we say 'no' to (h)im!" is taken seriously; if the vision of Blessed John Paul II (1995): "The battle against AIDS ought to be everyone's battle...I...ask pastoral workers to bring to their brothers and sisters affected by AIDS all possible material, moral and spiritual comfort. I urgently ask the world's scientists and political leaders, moved by the love and respect due to every human person, to use every means available in order to put an end to this scourge" becomes a reality.

As we have seen earlier, the response to the spiritual needs of the WLHA could come from different agents such as family members, health caregivers and members of the faith community. It is pertinent that the family members, healthcare providers and members of the faith community be cognizant of the spiritual component of HIV/AIDS and respond to the spiritual needs of the WLHA. Thus, the response of care for women's spiritual needs could, therefore, be considered as an important component of their overall healthcare quality.

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