

# *“I Am Dead to Them”*: HIV-related Stigma Experienced by People Living With HIV in Kerman, Iran

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*People living with HIV (PLWH) are often subject to discrimination. The causes, types, and consequences of this stigma in Iran are not yet fully understood. In-depth, semi-structured interviews were held with a purposively selected group of 25 PLWH recruited from a triangular HIV clinic in Kerman, Iran. Almost all participants reported experiencing internal and external stigma in a variety of contexts. Participants mentioned at least three major types of internal stigma (silence, shame, and feeling miserable). PLWH also reported experiencing external stigma from their families, communities, and the health care system. While previous studies have demonstrated that the Iranian public has reported fairly positive attitudes toward PLWH, our participants' experiences tell a different story. Therefore, it is imperative to engage both public and private sectors in continuing education programs to reduce the level of stigma faced by PLWH.*

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Stigma was defined by sociologist [Erving Goffman \(1963\)](#) long before the arrival of HIV as “an attribute that is deeply discrediting,” suggesting that the stigmatized person is reduced “from a whole and usual person to a tainted, discounted one” (p. 3). Building

upon Durkheim’s conception of social deviance, Goffman described a stigmatized person as one who deviated from socioculturally prescribed norms, a characterization that would spoil the individual’s sense of personal identity. Stigma has been defined as an influential, yet disgraceful social label that totally changes the way people perceive themselves and how they are seen as individuals by society ([Visser, Makin, Vandormael, Sikkema, & Forsyth, 2009](#)). However, while the phenomenon of stigma has engendered broad theoretical and practical research, there is still no definite and common theoretical framework on stigma in the sociology literature.

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Stigma interferes with the support, care, treatment, and prevention of illness. As stigmatized individuals possess a characteristic that tags them as “different” in a negative light, such attribution presents a series of profound implications on issues pertaining to their health. For instance, HIV-related stigma is associated with negative self-perceptions (Frable, Wortman, & Joseph, 1997), decreased health care utilization (Reece, Tanner, Karpiak, & Coffey, 2007), lower rates of HIV-status disclosure, lower rates of HIV testing (Venable, Carey, Blair, & Littlewood, 2006), decreased health-related quality of life (Holzemer et al., 2009), and lower medication adherence in both men and women (Carr & Gramling, 2004; Venable et al., 2006; Waite, 2008). Stigma can be felt internally, resulting in a reluctance to seek professional help. It can also be external, leading to discrimination from others based on HIV status or association with someone who is living with HIV (Holzemer et al., 2007). In other words, stigma and discrimination surrounding HIV can be as destructive as the disease itself (Marais & Crewe, 2005).

The number of people living with HIV (PLWH) has lately increased throughout Asia, including the Middle East (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2009). Additionally, UNAIDS states that in the Middle East and North Africa region, the HIV epidemic has been on the rise since 2001. The rise in the estimated number of PLWH in the region has been attributed to increased HIV prevalence among key populations at higher risks and transmission of the virus to a higher number of people who are normally at a lower risk of infection. In Iran, the HIV epidemic is rising at a considerable rate and is principally concentrated among injection drug users and sex workers (Fallahzadeh, Morowatisharifabad, & Ehrampoosh, 2009).

According to the Joint United Nations Programme on HIV/AIDS Global Report (UNAIDS, 2013), 95,000 people were estimated to be living with HIV in Iran by the end of 2012, and the HIV prevalence rate in Iran was estimated to be at 0.2%. No more than 10% of PLWH in the country were infected due to unprotected sexual contact, and most HIV infections appeared to be related to injection drug use (UNAIDS, 2009). However, sexually transmitted HIV infections are rising quickly, representing a shift in the mode of

transmission from drug use to sexual behaviors (Fallahzadeh et al., 2009; Haghdoost et al., 2011).

Although more than 25 years have passed since the epidemic's onset, PLWH in Iran, as in other global, sociocultural contexts, have been victims of stigmatization, experiencing discrimination in their interactions with society. While there is a growing literature on HIV-related stigma, very few studies have been conducted on this topic in Iran (Rahmati-Najarkolaei et al., 2010), and these have not addressed the perspectives of PLWH regarding their interactions with others, including family, friends, and society. A recent study reported that, of 289 HIV-infected patients recruited from six major cities in Iran, the majority had experienced considerable internal and external stigma (99% and 62%, respectively; SeyedAlinaghi et al., 2013). There is a crucial need to better understand HIV-related stigma in Iran. In our study, we concentrated on and explored the underlying social and contextual factors in Iran that could lead to stigmatizing attitudes and behaviors against PLWH at different micro and macro levels. Assessing how PLWH perceive and experience the behaviors and attitudes of others in society is of high importance and could help health care providers develop more efficient interventions. Therefore, our qualitative study was carried out to examine the less-often-explored scope of HIV-related stigma among PLWH and shed more light on their lived experiences in Iran.

## Methods and Procedures

In our qualitative study, a convenience sample of potentially eligible participants (those who were willing to take part in the study) was recruited between September and November 2011 from the triangular HIV center in Kerman; these patients were relatively easy to access. The triangular clinic provides specific services including medical and psychological care as well as methadone maintenance therapy to HIV-infected patients and was established in 2004 in Kerman. Because the patients did not know us, and would not have trusted us, the staff was approached to help build trust and urge patients to take part in interviews. Staff and counselors at the center were briefed on the objectives and methods of the study.

The physician at the clinic introduced patients who consented to participate in the study to the interviewer.

### Data Collection

Using a convenience sampling method, a total of 25 participants were recruited. They provided verbal consent to be interviewed and a nonmonetary incentive of food worth \$8 USD was provided to all the participants. The target number of recruits for the study was based on thematic saturation with the option to recruit further participants if saturation was not achieved. Saturation occurred after 25 interviews.

The main author conducted in-depth interviews in Persian in a private room in the triangular clinic. Participants were interviewed once, with the semi-structured interview consisting of open-ended and discovery-oriented questions, followed by appropriate probing regarding personal perceptions and lived experiences of HIV-related stigma. The interview questions included but were not limited to the following: *How do you feel about your disease? How has your disease influenced your interaction with your friends and family members? What have you experienced while seeking health care services?* Participants were asked to recount personal stories and to describe their viewpoints based on lived experiences. Participants appeared comfortable in the interviews, maintaining eye contact, and speaking openly. While the interviews followed an interview guide exploring five dimensions related to HIV, including addiction, high-risk sexual behaviors, stigma, methadone therapy, and knowledge about HIV, this paper presents only the findings regarding HIV-related stigma faced by the participants. Each interview lasted approximately 45 to 60 minutes, but some interviews lasted up to 90 minutes. Interviews were audio recorded and transcribed verbatim on the day of the interview. In order to explore the primary themes, transcripts were coded manually and put into categories. All co-authors then reviewed the transcripts and listened to the audio recordings of the interviews for accuracy.

### Data Analysis

The main author used the transcripts to conduct the data analysis. The transcripts were read several times, manually coded, and sorted into groups to explore the

primary themes. Using a thematic analysis, matrix-based method, the researchers identified key themes and associated sub-themes that collectively emerged from the interviews. Data were explored further for detection of recurring themes. All co-authors checked the data interpretation for credibility and ensured the systematic and verifiable nature of the analysis. Disagreements among the researchers about the data analysis, interpretation, and themes were settled through group discussions. Ultimately, two main themes were classified: internal and external stigmas.

### Ethical Considerations

Ethical issues in our study included the guarantee of the participants' confidentiality and consent. No demographic information was obtained from the participants. Participants were informed about the purpose of the study, the voluntary nature of their participation in the interviews, and the anonymity of all collected data before providing verbal informed consent for participation. Moreover, no information was shared with the staff of the center, and all records and transcriptions were coded and secured in a password-protected file. Verbal permission was obtained to record the participants' voices during the interview. Refusal to participate in the study did not in any way interfere with or influence the services provided to the participants or the treatment received in the center. The ethics committee of the Kerman University of Medical Sciences reviewed and approved the study.

## Results

### Participants

The 25 participants recruited for the study included 19 men and 6 women. Their ages ranged between 18 and 60 years; all were living with HIV and most had a history of drug use. The female participants were mainly widows, while male interviewees were either divorced or single. Most men believed they had become infected through sharing syringes, whereas women assumed that they had contracted the virus via sexual contact with their infected husbands. More detailed sociodemographic information was not asked in order to protect confidentiality.

Two main themes of HIV-related stigma were described by PLWH. The themes that emerged from the in-depth interviews were Internal Stigma and External Stigma. Table 1 shows an overview of the themes and sub-themes.

### Internal Stigma

The three main sub-themes of internal stigma experienced by the participants will be elaborated upon below. These themes include: nondisclosure of HIV-infection status, shame and isolation, and feeling miserable.

*Nondisclosure of HIV status.* Most of the participants had not revealed their diagnosis of HIV to anyone. Both men and women preferred to remain silent about it; however, some had disclosed their HIV-infection status to close family members only. A woman who had tried to conceal her disease in the early days of knowing about her HIV status said, “I didn’t let anyone, particularly my family, realize that I am HIV positive for a couple of years, but they finally figured it out somehow.” A male participant who was worried about revealing his HIV diagnosis stated,

“When I was told about my HIV infection after taking the test, the doctor asked me to inform my family, but I did not want them to know as my family would spread gossip about me.”

Participants who tried to satisfy their families’ curiosity by simply lying to them about their HIV status described similar perceptions. A woman whose mother-in-law had become suspicious about her disease indicated, “I did not tell anyone anything about my disease for 9 years. I even told my mother-in-law I am taking all this medication because of breast cancer.” Another woman who had given a similar excuse to her own mother declared, “When I found out about my disease, I told everyone that I am experiencing a ruptured ovarian cyst.”

Some individuals wanted to maintain their secret for the sake of their families’ reputations. They regarded nondisclosure of HIV as a sacrifice for their loved ones. A woman stated, “I have got a son and a daughter who are about to get married. I won’t let anyone know, specially because of our family reputation.” A middle-aged man said, “I don’t want to ruin my family’s reputation. I have children and I know how people would treat them if they find out about my health status.”

Some individuals reported having trouble talking about the disease to their lovers, as they were stricken with the dilemma of losing or infecting them. A young man who was concerned about HIV transmission to his lover indicated, “Although I am in a relationship, I will never get married so that no one would realize I am living with HIV. I don’t want to ruin someone else’s life.” A male patient described his brother’s experience this way, “I prefer not to tell anyone that I am HIV positive. You know, my brother is also infected with HIV and is in love with a girl, but he is scared of losing her if his secret is unveiled.”

*Shame and isolation.* Most participants felt inconvenienced and ashamed whenever they were obligated to let someone (i.e., health care providers) know that they were living with HIV. Most of them were afraid of being judged by others who they feared would classify the infection as a punishment for performing immoral acts and, therefore, a just reward for engaging in such immorality. A middle-aged woman remarked,

It is very difficult for me to tell my children about my infection and explain the reason behind it.

**Table 1. Identified Themes and Sub-Themes of HIV-Related Stigma in Iranian People Living with HIV Infection**

| Themes          | Sub-Themes  |
|-----------------|---|
| Internal stigma | Nondisclosure of HIV-infection status<br>Shame and isolation<br>Feeling miserable   |
| External stigma | Experiences with the family <ul style="list-style-type: none"> <li>● Avoidance, rejection, and anger</li> <li>● Family members’ fear of contracting HIV</li> </ul> Experiences with the community <ul style="list-style-type: none"> <li>● Being labelled or treated as a social outcast</li> <li>● Shunning behavior</li> <li>● Workplace experiences</li> </ul> Experiences with health care providers <ul style="list-style-type: none"> <li>● Refusal of care and service</li> <li>● Sub-optimal care</li> <li>● Unnecessary precautions and physical distancing</li> <li>● Degradation or verbal and non-verbal blaming</li> </ul> |

How am I supposed to convince them that it has not been my fault? How can I avoid that “you deserve this” look?

Some also preferred not to be seen at public events, such as wedding ceremonies, family reunions, and birthday parties. A young woman who was self-isolated declared, “Since I found out that I am HIV positive, I have not attended any family party or weddings. I do not want to see anybody or be seen.”

*Feeling miserable.* All participants expressed misery about their HIV status. Some individuals assumed that they were left alone to die and that people would no longer care about them and their living status. A woman, who blamed herself for her infection, complained about her situation, “Why am I so miserable? Who knows what is happening to us and how much we suffer?” A man who was an injecting drug user and reported being homeless said, “Sometimes when I sleep in the park and wake up in the morning, I find a stray dog lying next to me. What is this miserable life I am living?”

Most participants had lost hope and felt frustrated about the situation, with some preferring to die rather than continue to live. A middle-aged woman who was tired of her living conditions said, “I hate this wretched life and I detest myself. I hope it will all end soon. I wish I would die!” Another woman, who lamented her life, declared that, “Nobody knows about the way we strive to live. I feel useless and think my life is really pointless. I feel sorry for what I have done.”

A number of patients expressed regret about their former risky behaviors and a desire to turn back time and somehow prevent the infection. One woman shared her feelings, “You got to believe me; I am a devout and religious woman. Oh, God! What have I done to deserve this?” A young man who blamed himself for risky behaviors that resulted in his HIV infection said, “Sometimes I say to myself that if I had led a normal healthy life, I would have never ended up here. Sometimes, I feel this is mostly my fault. What if I could make it up somehow?”

### External Stigma

Three main subthemes of external stigma were identified. The main subthemes described HIV-related stigma experienced within the family, com-

munity, and health care system. Each main subtheme has additional subthemes.

*Experiences with family.* The two subthemes related to the family were: (a) avoidance, rejection, and anger; and (b) family members’ fears of contracting HIV.

PLWH in our study experienced extreme reactions of avoidance, anger, and rejection from their families. A middle-aged male injecting drug user stated, “My family doesn’t want to see me anymore and have asked me to contact them by phone only.” A young male participant who had started abusing drugs at the age of 11 years declared, “My brothers and sisters were avoiding me all the time; however, since the holy month of Ramadan, when I started fasting, they have started to treat me better.” Another man, whose wife had left him after discovering his HIV status, spoke of his family’s reaction, “My own family members say they hate me and that I am dead to them. What can I expect from others?”

Several female participants reported being mistreated by their own families; however, others had experienced stigma from their husbands’ families. A woman whose husband was a drug dealer said, “I am sure I got infected from my husband, but my father-in-law told everyone in the family that it was me who became HIV positive first and keeps blaming me.” The mother-in-law of another woman mistreated her in several ways and repeatedly gossiped about her disease in the neighborhood and even at her workplace. Accordingly, she could not find or keep a job, she added, “My mother-in-law called me names when she found out, and tells me, ‘you are dangerous!’” Another female participant reported, “My husband’s family treats me well, although most of them are addicts. However, my five brothers and sisters are very successful and respectable and I have not dared to tell any of them yet.”

Some family members kept a physical distance from their HIV-infected relatives, asking them to eat and sleep on their own, use distinct utensils, and a separate toilet. A man who was trying hard to educate his family about HIV transmission described his situation,

Even my parents left me when they found out about my disease, let alone my brothers and sisters. My step mom tells me not to kiss my

children as they may get infected. I have tried to educate them with a couple of brochures I got from the clinic.

One man who was living with his niece stated, "They don't want to eat with me and stand far away when speaking to me. Nobody kisses me anymore." (In the Iranian culture, people kiss each other on the cheek as a greeting custom, and refusing to do so is considered disgraceful.) A man who had not told anyone but his older sister about his disease said,

My family are scared of catching HIV from me; however, I keep telling them that it is not spread through casual contact, but they won't believe me due to literacy issues. I have to eat and sleep alone, and my sister does not want me to touch her kids.

Some PLWH indicated that their partners divorced or left them after becoming aware of their HIV-infection status. They believed this happened because of their partners' fears of catching the disease. A male participant indicated that, "My wife got divorced and left me when she realized about my disease and I am living on my own at the moment." Another man who had recently told his wife about his disease said, "My wife would not sleep with me anymore and keeps away from me. She told me to sleep on the sofa the very first night I talked about my HIV diagnosis."

*Experiences with the community.* The three sub-themes related to the community interactions were: (a) being labeled or treated as a social outcast, (b) shunning behavior, and (c) workplace experiences.

Participants often complained about people's perspectives, attributing HIV infection to immoral and unacceptable acts, such as drug injection and prostitution, whether or not these individuals had actually ever been involved in such behaviors. Furthermore, some participants reported experiencing the double stigma of both living with HIV and being an injection drug user. A man who reported being a rich contractor in a small town spoke of his experience, "I went to a supermarket to get a pack of cigarettes, but he refused to sell it to me. He also told me not to touch his scale because he assumed that I was dirty." A man who was living with his overcautious sister spoke generally about how people treat those who are both HIV-infected and injecting drug users,

"The way they treat us is disgusting, but I am used to their behavior. In fact, the way they treat addicts is very dishonorable, let alone us!" A male participant who was angry about the way people treated him indicated that, "We are all rejected everywhere and no one gives a damn about us. Sometimes I am treated as if I am an alien."

Most of the participants also reported not being happy with the fashion in which people on the street spoke to them in horrible disgraceful tones, merely due to their physical appearance. A female participant reported, "I told the taxi driver that my leg hurts and please drop me off a little farther away, but he rudely replied, 'Go get lost you filthy junky'."

Some of the PLWH complained that sometimes others diverted eye contact with them, gave them looks of pity, or whispered about them, making them feel insecure about themselves. Some people who knew our participants were living with HIV would leave when they arrived, would not sit next to them, and would avoid shaking hands with or touching them. A male drug user who complained about kids throwing stones at him stated,

They kicked me out of the house and I am living in the ruins of a house near a park. Everybody keeps a physical distance from me in the neighborhood. They never look me in the eye, and call me "dirty AIDS guy."

Interviewees made sure their disease remained hidden from the public by adopting certain behaviors. For example, people with visible signs of advanced HIV would try not to appear in public or would refrain from looking for a job. They tended to self-isolate as much as possible. A woman who was concerned about the way she would look in the future said, "I take the bus to get to the clinic so none of my neighbors would know about it. If they find out they would keep a distance from me."

Some also left their hometowns to save their families' reputations and to keep their secret. A middle-aged man who had traveled more than a thousand miles to keep away from his hometown indicated,

I come from a respectful family; my dad has a good reputation in town, and my sister is a religious woman. That is why I had to leave the town and move here. I didn't want to ruin my family reputation.

Another man had left his village and moved to Kerman to get away from shunning behaviors. He said, "It is not that big of a deal in Kerman. The parents take their son to the clinic to get his medication, but it is totally a different story in our town."

Both government and private employers served as major sources of rejection and resentment toward PLWH. Some PLWH assumed that their employers would fire them, demote their positions, or decrease their pay if their disease status were to be discovered. A male chef described, "When my employer found out about my disease, he fired me and told me that they do not need me anymore." Another man who reported being an instructor in an office stated: "I was working in an educational office in Kerman, but when they were told about my disease, I got the ax." One man was also denied employment due to his health status and refused to continue his job search, citing hopelessness. A man who had lost several jobs said, "Who is willing to give us a job? Absolutely no one!" And a man who declared being frustrated about finding a job reported, "I am unemployed since they found out about my infection. I won't look for a job anymore."

Some participants stated that close family members had been victims of stigma in their workplaces, and some had even lost their jobs. A woman who complained about being treated unfairly spoke of her sister's experience at work, "They asked my sister to take a test at work. This is really embarrassing for her. Who are these people?!" Another woman was angry with school staff for revealing her illness to her son. She said, "The way people treat me is really awful. They even disgrace my son at school by asking questions about my disease! He has done nothing wrong. He is only a kid for God's sake!" A man whose wife worked in a hospital complained, "My wife was working in the surgery ward of the hospital but got fired when the hospital staff realized I am HIV positive."

*Experiences with health care providers.* People living with HIV discussed the anger and avoidance they experienced with health care professionals. Participants believed that health care providers were afraid of contracting HIV and had a tendency to hold negative perceptions of drug injection, sex work, and faithlessness. The three subthemes related to health care providers were: (a) refusal of care and

service, (b) sub-optimal care, (c) unnecessary precautions and physical distancing, and (d) degradation or verbal and nonverbal blaming.

With no exception, all participants had experienced denial of care and service by health care providers. They stated that health care providers, including nurses, physicians, and dentists, sometimes refused to provide them with required health services after discovering that the person had HIV infection. PLWH felt that a major cause of this behavior stemmed from the fear of catching HIV. A young woman said, "I went to see a gynecologist one day and when I told her about being HIV positive she told me to leave and refused to examine me." Most of the participants had suffered stigma when seeing the dentist. A woman described her experience, "I went to the dentist the other day and when I told him about my infection, he yelled at me and said, 'I am sorry but I cannot help you. Go somewhere else'." A man complained about the service in a referral hospital and said,

I got hospitalized in a medical center some time ago, but when they realized about my infection, they released me from the hospital against my will immediately. Nurses would even refuse to remove my catheter for me and told me, "Do it yourself."

A number of participants reported receiving sub-optimal care after informing their health care providers about their illness. A man who was referred to a physician for his sore feet described his experience: "I went to see a doctor who has been aware of my infection. To my surprise, he didn't examine me at all and just wrote the prescription. He did not even bother checking my wound." Some stated that, due to the experience of being shunned by health care providers, they would no longer tell physicians anything about being infected with HIV so they could continue receiving health care. A woman who had never talked about her disease when seeking health care said, "I have never faced any problem because I never tell anyone." A man who preferred not to visit a physician anymore indicated that, "It is obvious that when I see how they mistreat me, I would not reveal my secret and refuse to see a doctor."

A few participants had experienced excessive and unnecessary precautions taken by their care providers to avoid disease transmission. Some described how a

provider would not touch them or would keep physical distance from them. Some were surprised by this reaction as they assumed that those involved in the medical profession were well informed about HIV transmission and would thus not fear contracting HIV through casual contact. A man who had attempted suicide several times reported,

Once, I attempted suicide by cutting a vein on my hand, but they took me to the hospital in time. I was covered with blood and I could see the fear in the doctor's eye. I told him to be cautious and put on medical gloves.

Another man, who had been referred to a hospital for X-ray studies stated, "Once, I was admitted into a hospital and they would change any sheet I would barely touch, immediately."

One female hospital staff member reported that she lost her job when the ward head learned about her HIV status. She said,

I used to work in the clinical examination ward in a hospital not a long time ago. I had to clean and scrub the surgical and clinical instruments, and one day the doctor in charge of that ward told everyone I might spread the infection. I felt terrible and resigned the next day.

Most participants described experiences of being humiliated and blamed, both verbally and nonverbally, by health care providers. Some reported providers whispering about them and calling them thieves. A female patient stated, "It is really hard when you are sick, and they give you the look. They think we are all thieves and criminals but I am not."

## Discussion

Our study adds to the findings of similar studies regarding stigma in Iran by analyzing new dimensions and themes of HIV-related stigma in the country (Rahmati-Najarkolaei et al., 2010). As the resulting narratives suggest, HIV-related stigma often leads to HIV nondisclosure by interview participants. Several reasons for nondisclosure were identified, reflecting PLWH attempts to avoid others viewing them and their families with disapproval.

We observed that PLWH tried to save face and avoid dishonor by concealing their disease, a behavior

that seems to have stemmed from various deeply rooted cultural standards. The concept of "face" can be described as a combination of social status, reputation, honor, and dignity, which collectively interact to form one's personal identity in the community. Thus, causing someone to lose face lowers them in the eyes of their peers, while saving face raises self-esteem and perceived social standing (Goffman, 1963). Several studies support the finding that many honor-based Asian countries care deeply about issues surrounding "face" on both individual and familial levels because family is the center unit of such societies (Busza, 1999). In a recent study in China, people assumed that having one HIV-infected family member was considered a terribly regrettable event for the whole family. Consequently, PLWH worried that disclosure of their HIV status to the community would negatively affect their families regarding employment and social support (Li et al., 2008).

Iran is a family-oriented society, in which individual experiences cannot be fully separated from family matters (Javidan & Dastmalchian, 2003). The concept of saving face in Iran may originate from traditional education. The finding that social stigma is associated with the presumption that HIV is transmitted through injection drug use, sex work, adultery, or other acts perceived to be morally dubious has been discussed in the literature (Busza, 1999; Carr & Gramling, 2004; Duffy, 2005). Likewise, a substantial percentage of Iranians are traditional and religious, not welcoming such immorally perceived behaviors, which consequently exacerbated the levels of stigma experienced by PLWH. Several themes described in our study may be associated with the Iranian cultural conception of saving face, in which people behave in a certain way to prevent themselves and their family members from being viewed negatively by the community. Our findings regarding saving face and avoiding dishonor reinforced the findings of two studies carried out in China and Vietnam describing how HIV-related stigma led to losing face among PLWH, bringing disgrace and embarrassment to the entire family (Gaudine, Gien, Thuan, & Dung, 2010; Li et al., 2008).

Although HIV is less prevalent in Muslim countries, likely due to religious beliefs and bans regarding HIV-related risky behaviors, HIV-related stigma in such countries is more profound (Ebrahim &

Nawab, 2007; Huang & Hussein, 2004; Kaadan, 2004). All participants in our research assumed that people's discriminatory behaviors were due to ignorance about how HIV is contracted. Interestingly, health care providers sometimes exemplified such behavior more than other people in society. In a recent qualitative study in Iran, participants experienced discrimination and stigma by their health care providers in various ways (Rahmati-Najarkolaei et al., 2010). The relationship between physicians and patients in Iranian culture is built on trust and physicians are considered to be confidants, to whom one can tell his or her confidential health data. Accordingly, when patients who are living with HIV face stigma and rejection from physicians, they find themselves in a frustrating situation, subsequently trying to find ways to avoid such stigmatization while continuing to seek health services. This discriminatory practice is not unique to Iran and has been frequently documented in health care providers around the world (Carr & Gramling, 2004; Gaudine et al., 2010; Lekganyane & du Plessis, 2011; Makoae et al., 2008; Rahmati-Najarkolaei et al., 2010). What is consistent with previous findings is that participants in our study faced a high level of stigma when going to the dentist (Burris, 1999; Carr & Gramling, 2004; Zukoski & Thorburn, 2009). As a result, rejection and discrimination caused some PLWH to conceal their HIV status and to stop taking their medications. Because these individuals no longer take antiretroviral medications, they are at an increased risk of having higher HIV viral loads. This increases the potential for transmitting HIV, which can decrease the effect of ongoing prevention programs and cause greater losses of public health financial resources. Discriminatory behaviors may have roots in the lack of education or the gap between knowledge and practice in health care providers. It seems that although medical education in Iran provides physicians with education about HIV during trainings, it has failed to fully translate the knowledge gained through curriculum into practice. Although strong evidence supports the low risk of contracting HIV for health care providers as long as basic safety precautions are carried out (Duffy, 2005; Genberg et al., 2009; Holzemer et al., 2009; Lekganyane & du Plessis, 2011), health care staff seem to be afraid of contracting HIV through

casual contact not known to spread HIV. Some studies have supported the opinion that misconceptions about modes of HIV transmission can lead PLWH to receive suboptimal care (Surlis & Hyde, 2001; Ulasi et al., 2009; Vance & Denham, 2008). Clearly, the importance of continuing education and putting knowledge into practice becomes even more important in managing HIV-related stigma.

One should bear in mind that the types of stigma and their associated themes experienced by PLWH can be dissimilar in different geographical locations. Studies have supported the idea that HIV-related stigma and its consequences may be experienced differently in Asian countries with their distinctive cultures (Huang & Hussein, 2004; Li et al., 2008). However, some of these consequences have been noted in similar studies around the globe (Carr & Gramling, 2004; Gaudine et al., 2010; Genberg et al., 2009). Regardless of location, discriminatory behaviors are concerning and can give rise to protective reactions such as self-isolation and concealing the disease from health care providers, families, and work colleagues.

### Limitations

Although our research explored the dimensions of HIV-related stigma in Iran, we acknowledge the limitations of this study. For instance, only 25 PLWH participated in the study in the only triangular clinic of Kerman. The level of stigma experienced by our participants may be different in different geographical regions with different cultures and the results may not be generalized to all Iranian PLWH. Moreover, the type and level of stigma experienced by people in earlier or later stages of HIV infections may vary, which was not taken into account in this study.

### Conclusions

Although Iran is one of the leading Middle East countries advancing HIV prevention programs (UNAIDS, 2009), very few studies have been conducted on HIV-related stigma in Iran (UNAIDS, 2009). More qualitative research is needed to shed additional light on the concept of HIV-related stigma in the country. Educating people, including clinical

staff (especially dentists) through continuing well-coordinated discussions in the media, in particular, could play an important role in reducing the level of stigma faced by PLWH in Iran. Our study also suggests that HIV clinics refer patients to health care providers through an official system so that PLWH would face fewer rejections when seeking medical and dental care. While Islamic teachings suggest strict penalties for adultery and sex work, it is also a religion of compassion and equity, which condemns discriminatory behavior against people. Such aspects of religion should be highlighted and used to lower the level of stigma and intolerance PLWH face in Iran. In addition, seeking help from clergymen to develop anti-stigma programs can be beneficial. Religious leaders should be educated about HIV and be encouraged to teach tolerance and acceptance of those living with HIV.

### Key Considerations

- Nurses in Iran can help individual patients disclose their HIV status to family members because disclosing to family members can help families accept people living with HIV infection (PLWH).
- Nurses as well as other health care workers can correct misbeliefs about HIV transmission in social and work situations throughout the country.
- Psychological nursing care can be an effective way to help PLWH re-establish a positive attitude toward life and keep their hopes high.
- As PLWH are highly sensitive to reactions from others, and health care workers in particular, nurses should avoid judging patients (intentionally or not) and should use unbiased words.

### Disclosures

The authors report no real or perceived vested interests that relate to this article that could be construed as a conflict of interest.

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### References

- Burris, S. (1999). Studying the legal management of HIV-related stigma. *American Behavioral Scientist*, 42(7), 1229-1243. <http://dx.doi.org/10.1177/0002764299042007012>
- Busza, J. (1999). Literature review: Challenging HIV-related stigma and discrimination in Southeast Asia: Past successes and future priorities. Retrieved from [http://www.popcouncil.org/uploads/pdfs/HORIZONS\\_paper.pdf](http://www.popcouncil.org/uploads/pdfs/HORIZONS_paper.pdf)
- Carr, R. L., & Gramling, L. F. (2004). Stigma: A health barrier for women with HIV/AIDS. *Journal of the Association of Nurses in AIDS Care*, 15(5), 30-39. <http://dx.doi.org/10.1177/1055329003261981>
- Duffy, L. (2005). Suffering, shame, and silence: The stigma of HIV/AIDS. *Journal of the Association of Nurses in AIDS Care*, 16(1), 13-20. <http://dx.doi.org/10.1016/j.jana.2004.11.002>
- Ebrahim, M., & Nawab, S. (2007). *HIV/AIDS prevention: An Islamic perspective experience from South Africa. Federation of Islamic Medical Associations Year Book (pp. 91-100)*. Amman, Jordan: Jordan Society for Islamic Medical Sciences.
- Fallahzadeh, H., Morowatisharifabad, M., & Ehrampoosh, M. H. (2009). HIV/AIDS epidemic features and trends in Iran, 1986-2006. *AIDS and Behavior*, 13(2), 297-302. <http://dx.doi.org/10.1007/s10461-008-9452-7>
- Frale, D. E. S., Wortman, C., & Joseph, J. (1997). Predicting self-esteem, well-being, and distress in a cohort of gay men: The importance of cultural stigma, personal visibility, community networks, and positive identity. *Journal of Personality*, 65(3), 599-624. <http://dx.doi.org/10.1111/j.1467-6494.1997.tb00328.x>
- Gaudine, A., Gien, L., Thuan, T. T., & Dung, D. V. (2010). Perspectives of HIV-related stigma in a community in Vietnam: A qualitative study. *International Journal of Nursing Studies*, 47(1), 38-48. <http://dx.doi.org/10.1016/j.ijnurstu.2009.06.004>
- Genberg, B. L., Hlavka, Z., Konda, K. A., Maman, S., Chariyalertsak, S., Chingono, A., ... Celentano, D. D. (2009). A comparison of HIV/AIDS-related stigma in four countries: Negative attitudes and perceived acts of discrimination towards people living with HIV/AIDS. *Social Science & Medicine*, 68(12), 2279-2287. <http://dx.doi.org/10.1016/j.socscimed.2009.04.005>
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York, NY: Simon and Schuster.

- Haghdoost, A. A., Mostafavi, E., Mirzazadeh, A., Navadeh, S., Feizzadeh, A., Fahimfar, N., ... Nasirian, M. (2011). Modeling of HIV/AIDS in Iran up to 2014. *Journal of AIDS and HIV Research*, 3(12), 231-239. <http://dx.doi.org/10.5897/JAHR11.030>
- Holzemer, W. L., Human, S., Arudo, J., Rosa, M. E., Hamilton, M. J., Corless, I., ... Moezzi, S. (2009). Exploring HIV stigma and quality of life for persons living with HIV infection. *Journal of the Association of Nurses in AIDS Care*, 20(3), 161-168. <http://dx.doi.org/10.1016/j.jana.2009.02.002>
- Holzemer, W. L., Uys, L. R., Chirwa, M. L., Greeff, M., Makoae, L. N., Kohi, T. W., ... Phetlhu, R. D. (2007). Validation of the HIV/AIDS Stigma Instrument—PLWA (HASI-P). *AIDS care*, 19(8), 1002-1012. <http://dx.doi.org/10.1080/09540120701245999>
- Huang, M., & Hussein, H. (2004). The HIV/AIDS epidemic country paper: Malaysia. *AIDS Education and Prevention*, 16(Suppl. A), 100-109. <http://dx.doi.org/10.1521/aeap.16.3.5.100.35532>
- Javidan, M., & Dastmalchian, A. (2003). Culture and leadership in Iran: The land of individual achievers, strong family ties, and powerful elite. *Academy of Management Executives*, 17(4), 127-142. <http://dx.doi.org/10.5465/AME.2003.11851896>
- Joint United Nations Programme on HIV/AIDS. (2009). 2008 Report on the global AIDS epidemic. Retrieved from [http://www.aids2031.org/pdfs/un aids\\_08executivesummary\\_en\(1\)http://www.aids2031.org/pdfs/un aids\\_08executivesummary\\_en\(1\).pdf](http://www.aids2031.org/pdfs/un aids_08executivesummary_en(1)http://www.aids2031.org/pdfs/un aids_08executivesummary_en(1).pdf)
- Joint United Nations Programme on HIV/AIDS. (2013). Global report: Report on the global AIDS epidemic, 2013. Retrieved from [http://www.unaids.org/en/media/un aids/contentassets/documents/epidemiology/2013/gr2013/UNAIDS\\_Global\\_Report\\_2013\\_en.pdf](http://www.unaids.org/en/media/un aids/contentassets/documents/epidemiology/2013/gr2013/UNAIDS_Global_Report_2013_en.pdf)
- Kaadan, A. (2004). The stigma attached to AIDS in Muslim countries: How to erase it. Retrieved from <http://d10.cgpublisher.com/proposals/412/index.html>.
- Lekganyane, R., & du Plessis, G. (2011). Dealing with HIV-related stigma: A qualitative study of women outpatients from the Chris Hani Baragwanath Hospital. *Journal of the Association of Nurses in AIDS Care*, 23(2), 155-162. <http://dx.doi.org/10.1016/j.jana.2011.05.003>
- Li, L., Wu, Z., Wu, S., Jia, M., Lieber, E., & Lu, Y. (2008). Impacts of HIV/AIDS stigma on family identity and interactions in China. *Families, Systems, & Health*, 26(4), 431-442. <http://dx.doi.org/10.1037/1091-7527.26.4.431>
- Makoae, L. N., Greeff, M., Phetlhu, R. D., Uys, L. R., Naidoo, J. R., Kohi, T. W., ... Holzemer, W. L. (2008). Coping with HIV-related stigma in five African countries. *Journal of the Association of Nurses in AIDS Care*, 19(2), 137-146. <http://dx.doi.org/10.1016/j.jana.2007.11.004>
- Marais, H., & Crewe, M. (2005). Buckling: The impact of AIDS in South Africa. Retrieved from [http://www.sarpn.org/documents/d0001789/Buckling\\_AIDS\\_2005\\_Full.pdf](http://www.sarpn.org/documents/d0001789/Buckling_AIDS_2005_Full.pdf)
- Rahmati-Najarkolaei, F., Niknami, S., Aminshokravi, F., Bazargan, M., Ahmadi, F., Hadjizadeh, E., & Tavafian, S. S. (2010). Experiences of stigma in healthcare settings among adults living with HIV in the Islamic Republic of Iran. *Journal of the International AIDS Society*, 13(1), 27. <http://dx.doi.org/10.1186/1758-2652-13-27>
- Reece, M., Tanner, A. E., Karpiak, S. E., & Coffey, K. (2007). The impact of HIV-related stigma on HIV care and prevention providers. *Journal of HIV/AIDS & Social Services*, 6(3), 55-73. [http://dx.doi.org/10.1300/J187v06n03\\_05](http://dx.doi.org/10.1300/J187v06n03_05)
- SeyedAlinaghi, S., Paydary, K., Kazerooni, P. A., Hosseini, M., Sedaghat, A., Emamzadeh-Fard, S., & Mohraz, M. (2013). Evaluation of Stigma Index among people living with HIV/AIDS (PLWHA) in Six Cities in Iran. *Thrita*, 2(2), 69-75. <http://dx.doi.org/10.5812/thrita.11801>
- Surlis, S., & Hyde, A. (2001). HIV-positive patients' experiences of stigma during hospitalization. *Journal of the Association of Nurses in AIDS Care*, 12(6), 68-77. [http://dx.doi.org/10.1016/S1055-3290\(06\)60185-4](http://dx.doi.org/10.1016/S1055-3290(06)60185-4)
- Ulasi, C. I., Preko, P. O., Baidoo, J. A., Bayard, B., Ehiri, J. E., Jolly, C. M., & Jolly, P. E. (2009). HIV/AIDS-related stigma in Kumasi, Ghana. *Health & Place*, 15(1), 255-262. <http://dx.doi.org/10.1016/j.healthplace.2008.05.006>
- Vanable, P. A., Carey, M. P., Blair, D. C., & Littlewood, R. A. (2006). Impact of HIV-related stigma on health behaviors and psychological adjustment among HIV-positive men and women. *AIDS and Behavior*, 10(5), 473-482. <http://dx.doi.org/10.1007/s10461-006-9099-1>
- Vance, R., & Denham, S. (2008). HIV/AIDS related stigma: Delivering appropriate nursing care. *Teaching and Learning in Nursing*, 3(2), 59-66. <http://dx.doi.org/10.1016/j.teln.2007.11.004>
- Visser, M. J., Makin, J. D., Vandormael, A., Sikkema, K. J., & Forsyth, B. W. C. (2009). HIV/AIDS stigma in a South African community. *AIDS Care*, 21(2), 197-206. <http://dx.doi.org/10.1080/09540120801932157>
- Waite, K. R. (2008). Literacy, social stigma, and HIV medication adherence. *Journal of General Internal Medicine*, 23(9), 1367-1372. <http://dx.doi.org/10.1007/s11606-008-0662-5>
- Zukoski, A. P., & Thorburn, S. (2009). Experiences of stigma and discrimination among adults living with HIV in a low HIV-prevalence context: A qualitative analysis. *AIDS Patient Care and STDs*, 23(4), 267-276. <http://dx.doi.org/10.1089/apc.2008.0168>