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Chinese Nursing Research

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Review article

Perceived health-related stigma among patients with breast cancer

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ARTICLE INFO

Article history: Received 11 June 2017 Received in revised form 11 July 2017 Accepted 15 August 2017 Available online 10 November 2017

Keywords: Stigma Social stigma Health-related stigma Disease-related stigma Breast cancer Patients with breast cancer Cancer

ABSTRACT

Breast cancer survivors face many challenges (particularly changes in body image) on their road to restoring physical and psychosocial health following diagnosis. Perceived health-related stigma (PHS) refers to the attachment of negative connotations to some types of disease diagnoses. PHS is common among patients with breast cancer and is associated with adverse emotions, attitudes and behaviors. This article summarizes the latest advances and new perspectives on PHS of breast cancer patients and approaches to block this deleterious process. Effects of PHS on patients with breast cancer, in this paper, and measures, predictors and interventions of PHS have been discussed in depth. Future studies should continue to develop more effective instruments that are specialized for measuring PHS of breast cancer patients, explore the predictors of PHS, and discuss effective interventions on the basis of the predictors. © 2017 Shanxi Medical Periodical Press. Publishing services by Elsevier B.V. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

1. Introduction

Breast cancer is the most frequently diagnosed cancer and the leading cause of cancer-related death in females worldwide, accounting for 23% of all cases of cancer and 14% of total cancer deaths. 1 Each year, a large number of women in the world are diagnosed with breast cancer, and the incidence of breast cancer has increased significantly in the past decade, making this cancer a common health problem among global women, particularly in rural areas.

Generally, breast cancer patients will be treated with surgery, chemotherapy, radiotherapy, or a combined treatment.² Nearly all patients who are diagnosed with breast cancer undergo surgical resection as an indispensable part of their cancer therapy.

Breast cancer patients can benefit from these treatments, but at the same time, they can also experience many deleterious effects. Many studies have shown that breast cancer diagnosis and treatment have considerable negative effects on the physical, psychological, and social health of patients and can reduce their quality of life.^{3–5} Many patients with breast cancer suffer from physical and cognitive impairments, changes in body image and sexuality, fear of recurrences, economic stress, poor social support, role functioning increasing public health concern. Studies of breast cancer stigma found that stigma extensively exists in patients with breast cancer because of their physical and psychosocial stress.^{4,6–13}

2. Perceived health-related stigma

The modern understanding of disease-related stigma owes much to sociologist Goffman, 14 who defined stigma as an attribute that links an individual to an undesirable stereotype. Goffman argued that the stigmatized person is reduced in other people's minds from a whole and ordinary person to a disgraced or discounted one. Stigma regarding disease can take on many different forms, which include discriminatory behavior from others, 15,16 delays in diagnosis or treatment, 16,17 reduced availability of healthcare services and limited research funding.¹⁸

constraints and family crisis throughout the entire disease process.⁶ Disease-related stigma is common among patients with breast

cancer. Whether patients receive mastectomy or breast conserving

treatment, they feel stigmatized similarly.⁴ The stigma of many diseases and disorders prevalent in the world has attracted

Because stigma is a rather broad topic, it is important to acknowledge the distinctive features of perceived health-related stigma (PHS) and the social burden of illness. The current research focuses on PHS, which was defined as a social process or personal experience characterized by the perception of exclusion, rejection, blame or devaluation that results from experience or

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Peer review under responsibility of Shanxi Medical Periodical Press.

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anticipation of an adverse social judgment about a group or person. ¹⁹ This judgment is based on an enduring characteristic of identity conferred by a particular health problem or health-related condition. ²⁰ Stigmatization includes negative emotions and attitudes (e.g., irritation, depression) as well as social avoidance of affected individuals. ²¹ PHS, which contributes to physical, psychological and social morbidity, has been identified as a barrier to health promotion. ²²

PHS has been extensively studied in illnesses that were poorly understood or defined, lacked effective treatment, and readily invoked fear within a population, such as mental illness, HIV/AIDS, epilepsy and physical disability. In recent years, cancer-related stigma has attracted increasingly more attention of researchers because public perceptions of cancer are often appraised more negatively than other serious diseases. Cancer and its treatment may leave visible physical marks, such as alopecia or scars, and may simultaneously generate invisible marks, such as PHS. 12,23 Researchers have suggested that cancer stigma may be driven by fear of the illness itself and fear of death. 21

3. PHS among patients with breast cancer

Compared with studies of stigma of other diseases, the studies of PHS of breast cancer started comparatively late. Although the quantity of relevant studies is limited, there is a rising trend in the number of studies year by year. The PHS of breast cancer is receiving increasingly more concern. This is as a result of the enormous negative impact PHS usually has on the patients and their families, and this impact could be felt at home, in the community and at the workplace. Breast cancer survivors face many challenges (particularly changes in body image) on their road to restoring physical and psychosocial health following diagnosis. According to studies of breast cancer stigma, PHS is common among patients with breast cancer and is associated with adverse emotions, attitudes and behaviors (such as depressive emotion, negative attitude and decreased healthcare seeking behavior).^{4,6–13}

4. Measures of PHS of breast cancer

4.1. Social Impact Scale (SIS)

To measure the PHS of patients with HIV/AIDS or cancer, File and Wright developed the SIS in 2000. 24 This 24-item scale includes four dimensions of PHS: social rejection (9 items, e.g., "I feel others avoid me because of my illness"), financial insecurity (3 items, e.g., "My job security has been affected by my illness"), internalized shame (5 items, e.g., "I feel I need to keep my illness a secret"), and social isolation (7 items, e.g., "I feel set apart from others who are well"). The total scale demonstrates good internal consistency reliability (Cronbach's $\alpha=0.95$), as do the subscales (Cronbach's $\alpha\geq0.81$). The SIS has been extensively used in studies of PHS of patients with HIV/AIDS or cancer. Whether this scale is suitable for the measurement of PHS of breast cancer patients depends on further examination.

4.2. Cancer Stigma Scale (CASS)

Marlow and Wardle provided the Cancer Stigma Scale (CASS), which can be used in the general population. ²⁵ The CASS is a 25-item scale and made up of six subscales, which are Awkwardness (5 items), Severity (5 items), Avoidance (5 items), Policy Opposition (4 items), Personal Responsibility (4 items) and Financial Discrimination (3 items). Multiple aspects of cancer stigma can be assessed by this multidimensional scale. All attitude items are based on a 6-point scale ('disagree strongly' to 'agree strongly' or 'definitely not'

to 'yes definitely') and reversely scored as needed. All subscales have good construct validity, internal and test-retest reliability, and fit well with the stigma-related literatures. This scale can be used in studies that assess PHS among patients with different types of cancer, including breast cancer. In another area of Marlow's research, which used the CASS to explore PHS between six different cancer types (lung, breast, colorectal, skin and cervical), this scale also showed good reliability and validity.²⁶

4.3. Body Image after Breast Cancer Questionnaire (BIBCQ)-body stigma subscale

The BIBCQ is a multidimensional assessment of the long-term specific impact of breast cancer on body image.²⁷ It is a self-report scale comprising 53 items, regardless of surgery type. Higher scores reflect greater body image disturbance. The BIBCQ is made up of six subscales (Vulnerability, Body Stigma, Limitations, Body Concerns, Transparency and Arm Concerns) for which good reliability was found (ranging from 0.77 to 0.87). The Body Stigma subscale comprises items associated with body shame and avoidant behaviors (e.g., "I try to hide my body"). The diagnosis and treatment of breast cancer have a profound impact on body image, and many patients have intense feelings of body stigma. For breast cancer patients, the intensity of the feeling of being ashamed of body image can be assessed by means of the Body Stigma subscale of BIBCO.²⁸

5. Predictors for PHS

Marlow and Wardle found that PHS of cancer patients was influenced by certain socio-demographic factors. ²⁵ Being male was found to be a predictor for more intense PHS, as was younger age. White British patients who were from an ethnic group had stronger PHS. Patients who were more educated were more inclined to experience higher PHS, while those who had at some time been around a person with cancer (whose family member or close friend has had cancer) or scored higher on social desirability (caring more strongly about what others think of them) were more likely to report lower PHS. Younger age predicted greater PHS, a similar finding confirmed by a multi-center study conducted in women who carried a BRCA1 or BRCA2-mutation. ⁹ Lebel and Devins showed that personal behavior that increases cancer risk induces PHS. ²⁹ That is, 'lifestyle' causes could influence PHS.

According to the related research findings, clinical factors are also predictors for PHS of cancer patients. Side effects of treatment are associated with PHS of cancer patients. For most breast cancer patients who had experienced chemotherapy, PHS was driven partly by chemotherapy-induced alopecia ¹² That is, breast cancer patients who experienced chemotherapy and relevant alopecia had stronger PHS than those without chemotherapy or alopecia. Vodermaier et al ⁹ reported that some female carriers of a BRCA1/2-mutation might experience PHS as a consequence of body disfigurement. More specifically, BRCA1/2-mutation carriers who have undergone prophylactic mastectomy experience stronger PHS in relation to women without this surgery, because prophylactic mastectomy has negative impacts on body image and sexuality.

6. Effects of PHS on patients with breast cancer

In other stigmatized diseases, such as mental illness and human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS), PHS has been shown to negatively affect patients and their health outcomes. Several studies about PHS of cancer suggest similar effects on patients with breast cancer. Stigma-related sentiments are commonly expressed by breast cancer survivors, for

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