

SPIRITUALITY AND IDENTITY RECONSTRUCTION IN NEPAL: LIVING WITH HIV IN KATHMANDU AND POKHARA VALLEYS

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ABSTRACT

Spirituality is an important means of reconstructing the identity of people living with HIV (PLHIV), irrespective of religious beliefs. Although there are some studies on stigmatization and discrimination attached to HIV and AIDS in Nepal, there is a dearth of studies on the role of spirituality in managing such stigmatization and on reconstructing the identity of people with PLHIV. This paper therefore investigates the role of spirituality in identity reconstruction. By following a qualitative methodology—in-depth face-to-face interviews with PLHIV sufferers in the urban valleys of both Kathmandu and Pokhara—the article investigates the role of spirituality in improving health, changing socio-economic status and reconstructing the identity of those affected. This paper has important policy implications for Nepal and for other countries with similar socio-cultural contexts with regard to PLHIV sufferers and other marginalised communities.

Background

Nepal is a multi-religious and multi-cultural country with 125 castes and tribes, and 123 languages (Central Bureau of Statistics 2012). Among the country's total population of 26.5 million, an overwhelming majority are Hindu (81.34 percent), followed by Buddhist (9.04 percent), Muslim (4.38 percent), *Kirat*, an indigenous religion, (3.04 percent), Christian (1.41 percent), with the remainder adhering to religions of various indigenous tribes (Central Bureau of Statistics 2012). Despite tolerance for one another's religious beliefs, prior to 2007, Nepal was officially a Hindu kingdom. In 2007, the interim Government declared Nepal a secular country. Both Hindus and Buddhists generally accept one other's practices and many people follow a combination of both religions. Likewise, others celebrate and practice religion in their own ways. In Nepal, people's lives are ruled by the concept that "God is everywhere and God sees everything," and people consider God a companion during times of either sorrow or happiness. Nepalese are taught about God from childhood and learn to pray for a better future. Their religious beliefs, irrespective of which religion they follow (and which have existed for centuries), seem to provide positive support for people, especially in the matter of helping and supporting other needy people in family and society.

There are main four caste groups in Nepal, namely, the uppermost rank of *Brahman*, followed by *Kshetree* (the second highest caste), *Vaishya* (the third caste group, which is considered lower than Brahman and Kshetree), and *Sudra*, the lowest and so-called "untouchable" caste (Dahal 2003; Hofer 2004; Jodhka and Shah 2010; Subedi 2010). Together with the classification of people into



Brahman, Kshetri, Vaisya and Sudra castes, people are now more recently also ranked according to class. This ranking is decided on the basis of background, employment and labour divisions, as well as societal perceptions of wealth (high class) or poverty (low class). Discrimination between caste, class and gender thus still exists in Nepal, especially in rural areas. Yet at the same time, religious and cultural beliefs are influential in improving communities that are marginalised because of caste, class, or gender, or because of the incidence of leprosy or HIV. From a cultural perspective, the general understanding is that everyone is equal, and should therefore be granted equal opportunities and rights. Furthermore, there exists also a strong cultural perspective that females, and poor and lower caste people should be given as much of a helping hand as possible for their betterment at every step of their lives.

The history of HIV in Nepal can be traced back to 1988. As of July 2016, there were 28,865 reported cases across the country (National Centre for AIDS and STD Control 2016). Among the total reported cases of PLHIV, there were 17,949 males, 10,824 females and 92 transgendered people. However, in 2016 the estimated number of PLHIV cases across the country was estimated to be nearly forty thousand (National Centre for AIDS and STD Control 2016). The reason for the difference between the reported and estimated cases of HIV and AIDS is that a significant number of PLHIV sufferers conceal their HIV status from family and society (Beine 2002; Neupane and Mishra 2014). The prevalence of HIV in Nepal is a gendered phenomenon, with more than three-fifths of the total reported PLHIV cases being male. This is probably due to both the volume of temporary male migrant labour into the country and poor investigation of the incidence of HIV and AIDS among females (New Era and SACTS 2009). The epidemic of HIV and AIDS in Nepal is attributed mostly to heterosexual transmission, although there is evidence of homosexual relations also contributing to the epidemic (National Centre for AIDS and STD Control 2016; Nepal 2007). Concerning the stigmatization, discrimination and life disruption that usually surrounds PLHIV, Nepal is no exception, since people consider HIV to be the result of extramarital sexual activities and drug usage, and these are activities that do not conform to normal Nepalese societal values (Family Health International 2004).

Nepal's relatively recent socio-political transition to multi-party democracy in the 1990s is presumed to have created a supportive environment for the transformation of the identity and status of marginalized communities in the country. The "People's War" (or "Maoist War") from 1996-2006 was later followed by a "second movement" in 2006, with the then underground Maoist party joining with most other political parties to fight against feudalism and the kingship regime. These political movements weakened the pillars of feudal Nepalese society, and gradually restored people's human rights by focusing on marginalised communities in order to bring about gender, caste, and class equality (Yami 2007). This study pertains to one of the marginalised and ostracised groups of people in Nepal—PLHIV sufferers—following the discovery of HIV in the country (Joshi et al. 2004).

Research Problem

In Nepal, cultural factors play a dual role—both positive and negative—in determining the identity of marginalized communities. In general, Nepali culture teaches the necessity for love, affection, respect, and harmony, as well as support for helpless persons in the family and society. In reality, however, in many cases the cultural practices are different. People are treated differently according to their gender, caste, and class. Males and those of higher caste and class are generally treated as superior, whereas females and those of lower caste and class are treated as inferior. These discriminatory cultural practices play a negative role in shaping the identity of marginalized communities. In this study, Hindus and Christians are the focus, since the overwhelming majority of the total population adheres to the Hindu religion, and Christianity increased at a much faster rate (268 percent) than any other religion during the period 2001-2011 (Dahal 2014). According to

the 2011 census data, the number of Christian followers in Nepal is 273,723. However, Dahal (2014: 22) makes the following comment:

...many Christian religion followers and associations are not satisfied with this number of the CBS [Central Bureau of Statistics]. While quoting an article of Subhas Sharma, Dhruvahari Adhikari (Kantipur 20 July 2014) writes that there are 1,000 Churches (Girgaghar), 805,000 Christian religion followers and 350 Christian mission offices, Bible colleges and Training Centres operating in Nepal.

This research begins from the basic premise that most previous studies of the Nepalese context have focused on a particular religion. There is, however, growing interest in spirituality, and its impact on the lives of people irrespective of religion, particularly in one of the most marginalized groups of people: those with PLHIV. There is very little research into the impact of spirituality on the lives of such people, especially in Nepal and other South Asian countries. With regard to those with PLHIV, there is “an endless process of negotiation whereby the individual’s identity is reconstructed” (Tsarenko and Polonsky 2011, 466). Most PLHIV sufferers believe that at every step of their lives, God is always a supporter. They are thus able to reconstruct their identities by adopting various means of managing stigmatization and discrimination. PLHIV sufferers often give God the credit for this transformation, regardless of whether they are Hindu or Christian.

In my own family background, I also had the opportunity to learn about poverty and its impact on identity issues. I was born and brought up in Dhading, one of the rural hills of Nepal, and despite being of the highest caste (Brahmin), my parents were illiterate, because of a lack of schools near the village and their very poor socio-economic conditions. Being the oldest son of nine children, from a very young age I was exposed to stigmatization, ostracism, and discrimination because of the poverty of our family. At the same time, however, I was also exposed to typical Hindu norms and values. My parents considered all nine children as gifts from God, as per Hindu cultural understanding. Despite our socio-economic condition, these religious values and norms made life more bearable at that time. I therefore developed a religious and spiritual inclination from a very young age, and to this day do not neglect any opportunity to visit spiritual teachers and study religious philosophies. The religious philosophies I have read have encouraged me to go forward in my life, spiritually, socially, and economically. The opportunities that I have been given so far, and the position and the respect I have managed to attain in society, I deeply credit to God. From my understanding of the religious and socio-cultural perspectives of the country and because of my own life history as a Nepali researcher, I am greatly encouraged to conduct this research into one of the marginalised communities, PLHIV, and explore how people reconstruct their identities and cope with various challenges after being diagnosed as HIV positive. This paper aims to challenge our concept of the identity of PLHIV sufferers as forever devalued, and argues that lives can be changed positively, from both health and socio-economic perspectives, if individuals, families, society and the various organizations in the field of HIV and AIDS all work actively together (Parker and Aggleton 2003). In this way, spirituality can be a powerful tool for improving lives, and for helping people forge ahead and cope with the many challenges of PLHIV.

Theoretical Framework

This study follows Goffman’s stigma theory, even though he developed his framework in 1963, before the diagnosis of HIV (Carnevale 2007). Goffman’s work is still important for understanding stigma because he considers how a person with a health deformity is discriminated against in family and society and how the stigmatized person then develops his or her identity through personal resilience and with the support of family and social groups (Burns 1992; Carnevale 2007). People who share the same stigma can provide one another with instruction on the “tricks of the trade”: i.e., how to navigate through society as a stigmatized person and how to

find a social sphere within which it is possible to feel “normal” (Carnevale 2007). Stigmatized people may become involved with a group of other people sharing the same disease, through which they can acquire skills for handling and interpreting their lives as substantially normal, and thus not underestimate themselves (Carnevale 2007).

Stigmatization, discrimination and disruption are part of the identity of PLHIV sufferers, an identity which then becomes “spoiled” (Anderson et al. 2008). Consistent with the existing stigma literature, such negative impact on human lives is termed a “spoiled identity” in this study also. “Transitional identity” describes the movement of those with PLHIV from a spoiled identity toward “identity reconstruction.” This movement involves positive change in their lives as they make “a transition to ordinariness after the diagnosis of a chronic illness” (Baumgartner 2007, 920). From this transitional identity, PLHIV sufferers then move further into identity reconstruction, managing stigmatization, discrimination and disruption more effectively as a result of better health and positive socio-economic change in their lives. In this study, this entire process is termed “identity reconstruction.” In the Nepalese literature, especially in the field of migration, the term “resources” is widely used to describe the availability of public services, overseas employment, and land in various forms, mostly in terms of economic opportunities, motives, and access, including aspects of economic family support (Subedi 1988).

Methodology

This study follows a qualitative research method in order to understand the kinds of experiences people have after being identified as HIV positive. Using a semi-structured questionnaire, I conducted in-depth face-to-face interviews with thirty-three participants from two urban locations, Kathmandu and Pokhara Valleys, the regions most affected by HIV and AIDS. The data for this study were collected through eight organizations working in the field of HIV and AIDS during the period July-November 2012, after ethical approval was granted by the host institution, Massey University (New Zealand) and the Nepal Health Research Council (Nepal). Because of the social and cultural issues of stigmatization and discrimination attached to HIV and AIDS, I maintained confidentiality carefully by using pseudonyms for research participants, and numbers, such as one, two, three, and so on, for organizations where I collected the field data. The snowball sampling method was used to recruit additional participants, based on information provided by earlier participants through the organizations.

The study follows a thematic analysis and takes a meaning-making approach. This approach allowed me to understand how those with PLHIV experience social stigmatization and discrimination, and how they manage these issues in their lives. During the course of the data analysis, this study adopted Bourdieu’s (1986) “forms of capital,” in terms of which one form of capital (e.g., social capital) can be converted into another form (e.g., cultural or economic capital). The categorization of forms of capital (social, cultural and economic) suggested by Bourdieu was applied to PLHIV sufferers. A PLHIV’s social capital (their nuclear and extended families, friends and other social networks), their cultural capital (knowledge/training), and their economic capital (employment, income, property) are interchangeable (Sen, Aguilar, and Goldbach 2010). Bourdieu’s ideas about capital have been widely extended to include access to resources such as social support in the field of health (Carpiano 2007). This formula has been applied in various ways in the field of HIV and AIDS, especially in terms of including access to networks of support people in social capital (Sen, Aguilar, and Goldbach 2010). Bourdieu (1986) also highlights the importance of reciprocity and association, i.e., the act of giving among equals often generates some sort of a return, whereas this same act among people who are perceived to be unequal can bind the weaker party (for example, a widow with HIV and her children) to the stronger party (e.g., her extended uninfected family members) and can create feelings of obligation.

Findings of the Study

Transitional Identity

Important ways of managing stigmatization and discrimination against PLHIV sufferers (even if they face their identity becoming spoiled), include developing migration strategies and pursuing effective treatment from various practices of traditional and modern medicine. Such strategies, for example migrating if something bad happens in family and society, help PLHIV sufferers move to a transitional identity. Likewise, when people undergo HIV treatment, their health and appearance improve, which ultimately reduces the stigmatization and discrimination in their lives. In the Nepalese context, where physical appearance is considered to be a measure of an individual's identity, a healthy physical appearance following HIV treatment is an important element in reducing stigma and discrimination, as well as reflecting an improving health status.

The research participants generally enjoy good rapport with those of their friends who are also living with HIV. These relationships help them develop migration strategies that protect them from stigma and discrimination in family and society should anything bad happen. There are examples of people who have already developed strategic plans of migration to cope with the expected social ostracism. They develop such plans in the course of their HIV treatment at hospitals in the cities and during their first stays at organizations where they form circles of friends also living with HIV. Sarita B, is separated from her husband, and, just as she imagined before going home after spending nine months receiving HIV treatment at an organization in the Kathmandu Valley, she encountered a problematic situation at her home. Her home environment was not suitable to her HIV status, as she had foreseen before she left the healthcare organization. She shares her experience of having a migratory strategy as part of coping with HIV stigma and discrimination. "After finding organization housing for such persons like me in Kathmandu, I stayed there. I spent nine months in Kathmandu...I was thinking whether my family members would not treat me well because of HIV. That is why I had taken phone numbers of my friends living with HIV when I met them in Kathmandu."

As she expected, she faced discrimination when she returned home, and so she followed her strategy of migrating to Pokhara, by first contacting her friend by phone.

When I reached home, my husband's first wife did not allow me to get entry into our home. I did not say anything and also did not force to get in. Then, I slept outside my home on the ground at that night... I thought deeply and remembered that if my family members showed such misbehaviours, villagers outside home would do the same, and I should not stay there anymore. With the situation, I realised I could not stay at home any longer. So I phoned a sister [Lila] in Pokhara. I received a positive response to come to Pokhara on Friday and I had phoned her on Wednesday... I left home for Pokhara at 4 am in the morning, taking my sick son. Sometimes, I wonder how I could do such things at that time.

There is also family migration from rural areas to cities after people have been stigmatized and discriminated against at home and in their local societies, especially in cases where both partners are living with HIV (Rita A).

Some participants follow both herbal and modern medicines one after another in the course of their HIV treatment. Lila, a widow, shares her experiences of treatment, describing how she followed the instructions of a traditional healer to limit most food items and not even drink water: "I did not drink even a drop of water for a year as a traditional healer suggested that I should not drink water at all for HIV treatment and my two children, son and daughter aged below 10 years, who were also HIV positive, did the same; we drank the urine of cows, buckwheat, and millet without any fruits."

Lila and her children followed the instructions of the traditional healer for one full year, and felt their health was deteriorating day by day. After fainting and falling unconscious to the ground for many hours, Lila realized herbal medicine did not work well for HIV treatment. That day all three family members living with HIV, herself and her two children, started breaking the instructions of the traditional healer and turned to modern medicine provided by an organization. Lila describes how she ignored the instructions to refrain from eating most foods and not even to drink water given to her by a traditional healer, and how she then turned to modern medicine:

After regaining consciousness, I asked my mother-in-law to give me and my children normal food from then on and that we would eat to our heart's content. She said there were six more months to go after which we would be free of HIV for ever [as instructed by traditional healer]. I retorted that I was going to die anyway, better die with a full stomach. Then I went to an organization where the health personnel told me to eat well and to take proper care of myself; the organization was in its early days then. If any medicines for the disease are discovered, we will provide them to you, they told me then.

Identity Reconstruction

The participants in this study manage their stigma and discrimination by following various approaches, depending on the degree to which they are able to access resources. The overwhelming majority of participants with limited access to resources manage their stigmatization and discrimination by leaving their place of origin after experiencing heavy ostracism and discrimination. Thus migration helps in managing HIV stigma and discrimination in their place of origin, and in keeping their HIV status secret in their new locations (Misa, Sushma, Mamata, Buddha, Sarita A, Pratima, Durga, Sarita B, Gita, Rita B, & Anu). When they move to a new place, most do not disclose their HIV status to other people, except to certain health personnel: doctors, nurses and the people working in organizations related to HIV, who are committed to keeping personal information confidential. This strategy protects the confidentiality of their HIV status in their new location, because those who have been living in urban areas for a long time often know how to maintain confidentiality.

Regardless of their degree of access to resources, many participants record feeling their health status improved following health counselling and after obtaining modern medicines at hospitals and other organizations working in the field of HIV. They appear as physically well as HIV negative people. Most participants are now physically fit to work any job, just as they did before, and just as other HIV-negative people do. Some participants, especially females who have been HIV positive for a long time, start to look dark and physically weak before taking modern medicine, but after starting modern medicine, they begin to look as good as others physically. Sushma, a female, comments as follows: "When I got sick due to HIV, I thought that I would die immediately. At that moment, I had thought that this was end of my life. But after treatment at hospital, nobody can say by looking at my face and body that I am an HIV positive person. I am more content now than before."

Like Sushma, most participants express the view that they are now as physically fit as HIV-negative people. HIV treatment (Anti-retroviral Therapy) has prolonged life expectancy of the PLHIV sufferers in this study substantially. After being informed by their doctors they have had HIV, almost all participants start counting the days to the end of their life; maybe that day or the next, in accordance with their earlier thinking about their future life. Yet in my field visits, I had the opportunity to obtain data from people who have been living with HIV for up to sixteen years (Jwala & Buddha).

Participants in this study feel certain that HIV is not considered as serious as other health problems, such as diabetes, blood pressure and cancer. This indicates that HIV is not like those other conditions, because it is not a life-threatening condition if people receive timely treatment.

Patients do not need to abstain from any type of food, whereas those with diabetes, blood pressure or cancer etc., have to be careful about many foods (Jwala, Buddha, & Rita A). In addition, they see that people suffering from those other diseases often die from them. Most research participants express similar feelings:

HIV is nothing for those persons who have enough money. Of course, I can eat anything I like. The main thing is that I have to eat a balanced diet and if I can eat and take good care of my health, that's it. I have come across many people who have had this [HIV] infection and have been surviving for fifteen years without taking any medicine. That person whom [in an economically better position] I met at the hospital has not reached such a stage of HIV infection that he has to take the medicine.
—Buddha, Female

Participants compare HIV with other diseases, and consider it a lower level problem. It is better to have HIV than cancer, diabetes or high blood pressure (Lila & Buddha). HIV is not a disease, but an infection (weakening the immune system) research participants explain. Jwala (a male) compares HIV with other diseases, using his father's disease as an example:

Disease is disease whatever it is. Every disease causes suffering to its patient in one way or the other. My father has a transplanted kidney and stays at home.... My father does not eat some types of food even if he wants to have them. I am free to eat anything. So my mother gives me everything that she cooks. I only have to take medicine. In fact HIV is far better than diabetes. If one can spend one's normal life having nutritious food, HIV is not a disease for that person. This is not a disease but an infection.

As stated above, there are many participants who do not feel seriously ill from their HIV. Sarita A shares her experience of HIV in this way: "I never felt seriously sick due to HIV. After becoming infected with HIV, I felt the same as other general [HIV-negative] people. After I was diagnosed with HIV, I started receiving treatment from the concerned organizations."

Pratima shares her experiences of becoming engaged in various activities as a social worker, compared with her life prior to her diagnosis. This activity as a social worker has enhanced her self-esteem, and she concludes that HIV is not the end, but is instead the start of life, now that she has received liberty from family members and is engaged in social work activities.

Now my philosophy about life has changed. An interest in doing social welfare has developed within me. I think I have to be involved in awareness programs concerning PLHIV. What happened to me should not happen to others. My attitude towards life has been totally changed and I desire to serve as a social worker and now many people know me. Now I have visited almost all the places of [the] district. I now think that HIV is not the end of life but a start of life for me. I was just concerned about my life before, but now I think about others. I have reached a very high level in [my] life now.

Publicly disclosing HIV status after forming a network of fellow PLHIV sufferers wins the sympathy of people working in government bodies (both VDC and Municipality) and also in non-government organizations related to HIV. This disclosure of their condition helps participants resist the prevalent stigmatization and discrimination. In my study, I came across a few participants who have disclosed their HIV status publicly in order to cope with the challenges related to HIV stigmatization and discrimination collectively, with the assistance of people working in this particular field. Females with limited access to resources are more likely to disclose their HIV status publicly than males. Disclosure is often motivated by the need to seek the collective strength and support of other people in resisting stigmatization and discrimination, as well as for improving social and economic status. Lila shares her experience of improved self-esteem and the support of

public inspiration after publicly disclosing her HIV status. People expressed appreciation, telling her that she was a “brave woman” after she gave a speech on her experiences of living with HIV:

When I spoke in front of everyone, they were all praises for me, calling me “a brave woman.” I had a talent to speak in public, one I had never realized. I think my life has been easier since I came clean of the fact I had HIV in public, if not in my personal life then my social life at least. I don’t know what people say behind my back but they don’t say anything bad to my face.

Like Lila, there are other participants who have publicly disclosed their HIV status (Misa, Nimesh, and Santosh). They have been able to win public sympathy and reduce HIV stigmatization and discrimination with the assistance of others working in the field of HIV. This disclosure also opens doors to work with HIV stigmatization and discrimination management programmes launched by various organizations working in this area.

Discussion

Many participants have a strong faith in God in accordance with their childhood backgrounds, and use their spiritual beliefs to aid their transitional identity and thus cope with stigmatization and discrimination. There are various ways of coping with their situation and progressing into their future lives. These include relying on God to save their lives (preventing suicide attempts), finding means of HIV treatment, and receiving deep love from family members despite their HIV status. Some participants feel that God punishes people who discriminate against them; they pray for continuity in their children’s education and that their children might have peaceful lives while facing discrimination at school. In addition, they give credit to God for help in finding jobs, regardless of which religion they adhere to or their access to resources. They have been able to change their social capital into cultural capital, and their cultural capital into economic capital while going through their own life journeys.

Many PLHIV sufferers consider spirituality a powerful tool for managing family and social issues of stigmatization, discrimination and disruption. Irrespective of their religion, they believe God helps them solve the family and social issues they face after being diagnosed HIV positive. They believe that if they face less stigmatization and discrimination from their families and communities than other PLHIV sufferers (especially receiving love instead of discrimination from their parents), it is because of their longing for God (Jwala & Raju A). They also attribute finding jobs, better HIV treatment, and obtaining leadership training and informal education through organizations working in the field of HIV to the grace of God. Participants consider spirituality a reliable resource for their betterment, and a directive force for the remainder of their lives. They also redefine the purpose and meaning of their future lives and many say they pray to God. In Nepalese society, it is believed that God sees everything (Gita) and God is considered a companion in times of both pain and happiness. People learn about God from their families and societies from childhood, and the survey participants pray for better future lives. Rajesh, a male, shares his experience as follows: “I remember God. When I have a deep grief, I remember God. I have in faith of God. Every time I take medicine and sleep on the bed, I remember God”. Similarly, Lila shares her experience of how she learned about and developed a strong faith in God:

I am a Hindu. I prayed to God since I was a child and have faith in God. I used to take *brata* [fasting] and attend *puja* [a ritual associated with worshiping God]. My parents also had immense faith in God. They used to go on different pilgrimages in hope of recovery for their disabled sons. Both my brothers couldn’t eat or drink by themselves. My father bought a he-goat and worshipped it and offered it to the Goddess. After that my younger brother who couldn’t even get out of bed started eating and drinking

himself. Then, my parents' faith in God grew further still... I have immense faith in God.

Some participants find their spirituality has been a life saver in terms of preventing suicide attempts. Homilies preached by priests have "recalled" participants and directed them towards their own and family obligations. Some participants say that they gave up thinking of suicide, realizing that suicide is considered a highly sinful deed (Lila). At the same time, fulfilling their family obligations, especially rearing children, is seen as imperative for a mother and a virtue in this present world, which one needs to do in every situation, as stated in their religious texts. Lila shares how she decided not to commit suicide after her husband's death from AIDS: "Then, I remembered the teachings of Garun Puran [a Hindu religious book] and decided that I would not take the poison and that I would live on, at least for my little children".

Some participants also believe that God has helped them in finding a traditional healer for HIV, and that things have been made simpler, just as they have wished, because of their *Bhakal* (promise) given to God. Lila shares her experience of finding a traditional healer and how life became simpler by the grace of God:

[God] made things simpler. After my husband's demise, I heard people say that HIV could be cured by taking herbal medicines given by [a] Vaidhya [traditional healer] who lived in [a certain] district. So, I sold my gold locket to get there and seek treatment. While starting my journey, I saw a temple and pledged that I would get the medicines. I took his medicines for one year. I don't know if they worked or not....On returning, I told my mother about the *Bhakal* (promise) I had made at the temple. She said that my pledge had been fulfilled, that I had met the man and got his medicines and so now I had to offer something to that temple. So, I worshipped with a sheep's kid and prayed again that nothing happen to me and my children for the next five years. After the promised five years, I again went back to the temple and made offerings in the names of my father, father-in-law, my husband's grandfather, my husband and my step-mother. I also recently made offering in my late mother's name after her yearly rites were performed. Once a soothsayer told me that I had witnessed a lot of troubles in my life because the Goddess had come inside of me. To get rid of my misery I needed to observe difficult fasting and praying. My ageing mother told me that the whole process was very difficult to follow. I should only do as much as my body would allow. I did so. I had immense faith in God.

Some participants state that they receive deep love from their families, even with their HIV status, and they give credit for this to the grace of God. Certain Christian participants have not experienced any HIV stigmatization and discrimination from their family members. They believe that their family members have been taught to love others as per the philosophy of Christianity. Jwala (from a Christian background) describes his experiences of the love which overcame HIV stigmatization and discrimination from his family members in this way:

I am from a Christian background. We believe in Jesus that God cures all kind of diseases. When my elder sister knew that I was HIV positive, she did not take it very seriously. When my mother knew it, she loved me....I have never seen God but I believe that God is the healer. I believe in God very much. My father also believes in God very much....I think it is Christianity that made our homely environment very lovely and cooperative. All the family members have learned to love and serve from Christianity and so they love me.

Spirituality is believed to have helped some participants in finding a job. Becoming economically independent by working is seen as a means of reducing stigmatization and discrimination. Participants pray and attribute their success in finding a job to the grace of God.

Buddha believes God and her ancestors have made efforts to save her life from many ordeals and helped her to get a job. She believes credit for this goes to God and to the blessings of the ancestors. She shares her experiences in this way:

I believe in God and in blessings of ancestors. I am doing all the rituals of the anniversary of my late husband and mother in law... I think it is not good to leave everything that our ancestors had shown in the path of worshipping God and the ancestors. I think that the credit goes to God for helping me make a success of my life by saving me from many ordeals... It seems to me that God has sent me to work at this organization.

Sushma also shares her experience of God helping her become economically independent: "Although I lost my husband due to HIV, I had reached to the mouth of death, I am now able to live by myself [economically independent] and I do not need any support from others. I feel that all these things [HIV treatment and economic independence] are attributed to God."

Policy Implications

Spirituality is one of the major factors in living positively. To address issues of the identity of PLHIV sufferers, it is necessary to guide people towards God and to follow God's paths, as it is written in Hindu and Christian religious books. This study has found several examples of research participants believing deeply that God has saved their lives in one or other way after being diagnosed HIV positive. The following section is therefore aimed at urging people become involved in spirituality, irrespective of their religion, in order to make life meaningful for themselves and others. It also attempts to help people become clear in knowledge of HIV and its treatment, of management of HIV stigmatization and discrimination, and of socio-economic empowerment.

Spirituality

In this study, PLHIV sufferers perceive spirituality as playing a vital role in changing their lives positively, by enhancing HIV awareness and improving their socio-economic status. Irrespective of any religion, spirituality provides compassion, love, affection, respect, and family and social harmony, which helps marginalised people such as PLHIV sufferers. Many females, especially widows and single women, receive a greater degree support from family, society and organizations while suffering from health and socio-economic problems. They want to give credit for this to God. Some have given up thoughts of suicide, recalling the teaching that suicide is sinful in Hindu belief. Likewise, some PLHIV sufferers have not faced stigmatization and discrimination in their families because of Christian beliefs, which teach the importance of love in family and society. PLHIV sufferers, either Hindu or Christian, have thus benefitted from spiritual teachings in one way or another. There are important policy implications for impacting the lives of people positively, despite them facing the stigmatization and discrimination attached to HIV. This study thus aims to encourage the preservation of religious and cultural values for the present and the future, in order to reconstruct the identity of marginalized communities and those who are stigmatized and discriminated against because of gender, caste and class.

HIV Education and Nutritional Habits

Health is one of the major factors in reducing stigmatization and discrimination, not only from a physical and mental perspective, but also from an economic and social perspective. PLHIV sufferers need to follow HIV treatment after diagnosis and gain knowledge of the disease. This knowledge relates to dietary habits, transmission of the disease, and the meaning of HIV and AIDS. Such a requirement places the responsibility on the HIV person, and not on stigmatization by society or culture. Knowledge about HIV helps those diagnosed become self-confident about their

own health and identity management. Therefore, people working in the field of HIV need to enhance awareness and knowledge of HIV. Treatment is the backbone in lessening stigma and discrimination. Following HIV treatment in hospitals, PLHIV sufferers feel themselves to be healthy, and they also seem healthy in the eyes of others. Thus it is necessary to make effective HIV treatment available to all PLHIV, including people living in rural areas. At the same time, it is also necessary to provide information on the availability of HIV treatment and its positive effectiveness in achieving health and prolonging life expectancy. After HIV treatment at hospital, PLHIV patients can be found working equally with others, even in farming, where they are not considered inferior to HIV negative people from a health perspective. Thus it is necessary to make effective HIV treatment available to all PLHIV sufferers, including those living in the rural areas.

Nutritious food is essential for physical and mental health and wellbeing, and relates to the personality of a person and his/her identity. This claim is supported by participants in reference to the physical appearance of rich versus poor PLHIV sufferers. In this study, some participants, aged sixty years and above, found that they could work as actively as other people. It would thus be fruitful to deliver knowledge of the importance of nutritious food in maintaining the immune system of PLHIV sufferers. This knowledge will also help them manage their social stigmatization and discrimination. Most importantly, a balanced diet seems to be as important as HIV treatment as it keeps people healthy and enhances their identity from a health perspective.

Socio-economic Empowerment

Social awareness and economic independence assist PLHIV sufferers to integrate in their families and society. This study demonstrates that PLHIV sufferers, especially females, do not face family and social stigmatization and discrimination after becoming socially and economically independent. Empowering PLHIV people, especially females, is necessary for them to become socially active. This is achieved by providing informal education, leadership training (including counselling on HIV and AIDS), and involvement in a circle of friends also living with HIV. Therefore, government and non-government organizations working in the field of HIV need to provide education and income-generating skills for PLHIV patients, especially widows and other females without economic support, so that they can fit in everywhere, either in individual or collective society, or as part of either a nuclear or an extended family. Empowerment through becoming socially active strengthens people in resisting HIV stigmatization and discrimination. As some participants express it, PLHIV patients need education for their field of employment, especially in organizations where they are working. Thus, organizations working in the field of HIV need to provide education and leadership training, not only for enhancing people's work efficiency, but also for resisting stigmatization and discrimination.

Furthermore, with regard to the economic independence of PLHIV sufferers, collective efforts in engaging in economic activities appear to be a good way of generating livelihood, especially in rural areas. In this study, some illiterate participants report initiating collective agricultural food production of wheat, maize, millet, vegetables and fruit etc., after buying farmland, as well as working other people's land. This kind of initiative in collective farming would be very useful in other parts of the country, especially in rural Nepal where agricultural land is available cheaply. As observed in my field work, some participants, irrespective of gender, caste, or class, have started living together as an association of PLHIV (using the same kitchen and the same residence). After gradually becoming economically independent, they are now gaining respect from other villagers. To multiply this programme effectively in other parts of Nepal, it would be advantageous to receive the support of the Nepal government, through both government and non-government organizations that are working for the empowerment of marginalised people.

Conclusion

In this study, many PLHIV sufferers consider spirituality to be a powerful tool in managing family and social issues of stigmatization and discrimination, and in reconstructing their identities. They feel much softer in their lives with the names of God, irrespective of any religion, whether they are Hindus or Christian. Spirituality plays an important positive role in changing the lives of PLHIV patients in Nepal. Spirituality and identity reconstruction also are intrinsically related to each other.

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