# Stigma, Discrimination, and the Consequences of HIV-AIDS for People Living With It in Iran

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**Abstract:** There is evidence that a significant proportion of People Living with HIV ( PLWH) still deal with stigma and discrimination in their everyday life. The social factors attached to HIV/AIDS are a major obstacle in the curtailment of the disease requiring urgent action. This qualitative study explored perceptions of PLWH regarding HIV/AIDS Consequences in the Islamic Republic of Iran. In-depth, semi-structured interviews were held with a purposively selected group of PLHIV recruited from three HIV care clinics in Tehran. All interviews were recorded and typed, and the codes were extracted after reviewing them several times Data were analyzed using the content analysis approach. In this study 34 participants were interviewed. Of the participants, 26 were HIV-positive, 22 of which were men and four women.. In addition, five healthcare workers and three wives of HIV-patients were interviewed. Participants were referred to the following consequences: Social, mental, physical and economic. Most of the participants named social outcome (discrimination and stigma) as the most important consequences for HIV/AIDS. The most important outcome of mentioned by the HIV-positive patients, healthy spouses, and healthcare workers was social consequence (discrimination and stigma). We need effective strategies to reduce HIV stigma as treatment and care resources are scaled up in the settings that are most heavily impacted by the HIV epidemic.

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## 1. Introduction

Since the beginning of AIDS epidemic in 1981, some 60 million people have been infected and 25 million deaths have been caused by HIV-related symptoms (UNAIDS, 2009). Therapeutic progress has improved the health condition of HIV-AIDS patients and their longevity (Strebel, 2009; Poudel, 2007; Guimaraes, 2008; Eisele, 2009). Thus, the number of people living with HIV (PLWHs) is increasing, as well. The attitude of people toward PLWHs is different in various societies, and in many cases, it is negative and discriminative. The way people look at individuals living with the disease depends on the social acceptance of disease transmission in the society. Stigma, discrimination, and phobia are among the most common worries of healthcare workers who provide services for these patients, and the therapeutic staff sometimes avoids interacting with the patients (The World Bank Report, 2011). Fear of stigma, anxiety, disappointment, depression, stress, lower perceived quality of life are among the problems patients face after their HIV diagnosis (The World Bank Report, 2011; Maman, 2009; O'Connell, 2003).

In Iran, the first HIV case was reported in 1987, and it was caused by polluted blood products. Subsequently, more cases were identified in the country's prisons. It's believed that Iran has the most number of intravenous drug users in the Eastern Mediterranean region and North Africa, and the AIDS epidemic is concentrated in this group. According to a 2007 estimate, 14 percent of intravenous drug users in the country are infected by HIV (UNAIDS, 2011). Currently, the low-level epidemic in Iran has increased to a concentrated epidemic. Studies performed by WHO indicate an estimated 80,000 infected individuals in Iran but just a one-fourth, 23,125, of patients have been identified as of June 2011. Among the infected, 91.5 percent are men and 8.5 percent are women. It was reported that in 69.8 percent of cases, the virus was transmitted through infected needles and syringes for injection, and 10 percent through sexual relationship. In 18.3 percent of cases, the cause of transmission is not clear (Center for Disease Control, 2011). Although the percentage of sexual transmission among the identified cases has remained constant during recent years, its absolute number has been increasing continuously. The percentage of unknown transmission has gone up as well during recent years, at least in part related to the increase in sexual transmission, which usually remains unknown because of the stigma associated with this disease (National AIDS Committee Secretariat, 2010). This stigma can also affect preventative actions, such as using condoms, testing, and measures to prevent the vertical transmission of disease from mother to child (Maman, 2009). Therefore, special attention should be paid to prevention plans due to the sexual transmission of HIV in the country.

Investigation of perceived experiences of PLWHs about the consequences of being infected by this disease and the derived stigma and discrimination can improve prevention and social behaviors among this group. On the other hand, planning to preserve the social rights of PLWHs can improve the quality of their lives by reducing this stigma and discrimination. Since qualitative research can help us to understand what people believe and their real lives (Gerish, 2006), the present study is conducted with a qualitative approach aiming to investigate the attitude of PLWHs toward the consequences of AIDS affliction, and its results can be applied to improve the quality of their lives, encourage voluntary disclosure of their disease while using therapeutic services, and persuade them to consider prophylactic sexual behavior.

## 2. Material and Methods

To investigate the attitude of people with HIV-AIDS toward the consequences of being afflicted, qualitative research has been applied in the present study. In 2010, the research was performed during nine months in three HIV care clinics (consulting clinics of behavior disorder) in Tehran. Two clinics were attached to Shahid Beheshti University of Medical Sciences and Health Services (Valfajr and 12th of Farvardin) and the other one (Consulting Clinic of Imam Khomeini Hospital) is attached to Tehran University of medical Sciences. The Consulting Clinic of behavioral disorders of Imam Khomeini Hospital is one of the biggest centers that provides services for people living with HIV and makes it possible for patients to use professional medical services as it is located near Imam Khomeini Hospital. The studied sample in this research includes people with HIV-AIDS. Considering the limited access to patients and the limitations of investigation, the convenience sampling was applied and the referees (PLWHs) to these clinics were included. At last, it was decided to apply the theoretical sampling with maximum variation and those with different viewpoints toward the issue were chosen. The most possible variation by age, marital status, education, and employment was attempted. The interviews continued until data saturation was reached. The questions included were deep and semi-structured. Having the prior permission of interviewees, after recording their demographic information on paper, a tape recorder was used to record the interview. All of the interviews were transcribed and typed at the earliest convenience. Then, the data was analyzed by content analysis. Firstly, the interviews were reviewed several times and a perfect acquaintance was achieved, then the codes were extracted and categorized and the main themes were specified. After coding each interview, the procedure was performed for the next one.

To confirm the credibility of qualitative data, some of the coded interviews were returned to the participants to be reviewed by them to find if the interspersion of results is in accordance with their attitude or not. The long-term involvement of researchers with participants and the devotion of adequate time by them also confirm the creditability of this study. The external check applying the complementary comments of coworkers by separated coding of half of the interviews was performed as well. The triangulation through reconciliation of data collecting methods (interviewing the patients and revision of their cases), reference reconciliation of data (interviewing male and female patients, therapeutic staff, non-infected wives of patients), choosing the participants from different consulting clinics of behavior disorder, and performing a maximum variation sampling, were all attempted in this research, which increases its creditability. Dependability of achievements was evaluated by external check. To investigate any possible incoherence in coding, the transcripts of several interviews were given to another researcher to be coded separately. The incoherent achievements were investigated to evaluate their validity and the causes were identified. The opinions of qualitative researchers were applied as well. The research methodology was described in detail to confirm its transferability.

To start the task in consulting clinics of behavior disorder, we first got the approval of assistants of Tehran and Shahid Beheshti University of Medical Sciences and Health Services. At the beginning of the interview, the aims of the research were described, and the interviewees were asked if they were ready for the interview. The interview was not performed in cases of discomfort. The participants had the right to end the interview in any stage. The verbal and conscious acquiescence of interviewees was taken for participation in the research and recording their interview. The protection of privacy due to personal information was considered at all stages. The interview was performed in separate rooms in absence of therapeutic staff and the possibility of other patients passing. The duration of interviews ranged from 41 to 90 minutes, depending on their process. The interviews continued until data saturation was reached.

To achieve a wider range of opinions, the interview was also performed for five employees of consulting clinics of behavior disorder (including doctor, psychologist, social worker, and consultant) and they mentioned the consequences for their patients that they had found out during visiting and consulting their patients. Three negative HIV women with infected husbands were also interviewed and they expressed the consequences from the viewpoint of their husbands. In four cases, the interview was performed in two sessions. In this research, three people among those asked were not willing to be interviewed.

## 3. Results

In this study, 34 people were interviewed, 26 of whom were infected by HIV-AIDS. Twenty-two patients were men with an average age of 37.5 and a standard deviation of 7.13. The minimum age of men was 27 and the maximum was 53. Four patients were women whose average age was 34 with a standard deviation of 3.04. The minimum age of women was 30 and the maximum was 38. The diagnosis duration for men was about five years and for women it was 7.5 years. Due to the stage of disease, in 64 percent of men and 50 percent of women it had progressed to AIDS. The demographic and behavioral characteristics of patients can be observed in table 1.

**Table 1:** Demographic and behavioral characteristics of the studied HIV patients

| variant | Men (22 individuals) | Women (4 individuals) |
|---|---|---|
| age | 19-29 years (3)<br>30-39 years (11)<br>20-49 years (6)<br>Elder than 50 (2) | 30-39 years (4) |
| Marital status | Single (11)<br>Married (9)<br>Divorced (2) | Married (1)<br>Divorced (1)<br>Widowed (2) |
| employment | Unemployed (8)<br>Employed (13)<br>Retired (1) | Housewife (unemployed) (2)<br>Employed (2) |
| Education | Uneducated (2)<br>Elementary (3)<br>Lower secondary (6)<br>Upper secondary- diploma (10)<br>Further education (1) | Lower secondary- orientation cycle (2)<br>Upper secondary- diploma (2) |
| Imprisonment record | Positive(19)<br>Negative (3) | Positive (0)<br>Negative (4) |
| Sexual contact | Have used condom in last sexual contact (11)<br>Had non in last year (9)<br>Haven't have used condom in last sexual contact (2) | Have used condom in last sexual contact (1)<br>Had non in last year (3) |
| Previous drug addiction | Methanol Maintenance Treatment (9)<br>Narcotics Anonymous Recovery (11)<br>No addiction record (2) | No addiction record (4) |
| High risk behavior | Intravenous drug addiction (10)<br>Unprotected sexual relationship (2)<br>Intravenous drug addiction & unprotected sexual Relationship (10) | Sexual relationship with infected Husbands (4) |

**Table 2:** The issued themes and subthemes about the consequences of HIV-AIDS affliction

| themes | subthemes |
|---|---|
| Social consequences | 1. stigma and discrimination on people with HIV-AIDS and their excommunication from the society, entourage and family<br>2. limitation due to the social activities and employment<br>3. limitation in starting family and protecting it and the impossibility of having a child<br>4. the stigmatization of patients by therapeutic staff which limits them in receiving therapeutic services |
| psychological consequences | 1. Chronic stress and anxiety before the certain diagnosis of disease<br>2. depression and seclusion after the certain diagnosis of disease<br>3. the constant worry due to the future and how long they would live<br>4. desire for death, thinking about suicide and proceeding to its committal<br>5. the effects of thinking about the disease on their daily lives and nightmares |
| Physical consequences | 1. losing weight, physical abilities and disability in doing their jobs and activities<br>2. the consequences of taking Antiretroviral drugs |
| Economical consequences | 1. spending time for diagnostic and therapeutic tasks<br>2. spending money (financial cost) for therapy<br>3. unemployment derived by their affliction |

Interviewees' answers to questions such as "what problems were raised by the affliction for the infected people?"; "what problems you have been through because of this disease and how much do you think this disease has affected you?"; "what kind of disease do you think the AIDS is?" helped us to investigate their attitude toward perceived severity of HIV-AIDS after being infected.

The mentioned consequences after HIV infection are categorized in four main themes including social, mental, physical, and economic consequences. The themes and subthemes issued by the interviewees are observable in table 2.

### 3.1 Social Consequences

According to the majority of patients, therapeutic staff and the healthy women with infected husbands, the social consequences are the most significant ones and many of them consider it even more important than physical consequences and economic problems caused by the disease. Among the issued subthemes in theme of social consequences, the stigma and discrimination are given higher priorities. According to almost all of them, the stigma and discrimination on PLWHs and their excommunication from society, relatives, and family are the most significant consequences of HIV in Iran. Regarding the excommunication of infected people a 40-year-old married man said: "We made a mistake by telling everyone about our problem. First we told my mother, my mother told my sister, and she announced it to all relatives. From then on, we were embarrassed wherever we went. We are now absolutely rejected. We have moved house to the middle of desert. We go to no one's house and we don't let anyone comes over."

About the existing stigma among the society even the therapeutic staff, toward the patients and female ones in particular, a 30- year old infected woman said: "My leg was wounded. The doctor wanted to touch it when I told him not to. I'm HIV-positive. His secretary said: 'are you HIV positive? How did you get it! You don't seem to ...' if they understand that a woman is infected they would immediately think that she must have been infected through adultery."

A 37-year-old single man described the negative attitude of society toward the patients: "If they do not have a set of information, they would look at you as if they are looking at a mare microbe or an injection!" The doctor of the consulting clinic, who is in charge of visiting the patients and consulting with them, believes that: "AIDS is like cancer. Everyone looks for cancer patients to express their sympathy, but as to AIDS patients, they are all abandoned because of the stigma against them."

More than half of the individuals mentioned the limitation due to the employment, having social activities, and the impossibility of disclosure of their disease in workplace. A 34-year-old single man said: "Someone found me a job not long ago to go and work in the kitchen of a company, they would even insure me. I had to lie to avoid accepting this job, for which I was blamed too much. I was told that I wasn't diligent; otherwise I wouldn't miss such a good job."

The existing limitation to start a family is another social consequence mentioned by the majority of patients and the non-married ones in particular. A 41-year-old single man said: "Since the beginning of this year, I have decided to get married, but I still haven't found a good case. I think you should spend time on the marriage of HIV-positives. Consider me as well. We are so lonely." Most of the single patients and the married ones who have no children mentioned having children as one of their distresses. A 33-year-old divorced woman said: "I wish to have a child and take him (her) to school. I wish to see him (her) until the age of 7 or 8. It's the only wish I have, and then I would die." Another social consequence mentioned by the majority of patients is the lack of receiving therapeutic services after revealing their disease to the therapeutic staff. A 36-year-old married man said: "I have seen this bad reaction even by the doctors. Right now, I myself have a hernia. Where ever I go for the surgery, they avoid it after finding out that I'm HIV-positive. I remember when I went to hospital for a lung surgery several years ago. The doctor forced me out of his room with a harsh reaction as soon as he learned about my disease."

### 3.2 Psychological Consequences

All the patients mentioned that they have been dealing with psychological complication after becoming aware of their affliction. They pointed out their chronic anxiety and stress before the diagnosis of the disease and the lack of psychological comfort in their lives. A 38-year-old married man described his anxiety before HIV diagnosis: "The doctor said: we guise it should be this disease, but it takes 10 days to answer you certainly. During those 10 years I had too much stress which caused me to loose some 10 kilograms. I caught shingles. The doctor said it's caused by chronic stress."

Most of the patients mentioned depression as the most important psychological consequence of HIV affliction. A 38-year-old widow said:

"There is stage for all who first understand that they are HIV-positive, which really cause them a lot of psychological difficulty. I myself have passed a six-month deep depression. I wanted to see no one and go nowhere. I was fighting with God asking why me. I couldn't understand why I should be in such pain."

Less than half of the patients mentioned their worry for the future considering their disease. A 51-year-old married man said: "Is there any idea about me and the future of my disease? ... Have anybody thought about my AIDS, or they are merely waiting for me to die and become eliminated?"

Another psychological consequence mentioned by fewer patients was the desire for death and suicidal thoughts.. A 53-year-old married man mentioned: "Sometimes I touch the electrical wire. I'd really like to kill myself if it wasn't a sin. The improper reactions of others I went to do it several times. The wire was in this hand, but I didn't have the power to put it on the other one." The effect of thinking about the disease on the daily life and the nightmares was expressed by a 35-year-old single man: "... I think that I'm dying right now, I smell death. I don't know if you have ever gone to a cemetery. Have you smelled its soil? When I sleep, there are nightmares, when I get up, I smell death."

### 3.3.Physical consequences

AIDS affliction causes many physical problems for patients. The majority of patients, especially those in AIDS stage, pointed out weight loss, reduction of physical abilities, and disability due as the physical consequences of their affliction. A 36-year-old single man said: After AIDS affliction, one becomes tired and weak. He doesn't have the power to do his job. I don't have the energy to work. After two months, I found that I can't work eight hours a day anymore."

The symptoms caused by adverse effects and interactions of the drugs taken, was mentioned by the majority of patients and in particular, those taking Anti Retro Viral in AIDS stage. A 44-year-old man described the adverse effects of Anti Retro Viral: "When I start taking pills I couldn't walk more than three steps. I had pain in my heart and chest, I had tremendous headaches and my eyes were puffy. I had a bone marrow biopsy and they told me that these are caused by one of the drugs. Things were fixed when I stopped taking that one." A 35-year-old single man under methanol maintenance treatment described the drug interaction: "The drugs have inactivated the effect of methadone. When I take my AIDS drug, my head tumbles spontaneously while having food. Everyone think that I'm slumbering. My spoon suddenly falls which is because of the adverse effects of drugs on me and the methadone I take. After 8 o clock, I have such a terrible situation that my mother cries with me."

### 3.4. Economic Consequences

Some of the patients mentioned economic problems as the consequences of AIDS-affliction and they said that such problems are caused by spending time and money for therapy and unemployment resulting from their HIV-affliction. A 36-year-old married man said: "During several recent years, this disease has caused me to lose a lot of time. If I weren't HIV-positive, I would be in a better economic situation. On the other hand, I should spend a lot on my therapy. I should eat more nutrient food and take better drugs and vitamins, so I should spend more on them. I should come to hospital every week which would cost me a lot of carfare."

### 3.5 Disease description

The description of AIDS by patients was either in negative or positive forms. The majority of them described the disease negatively using terms such as: "terrible disease, incurable, suffering, and high-risk disease, a tragedy, assuming them dead, from the moment they got the disease, a parameter which results in loosing life, a disease which devastates all one's golden years." Just two patients thought that their affliction had some positive effects. They believed that HIV-affliction had improved their self-confidence and ability.

## 4. Discussions

The AIDS epidemic has caused people to have some negative reactions, including prohibiting HIV-positives to come to their houses and isolation from family, their dismissal from workplace, and refusing to accept infected children in schools. The negative reactions create behaviors in infected individuals, which limit the efficiency of preventing activities such as using condoms and plans to prevent vertical transmission of disease from mother to child and doing HIV tests. AIDS causes anxiety as death comes along with it. HIV-infected individuals receive less social support compared to cancer patients (Mawar, 2005). PLWHs would face many problems after their affliction and they are exposed to the risk of psychological problems such as depression and anxiety. Having the experience of an acute illness, the change in employment situation, and the adaption to complicated drug diets are all continual sources of stress for the infected individuals. Medicinal treatments can have chronic adverse effects. Apart from such effects, taking drugs is a daily reminder that the person is ill. This can also be included as a source of stress for the patient. In many cases, the HIV diagnosis would cause a certain discrimination and excommunication for the infected person. Despite some successful treatments, the early death of patients caused by high-risk behaviors and suicide is still possible (Scheid, 2008).

In the present study, the majority of patients, therapeutic staff, and even the wives of patients believed that the social consequences are the most important ones caused by HIV-affliction. According to all of them, among the social consequences, the stigma and discrimination toward patients and their excommunication from society, relatives, and family are the most significant problems. The limitation in social activity and employment, starting a family and protecting it, the impossibility of having children, and the stigmatization of patients by therapeutic staff, which limits them in receiving therapeutic services, are the social consequences mentioned in lower levels of significance. PLWHs would be encouraged to reveal their disease to their families voluntarily, as they need the emotional and family support especially to start Anti Retro Viral Therapy. Disease disclosure would accelerate the discriminative behaviors of family members (Mills, 2009). Stigma seems to be a key stop that decreases the quality of therapeutic care (Chan, 2008). Many studies on the stigma and discrimination against HIV-patients have been performed in Iran. According to the survey performed by Montazeri, the achievements indicate that although there is some wrong perceptions about AIDS in Iran, by and large a rather good knowledge and positive attitude toward the disease and the patients is prevalent among healthy individuals of the society (Montazeri, 2005). According to Cao et al., 80 percent of studied people in China were afraid of PLWHs and this negative attitude was directly related to their lower levels of awareness and education, and older ages (Cao, 2010).

According to the study by Kabbash, et al., in Egypt, the majority of infected people were dealing with anxiety, hopelessness, depression, anger, and feelings of disability and helplessness. Half of them mentioned the stigma they feel from the other members of society. Being afraid of such stigma has caused two thirds of them to isolate themselves from society. Half of them had a feeling of uselessness in their society. The patients mentioned that they need a social support for they are afraid of revealing their disease, pain, the future of themselves and their families, and death. The change in their employment situation, inability to perform their job and the same activities they used to do before their affliction, the lack of facilities for job promotions and the opportunities for leisure activities, were also indicated by the patients. The patients experienced economic difficulties and they were afraid because they thought it would prevent them from having nutritious food and using adequate care services in future. Although some of the patients were upset about the negative attitude of therapeutic staff toward them after knowing about their disease, most of them mentioned that they have been truly supported by healthcare workers of AIDS programs, especially when needing vital care such as surgery. The need to have a life without stigma, fear, or stress was also mentioned by the patients. Most of them said that they have had to change their sexual behavior pattern (Kabbash, 2008).

According to the qualitative study of Rahmati, et al., on HIV patients in Iran, almost all of the patients have felt stigmatized and discriminated by healthcare workers. As a consequence of such stigma and discrimination, the patients would postpone or avoid receiving therapeutic services or revealing their disease to therapeutic staff, their motivation to protect their health would decrease, they would feel a sense of malice or vengeance, they might use alternative medicine or they would feel emotionally stressed (Rahmati, 2010). In the study by Xianhong, et al., more than half of the PLWHs had experienced the stigma. Social excommunication and financial insecurity reflected the external stigma and 84 percent of them have experienced financial problems. The internal stigma included negative self-worth, interpersonal security, and the anxiety for disease disclosure, respectively reported by 78 percent, 75 percent, and 58 percent of individuals (Xianhong, 2009). The study performed by Liamputtong, et al., on HIV infected women in Thailand, indicated that the beginning of AIDS-related physical changes and symptoms in their body would cause more stigmas against them. For such changes represent an imminent death. Losing the job is another consequence of HIV affliction (Liamputtong, 2009).

The studies indicate that AIDS-related stigmatization against the patients by health workers is usually caused by their lack of awareness, fear of having accidental contact with the patients, and association of the AIDS patient with immoral behaviors. Thus, to remove such stigma, interventions should be performed in three individual, environmental, and policy levels (Nyblade, 2009). The results of other studies also indicate that a part of such stigmatization and discrimination by family, society, and therapeutic staff can be related to their unawareness of methods of transmission of the disease or unreasonable fear. By improving the level of awareness, particularly through public media, besides the obviation of the AIDS obscenity, the social excommunication, stigma, and discrimination toward PLWHs can be prevented as well. The derived psychological effects in patients not only go back to their beliefs about incurability of their disease, but they can also be related to the AIDS obscenity in Iran caused by the negative attitude of people toward AIDS as a sexually transmitted disease. Improving the public awareness and the services provided can remove the psychological consequences and promote the life quality of PLWHs. On the other hand, it would prevent further transmission of the disease among families, health care centers, and sexual partners because of non-disclosure of disease. Losing the job and the limitation of insurance coverage affects the utilization of patients from therapeutic services. Despite the fact that in Iran, many outpatient therapeutic and in vitro services are free for this group of patients, because of the increase in their longevity and the more need to professional and clinical therapeutic services, it is required to widen the insurance coverage and upgrade the level of commitment because of these patients. As was clear in other studies as well, the sense of belonging to a supportive AIDS group helps the patients to counter the stigma and discrimination they feel in society (Liamputtong, 2009). Therefore, supporting those in charge of supportive groups for PLWHs can help them remove such stigmas and discriminations from the patients.

Based on the achievements of the present paper, it is suggested that to remove such stigma and discrimination from the patients, the awareness of society and therapeutic staff has to be increased, which requires broadcasting continual and public training. On the other hand, it is also suggested to encourage and support the ones in charge of forming AIDS support groups to help them to remove the stigma and discrimination from the patients. Finally, the public and general insurance coverage affect the better utilization of infected patients from professional therapeutic services, which is possible through some changes in policy and planning by those in charge.

Despite all efforts to increase trustworthiness and rigor of this research, it still has some limitations which are observable in all qualitative studies. One of these limitations is that unlike quantitative studies, the sample volume is usually small in qualitative ones and it might not be that much comparative and distributable to society (Adib Hajbagheri, 2007). In this study, just the attitudes of referee PLWHs to consulting clinics of behavior disorders were investigated, and the achieved results might be rather different with results related to those who don’t come to such clinics. Not telling the truth is another limitation related to cultural-social problems due to people’s self report, especially as the individual would be in a face-to-face situation with interviewer while being interviewed for a qualitative research. In this study, the researchers attempted to gain the maximum trust of interviewees by establishing appropriate relationships and showing the interest of researcher in statements of participants. Thus, it is necessary to consider these limitations during result interpretation.

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