"I Am Dead to Them": HIV-related Stigma Experienced by People Living With HIV in Kerman, Iran

Mohammad Karamouzian, DVM
Maryam Akbari, MSc
Ali-Akbar Haghdoost, MD, PhD
Hamidreza Setayesh, MD, MPH
Farzaneh Zolala, PhD

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.

(Journal of the Association of Nurses in AIDS Care, 26, *46-56*) *Copyright © 2015 Association of Nurses in AIDS Care*

Key words: *HIV, Iran, people living with HIV infection, stigma*

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.

Mohammad Karamouzian, DVM, is a Research Assistant, Regional Knowledge Hub for HIV/AIDS Surveillance, Institute for Futures Studies in Health, Kerman University of Medical Sciences, Kerman, Iran, and MSc student at the School of Population and Public Health, University of British Columbia, BC, Canada. Maryam Akbari, MSc, is a Research Assistant, Research Center for Modeling in Health, Institute for Futures Studies in Health, Kerman University of Medical Sciences, Kerman, Iran. Ali-Akbar Haghdoost, MD, PhD, is Professor, Research Center for Modeling in Health, Institute for Futures Studies in Health, Kerman, Iran. Hamidreza Setayesh, MD, MPH, is UNAIDS Country Coordinator, Khartoum, Sudan. Farzaneh Zolala, PhD, is Associate Professor, Regional Knowledge Hub for HIV/AIDS Surveillance, Institute for Futures Studies in Health, Kerman University of Medical Sciences, Kerman, Iran.

JOURNAL OF THE ASSOCIATION OF NURSES IN AIDS CARE, Vol. 26, No. 1, January/February 2015, 46-56
http://dx.doi.org/10.1016/j.jana.2014.04.005

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 (Vanable, 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; Vanable 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.