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# Stigmatization and coping strategies among people living with HIV/AIDS: A narrative review

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***Abstract***

**Introduction:** Human immunodeficiency virus infection /acquired immunodeficiency syndrome has grown to be one of the world's most momentous pandemics. The present study aimed to explore the effects of stigma on people living with HIV/AIDS (PLWHA) and recommend coping strategies to reduce this phenomenon.

**Materials and Methods:** Using a narrative literature review, the related articles were searched, retrieved, and selected from the databases of Noor Specialized Magazines (Noormags), Elmnet, Scientific Information Database of Academic Center for Education, Culture, and Research (SID), IranMedex, and Magiran via the keywords of "Stigma, Social Stigma, Labeling, Acquired Immunodeficiency Syndrome, AIDS, Human Immunodeficiency Virus, and HIV" in Persian and in the databases of PubMed and Scopus in English. The same procedure was further performed in Google Scholar in both languages. The inclusion criteria were the full-text articles in Persian and English and the exclusion criteria were no access to the full-text articles, while review articles were removed.

**Results:** Considering the inclusion and exclusion criteria and excluding the duplicate studies, 16 articles were recruited in total for review purposes. The effects of stigma on PLWHA consisted of individual and social consequences. As well, the most appropriate coping strategies to reduce stigma were acknowledged as "providing psychosocial support for infected people", "raising awareness in the public and medical staff", "cultivating spirituality and a close relationship with God", "developing and implementing counseling strategies", and "establishing specialty clinics for PLWHA".

**Conclusion:** Given the study findings, it can be suggested that policy-makers and community healthcare managers pay much more attention to the individual and social consequences of HIV/AIDS and make further efforts to increase awareness in the public and medical staffs, strengthen spirituality in PLWHA, and set up specialty clinics for such individuals to cope with stigma.

**Keywords:** AIDS, Coping, HIV, Patient, Stigma

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## Introduction

Human immunodeficiency virus infection /acquired immunodeficiency syndrome (1) is known as one of the major infectious diseases in the world and an important barrier to development in unindustrialized nations. The prevalence rate of this condition is also growing in the Middle East (2). Regarding some statistics, HIV/AIDS is the largest lethal infectious disease and the fourth leading cause of death worldwide (3). Moreover, it is a chronic disease without any treatments and vaccines, leading to an annually significant case fatality rate and currently affecting 24 million people worldwide, as reported by the World Health Organization (WHO). According to the WHO, the prevalence rate of HIV/AIDS in Iran has been expected to reach 10% by 2021. Therefore, Iran is one of the at-risk countries in the world in this respect (2).

HIV/AIDS is one of the health problems that can influence not only physical dimensions but also mental-social health in the infected people in terms of negative attitudes in society, causing many challenges to the daily living activities of these individuals. In this sense, social stigma has been introduced as the main product of such negative attitudes (4,5). Stigma refers to a complex social process that involves labeling, stereotyping, and discrimination. Research studies have thus far demonstrated that such types of stigma can have a major impact on quality of life and overall health outcomes in people living with HIV/AIDS (PLWHA) (6).

HIV/AIDS-related stigma is thus often felt as social rejection, disapproval, and discrimination, which leads to intensified shame, disclosure-induced fear, positive serostatus concealment, reduced psychosocial support, depression and disabilities, economic stress, and refusal to go to the doctor (4,5,7). Stigma interferes with successful treatment and a continuum of care among HIV/AIDS patients (8). In a study conducted by Turi et al., perceived stigma is associated with depression and poor social support (9). In one study reflecting on the problems experienced by women living with HIV/AIDS from marital relationships, it had been reported that such cases were facing some pressures, including HIV/AIDS and its burdens on the one hand and the labeling of sexual intercourse outside of marriage and its social consequences on the other hand (10). HIV/AIDS has been further stigmatized and associated with shame worldwide, so access to testing, treatment, care, or counseling for this condition might seem very difficult due to the persistent fear of being judged by others (1). A phenomenological study in Iran revealed that HIV/AIDS patients used concealment, denial, social isolation, informed group membership, and normalization to manage the stigma induced by HIV/AIDS disease (11).

Also, stigma is socially constructed, and it is attributed to culture, society, and historical and situational factors (12). People feeling stigmatized, seeking the meaning of life, often find themselves in a perplexing situation wherein they look differently at the values and aspects of their lives and ask themselves some questions such as: "Are my relationships with friends as meaningful as they should be?" and "Are my beliefs about life correct enough?" As the meaning of life is deeply personal, individuals address such questions only in particular circumstances because by doing so, human security may be disrupted in daily life (13).

As a whole, examining the effects of stigma is of utmost importance because the identification of its consequences can draw policy-makers and the health system officials toward directing the modes of treatment and interacting with these people with fewer social consequences (14, 15). Therefore, to better understand what effects stigma can have on PLWHA and its consequences and solutions to reduce them, this study aimed to explore the effects of stigma on PLWHA and recommend coping strategies to reduce this phenomenon.

## Materials and Methods

This study was conducted as a narrative literature review. Henceforth, the related articles published from 2010 to 2020 were searched, retrieved, and selected from the databases of Noor Specialized Magazines (Noormags), Elmnet, Scientific Information Database of Academic Center for Education, Culture, and Research (SID), IranMedex, and Magiran via the keywords of "Stigma, Social Stigma, Labeling, Acquired Immunodeficiency Syndrome, AIDS,

Human Immunodeficiency Virus, and HIV" in Persian and in the databases of PubMed and Scopus in English. The same procedure was further performed in Google Scholar in both languages. To search for the studies in English, the same keywords were also utilized in the databases of PubMed and Scopus, published at the same time. Besides, the Google Scholar database was searched in Persian and English. The inclusion criteria were the relevant full-text articles in Persian and English published in the given databases and consistent with their titles. The exclusion criteria were no access to the full-text articles in both languages, while reviews were removed. The Persian and English studies were intended to be in harmony with their abstracts in the searches.

As the searches in the databases were completed, 884 articles were found in total and 16 cases meeting the inclusion and exclusion criteria were included, and the duplicate ones were omitted (Table 1).

**Table 1.** The process for searching, retrieving, and selecting the relevant articles

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| Articles retrieved from Magiran n=62 | Articles retrieved from SID n=62 | Articles retrieved from IranMedex n=62 | Articles retrieved from Elmnet n=62 | Articles retrieved from Noormags n=62 | Articles retrieved from Google Scholar n=62 | Articles retrieved from PubMed n=62 | Articles retrieved from Scopus n=62 |

Articles selected after removing duplicates

N=884

Articles selected after reviewing abstracts

N=100

Selected full-text articles

N=16

## Results

The study results revealed that 10 cases out of 16 relevant articles selected (Table 2) had been fulfilled in Iran. Nearly all studies had adopted a qualitative research design.

The most common HIV/AIDS transmission method among the patients examined occurred through injection drug use (IDU), sexual intercourse, blood transfusion, and mother-to-fetus transmission, respectively.

The majority of these articles were also performed on women, particularly those with mental health disorders. The bulk of the infected cases were married.

The largest part of the PLWHA had also felt fears of disclosing their condition and had not informed others of their infection due to stigmatization and labeling. Stigma had also been negatively correlated with social support, self-esteem, and self-acceptance.

Among the coping strategies recommended in these articles to reduce stigma were "providing psychosocial support for infected people", "raising awareness in the public and medical staff regarding the fact that HIV/AIDS was not specific to prostitutes", "holding training classes on the effects of stigma on patients as well as its social consequences", "cultivating spirituality and a deeper relationship with God", "developing and implementing counseling strategies", and "establishing specialty clinics for patients living with this condition, particularly regarding various medical, laboratory, and psychological services". In addition, among the suggestions cited in the articles was to hold training classes for the medical staff involved in such clinics on how to deal with these patients (3,16,17). Moreover, stigma had resulted in different effects on PLWHA, as illustrated in Table 3.

**Table 2.** Selected articles reviewed

| Author(s) | Publication date | Title | Country | Methods | Samples | Data collection tools | Results |
|---|---|---|---|---|---|---|---|
| Kalateh Sadati et al. (10) | 2019 | Challenges experienced by HIV/AIDS-positive women in marital relationships | Iran | Qualitative research design | 10 women infected with HIV/AIDS from marital relationships | Individual interviews | The data analysis demonstrated that the study participants could live through some kind of forced separation from society and fail to interact with anyone other than their own family members. The patients had also suffered from serious and devastating stigma at society level, which was associated with being labeled as having illicit sexual behavior. The data analysis had further established three main themes, i.e., fear, reluctance, and marital status and stigma. |
| Masoudnia & Chenaninasab (3) | 2016 | Impact of perceived social stigma on self-esteem in patients with acquired immunodeficiency syndrome | Iran | Correlation and cross-sectional study | 63 PLWHA referred to the Behavioral Diseases Counseling Centers for counseling and treatment in the city of Yazd, Iran | The patients had been selected using the convenience sampling method. As well, the modified Cochran's formula had been employed to determine the sample size. In addition, the Rosenberg Self-Esteem Scale and the modified HIV/AIDS Stigma Scale had been administered for measurement purposes | In total, 63 patients (namely, 48 males and 15 females) with HIV/AIDS symptoms had been studied. The relative age range of the respondents had been 14-56 with an average of 36±7.7. The methods of HIV/AIDS transmission had been IDU (n=33, 52.6%), sexual intercourse (n=17, 27%), unspecified cause (n=9, 14.3%), blood transfusion and blood products (n=3, 4.8%), and mother-to-fetus transmission (n=1, 1.6%). The duration of HIV/AIDS had been also 1-15 years with an average of 7.85±3.15. No significant difference had been observed between men and women with regard to HIV/AIDS symptoms in terms of perceived social stigma. The method of transmission had not even made a difference in patients' perceived social stigma. There had been additionally a significant inverse correlation between perceived social stigma and self-esteem ($P< 0.01$) and self-acceptance ($P< 0.01$). Moreover, A significant inverse correlation had been established between perceived social stigma and personal stigma and self-esteem ($P< 0.05$) as well as negative self-concept and self-esteem ($P< 0.01$). |
| Tavakol | 2012 | Stigmatization, | Iran | Qualitative | Six | In-depth semi- | HIV/AIDS-related stigma had |

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| and Nikayin (18) | | doctor-patient relationship, and curing HIV/AIDS patients | | research design | patients and seven doctors specialized in infectious diseases | structured interview techniques for infectious disease specialists | aroused misplaced fears in the medical staff, affecting the interactions between doctors and HIV-positive patients, leading to therapeutic discrimination in many cases. |
| Hejazi et al. (13) | 2018 | Psychosocial consequences for married women infected with HIV/AIDS | Iran | Qualitative research design and phenomenological study | 14 women infected with HIV/AIDS | Individual semi-structured interviews | Although all the study participants had been infected with HIV/AIDS for a very common reason, and they had been in fact the victims of their husbands, they had experienced stigma, labeling, and discrimination. Unfortunately, they had not been treated fairly in society. They had also faced various challenges in their lives and had further adopted different coping strategies to tackle the problems. Besides, spirituality had been introduced as one of the most important coping strategies by the majority of the patients. All infected women had undergone severe shocks, fear, disgust, sadness, depression, and isolation after learning about their condition. In addition, the bulk of these women had shown no hope for the future and had felt no meaning in their lives. It seemed that providing counseling solutions could play an effective role in boosting adaptation skills in these women and empowering them to deal with new living conditions. |
| Rasoolinejad et al. (17) | 2018 | The effect of psychosocial problems on risky behaviors in people living with HIV in Tehran, Iran | Iran | Cross-sectional study | 450 HIV/AIDS-positive patients from the Infectious and Behavioral Diseases Clinic at Imam Khomeini Hospital | Sociodemographic questionnaire, the General Health Questionnaire-28, the Berger HIV Stigma Scale, as well as the Lazarus Ways of Coping Questionnaire (WOCQ) | Mental health and stigma along with problem-oriented adaptation mechanisms had been associated with high-risk behaviors ($P< 0.05$). Stigma had been also reported to be higher in women and mental health had been lower in this group as compared with men. |

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| Rahmati Najarkolaei et al. (15) | 2012 | HIV/AIDS patients' experiences about stigma | Iran | Qualitative research design | 61 PLWHA selected using purposeful and convenience sampling methods | Interviews | Two main themes had been developed, i.e., extrinsic stigma (i.e. taunting, bashfulness, and discrimination) and intrinsic stigma (i.e. rejection, seclusion, and frustration). |
| Masoudnia et al. (12) | 2016 | Relationship between illness perception and perceived stigma in patients with HIV symptoms | Iran | Cross-sectional and analytic study | 63 PLWHA | Standardized Illness Perception Questionnaire and the modified Perceived Stigma Questionnaire | Perceived stigma had a significant correlation with consequent illness perception components, which could be the external causes and had a timeline in terms of being acute or chronic, but no correlation existed with other components such as emotional manifestations, a periodic timeline of the disease, and personal control. Hierarchical multiple regression analysis had also shown that the illness perception components had explained 38.1% of the variance in perceived stigma. |
| Shrestha et al. (14) | 2019 | HIV serostatus non-disclosure among HIV-infected opioid-dependent individuals: The roles of HIV-related stigma, risk behavior, and social support | the United States | Qualitative research design with clinical randomized controlled trials | 133 HIV-infected opioid-dependent individuals | Self-reporting | 23% of the patients had not reported their HIV serostatus. Those who had multiple sexual partners had also undergone a high level of concealment of their disease. Injection equipment (70.5%) and inappropriate use of condoms (93.5%) as well as the use of anti-retroviral drugs had further contributed to a high share in disease transmission. HIV-related stigma had been further associated with factors such as having multiple sexual partners. In addition, a significant interaction had been observed between HIV-related stigma and living with family and friends, and they were more likely to admit that they had not disclosed their HIV/AIDS serostatus. |
| Kemp et al. (19) | 2019 | HIV stigma and viral load among African-American women receiving treatment for HIV | the United States | Longitudinal and analytic study | 234 African-American women receiving care for HIV/AIDS | Self-reporting plus randomized intervention experiment | HIV/AIDS-related stigma had been significantly associated with the mode of transmission, but social support and depressive symptoms had not been introduced as statistically significant mediators. |
| Naji et al. | 2014 | The experience of social stigma | Iran | Qualitative and | 13 patients | In-depth unstructured | The most important sub-themes extracted from the studies had |

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| (20) | | in AIDS patients: A phenomenological study | | phenomenological procedure using Colaizzi's method of data analysis | with HIV/AIDS selected using purposeful sampling method | interviews | been inappropriate labels, rejection, worthlessness, and lack of support, all named under the main theme of stigma. |
| Behravan & Abachi (21) | 2012 | The causes and consequences of labeling in patients with HIV/AIDS | Iran | Qualitative case study | Seven patients (four men and three women) | In-depth semi-focused interviews | The results had shown that labeling could have some effects on human rights violations and non-adherence to treatment. The study findings, in line with other surveys inside and outside Iran, had demonstrated that HIV/AIDS had both personal and general dimensions. In addition to the patient, others who were in some way in contact with them might react to this condition. Such reactions could thus help shape personal changes in attitudes about the patient and pose challenges to their self-understanding as well as relationships. |
| Abachi & Behravan (22) | 2013 | The analysis of stigma impact on quality of life in patients with HIV/AIDS: A phenomenological study | Iran | Qualitative and phenomenological study | Eight patients (five men and three women) | In-depth interviews | Lack of social support and disclosure of the person infection could bring negative psychological effects such as anxiety, depression, sadness, sense of guilt, isolation, reduced life expectancy, further limitations of social networks, unemployment, loss of income, and misunderstandings in the effectiveness of social communications. |
| Elizondo et al. (23) | 2015 | Dentistry and HIV/AIDS-related stigma | Mexico | Qualitative research design | 134 HIV-positive people (30% female and 70% male) | Structured, analytical, self-administered, anonymous questionnaire using factorial, non-hierarchical, and cluster analysis | Social inequalities had been detected in the search for public and private dental professionals and services, wherein most patients had reported ignoring going to the dentist for the non-disclosure of their illness. The factorial analysis had further shown that there were elements including experiences of stigma and discrimination in dental appointments and feelings of concern about the attitudes of specialists or their teams towards the serodiagnosis of HIV/AIDS in patients. Cluster analysis had additionally identified three groups, including users who had not experienced stigma or discrimination (85%), those |

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| | | | | | | | who had not faced such experiences but were somewhat concerned (12.7%), and the ones stigmatized and discriminated (2.3%). |
| Herrmann et al. (24) | 2013 | HIV-related stigma and physical symptoms have a persistent influence on health-related quality of life in Australians with HIV infection | Australia | Qualitative research design | 15 in-depth interviews and 102 Health-Related Quality of Life (HRQL) surveys of HIV/AIDS-positive people | In-depth interviews and surveys using the HRQL tool | Observations had revealed the long-term problems of living with HIV/AIDS, especially in terms of intimacy and relationships with friends. A tool had been further employed to examine the impact of discrimination and stigmatization by reflecting on the use of antiviral pills and the duration of treatment. If patients had become more sensitive to the diagnosis, i.e., newly diagnosed, depression and unemployment or a large number of adverse symptoms could be significantly relieved by the perceived stigma. One-third of the patients surveyed had further reported a persistent fear of exposure to HIV/AIDS and infecting others. |
| Levi-Minzi & Surratt (16) | 2014 | HIV stigma among substance abusing people living with HIV/AIDS: Implications for HIV treatment | the United States | Qualitative research design | 503 HIV-positive abusers | Interviews and self-report through direct and indirect communication and distribution of study cards and flyers | The stigma measurement had established four subscales, including stigmas about HIV/AIDS, self-acceptance, disclosure concerns, and social relationships. As well, 35.5% of the respondents had been severely addicted to drugs and 54.7% had been feeling depressed and their condition had become worse. The use of antiretroviral drugs in such individuals had been also reported to be illicit. These people had further undergone significant stigma in terms of their acceptance, disclosure of information, and social relationships, using multivariate linear regression, indicating depression and social support, which were among the major supports in the area of stigma. The findings had further suggested that interventions to reduce HIV-related stigma might be an important component of the initiatives to augment interactions in HIV/AIDS care. |

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| Shacham et al. (25) | 2015 | Persistent HIV-related stigma among an outpatient US clinic population | the United States | Qualitative research design | 201 people living with HIV/AIDS | Interviews and self-report using the Reece Stigma Scale | The study participants from the United States had been of African American descent. The average total score of their stigma had been also 21.7. Younger women and people with less education had further obtained higher stigma scores. In cases with relatively poor general health, moderate-to-severe symptoms of depression and anxiety, and in the ones with alcoholism, generalized anxiety disorder, agoraphobia, and pain, high stigma scores had been reported. Prominent analysis had correspondingly shown that stigma could persist among patients PLWHA and might play an important role in care services for such a condition. |

**Table 2.** Effects of stigma on PLWHA

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| **Individual consequences** | Severe shocks, disgust, worthlessness and lack of support, loneliness, isolation and depression, refusal to visit a healthcare center, forced separation, fear, sense of hopelessness, despair in life and treatment, concealment, refusal to marry, unwillingness to marry, expecting to die, suicide attempts, low self-esteem, negative personal experiences, non-adherence to healthcare activities, non-adherence to treatment as a result of misbehavior in society and others, and reluctance to disclose HIV/AIDS serostatus to others |
| **Social consequences** | Blame and embarrassment, blaming patients, misjudgment and curiosity about the mode of infection, labeling of sexual intercourse outside of marriage, repulsive and precautionary behaviors of medical staff, failure to treat patients, unemployment and dismissal, and deprivation of social services |

## Discussion

This study aimed to explore the effects of stigma on PLWHA, wherein the results showed that the given phenomenon could have both individual and social consequences. Rasoolinejad et al. (17) conducted a cross-sectional study on 450 positive HIV patients. The results showed that stigma was associated with high-risk behavior. Also, stigmatization could cause problems at home and work and even in how to make the best use of healthcare services, ultimately inducing feelings of depression, low self-esteem, and humiliation, leading to the disintegration of friendly, social, and familial relationships. Masoudnia et al. (12) performed a cross-sectional study on 63 positive HIV patients. The results of the late study revealed that patients with negative personal experiences had undergone low self-esteem due to being rejected for HIV/AIDS and feared the consequences of public awareness of their condition, such as losing friends and experiencing others' reluctance to encounter them. Therefore, the need for developing and implementing psychological counseling in these patients and the need for large-scale training through the national media is highly encouraged. A qualitative study on 16 positive HIV patients by Khoshtarash et al. (26) showed that considering the three main issues in health-related lifestyle, including physical, psychological, and social aspects, should be considered.

As reported in the qualitative study on 61 positive HIV patients by Rahmati Najarkolaei et al. (15), one of the complications of stigma in

PLWHA was blame and shame in blaming patients, incorrect judgments, labeling, and curiosity about the methods of infection. Discrimination in the form of repulsive and precautionary behaviors of medical staff and failure to treat patients, unemployment and dismissal, feelings of rejection, and refusal to visit medical centers were also, among other consequences of stigma. Shrestha et al. (14) had also shown prejudices and rumors about PLWHA wherein ignorance, lack of accurate information about HIV/AIDS, and misunderstandings about its transmission were the common sources of stigmatization. For that reason, holding training classes for such patients, the public, and the medical staff was recommended.

One of the study findings attempted to conceal the disease attributed to its social consequences. A phenomenological study on 15 patients in Iran showed HIV-positive people afraid that their disease may reveal. So, they experience social pressure and attempt to conceal their condition (11). In the qualitative study by Abachi and Behravan (22), in most cases, just the patients were aware of the illness, so receiving stigma and labeling could have a very negative effect on their lives, which was consistent with the finding the study. Furthermore, the qualitative study findings by Herrmann et al. (24) had established that Australian PLWHA were concealing their condition from others, and fear of disclosing their infection was due to labeling, stigmatization, and depression.

Medical staff's repulsive and precautionary behaviors were among other results in the present study—a cross-sectional study conducted on 400 health care workers in Iran. In addition, the results of a recent study showed dentists and laboratory staffs had higher HIV-induced stigma (27). In agreement with these outcomes and concerning the impact of discrimination in the provision of medical and dental services, a survey conducted in Nigeria by Elizondo et al. (23) showed discriminatory attitudes towards PLWHA among dentists. Accordingly, raising awareness and broadening communication skills in medical staff was suggested.

The limitation of the current study was that we assessed the Persian and English articles, and other studies related to our study aim were ignored. Therefore, it is suggested that further studies, including the effect of psychological and nursing interventions on stigma improvement of HIV/AIDS patients, be designed.

## Conclusion

The present study reflected the effects of stigma, including personal and social consequences in PLWHA, and recommended coping strategies to reduce this phenomenon. The strategies to diminish stigma included: providing psychosocial support for infected people, raising awareness of the public and medical staff, holding training classes on the impact of stigma and its social consequences, cultivating spirituality and a deeper relationship with God, developing and implementing counseling strategies, establishing specialty clinics for PLWHA. Based on the study findings, policy-makers and community health managers were suggested to make further efforts to reduce the effects of stigma by applying the strategies mentioned above.

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