

Stigma and Related Factors in Iranian People with Cancer

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Abstract

Introduction: Stigma is one of the psychosocial and intercultural issues that can be found in chronic diseases, including cancer. Stigma may reduce communication due to social isolation, feeling shame and others' judgment, and these factors make far from professional services and poor health outcomes in individuals with cancer. Assessment of stigma can help determine and recognize the overall levels of stigma in the community and identify situations that need intervention. **Objective:** The aim of this study was to determine stigma and related factors in individuals with cancer in Iran. **Methods:** This descriptive cross-sectional study was conducted on 142 patients with cancer selected via convenience sampling method in two hospitals affiliated to Shahid Beheshti Medical University. A demographic as well as clinical record form and "A questionnaire for measuring attitudes toward cancer (cancer stigma) - Patients version" by Cho et al., (2013) were used for data collection. Data were analyzed using descriptive statistics and regression analysis. **Results:** More than one quarter of participants (26.1%) had negative attitudes toward cancer and high stigma score ≥ 2.5 . More than half of the participants (57.5%) agreed that their job performance would be reduced even after treatment. 54.5% of the patients considered it difficult to regain health after being diagnosed. There was a significant correlation between the stigma score and the level of education ($p=0.033$, $OR=0.78$). **Conclusion:** The results showed that stigma in dimensions of impossibility of recovery and stereotypical aspects of cancer were more common. These findings can lead to interventions and educational efforts on cancer coherence which may help in treatment, rehabilitation and return to normal life.

Keywords: Cancer- stigma- Iran

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Introduction

The incidence of cancer in Iranian women is about 120 per 100,000 and 134 per 100,000 men. Cancer is the third leading cause of death in Iran, and death from cancer is 41.2 and 60 per 100,000 men and women, respectively (Badihian et al., 2017). Cancer diagnosis is one of the biggest challenges and stresses for individuals; because cancer is considered a life-threatening illness (Ehsani et al., 2016).

Cancer affects the whole life of affected people, as well as the biological and psychosocial problems that cause many physical and mental discomforts in people with cancer (Sette et al., 2016). Stigma is one of the psychosocial issues in cancer (Tang et al., 2015). Stigma is a set of negative attitudes, beliefs, thoughts, and behaviors toward someone who experiences different situations (Suwankhong and Liamputtong, 2015; Zamani and Farahani, 2012). One of the negative attitudes about cancer is that cancer is usually the synonym of suffering and death (Sette et al., 2016). From the points of view of many people, thinking about cancer automatically leads

to death (Marlow et al., 2015). The image of death, bad fate, disaster and misery are parts of the attitudes toward cancer (Wilson and Luker, 2006).

In some parts of Asia, cancer is a taboo. People have a wrong understanding of the cause of cancer (Karbani et al., 2011). Even with extensive information on all aspects of the disease and advanced medical technologies that are currently available, there are many negative myths and images about cancer and cancer is one of the diseases associated with social stigma (Cho et al., 2013a; Yilmaz et al., 2017). The high prevalence of cancer stigma in studies has been shown in samples from countries such as the United States, Japan, England and Korea (Fujisawa and Hagiwara, 2015). In Thailand, there is a high level of cancer stigma, especially in rural areas (Suwankhong and Liamputtong, 2015). Badihian and colleagues reported frequently negative attitudes and social stigma toward people with cancer in urban Iranians (Badihian et al., 2017).

Stereotypes and negative attitudes towards cancer make people less likely to disclose cancer to neighbors or associates ((Badihian et al., 2017; Yilmaz et al., 2017).

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Patients sometimes feel, as soon as the cancer is detected, others avoid them. Fear of being stigmatized can be an obstacle to the disclosure of cancer diagnosis (Marlow and Wardle, 2014).

Fear of stigma and social judgment, or the attribution of the cause of the disease to individual behaviors, can lead to deprivation, fear, rejection of others' favor, avoidance of communication with others, and the feeling of distinctness, worthlessness, confusion, blame, and aggravation of disability, deficiency and depression (Tang et al., 2015; Zamani and Farahani, 2012; Yilmaz et al., 2017; Mazhari azad et al., 2010; Cho et al., 2013b).

Cancer stigma can be more difficult and even more unbearable than disease itself and cancer treatments (Marlow and Wardle, 2014). Rejection and social isolation due to stigma result in less social support and lower levels of emotional well-being and poorer outcomes in patient's health (Yilmaz et al., 2017).

Wide ranging research is currently underway worldwide to assess stigma, perception of cancer stigma and related factors in reducing stigma and helping to improve patient's outcomes (Marlow and Wardle, 2014). Despite the high prevalence of cancer in Iran and the expansion of medical centers and the provision of extensive specialized services in cancer, limited research has been done on negative attitudes and the cancer stigma in Iran. Quantitative researches have also focused on general attitudes toward cancer (Badihian et al., 2017); while the severity of stigma and its impact on patient outcomes has not been studied.

Iran is a vast country with different cultures and geography. This sociocultural diversity can affect people's attitudes toward diseases. This is the first quantitative report on stigma in Iranian people with cancer. This study was designed to examine the rate of stigma in cancer patients as an introduction to further research and understanding of relevant factors for finding methods to reduce stigma in cancer.

Materials and Methods

Design and setting

This cross-sectional cross-sectional study was conducted on people with cancer, hospitalized or referred to two university hospitals in Tehran during three months from October to December 2017 via convenience sampling. The sample size was calculated to measure the mean scores of stigma in the patients by using the formula, taking into account the alpha level of 0.05, the number was 140 (Else-Quest et al, 2009). With the probability of attrition risk, 150 questionnaires were distributed and 142 completed questionnaires were collected.

Participants and eligibility criteria

The participants in this study were all patients with any types of cancer who were admitted to the hospital or referring to the oncology clinic. The inclusion criteria were patients at least 18 years of age with definite diagnosis of cancer and awareness of their diagnosis (according to the patient reporting), Iranian citizenship, and the ability to understand and speak Persian.

Instruments

The instrument used in this study was "A questionnaire for measuring attitudes toward cancer (cancer stigma) - Patients version" by Cho et al., 2013, and a demographic information and a clinical record form. First, we sent an email to the developer of the questionnaire and got a permission to use the questionnaire. With the help of the developer of the questionnaire we were able to gain access to the Persian version questionnaire, which was used by Badihian et al., (2017). This instrument has been used in Iran by performing content validity, and determining the internal consistency to measure the amount of stigma in the general population of Isfahan city. Cronbach's alpha for three factors of impossibility of recovery, stereotypes, and discrimination was 0.67, 0.38 and 0.66, respectively (Badihian et al., 2017). Validity and reliability of Turkish version of the instrument were reviewed and approved by Yilmaz et al., (2017) also. The questionnaire has 12 statements evaluated in three factors: the impossibility of recovery, stereotypes, and discrimination, and four-point Likert scale ranging from 1 (strongly disagree) to 4 (strongly agree). The mean score of 2.5 and above represents a negative attitude toward cancer and means high stigma. In order to use the present questionnaire, a methodological research was carried out to measure the instrument's psychometrics. In this step, face validity, content and construct validity and the reliability of internal consistency of the questionnaire were examined by 110 samples (n= 9 for each statement).

The final internal consistency of the questionnaire was also calculated, and the optimal Cronbach's alpha was 0.77, 0.66, 0.56 and 0.61, respectively, for the whole questionnaire and three factors.

Ethical consideration

To conduct the study, firstly, necessary permissions and code of ethics No: IR.SBMU.PHNM.2016.570; were obtained from the Ethics Committee of the School of Nursing and Midwifery of Shahid Beheshti University of Medical Sciences.

Statistical analysis

To describe the samples, descriptive statistics such as mean and standard deviation, frequency and percentage were used. In the next step, One-variable and multivariate logistic regression analysis was used to study the factors associated with the stigma score. Statistical analyses were performed with SPSS version 20.

Results

The mean age of the participants in the study was 52.1 ± 14.1 years. The mean time past from diagnosis was 18 ± 23.4 months and between one month and 120 months. 97.9% of the patients received at least one of the treatments for cancer, including chemotherapy, radiation therapy, surgery, and so on. 92.1% of the patients experienced at least one complication of treatment. Other demographic and clinical characteristics of the patients are presented in Table 1.

To measure the score of stigma, scoring was considered

Table 1. Demographic and Clinical Characteristics of Participants in the Study

Variable	Classes	Frequency	Percent
Gender	Female	94	66.7
	Male	47	33.3
Marital status	Married	115	82.1
	Single	9	6.4
	Divorced	4	2.9
	Widowed	12	8.6
Location	City	127	90.1
	Village	14	9.9
Place of residence	Tehran (Capital city)	76	54.3
	Other cities	64	45.7
Income	Adequate	49	35.8
	Inadequate	88	64.2
Education	Illiterate	18	12.9
	Elementary school	31	22.1
	Secondary school	15	10.7
	High school	38	27.1
Job	Universities	38	27.1
	Employed	25	17.9
	Unemployed	17	12.1
	Housewives	69	49.3
	Retired	21	15
Cancer type	Missed	8	5.7
	Breast	48	34.8
	Digestion	27	19.6
	Uterus and Ovary	10	7.2
	Prostate	9	6.3
Family history of cancer	Others	44	31.9
	Yes	62	55.1
	No	76	44.9

in two classes of less than 2.5, meaning lower cancer stigma, and equal to more than 2.5, high cancer stigma. The statistical results of the attitude and belief in the cancer stigma questionnaire showed that in 73.9% of

Table 2. Results of Stigma Score

Variable	Score*	Frequency	Percent
Stigma	<2.5	105	73.9
	>= 2.5	37	26.1
	Total	142	100

*Stigma scores greater than or equal to 2.5 mean high stigma and scores < 2.5 means low stigma

participants, the stigma score was less than 2.5 and 26.1% had a score of 2.5 and higher (Table 2). Thus, 26% of the patients reported a negative attitude and a high level of cancer stigma. In the dimension of impossibility of recovery, 30% agreed or strongly agreed that the affected person could not be active in social work, and 16% agreed that the affected person could not have social participation. 57.5% of the people agree or strongly agree that job performance is reduced even after treatment. 44.3% of the patients reported problems with their family or marital life due to illness.

In dimension of stereotypes, 54.5% of participants found it difficult to regain health after experiencing cancer and 11.8% of them considered it impossible. 51.5% agreed that people with cancer would have a difficult time having sexual intimacy. In terms of discrimination experience, a small percentage (about 5%) had experience of avoidance by friends and neighbors. The rest of the information is presented in Table 3.

Also, to examine the association between the severity of the cancer stigma and the demographic variables, regression analysis of variables was performed. Only the variables of job and education were significant.

In the next stage, for multivariate logistic regression, only the education variable was significant. This means that by increasing one unit in the academic grade, the chance of being highly stigmatized is reduced by 22% (Table 4).

Discussion

In this cross-sectional survey on people with cancer, the results showed that more than one quarter of

Table 3. The Mean of Stigma Score for Each Item (n=12)

Items	Strongly disagree %	Disagree %	Agree %	Strongly agree %	Mean (SD) %
Impossibility of recovery					
A person with cancer cannot be socially active once diagnosed with cancer (occupation and work).	32.4	37.4	22.3	7.9	2.05(0.93)
Cancer patients would not be able to make contributions to society (Participation in the session, activities of the mosque, cinema, etc.).	42.8	41.3	8	8	1.81 (0.89)
Job performance at the workplace may decrease even after successful cancer treatment	13.4	29.1	44.8	12.7	2.56 (0.87)
I have problems with my family/married life because of cancer	21.4	34.3	31.4	12.9	2.35 (0.96)
Stereotypes					
It is very difficult to be healthy again once a person is diagnosed with cancer	14.8	30.4	41.5	13.3	2.53 (0.9)
Cancer is impossible to treat regardless of highly developed medical science	33.8	54.4	10.3	1.5	1.8 (0.57)
Cancer patients would have a difficult time having sexual intimacy	19.7	28.8	40.9	10.6	2.42 (0.92)
Cancer patients are easily recognized by their appearance	16.8	32.8	33.6	16.8	2.5 (0.96)
Affected people in the community do not protect	21.2	37.2	20.4	21.2	2.41 (1.04)
Discrimination experience					
Some friends avoid me because of cancer	55.1	39.9	3.6	1.4	1.51 (0.64)
Some neighbors tend to avoid interacting with me because of cancer	46	48.9	4.4	0.7	1.59 (0.61)
Patients are discriminated against in their workplace	22	48.8	22.8	6.3	2.1 (0.82)

Table 4. Multivariate Logistic Regression Results to Examine the Impact of Occupation and Education on the Stigma Score

	B	S.E.	Wald	df	P value	OR	95.0% C.I. for OR	
							Lower	Upper
Step 1 ^a								
Education	-0.241	0.113	4.542	1	0.033	0.786	0.63	0.981
Employed	-0.99	0.655	2.285	1	0.131	0.371	0.103	1.341
Unemployed	-0.209	0.675	0.096	1	0.757	0.811	0.216	3.046
Housewives	-0.572	0.532	1.154	1	0.283	0.564	0.199	1.602
Retired	0.004	0.617	0	1	0.995	1.004	0.3	3.361
Reference (Unable to work)	0.167							

^a Variable(s) entered on step 1: Education, Job

participants (26.1%) had a negative attitude that means high stigma toward cancer. According to the findings of the present study, in the study of Cho et al. 2013, more than 30% of survivors reported a feeling of stigma (Cho et al., 2013b). In the qualitative study of Tang et al., (2015), most women participating in their study experienced stigma after diagnosis and the negative consequences of it. Our study was conducted on cancer patients; however, the report of a study from Iran by Badihian et al., (2017) about public attitudes toward cancer also suggests that negative attitudes toward cancer and impossibility of recovery among general populations are also common. A survey of the general population attitude in Korea also suggests that, despite the clinical progress and recovery of survivors, more than half of the people still have negative attitudes, stereotypes and discriminatory attitudes toward cancer patients (Cho et al., 2013a).

In this study, three dimensions of beliefs and attitudes toward cancer, including impossibility of recovery, stereotypes, and experiences of discrimination were studied. The results showed that stigma in dimensions of impossibility of recovery and stereotypical aspects of cancer were more common. 30 percent agreed or strongly agreed that the affected person could not be active in terms of social work and 16 percent agreed that the patient could not have social participation. More than half of the affected people (57.5%) agreed that their job performance would be reduced even after treatment. This result may indicate that a greater proportion of patients in their occupational activities after disease have difficulties, but experience fewer restrictions for attending other social activities. Participants in Cho et al., (2013b)⁷ study also had believed that cancer is irreversible and prevents social activities and occupations, and had negative attitudes toward cancer and stereotyped attitudes about themselves. 44.3% of participants had problems with their family or marital life due to illness. Shaban et al., (2004) found that patients' difficulties have a correlation with physical and psychological problems associated with disease and treatment and reported lower quality of life in cancer patients. Also, the distress of people is largely associate with the physical constraints of treatment and perhaps one of the reasons for persisting problems and physical disability is the lack of adequate referral to professional rehabilitation programs after cancer treatment (Minnesota Cancer Plan, 2016).

In the stereotypical dimension, 54.5% of the patients considered it difficult to obtain health in cancer and 11.8% considered treatments are impossible. Interestingly, while we did not find a correlation between the age and the stigma score, Badihian et al., (2017) found that younger people had a more negative attitude toward cancer enhancement; due to the linkage between younger people and health-related media's negative reports on the incidence and mortality of cancer are known as the "tsunami of cancer".

In our study, 51.5% agreed that people with cancer would have a difficult time having sexual intimacy. In a review by Badihian et al., 25% of people believed that patients had difficulty in sexual relationships (Badihian et al., 2017). Sexual problems in cancer are different in all stages of the disease, including anxiety and fear of death in the early stages of diagnosis, cancer complications such as pain, side effects of medications, physical impairment, feeling guilty due to wrong beliefs about origin of disease and distress related to interpersonal relationships (Ebrahimi, 2010; Vanderbilt-Ingram Cancer Center). Even after the treatment, feelings of reduced sexual attractiveness, fear of relapse and depression are also other problems. In the point of view of Ebrahimi (2010), one of the reasons the enduring emotional and sexual problems is the lack of social support services in Iran, and patients do not want to tell the doctor about these issues. He recommends counseling for patients and their spouse. According to reports half of women with breast and genital cancer have sexual problems (Vanderbilt- Ingram Cancer Center); In our study, there was a high proportion of female patients, and the results may be related to them. Meanwhile, it is not common in the Iranian society to express sexual issues and these issues may remain unresolved.

While in our study half of participants found it easy to detect cancer from the appearance of people; the results of the general attitude toward cancer in Korea, suggest that about 35% of people say that it's easy to detect cancer from the appearance of patients (Yilmaz at al., 2017). Badihian et al., (2017) found, a lower percent (15%) it is easy to detect cancer from the appearance of patients, and it was probability related to the fact, that in the Iranian society, people with a disorderly appearance due to illness or with physical disabilities are not seen in public places and they prefer to stay at home. They have

identified factors such as the lack of rehabilitation services and the lack of education in this area. While our findings did not agree with this conclusion, more than half of the patients felt stigmatized about the diagnosis of the disease by Appearance.

In discrimination experience, about 29% of people believed that patients at work were being discriminated against. Similarly, in the United States, nearly one fifth (18.2%) of cancer survivors who worked before or after illness had problems with their employment due to illness (Yabroff and Lawrence, 2004).

Although almost half of the women did not work and a small percentage of the participants were employed (about 18%), they have had the impression of discrimination at work. Mirzai Najmabadi et al., (2014), in a cross-sectional study on 175 women diagnosed with breast cancer showed that many of the women had received support at work. But the disclosure of the disease caused problems at the workplace and reduced the close relationship between them and others after the diagnosis of the disease.

In this study, only 5% of people had experienced discrimination in the relationships between their neighbors and friends due to illness. Another study in Iran says most women with breast cancer receive support from their family, spouse, friends, colleagues, and employer (Mirzaii Najmabadi et al., 2014). We can conclude that the cultural and religious dimensions of socialization in our country persuades people to stay close to the sufferer, and the desire for more communication can be seen in the cultural context of Iran. Although Badihian et al., (2017) point out, unnecessary compassion and pity can be one of the barriers to the disclosure of illness for neighbors and acquaintances in Iran.

In the present study, there was no relationship between the scores of stigma with age, sex, occupation, economic status and ethnicity of the participants. Also, there was no relationship between the clinical characteristics of the disease, such as duration of diagnosis, type of cancer, treatment, etc. with stigma. Marlow and Wardle (2014) in reviewing the general stigma of cancer found that male gender and age is associated with a greater stigma score in some aspects of stigma. Ethnicity is also involved in the score of the stigma. Molavi Vardanjani et al., (2015), in their research on cancer screening in Iranian families, found that women report more stigma than men. Edelen et al., (2014) in the study of general stigma found that male gender and low income is associated with higher stigma score. Also, those who are close to a person who has cancer report less stigma, but people with cancer report more stigmas.

Research results suggest that some types of cancers, like lung cancer, are associated with more stigmas because they associate smoking with lung cancer. Therefore, the responsibility for individual behavior in the incidence of cancer leads to more social and individual stigma (Marlow et al., 2015; Fujisawa and Hagiwara, 2015). Also, Phelan et al., (2013) have pointed to the emergence of stigma and more shame in cancers with visible or unpleasant symptoms such as colon and rectum cancer.

Perhaps the discrepancy between our results and the findings of previous studies is due to the lower number of

participants in the study and the minority of these cancers in our sample. In addition, a larger proportion of samples included breast cancer that has more extensive statistics in Iran and more support and control programs than other types of cancer.

Only the level of education was associated with the score of the stigma, and the results showed that higher education is associated with a lower score for the stigma. It can be said that an increase in the level of education is effective in reducing the negative attitudes toward cancer; perhaps higher-educated people are more likely to seek the right information or to become aware of the illness or to have access to information sources such as the Internet. In several studies, increasing awareness has been mentioned as one of the effective factors in reducing stigma (Neal, 2013; Molem, 1999; Asadzadeh et al., 2011; Criswell, 2016). Public attitudes and stereotypes are more prevalent among less educated patients, but some believe they may equally affect educated people (Parsa et al., 2006).

In conclusion, this study examined the stigma and attitudes and beliefs of people with cancer in relation to illness. The results of the study showed that one-fourth of participants had high stigma and had more negative attitudes in dimensions of impossibility of recovery and stereotypes.

The score for Stigma was related to the level of education of individuals. Given the increased availability of information and increased awareness among people with higher education, special attention should be paid to raising public awareness in the community. Also, considering the psychosocial and social issues caused by stigma and its impact on the quality of individual, family, occupation, and treatment and recovery process; the members of the health care team, especially nurses, can help improve the quality of care and quality of life by examining patient and family history of stigma and designing care plans that reduce it.

This study had some limitations. This research was conducted only in medical centers of Shahid Beheshti University of Medical Sciences and did not include other medical centers; also, coverage of all types of cancer and their classification was not possible for further examination due to lack or low number of some cancers. It can affect the generalization of the results to the total population of cancers. It is suggested that further studies be conducted with a larger sample size and in separate populations of cancer and in different geographical, cultural and social areas of Iran.

Conflict of interest

None.

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