# **RESEARCH ARTICLE**

# Different Sources of Dignity-Related Distress in Women Receiving Chemotherapy for Breast Cancer

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# Abstract

**Background:** Identification of different sources of dignity-related distress experienced by people nearing the end of life may help nurses to provide better care services. This study was conducted to determine sources of dignity-related distress from the perspective of women with breast cancer undergoing chemotherapy. **Materials and Methods:** In this cross sectional study, the participants comprised 207 women with breast cancer undergoing chemotherapy in chemotherapy clinics in hospitals of Tehran, Iran. The Cronbach's coefficient alpha for the PDI was 0.76. Validity of PDI by confirmatory factor analysis shows that the comparative Fit Index of this instrument is 0.96 and so it is appropriate for application in different setting. Data were analyzed by Stata version 13. **Results:** Patients were mostly concerned about the distress caused by disease symptoms (mean; 2.4061, S.D.; 0.96), followed by existential distress (mean; 1.8784, S.D.; 0.75), peace of mind (mean; 1.871, S.D.; 0.77), dependence (mean; 1.8647, S.D.; 0.98), and social support (mean; 1.4097, S.D.; 0.99), respectively, in order of highest scores. **Conclusion:** Considering that the patients were mostly concerned about the distress caused by disease symptoms, followed by existential distress, peace of mind, dependency, and social support, it seems necessary to take further measures toward addressing these issues.

Keywords: Patient dignity- breast neoplasms- chemotherapy- dignity-related distress

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## Introduction

Despite the remarkable advances in medicine, cancers are still a major challenge facing the health system and cause of eight million deaths during 1990-2010 in the world and third cause of death after heart diseases and car accidents in Iran (Naderimagham et al., 2014). Of the cancers, breast cancer is the most common cancer in women. Based on the latest report of the American Cancer Society, in 2017 in the U.S., 40,610 women would die of breast cancer and 252,710 women would be diagnosed with invasive breast cancer; another 63,410 women would be diagnosed with breast cancer in situ (Siegel et al., 2017). The annual prevalence rate of breast cancer is 1%-2% in developed countries and increases by 5% in developing countries (Mohaddesi et al., 2013). The prevalence rate of breast cancer in Iran has been estimated 22.9% per 100,000 people (Hoseini et al., 2014). Breast cancer occurs at least one decade earlier in Iranian women than in their peers in developed countries, which shows the importance of this disease (Naderimagham et al., 2014). Furthermore, patients with breast cancer enjoy a long survival (Kesson et al., 2012) and consequently, deal with cancer and its complications and outcomes for a longer time (Darby et al., 2013). About 20%-40% of patients with cancer experience many emotional distresses (Chochinov et al., 2012). The potential sources of distress include physical symptoms, sorrow at the current and future losses, worry about the attachment to others and being a burden for others, and doubt about the future (Hall et al., 2014).

The distress caused by the diagnosed cancer and its treatment is closely associated with the functional, physical, and cognitive problems. Furthermore the side effects of chemotherapy may reduce patients' quality of life and performance (Smith et al., 2013). Chemotherapy is used for cancer patients in order to kill cancer cells, and although it increases the survival rate, it causes many physical, sexual, mental, and social side effects (Ewertz and Jensen, 2011). Chemotherapy kills all the cells that have a high proliferation rate including blood cells, epithelial cells of the gastrointestinal tract, and hair follicles besides cancer cells. Therefore, complications, such as infections, fatigue, hair loss, oral lesions, nausea, and diarrhea are observed in most patients undergoing

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# chemotherapy (Beusterien et al., 2014).

The correlation of dignity-related problems with lower quality of life and higher level of depression has been reported in patients with cancer (Hall et al., 2014). Dignity implies a state in which people feel valued and respected. Types of dignity include the innate dignity (basic) and social dignity. Innate dignity means the respect for basic rights of people in various areas, and social dignity involves feeling worthy in relation to individual objectives and social situations (Albers et al., 2011). Although nurses are the integral part of the high-quality care providing system (Spilsbury et al., 2011). Studies have shown that medical and nursing personnel are not much aware of the importance of patients' privacy and dignity and perceive these concepts in different ways. Therefore, health service providers should recognize the aspects and factors influencing patients' privacy and provide strategies for promoting and supporting the dignity in clinical settings (Torabizadeh et al., 2012). Moreover, nurses are professionally obliged to acquire knowledge about the development, maintenance, and promotion of dignity in every patient given the underlying differences. Recognizing and emphasizing the influential factors help nurses to maintain and promote patients' dignity and provide healthcare while respecting their dignity (Manookian et al., 2014). If patients' dignity is respected, they feel comfortable, confident, and worthy and can make necessary decisions pertaining to their healthcare and treatment; otherwise, the patients' therapeutic and caring outcomes may be influenced, and they may be hospitalized for a longer time besides feeling uncertain, humiliated, and embarrassed (Baillie et al., 2008).

Undermining patients' dignity may affect their body, mind, mood, and spirituality and make them stressed (Borhani et al., 2014). All the studies performed on the dignity of patients undergoing palliative care have emphasized the need to further studies identifying different sources of stress associated with dignity in this group of patients. This study was aimed to determine the sources of dignity-related distress from the perspective of women with breast cancer undergoing chemotherapy in Iran.

# **Materials and Methods**

## Design

The participants in this cross-sectional study comprised 207 women with breast cancer going to chemotherapy clinics in three hospitals of Shahid Beheshti University of Medical Sciences in Tehran (Tehran is the capital city of Iran and also it is the most populous city in Iran and Western Asia). The hospitals were selected through purposive sampling, and the patients were selected through convenience sampling method. With regard to the objectives, 3 hospitals were selected as the setting of the study. The selection of participants began in late December 2014 and lasted two months. At baseline, the researcher provided some information on the objectives of the study for the participants and explained how to complete the demographics questionnaire and the Patient Dignity Inventory (PDI) after adopting the verbal consent of the participants. Patient dignity inventory is a modern,

valid, and reliable instrument designed for detecting the distresses associated with the dignity experienced by the patients undergoing palliative care by Chochinov in 2008 (Chochinov et al., 2008) and used in this article.

#### Eligibility criteria

The inclusion criteria were as follows: minimum age of 18 years and maximum age of 70 years, patients' awareness of their breast cancer, the ability to speak Persian, willingness to participate in the study, and the patients with stage 3 and 4 of breast cancer (End stage patients).

#### Instruments

Distresses associated with dignity were measured using PDI that includes 25 items on the distress caused by disease symptoms, dependency, social support, existential distress, and peace of mind (Di Lorenzo et al., 2017).

The demographics questionnaire included the information on age, marital status, occupation status, education level, satisfaction with family monthly income, place of residence, the time passed since the diagnosis, and history of mastectomy. The Cronbach's coefficient alpha for the PDI was 0.76. Validity of PDI by confirmatory factor analysis show that comparative fit Index of this instrument is 0.96 and so it is appropriate for application in different setting.

#### Statistical Analysis

The data were presented using descriptive statistics (mean, standard deviation (S.D.), and percentage). The Shapiro Wilk test was used for assess the normality assumption and linear regression model was used to examine the relationship between independent variables and dimensions of PDI. The data were analyzed by using Stata software version 13, EQS6.1 and Fitting Model Indexes. A p value of less than 0.05 was considered significant.

#### Ethical consideration

This project was confirmed by the Ethics Committee of Shahid Beheshti University of Medical Sciences and also informed verbal consent was obtained from all patients.

# Results

The response rate was 100%. In relation to the personal specifications of the participants the mean age were 48.86 years (S.D.; 10.74, 95% CI: 47.39-50.33 years). As shown in Table 1, 67.6% of participants were not much satisfied with their monthly income and also 68.1% were married, 95.2% were resident in city, 46.9% has a history of mastectomy, most of patients (84.5%) were housewife, and 56.52 % has a less than 1 year time of diagnosis of cancer. The mean of child number were 2.23 (S.D.; 1.80, 95% CI: 2.07-2.57).

Total mean score of dignity was 1.94. Mean scores of different dimensions of dignity are shows in Table 2.

In the assessment of relationship between the dimensions of human dignity and demographic variables, age marital status, education level, occupation status,

Variables		NO.	(%)
Marital Status	Married	141	68.12
	Single	24	11.59
	Divorced	17	8.21
	Widowed	25	12.08
Employment Status	Housewife	175	84.54
	Employed	20	9.66
	Unemployed	12	5.80
Education Level	Illiterate	25	12.08
	Primary	76	36.71
	Diploma	58	28.02
	Academic	48	23.19
Place	City	197	95.17
	Village	10	4.83
Mastectomy	Yes	97	46.86
	No	110	53.14
Diagnosis Time	Less than 1 year	117	56.52
	More than 1 year	90	43.48

 Table 1. The Frequency Distribution of Patients'

 Demographic Variables

Table 2. Mean Score of Different Dimensions of Dignity in Cancer Patients

Dimensions	Mean	S.D.	95% CI of mean	
Social Support	1.33	0.55	1.26-1.41	
Peace of Mind	1.87	0.77	1.76-1.97	
Existential Distress	1.87	0.75	1.76-1.98	
Symptom Distress	2.4	0.96	2.27-2.53	
Dependency	1.71	0.77	1.76-1.97	

income satisfaction, place of residency, diagnosis time and history of mastectomy were included in the liner regression model as potential confounder. All regression coefficients in Table 3 were adjusted for other included variables in the model. The results of this analysis were presented in Table 3 and just significant relationship was reported. Based on this table, marital status has a significant relationship with all dimension of patient's dignity. Age has a significant relationship with Peace of Mind and Existential Distress. The results showed a significant relationship between history of mastectomy with Social Support, Existential Distress and Dependency. There was a significant relationship between education level and Social Support, Peace of Mind, Symptom Distress and Dependency. And also Income satisfaction has a significant relationship with Existential Distress and Symptom Distress.

# Discussion

Our finding shows that patients were mostly concerned about the distress caused by disease symptoms and the existential distress, peace of mind, dependency and social support respectively gained the highest score.

The Cronbach's coefficient alpha for the PDI was

Table 3. The Relationship between the Dimensions of Human Dignity and Demographic Characteristics by Liner Regression Model

Dependent variable	Independent variable	Beta	P value	95% CI for Beta
Social Support	Marital status	0.142	0.006	0.014-0.243
	Education level	0.123	0.005	0.038-0.208
	Mastectomy	-0.155	0.047	-0.307
Peace of Mind	Age	-0.018	0.001	-0.02
	Marital status	0.292	0.001	0.154-0.429
	Education level	0.193	0.001	0.077-0.309
Existential Distress	Age	-0.015	0.004	-0.021
	Marital status	0.0243	0.003	0.084-0.403
	Income satisfaction	-0.162	0.039	-0.324
	Mastectomy	-0.321	0.004	-0.436
Symptom Distress	Marital status	0.205	0.024	0.027-0.382
	Education level	0.159	0.037	0.009-0.308
	Income satisfaction	-0.285	0.004	-0.382
Dependency	Marital status	0.196	0.008	0.052-0.340
	Education level	0.136	0.028	0.014-0.257
	Mastectomy	-0.324	0.004	-0.438

0.76. Validity of PDI by confirmatory factor analysis show that comparative fit Index of this instrument is 0.96 and so it is appropriate for application in different setting. The comparison of the total score of dignity in patients undergoing chemotherapy in number 2 Hospital with patients in other studied hospitals revealed higher feeling of being dignified in those patients, which might be due to the free medications used in that hospital and the presence of charity center and free consulting services in that hospital.

The results showed that the most frequent problem in relation to dignity in women with breast cancer undergoing chemotherapy was the distress caused by disease symptoms. The patients undergoing mastectomy expressed higher level of social support and dependency distress than patients not undergoing the surgery.

In Hall et al study (Hall et al., 2014) on 45 patients with cancer, the distress caused by disease symptoms and inability to do daily tasks were reported in over one third of the patients. These results conform to those of the present study and could be attributed to the pain, dyspnea, nausea, vomiting, and diarrhea caused by the disease and treatment-related complications in patients with cancer. Hall et al. also reported the correlation of dignity-related problems with lower quality of life and higher level of depression in patients with cancer (Hall et al., 2014).

According to the results mean score for the distress caused by disease symptoms, existential distress, peace of mind, dependency, and social support was obtained respectively as 2.4061, 1.8784, 1.871, 1.8647, and 1.4097 out of the maximum score of 5. In Borhani et al study (Borhani et al., 2014) performed on 280 patients hospitalized in internal and surgical wards, the patients were mostly concerned about the distress caused by disease symptoms (mean and standard deviation of  $2.09\pm0.92$ ), and the dimensions of peace of mind (mean and standard deviation of  $1.91\pm0.97$ ), dependency (mean

and standard deviation of 1.89±1.01), existential distress (mean and standard deviation of 1.88±0.96), and social support (mean and standard deviation of 1.60±0.89) respectively gained the highest score. According to Borhani et al study (Borhani et al., 2014) the distress caused by disease symptoms was the most frequent concern in both patients hospitalized in the internal and surgical wards. As mentioned before, nausea, vomiting, and sleep disorders are common symptoms of distress in women with breast cancer undergoing chemotherapy (Yazdani, 2010). The experienced pain, concerns about symptoms of distress, and loss of dependency due to the decreased performance are considered as major threats to the feeling of individual dignity, and the experience of severe symptoms of distress may make patients think of death as the only option (Hall et al., 2014). Therefore, it seems necessary to pay special attention to the reduction of distress caused by disease symptoms, especially in patients with cancer who undergo chemotherapy and experience severe symptoms, in order to maintain and promote their dignity.

In this study, the total mean score of dignity was 1.94. In Borhani et al study (Borhani et al., 2014) performed on patients hospitalized in internal and surgical wards, the total mean score of dignity was obtained as 1.89. Through a more detailed examination of the items in PDI and comparison of the two studied groups of patient in terms of the mean score, the different scores can be attributed to the fact that the diagnosis of cancer might cause higher depression and anxiety in patients in the present study than in patients hospitalized in internal and surgical wards. Actually, depression and anxiety are the most frequent mental disorders in patients with cancer (Carlson et al., 2013) and considerably reduce dignity in patients. Chochinov et al (2011) conducted an analysis on 326 patients receiving palliative end-of-life care and reported that the patients did not bear considerable stress in relation to different dimensions of dignity (Chochinov et al., 2011). Although most patients in Chochinov et al study (98%) suffered cancer, only 8.9% of them suffered breast cancer. The difference between Chochinov et al study and the present study in terms of dignity-related distress might be due to the involvement of different organs in cancer and different stages of the disease that directly influenced the level of dignity in patients studied by Chochinov et al (Chochinov et al., 2011).

We examined the effect of the type of hospital on patients' dignity was, and it was found that only the existential distress significantly correlated with the type of hospital. The patients studied in number 2 Hospital gained lower score for the existential distress, which showed the more favorable condition of this dimension of dignity in these patients. Moreover, the comparison of the total score of dignity in patients undergoing chemotherapy in number 2 Hospital with that in patients in other hospitals revealed higher feeling of being dignified in those patients, which might be due to the free medications used in that hospital and the presence of a charity center and free consulting services in that hospital. According to the participants, the good behavior of most personnel working in Hospital number 2 significantly increased their satisfaction and reduced their distress. In fact, the hospital's atmosphere should provide the physical structure for promotion of human dignity, and every personnel also should promote the patient dignity through their own behavior toward patients and be aware of the effect of their behavior in every encounter on patient dignity (Tadd et al., 2011; Sharifi et al., 2016).

Although the atmosphere of hospital and personnel's behavior are factors influencing the patients' dignity (Baillie et al., 2008), the present study, as mentioned before, did not show any significant correlation between patient dignity and type of hospital. However, Borhani et al. (Borhani et al., 2014) revealed a significant correlation between type of hospital and total score of dignity, the distress caused by disease symptoms, peace of mind, and social support, which might be due to the diverse physical and geographical atmospheres of the studied hospitals, the large number of studied centers, and better psychological condition in some of those hospitals. In Lam's study (2007) conducted on 50 patients receiving palliative care, two thirds of patients studied in the hospital reported that their feeling of dignity had been endangered (Lam, 2007).

In the present study, the score of existential distress in educated women was higher than that in other women although no significant difference was found between different educational levels and score of dignity. Considering the items of PDI, the higher score of existential distress in educated women might be related to the fact that educated patients expect themselves to act more efficiently in life regarding the knowledge they acquired, and as the disease reduces their efficiency and power, they experience more stressful situations. Chochinov et al. conducted a study (2009) on 253 patients receiving palliative care and reported that the educated patients with sexual partner suffered specific problems, especially in the existential distress dimension. This result confirm to that of the present study (Chochinov et al., 2009).

In this study, the patients with more satisfaction with their income mentioned less stress in relation to the 3 dimensions of the distress caused by disease symptoms, existential distress, and social support. In fact, the economic level and social welfare is one of the important factors of the social aspects of the disease (Zavras et al., 2013). Although the patients were spending different stages of treatment during the study, and many expenses of patients had been reduced due to the beginning of the plan for development of the health system, the patients' inability to pay for their required medications, especially in hospitals that were not supported by charity institutes, increased patients' mental and physical stress. For instance, patients' inability to pay for the anti-nausea drug made them experience physical symptoms either in the chemotherapy ward and at home, and as mentioned before, the problem endangered patients' feeling of worth and they deem themselves inefficient and disabled in their role as a mother and a wife besides experiencing the symptoms of stress. Furthermore, the physical weakness caused by the disease, its treatment, and its complications and patients' urgent need to others' support made the patients feel like a burden. Such a situation made the

patients concerned about others' change of attitudes toward them and developed a sense of meaninglessness in patients. Moreover, the patients with poor financial status may enjoy a low level of social support. Borhani et al also found a significant correlation between level of satisfaction with family income and the distress caused by disease symptoms, dependency, and existential distress, which conforms to the results of this study.

The reduced physical health is both the cause and the effect of the disease, poverty, and lifestyle. Patients get poorer and poorer because they lose their job and income((Tadd et al., 2011). The higher existential distress in such patients may be due to the fact that poverty is accompanied with distress. Feelings of fear, insecurity, dependency, depression, anxiety, shame, disappointment, loneliness, and disability are immeasurable states experienced by low-income patients. This group of people has difficulty supplying food, accessing health services, and working, which may affect specific dimensions of human dignity (Borhani et al., 2014). The treatment of cancer is very costly and may threat patients' financial status because it requires frequent hospitalizations, laboratory and advanced diagnostic tests, chemotherapy, and expensive drugs. In this regard, activities, such as the further cooperation of charity centers in oncology wards and the government's more efforts for supplying expenses of patients with cancer seem effective in reducing the dignity-related distress in these patients.

According to the result, there was no significant difference between different occupations. Moreover, the peace of mind and social support significantly differed from one educational level to another one. Borhani et al did not report any significant correlation of occupational status and educational level with dimensions of dignity. Considering the items of the inventory, the difference might be due to the fact that the educated patients expect themselves to act more efficiently in life regarding the knowledge they acquired, and as the disease reduces their efficiency and power, they experience more stressful situations.

In this study, a significant correlation was found between peace of mind and social support and marital status. However, Borhani et al did not find any significant correlation between marital status and score of dignity. Hall et al also did not report any significant correlation between patients' level of dignity and marital status. Although the score of dignity in married women partially differed from that in the single women, it should be noted that married patients with cancer find their role as a mother and a wife in danger and experience more stress than single patients due to their physical and mental problems (Mehdipour-Rabori et al., 2016) related to the disease and its treatment, especially the complications caused by chemotherapy and mastectomy. Furthermore, patients undergoing chemotherapy experience many sexual problems (Moradi N et al., 2013) that affect their feeling of dignity adversely.

#### Limitations of the study

Considering that the present study was performed only on the patients going to the cancer clinics of the selected

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hospitals affiliated to Shahid Beheshti University of Medical Sciences, further studies should be performed in other clinical areas in order to generalize the results. The limited time of the study and problems, such as ideas of some participants about uselessness of participation in the study might be other limitations of this study. Moreover, few articles were found in this regard because only one similar article had been publish in Iran, and it is hoped that future studies improve further knowledge in this regard.

#### Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and publication of this article.

In conclusion the results showed the total score of 1.94 out of 5 for patient dignity, as the lower score implies that the patient enjoys more favorable status of dignity. With regard to the specific objectives of the study, the results showed that the patients gained a higher score respectively in the distress caused by disease symptoms, existential distress, and peace of mind, dependency, and social support. Among the demographic variables, a significant correlation was found between dignity and marital status, education, satisfaction with family income, and mastectomy in patients with breast cancer undergoing chemotherapy in the studied hospitals.

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#### Conflict of Interest

The authors, all of them declared no conflict of interest.

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