

# **SPIRITUALITY AND DEVELOPMENT IN A MARGINALIZED COMMUNITY: A STUDY OF PEOPLE LIVING WITH HIV IN KATHMANDU AND POKHARA**

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## **ABSTRACT**

Spirituality and development are intrinsically related. People living with HIV (PLHIV), who make up a marginalized community, are discriminated against by family and society. There is a dearth of studies on how people living with HIV use their faith to go ahead in improving their quality of life, especially in the context of Nepal. This study attempts to examine the lived experiences of PLHIV in relation to their spirituality and development. It follows a qualitative research methodology, based on in-depth interviews with PLHIV in two cities of Nepal: Kathmandu and Pokhara. PLHIV give credit to God for improving their quality of life, by helping them find a job and/or re-imagining their social status through networking. This paper concludes that spirituality and better quality of life proceed side-by-side in marginalized communities, especially for PLHIV, both in Nepal and in other Asian countries with similar socio-cultural contexts.

## **Background**

From time immemorial, people have used their consciousness to seek the infinite, or have realized the cosmic entity as a result of their religious and spiritual efforts. Human beings use their physical bodies to attain spiritual power and a sense of spirituality. Spirituality is generally thought to be a path of longing for God, irrespective of people's different religious affiliations (Watch Tower Bible and Tract Society of Pennsylvania 2006). It is believed that longing for God is a way of improving our health of both body and mind, and also of attaining spiritual wellbeing. Therefore, those people who make use of their consciousness, and follow religious and spiritual paths find themselves having healthier and better lives (Sarkar 1998), even though they might follow various ways, such as visiting temples, churches, or mosques, and a variety of practices, such as worshipping, meditating, practicing yoga, and so forth. Pursuing a religious path as described above is not only a way of attaining spiritual health, it is also a way of making the human body and mind much healthier, thus making day-to-day human actions more effective (Labbs 1995).

Nepal is the birthplace of many saints, famous for religious teaching both inside and outside of the country. For example, the birthplace of Maharishi Ved Vyas, known as a scholar of the Hindu religion, is considered to be in Vyas Municipality in Nepal. He was the writer of eighteen *Purans*, or Hindu religious books (Van der Geer, Dermitzakis, and de Vos 2008). Likewise, Gautam Buddha was born in Lumbini in Nepal, before becoming famous for originating Buddhist philosophy (Khetan 1996). These Hindu and Buddhist philosophies became extremely famous, not only in Nepal, but all over the world. Other religions, such as Islam and Christianity, have also been



followed in Nepal for a long period of time (Central Bureau of Statistics 2012; Dahal 2014). Thus, people use religious and spiritual practices in one way or other in accordance with their own beliefs and traditions.

Nepal is multi-cultural, multi-ethnic, multi-lingual and a religiously diverse country. Despite the present-day existence of tolerance toward one another's religions, prior to 2007 the country was officially a Hindu kingdom. The overwhelming majority of people in the country are Hindu. According to the 2011 census, 81.3 percent of the Nepalese people were Hindu, followed by Buddhists at 9 percent, Muslims at 4.4 percent, Kiratist (an indigenous ethnic religion) at 3 percent, and Christians at 1.4 percent (Dahal 2014). In 2007, the interim Government of Nepal declared the country a secular nation. Both Hindus and Buddhists usually accept each other's practices and many people follow a combination of both religions. Likewise, other religious people celebrate and practice in their own ways.

The basic premise of this paper is that spirituality is not only a way of gaining a sense of well-being in relationship to God (a vertical relationship), but is also a means of obtaining a sense of life purpose and life satisfaction (a horizontal relationship). Indeed, happiness is derived from getting what one desires. Generally, people have two major goals in life: one is to obtain health of physical body and mind, along with basic human needs, such as food, shelter, and clothes, and the other is to obtain a sense of well-being in relation to God. Out of this background, an attempt is made here to examine the lived experiences of PLHIV, a marginalized group of people in Nepal, in relation to their religious practices and their quality of life, and in terms of their spirituality and development, using a qualitative research approach.

It might first be helpful to link this article with my earlier essay on identity that deals with spirituality and identity reconstruction, so that readers may form a clear understanding of spirituality and identity reconstruction in tandem with spirituality and development. The earlier article focuses on spiritual practices and lived experiences in terms of a fluidity of identity that moves from spoiled identity to identity reconstruction. In that paper there is an attempt to address how PLHIV feel and how HIV negative people treat those with HIV, given identity is not a single phenomenon. By contrast, this paper deals with spiritual practices and their lived impact on quality of life, focusing on the overall development of an individual living with HIV, irrespective of questions of identity.

## **Terminology**

The term spirituality is associated with the colonization of religion by psychology and is perceived as synonymous with religion (Doherty 2003; Ferm 1963). In any event, in this study, the term is used as a symbolic word for all religions, while well-being is defined as a state of balance between the dimensions of the physical, social, spiritual, ecological, and psychological (Adam et al. 2000). Taken together, spiritual well-being is viewed as a sense of peace and contentment stemming from an individual's relationship with the spiritual aspects of life. Likewise, development is positive change in people's lives, leading to better quality of life. Most participants in this research give the credit for this to God. A marginalized group of people refers herein to those people who have been living with HIV and have been stigmatized and discriminated against in family and society. (HIV is considered a culturally sensitive issue in Nepal.)

## **Conceptual Framework**

If we look at spirituality, health and development in a global context, we find they are intrinsically related. Along with global modernization and urbanization, spiritual, religious and cultural values are gradually declining, especially among young adults. Many people are too immersed in the modern materialistic world, while spiritual, and religious and cultural values are

retreating into the shadows. Spiritual and religious teachings are needed now more than ever. Expanding these teachings in Nepal and even in the global context, with courage, strength, compassion and grace, is extremely important during these times. By connecting to our inner strength and elevating our consciousness as living beings, it is possible to support people in need with courage, love and compassion (Sarkar 1998). In order to build these qualities in human beings, this study seeks to dig out spiritual and religious practices along with their impact on physical health and spiritual wellbeing. Given humans are indeed superior to any creaturely beings in existence, their role and responsibility should be greater than that of other creatures in this world: i.e., to make themselves happy and to make others happy by supporting them in need. Sarkar states his view on how people can become happy through a manifestation of consciousness in this way:

Human beings are the highest evolved beings. They possess clearly reflected consciousness and this makes them superior to animals. No other being has such a clear reflection of consciousness. Human beings can distinguish between good and bad with the help of their consciousness, and when in trouble they can find a way out, with its help. No one likes to live in misery and suffering, far less human beings, whose consciousness can find means of relief. Life without sorrow and suffering is a life of happiness and bliss, and that is what people desire. Everyone is in quest of happiness; in fact it is people's nature to seek happiness. (Sarkar 1998, 1)

The main root of religious thinking originates from the fear of death; the desire for life after death; and reasoning and logic regarding good or bad deeds (Sarkar 1998). The longing for life or fear of death are the cornerstone of religion, which is why most of the primitive religions worship very basic things like fire, sun and moon. This is because for early people, who were living in caves, for example, fire offered an important protection against wild animals, especially in the night. It is thus obvious why fire has a sacred position in most ancient civilizations. Likewise, other primitive peoples regarded different natural forces, such as the sun, the moon, and the stars, as important deities or gods, whom they thought protected them, and so they worshiped them. These types of practices or nature worship religions were prevalent in most ancient civilizations. Every individual's spiritual well-being develops in accordance with the principle of synergism, which means the domains of spiritual well-being both build on one another and build one another up (Fisher 1999). In this synergism, the central role belongs to the transcendent (Ellison 1983). Spiritual well-being is also externally integrated with physical well-being and psychological well-being.

Irrespective of any particular religion, spirituality is considered to have a positive role in every walk of life, as it teaches us humanity and the necessary qualities of human life. From time immemorial, people have considered God a supernatural power who is invisible, but who controls human life based on the work done in past and present lives. The good deeds we do in our lives are considered virtue, and the bad are considered sin, and for the particular individual these open up either heaven or hell. It is also believed that people gain supernatural power given by God through their bodies. Meditation and yoga are ways of achieving higher consciousness, transcendence from the physical body, and life on a spiritual realm.

This study follows Goffman's theory in relation to the stigmatization and discrimination attached to HIV, as this theory relates to various strategies for greatly reducing such negative reactions. This process of reducing stigmatization and discrimination helps in achieving positive changes in the lives of PLHIV after being diagnosed. Likewise, this study also follows the World Health Organization (WHO)'s conceptual framework with regard to Quality of Life (QOL), including Peterson and Roy's three major pathways for obtaining better health. According to WHO, QOL is defined as a person's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns (World Health Organization, Division of Mental Health and Prevention of Substance Abuse 1997).

Likewise, Peterson and Roy (1985) state that there is a connection between religiosity and spirituality and better health. They suggest three major pathways for how religion and spirituality play a role in people's lives as follows: 1) religiosity and spirituality offer hope, comfort, and optimism, 2) they provide meaning and purpose to individuals concerning their existence, and 3) religious participation can provide social support through interpersonal relationships that offer encouragement and sympathy.

## **Data and Methods**

This paper follows a qualitative research methodology as it seeks to understand and describe how people feel, think and behave within a particular socio-cultural context (Bryman 2012). The study of HIV and AIDS in Nepal is considered a sensitive area. I have chosen a path of data collection through organizations working in the field in order to maintain confidentiality of both participants and organizations. I use pseudonyms for thirty-three interviewees, and a numerical order—one, two, three and so on—for eight organizations from which data were collected. From an understanding of qualitative research, this study utilized a semi-structured questionnaire with a framework of various themes to be explored, drawing on the lived experiences of research participants after being HIV diagnosed. Ethical approval was gained from Massey University, New Zealand, as study institution, and also from the Nepal Health Research Council (NHRC) in the home country, where field work and data collection took place. I, as a researcher, was fully involved with the interviews, face-to-face with interviewees, collecting data using open-ended questions and understanding their lived experiences of spiritual practices and their attainment. After completion of data collection, the field data were translated from Nepali into English. This study used a thematic analysis to examine the responses provided by participants in the research field. In this study, themes and sub-themes were thus generated to analyze field data about Nepalese socio-cultural perspectives in relation to spiritual practices and their attainment.

This study used a thematic analysis, examining the responses provided by participants in the research field. In this study, I read the translated Nepali-English raw data several times and coded English texts using different themes while analyzing the data. Thereafter, the different themes were classified into main themes and sub-themes of spirituality and development as per the objectives of this study. After identifying the main themes and sub-themes, I analyzed the field data based on Nepalese socio-cultural perspectives, in relation to the participants' spiritual practices and their lived experiences, especially for attaining quality of life. This study has been based on an inductive analysis of participants' lived experiences in accordance with a qualitative research approach (Shank 2006).

## **Results**

Nepal has multi-religious and multicultural societies, where, according to the 2011 census of the country, 123 native languages and 125 castes/tribes are in existence (Central Bureau of Statistics 2012). From a humanistic and social work perspective, people seem to be proactive, irrespective of their religious beliefs, in saving other people's lives when something bad happens. In this matter, Nima, one of the participants, told of his lived experiences of being fully supported after having an accident while heading elsewhere in Pokhara by motorcycle. He shared his experiences of being saved in this way:

At that time, all the people in Pokhara had given up hope of my survival. I was told about my HIV in hospital, [in] Kathmandu. None of the hospitals in Pokhara would take me in, so I was taken to Kathmandu. I was too gravely injured. I had a broken neck and an injured spine. At hospital, the doctors said that I could be saved by being

given oxygen for twenty-four hours and that I should be rushed immediately to Kathmandu. At that moment, my guru (who is a Rotary club member) and my well-wishers from Pokhara raised money and took me to Kathmandu. In the three weeks of my hospital stay there, 900,000 Nepali rupees were spent on my treatment. After that, I was discharged. There I was informed that I was HIV positive. . . . After three weeks, I was shifted to [a] hospital in Pokhara. During my stay, through the doctors, I came in contact with this institution (venue of interview). In [this] hospital, I was told that I was HIV positive and they suggested that it would be good for me to contact an institution that dealt with the issue of HIV. (Nima, Male)

Religious people often consider other people (or other religious people) suffering a disease or an infection or an injury with a positive attitude and a humanistic approach. HIV knowledge is very important when dealing with people living with HIV. Nima further shared his experiences of how people with knowledge of HIV treated him well:

He [a religious teacher] was from Malaysia. A short while back, we gave yoga training to more than 500 people in Gharepatan, Pokhara. At that time, my gurus also came from abroad. They know I am an HIV positive. They don't look at me from a negative point of view. They never said that it [HIV] was a big, dreadful disease. They and their doctors say that by eating from the same plate, by sleeping together, by walking together and sharing clothes, this disease is not transmitted. (Nima, Male)

Many people in Nepal understand that there are causes and consequences for everything we do in life. It is also believed that the present life's daily occurrences are also the outcome of the karma from our previous life: what we did, good or bad. Furthermore, people attempt to do good works to attain salvation. They pray to God to make their present life better and they even pray for their future. In this matter, Gita shared her experiences of spirituality and wellbeing in the present and for the future and recounted how she consoled herself in this way:

I think [Good or Bad Karma], depends upon our previous life, what we have done—good or bad works. This life is also related to our past life. Maybe I did bad karma in the previous life and got such a disease (HIV). It may depend upon time of birth. . . . I believe in GOD. I pray to GOD and my life is getting better than before. In the beginning, people used to say that people with HIV die soon as there is not any medicine to cure it. But these days, there are medicines to give pain relief and a longer life. (Gita, Female)

Gita added one more experience that shows how God sees everything what we do in our life. We do not need to wait a long time for the outcome of our work. We do good work in our life and we have a good outcome immediately in our present life. She shared her personal experiences in this way:

I feel much better than before. My daughters are also convincing my family members (about HIV) at home. I looked after my daughters well when they were small. That's why they treat me well now. GOD shows everything we do in our life immediately. Imagine how I survived, caring for my small son and daughters after my husband's death. (Gita, Female)

Spirituality teaches people that it is necessary to overcome discrimination based on class and caste. To make all people equal, we need to treat them equally, so that everyone can have an opportunity to uplift themselves, and search for possibilities based on their capability. Nima added the following in this regard:

The rich have indeed subjugated the poor. If the rich worked for the benefit of the poor, the distance between them could be covered; even the poor would nurture some hope. Our foreign gurus have made schools in the Ghandruk region [one of the hilly regions of Nepal] for the children of the poor, and have done a really good deed. But the poverty hasn't been alleviated, caste-based discrimination still exists. At first, this type of discrimination was rampant. Even when we were young, such things existed. They said that *damai/kaami/sarki* (the so-called untouchable caste) couldn't enter another's doorstep and they weren't allowed to. I didn't like it, because I believe that everyone is equal. I used to fight with my father and mother about it. We could play together with kaami/damai but we could not eat with them; we could not bring them to our homes. . . . When I used to return home after playing with the children of kaami/damai, after going to their homes, my mother used to sprinkle me with gold-water (water touched by gold). They used to say that by doing so, we would be purified again. If we ever mingled with them by mistake, the belief remained that one needs to be purified by sprinkling gold-water. (Nima, Male)

## Discussion

When it comes to issues of people living with HIV, gender, caste, and class have become intertwined. Consequently, such people face multiple problems in their lives. However, most of them have felt their health status improving following HIV treatment at the allopathic (western modern medicine) hospital in Nepal. When their health status improves, they are able to become literate through informal education programs launched by the government and non-governmental organizations, even after being HIV diagnosed and having to leave their homes due to stigmatization and discrimination. This has made it easier to find jobs in organizations working in the field of HIV, and in other places through their networks of people, either people living with HIV or those who are HIV negative. Ultimately, the processes of obtaining HIV treatment, informal education, and jobs, have simultaneously made people with HIV independent socially and economically, much like HIV negative people are. As PLHIV find their health status improving and as they become independent socially and economically, they find their stigmatization and discrimination to be considerably reduced. Some PLHIV have been reunited with their family members after reconstructing their identities, socially and economically, after migrating to urban areas due to the HIV stigmatization and discrimination (Aryal 2015). Most PLHIV give credit to God for their economic independence, for reducing the stigmatization and discrimination, despite the fact that they are HIV positive.

People in Nepal are taught to call upon God's name, as per their own religion, by the older citizens in their family and society. Hindus, Buddhists, Moslems, Christians and others—use different names, such as Ram, Krishna, Shiva, Buddha, or Allah. They often believe that calling on these names as per their own religious traditions provide them with positive vibrations that give them strength in their bodies and comfort in their daily activities. Furthermore, they also believe that calling on God's name is a way of reaching heaven after death. Most PLHIV in this study share this experience: "It comes from within. If I am in a trouble, I remember God and say, 'Oh, my God!'" (or Mira, Jwala, Sushma, Mamata, Nabin, Buddha, Basant, Rajesh, Nima, Min, Durga, Gita, Sarita, Laxmi, etc.). Indeed, these people consider God to be the ultimate friend in their lives upon whom they depend.

Spirituality is considered to have helped some participants in joining organizations that are working in the field of HIV and AIDS. Becoming economically independent was found to be a significant way of reducing stigma and discrimination. The participants prayed to God and attributed their success in finding a job to the grace of God. There are different kinds of people in society: some have positive attitudes while others have negative ones. Those people who have positive attitudes seem to be dedicated to the upliftment of marginalized groups of people like PLHIV. They support marginalized communities, providing services, money, and logistical

support, such as food, shelter, clothes, and so forth. It is also believed that helping a marginalized community with such services makes God happy. When God becomes happy with people's contribution a path to reach heaven opens up. Such people believe that they can obtain salvation after death takes place. This notion is deeply rooted in Nepal. Some people living with HIV shared their experiences of how they consoled themselves and their friends by functioning as social workers at an organization that in the field of HIV and AIDS. Anu, one of the female participants, shared her experiences through in this way:

At first I would think that I could not do anything, but later after I had training as an HIV positive person I became more familiar with persons in organizations working in the field of HIV. I had the chance to counsel my HIV-infected friends, thus giving them positive feelings by telling them that HIV is not as big an issue as people think. . . . Similarly I had the chance to share with many friends who have similar problems as mine. I had the chance to find many HIV infected friends; it is not just me who has this problem. I counseled them that HIV is not a very dangerous issue. We can fight HIV by taking good care of our health and with timely medication. In this way I developed positive feelings about myself and about my friends living with HIV simultaneously. (Anu, Female)

Exploring the lives of PLHIV at individual, family, and societal levels, reveals they have been able to develop their careers in multiple ways after acquiring HIV knowledge and treatment at an allopathic hospital, gaining an informal education, and obtaining jobs. With a multi-party democracy and republic, Nepal's government has focused on the upliftment of marginalized communities because of society's unjust treatment of those of untouchable caste, the poor, PLHIV, and people with leprosy. These groups of people find spirituality is one of the major determinants in improving their lives in comparison to the past. One of the female participants shared her experiences of the time she came to know that she had contracted HIV:

I think I was not born before being HIV positive, I was born only after being HIV positive. I had not seen any other alternatives, except weeping, after being beaten seriously by my husband. (Pratima, Female)

Later on, she had the chance to interact with organizations working in the field of HIV and AIDS. She then changed her philosophy in this way:

Now my philosophy of life has changed. An interest in doing social welfare has developed within me. . . . I now think that HIV is not the end of life for me, but a start. I was just concerned about my life before, but now I think about others. I have reached a very high level in life now.

Knowledge of a particular subject, such as HIV, is most important in changing someone's life. In linking religion (or religions) with development, every religion illustrates that true knowledge connects not only to individuals and families, but also to national life and the world. This knowledge generates a collective vibration among people at all levels—individual, family, societal, national and international levels. Indeed, spiritual and religious teachers, irrespective of whether they are Christian, Hindu, Buddhist, Moslem, etc. have taught that religious and spiritual knowledge make the family, society, nation and the world livable places. In this context, it is relevant to cite a statement quoted in a religious book, which considers knowledge a basic element in changing people's lives:

When true knowledge is achieved, then the will becomes sincere; when the will is sincere, then the heart is set right. . . . when the heart is set right, then the personal life is

cultivated; when the personal life is cultivated, then the family life is regulated; when the family life is regulated, then the national life is orderly; and when the national life is orderly, then there is peace in this world (Watch Tower Bible and Tract Society of Pennsylvania 2006, 181).

## **Conclusion**

This paper concludes that spirituality a powerful a tool for bringing positive changes in the lives of PLHIV, one of the marginalized groups of people in Nepal. Indeed, spirituality and development are intrinsically interdependent. Spirituality helps with development activities, and through these people in marginalized communities in Nepal and other countries with similar socio-cultural contexts attain quality of life.

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