

# In what way do Nepalese cultural factors affect adherence to antiretroviral treatment in Nepal?

Sharada Prasad Wasti<sup>1</sup>, Julian Randall<sup>2</sup>, Padam Simkhada<sup>3</sup>, Edwin van Teijlingen<sup>4</sup>

1. PhD Student, MSc, MHCM, MA, Section of Population Health (SchARR), University of Sheffield, UK
2. PhD, MSc, BA, Senior Lecturer, Business School, University of Aberdeen, Scotland, UK
3. PhD, MSc, Senior Lecturer, Section of Population Health (SchARR), University of Sheffield, UK
4. PhD, MED, MA (Hons), Professor, Maternal & Perinatal Health Research, School of Health & Social Care, University of Bournemouth, England, UK

## Abstract

Individuals' self administration of medication is an essential component of disease management because incorrect and incomplete medication can result in increased morbidity, mortality and healthcare costs and also spreads drug resistance. Its impact is necessarily wider than just medical and includes the cultural and managerial considerations which govern success in medical interventions. This review paper is aimed at how Nepalese cultural factors (beliefs, religious practices, customs and traditions) may affect adherence to antiretroviral (ARV) medication among people living with Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS).

**Results:** Cultural factors (individual beliefs and perceptions) are notoriously complex concepts and shape people's identities and influence their attitude and behaviours. The individual behaviours and beliefs about health and seeking treatment can adversely affect health care utilization and adherence to medication. These factors create a complicated and unforgiving environment for patients who are struggling to endure a chronic, life-threatening illness with life-long treatment. We cannot disregard patients' cultural beliefs or practices in order to provide ARV treatment and their adherence because patients and clinicians come from different cultural groups.

**Conclusion:** It is the purpose of this paper to contribute to the policy makers by exploring the pertinent cultural factors relating to the uptake of ARV treatment and its adherence.

**Keywords:** HIV/AIDS, culture, antiretroviral, adherence, Nepal

## Corresponding author:

Sharada Prasad Wasti  
PhD Student  
Section of Population Health (SchARR)  
University of Sheffield  
30 Regent Street, The Innovation Centre  
S1 4PD, UK.  
Tel: +44(0)1142226389  
E-mail: s.wasti@sheffield.ac.uk  
spwasti@yahoo.com

## Introduction

Culture is defined as the system of values and norms shared by a group or society or that shaped by social knowledge<sup>1</sup>. It is the collective consciousness - a way of acting, feeling and thinking by groups of people and shaped by a sense of shared customs, knowledge, beliefs and perceptions that define individual behaviours. So it is described as social glue<sup>2</sup> and commonly held in individual and group perceptions. Thus, culture involves a larger group of individuals which is a socially constructed phenomenon, a human product, and is shaped by people belonging to various groups<sup>3</sup>.

Individuals are socialized into society by being taught and learning the behaviour and belief patterns that deal with human systems. It consists of the unwritten rules of social relationships with the collective programming of the mind, which distinguishes the members of one group of people from another<sup>4</sup>. It is a pattern of shared basic assumptions which is invented and developed within a society or group that has worked well enough to be considered applicable to diverse communities with different values. Therefore, it is taught to new members of the groups as the correct way to perceive, think and feel in relation to those problems<sup>5,6</sup>.

The way people make sense of illness is in part culturally determined. Existing beliefs and presuppositions shared by a cultural knowledge regarding illness play a significant role in shaping an understanding of newly emerging illness in any given culture<sup>7</sup>. Certain elements of culture tend to remain over time while others change, like negative beliefs and individual health practices such as side effects of ARV drugs rather than a positive outcome. How individuals make sense of their situation and share realities may become objectified with their everyday life<sup>8</sup>. Thus, cultural relativities affirm that one culture has no absolute criteria for judging the activities of another culture. However, every culture can and should apply such judgement to its own activities,

because its members are actors as well as observers<sup>4</sup>. Social scientists argue that culture is learned, shared, transmitted inter-generationally and reflected in a group's values, beliefs, norms and the practices of individual and family roles and other social regularities<sup>9</sup>. It is further explained that culture is a basic assumption and that beliefs operate unconsciously from generation to generation<sup>10</sup>. It is the purpose of this paper to investigate such emerging perceptions and to discover whether they have significant influence on treatment adherence in HIV/AIDS.

## Methodology

Various electronic databases (Medline, Science Direct, Google and Google Scholar) of scientific literature and reports were accessed through the internet publications that looked at health, illness, HIV/AIDS, treatment and its relationship with the cultural factors (beliefs, religious practice and customs) of HIV/AIDS treatment and adherence to ARV medication. Various hard copies of related textbooks, scientific journal and relevant documents were also incorporated for the relevant topics, making use of a reference list of publications and citation searches.

## Health beliefs and use of health care facilities in Nepal

Health and illness are not only physical conditions but are based on perceptual judgements. This may influence the health care choices and decisions to seek health services, trust between health care providers and the treatment regimen and even their actual physical responses to health care treatment<sup>11</sup>. These all have an intimate linkage between disease, medicine and human culture and the cultural perspective on the relationship of health beliefs.

### How individuals make sense of illness

The word health is primarily associated with illness, disease and medical treatment

which are all biological phenomena. Health and illness are not equal opposites, but health is disrupted by illness and medicine is the clinical application for disease<sup>12</sup>. Nepal is a multicultural and multiethnic society with over one hundred ethnic and caste groups<sup>13</sup>. But Nepalese health and illness beliefs may vary, attributing illness to biomedical, natural or supernatural causes or any combination of these different categories. These illness beliefs and practices have been influenced by many different sources throughout history. For instance, illness is believed to be caused by a “supernatural attack” and, in many cases, demons or witches are sometimes believed to be the cause of illness<sup>7</sup>. But it must be asked how common-sense guides our beliefs and behaviour towards other people<sup>14</sup>. Sense making is grounded in both individual and social activity as well as a process in which individuals develop cognitive maps (i.e. beliefs and behaviour) of their environment, i.e. illness caused by supernatural attacks<sup>8</sup>.

### Supernatural account of causes and treatment of illnesses

The notion of health is encouraged by a purely medical conception of health and illness. According to Dixit, Nepalese people are praying to various deities for protection from disease and illness, not only at times of stress but also for comfort and future wellbeing. There are specific deities to whom specific offerings are made; a particular purpose for one such as *Bhatbhatini* is for children frightened by spirits; *Santaneswar/Gyaneswar mahadev* is for infertility; bathing in *Kumbeshwar* is said to cure several skin diseases including leprosy<sup>15</sup>.

Similarly, health and ill health can be attributed to one's relationship with the spirit world of gods and anti-gods (demons). Attribution theory as formulated by Heider and used to frame beliefs and values may lead to particular patterns of behaviour. It links to a person's perception about the intention and disposition of others and raises questions on how individuals interpret events

and how this relates to thinking and behaviour<sup>14</sup>. A person seeking to understand why another person did something may attribute one or more causes to that behaviour<sup>14, 16</sup>. These traditional beliefs and superstitions can explain illness in terms of religion or fate, prevent illness by properly attending to ritual, making promises to the gods, giving offerings, sacrificing animals or through prayer. It shows that health beliefs are related to causal explanations and that perceived risk seems to be especially influenced by attributions and is also related to locus of control<sup>17</sup>.

Some individuals may attribute certain classes of illness to be caused spiritually and others caused naturally. Illness is diagnosed and cured by *Jyotisis* (astrologers), *Guru-Purohits* (priests) or monks through prayers and to the *Dhami and Jhankri* (traditional healers), *Gubaju*<sup>11,18</sup>. Treatment is done by chanting mantras and shouting at the spirits to leave the person's body, violent exorcisms in which the patient is burned, frightened and beaten until the spirits flee the patient's body, and by giving offerings and sacrificing animals<sup>11</sup>. Faith healing has been one of the most significant health care systems in Nepal since early time<sup>19</sup>. An individual has the right to get medical services, diagnose their condition with respect to norms and prescribe drugs to return to normal life<sup>20</sup>. There is a question about how sense making is fundamentally concerned with this multiethnic and multicultural diverse Nepalese community towards health and illness<sup>21</sup> because health is an area of intercultural interference of individual perception of health concepts and attitudes to effective treatment.

### Nepalese cultural issues in fuelling HIV/AIDS

#### Folk beliefs about effective treatment

Nepalese people perceive HIV/AIDS as a bad person's disease, as a result of bad *karma* [works done in a past life that either earn merit (if good) or punishment (if bad) in present life] and the belief in a strong

connection between worry and disease<sup>7</sup>. Thus, HIV/AIDS related sickness is perceived as a punishment for some wrong doing that has been committed. This shows that personal attribution is more likely than a situational one, that people can be punished and therefore that some control over that cause can be effected<sup>17</sup>.

Nepal is experiencing a spread of the HIV epidemic from high-risk behaviour groups (sex-workers, migrant workers) to the low-risk behaviour population such as housewives<sup>22</sup>. Besides issues of personal choice there are also many widely held beliefs and cultural practices that are contributing to the spread of HIV/AIDS in Nepal<sup>23</sup>. Most of these are related to folk beliefs about prevention and treatment for HIV/AIDS, such as that having sex with 108 virgins will cure AIDS and STD, cleaning the penis with urine, Detol soap or Coke will cure AIDS and STD, Nag puja (festivals) will cure HIV, anal sex will cause HIV, HIV is prevalent only in Bombay and a tika from Sai Baba placed on the penis will cure STDs and AIDS<sup>23</sup>. Such faith in a higher power may help clients to make sense of their world and acts as a foundation for daily decision making. But if patients are more likely to follow treatment advice they perceive this to be a common-sense approach to maintaining their health<sup>17</sup>. Thus, it is important to find out whether or not such beliefs influence adherence to medical treatment.

#### **Cultural norms - family/moral affront/social stigma**

Nepalese culture is not open to discussion about sex and sexuality. For instance, Nepali people are bound by the culture of silence around sexual matters. Cultural values such as shyness prevent open discussion and education on sexuality. People dislike hearing and discussing such subjects among the family members. This can be illustrated by the experience of a radio program in Nepal, called "Chatting with my best friend," that spread knowledge and awareness of HIV/AIDS. According to the programme producer, "the programme

initially received many letters complaining about the discussion on use of condoms, sex and sexual organs"<sup>24</sup>

Since HIV/AIDS has been associated with prostitution, drug use and traditional ideas concerned with promiscuity, religious or moral beliefs lead people to believe that HIV/AIDS is the result of moral faults such as "promiscuity or deviant sex" and is considered as a bad person's disease and the result of bad deeds in an earlier life, so they deserve to be punished. Sex workers and drugs users go against the moral and traditional customs<sup>23, 25</sup>.

People living with HIV are often subject to stigmatization and discrimination and still this is a much talked about issue in Nepal<sup>22</sup>. It is noticed that stigma against HIV may be an obstacle to undertake preventive and treatment services. Fear of stigmatization and discrimination prevents people from accessing testing and seeking treatment services, which make them vulnerable to HIV/AIDS infection. The self stigma and hostility in people living with HIV/AIDS inhibits them from disclosing their HIV status and seeking medical assistance, therefore remaining in the shadows and so passing the infection on to others<sup>23, 25, 26</sup>. HIV infection is associated with behavior that is considered deviant. HIV related stigma and discrimination impedes every step in mounting an effective response for prevention, treatment and ultimately adherence to the medication.

#### **Institutional prostitution**

Nepal is a multi-cultural and multi-ethnic society. Its different cultures and castes have their own norms and values regarding sexual practices. Due to changing values and norms their unsafe sexual practices exist and people are increasingly vulnerable to HIV/AIDS<sup>27</sup>. There are certain cultural traditions in Nepal "that approve the sale of girls and prostitution"<sup>23</sup>; these tribes are Badi and Deuki. Badi girls have their own thoughts and they have been involved in prostitution from puberty, continuing until they became too old<sup>28</sup>. Similarly, they do not

use condoms and prefer “the desirability of pregnancy and creating more female sex workers within the family”<sup>23</sup>. The Badi became one of the archetypes of commercial sex work in Nepal and serve as an example of what has been variously described as religious, cultural or traditional prostitution as well as part of an evil tradition<sup>29</sup>.

Similarly, in far western Nepal, parents of Deuki offer their daughters to a temple deity in order to improve health, get a new job, bear a son or a number of other such reasons. The girls are unmarriageable, sex with a Deuki is said to ensure eternal bliss<sup>23</sup>. There is danger in moralizing. Thus, there will be questions on how sense making is fundamental to accept the diversity and transformation of those diverse situations<sup>21</sup>.

### Position of women in society

Nepalese culture does not permit a female to make her choice in marriage and kinships practices vary across the different ethnic groups. Some ethnic groups of the Himalayan region practice polyandry (a woman is married to all the brothers in the family). Such fragility of marriage contributes to the risk of HIV infection in women. Nepalese women have limited decision making powers; they will be abandoned by their husbands and they are not allowed to make their own choices due to cultural or religious instructions on having sex, whether to use condoms, the number of children to bear. This and the preference of sons in society and in the family all make women highly susceptible to HIV infection as these limits control safer sex<sup>30</sup>. This traditional belief helps to make sense of the HIV/AIDS horror and it implies that individuals cannot be held responsible or accountable to overcome this over time<sup>31</sup>.

### Complicated treatment regimes

Life-saving anti-retroviral drugs (ARVs) help people living with HIV to have longer and healthier lives; however, low adherence seriously compromises the efficacy of this treatment<sup>32, 33</sup>. Maintaining a high level of

adherence over the long-term often proves difficult<sup>34, 35</sup>. Although availability of adequate resources and health infrastructures (physical, human & financial resources) are essential for HIV prevention and treatment, they may not always be sufficient because human behaviour and beliefs are also critical elements. Personal experiences, social network attitudes and health beliefs interact with and influence health seeking behaviour. Inadequate knowledge of and negative attitudes towards ARVs, fear of side effects and complexity of regimens may all be significant barriers to prevent patients from undertaking treatment or maintaining adherence<sup>36</sup>.

Similarly, people insist on their cultural rights but there are a number of issues raised in HIV/AIDS treatment. Ethnicity and culture have multiple constructive and destructive roles for the promotion of ARV adherence<sup>7</sup>. Life-long and complicated treatment regimens as in the case of HIV are negatively correlated with a patient’s ability to complete ARV treatment. There is a big question about how and why people follow or deviate from the doctor’s prescribed medication. Adherence is a concept developed from the clinician’s (doctor’s) perspective. Cultural factors compromising adherence to ARV do not end with the influence of Nepalese existing knowledge, beliefs and practices, which are deeply embedded individual behaviours that can deter a patient’s inclination to take ARV medication.

### Conflicts between traditional and western medicines

Nepalese beliefs make it distinctively challenging to practice traditional and western medical services in multicultural and multiethnic peoples in Nepal, although the western and traditional medical practices make it distinctively challenging and these philosophies are not always mutually exclusive. There can be serious interactions between conventional and traditional therapies and conflicting notions can negatively impact adherence to prescribed

ARV medications<sup>37</sup>. Thus, Gill et al. stated that "if all structural barriers of adherence to ARVs are removed, ARV programmes can still fail if they do not adequately address the behavioural factors influencing adherence"<sup>38</sup>.

It is not unusual for clients who hold traditional cultural beliefs to consult traditional healers to treat the illness but this may impact negatively on their adherence to ARVs. An individual behavioural or cultural problem may constitute a further hindrance to adherence to ARV treatment.

### **Theoretical consideration: attribution theory and locus of control**

Cultural factors (beliefs, perceptions and behaviour) necessarily influence the decision making process to seek health services. People seek different sorts of healers (faith healers or modern health) based on their perception and beliefs regarding the illness<sup>11</sup>. This makes it very challenging to distinguish individual behaviours from illness, i.e. seeking diagnosis and behaviours like adhering to a medication<sup>39</sup>. These both positive and negative health beliefs affect individual behaviour and perception. In order to understand these cultural issues and how they affect ARV adherence we must focus on theory of attribution and locus of control<sup>40</sup>.

Attribution theory discusses how people make casual explanations about a variety of events and how those attributions motivate their behaviour. It creates complex models of common-sense attribution. Causal attributions are beliefs about what caused something to happen. They may attribute the cause of an event to factors which they believe are outside of their own control (i.e., luck or fate) rather than to their own control<sup>14,17</sup>. For instance, in adhering to a prescription for ARVs, a person's attitude is expected to be determined by their beliefs about medicines; if the clients think ARVs are necessary, the individual is more likely to be adherent and if a client think that ARV drugs can be harmful, then non-adherence is more likely. The necessity of medication use is assumed to be determined by the severity

of the symptoms, quality of life and the attributions of patients' behaviours. But human behaviour is so complex that it cannot be explained through single concepts.

Thus, this individual human behaviour explains a social learning theory: locus of control. Locus of control refers to an attribution of responsibility for outcomes of internal versus external events. The locus of control dimension is linked most strongly to cause, such as efforts. It deals with the person's beliefs, either internal or external factors. People believe their health is determined by internal or external factors; internal (information, ability) or external (fate, luck, opportunity or dependence on others) to the presence and is influenced by the person's expectations of the outcome<sup>17, 40, 41, 42</sup>. According to this approach, an individual's state of health (or illness) is either a result of their own behaviour (health internal) or that their health is determined generally by such things as chance or other powerful factors over which they have poor control (health externals)<sup>43</sup>.

Specific behaviours where locus of control is relevant are seeking information, taking medication, making and keeping physician appointments and maintaining adherence to medication. Internals generally show more positive behaviours in each of these areas. The general assumption is for adherence to ARV medication. A person's attitude is expected to be determined by his/her beliefs about medicines. If the person thinks medicines are necessary, he/she is more likely to be adherent. However, if a patient has serious concerns about medication use and thinks that medication can be harmful then non-adherence is more likely<sup>44</sup>. However, this topic is unexplored in Nepalese context and is open for further research, particularly on adherence to ARV medication within Nepalese culture and its link to locus of control.

### **Impact of culture upon ARV adherence**

Individual self administration of medication is an essential component of any

disease management, because incorrect and incomplete medication can result in increased morbidity, mortality, healthcare costs and spread of drug resistance<sup>32</sup>. Adherence is considered as an individual management issue between patient (ARV receivers) and healthcare providers (clinicians)<sup>37</sup>.

Health service providers inevitably blame those beliefs and identify them as cultural barriers. Beliefs are often used as a proxy for culture. Biomedical perspective beliefs connote erroneous ideas that constitute obstacles to appropriate individual behaviour, because adherence to ARV medication is an individual choice. That's why individual negative practices could be labelled as such because of their beliefs and behaviour and are often considered as barriers to the uptake of HIV treatment. It has become widely associated with negative individual health beliefs and practices which might be a reason for the poor uptake of HIV treatment<sup>45</sup> and it is this aspect that the present research intends to shed light on - the cultural aspect of adherence to ARV treatment.

The impact of beliefs and practices on adherence to ARV treatment have been numerous and significant and will continue to be so. The issue for providers is to attempt to meet the treatment goals within the patient's beliefs about medicines and perceptions of personal sensitivity to the adverse effects of taking medicines. These factors may in turn limit the behavioural choices and uptake of services such as going for an HIV test (disclosure of status), beginning ARV treatment and then adherence to medication.

HIV/AIDS has been associated with sexual contact and with promiscuity. Religious or moral beliefs lead people to believe that HIV/AIDS is the result of moral fault such as "promiscuity or deviant sex" and is considered as a bad person's disease and the result of bad deeds in an earlier life - so they deserve to be punished<sup>23, 26</sup>. Such general perceptions may influence treatment preferences, pathways to care and adherence to medication because we are

aware that HIV is a stigmatized disease and hence likely to remain a sensitive issue in Nepal<sup>25</sup>.

Societal negative attitudes and beliefs toward HIV/AIDS and its treatment, uptake and maintenance of adherence will directly affect the proposed study. For instance, HIV is a highly stigmatized disease and sensitive issue in Nepal; because of this, people may not want to participate in the study. People still do not openly discuss HIV and in general people believe that HIV is a bad person's disease; in this sense ARV recipients (study respondents) may refuse to participate and discuss their personal behaviours and beliefs regarding adherence to ARV treatment.

### **Approaches to eliminate cultural barriers on ARV adherence**

In all domains of practice, the service providers (doctor, nurse etc.) demonstrate skills and expertise not only in appropriate interventions, but also in their attitudes and beliefs about the value of the cultural context of the patient's life. Individual health beliefs, perception behaviour and traditional values should be given due importance in order to maximize the adherence to ARV treatment. Historically, Nepalese health seeking behaviour is found to be mostly of a dual approach - traditional and western medicine. The effect of traditional medicine use on ARV adherence has not been reported yet. Traditional medicine use appeared to affect adherence negatively in Africa but we do not have any research in Nepal<sup>46</sup>.

In order to fully relate to another culture and to be sensitive to the patient's beliefs and practice about their health seeking behaviour, a health care service provider must be aware of and sensitive to their own (clinician's) culture. However, a culture-centred approach is required to adequately address the increasing number of HIV/AIDS cases in Nepal, because beliefs and perceptions influence individual, family and community behaviour. Individual, family and community values are powerful in influencing

people's behaviour<sup>45</sup> and we will seek to explore this more during our research.

Fear of stigmatization and discrimination may prevent people from accessing testing or getting involved in education, preventive measures and treatments services. This makes them vulnerable to HIV/AIDS infection. The self stigma and hostility in people living with HIV/AIDS inhibits them from disclosing their HIV status, seeking medical assistance or advice and so they remain in the shadows, passing the infection to others. Perhaps befriending support intervention (education) programmes (persuading: attitude and value change) should be developed, culturally appropriate to overcome the stigmatization and discriminations toward ARV treatment and adhering to medication either from health institutions or the community.

Different cultural practices (whole day fasting) may hinder female patients from adhering to ARVs because we cannot change or skip an hour of ARV dose and ARVs need to be taken after food, otherwise there is a high chance of non-adherence.

Individual (patients') cultural beliefs or practices cannot be disregarded in order to provide information and education about ARV treatment. We must modify the ARV treatment plan to "fit" within the patient's cultural beliefs and practices, even if we have to institute treatment that we believe is less than optimal, for instance, Direct Observed Short Course Therapy (DOTS) and community based ARV treatment. DOTS has a good track record for tuberculosis control in Nepal and if the same model can be followed for the delivery of ARV treatment services this may help adherence to ARV treatment<sup>47</sup>.

Disclosure by family and friends about HIV/AIDS and treatment status may build a positive attitude and consequently increase adherence. Non-disclosure of HIV status and ARVs medication may limit the uptake and adherence to treatment<sup>48</sup>. Thus, family and friends should encourage each other to disclose their HIV status so that they can support the patient in adhering to the treatment plan where necessary.

A comprehensive cultural approach to development requires that policymakers design and implement policies that maximise the positive aspect of culture while avoiding the negative. Thus, the role of culture works against or improves the success of the prevention and treatment interventions needed to be understood to reduce the spread of HIV at each level. That may influence the patient's proper use of prescribed medications positively or negatively towards adherence to the regimen. For instance, optimum adherence (95% and more) to ARVs reduces morbidity and improve quality of life<sup>49</sup>.

Adherence to ARVs is a multifactorial behaviour and it requires a multifactorial response to achieve optimum levels (greater than 95%) because people hold diverse perceptions of health and illness, which influences attitude and behaviours. Therefore, strategies to encourage adherence must not only address interpsychic factors such as knowledge of regimen, beliefs in advantages of treatment and attitudes toward medication behaviour but we also need to see the interpersonal relationship between health providers and clients, family and peers support (community ARVs). Healthcare providers who are directly working with patients often need to educate on the value of adherence. Thus, a holistic approach needs to be tailored to promote ARV adherence. Otherwise, Nepalese cultural derivation will be influenced and non-adherence to ARVs will be more likely.

## Conclusion

Culture can play a vital role in establishing the practices, values and attitudes of the public towards people living with HIV, which creates stigma and discrimination. This factor may in turn limit the behavioural choices that resulted in a barrier to go for test, begin treatment and then adhere to the medication. It affects people's lives, whether that might be to enrich or constrain them. Thus, to reduce stigma and discrimination significantly, single level and single group approaches are

not enough. It could be a patient-centred approach at the grass root level. It is quite clear that there is no magic bullet that will help all ARV patients adhere to prescribed regimens. Optimum adherence could be achieved by valuing patients' perspectives and acknowledging the impact of individual's beliefs on their response to treatment. We have also identified the need to address the cultural constraints which may limit the use of services offered.

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