

Development of the Breast Cancer Stigma Scale for Arab Patients

Mashaël F. Dewan¹, Dena Hassouneh², Minkyoung Song², Karen S. Lyons³

¹School of Nursing, Fakeeh College for Medical Sciences, Jeddah, Saudi Arabia, ²School of Nursing, OHSU, Oregon, Portland, ³School of Nursing Boston College, Chestnut Hill, MA, USA



Corresponding author: Mashaël F. Dewan, BSN, MSN, RN, PhD

School of Nursing, Fakeeh College for Medical Sciences, Jeddah, Saudi Arabia

Tel: +966126588650 ext. 502

E-mail: mashaeldewan469@gmail.com

Received: October 25, 2019; Accepted: April 07, 2020; Published: June 26, 2020

ABSTRACT

Objective: Health-related stigma is associated with depression, but there is a lack of studies examining the stigma of cancer in Arab patients. The purpose of this study was to establish the reliability and validity of a newly developed, culturally sensitive measure of stigma among Arab women with breast cancer.

Methods: The sample consisted of 59 Arab women with breast cancer who were Muslim, on active oncology treatment. The mean age of women was 49 years (standard deviation = 8.31). Content validity was assessed by calculating a Content Validity Index (CVI) based on ratings from seven oncology experts. Convergent validity was assessed by examining the association with a measure of depressive symptoms. Reliability

was assessed by calculating Cronbach's alpha. **Results:** The measure demonstrated strong content validity (item-CVIs ranged from 0.85 to 1.0 and the scale-CVI was 1.0) and good convergent validity (higher levels of stigma were significantly associated with higher levels of depressive symptoms). Finally, the reliability of the measure was also found to be adequate (alpha = 0.79). **Conclusions:** The initial examination of the Breast Cancer Stigma Scale for Arab Patients indicated that the scale is both valid and reliable to be used in Arab women with breast cancer.

Key words: Cancer, reliability, stigma

Introduction

The purpose of this article is to describe the initial development of a psychometric measure of breast cancer stigma for use in Arab patient populations. Stigma is a social process that “discredits a person, reducing them from a whole and usual person to a tainted, discounted one.”^[1] Stigma leads to social exclusion and is often linked

to societal stereotypes based on race/ethnicity, gender, and/or religious affiliation.^[2] Hence, stigma is contextual and may be directed at the specific aspects of human identity.

The current study specifically focuses on health-related stigma, defined as “stigmatization of an illness, which can be applied to an individual or a group of people with the

Access this article online

Quick Response Code:



Website: www.apjon.org

DOI:
10.4103/apjon.apjon_14_20

This is an open access journal, and articles are distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as appropriate credit is given and the new creations are licensed under the identical terms.

For reprints contact: WKHLRPMedknow_reprints@wolterskluwer.com

Cite this article as: Dewan MF, Hassouneh D, Song M, Lyons KS. Development of the Breast Cancer Stigma Scale for Arab Patients. *Asia Pac J Oncol Nurs* 2020;7:295-300.

illness.”^[3] Qualitative research suggests that because breast cancer is often viewed as having a genetic origin, Arab women with breast cancer in the Middle Eastern societies experience health-related stigma.^[4,5] For instance, some Arab women with breast cancer have reported being avoided by others due to their illness and blamed for contracting their disease.^[5] In addition, Arab women with breast cancer reported fears of abandonment and divorce.^[5] Women have also reported being afraid that they would jeopardize the name of their family; they were concerned that their breast cancer might prevent their daughters or sisters from getting married.^[5] This is concerning, because in Arab societies protecting family honor or reputation is the duty of each family member.^[5] Therefore, individuals are socialized to avoid anything that might negatively affect or stigmatize the honor of their family^[5] and families often respond to social stigma and its concomitant threat to family well-being by maintaining strict secrecy about breast cancer.^[5]

Despite the information available from qualitative studies on breast cancer stigma in Arab populations, there is a lack of Arabic-validated scales for quantitative measurement of this phenomenon and lack of items specific to the experience of Arab women such as shaming the family name.^[6] Most cancer-related stigma scales have been developed and tested in non-Arab populations (i.e., in the U.K. and South Korea).^[7,8]

Therefore, we sought to begin the process of developing a culturally sensitive Breast Cancer Stigma Scale for use with Arab patient populations (BCSS-A). In addition, studies in Korea and the United States found that stigmatized cancer patients had higher levels of depressive symptoms than non-stigmatized cancer patients.^[9,10] Therefore, we examined the convergent validity by assessing the correlation between our stigma measure and a measure of depressive symptoms.

Stigma concepts

Health-related stigma is a multidimensional concept, and Jones and Jones have divided this concept into six categories.^[11] The six components are as follows: (1) perceived danger (i.e., that life-threatening illness is perceived as contagious and so proximity to the stigmatized person with the illness should be avoided); (2) deterioration of health over time (i.e., that the stigmatized person with the illness will decline and lose functionality); (3) blame (i.e., the belief that stigmatized people cause their illness); (4) concealability (i.e., efforts by the stigmatized person with the illness to hide their illness); (5) disruptiveness (i.e., the impact of stigma on the quality of interpersonal interactions for the person); and finally, (6) esthetics (i.e., whether illness detracts from a stigmatized person’s appearance). We adopted Jones and Jones’ conceptualization as the theoretical basis for

the development of our own measure but chose to omit the concept deterioration of health over time, because it is not applicable to all breast cancer patients. In place of deterioration of health over time, we chose to add the concept, shaming and devaluation of patients or their families, to ensure that our measure captured this culturally relevant component of the phenomenon.

The goals of the current study were to (1) establish the content validity of the newly developed BCSS-A and (2) provide initial evidence of the measure’s reliability and convergent validity with a sample of Arab women with breast cancer residing in the Middle East.

Methods

Design

The current study was an instrument development study.

Instruments

Breast cancer stigma scale for Arab patients

The BCSS-A has six subscales that map to the five dimensions of health-related stigma described by Jones and Jones: Perceived danger (items 1 and 2), blame (items 3 and 4), concealability (items 5 and 6), disruptiveness (items 7 and 8), esthetics (items 9 and 10),^[11] plus our additional concept of shaming, and devaluation of patients or their families (items 11 and 12). Thus, each subscale consists of two items for a total of 12 items on the full scale. We used a five-point Likert scale: 1 (strongly agree), 2 (agree), 3 (neutral), 4 (disagree), and 5 (strongly disagree) for response options (total score ranges from 1 to 5). Lower scores indicated higher levels of stigma [See items in Appendix 1]. Items were originally written in Arabic as this was the language used to distribute the measure to participants. Back translation of the items to English occurred to ensure conceptual meaning remained similar across the language versions as differences between the Eastern and Western cultures can result in translation errors that lead to differential meaning.^[12] During the analysis phase, the BCSS-A was available for review in English and Arabic, as not all study members are proficient in the Arabic language.

Content validity is “the degree to which a sample of items, taken together, constitute an adequate operational definition of a construct.”^[13] The content validity of the stigma measure was evaluated by assessing the Content Validity Index (CVI). The items were rated by seven bilingual persons, with an oncology background, in both Arabic and English. Each expert rated the relevance of each item of stigma scale to the subscale’s definition by using the following rating system: (1) not relevant to the

construct, (2) somewhat relevant to the construct, (3) quite relevant to the construct, and (4) highly relevant to the construct. We computed item-CVIs of 0.85–1.0 and a total scale-CVI (S-CVI) of 0.98 based on ratings received from seven experts in the field [Table 1]. I-CVI was calculated by computing the average of items, and the S-CVI was computed as S-CVI/average.^[13] The measure was, therefore, determined to have more than adequate content validity to be tested with a sample of Arab women with breast cancer.

Depressive symptoms

The Arabic Version of the Center for Epidemiological Studies-Depression (CES-D) Scale is a 20-item measure of depressive symptoms.^[14] Participants respond (based on feelings during the past week) using the response categories: 0 (rarely or none), 1 (some or a little), 2 (occasionally or moderate), and 3 (most or all), with higher scores indicating greater depressive symptomatology. The CES-D scale has been used widely, demonstrating Cronbach's alpha = 0.84.^[14] In our study, the Cronbach's alpha was = 0.88.

Sociodemographic information

A sociodemographic form collected information about the participants' marital status (married, single, divorced/separated, and widowed), age, level of education (college graduates vs. noncollege graduates), and nationality (i.e., Saudi vs. non-Saudi) with the option to write their nationality for non-Saudis, family income, employment, number of children, comorbid conditions, and current treatment types (i.e., chemotherapy, radiotherapy, surgery, and hormonal), type of surgery (mastectomy vs. lumpectomy), and hospital type (private vs. government).

Data collection

Between December 1, 2018, and February 28, 2019, we enrolled 59 Arab women with breast cancer from Oncology

Departments at the International Medical Center (IMC), Jeddah-Saudi Arabia and Breast Cancer Organizations. Convenience sampling was used. Recruitment was completed by using two methods: a face-to-face paper-based survey and an online survey via a URL link that was posted daily on the Oregon Health and Science University (OHSU) Facebook account. Arab women with breast cancer were included if they were 18 or older, Muslim, and had a self-reported diagnosis of breast cancer at any stage. There were no exclusion criteria to maximize data enrolment. Potential participants were not given the survey until they provided written consent to be involved in the study. Only two interested participants declined to sign the consent form. Importantly, the study was described as a study to understand the cancer experience and was not specifically described as a study about stigma.

Data analysis

Reliability of the BCSS-A was assessed by examining the Cronbach's alpha and item-total correlations to determine the internal consistency of the measure and the homogeneity of items.^[15] Both content and convergent validity of the BCSS-A were examined. Content validity was examined by calculating the CVI of the BCSS-A.^[15] An acceptable CVI for a new measure should be between 0.80 and 1.0.^[16] Convergent validity (a type of construct validity) was analyzed with correlations between the BCSS-A and measures theoretically related to the phenomenon of interest, that is, depressive symptoms.^[15]

Ethical approval

The approval of the Institutional Review Board was granted from OHSU in the United States and the IMC in Saudi Arabia. All participants consented before participating in this study.

Rater 1	Rater 2	Rater 3	Rater 4	Rater 5	Rater 6	Rater 7	Number of items rated 3 or 4	I-CVI
4	4	4	4	4	4	3	7	1
4	4	4	4	4	4	1	6	0.85
4	4	4	4	4	4	3	7	1
4	4	4	4	4	3	3	7	1
4	4	4	4	4	4	4	7	1
4	4	4	4	4	4	4	7	1
4	4	4	4	4	4	4	7	1
4	4	4	4	4	4	3	7	1
4	4	4	4	3	4	3	7	1
4	4	4	4	3	4	4	7	1
4	4	4	4	3	4	2	6	0.85
4	4	4	4	4	4	3	7	1
Mean I-content validity index								0.97
Scale-CVI								1
CVI: Content Validity Index								

Results

Patients' sociodemographic characteristics

The total number of the participants in this study was 59 Arab women with breast cancer. The mean age was 49 years (standard deviation = 8.31), and the majority were married (86.4%). More than half of the participants had at least a college degree (58%). Just under half of the participants had metastasis to other organs (44%). The largest group of participants was non-Saudi (62.7%). The non-Saudi nationalities included Egyptian (20.3%), Syrian (15.3%), Palestinian (6.8%), Jordanian (5.1%), Yemeni (6.8%), Hadramot (1.7%), Sudanese (3.4%), and Moroccan (1.7%). The majority of the participants were treated at private hospitals (69.5%). In addition, almost half of the participants were on hormonal therapy (46%). Other treatments received included chemotherapy treatment (23.7%), biological therapy (6.8%), and immunological and surgical treatments (5.1%) [Table 2].

Reliability of the scale

Internal consistency analysis

The Cronbach's alpha for the BCSS-A was 0.79. Further examination of item total correlations showed that there would be no increase in Cronbach's alpha except when item 8 ("I asked people closest to me to keep my breast cancer a secret") was deleted. However, we did not delete item 8, as the alpha would only increase to 0.80 indicating a minimal improvement for the entire measure. An alpha of 0.79 is considered within the acceptable range for internal consistency of a measure [Table 3]. Furthermore, the item in question was deemed to be important for the measure's validity. For example, 27.1% of the participants answered this item as strongly agree and 8.5% of the participants answered it as "agree."

Content Validity Index

The results of S-CVI and item-CVI are listed in Table 1.

Convergent validity

Convergent validity was examined with a Pearson correlation between the BCSS-A Scale and the CES-D Scale. Low scores on the stigma scale (strongly agree) indicate high levels of stigma. High scores on the CES-D scale indicate high levels of depressive symptoms. Pearson correlation between the stigma and CES-D scale totals was $r = -0.31$ ($P = 0.01$), which indicates a low-moderate and statistically significant negative correlation between stigma and depressive symptoms in our sample as expected.^[17] Thus, we found a significant association in the expected direction demonstrating convergent validity of our new measure.

Table 2: Sample characteristics

Patients Sociodemographic Characteristics	n (%)
Age, mean (SD)	59, 49 (8.3)
Marital status	
Single	2 (3.4)
Married	51 (86.4)
Divorced/separated	4 (6.8)
Widowed	2 (3.4)
Treatment	
Chemotherapy	14 (23.7)
Surgical	3 (5.1)
Hormonal	27 (45.8)
Immunology	3 (5.1)
Biology	4 (6.8)
Metastasis ^a	
No	30 (50.8)
Yes	26 (44.1)
Educational level	
No college degree	25 (42.4)
College degree and above	34 (57.6)
Saudi nationality	
No	37 (62.7)
Yes	22 (37.3)
Hospital type	
Government	17 (28.8)
Private	41 (69.5)

^aMetastasis to other organs. SD: Standard deviation

Table 3: Cronbach alpha interitem correlation

Items	Alpha if item deleted
Avoidance (A) 1	0.77
Wholeness (W) 2	0.76
PR 1	0.76
Functioning (F) 1	0.76
Functioning (F) 2	0.75
Wholeness (W) 2	0.74
PR 2	0.75
Concealment (C) 1	0.80
Concealment (C) 2	0.78
Shaming (S) 1	0.76
Shaming (S) 2	0.76
Avoidance (A) 2	0.75

PR: Personal responsibility

Discussion

Research has found that the experience of stigma places people at risk for unnecessary negative outcomes, such as high levels of depressive symptoms or low levels of quality of life.^[9,18] Although qualitative evidence has found that Arab women with breast cancer reported health-related stigma,^[4,5] the ability to further examine this phenomenon among these vulnerable women and tailor interventions to support them is limited by the lack of culturally-appropriate measures. The purpose of the current study was to provide initial psychometric evidence for the reliability and validity

of the newly developed BCSS-A. We found strong evidence for the content validity of our measure and acceptable evidence for the reliability and convergent validity of the measure.

Not only did the BCSS-A demonstrate adequate internal consistency reliability in our sample of Arab women with breast cancer, but also we also found evidence of an association between high levels of stigma (as measured by the BCSS-A) and high levels of depressive symptoms, thereby supporting the convergent validity of the scale. This result was consistent with a study in Korea, which aimed to examine the association between cancer stigma and depression in cancer survivors.^[9] The Cancer Stigma Scale in the Korean study had three subscales: impossibility of recovery, stereotypes of cancer patients, and experience of social discrimination. The stigmatized cancer patients were 2–3 times more likely to develop depression compared to non-stigmatized patients.

Strengths and limitations of study

To our knowledge, this is the first psychometric scale that assesses breast cancer stigma in Arab patients. A major strength of this study was that the scale was developed based on the cultural context and experiences of Arab women with breast cancer. However, there were a few limitations. Most of our participants were married and on hormonal therapy. Hence, we cannot generalize these findings to single women or to patients undergoing other types of treatments, such as chemotherapy or radiotherapy. The majority of our participants were non-Saudi nationals living in Saudi Arabia. Therefore, the generalizability of our findings to Saudi breast cancer patients may also be limited. It is also not known how participants, who consented to participate and completed the survey, differed from those who did not. Additional research is needed to validate our measure with populations with different socioeconomic status (e.g., lower income and low literacy populations).

Implications for practice and research

Although we found our newly-developed scale to be both reliable and valid, our findings may be limited to our sample. Future longitudinal research is needed to further examine the role of stigma over the cancer trajectory. In addition, factor analysis should be conducted to confirm the construct validity of the measure with a larger sample size. Identifying common predictors of stigma is another line of inquiry that could extend the current findings and provide a basis for risk assessment and intervention in future. Research has indicated that breast cancer stigma is associated with worse levels of depression. Therefore, clinicians should identify those patients as they may be at increased risk for stigma and in need of stigma-coping skills and other support. In

addition, public awareness campaigns against breast cancer stigma should be initiated to enhance the public perception about breast cancer stigma within Middle Eastern cultures.

Acknowledgments

The authors would like to thank to oncology and research departments at the Internal Medical Center Hospital.

Financial support and sponsorship

This work was financially supported by King Salman bin Abdul-Aziz Al-Saud Scholarship, Saudi Arabia & Dean Award at School of Nursing Oregon Health and Science University, Portland, Oregon, USA.

Conflicts of interest

There are no conflicts of interest.

References

- Goffman E, Stigma; Notes on the Management of Spoiled Identity. New York, NY: Simon & Schuster; 1963.
- Weiss MG, Ramakrishna J, Somma D. Health-related stigma: Rethinking concepts and interventions. *Psychol Health Med* 2006;11:277-87.
- Scambler G. Health-related stigma. *Sociol Health Illn* 2009;31:441-55.
- Hammoudeh W, Hogan D, Giacaman R. From a death sentence to a disrupted life: Palestinian women's experiences and coping with breast cancer. *Q Health Res* 2016;27:478-96.
- Jassim GA, Whitford DL. Understanding the experiences and quality of life issues of Bahraini women with breast cancer. *Soc Sci Med* 2014;107:189-95.
- Yilmaz M, Dişiz G, Demir F, Iriz S, Alacacioglu A. Reliability and validity study of a tool to measure cancer stigma: Patient version. *Asia Pac J Oncol Nurs* 2017;4:155-61.
- Marlow LA, Wardle J. Development of a scale to assess cancer stigma in the non-patient population. *BMC Cancer* 2014;14:285.
- Cho J, Smith K, Choi EK, Kim IR, Chang YJ, Park HY, *et al.* Public attitudes toward cancer and cancer patients: A national survey in Korea. *Psychooncology* 2013;22:605-13.
- Cho J, Choi EK, Kim SY, Shin DW, Cho BL, Kim CH, *et al.* Association between cancer stigma and depression among cancer survivors: A nationwide survey in Korea. *Psychooncology* 2013;22:2372-8.
- Ostroff JS, Riley KE, Shen MJ, Atkinson TM, Williamson TJ, Hamann HA. Lung cancer stigma and depression: Validation of the Lung Cancer Stigma Inventory. *Psychooncology* 2019;28:1011-7.
- Jones EE, Jones EE. *Social Stigma: The Psychology of Marked Relationships*. New York: W.H. Freeman; 1984.
- Wong N, Rindfleisch A, Burroughs JE. Do reverse-worded items confound measures in cross-cultural consumer research? The case of the material values scale. *J Consumer Res* 2003;30:72-91.
- Polit DF, Beck CT. The content validity index: Are you sure you know what's being reported? Critique and recommendations. *Res Nurs Health* 2006;29:489-97.
- Kazarian SS, Taher D. Validation of the Arabic center for epidemiological studies depression (CES-D) Scale

- in a Lebanese community sample. *Eur J Psychol Assess* 2010;26:68-73.
15. DeVellis RF. *Scale Development: Theory and Applications*. Newbury Park, Calif.: Sage; 1991.
16. Lynn MR. Determination and quantification of content validity. *Nurs Res* 1986;35:382-5.
17. Mukaka MM. Statistics corner: A guide to appropriate use of correlation coefficient in medical research. *Malawi Med J* 2012;24:69-71.
18. Johnson B, Cati G, Brodsky JL, Cataldo JK. Lung cancer stigma, anxiety, depression, and quality of life. *J Psychosoc Oncol* 2014;32:59-73.

Appendix 1: Breast Cancer Stigma Scale for Arab-patient version (English)

5-point Likert Scale:

- | | |
|-------------------------------|----------------------|
| 1. Strongly agree | 4. Disagree |
| 2. Agree | 5. Strongly disagree |
| 3. Neither agree nor disagree | |

Items	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Item 1: Some people avoid me because they think breast cancer is a contagious disease					
Item 2: Some people avoid me because of my breast cancer reminds them of death					
Item 3: Some people believe that I got breast cancer because God is punishing me					
Item 4: Some people believe that I got breast cancer because of my sins					
Item 5: I asked people close to me to keep my breast cancer a secret					
Item 6: I try to conceal my breast cancer					
Item 7: Some people think that I cannot be productive at work because of breast cancer					
Item 8: Some people think that I cannot take care of my family because of breast cancer					
Item 9: Some people think that my femininity has been diminished because of breast cancer					
Item 10: Some people think that I am not a whole person because of breast cancer					
Item 11: I am worried that I will be socially stigmatized because I have breast cancer					
Item 12: I am worried that people will look down on my family because I have breast cancer					