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Original Article

Exploring perceived dignity among AIDS/HIV patients in behavioral disease counseling centers in Iran

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Abstract

Background and aims: People with HIV/AIDS may encounter several problems, such as discrimination and social challenges, which affect their perceived dignity. The purpose of this study was to evaluate the perception of dignity among HIV/AIDS patients in a healthcare setting in Iran.

Methods: This cross-sectional study was done on HIV/AIDS patients referring to behavioral disease consulting centers affiliated with a mainstay of health and medical education, Iran, in 2023. The study sample consisted of 220 patients selected using the available sampling method. A patient dignity questionnaire was used to collect data. The validity and reliability of the questionnaire were confirmed. The collected data were analyzed by SPSS 25 software using parametric tests.

Results: Findings showed that the mean age of patients was 37; 51.1% of participants were men, 46.1% were married, 4.2% had primary education, 55.9% were employed, and 66.7% were in the asymptomatic stage of the disease. The overall score for perceived dignity was 1/96 out of 5 and was evaluated well. The mean scores for mental abilities and perceptions, personal and social concerns were 1.37 (SD: 0.44), 2.85 (SD: 0.94), and 1.37 (SD: 0.48), respectively. There was also a statistically significant relationship between perceived dignity score and the levels of education and being under treatment.

Conclusion: Although the studied patients had a well-perceived status of dignity and were satisfied with their abilities and social communication, their greatest concern was personal concerns. It is recommended that psychological support and therapies be provided to these patients.

Keywords: Dignity, AIDS/HIV, Behavioral disease consulting center

Introduction

Since 1981, when the first case of AIDS was diagnosed, the disease has become a global epidemic. It is considered a crisis for the health of communities due to its rapidly spreading and the number of new cases (1). AIDS is a disease that affects patients not only physically but also in terms of mental health. It creates many social problems, including negative and social labels, and changes that change patients' way of life, reduce their self-confidence, and increase their vulnerability to physical diseases (2). HIV-infected people are considered socially unusual. The patients are not accepted by their family, friends, and community, which leads to isolation, depression, humiliation, and suicide in infected people (3). Because the community might not have a positive attitude towards this disease (4), most patients receive low-income family social support (5), and health personnel do not have the skills to provide proper care services in the dignity of these patients (3). There is a clear negative attitude about these patients due to the fear of being infected (6). This separation and rejection cause a feeling of worthlessness in patients, and with loss of self-esteem, their life becomes more difficult (3), so that even patients in whom the disease has been largely controlled by proper treatment are still in a fragile situation (7). For this reason, the principle of dignity is much more important than the principle of life (6). Since one of the goals of any health system is to meet the non-medical needs of patients and respect for dignity, managers and policymakers in the health sector should promote patient dignity and community and families and healthcare staff awareness about this issue (4).

In a study entitled Health Care Neglect, Perceived Discrimination, and Dignity-related Distress among Chinese Patients with HIV in 2016, a significant correlation was found between physical and psychological symptoms, neglect in care, and perceived discrimination

(8). The study of Momenabadi et al showed that most HIV-infected patients receive poor social support from family (7). A study by Shafi'i et al entitled Nurses' Performance and Attitudes in Dealing with HIV / AIDS Patients showed that although most nurses reported adherence to ethical commitments in caring for these patients, most had discriminatory attitudes and beliefs (9). The result of Masoudnia et al study showed that perceived social stigma is a major risk factor in self-esteem failure of these patients (10). Since maintaining and promoting dignity in patients with human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) are of particular importance, by conducting this study, we aimed to introduce a new tool to assess the perceived dignity of patients living with AIDS/HIV to researchers and health managers and apply it in a healthcare setting.

Methods

This study is descriptive and cross-sectional. The population of this study includes patients living with HIV/AIDS referred to the behavioral diseases counseling center affiliated with Mainstay of Health and Medical Education, Iran. The study sample consisted of 220 patients selected using the available sampling method. Data collection started in February 2023 and lasted for five months. The inclusion criteria included all patients older than 15 years living with HIV and AIDS who had health records and continuous referral to the center for follow-up treatment.

The data collection tool is a questionnaire that assesses the perceived dignity of the patient living with HIV/AIDS. After examining the psychometric properties, this questionnaire was designed as a Persian version of the Patient Dignity Inventory (PDI) questionnaire. Chochinov et al initially designed the PDI questionnaire to assess status-related distress in cancer patients and includes 25 questions in 5 areas, including distress symptoms, existential anxiety, dependence, peace of mind, and social support (11). Distress symptoms refer to physical and mental factors. Existential anxiety includes how others see one's changes, the sense of worth to others, and the sense of being able to do important things. The dimension of peace of mind refers to the concerns about the spiritual life, unfinished business, and not having a meaningful relationship. Dependence includes being unable to do daily tasks and physical functions and, as a result, a decrease in privacy. The social support dimension measures the feeling of not being supported by family, friends, and healthcare providers. The questionnaire was adjusted to the conditions of AIDS patients by using the opinion of the counseling center's opinion. Demographic variables were also extracted from similar studies on AIDS patients (3), and experts removed sensitive questions.

The opinion of 13 specialists in various fields was collected. The content validity ratio (CVR) and the content validity index (CVI) were measured to approve the validity of the translated version of the questionnaire and measure the content validity. Ten questions were removed; for the rest, the CVR score was above 0.54, and the CVI score was above 0.79. The target community approved the face validity of all questions. Then, the factor analysis method was used to construct the validity of the questionnaire. The questions were categorized using factor analysis.

The questionnaire was given to 30 patients to complete and again 72 hours later to approve the reliability. The intra-cluster correlation coefficient was calculated to be 0.84, and Cronbach's alpha was calculated to evaluate the internal consistency, the value of which was 0.77. Finally, the questionnaire contains 22 items in two parts: demographic questions and 10 questions assessing the status of people living with HIV/AIDS) was given to the study participants. The range of answers to the questionnaire expressions according to the 5-point Likert scale is from no problem (score 1) to unbearable problem (score 5). Each question was assigned a score between 1 to 5. The range of perceived dignity scores in this study was 10 to 50, which, with a reverse scoring system, a score of 10 means a higher dignity level and a score of 50 means a lower dignity level.

Data collection was done in the field through interviews conducted by the researcher or counseling center's staff or self-completion questionnaires. After collecting data and recording information in SPSS software version 25, the data were analyzed in two descriptive and analytical formats. The significance level in this study was considered to be 5%.

Results

The mean age of participants was 37, and the mean years of knowing that they were infected was 5.23 years. 51% of participants were male, 46.1% were married, 41.2% had primary education, 55.9% were employed, and 66.7% of patients were in the asymptomatic stage of the disease. 81.4% of the patients were under the treatment of HIV and AIDS, and 74.5% were aware of their illness. 89.2% used counseling services, 72.5% of the patients stated that they do not use sedatives, and 67.6% used social counseling services.

The mean score of perceived dignity in male patients was 1.93, and in female patients, it was two. This difference was not statistically significant ($P=0.498$). The mean score of perceived dignity in employed patients was 2.02, and in non-employed patients, 1.98. This difference was not statistically significant ($P=0.211$). The mean perceived dignity score in patients receiving main treatment was 1.88, significantly lower than that in patients not receiving main treatment (2.31) ($P=0.001$). A lower score indicates a higher perceived dignity, so the perceived dignity was higher in patients receiving primary treatment. The mean score of perceived dignity in patients whose families were aware of their disease was 1.94. In patients whose families were unaware of their disease, it was 2.03, which was not statistically significant ($P=0.4$). The mean score of perceived dignity in patients who sought counseling if needed was 1.96; in patients who did not use counseling, it

was 2.01, which was not statistically significant ($P=0.830$). The mean score of perceived dignity in patients who took sedatives was 1.93; in patients who did not, it was 1.98, which was not statistically significant ($P=0.649$). The mean score of perceived dignity in patients who used social counseling services was 1.98; in patients who did not, it was 1.92; this difference was not statistically significant ($P=0.54$) (Table 1).

Perceived dignity was lower in divorced patients, although there was no statistically significant relationship between marital status and perceived dignity score ($P=0.839$). A statistically significant relationship existed between education level and perceived dignity score ($P=0.007$). The mean score of perceived dignity was 2.35 in patients with university education and 1.82 in patients with primary education. A lower score indicates a higher perceived dignity for people with primary education. Although there is no statistically significant relationship between the stage of the disease and the perceived dignity score ($P=0.092$), patients in the stage with advanced symptoms had the lowest perceived dignity (Table 2).

The Pearson correlation coefficient test showed no statistically significant relationship between age and perceived dignity score (r=0.134; p-value=0.185). The Pearson correlation coefficient test showed no statistically significant relationship between the years of knowing about having the disease and the perceived dignity score (r=0.115; p-value=0.253).

Fisher's exact test showed no statistically significant relationship between the overall dignity score and the variables of gender, marital status, education, employment status, stage of illness, receiving treatment, family awareness, counseling, sedative consumption, and social counselin. (Table 3).

Mann-Whitney test showed that the age and duration of knowing about the disease did not differ statistically significantly (Table 4).

The average score of perceived dignity in personal concerns was the highest. According to the results, the perceived dignity of patients in the dimension of personal concerns was lower than the average score of dignity in other dimensions, indicating patients' greater concern

Table 1. Correlation table of general dignity and two-mode qualitative demographic variables

Variable	Sub-variable	Mean±SD	T (*P* value)
Gender	Male	1.0±00.93	0.681 (0.498)
	Female	2.0±00.51	
Employment status	Employed	2.02±0.47	1.260 (0.211)
	Un Employed	1.89±0.54	
Main treatment	Yes	1.88±0.47	3.40 (0.001)
	No	2.31±0.52	
Family awareness	Yes	1.94±052	0.829 (0409)
	No	2.03±0.48	
Seek counseling	Yes	1.96±0.47	0.220 (0.830)
	No	2.01±0.76	
Took sedatives	Yes	1.93±0.55	0.457 (0.649)
	No	1.98±0.49	
Used social counseling	Yes	1.98±0.47	0.606 (0.546)
	No	1.92±0.57	

Table 2. Correlation table of general dignity and multi-state demographic qualitative variables

Variable	Sub-variable	Mean (SD)	F (*P* value)
Marital status	Single	1.0 (95.392)	0.281 (0.839)
	Married	1.0 (95.513)	
	Divorced	2.0 (05.685)	
	Widow	1.0 (89.368)	
Education level	Illiterate	1.0 (86.450)	4.246 (0.007)
	Diploma	1.0 (82.489)	
	Primary education	2.0 (02.475)	
	University education	2.0 (35.550)	
Stage of the disease	No symptoms	2.0 (0.503)	2.448 (0.092)
	Primary symptoms	1.0 (83.476)	
	Advanced symptoms	2.0 (40.845)	

Table 3. Correlation table of the overall categorized dignity score and qualitative demographic variables

Variable	Sub-variable	Overall score of dignity		*P* value
		No problem or with a minor problem Number (%)	Having a problem Number (%)	
Gender	Men	51.0 (51)	50.0 (1)	0.743
	Female	49.0 (49)	50.0 (1)	
Marital status	Single	22.0 (22)	0.0 0(0)	0.589
	Married	46.0 (46)	50.0 (1)	
	Divorced	20.0 (20)	50.0 (1)	
	Widow	12 (12.0)	0.0 (0)	
Education level	Illiterate	10.0 (10)	0.0 (0)	<0.999
	Diploma	41.0 (41)	50.0 (1)	
	Primary education	36.0 (36)	50.0 (1)	
	University education	13.0 (13)	0.0 (0)	
Employment status	Employed	57.0 (57)	0.0 (0)	0.192
	Un employed	43.0 (43)	100.0 (0)	

Table 4. Correlation table of the overall grade of categorized dignity and quantitative variables

Variable	Sub-variable	Mean (SD)	Median (interquartile range)	*P* value
Age	No problem or with a minor problem	36.98 (8.71)	37 (12)	0.238
	having a problem	41.40 (5.68)	40(9)	
Awareness	No problem or with a minor problem	5.23 (3.83)	4 (5)	0.325
	having a problem	6.40 (2.97)	6 (5)	

regarding this dimension.

Spearman correlation coefficient showed that there was a statistically significant relationship between the first dimension (mental abilities and perceptions) and the second dimension (personal concerns) at the intermediate level ($P<001$; $r=0.371$). Moreover, it showed a statistically significant relationship between the first dimension (mental abilities and perceptions) and the third dimension (social concerns) at the intermediate level ($P<001$; $r=0.362$). Spearman correlation coefficient showed that there was a statistically significant relationship between the second dimension (personal concerns) and the third dimension (social concerns) at the intermediate level ($P=0.001$; $r=0.326$).

Discussion

In the present study, patients had a well-perceived dignity (mean score of 1.96 out of 5). In other words, considering that the average achievable score was between 1 and 5 and a lower score indicates higher perceived dignity in the total and its. In this regard, Bagheri et al reported a good level of intrinsic dignity (4.6 out of 6) for patients with heart failure (4). The study by Bagheri et al showed that the patients' intrinsic dignity score was lower than that of nurses from the patients' point of view. The need to pay more attention to any factors related to maintaining or promoting patients' intrinsic dignity was suggested (4). Chochinov et al conducted a similar study on 211 cancer patients. The dignity of patients (score of 16 out of 22) was at a low level (11). The high score of perceived dignity in the present study might be due to having family support and attention and the culture of patient support that promotes patient dignity.

The findings of the present study showed no statistically significant relationship between age and the mean score of perceived dignity, which is consistent with the study of Ateneh et al (12). According to Wang et al, in cancer patients in China, there was a significant relationship between age and lost dignity. Moreover, young people were more likely to feel that their dignity had been lost due to the effects of China's culture and social environment (8). In the studies of Pourjam et al and Ramírez-Ortiz et al, there was a statistically significant and inverse relationship between the patient's age and dignity. Along with the increase in age, dignity decreased due to the unfavorable attitude of medical staff towards the phenomenon of aging (13,14). The relationship between dignity and age was not significant in our study because the patients studied at all ages participated in classes and gatherings of behavioral disease counseling centers and accessed a counselor.

The present study showed a statistically significant relationship between education level and perceived dignity score, as the average perceived dignity score was higher in patients with university education than other educational levels. In other words, patients with academic education perceived a lower level of dignity. The study by Fauk et al showed a statistically significant and inverse relationship between education level and mean intrinsic dignity score so that with increasing the level of education, patients' mean innate dignity score decreased (15), which is consistent with the present study. Han et al showed a statistically significant relationship between education and perceived dignity. The mean dignity score was higher in illiterate patients, i.e., illiterate people had lower perceived dignity (16), which is different from the results of the present study. The reason might be different attitudes and expectations in patients with university education than in patients with lower levels of education. It is worth mentioning that in the research of Tehranineshat et al as well as Zirak et al, there was no relationship between different levels of education and dignity (17,18)

According to the present study's findings, there was no statistically significant relationship between gender and perceived dignity score. The research of Ebrahimzadeh et al showed that the score of dignity in women was higher than in men; in other words, the dignity of women has been more threatened (5). According to the research of Shafi'i et al and Ramírez-Ortiz et al, perceived dignity was lower among women (9,14)

The results of the present study did not show a significant relationship between employment status and perceived dignity. In the study of Tehranineshat et al, there was no significant difference between different jobs and overall dignity score (17). In the study of Mohammadi et al, there was no relationship between employment status and dignity score (19). The reason may be that patients fear others being informed of their illness and consequently losing their jobs, negatively affecting their dignity, or they may be working in a job that does not fit their personality. In Liang and colleagues' study, a statistically significant relationship was reported between employment and dignity because, with increasing income, social support for patients increases, and their feeling of dignity increases (20). In the study of Avestan et al, the average dignity score for the unemployed was higher than for the employed, and these people had a higher perceived distress about dignity; in other words, their dignity was lower (21).

According to the present study's findings, no relationship

was reported between marital status and patients' perceived dignity score. The study of Pourjam et al did not show a significant relationship between marital status and dignity (13). However, Zirak and colleagues' research showed that the status of perceived dignity among married patients is higher than that of the unmarried (18). These studies are different from the results of the present study. In Hosseini and colleagues' study, no significant relationship was reported between dignity and marital status (22), which is consistent with the results of the present study.

In the present study, no relationship was found between the stage of the disease and the perceived dignity score. In the research of Wang et al, there was a significant and direct relationship between lost dignity and the stage of the disease. Patients in the advanced stages of the disease had a greater sense of lost dignity (8). These results are not consistent with the present study. The reason might be that the number of patients at the advanced stage of the disease was low in the present study. In addition, the study population and data collection tools were also different in the two studies. Shah Hosseini et al stated that there was no statistically significant relationship between the time of diagnosis and the dimensions of dignity in patients with breast cancer (23). These results are consistent with the results of the present study.

In this study, the overall perceived dignity of patients was reported to be high. The mean score of perceived dignity about the dimension of change in mental abilities and perceptions and social concerns was similar. However, it was the highest in the dimension of personal concerns. In the study of Mohammadi et al, the total score of dignity was 1.39, the mean score in losing dependence was 3.94 and in emotional distress was 3.63, the change in mental abilities and perceptions was 3.57 and in the dimension of the lack of perceived dignity was 3.3 (24). In the research of Anteneh et al the least concern was reported in the dimension of social support. Most concerns were related to distress (12).

In comparison between the dimensions in the present study, the average dignity score was higher in the dimension of personal concerns than in other dimensions, indicating that HIV/AIDS patients were concerned about this dimension. Immunodeficiency syndrome, regardless of whether the community and family are aware of the disease or not, affects patients' personal lives and negatively affects their self-esteem. Therefore, a person's self-image will greatly impact his behavior and attitude.

Limitations of the study

This study was performed with the mentioned tool for the first time and only on the part of patients with AIDS and HIV, so the generalization of the results should be done carefully. Lack of access to more patients to perform a confirmatory factor analysis of the questionnaire is also one of the limitations of this study.

Conclusion

In general, it seems that the implementation of interventions such as non-discriminatory counseling and psychological support of patients, raising community and family awareness about the disease, as well as providing work and social conditions commensurate with the situation of patients can help enhance the perceived dignity of these patients so that while believing in themselves and their abilities, they can become useful elements in the family and society.

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Authors' Contribution

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Competing Interests

The authors declare that there is no conflict of interest.

Ethical Approval

This article presents the result of a master's thesis approved by the National Ethics Committee in Biomedical Research of the university in 2020 (the code of ethics No. IR. MUMS.REC.1397.116).

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