

## Research paper

# The lived experience of living with HIV/AIDS in the western region of Saudi Arabia

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### What is known

- People living with HIV/AIDS face significant psychological and social problems in addition to their physical condition, primarily related to AIDS stigma and discrimination.
- Research conducted in Saudi Arabia confirms that attitudes towards people with HIV/AIDS are shaped by the religious, social and cultural framework. There are profound misconceptions among the general population and healthcare providers about methods of HIV transmission.
- HIV is heavily stigmatised in Saudi Arabia as Islam prohibits non-marital sex, homosexuality and intravenous drug use, which are behaviours generally said to be associated with transmission of the disease.

### What this paper adds

- In Saudi Arabia, people who were HIV/AIDS-positive limited disclosure of their diagnoses to their treating physician and one other person, usually their spouse.
- All participants experienced a feeling of stigmatisation, discrimination and shame as well as fear of disclosure and causing shame to their family.
- Spiritual coping strategies were used to deal with the fears of punishment from God, fear of the disease and death, lack of psychosocial support and feelings of isolation.

## ABSTRACT

People living with HIV/AIDS face significant psychological and social problems in addition to their physical condition, primarily related to AIDS stigma and discrimination. This stigma is profound in Saudi Arabia as Islam prohibits behaviours associated with risk factors related to transmission of HIV, such as non-marital sex, homosexuality and intravenous drug use.

In this study qualitative research methodology using narrative interviews was used to explore the experiences of people living with HIV/AIDS in Saudi Arabia. Data were collected from 18 male and female participants. Interviews were conducted in Arabic and each interview lasted 30 to 60 minutes. The interviews were transcribed, translated and analysed using a descriptive phenomenological approach until saturation of themes was achieved.

Data analysis revealed five main themes: stigmatisation, disclosure, fear and vulnerability, lack of psychosocial support, and religiosity. Societal attitudes

towards HIV/AIDS were a key factor in stigmatisation, which leads to discrimination and stereotyping. Participants experienced a negative self-image, feelings of shame and a threat to self-worth. Disclosure (when and to whom) of their positive HIV status was a great concern, while non-disclosure was a protective measure against stigmatisation. Confidentiality of HIV status was very important and people feared disclosure by the healthcare team to others. Fear and vulnerability included fear of punishment from God, fear of being discovered as HIV/AIDS-positive and fear of the future and death. Participants experienced isolation and lack of psychosocial and emotional support. In response to their experiences all participants accepted their diagnoses as destiny (*ghader*) and became more religious, using spirituality as their main coping strategy.

**Keywords:** Arabic culture, disclosure, HIV/AIDS, HIV and Islam, HIV attitudes, religion, stigma

## Introduction

HIV/AIDS has emerged as a global public health concern requiring a multidimensional response. According to the World Health Organisation (WHO, 2011), 34 million individuals are living with HIV/AIDS; the majority, 30 million, are adults. In 2011, 2.7 million persons become infected while 1.7 million died of HIV/AIDS (UNAIDS: The Joint United Nations Programme on HIV and AIDS, 2011; WHO, 2011; UNAIDS, 2012).

In the Middle East and North Africa, the number of new HIV infections in the region increased by more than 35% from 27,000 in 2001 to 37,000 in 2011. The total number of persons living with HIV/AIDS in the region was estimated at 300,000 at the end of 2011 while HIV/AIDS-related deaths increased by 17% from 20,000 to 23,000 between 2005 and 2011 (UNAIDS, 2012). There are presently half a million people living with HIV/AIDS in the Arab region (UNAIDS, 2012). However, the prevalence of HIV infection in Arab countries is low compared to other countries as Islam is an influence in reducing HIV/AIDS at-risk behaviours such as multiple sex partners, homosexual relations and intravenous drug use (AlMadani *et al*, 2004; Gray, 2004; Gatrad and Sheikh, 2004; Gilbert, 2008; Badahdah, 2010).

Saudi Arabia is one of the largest countries in the Middle East with an estimated population of 25.7 million of whom 20% are expatriates. Between 1984 and 2001, a total of 7,331 HIV cases were reported; 21.3% were Saudi nationals (Mazroa *et al*, 2012). The most recent report on HIV notification (Mazroa *et al*, 2012) found that 10,217 new cases were reported from 2000 to 2009. Non-Saudi residents continued to have significantly higher infection rates than Saudi nationals in this period, with 13.2 cases per 100,000 compared to 1.5 cases per 100,000 for Saudis. Males account for the majority of cases among Saudi and non-Saudi residents; the male:female ratio for Saudi nationals is 4.4:1 and 80% of Saudi cases occurred between the ages of 15 and 49 years; 16% were over the age of 50 and 4% were children. Jeddah has the largest number (47%) of HIV cases (Saudi and non-Saudi residents); Riyadh city (9%) and Dammam (6.8%), with the remaining cases in other areas of the country.

Data on cases in Saudi Arabia are gathered by routine surveillance and HIV case data reported to the Ministry of Health. This surveillance is done by screening the contacts of an HIV-infected patient, routine screening of blood and organ donors, testing of all prisoners, intravenous drug users and patients with other sexually transmitted diseases, mandatory expatriate pre-employment and annual medical screenings and the introduction of premarital screening for Saudis in the late 1990s (Mazroa *et al*, 2012). However,

this surveillance faces many challenges due to under reporting and difficulties in reaching high-risk groups (Alrajhi *et al*, 2004).

Reliable data on HIV transmission from countries in the Eastern Mediterranean Region, including Saudi Arabia, are scarce. In Saudi Arabia, the subject of HIV/AIDS is still a taboo subject as it was in the rest of the world for many years. Of the 10,000 HIV cases reported since 1986, 21.3% are Saudi and 87% are expatriates from different countries. A total of 78.4% of cases were infected via sexual intercourse; 21.6% of the cases via other modes of transmission such as imported blood transfusion supplies, needle sharing and mother-to-child transmission. Men were reported as infected at three times the rate of women (Badahdah, 2010; Badahdah and Sayem, 2010; UNAIDS, 2012). A study on the mode of transmission by Alrajhi *et al* (2004) at King Faisal Specialist Hospital and Research Centre, the major HIV referral and care centre for the country, revealed that heterosexual transmission was the main mode of acquiring HIV among Saudi patients. Women acquire the virus from their spouses, whereas heterosexually infected men acquire it from extra-marital sex. There was low prevalence of HIV by intravenous drug users and low prevalence related to blood and blood products transfusion.

## Impact of stigma

Research in most cultures finds that people living with HIV/AIDS face significant psychological and social problems in addition to their physical ones (Sun *et al*, 2007; Andrade and Anderson, 2008). AIDS-related stigma and discrimination have been seen all over the world, although they manifest themselves differently between countries, communities, religious groups and individuals. AIDS-related stigma refers to unfavourable evaluation, treatment and discrimination of people living with HIV/AIDS. Stigma may also affect the people associated with the person living with HIV/AIDS (Badahdah, 2010). This stigma makes it more difficult for people living with HIV/AIDS to cope with and manage their illness and also makes it difficult to fight the AIDS epidemic as a whole. There is a silence around HIV and it is not straightforwardly discussed in public. If HIV is discussed, it is in an openly prejudiced way, which makes individuals feel overtly discriminated against due to their disease (Daftary, 2012).

HIV stigma contributes significantly and independently to the perception of the quality of life of patients living with HIV/AIDS (Holzemer *et al*, 2009). The UN Secretary-General Ban Ki-Moon stated (Moon, 2008): 'Stigma remains the single most important barrier to public action. It is the main reason why too many people are afraid to see a doctor to determine whether

they have the disease or to seek treatment if so. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world.' The consequences of stigma for persons living with HIV/AIDS were grouped by Holzemer *et al* (2007a,b) under four categories: general health, violence, poor quality of life, and reduced access to care. Holzemer *et al* (2009) reported six main factors related to the stigma of HIV: negative self perception, social isolation, verbal abuse, healthcare neglect, fear of contagion, and workplace stigma.

Saudi Arabia is a conservative society that adheres to a strict interpretation of Islam. Data on the social aspects of HIV/AIDS in the Middle East and North Africa region are insufficient compared to other regions in the world (Obermeyer, 2006; Badahdah, 2010) and the subject of HIV/AIDS is still taboo. Within Saudi Arabia, AIDS is viewed as a moral-religious issue rather than a health condition; the majority of people believe that AIDS is a punishment from God for violating social and religious mores (Badahdah, 2010). The perceived violation of social and religious values arises from the risk of HIV/AIDS transmission from behaviours that Islam prohibits: non-marital sex, homosexuality and intravenous drug use.

Research in Saudi Arabia confirms that attitudes towards people with HIV/AIDS are shaped by the religious, social and cultural framework, and by misconceptions about the methods of HIV transmission among both the general population and healthcare providers (Al-Ghanim, 2005; Badahdah, 2010). This lack of knowledge is significantly and negatively related to stigmatisation of people with HIV/AIDS (Badahdah, 2010); people with more knowledge about HIV/AIDS have more positive attitudes towards people with HIV/AIDS. The concept of shame as a cultural value is closely related to AIDS stigma. In a study of 162 male college students' perceptions of people living with HIV/AIDS, participants believed people with HIV/AIDS should experience shame; it was shameful to have a relative with HIV and shameful for people with HIV/AIDS to live in Saudi Arabia. Participants also believed that people with HIV/AIDS should be isolated from the public (76.3%) and fired from their jobs (59.4%). Some 39% of participants would sever their relationship with a friend who contracted HIV (Badahdah, 2010).

The majority of research on HIV/AIDS in Saudi Arabia measures attitudes and knowledge about HIV/AIDS; no studies have reported on the experiences of those living with HIV/AIDS in Saudi Arabia. This study addressed this issue by exploring and describing the lived experience of people with HIV/AIDS in Saudi Arabia with regards to disclosure of their HIV status;

acceptance by the community; impact on roles, responsibilities and relationships within the family and at work; and accessing health and social services.

## Methods

A descriptive phenomenological approach was used. Husserl valued the experience of phenomena as perceived by human consciousness to reach true meanings through engaging in-depth into real experience (Lopez and Willis, 2004; Abu Shosha, 2012). To ensure validity of data collection, bracketing was used by the researcher in order to declare and put aside personal biases, assumptions and presuppositions. Husserl believed that bracketing helps to gain insight into the common features of any lived experience (Speziale and Carpenter, 2003).

The study was approved by the King Saud Bin Abdul Aziz University for Health Sciences Ethics Committee and the King Khalid National Guard Hospital, Jeddah.

## Sample

A total of 18 adult male and female individuals, aged between 24 and 54, with HIV/AIDS and living in the western region of Saudi Arabia agreed to take part (Table 1). Participants were approached using purposive sampling while attending follow-up HIV clinic appointments at King Khalid National Guard Hospital, Jeddah, from February to October 2012. None of them refused. Participants received an invitation letter describing the purpose of the study, research procedure, and a guarantee to maintain anonymity, privacy and confidentiality of the information. Written consent was obtained prior to the interview. No individual names were recorded during taping or note-taking, or disclosed during interviews. Transcripts were confidential to the primary investigator who completed all transcriptions secured in password-protected confidential files. There was no predetermined sample size but collection continued until saturation of themes was achieved. This occurred at interview 15 and a further three interviews were held to ensure that there was indeed saturation and transferability of the findings.

## Data collection and analysis

Each participant was interviewed once for between 30–60 minutes (Table 2). The recorded interviews were transcribed in Arabic, translated into English, then managed using NVivo 2.0 software. Interview tapes and the transcriptions were validated by two

**Table 1** Participants' profile

	No.		
Gender	18	Male	14
		Female	4
Marital status	18	Single	5
		Married	12
		Divorced	1
Nationality	18	Saudi	18
		Non-Saudi	0
Working status	18	Working	7
		Not working	11
Education	18	Less than High School	9
		High School	9

**Table 2** Interview questions

When and how you know you are infected with HIV/AIDS?  
 Tell me what it meant to you when you discovered you had HIV.  
 How you told your family and how they perceived it?  
 Describe to me how your disease affected your life.  
 Tell me about the problems you encounter and how you handle them?  
 How do you handle the notions of others?  
 Describe to me how you see yourself and your future.  
 Tell me about your experience with the healthcare system.  
 Do you want to add anything else?

persons. The Colaizzi (1978) process for phenomenological data analysis (Speziale and Carpenter, 2007) was used to guide extracting, organizing and analysing the narrative dataset. Each transcript was read several times to obtain a general sense of the whole content. Statements about HIV/AIDS were extracted and recorded. Meanings were formulated from these significant statements and then sorted into themes and subcategories. The findings were integrated into an exhaustive description of the phenomenon and validated with the research participants to compare the researcher's descriptive results with their experiences to validate researcher understanding.

Rigour and trustworthiness were achieved through several techniques to ensure credibility and confirmability. The research team included two Saudi health professionals (nurse and physician) with cultural knowledge of the topic, society and study site, with prolonged engagement with the participants. Peer

debriefing for external validation, in which all the researchers met together, was used after data saturation to examine all aspects of data analysis and findings.

This is done to establish dependability through an audit trail for all aspects of the research process; during data collection, analysis, coding, reflective notes and data reconstruction (Koch, 2006). Following the recommendation of Guba and Lincoln (1985), auditability is the criterion for rigour when dealing with the consistency of data. A study is considered auditable when another researcher can clearly follow the decision trail used by the investigator in the study. In addition, another researcher could arrive at the same or comparable but not contradictory conclusions given the researcher's data, perspective and situation. In this project, an audit trail was established for all aspects of data collection, analysis, and coding, reflective notes and data reconstruction, where construction of

the situation (the experiences of HIV/AIDS patients) relied on fusing all sources of data (Koch, 2006).

## Findings

Data analysis revealed five main themes: disclosure, stigmatisation, religiosity, fear of vulnerability, and lack of psychosocial support from healthcare services. Table 3 shows the frequency of the patterns of the themes and related subcategories.

### Disclosure

All 18 participants expressed great concerns about disclosing their positive HIV status to others: the decision to disclose, to whom and when to disclose was a major issue for them. Three subthemes emerged: to whom to disclose, non-disclosure as a protective measure, and fears about confidentiality.

Participants stated that they would be judged and blamed by others if they disclosed their condition; they did not want anyone to know about their positive HIV diagnosis except their treating physician. For 16 out of 18 participants, only their treating physician and their husband or wife knew about their HIV-positive status. The other two limited the disclosure to one other family member.

'I do not want any person to know about my disease condition...what people will do for me, I don't want even any physician to know, only my treating physician to know.' (Participant no 2)

'People will judge me if they discover my condition. I did not want to tell my spouse at the beginning but I had to do because she has to take all the necessary investigations. She is the only person who knows about my disease condition, no one else knows and she promised me she will not tell anyone else.' (Participant no 12)

Disclosure exposed participants to stigma and discrimination from individuals and from the society as a whole. To protect themselves, they disclosed their positive HIV status to very few people.

'If others know they will not help me, instead they will blame me and distance themselves away, so I do not want anyone to know my disease condition.' (Participant no 8)

'I did not tell anyone except my wife because I fear the discrimination and public negative views.' (Participant no 1)

'I informed my wife immediately because we need to do some family arrangements if I will become very sick or I die.' (Participant no 6)

Participants feared that anyone who knew their HIV diagnosis might tell other people. They worried that the healthcare team would not maintain confidentiality.

'I hope that the hospital keeps my HIV status secret so no one knows. I told my doctor not to tell anyone, especially I have a cousin working in this hospital and I don't want him to know...[cried].' (Participant no 3)

'I asked the medical record clerk once to give me a sick leave (certificate) without writing my diagnosis so people at my work place would not know my disease and it will stay confidential. It is very difficult that people at work know you are an AIDS patient.' (Participant no 17)

**Table 3** Themes and related subcategories

Themes	Subcategories	No.
Disclosure	To whom	18
	Protective measure	14
	Confidentiality	17
Stigmatisation	Discrimination and stereotyping	15
	Society attitude towards HIV	13
	Negative self-image	15
	Feeling shame	18
Religiosity	Religion influence as behaviour	18
	Using religion as coping strategy	16
Fear and Vulnerability	Fear of God punishment	18
	Fear of being discovered	16
	Fear of future and death	17
Lack of psychosocial support		14

The concern about disclosure also impacted on the recruitment of participants into the study as agreement to participate meant disclosure of their diagnosis outside the treating physician and immediate family member. As a result, the recruitment of sufficient participants took longer than expected.

## Stigma

All participants experienced stigmatisation. Three sub-categories emerged under stigmatisation: discrimination and stereotyping; society attitudes towards HIV/AIDS; and feelings of shame and negative self image.

Participants felt that HIV patients were discriminated against by individuals and by society, which affected their ability to work. Fear of discrimination against themselves and their family members contributed to the decision to limit disclosure of their diagnosis.

'I know a neighbour who is HIV-positive after kidney transplantation outside the country; no one is talking to him or visiting their house. I don't want my sons and daughter to suffer discrimination because of my HIV disease.' (Participant no 5)

'I was forced to have early retirement because at my work place they discovered that I'm infected with AIDS. I had a long sick leave so the hospital sent a report and this is how they discovered, and after that I was retired and I am only 40 years old.' (Participant no 17)

Participants felt that people were not as sympathetic toward people who were HIV-positive as they were towards those with other conditions.

'People's feelings toward HIV patients are very bad and they think it is a punishment from God for their sin.' (Participant no 3)

'As a woman I cannot live in my community if they know I am HIV/AIDS patient. People look to AIDS patients as criminals...[crying]... I feel it is better to live alone than having people around me. I did not tell anyone and I don't want anyone to know.' (Participant no 4)

'The attitude of our society on HIV is very bad. We live in the dark and are scared of the people to know because they will treat us bad and look to us bad.' (Participant no 9)

Participants felt helpless and angry as a result of stigmatisation.

'I cry alone, when I feel helpless. I am very scared because I have an 11-years-old daughter...[crying]...who is very close to me and I feel I am not a good mom. I have a very negative self-image.' (Participant no 16)

'I view myself as nothing; I deserve what happened to me. I'm so angry with myself. My disease is a punishment and I want to be punished because I deserve the punishment

more and more. I'm stupid and worthless.' (Participant no 11)

They felt ashamed of themselves and of how their HIV-positive status affected others close to them.

'I'm ashamed of being an AIDS patient. Not only me even my wife has the same feeling, although she does not have the disease.' (Participant no 7)

'I'm an AIDS patient...[crying]...That means I'm cursed ...I'm an evil person...[continued crying]...I'm ashamed for my children because they do not deserve to be judged because of me.' (Participant no 4)

## Religiosity

All participants became more religious after receiving their HIV diagnoses, which they all accepted as destiny (*ghader*, literally 'from God') which is part of the Islamic faith.

'I feel both me and my husband became very religious and our behaviour changed dramatically after our diagnosis. He prays, fasts, pays Sadaqah [meaning charity], reads Qur'an, which were not parts of his life before. We both became near to God.' (Participant no 1)

Spirituality also provided a coping strategy for most of the participants.

'After I was diagnosed I felt so bad and I hated myself but then I calmed down and I visited Makkah and performed *o'mrah*. Then I felt good and that I accepted my disease as wrath of God brought upon me because I committed sin.' (Participant no 13)

## Fear and vulnerability

Participants experienced fears and vulnerability associated with the physical, psychological, spiritual and social changes that occur with the infection of the HIV virus and the prospect of death. These fears included being found out by others and disgrace that would follow and punishment by God because their infection was a punishment for their sin.

'I have fear from God because our god is the only one on earth who knows our inside, good or bad. God knows our thinking, our actions. I am afraid that God will not cure me because I committed a sin, but deep inside I know God is merciful.' (Participant no 15)

'I fear from God. I consider my disease as a purity from all my sins...[crying]...I'm so scared of God's punishment, because it is now and after death.' (Participant no 12)

## Lack of psychosocial support from healthcare services

Participants felt that the healthcare services only provided physical treatment; there was no attention

to psychological or social wellbeing. The damage to their physical health was less than the psychological changes resulting from trying to cope with the diagnosis.

'We need to be referred and seen regularly by someone who can help us cope with this disease and live with our families and society. They only give us medications for the virus, but we suffer psychologically and emotionally.' (Participant no 8)

'Sometimes I feel very depressed and I cry. I feel I need help from other doctors in psychology or a social worker—someone to help me adapt and cope with my new life. My life has changed a lot after this disease.' (Participant no 5)

## Discussion

This first qualitative study about the lived experience of living with HIV in Saudi Arabia confirms the findings of quantitative studies of the local knowledge about social attitudes towards persons living with HIV/AIDS (Badahdah and Foote, 2010; Badahdah and Sayem, 2010). This lived experience was expressed in five themes: disclosure, stigma, religiosity, fear and vulnerability, and lack of psychosocial support.

Disclosure was a major concern and a determining factor for HIV-related stress related to fear of stigmatisation, discrimination and rejection (Rodkjaer *et al*, 2011). The lives of people living with HIV are significantly affected by the process of revealing or hiding their illness status. People living with HIV/AIDS need to maintain control over the decision to disclose their positive illness status and selecting to whom to disclose. These findings are consistent with those of similar studies in African countries (Greeff *et al*, 2008) and among Latina women with HIV/AIDS. Non-disclosure is a way of protecting the self. In cultures in which HIV/AIDS is highly stigmatised the likelihood of disclosure is low (Greeff *et al*, 2008) because of risks to the self and others.

This protective measure isolates the person from both family and external support systems. In Saudi Arabia, the family structure is hierarchical and decisions about an individual's health are made by others, while disclosure of personal and familial issues outside of the family is strongly discouraged (Long, 2011). The person living with HIV is isolated not only from their family support system but from any other support system such as support groups or counselling because disclosure would bring shame on them and their family.

Disclosure also carried the risk that someone would reveal their HIV-positive status to others. Not surprisingly, participants reported lack of psychosocial support. According to Zhou (2009), patients with

HIV/AIDS perceive health workers as being among their most important people and as sources of social support. However, accessing support requires the person to have confidence that confidentiality will be maintained and that they remain in control of their disclosure of diagnoses. This cycle of fear of disclosure, stigma and lack of support was similarly reported in a study of the psychosocial and healthcare needs of persons living with HIV/AIDS in Egypt which has a similar cultural-religious context to Saudi Arabia (Kabbash *et al*, 2008).

Stigma has always been closely associated with HIV/AIDS (Emlet 2007; Liamputtong *et al*, 2009; Badahdah and Foote, 2010; Greeff *et al*, 2010; Sowell and Phillips, 2010). Stigma is classically defined as a social phenomenon that devalues individuals with specific attributes (Goffman, 1963). Lack of knowledge about HIV is major cause of stigmatisation (Badahdah, 2010, Badahdah and Sayem, 2010; Sowell and Phillips, 2010). Perceived HIV stigma has a significant negative effect on the quality of life of people living with HIV/AIDS (Greeff *et al*, 2010) and profound effects on the prevention and control of HIV/AIDS (Hosseinzadeh and Hossain, 2011). Within the context of an Islamic society, AIDS-related shame was found to be a strong predictor of AIDS stigma in a study done in three Arab countries (Badahdah and Foote, 2010).

Saudi Arabia is a very conservative society compared to other Islamic and Arabic countries. HIV/AIDS in Saudi society is perceived as a moral disease and people with HIV/AIDS are perceived as deviant and as deserving the disease for having violated social and religious rules (Hasnain, 2005). These attitudes are a key factor shaping the lived experience of study participants living with HIV/AIDS in Saudi Arabia and stigmatisation of HIV/AIDS persons and their families. Negative and intolerant social attitudes in Saudi Arabia and other Islamic societies such as the United Arab Emirates, Jordan, Bahrain, Kuwait and Yemen are shaped by lack of knowledge about HIV disease (Al-Ghanaim, 2005) in addition to the social-religious context.

Badahdah and Foote (2010) revealed that families and caregivers of persons with HIV/AIDS experience stigma by association and/or have been a target of discrimination in Saudi Arabia. Similar to Badahdah and Foote (2010), the participants in this study confirmed the fear of stigmatisation and family members' stigmatisation by association and this contributed to their feelings of vulnerability. The experience of vulnerability starts when a person is initially confronted with the diagnosis of HIV infection in the absence of psychosocial support and the surrounding stigma of HIV (De Santis and Barroso, 2011); these factors impact on persons living with HIV/AIDS in Saudi Arabia.

Participants used religion as a coping strategy to find meaning or acceptance of their diagnosis. In Islam, the individual needs to seek forgiveness from Allah for sins which, in this instance, led to their positive HIV status. They needed to find acceptance of their condition as predestined (*ghadar*). The use of spiritual actions, such as daily prayers, reading the Qur'an, performing the pilgrimage to Makkah became the path back to their relationship with Allah from which they believed they had strayed through behaviours that are prohibited by Islam. Research in other cultural contexts indicates that individuals with HIV/AIDS reflect on their spirituality after being diagnosed with HIV/AIDS (Turakeshwer *et al*, 2006) and incorporate religious actions in their coping process (Cotton *et al*, 2006; Ironson *et al*, 2006; Trevino *et al*, 2007)

### Limitations

A limitation of this study is the small sample which will hinder the generalisability of the results. It was not possible to interview people who were not registered with and attending a clinic. Also, all interviews were carried out by the first author and this may have caused some bias. However, transcripts were reviewed by the second author. Finally, due to the nature of the subject and the stigma of HIV/AIDS, participants may not have spoken freely during the interviews.

### Conclusion

This study explored the lived experience of persons living with HIV/AIDS in the Islamic society of Saudi Arabia. Societal attitudes towards HIV/AIDS are a key factor in stigmatisation, which leads to discrimination and stereotyping. Participants experienced negative self-image, feelings of shame and a threat to self-worth. Disclosure of their positive HIV status was a great concern including when and to whom; while non-disclosure was a protective measure against stigmatisation. Confidentiality of HIV status, including exposure by the healthcare team was linked to fear of disclosure. Fear and vulnerability included fear of punishment from God, fear of being discovered as an HIV/AIDS patient, and fear of the future and death. Participants experienced lack of psychosocial and emotional support and isolation. In response to the HIV/AIDS experience, all participants accepted their diagnosis as destiny (*ghader*) and became more religious, using spirituality as their main coping strategy. In summary, people living with HIV/AIDS in Saudi Arabia face profound stigma and have great fear of disclosure of their HIV status. Spiritual coping strat-

egies are used to deal with the fears and lack of psychosocial support and feeling of isolation.

### ACKNOWLEDGEMENTS

The authors are sincerely grateful to King Abdullah International Medical Research Centre at National Guard Health Affairs for funding and supporting this research.

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