

RESEARCH ARTICLE

Perceptions of Iranian Cancer Patients Regarding Respecting their Dignity in Hospital Settings

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Abstract

Background: There are several factors that threaten the dignity of cancer patients in hospital settings. However, there is limited literature regarding the degree to which dignity of cancer patients is actually respected in daily clinical practice. The aims of this study were therefore to explore cancer patient perceptions of respecting their dignity and related variables in an Iranian cancer specific center. **Materials and Methods:** This descriptive-correlational study was carried out among 250 cancer patients admitted to a cancer specific center in East Azerbaijan Province, Iran. These patients were selected using a convenience sampling method. The Patient Dignity Inventory (PDI) was used for data collection. Descriptive and inferential statistics were used for data analysis. **Results:** The patients' scores in 18 out of 25 items of PDI were 3 or greater which indicate the importance of considering these items in clinical settings. Also, the score of patients in three sub-scales of PDI including illness-related concerns, personal dignity, and social dignity were 74, 65 and 57, respectively (based on a total 100). The overall score of PDI was statistically associated with age, history of disease recurrence, education, employment and economic status of participants. **Conclusions:** According to the study findings the dignity of Iranian cancer patients is not completely respected in clinical settings which require special considerations. As nurses spend more time at patients' bedsides, they have an important role in maintaining and promoting dignified care.

Keywords: Dignity - cancer patients - ethical treatymt - Iran

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Introduction

In addition to death, cancer diagnosis is accompanied by lots of complications for patients. The most negative consequences of cancer include but not limited to anxiety and fear, doubt about belief and religious values, impaired identity and body image, sleep disorders and role function problems (Esmaili et al., 2012; De Sousa et al., 2012; Afrooz et al., 2014). All of these problems as well as, financial distress, marital issues and ambiguity regarding the future can led to patients' perception of lack of respected dignity (Chochinov et al., 2007; Fathollahzade et al., 2014; Ghasempour et al., 2014).

Dignity is a main part of human rights (Parmar et al., 2014) and preserving and enhancing patients' dignity is one the essential part of nursing care (Jacobson, 2007; Nasrabadi et al., 2011). The importance of patient dignity is also reflected in various nursing codes of ethics worldwide (International Council of Nurses, 2001; Sanjari et al., 2011). Providing dignified care also has undeniable effects on health indicators including life expectancy and quality of life (Chochinov et al., 2005). On the other

hand, violation of patients' dignity may influence their psychological and spiritual status and also adversely affect their cooperation with medical staff (Walsh and Kowanko., 2002).

Cancer patients are constantly at risk for loss of sense of dignity. However, factors such as change in living environment, unfamiliar setting and dependence on health care workers significantly affect patients' dignity during hospitalization (Walsh and Kowanko., 2002). The three most significant factors that affect patients' dignity include illness-related concerns, personal and social factors. Pain, anxiety, fear of death, and feeling uncertain regarding illness and treatment are categorized as illness-related concerns. Personal factors include psychological integrity, hopefulness, and maintaining independence and self-esteem. Also, providing a private environment, social support and interactions with others, especially family and healthcare workers are social factors that affect patients' perception of dignity (Chochinov et al., 2008). Recognizing and focusing on these factors will help healthcare workers to preserve and promote patients' dignity (Thompson and Chochinov., 2008; Li et al., 2014).

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Despite the importance of dignity, this concept is not well-investigated among cancer patients. Generally, other concepts such as respect, privacy, self-esteem and independence were related to dignity (Haddock., 1996). This complexity has led to many conflicting strategies for maintaining and improving patients' dignity (Walsh and Kowanko., 2002, Woogara., 2005). Identifying patients' perception of respectful and dignified care is one the most strategies for further clarification of this concept (Franklin et al., 2006). The findings of a qualitative survey, which explored the meaning of dignity among Iranian patients, highlighted the lack of dignified care (Torabizadeh et al., 2013). In an extensive literature review there was no study which examined the Iranian cancer patients' perception of dignity using quantitative approach. Accordingly, the aims of this study were to explore cancer patients' perception of respecting their dignity and related variables in an Iranian cancer specific center.

Materials and Methods

This descriptive-correlational study was conducted in Ghazi Tabatabay hospital affiliated to Tabriz University of Medical Sciences, Iran. This center is the only comprehensive cancer specific center in north eastern of Iran. The study population included all patients who were referred to the centers during the study period and met the following criteria: (a) having confirmed cancer diagnosis; (b) be at least 18 years old; (c) willing to participate in the study; (d) at least 5 days passed since they admitted to the hospital; and (d) were aware of exact diagnosis. The sample size (n=235) was calculated based on a pilot study. Considering a 10% attrition rate, 265 eligible patients were invited to participate in the study using convenience sampling method. Finally, 250 cancer patients accepted to be enrolled in the study (response rate = 94%).

The instrument for data collection composed of two main parts. The first part was to collect some demographic and disease - related characteristics of participants which gathered according to patients self-report or using their medical records. The second part included Patient Dignity Inventory (PDI) developed by Chochinov in 2008 (Chochinov et al., 2008). This 25 items scale has three major sub-scales including illness related concerns (8 items), personal dignity (12 items) and social dignity (5 items). These items classified according to a 5-point Likert scale ranging from 1 (not a problem) to 5 (an overwhelming problem). The total score of PDI is 25 to 125 points (the higher scores indicating higher perceived dignity-related distress). Items with a score of 3 or greater, indicating the importance of considering these items in clinical settings (Chochinov et al., 2009).

For using the scale, PDI was translated into Persian and then, its accuracy and fluency confirmed by a translator expert in both Persian and English languages. The scales face and content validity were assessed and verified by the expert panel constituted ten academic members. The final version of the questionnaires was tested for reliability in a pilot study involving 30 cancer patients. Cronbach-Alpha coefficient value for PDI was 0.92.

Before data collection, the study proposal was

approved by the Regional Ethics Committee at Tabriz University of Medical Sciences. Next, researchers were referred to the center to identify eligible cases and patients who met criteria for the study were identified and invited to participate. After being presenting basic information, willing patients were asked to participate in a private interview for data collection. All patients who participated in the study gave informed consent. Data collection lasted from July to December 2014.

Data were analyzed using SPSS version 13. Descriptive statistics such as the frequency, percent, mean and standard deviation were used to describe demographic data and dignity scores. Relationships between patients' characteristics with dignity scores were assessed by

Table 1. Participant Characteristics (n=250)

Variable	n (%)
Gender	
Female	125 (50)
Mail	125 (50)
Level of education	
Illiterate	146 (58.4)
Under diploma	38 (15.2)
Diploma	46 (18.4)
University degree	20 (8)
Employment status	
Housewife	94 (37.6)
Employee	35 (14)
Hand -worker	40 (16)
Unemployed	81 (32.4)
Marital status*	
Single	30 (12)
Married	210 (84)
Divorced \ Widow	1 (4)
Economic status	
Earn equal with expense	19 (7.6)
Earn more than expense	7 (2.8)
Earn less than expense	224 (89/6)
History of recurrence*	
Yes	113 (45.4)
No	136 (54.6)
Disease	
Blood	97 (38.8)
Lung	11 (4.4)
Digestive	72 (28.8)
Breast	34 (13.6)
Head and Neck	10 (4)
Prostate	7 (2.8)
Genital	9 (3.6)
Other	10 (4)
Relationship with family	
Excellent	191 (76.4)
Good	37 (14.8)
Bad	22 (8.8)
Treatment models**	
Chemotherapy	250 (100)
Radiotherapy	137 (45.5)
Surgery	139 (55.6)
Other	47 (18.8)
Age in years, mean (SD)	50.5 (17.7)
Since awareness of the diagnosis in month, mean (SD)	22.8 (29.5)

*some participants did not respond; ** participants be able to select more than one choice; SD = standard deviation

Table 2. The Response of Participants to all Items of Patient Dignity Inventory

Variables)	Mean (SD)
Not being able to carry out tasks associated with daily living	1.5 (0.49)
Not being able to attend to my bodily functions independently	2.9 (1.36)
Experiencing physically distressing symptoms	3.7 (1.33)
Feeling that how I look to others has changed significantly	3.3 (1.28)
Feeling depressed	4.1 (1.20)
Feeling anxious	4.1 (1.20)
Feeling uncertain about my illness and treatment	4.1 (1.22)
Worrying about my future	4.2 (1.11)
Not being able to think clearly	3.6 (1.24)
Not being able to continue with my usual routines.	3.9 (1.09)
Feeling like I am no longer who I was	3.5 (1.15)
Not feeling worthwhile or valued	3.1 (1.31)
Not being able to carry out important roles	3.4 (1.21)
Feeling that life no longer has meaning or purpose	3.3 (1.19)
Feeling that I have not made a meaningful during my lifetime	3.3 (1.35)
Feeling I have 'unfinished business'	3.9 (1.21)
Concern that my spiritual life is not meaningful	1.2 (1.00)
Feeling that I am a burden to others	3.7 (1.35)
Feeling that I don't have control over my life	3.3 (1.27)
Feeling that my illness and care needs have reduced my privacy	3.2 (1.38)
Not feeling supported by my community of friends and family	2.1 (1.26)
Not feeling supported by my health care providers	2.8 (1.63)
Feeling like I am no longer able to mentally 'fight' the challenges	3.1 (1.28)
Not being able to accept the way things are	2.9 (1.34)
Not being treated with respect or understanding by others	2.5 (1.42)
Illness-related concerns (based on 100)	74.0 (19.12)
Personal dignity (based on 100)	65.4 (17.68)
Social dignity (based on 100)	57.6 (22.12)

*SD = standard deviation

Table 3. Relationship of Participants' Perception about Respecting their Dignity with Some Demographic and Disease Related Factors

Variable	Mean (SD)	Statistical analysis
Gender		
Female	80.84 (20.68)	P=0.39
Male	83.10 (21.45)	t=0.84
Level of education		
Illiterate	85.60 (17.70)	
Under diploma	80.28 (22.10)	P=0.007
Diploma	74.89 (25.47)	F=4.15
University degree	74.95 (25.54)	
Employment status		
Housewife	79.68 (20.74)	
Employee	76.31 (22.31)	P=0.07
Worker	85.10 (20.26)	F=2.31
Unemployed	85.53 (20.75)	
Marital status		
Single	77.80 (27.12)	P=0.35
Married	82.79 (20.15)	F=1.00
Divorced \ Widow	77.20 (19.14)	
Economic status		
Earn equal with expense	59.78 (26.49)	P=0.001
Earn more than expense	77.77 (16.26)	F=12.81
Earn less than expense	83.98 (19.62)	
History of recurrence		
Yes	85.00 (21.70)	P=0.03
No	79.37 (20.29)	t=2.11
Disease		
Blood	81.65 (21.89)	
Lung	84.36 (24.38)	
Digestive	84.23 (18.23)	P=0.57
Breast	78.23 (22.97)	F=0.81
Head and Neck	91.00 (15.63)	
Prostate	82.28 (22.53)	
Genital	75.00 (18.69)	
Other	75.80 (27.69)	
Relationship with family		
Excellent	81.62 (22.18)	P=0.89
Good	83.27 (18.91)	F=0.11
Bad	82.77 (13.82)	

*SD =standard deviation

inferential statistics including independent t-tests, ANOVA and Pearson's correlation as appropriate.

Results

Table 1 shows some demographic and cancer-related characteristics of participants. As shown in this table, most of participants were married, illiterate, housewife and had a financial condition of income less than expense. The mean of participants' age (in years) and awareness of cancer diagnosis (in months) were 50 and 23, respectively.

Table 2 shows the mean of participants' scores in each of PDI items. It also shows patients scores in three main sub-scales of PDI including illness - related concerns, personal dignity and social dignity. The patients' scores in 18 out of 25 items were 3 or greater which indicate the importance of considering these items in clinical settings. As shown in this table the highest score (higher perceived dignity-related distress) was related to illness - related concerns and the lowest score (lower perceived dignity-related distress) was associated with social dignity category.

The associations of patients' perception of dignity with some demographic and disease -related characteristics are displayed in Table 3. As shown in this table, patients with history of disease recurrence had higher PDI score. The study finding also revealed that some of demographic and disease-related characteristics including education (p=0.007), employment (p=0.07), economic status (p=0.001), and history of disease recurrence (p=0.03) were significantly associated with the patients' perception of dignity. In this regard, Tukey's post-hoc test showed that patients who were illiterate (p=0.01), unemployed

($p=0.001$), and income less than cost ($p=0.001$) had higher PDI scores (higher perceived dignity-related distress). In addition, patients' perception of dignity was significantly correlated with their age ($r=0.14$, $p=0.027$).

Discussion

The aims of present study were to explore cancer patients' perception of dignity and the related variables in an Iranian cancer specific center. According to extensive literature review, this is one of the first studies which investigated cancer patients' perception of dignity among Iranian cancer patients.

According to the study findings the dignity of Iranian cancer patients is not properly maintained in clinical settings and in 18 out of 25 items of PDI requires special considerations. The study findings also showed that dignity-related distress was higher in illness related concerns sub-scale. The findings of Chochinov et al. (2006) revealed that 87% of terminally ill cancer patients were not treated based on dignity (Chochinov et al., 2006). In another study Chochinov et al. (2002) also showed that 46% of hospitalized cancer patients expressed their concerns regarding lack of preserved dignity in medical centers (Chochinov et al., 2002). The findings of a qualitative study by Matiti et al. (2008) in the UK revealed that many patients were not satisfied with the maintenance of their dignity in clinical settings (Matiti et al., 2008). Similarly, the findings of Rehnsfeldt et al. (2014) study in Denmark, Sweden and Norway showed that patients care was carried out based on routinized care without considering individual's self-worth and dignity (Rehnsfeldt et al., 2014). Although there is lack of evidence regarding cancer patients' perception of dignity in Iranian context, but the findings of few studies suggest that the dignity of Iranian patients is not completely maintained in clinical settings (Wilson et al., 2005; Nayeri et al., 2011; Ebrahimi et al., 2012).

Higher perceived dignity violation in illness - related concerns sub-scale was one of the most important findings of this study. It also revealed that the sense of anxiety and depression, uncertainty regarding the disease and treatments, and worrying about the future were the main symptoms of lack of preserved dignity in this sub-scale. Previous studies also showed that anxiety and depression are the potential symptoms of lack of preserved dignity in cancer patients (Coyle and Sculcoet al., 2004; Chochinov et al., 2008). Cancer patients often experience high levels of anxiety and depression due to pain and physical and psychological suffering that may adversely affect their dignity (Coyle and Sculco et al., 2004). The findings of other studies in Iran also revealed high levels of anxiety and depression among Iranian cancer patients (Mashhadi et al., 2013; Moeini et al., 2014). Previous studies showed that fear regarding the future (Boyes et al., 2012; Vehling et al., 2014) and uncertainty (Hashemi et al., 2014) are common feelings among cancer patients that can influence their sense of dignity. The high prevalence of anxiety, depression and uncertainty among Iranian cancer patients (Aghdam et al., 2014) served as further confirmation of our findings.

The results of present study showed that disease symptoms and uncertainty regarding the ability to work and keeping job were the main factors that led to patients' sense of loss of dignity in personal dignity dimension. Chochinov et al. (2009) showed that main concerns of cancer patients focused on fears regarding keeping job and not being able to carry out important roles (Chochinov et al., 2009). According to Vehling et al. (2014) the main cause of cancer patients' perception of lack of dignified care was due to physical related symptoms (Vehling et al., 2014). Faghani et al. (2014) showed that Iranian cancer patients experience many physical symptoms such as pain during the survival period (Abdollahzadeh et al., 2014).

In this study patients' perception of dignity was more desirable in social dignity than other dimensions. However, patients perceived that their dignity was not properly preserved in some items such as sense of burden to others and reduced privacy. Similar to our findings, in Chochinov et al. (2007) study 40% of cancer patients reported "sense of burden to others" which adversely affects their sense of dignity (Chochinov et al., 2007). The finding of other studies also showed that the respect for patients' privacy and dignity are interconnected. The lack of privacy in medical centers threatened patients' dignity (Matiti et al., 2007; Ebrahimi et al., 2012; Torabizadeh et al., 2013). The findings of some studies in Iran also revealed that patients' privacy is not protected appropriately (Nayeri et al., 2010; Bagheri et al., 2012).

The study findings also showed significant associations between patients' perception of dignity with some demographic and disease-related characteristics. In congruent with the findings of other studies, in current study patients' perception of dignity improved with increasing in patients' age. The findings of other studies showed that dignity violation is more prevalent among older people (Hall et al., 2009; Oosterveld-Vlug et al., 2013). However, it also has been reported that sense of dignity violation is more common among younger people due to importance of physical appearance, lack of job performance and control over life, early death, and a lesser time to achieve life goals (Calnan et al., 2004; Chochinov et al., 2009).

In the current study the history of disease recurrence have a negative influence on patients' perception of dignity. Although advances in current treatments dramatically increase the number of cancer survivors in recent years, fear of recurrence is still a main concern for cancer patients (Kim et al., 2012). The findings of some studies conducted in Iran also indicated fear of recurrence as one of the major concerns among Iranian cancer patients (Taleghani et al., 2006; Abdollahzadeh et al., 2014). It seems fear of recurrence negatively influence patients' perception of dignity. The study findings also revealed that perceived dignity was significantly associated with patients' education, employment and economic status. However, it seems financial status has greater influence on patients' psychological condition than other demographic variables. Other studies have already shown similar findings (Rustøen and Wiklund., 2000; Kyngäs et al., 2001).

The study findings will help professionals to design

supportive programs for maintaining and promoting cancer patients' dignity and providing more dignified care. According to the study findings the dignity of Iranian cancer patients is not completely respected in clinical settings which require special considerations. Dignity is an important part of care and should be considered as other important clinical goals. As nurses are more in touch with such patients, then they have an important role in maintaining and promoting their dignity.

Despite the strength of this study, it also has some limitations. First, a sample of patients admitted to one medical center in East Azerbaijan Province in northwest of Iran cannot represent the overall state of perceived dignity among Iranian cancer patients. Next, the sense of dignity was only explored from the patients' perspective. In relation to future research, replicating such studies in other Iranian regions is required. Exploring family and healthcare workers' perception of dignity is also recommended.

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