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Investigation of Stigma Phenomenon in Cancer: A Grounded Theory Study

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Abstract

Background: Adjustment to cancer as a stressful event is affected by bio-psycho-social factors.
Objectives: This study aimed to investigate stigma phenomenon, the process of formation, and its impact on cancer patients and their families.
Methods: This research was conducted based on the grounded theory study. Semi-structured interview was used with 12 cancer patients (7 women and 5 men), one of the immediate family members (spouse, parent or sibling) and 8 oncology staff members. Participants were selected in a purposeful non-probability sampling method and data analysis was performed in three steps: open coding, axial coding and selective coding.
Results: Four conceptual categories with sub-categories were emerged through three-step analysis of the grounded theory study: social stigma, self-stigma, coping strategies and acceptance as a main concept. Results showed gradual process of stigma formation to cancer and its different dimensions.
Conclusions: Comprehensive assessment of stigma through various information sources may provide a deep understanding of this phenomenon in social context. The results of this study may lead to development of effective therapeutic protocols for promotion of community awareness, and improvement of mental health levels in patients and their families by eliminating all dimensions of this phenomenon in the context of society.

Keywords: Stigma, Cancer, Grounded Theory, Qualitative Study

1. Background

Stigma is a powerful phenomenon that inextricably linked to the social identity and as a social construct includes at least two fundamental components: 1) recognition of difference based on some distinguishing characteristic or label, and 2) devaluation of individuals due to these differences (1). The origin of stigma theory is derived from the book "STIGMA: Notes on the Management of Spoiled Identity", by Erving Goffman who believed that stigma is an attribute in order to discredit a person from a normal person to a defective and worthless one (2). Stigma applies its effects by four mechanisms: 1) negative attitudes and direct discrimination; 2) self-fulfilling prophecy; 3) stereotyped attitudes; and 4) identity threat processes (3).

Health-related stigma (HRS) is also a social process that is characterized by exclusion, rejection, blame or devaluation and results from experience, perception or reasonable anticipation of an adverse social judgment about a person or a certain group. This judgment is based on an enduring feature of identity that has been created by a health-related condition (4). Brakel introduced four approaches in assessment of health-related stigma: 1) Evaluation of discrimination experience and participation restriction in society; 2) Evaluation of perceived stigma by interviewing about feelings such as fear, shame and guilt; 3) Evaluation of community attitude about those who are experiencing certain health-related condition; 4) Screening stigma and discrimination in health services, legislation, media and educational material (5).

In addition to being a menace to human health, cancer may cause a deviation from the norm with undesirable quality. Cancer is not only a physical illness. It can make changes in patients' identity that leads to the perception of "I am cancerous". Results showed that, recognition of self as a cancer patient with all unpleasant symptoms, adverse effects of treatment, experience of emotional distress and social dysfunction are consequences of physical and emotional changes, social stigma and marginalization from social context (6). Literature review about cancer stigma revealed that lung cancer has the highest level of stigma because of patients' lifestyle and personal responsibility attributions in etiology. Other types of cancer were

also not exempt from this phenomenon (7-9). Generally, cancer is a threatening factor for psychological and physical health and as a chronic condition can affect patients' adjustment after diagnosis and throughout the treatment process.

2. Objectives

Review of literature demonstrated adverse effects of cancer stigma on psycho-social health. However, this powerful phenomenon, dimensions and the process of its formation have not been sufficiently addressed and we were not found any studies in Iran to investigate cancer stigma. Since stigma arises from social attitudes and it may be considered as a particular culture of each society, current study is trying to fill this gap by a qualitative study.

3. Methods

3.1. Study Design

This research was conducted by the grounded theory study. Grounded theory, as one of the qualitative methods, was introduced by Glaser and Strauss in 1967 and is applicable for those studies that are trying to theorize about specific issues (10). They have developed a method that leads to the theory without any predetermined hypothesis in researchers' mind. It is only based on analysis of collected data. Three stages of data analysis are being used in this method: 1) Open coding; 2) Axial coding; and 3) Selective coding. In the first stage, related codes are extracted by detailed and comprehensive checking of the obtained data. Second, during the axial coding stage, main categories with their subcategories are considered related to extracted concepts. Finally in selective coding, all categories are unified around a central core with the highest repeatability. This core category might emerge from the categories already identified or might find as a more abstract concept to explain the main phenomenon (11).

3.2. Trustworthiness

Guba and Lincoln criteria were used in order to ensure trustworthiness. They introduced four criteria: 1) Credibility; 2) Transferability; 3) Dependability; and 4) Confirm ability (12). In order to achieve mentioned criteria, prolonged contacts with participants and continuous observations in research environment were conducted. Also we tried to use a variety of sources to collect information. Data were checked by colleagues. Separated coding was conducted by two members of research team. Concepts were reviewed and approved by professors who were not involved in this study. Finally, we tried to avoid subjective assumptions interference in all process of collecting and coding the interviews.

3.3. Participants

All patients and oncology staff in hospitals of Rasht (one of the northern cities of Iran) were target populations. Among them, 12 cancer patients (7 women and 5 men), one of the immediate family members (spouse, parent or sibling) and 8 oncology staff members were interviewed. They were selected by a non-random purposeful sampling method. Inclusion criteria were: 1) At least 6 months after initial diagnosis; 2) Age between 20 to 65 years; 3) Tendency to participate in the research; and 4) at least 2 years of experience in oncology ward for staff members.

3.4. Procedures

Semi-structured interviews were used in order to collect data. 45 to 60 minutes were allocated to everyone. This process continued for 4 months. Interviews were performed face to face with agreement of the participants in natural setting (hospital). In addition to oral consent, written consent forms were obtained. Participants were assured of non-disclosure of identity. They were also aware of confidentiality and right to withdraw the collaboration with researcher. Interviews included personal information form and main questions. In some cases, interviews were held in two sessions in order to clarify the received information. According to principles of semi-structured interviews, conversation began with the general issues and then more specific questions were asked in order to follow up.

3.5. Analysis

Data analysis was conducted simultaneously with data collection. Data were collected by taking notes and audio recording and were analyzed from the first interview. According to the triple stages of the grounded theory, primary concepts were extracted and coded with detailed review in the first stage. More interviews were conducted in order to identify more concepts until data saturation. In the second stage, extracted codes were summarized. Codes in each interview were compared with other interviews in a continuous process in order to make main categories. These categories with sub-categories were revised constantly. Afterward, categories were integrated and the core category was inferred in the selective coding.

4. Results

Demographic characteristics of participants are shown in Table 1. Results indicate four conceptual categories: social stigma, self-stigma, coping strategies and acceptance as a core concept. Four categories with sub-categories are shown in Box 1. In this section, these concepts will be presented.

4.1. Social Stigma

The concept of social stigma includes negative attitudes, prejudgment and inadequate information about etiology and treatment. Most of participants believed that they were confronted with adverse judgments and wrong attitudes about cancer. Regarding this issue, a cancer patient said,, "After receiving cancer diagnosis, I was faced with such behaviors which reflects my relatives fear and worries about contagion of cancer to them, for example: Lack of physical contact and separating my dishes from others" (Patient No. 5). Family members also reported similar experiences about their initial prejudgment and relatives annoying reactions. For instance, one participant stated: "After being informed of my husband's cancer diagnosis, I was preparing myself for full-time nursing" (Family member No. 2). Another participant said," "Unfortunately no one is willing to marry my daughter. Even with completion of treatment courses. she will never be seen as a healthy and fertile woman" (Family member No. 11).

According to oncology ward staff, the majority of people have no accurate understanding of cancer. Most patients have ambiguous imagination about future. People recognize cancer as an uncontrollable and unpreventable event and they express fear of cancer as a reason for avoidance of preventive behaviors. Many of the hospital staff believed that people often consider cancer as a completely random event. One participant stated: "Many people believe that cancer is a genetic illness and they are completely safe against it, in absence of family history" (Staff No. 3). Another participant said, "Some patients attribute their cancer causes to the misfortune and fate" (Staff No. 8). These findings confirmed the importance of attitudes and society knowledge, especially family members in explanation of cancer stigma.

4.2. Self-Stigma

Self-stigma may be formed, while patient experiences social stigma. Self-stigma includes: feelings of shame, self-blame and low self-efficacy. According to many patients' beliefs, prejudgment and negative attitudes of those who are around them and loss of beneficial roles are the major reasons for the shame. One participant stated, "My close relatives are completely unaware of my illness, because it is not pleasant for me to be known as a person with cancer" (Patient No. 7). In many cases, patients blamed themselves for their role and responsibility. It was more obvious about some types of cancers, such as lung, colon and cervix cancer. Lack of attention to risk factors and irresponsibility to health condition may provide a context for self-blaming. One of the patients stated, "Definitely, I could have saved myself with paying attention to signs and by self-examination" (Patient No. 10). Self-blaming was also considerable among patients and families because of stress, conflicts and socio-economic factors. For example, one participant expressed, "My cancer is a consequence of all destructive stresses that I had in life" (Patient No. 1).

Another sub-category of self- stigma is the low self-efficacy. Many patients reported similar experiences about their inability to control and change the current situation. They considered this feeling slightly related to incorrect and annoying attitudes of family members to their capabilities. For instance, a middle-aged mother expressed, "I am sure that I can never go back to my previous beneficial role" (Patient No. 9). And another participant said, "I have lost my opportunity for jobs, income and marriage in the best possible age. I've become completely a dependent individual who needs others for managing all aspects of life. Because of these problems, no one dares to marry a sick person" (Patient No. 11). Interviews showed that social stigma by affecting people's minds may lead to self-stigma. As a result, feeling of shame, self-blame and low self-efficacy may be experienced by patients.

4.3. Coping Strategies

Coping strategies included two concepts: 1) Non-disclosure; and 2) Limited interaction and avoiding making new relationships. Patients and their families tend to hide their cancer diagnosis and this issue was the most noticeable code in interviews. Aversion of others sympathy, concerning about people's negative attitude towards them and in some rare cases, people's fear of contagion were the most considerable reasons. One of the patients stated, "When others became aware of my illness, many of them tried to be kinder with me because they considered me on the verge of death" (Patient No. 6). Another participant said, "I was afraid that my relatives think that I am a disabled and miserable wife" (Patient No. 7).

Inaccurate and sometimes disappointing information transference about cancer was mentioned by many participants as the most considerable reasons for limited interaction with others. They were forced to limit their connections to stop receiving misinformation. One of the family members stated, "After my mother's surgery, some visitors unintentionally described examples of similar cases

Table 1. Demographic Characteristics

Variables	Patient		Family		Staff	
	F	P	F	P	F	P
Gender						
Female	7	58.33	8	66.66	6	75
Men	5	41.66	4	33.33	2	25
Education						
Under diploma	4	33.33	5	41.66	0	0
Diploma	6	50	3	25	0	0
Bachelor's degree	2	16.66	3	25	3	37.5
Higher education	0	0	1	8.33	5	62.5
Marital status						
Single	3	25	5	41.66	2	25
Married	9	75	7	58.33	6	75
Age						
25 - 45	3	25	2	16.66	7	87.5
45 - 55	7	58.33	6	50	1	12.5
55 - 65	2	16.66	4	33.33	0	0
Total	12		12		8	

Box 1. Conceptual Categories And Sub-Categories

Main category	Sub-Categories
Social stigma	negative attitude and prejudgment
	insufficient and inaccurate information
Self-stigma	shame
	self-blaming
	self-efficacy
Coping strategies	non-disclosure of illness
	limited interaction and avoiding of making new relationships
Acceptance	cognitive beliefs
	changes in social roles

that died with my mother's illness. Description of these incurable problems had adverse effects on my mother's hope and expectation of recovery" (Patient No. 9). Coping strategies may protect people against stigma. This means patients and their families prefer to hide their condition and limit their relationship in order to avoid the social and self-stigma.

4.4. Acceptance

Acceptance includes two sub-categories: 1) cognitive beliefs, and 2) changes in social roles. In addition to the highest repeatability than other data, the concept of acceptance has strong connection with other categories described above. Patients react to internal and external threats with acceptance approach and they use coping strategies passively in order to defend themselves. Many participants were completely dissatisfied with the low level of community awareness. However, they indirectly confirmed the accuracy of negative attitudes and adverse feedback. They considered the occurrence of cancer equal to death, hopelessness or frustration. One of the patients stated, "If I were healthy, I would not want to marry a person with cancer" (Patient No. 11).

Subsequently, coping strategies, such as non-disclosure and limited interactions, have been used as defensive mechanisms. Coping strategies may reinforce the connection between social stigma and self-stigma. It may minimize individual's motivation to make changes in their situation. One of the participants stated, "I prefer to communicate only with those who have the same problem as me, instead of spending my time to convince others that I am not dying and I can go back to my past abilities" (Patient No. 6). Changes in social roles as the second sub-categories of acceptance refer to the reconstruction

of one's life which is influenced by negative attitudes of social stigma and adverse consequences of self-stigma. In this regard, a family member said, "None of us expect our father to return to work and past abilities" (Patient No. 4).

Based on the findings of the current study, acceptance as a latent and influential concept can be inferred from the first layers of stigma phenomenon formation. Also following the experience of social stigma and self-stigma, coping strategies are congruent efforts with acceptance.

5. Discussion

The findings of the current study showed that the stigma phenomenon began from social context during a gradual process. The previous results indicated that cancer patients frequently faced social stigma and negative attitudes (13, 14). Findings of a study about public attitudes toward cancer survivors showed 58.5% of participants believed that it is impossible to treat cancer regardless of highly developed medical science, 71.8% agreed that patients would not have a useful role, and 23.5% believed that they would avoid working with patients. Finally, about half of the participants acknowledged they would not disclose their cancer to others because of community negative attitudes (15). Despite successful clinical advances in treatment and subsequently a considerable increase in the number of cancer survivors, negative attitudes, stereotypes and discrimination against patients are so common. The diagnosis of cancer and even hearing the cancer word can stimulate cliched thoughts. Typically, cancer is associated with death, fear and emotions such as anxiety, agitation, painful and uncontrollable situation (16). Investigating of women's beliefs about cancer showed that the concepts of fear, mystery, contagion, and stigma are considered as a nature of cancer and lifestyle, stress, environment, genes, unknown causes and destiny are identified as explanations about the cancer causes and in some cases, factors such as black magic were considered as a cause of cancer (17, 18).

Results confirmed that patients' social life are affected by others' attitudes at the beginning of the diagnosis (19). Even the expectation of social stigma, especially from family members and friends can be related to the reduction of quality of life in patients with chronic diseases (20). Social stigma and self-stigma are closely related together and as long as a person believes that others have stigma attitudes toward him/her, self-stigma such as feeling of shame and low self-esteem can also be experienced (21). These feelings arising from self-stigma have strong relation with incidence of depression. Results showed cancer patients who are experiencing attitudes associated with stigma are more prone to depression (22, 23). Perceived stigma may lead to psychological distress by increasing the feelings of shame and self-blaming, limiting the social support and non-disclosure of cancer experiences. Generally, these results showed the important role of cognitive and social factors which are associated with stigma phenomenon (24).

Self-efficacy including the patients' attitudes to their capability, one's belief in ability to succeed in specific challenges and ability to control the situation and return to previous level of quality of life, is one of the another subcategories of self-stigma. According to patients' belief, their ability to return to a normal life, especially at the beginning of illness is less estimated by others. Many people react to current critical event with pity and sympathy. Also, patients gradually internalize others' approaches and negative expectation to their own abilities. Lack of control on life obstacles and unpredictability of illness future status were other main reasons for reduction of self-efficacy. The majority of people with chronic illness experienced self-stigma with low self-esteem and self-efficacy as obvious negative consequences (25). Corrigan, Larson and Rüsch introduced "why try" effect in order to explain the reduction of self-esteem and self-efficacy following self-stigma. They believed that self-stigma consists of three phases: 1) Awareness of stereotypical beliefs (such as incompetence); 2) Acceptance and agreement with stereotypical beliefs; and 3) Application or description of self, based on these stereotypical beliefs. The results of this process are low self-esteem and self-efficacy which dissuade people from pursuing the life goals (26).

Kato, Takada and Hashimoto identified three aspects of self-stigma: 1) Cognitive factors (patients' beliefs about potential adverse effects of illness); 2) Emotional factors (including all negative emotions); and 3) Behavioral factors (avoiding of making contact with others, hiding illness and restricting social communications) (27). Hence, stigma which is influenced by these factors may adversely affect patients' coping strategies. Most of participants insisted on non-disclosure of their illness. They argued that fear of others' negative reactions, aversion of pity and receiving false and disappointing information are the most important reasons of avoidance. Results illustrated that patients were not willing to disclose their illness when social stigma exists (24). According to what was explained, non-disclosure as one of the coping mechanisms may reduce internalized stigma, while defending patients against social stigma.

The concept of acceptance was identified as a core category because of the highest repeatability. Acceptance slightly leads to maintenance of adverse effects of stigma. Many patients admitted that they have had negative stereotypical beliefs before diagnosis of cancer which made them endure social stigma. Many patients try to

use coping strategies, such as non-disclosure of cancer and contact limitation with others. It may be done by patients and their families in order to avoid social stigma. This type of acceptance against stigma despite maintenance of negative impacts of this phenomenon, can also act as a passive coping strategy.

Most patients experienced stigma in form of negative reactions to themselves. It is because of obvious deviation from normal state and unpleasant quality of illness. This leads to negative consequences such as depression, anxiety, anger, and low self-esteem (28). People who are stigmatized greatly benefit the wide ranges of coping strategies in order to cope with these adverse effects. Inevitably, one of the beneficial ways to overcome stigma consequences is acceptance of this critical situation where there is no possibility for taking control and applying changes (29). For greater transparency, while acceptance as a coping mechanism may protect patients against stigma, it cannot operate as an effective mechanism. Acceptance simultaneously involves passive and active processes. In some cases, participants gradually accept social stigma. They acknowledge negative thoughts and attitudes easily and act based on them. But in other cases, acceptance is based on mindfulness and patients show willingness to accept social and self-stigma without engaging in order to suppress or trying to avoid them. This process describes active acceptance. Literature review showed that it can play an important role in reducing anxiety, depression and improving the quality of life in cancer patients (30-32).

5.1. Limitation

This study had also some limitations that should be noted. These limitations include: 1) lack of socio-economic characteristics control that can reduce the generalization of current findings and 2) cross-sectional study and neglecting the stigma changes over time.

5.2. Conclusion

This study investigated cancer stigma phenomenon formation by extracting four conceptual categories including social stigma, self-stigma, coping strategies, and acceptance by a grounded theory qualitative methods. Comprehensive assessment of stigma through various information sources can provide a deep understanding of this phenomenon. Results of current study may lead to the development of effective therapeutic protocols for promotion of community awareness and improvement of mental health levels in patients and their families by considering stigma effects. Also social stigma was expressed by participants as one of the dissuasive factors related to preventive behavior. Hence, psychology community, health policy makers, organization and institutions can design efficient training plans with the aim of cancer risk reduction. Consequently, eliminating the adverse effects of stigmatization and identifying the ways to overcome it may lead to psycho-social health promotion.

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Footnotes

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