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Perception of patients with COVID-19 about respecting their dignity in hospital settings: a cross-sectional study

Running title: **Perception of patients about their dignity**

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Abstract

Background: Dignity therapy is a psychotherapy intervention whose main goal is to improve the quality of life, promote spiritual and psychological health, and reduce suffering in people with life-threatening diseases. Deteriorating health status is associated with low perceived dignity. The COVID-19 pandemic has been associated with growing concerns about the quality of health care. Therefore, the present study aimed to examine the perception of patients with COVID-19 about respecting their dignity in the hospital settings and related variables.

Patients and methods: A cross-sectional study was conducted in 2021, on 206 patients with COVID-19 in hospitals. Patient Dignity Questionnaire (PDI) was used to collect data and descriptive and inferential statistics were used to analyze the data.

Results: The mean age of the participants was 54.83 ± 14.98 years and the majority of them were male (67.5%). The mean score of overall perceived dignity was 69.76 ± 10.62 out of 125. Participants rated 7 out of 25 items as 3 or higher, indicating the importance of these items in the clinical setting. The highest and lowest mean scores were in the dependence (3.28 ± 0.55) and social support (1.49 ± 0.59) subscales, respectively. The mean dignity score was associated with the patients' educational level and gender ($p = 0.012$) ($p = 0.065$).

Conclusions: Patients with COVID-19 were concerned about respecting their dignity. Our patients were more concerned about the dimensions of symptom distress, existential distress, and dependence. Conducting training workshops on respecting human dignity in patients with COVID-19 can improve nurses' knowledge and skills in this area and promote respect for patient dignity.

Key words: palliative care, patient dignity inventory, hospital setting, COVID-19

Introduction

Human dignity has always been at the center of the attention of scholars and divine religions. This concept was first highlighted in the Ethical Charter for Nurses by the American Nurses Association [1]. Thereafter, the importance of dignity in healthcare and treating people with respect has been increasingly emphasized worldwide. Human dignity is a human value that is considered a basic right for all [2]. It is associated with sensual perfection [3]. Respect for human dignity is an inherent value, and all health care providers should make a conscious effort to respect human dignity when providing care. The Oxford Dictionary defines dignity as “a calm and serious manner that deserves respect” and “a sense of being honored and respected by people” [4]. Violations of human dignity when providing health services can adversely affect the care and treatment process [5]. Respect for human dignity was identified as a criterion for human rights in the Universal Declaration of Human Rights (UDHR) [6]. Respect for patient rights and human dignity is also one of the most important moral obligations in the nursing profession [7].

Studies show a close relationship between patient satisfaction and the feeling of respect for human dignity during care [8]. Maintaining dignity in medical care requires careful consideration of individualized care, respect, advocacy, and active listening. Other factors that promote human dignity include a culture of care, the attitudes and behaviors of health care

providers, and the performance of specific care activities [9]. Dignity therapy or observing human dignity is considered a psychosocial palliative care intervention [10] that can improve the quality of life, promote spiritual and psychological well-being, and reduce suffering in people with existential-psychological disorders and severe diseases [11]. A recent study of the end-of-life experiences of patients with COVID-19 found that "providing meaningful moments at the end of life" and "compassionate professional support" help patients and their relatives feel dignified. It has also been found that human interactions of caregivers are the most important factor affecting the sense of dignity among patients' relatives [12]. On the other hand, disregard for human dignity has consequences such as sadness and frustration, distrust, and feelings of humiliation in patients and adversely affects their health [13, 14].

As health deteriorates, especially after a life-threatening illness, patients develop social and psychological disorders that compromise their sense of dignity [15, 16]. COVID-19 is one of the diseases that have caused numerous problems for patients and the health care system. The rapid spread of COVID-19 has worried the international community and raised concerns about psychiatric services for the general population [17]. According to official statistics published by Iran's Ministry of Health and Medical Education, by March 1, 2021, more than 6.6 million people have been infected with COVID-19 and 137,267 people have died from the disease [18]. The need for isolation, quarantine, and social distancing, as well as the need to provide medical services to patients despite limited resources and time, were among the ethical challenges at the time of the COVID-19 epidemic [19]. The recent pandemic also affected all aspects of nursing. The healthcare system faced a shortage of nurses and concerns about the quality of care services [20]. The shortage of nurses, the sharp increase in the number of patients in need of care, and the need to maintain physical distance limited nurses' face-to-face interactions with some patients and may have led to an unintended reduction in health services [21]. The pandemic forced health care providers to engage in what some refer to as impoverished care, where patient care obligations must be balanced against obligations to protect oneself and one's family [22]. In such situations, patients may feel that they are not being cared for and that their dignity is not being respected. Studies have shown that patients who are isolated for medical reasons are more prone to depression, anxiety, anger, and decreased self-esteem [23]. Families of these patients are also unable to adequately support their patients because they cannot visit them, many of their questions remain unanswered, and they worry about the quality of care their loved ones are

receiving [22]. Although many studies have been conducted in the field of human dignity related to the COVID-19 pandemic, we found no study examined the condition of these patients and the challenges that arise from COVID-19 in the clinical setting. Considering the importance of human dignity and the challenges associated with respecting patients' dignity during the COVID-19 epidemic, the present study was conducted to investigate the understanding of patients with COVID-19 about respecting their dignity in the hospital setting.

Patients and methods

This cross-sectional study was conducted in teaching hospitals of Qom, Iran, during August and September 2021. A two-part instrument was used to collect the study data. The first part included 11 questions about patient demographics, comorbid disorders, use of psychoactive medications, and previous hospitalizations. The second part was the Patient Dignity Inventory (PDI). The PDI was developed by Chochinov et al. [24] in 2008. It contains 25 items in five subscales on symptom distress, existential distress, dependence, peace of mind, and social support. Each item was rated on a five-point scale (1 = not a problem; 2 = a slight problem; 3 = a problem; 4 = a major problem; 5 = an overwhelming problem). A higher score indicates a greater problem associated with patient dignity. The validity and reliability of this instrument was confirmed in Iran by Abbaszadeh et al. [25] and its Cronbach's alpha was 0.85.

The inclusion criteria were a medical diagnosis of COVID-19, CT scan evidence of lung involvement (diagnosed by the concerned physician), age of 16 years and over, passing at least one day since admission to the general ward, willingness to participate in the study, and ability to answer the study questionnaires. Those who could not answer the questionnaires completely were excluded. Researchers then referred to the study settings, found eligible subjects conveniently, briefed them and their companions on the study objectives and process, invited them to participate in the study, assured them that the data would be kept confidential, and if agreed they were provided with a copy of the informed consent to be signed. In the case of illiterate patients, a cross sign was taken as a signature. As most patients were illiterate or low literate, all of the questionnaires were completed by the researcher by asking the items from patients.

The sample size was calculated at 206 based on the results of a pilot study and the formula ($n_0 = \frac{Z^2 p(1-p)}{e^2}$) for estimating the mean of the population. Data analysis was performed using the

SPSS software version 23. As some of our data did not show normal distribution and equal variance not assumed, parametric and nonparametric statistical test methods were used in the present study. Descriptive statistics such as frequency, percentage, mean and standard deviation were used to describe the demographic data and dignity scores. Independent samples t-test, analysis of variance, and Mann–Whitney U tests were used to compare mean dignity scores between subgroups of participants. Also Pearson's and Spearman's correlation coefficients were used to examine the association between age and Number of days of hospitalization with dignity scores. A p-value < 0.05 was considered statistically significant. The study protocol was approved by the ethics committee of Qom University of Medical Sciences (approval code: IR.MUQ.REC.1400.059).

Results

The mean age of the participants was 54.83 ± 14.98 years. A majority of them were male (67.5%), married (91.7%), illiterate (34%), had excellent family relations (61.7%), earn enough for their expenses (73.8%), were hospitalized for an average of 7.90 ± 6.84 days, and had some comorbid disorders (45.6%), but 92.7% had no history of psychoactive medication use (92.7%) (Table 1).

Table 1 also shows that the mean perceived dignity did not significantly differ between subgroups of participants, except for those with different education levels. Illiterate people possessed the highest mean perceived dignity, whereas those with academic degrees had the lowest mean score.

The mean scores for the individual items of the perceived dignity scale are presented in Table 2 and show that the participants scored 3 or higher in 7 out of 25 items, indicating the importance of these items in the clinical setting.

The mean overall perceived dignity was 69.76 ± 10.62, with the highest and lowest mean scores for the dependence (3.28 ± 0.55) and social support (1.49 ± 0.59) subscales, respectively (Table 2).

Discussion

Patients who participated in the present study scored approximately 55% on the total human dignity score. They also gave 18 out of 25 items of the Human Dignity Scale a score of less than 3. This finding shows that, from the patients' point of view, their human dignity is not adequately respected. The inadequate attention to the human dignity of patients with COVID-19 may be partly attributed to the occurrence of unprecedented epidemic, the unprecedented increase in nurses' workload, and the severe shortage of nurses during the epidemic [26]. In such a situation, the moral obligation to care for patients and protect themselves forced nurses to balance the ethical principles of patient care and equality [27]. However, the findings of the present study may also suggest that patients were not adequately informed of their rights, which may have resulted in nurses not respecting patients' rights and human dignity. Previous studies also indicate that patients are not fully aware of their rights [28] and also show that there are shortcomings in respecting patients' human dignity [29]. Sahebi et al. [30] also reported that in Iran, most patients do not know their rights, which leads to problems for patients and organizations providing health services.

In the present study, the mean scores of the items in the peace of mind subscale indicated a relatively favorable level of care in this dimension. This finding may be attributed to the religious beliefs of our patients [31]. Qom is one of the most religious cities in Iran. Islamic beliefs consider illness as a divine trial and encourage people to be patient and endure suffering [32]. Therefore, patients seem to have maintained their peace of mind by relying on their religious beliefs.

The responses of our patients to the items on social support indicate a relatively good level of care in this area. However, this finding may also indicate that patients are unaware of their rights. They may also have recognized the critical state of the healthcare system due to the epidemic, which had lowered their expectations. Nonetheless, highlighting the patients' expectations of caregivers to be understood and treated appropriately, a study reported that nurses do not understand patients' expectations well and do not examine their needs [33]. In a study of the bereaved relatives of patients who died during the COVID-19 epidemic in the Netherlands, four main themes were identified: “dealing with an unknown disease”, “isolation”, “short-term farewell”, and “insufficient attention and communication”. These themes represent the main issues affecting the dignity of patients and their relatives during the epidemic and show that the

isolation of patients with COVID-19 and inadequate communication with them because of the unknown disease damaged their sense of dignity [12].

Our patients scored relatively high on the existential distress items. However, they scored lower on the items on worthlessness and meaninglessness of life. In other words, they had a better perception of respecting their dignity on the latter items. Such a better perception might also be attributable to the religious beliefs of the participants.

Privacy is one of the most important issues affecting human dignity. Hospitalization usually threatens patients' privacy, leading to anxiety, aggression, refusal to cooperate with the therapist, and reduced patient satisfaction with care [34]. Our patients gave high scores to items related to invasion of privacy, confirming that their privacy is not adequately respected in the hospital setting. Perhaps this is why they feel that nurses do not care about their dignity.

In the present study, the dependency subscale scored the highest mean. The mean score of the item related to the feeling of being a burden to others was also relatively high. This finding indicates that patients' dignity is not adequately addressed in this area. COVID-19 and hospitalization seem to prevent patients from performing their personal and daily tasks. Patients may even require the help and assistance of others for activities such as bathing and changing clothes. A study found that dependence in personal matters is often accompanied by feelings of being a burden to others [35]. A study of patients with advanced amyotrophic lateral sclerosis also showed that patients' dependence in personal affairs reduces their self-esteem and dignity and is associated with a feeling of being overburdened [36]. Other studies have shown that patients with COVID-19 have significant functional impairments [37] and severe stress during the acute phase of the disease, which affects not only their physical functions but also their mental health [38]. Li et al. [39] also reported that the sense of dignity is related to people's mental state, and a decreased sense of dignity in patients may prolong their mental health problems.

Studies in patients with cancer and cardiac disorders have also shown that caregivers' inattention to patients' dignity causes more distressing psychological symptoms in women than in men [40, 41]. However, in the present study no significant relationship was found between the feeling of human dignity and gender .In a qualitative study of the perceived dignity in cancer patients undergoing chemotherapy, Xiao et al. [42] found no association between financial status

and patients' perceived dignity. However, a study in patients with breast cancer showed that appropriate financial status was significantly correlated with feelings of social support and existential distress, as two dimensions of human dignity [16]. However, we found no significant relationship between financial status and perceived dignity. Apart from cultural factors, the contradictory results could be attributed to the high cost of treating chronic diseases such as cancer. In Iran, meanwhile, the healthcare and insurance systems have covered most of the treatment costs of COVID-19.

In our study, patients with lower levels of education were more concerned about their dignity than those with academic degrees. However, two studies of cancer patients have reported that with increasing education, people are more concerned about their dignity [29, 43]. The conflicting findings can be attributed to the unknown and emerging nature of COVID-19. This has likely resulted in patients with low levels of education not having accurate information about the disease, which has made them more concerned.

We found no significant association between perceived dignity and age or duration of the disease. This finding is consistent with the results of a study by Oechsle et al. [44] on terminally ill cancer patients.

Limitations

This study was performed on patients with COVID-19 admitted to public hospitals in Qom, Iran, and the results may not be generalizable to those in other cities or patients admitted to private hospitals. Therefore, it is recommended that the same studies be replicated in other hospitals and cities. In addition, the clinical condition of the patients might have influenced their responses, which was beyond the control of the researchers. Also, due to the use of a self-report questionnaire, the results may have been prone to social desirability bias.

Conclusions

According to the findings of the present study, there are concerns about respecting human dignity in patients with COVID-19. Our patients perceived an appropriate level of dignity in the two dimensions of peace of mind and social support. Nevertheless, our patients were more concerned about the dimensions of symptom distress, existential distress, and dependence. Given

the special circumstances arising from the COVID-19 epidemic and the many challenges that come with it, nurses and other health care providers should pay more attention to the human dignity of patients with COVID-19. Holding training workshops on respecting human dignity in patients with COVID-19 can improve nurses' knowledge and skills in this area and promote respect for patient dignity.

Finally, due to the increase of epidemics in the past decades, the results of the present study could be used for the importance of privacy in relation to the dignity of treatment, which has a significant impact on the treatment process of patients with particular diseases.

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Conflicts of interest

The authors of this study hereby declare that they no conflicts of interest to disclose.

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Table 1. Demographics characteristics of the study population and their correlation with patient dignity inventory scores

Demographics characteristics	**N (%)**	**Mean ± *SD**	**p-value**
Gender			
Female	67 (32.5)	71.73 (10.19)	0.06
Male	139 (67.5)	68.81 (10.72)	
**Degree of education			
Unlettered	70 (34.0)	72.85	0.04
Under diploma	60 (29.1)	69.33	
Diploma	30 (14.6)	68.26	
University degree	46 (22.3)	66.58	
Marital status			
Single	15 (7.3)	66.66 (10.86)	0.36
Married	189 (91.7)	69.94 (10.58)	
Widow/divorced	2 (1.0)	76.00 (12.72)	
Employment status			
Housewife	64 (31.1)	71.14 (9.60)	0.50
Employee	49 (23.8)	68.10 (10.45)	
Worker	82 (39.8)	69.78 (11.25)	
Unemployed	11 (5.3)	69.00 (12.36)	
Relationship with family			
Bad	5 (2.4)	70.60 (5.12)	0.26
Good	74 (35.9)	71.33 (11.01)	
Excellent	127 (61.7)	68.81 (10.48)	
**History of recurrence			
Yes	91 (44.2)	70.94	0.16
No	115 (55.8)	68.82	
The economic situation			
Equal with expenses	152 (73.8)	69.53 (10.07)	0.87
Less than expenses	53 (25.7)	70.35 (12.21)	
More than expenses	1 (0.5)	72.00 (0.0)	
Taking neuroleptic medicine			

Yes	15 (7.3)	67.60 (10.93)	0.41
No	191 (92.7)	69.93 (10.60)	
**Underlying disease			
No illness	94 (45.6)	69.19	0.80
One illness	90 (43.7)	70.07	
Two or more illnesses	22(10.7)	70.90	

**The Degree of education data had a non-normal distribution and the non-parametric test (Kruskal-Wallis H) was used for analysis. History of recurrence and underlying disease data had heterogeneous variance and non-parametric tests (Mann-Whitney U and Kruskal-Wallis H) were used to analyze them, respectively

*SD — standard deviation

Table 2. The average response scores to each of questionnaire items and domains

Items and domains	**Mean ± SD**
1. Not being able to perform tasks associated with daily living	4.34 (0.93)
2. Not being able to attend to my bodily functions independently	4.50 (0.82)
3. Experiencing physically distressing symptoms	3.48 (1.02)
4. Feeling that how I look to others has changed significantly	2.14 (0.91)
5. Feeling gloomy	2.55 (1.02)
6. Feeling solicitous	3.09 (0.97)
7. Feeling uncertain about my illness and treatment	2.25 (0.97)
8. Concern about my next	2.42 (1.08)
9. Not being able to think distinctly	1.84 (0.84)
10. Not being able to continue with my usual routines	4.11 (0.82)
11. Feeling like I am no longer who I was	2.24 (0.90)
12. Not feeling worthwhile or valued	1.84 (0.99)
13. Not being able to carry out important roles	3.48 (0.99)
14. Feeling that life no longer has point or object	1.80 (0.82)
15. Feeling that I have not made a meaningful during my lifetime	1.39 (0.61)
16. Feeling I have “unfinished business”	1.69 (1.13)
17. Concern that my religious life is not significant	1.62 (0.74)
18. Feeling that I am a burden to others	3.19 (1.02)
19. Feeling that I don’t have rein over my life	2.60 (0.95)
20. Feeling that my illness and care needs have decreased my privacy	2.33 (0.84)
21. Not feeling supported by my community of friends and family	1.21 (0.62)
22. Not feeling supported by my medical caregivers	1.74 (0.83)
23. Feeling like I am no longer able to mentally ‘fight’ the challenges	1.99 (0.89)
24. Not being able to accord the way things are	1.83 (0.82)
25. Not being treated with regard or understanding by others	1.54 (0.78)
Symptom distress	2.43 (0.59)
Existential distress	2.67 (0.50)
Dependency	3.28 (0.55)
Peace of mind	1.56 (0.51)

Social support	1.49 (0.59)
Total	**69.76 (10.62)**

*All the analyzed data in Table 2 had a normal distribution and therefore parametric test was used to analyze them