



Original Article

Preliminary testing for affiliate stigma scale: A reliable and valid stigma measure for caregivers of women with breast cancer



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ABSTRACT

Objective: Families of breast cancer patients may face discrimination and societal rejection due to prevailing myths, misconceptions and causal beliefs related to breast cancer. This study aims to develop and validate a measurement tool that is sensitive to the affiliate stigma experienced by caregivers of women with breast cancer.

Methods: The scale was developed in two phases: (1) item generation based on interviews amongst 18 caregivers of women with breast cancer; (2) psychometric properties of the scale, including content validity, structural validity, and internal consistency reliability. Data were collected from May to June 2023 in 426 caregivers of women with breast cancer from 5 tertiary A hospitals.

Results: An exploratory factor analysis produced a 24-item scale across four dimensions, including internal stigma, social isolation, perceived stigma, and reaction. The scale showed good internal consistency and test-retest reliability. The total score of the scale was significantly and positively correlated with scores in caregiving burden and negatively correlated with scores in self-esteem and in social support. The item-level content validity index fell within the range of 0.8–1.0.

Conclusions: This is a valid and reliable instrument captured the spectrum of stigma relevant to caregivers of women with breast cancer and may serve as a unique instrument that can be used globally. This study is a step forward for stigma-related studies among caregivers of women with breast cancer and provides a reference for developing effective interventions for those with potentially stigmatized conditions.

Introduction

Goffman first proposed 'stigma' as 'an attribute that is deeply discrediting' and 'from a whole and usual person to a tainted, discounted one'.¹ Research on stigma is clearly multidisciplinary and includes studies in the fields of psychology, sociology and anthropology. However, there are some differences in the definition of stigma. Stigma is defined inconsistently throughout the literature, and hence received a set of criticisms regarding the way in which the stigma concept has been applied from some researchers. Addressing this vaguely defined and individually focused concept, Link et al. proposed that 'stigma' be

described with reference to the relationships between a set of interrelated concepts. As such, they defined 'stigma' as the co-occurrence of its component-labelling, stereotyping, separation, status loss and discrimination.² There are two types of stigma: one is the public perception of family member as 'courtesy stigma' or 'associated stigma', while the other is the internalisation of stigma from the public's negative view amongst primary caregivers known as 'affiliate stigma'.^{3,4} Courtesy stigma is stigma by association, involving public disapproval evoked as a consequence of associating with stigmatized persons.⁵ Taking reference to Mak et al.,³ affiliate stigma is the self-stigma and corresponding psychological responses of the associates of targeted individuals. In the

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caregiving context, caregivers with affiliate stigma may perceive a greater sense of burden and strain in their caregiving duties because stigma might have distorted their views towards the care recipients and affect their relationships with them.³

Apart from breast cancer patients experiencing self-blame and stigmatisation, their families may also experience discrimination and societal rejection.^{6,7} The prevailing myths, misconceptions and causal beliefs in breast cancer invariably engender gossiping and stigmatisation from others.^{8,9} The belief that cancer is a refractory disease and synonymous with death^{9,10} worsens the internal unrest of the caregivers and leads to their sensitivity to others.¹¹ Close relatives and acquaintances behave differently, sometimes even uncomfortably, after being informed about the diagnosis, which might trigger the caregivers' unfavourable reactions.^{1,11} Most of their weakening behaviours cause unrest, and the caregivers consider these behaviours as destructive factors to the spirit of the patients and their family. Caregivers also find it difficult dealing with people who are not supportive, such as people were uncomfortable finding out that their family member had breast cancer.¹ Besides, some caregivers cannot react very well to some people's responses, because caregivers did not want to put them down and consequently these caregivers had to put up a shell.¹

Meanwhile, 'misplaced sympathy' is a term used to describe the situation wherein people use phrases or words especially in a tone that hurts their feeling.¹¹ These people find it difficult when friends and co-workers ask about the illness.¹² In addition, some people do not want to get close to those who are perceived to have a relationship with patients, regardless of the closeness of their existing relationships as husbands or just distant relatives.¹³ Therefore, caregivers are compelled to keep the diagnosis of their family member to themselves to avoid perceived and actual stigma, often solely assuming the caregiving role.^{8,10} At the same time, a cancer diagnosis places many restrictions on caregivers' social life, preventing them from engaging in social activities given the gossiping and people's bad attitudes.⁸ In particular, women's breasts are considered a symbol of physical and sexual attractiveness and femininity.¹⁴ People who are diagnosed with breast cancer face a great possibility that their breasts will be removed. Caregivers feel they could not discuss the breast reconstruction surgery with friends or even family members. This may be perceived as vanity or be met with disapproval and lack of sympathy because those with healthy breasts may not understand the situation.¹⁵ Moreover, acting normal is a routine in interpersonal relationships and may be interpreted as a strategy to maintain the integrity of social interactions and avoid stigma. This behaviour may also be interpreted as a domain of the attribute of 'saving face'.¹⁶ In terms of affiliate stigma, if one of the family members has breast cancer, to some extent, other family members may also be affected. In summary, considering beliefs towards breast cancer and the traditional value of saving 'face', affiliate stigma may be particularly salient amongst caregivers. Caregivers who restrict disclosure to protect their social image may potentially experience loss of social support, increases stress and affiliate stigma.³

For the current study, we searched for scales that can measure affiliate stigma. Currently, there are four existing scales that could be used to assess caregivers' affiliate stigma, although one of them targets caregivers of cancer patients,¹⁷ while the other three target caregivers of individuals with mental disorders.^{3,18,19} In particular, the stigma scale developed by Squiers et al. measures affiliate stigma in caregivers of cancer patients and has three dimensions: perceived, experienced and internalised stigma.¹⁷ This scale adapted items from a scale measuring HIV-related stigma,^{20,21} with modifications to the local context of cancer in India. However, the psychometric properties of this scale were only tested with 20 cancer patients and not with cancer caregivers. The content validity of the scale is also in doubt as some of the items are not related to affiliate stigma (e.g., 'Have you ever been denied health care?'; 'Have you ever been denied health insurance?'; 'Have you ever lost a job or a source of income?'). Therefore, to fully understand the stigma status of caregivers of women with breast cancer and to develop interventions to help these stigmatised individuals, the initial step is to create an effective evaluation

measurement designed specifically for them. As such, this study aimed to develop and validate a measurement tool that is sensitive to the affiliate stigma experienced by caregivers of women with breast cancer.

Methods

We used the COSMIN checklist to determine the steps for the validation study design.²² We also referred to a published method of examining the construct validity of newly developed instruments for creating objective measurements.²³ A total of two phases were included in this study. The first phase consisted of the conceptualisation and development of an initial item pool and has two components: (1) qualitative interviews and (2) content validation and pilot testing of the scale. The second phase involved the psychometric testing of the affiliate stigma scale on a sample of caregivers of women with breast cancer.

Phase 1: Scale development and item generation

Qualitative interviews

We conducted semi-structured interviews with 18 caregivers of female breast cancer patients in April 2023. The first author (female, Chinese registered nurse and a PhD candidate with substantial training in qualitative methods) conducted the interviews, which lasted 15–90 minutes per participant. The interviews were conducted face-to-face in a private room or somewhere outside the wards in two tertiary A hospitals in China. For those interviews conducted outside the ward, conversations were not heard by anyone else. All interviews were recorded by a digital voice recorder and subsequently transcribed verbatim within 24 hours. The interviews were deductively analysed, applying Colaizzi's method of phenomenological analysis.²⁴ Data collection ended once no further information was extracted. The concepts obtained in the qualitative interview data were then used as the conceptual framework to guide the development of the scale. The items were generated from the direct quotations in the interview, with reference to the existing affiliate stigma scales.

Content validity

We examined the initial items using the Delphi method to explore the content validity of the newly developed scale. The Delphi method is an approach commonly employed to gain the most reliable consensus amongst a panel of experts using a range of questionnaires.²⁵ We listed specific dimensions and the item pool during two rounds of Delphi. Between each round, we revised the content based on the experts' feedback. We recruited experts from our resource network. An invitation to participate in the consultation and a content description was sent to the participants by WeChat. Experts with more than 5 years of research or working experience related to breast cancer, stigma, or psychology, as well as at least with a master's degree and have published one academic paper in peer-reviewed journal were invited. A total of seven experts were involved, two of whom majored in psychology and five majored in nursing. Two experts have substantial research experience in stigma. They independently reviewed the content, commented on the wording of the items, and evaluated the relevance of each item using a five-point Likert-type scale (ranging from 1 = 'not relevance' to 5 = 'very relevance'). Once expert feedback was received, we summarized all the comments and discussed it within the research team. Suggestions that were suitable were taken on board. After two rounds of Delphi, an expert-validated version of the scale was produced.

Pilot testing

Finally, to gauge the comprehensibility of each item, a pilot test on the wordings, expression and appropriateness of the items was performed amongst 10 caregivers of women with breast cancer by completing the expert-validated version of the scale. After this stage, a preliminary version of the scale was generated for further psychometric testing.

Phase II: Psychometric properties of the affiliate stigma scale

A psychometric evaluation was performed to determine the structural validity, internal consistency, reliability and test–retest reliability of the newly developed scale.

Participants

Using convenience sampling, caregivers of women with breast cancer were recruited in four tertiary A and provincial hospitals located in Hunan Province and one tertiary A and municipal hospital in Jiangsu Province from May to June 2023.

The sample size should be 3–20 times larger than the number of items in the scale for exploratory factor analysis (EFA).²⁶ We recruited a sample size of about 390 (15 cases $\times$ 26 items). The inclusion criteria were as follows: (1) self-identified caregivers of women with breast cancer at stages I–IV undergoing any type of treatment, such as surgery, chemotherapy, radiotherapy, hormone therapy and targeted therapy; (2) with clear consciousness and able to complete the questionnaire; and (3) provided consent to participate in this study. Participants were excluded if they had any sign of psychiatric disease.

Measures

Demographic information, including age, religion, place of residence, employment status, education level, family history of cancer, relationship with the patient, communication with others about family member's disease, and time for caring were collected.

The newly developed 26-item affiliate stigma scale for caregivers of women with breast cancer. The participants rated their experiences of stigma by using a four-point Likert-type scale ranging from 1 ('strongly disagree') to 4 ('strongly agree'). The scale intends to measure four dimensions. Higher scores indicating higher levels of affiliate stigma.

The Chinese version of the Zarit Caregiver Burden Interview. This is a validated scale that measures the caregiver burden in terms of caregiver's health, psychological well-being, social life, finances and the relationship between the caregiver and patient.^{27,28} This scale comprises 22 questions, and information was gathered using a 5-point Likert scale ranging from 0 ('never') to 4 ('always'), based on the presence or intensity of an affirmative response. Scores ranged from 0 to 88, with higher scores indicating higher levels of caregiver burden. Good internal consistency of the Chinese version of the scale was reported, with a Cronbach's α of 0.875.²⁸ The internal consistency Cronbach's α of the scale was 0.892 in the present study.

The Chinese version of the Rosenberg Self-esteem Scale. This is a validated scale that measures the level of self-esteem.^{29,30} This scale comprises 10 items with a rating ranging from 1 ('strongly disagree') to 4 ('strongly agree'). Scores ranged from 10 to 40, with high scores indicating high levels of self-esteem. Good internal consistency of the Chinese version of the scale was reported, with a Cronbach's α of 0.875.³⁰ Cronbach's α was 0.833 in the present study.

The Chinese version of the Social Support Rating Scale. This is a validated scale developed by Xiao et al., with three dimensions measured by 10 items, including objective support, subjective support and utilisation of social support.³¹ An overall score of social support is calculated. The total score is 66 points, with higher scores indicating higher levels of social support. This scale is widely used in China, with test–retest reliability of 0.92.³¹ In the present study, the internal consistency for this scale was 0.743.

Data collection procedure

A total of five trained data collectors were involved in data collection. The data collectors recruited the caregivers via women with breast cancer in the participating hospitals. With the referral by these women with breast cancer, the data collectors assessed the eligibility of their caregivers and explained the study procedures when these caregivers visited the hospitals. After providing informed consent, the participants self-completed the questionnaires. Any questions about the

items in the survey were answered by the data collectors. If the participants had difficulty in reading the written questions, the data collectors read the questions and options to them without inducement. For the test–retest survey, we identified those caregivers who filled in the questionnaire before and approached them again within a period of 7–21 days.

Data analysis

All statistical analyses were performed using the IBM SPSS 26.0 software, with P -value of 0.05 for statistical significance. General and disease-related characteristics were presented as numbers, mean and SD (standard deviation). The validity evaluation of the scale included content validity, factor structure, and convergent validity, while the reliability evaluation comprised internal consistency and test–retest reliability.

Phase 1: Content validity. Content validity is the degree to which a scale accurately and fully reflects the concept being measured. In this study, we assessed the content validity of the affiliate stigma scale at item level using the item-level content validity index (I-CVI) which was calculated for each item in the scale by dividing the number of experts who rated the item as highly relevance (i.e., a rating of 4 and 5 given by experts) by the total number of experts who took part in the rating.³² We predefined a mean score of no less than 4 for the items to be included.

Phase 2: Factor structure. The factor structure of the scale was examined in two steps. In Step 1, item reduction based on the item–total correlation was performed. Any item with an item–total correlation coefficient below 0.3 was removed.³³ In Step 2, EFAs were conducted on the items remaining after Step 1. The Kaiser–Meyer–Olkin (KMO) and Barlett's tests checked for the appropriateness of conducting EFA. The factor retention was based on four criteria: (1) eigenvalues > 1 , (2) scree plot, (3) interpretability of the retained factors and (4) factor loadings > 0.3 . The eigenvalue represents the amount of variance each factor accounts for, with eigenvalues over 1 are stable. A scree plot is a line plot of the eigenvalues of factors or principal components in an analysis. The factor loading is the correlation between the item and the factor; a factor loading of more than 0.30 usually indicates a moderate correlation between the item and the factor.³⁴ For items cross-loaded on factors, the retention of the item to the factor was determined by two criteria: (1) a higher loading effect of the item onto the factor and (2) the item's interpretability.

Reliability. Internal consistency was assessed using Cronbach's α . A Cronbach's α of 0.7 or above indicated good internal reliability.³⁵ With values of Cronbach's alpha at this level and higher, the items are sufficiently consistent to indicate the measure is reliable. Test–retest reliability was examined through intra-class correlation coefficients (ICCs), with an interval of 7–21 days between assessments. An ICC greater than 0.75 indicates a good test–retest reliability.³⁶

Floor and ceiling effects. Domains in the affiliate stigma scale were checked with floor or ceiling effects, defined as the proportions of respondents who scored the minimum and maximum values in the domains of the scale exceeding standards pertaining to score distributions. Floor or ceiling effects are considered present if more than 30% of the respondents report the lowest or highest possible score.³⁷

Convergent validity. The convergent validity of the scale was assessed by correlation analysis. Pearson's correlation was used for normally distributed variables, and Spearman correlation for nonnormally distributed variables. A variable with either an absolute skew value larger than 2 or an absolute kurtosis (proper) larger than 7 was considered as nonnormally distributed.³⁸ We hypothesise that caregiver's affiliate stigma would correlate with caregiver burden positively and with self-esteem and social support negatively.^{3,19,39}

Homogeneity testing. To explore the differences in caregiver's affiliate stigma level across levels in demographic variables, univariate analyses were conducted: Independent t-tests for binary variables (employment status, family history of cancer, religion, relationship with the patient and communication with others about family member's disease) and ANOVA for other categorical variables (age, place of residence, educational level, religion and time for caring).

Ethical considerations

This study was approved by the Ethics Committee of Hunan Cancer Hospital (Quick review No. 34 in 2023). The study was conducted with the support of the managers of the nursing department in each included hospitals. The participants provided their written informed consent to participate in this study.

Results

Phase I: Conceptualisation and generation of items

Qualitative interview

The ages of the 18 caregivers of women with breast cancer ranged from 20 to 66. Among the participants, 15 were males and 3 were females; 14 were partners while 4 were children of the patients. The authors analysed the transcripts independently by bracketing data on preconceived ideas and strictly following Colaizzi's method. The findings were then compared and discussed by the team until we achieved consensus on themes, theme clusters and categories. Four structural concepts were extracted related to the stigma process revealed through these interviews: 'perceived stigma', 'internal stigma', 'social isolation' and 'reaction'.

Theme 1: Internal stigma. 'Internal stigma' refers to the shame and expectation of discrimination that prevents people from talking about their experiences and stops them seeking help. This worsened the internal unrest of the caregivers and led to their sensitivity.

'We did not tell anyone as there were too many negative effects.'

'When people ask us, we just say it's a cough. We went to the hospital for treatment.'

'Relatives may be afraid that we borrow money from them (to pay for the treatment) when we disclose the diagnosis to them'.

Theme 2: Social isolation. 'Social isolation' is a lack of social connections, which can lead to loneliness in some people, while others can feel lonely without being socially isolated. Social isolation is a state of complete or near-complete lack of contact between an individual and society. It differs from loneliness, which reflects temporary and involuntary lack of contact with other humans in the world.⁴⁰ Close relatives and acquaintances behaved differently after being informed about the diagnosis.

'Cancer is *hui qi*. Taboo is the biggest characteristic of China, and sometimes they are reluctant to communicate.'

'When others know you got cancer, and they are fear. They will alienate you and will not visit your family anymore'.

'Several of my old classmates' wives were diagnosed with breast cancer, and I just told them 'You have to be strong, and I give you a blessing in my heart.' I did not say too much, because others may feel uncomfortable, and they also need face'.

Theme 3: Perceived stigma. 'Perceived stigma' is the fear of being discriminated against or the fear of enacted stigma, which arises from society's belief. The misconceptions and causal beliefs in breast cancer is still very strong, which may be destructive factors to the spirit of the caregivers.

'Cancer is scruple. Being afraid of other's strange vision.'

'People may say it behind your back, for example, you have a high income, you should get this disease. People in rural area may have an unbalanced mentality.'

Theme 4: Reaction. 'Reactions' are actions taken by caregivers after the breast cancer diagnosis of the patients.

'I think the wife's illness has something to do with what my father had done before. I will go back and ask my father why they used to eat vegetarian food.'

'I bought her artificial breasts. After wearing the artificial breast, it is unrecognizable and same with the health breast.'

Delphi study and pilot testing

The item generation was based on qualitative interview. Items were extracted related to the affiliate stigma process revealed through these interviews, with 15 items in internal stigma domain, 8 items in social isolation domain, 9 items in perceived stigma domain, and 6 items in reactions domain. After two rounds of Delphi consultations, modifications to the preliminary version of the scale were made. A total of 15 items were deleted, with nine items were judged irrelevant to stigma and six items were redundant. Three new items were added based on experts' comments. Wordings of 10 items were modified because they were with expression and vocabulary issues. No domains were revised.

For the first round of Delphi study, a scale with four domains and 38 items was sent for expert review. Based on their comments, 7 items were deleted as they were irrelevant to stigma, for example, "I feel helpless after my family member diagnosed with breast cancer", "Breast cancer in my family took a toll on my reputation", and "I felt stressed after my family member diagnosed with breast cancer". Four items were merged because one item was redundant compared to other items, for example, items of "I avoid talking to others about my family's illness" and "I don't like to talk to others about my family's disease too much" were merged to "I would avoid talking too much about my family member's breast cancer disease with others"; items of "I care about the changes in appearance of my family member after treatment, such as hair loss/breast loss/weight loss, etc." and "I feel the appearance of my family member is not perfect any more after surgery and chemotherapy" were merged to "After my family received treatment for breast cancer, I felt humiliated or ashamed about her appearance (e.g., missing breast, hair loss, hyperpigmentation, and weight change)". Wordings of eight items were modified, for example, phrase of "discriminate against me" was changed to "strange looks from others"; "low key" was revised to "reticent"; "uncomfortable was changed to "embarrassed". Three items were added, for example, "I was worried that others would think there was a hereditary risk of breast cancer in my family"; "After my family member was diagnosed with breast cancer, I was afraid of others paying attention or judging her sex life".

In the second round of Delphi study, a scale with four domains and 28 items was sent for expert review again. Two items were deleted as they were not related to stigma or redundant, and two items were revised because they were with expression issue. For example two items of "I didn't want to tell anyone that my family had breast cancer" and "I felt guilty for not paying enough attention to my family member so that she didn't detect the illness and seek medical treatment in time" were deleted as they were redundant or not related to stigma. Two items were revised due to expression issue, such as "I was excluded from social activities (meals, parties, etc.)" was revised to "my family and I were discriminated against or excluded from social activities (meals, parties, etc.)"; "anxious" was revised to "ashamed". The initial 26-item scale was thus developed, and more applicable and appropriate to affiliate stigma in caregivers of breast cancer. The I-CVI was calculated for each item, with values ranging from 0.8 to 1.0. The results of the Delphi study are shown in [Supplementary Table S1](#). The 10 caregivers found that the wordings of the scale

were easy to understand and took acceptable time to complete. Hence, no further modification was made to this version of the scale in the pilot testing phase.

Phase II: Psychometric properties

Sociodemographic characteristics

A total of 426 questionnaires were distributed to caregivers, and 400 (93.9%) valid questionnaires were received. The mean age of the respondents was 43.66 years (SD = 12.57), with a range of 15–74 years. Majority of the caregivers lived in 13 cities and 1 autonomous prefecture in Hunan Province, while a small number came from two cities in Jiangsu Province as well as some other provinces, including Anhui, Jiangxi and Xinjiang. Details are shown in Table 1.

Item total correlation

Table 2 shows the item–total correlation statistics of all the 26 items in the scale. Item 26 (‘I do not hope others sympathise with me due to my family member being diagnosed with breast cancer’) in the reaction domain had an item–total correlation < 0.3, indicated in bold. Thus, it was removed from the scale. A total of 25 items were retained in the scale to measure four subdomains of internal stigma (7 items), social isolation (8 items), perceived stigma (5 items) and reaction (5 items). These 25 items were subjected to EFA.

Exploratory factor analysis

Table 3 shows the EFA results. The maximum likelihood analysis with direct oblique rotation was performed using the data of the remaining 25 items. KMO measure of sampling adequacy with a value of 0.942 and a highly statistically significant Bartlett’s test of sphericity ($P < 0.0001$) indicate that the data are suitable for EFA. A four-factor solution was retained in the EFA based on eigenvalue > 1, and the sharp drop in the slope after four factors in the Scree plot (Supplementary Fig. S1). Item 16 (‘I was worried that others would think there was a hereditary risk of breast cancer in my family’) has all four factor loadings below 0.30; hence, it was removed from the scale.

We re-ran EFA on the remaining 24 items. The KMO measure was 0.939 and Bartlett’s test was statistically significant ($P < 0.0001$), suggesting the appropriateness of the data for EFA. Four factors were retained in accordance with the eigenvalue criteria, the scree plot (Supplementary Fig. S2), which explained 61.44% of the total variance.

Table 1
Sociodemographic characteristics of the caregivers (N = 400).

Variable	Group	n	%
Age (years)	≤ 44	216	54.0
	45–59	137	34.3
	≥ 60	47	11.8
Religion	Yes	28	7.0
	No	372	93.0
Place of residence	City	212	53.0
	Township	101	25.3
	Village	87	21.8
Employment status	Unemployed	121	30.3
	Employed	279	69.8
Education level	Primary school or below	31	7.8
	Junior school	96	24.0
	High school or college	124	31.0
	University or above	149	37.3
Family history of cancer	Yes	132	33.0
	No	268	67.0
Relationship with the patient	Partner	220	55.0
	Others (e.g., children, parents, relatives)	180	45.0
Communication with others about family member’s disease	Yes	175	43.8
	No	225	56.3
Time for caring	≤ 1 year	350	87.5
	1–5 years	30	7.5
	≥ 5 years	20	5.0

Table 2
Item–total statistics of the scale.

Number	Items	Item-total correlation
1	I would avoid talking too much about my family member’s breast cancer disease with others.	0.594
2	When I’m with my family member who has breast cancer, I’m sometimes more reticent.	0.623
3	After my family member was diagnosed with breast cancer, I had less contact with relatives and friends.	0.615
4	After my family member was diagnosed with breast cancer, I was more concerned about others’ opinions.	0.615
5	After my family member was diagnosed with breast cancer, I was afraid to participate in social activities because I was afraid of people asking about my family’s breast cancer status.	0.713
6	I was reluctant to allow my family to attend social activities because I was worried that others would find out she had breast cancer.	0.708
7	I am afraid to attend breast cancer-related activities in case others suspect that my family member has breast cancer.	0.682
8	I get nervous or embarrassed when my family member needs to talk about her breast cancer in public.	0.482
9	After a family member was diagnosed with breast cancer, I was afraid of others paying attention or judging her sex life.	0.456
10	I didn’t want people to know that my family member was diagnosed with breast cancer.	0.563
11	I feel embarrassed when others talk with me that my family member suffer from breast cancer.	0.649
12	I feel shame and remorse about not being able to afford the expensive treatment.	0.422
13	After my family member went through breast cancer treatment, I felt uncomfortable when people stared at her chest or head.	0.461
14	I didn’t want others to see my family member emaciated after suffering from breast cancer.	0.384
15	I have advised my family not to tell others that someone in our family has breast cancer.	0.608
16	I was worried that others would think there was a hereditary risk of breast cancer in my family.	0.614
17	After my family member suffered from breast cancer, I felt the strange looks from others.	0.687
18	After my family member suffered from breast cancer, I felt like someone was talking about our family or about her disease.	0.651
19	After my family member was diagnosed with breast cancer, I often felt someone was staring at her chest or head.	0.635
20	After my family member was diagnosed with breast cancer, others were unwilling to have contact with our family.	0.665
21	After my family member was diagnosed with breast cancer, my family and I were discriminated against or excluded from social activities (meals, parties, etc.).	0.638
22	After my family member was diagnosed with breast cancer, I avoided communicating with her.	0.594
23	After my family member was diagnosed with breast cancer, I tried to distance myself from her.	0.447
24	After my family received treatment for breast cancer, I felt humiliated or ashamed about her appearance (e.g., missing breasts, hair loss, hyperpigmentation, and weight change).	0.608
25	I am afraid that others will think that my ancestors did something bad that caused breast cancer in my family.	0.590
26	I do not want others to sympathise with me because my family member has breast cancer.	0.223

Bold indicate item–total correlation < 0.3.

The 4-factor solution resembles the original structure, with factor 1 covering items in internal stigma domain, factor 2 with items in social isolation domain, factor 3 with items in perceived stigma domain and factor 4 with items in reaction domain. However, a total of 7 items were cross-loaded on factors. Three items (Items 1, 7 and 15) doubled on factors 1 and 2. Items 1 and 7 were retained in factor 1 because of the

Table 3Results of exploratory factor analysis ($N = 400$).

Intended domain		First round with 25 items				Second round with 24 items			
		Factor 1	Factor 2	Factor 3	Factor 4	Factor 1	Factor 2	Factor 3	Factor 4
Item 1	Internal stigma	0.439	0.296	0.120	−0.138	0.430	0.302	0.119	−0.130
Item 2		0.503	0.078	0.104	0.093	0.497	0.082	0.104	0.096
Item 3		0.608	−0.046	0.206	−0.044	0.601	−0.040	0.207	−0.040
Item 4		0.436	0.163	0.158	0.079	0.432	0.165	0.156	0.081
Item 5		0.838	0.023	−0.032	0.032	0.831	0.027	−0.027	0.032
Item 6		0.827	−0.092	0.041	0.103	0.830	−0.092	0.046	0.099
Item 7		0.486	0.327	−0.037	0.112	0.486	0.328	−0.033	0.111
Item 8	Social isolation	0.042	0.545	−0.026	0.153	0.044	0.544	−0.025	0.152
Item 9		−0.081	0.705	0.034	0.023	−0.078	0.703	0.033	0.022
Item 10		0.157	0.745	−0.142	0.036	0.155	0.747	−0.141	0.038
Item 11		0.253	0.536	−0.090	0.224	0.253	0.537	−0.088	0.223
Item 12		0.024	0.330	0.204	0.025	0.023	0.331	0.202	0.026
Item 13		0.073	0.559	0.169	−0.218	0.072	0.561	0.169	−0.214
Item 14		−0.104	0.598	0.145	−0.127	−0.106	0.598	0.141	−0.122
Item 15	Perceived stigma	0.363	0.364	0.023	0.052	0.360	0.367	0.025	0.055
Item 16		0.286	0.137	0.231	0.163	/	/	/	/
Item 17		0.117	0.070	0.616	0.173	0.118	0.075	0.611	0.179
Item 18		0.003	0.116	0.732	0.086	0.007	0.119	0.724	0.092
Item 19		0.141	0.022	0.734	−0.031	0.145	0.024	0.733	−0.028
Item 20		0.156	−0.057	0.505	0.369	0.158	−0.054	0.505	0.375
Item 21		0.027	0.022	0.374	0.588	0.026	0.026	0.370	0.595
Item 22	Reaction	0.421	−0.039	0.045	0.415	0.419	−0.036	0.046	0.414
Item 23		−0.022	0.040	0.047	0.719	−0.021	0.041	0.044	0.720
Item 24		0.275	0.054	0.140	0.409	0.276	0.056	0.141	0.409
Item 25		0.327	−0.077	0.126	0.486	0.328	−0.076	0.124	0.483

Bold indicates factor loading > 0.3 .

larger factor loading on factor 1 than that on factor 2. Item 15 (“I have advised my family not to tell others that someone in our family has breast cancer”) had factor loadings with similar magnitude on both factors but was retained in factor 2 based on interpretation because the content of Item 15 is closer to factor 2 of social isolation by keeping the diagnosis of the patient from others rather than factor 1 of internal stigma regarding the shame and expectation of discrimination. Items 20 and 21 were also double-loaded on factors 3 and 4. Item 20 was retained on factor 3, while Item 21 was retained on factor 4 based on the magnitude of the factor loadings. Items 22 and 25 were double-loaded on factors 1 and 4. Item 25 was retained in factor 4 because of the magnitude of the factor loadings while Item 22 (“After my family member was diagnosed with breast cancer, I avoided communicating with her”) was also retained in factor 4 because avoiding communication with the patient is a reaction taken by caregivers after the breast cancer diagnosis of the patients, rather than a feeling of perceived stigma.

Reliability and ceiling and floor effects

Table 4 presents the number of items, internal consistency, ceiling and floor effects of the finalised affiliate stigma scale. Cronbach's $\alpha > 0.82$ indicates good internal consistency and ICC > 0.74 indicates good test-retest reliability in the overall scale and the four domains. The ceiling and floor effects were calculated for the total scale and for each of the

Table 4

The internal consistency, test-retest reliability, ceiling, and floor effects of the scale.

Scale/ dimension	Number of Items	Cronbach's α	ICC	Ceiling effect n (%)	Floor effect n (%)
Internal stigma	7	0.876	0.789	3 (0.8)	18 (4.5)
Social isolation	8	0.827	0.756	2 (0.5)	4 (1.0)
Perceived stigma	5	0.887	0.813	2 (0.5)	40 (10.0)
Reaction	4	0.825	0.749	1 (0.3)	63 (15.8)
Total scale	24	0.932	0.914	1 (0.3)	3 (0.8)

ICC, intra-class correlation coefficient.

four dimensions. For the whole scale and the four domains, a very small proportion of the respondents attained the highest score, ranged from 0.3% to 0.8% ($< 30\%$), indicating that there were no ceiling effects. For the floor effect, the percentages of the participants who had achieved the lowest score in the whole scale and the four domains ranged from 0.8% to 15.8%, once again indicating no evidence of floor effect.

Convergent validity

Pearson correlations (r) were performed, as all the studied variables were normally distributed based on the skewness (> 2) and kurtosis (> 7) tests. The results are shown in Table 5. As can be seen, the total score of the scale was significantly and positively correlated with the scores in caregiving burden ($r = 0.194$, $P < 0.001$) and negatively with the scores in self-esteem ($r = -0.278$, $P < 0.001$) and in social support ($r = -0.135$, $P < 0.001$). Internal stigma and social isolation were correlated significantly with self-esteem, social support and caregiving burden in the expected directions ($P < 0.05$). Perceived stigma was negatively correlated with self-esteem and positively correlated with caregiving burden, while reaction was negatively correlated with self-esteem and social support. However, the correlations of perceived stigma with social support, and reaction with caregiving burden were non-significant, although they were in the expected directions.

Affiliate stigma level in caregivers and correlation of variables with affiliate stigma

According to the homogeneity test, we identified four variables, including age, family history, relationship with the patient and communication with others about family member's disease have significant differences in caregivers' affiliate stigma level (Table 6). For age subgroups, pairwise comparison indicated that caregivers aged 45–59 have significantly higher affiliate stigma level than those aged 44 or younger.

Discussion

This study aimed to develop and test the psychometric properties of the newly developed affiliate stigma scale for caregivers of women with

Table 5

Relationship of the overall score of affiliate stigma and domain scores with self-esteem, social support and caregiving burden.

Affiliate stigma	Self-esteem		Social support		Caregiving burden	
	Correlation	P-value	Correlation	P-value	Correlation	P-value
Overall	-0.278	< 0.001	-0.135	0.007	0.194	< 0.001
Domain						
Internal stigma	-0.180	< 0.001	-0.112	0.025	0.183	< 0.001
Social isolation	-0.297	< 0.001	-0.150	0.003	0.209	< 0.001
Perceived stigma	-0.237	< 0.001	-0.072	0.148	0.145	0.004
Reactions	-0.214	< 0.001	-0.105	0.036	0.065	0.192

Table 6

Affiliate stigma level in caregivers (N = 400).

Variable	Group	Affiliate stigma (Mean $\pm$ SD)	P-value
Age (years)	≤ 44	49.41 $\pm$ 11.08	0.016*
	45–59	52.50 $\pm$ 8.23	
	≥ 60	50.70 $\pm$ 7.20	
Religion	Yes	53.68 $\pm$ 8.89	0.089
	No	50.39 $\pm$ 9.90	
Place of residence	City	50.13 $\pm$ 10.00	0.506
	Township	50.84 $\pm$ 9.36	
	Village	51.56 $\pm$ 10.13	
Employment status	Unemployed	50.43 $\pm$ 9.76	0.610
	Employed	51.06 $\pm$ 10.12	
Education level	Primary school or below	53.23 $\pm$ 9.95	0.562
	Junior school	51.97 $\pm$ 7.72	
	High school or college	50.31 $\pm$ 8.97	
	University or above	49.48 $\pm$ 11.53	
Family history	Yes	49.23 $\pm$ 9.88	0.047*
	No	51.31 $\pm$ 9.80	
Relationship with the patient	Partner	52.32 $\pm$ 8.62	0.022*
	Others (e.g., children, parents, relatives)	48.55 $\pm$ 10.87	
Communication with others about family member's disease	Yes	47.71 $\pm$ 9.21	< 0.001*
	No	52.88 $\pm$ 9.78	
Duration for caring	≤ 1 year	50.58 $\pm$ 9.89	0.562
	1–5 years	61.63 $\pm$ 11.19	
	≥ 5 years	60.99 $\pm$ 10.98	

*: $P < 0.05$.

breast cancer. To the best of our knowledge, the present study is one of the first attempts to develop a quantitative measure of affiliate stigma to understand its relationships with the caregiving in the cancer area. Compared to the existing affiliate stigma in caregivers of cancer patients by adapting from a scale measuring HIV-related stigma and without psychometric testing, our affiliate stigma scale was developed to fully understand the stigma status of caregivers of women with breast cancer from perspectives of caregivers and health care professionals, and then psychometrically tested with a wide coverage of caregivers of women with breast cancer. The scale showed excellent convergent validity and internal consistency after adjusting the scale by psychometric techniques. These results indicate that the 24-item affiliate stigma scale for caregivers of women with breast cancer is a valid and reliable instrument to assess affiliate stigma status in caregivers of women with breast cancer. From our literature review of caregivers' experience, we also found that affiliate stigma in caregivers was frequently reported in the literature. Many studies from collective and individual countries, such as Northern and Latin America, the Middle East, and Africa, including Brazil, Iran, and Ghana,^{1,8–11,41} have mentioned cultural perceptions and historical stigma regarding breast cancer in society, mostly reporting that breast cancer is considered an incurable disease, almost like a death sentence for some. Gossiping and stigmatisation from society usually trigger others' uncommon behaviours.⁹ To protect their social image, caregivers

usually restrict disclosure and keep the cancer diagnosis to themselves.⁹ Therefore, this scale can serve as an unique instrument for the assessment of affiliate stigma amongst caregivers of women with breast cancer in China and potential globally.

Factor analysis indicated that a 24-item scale with four factors was optimal. Four factors explained 61.44% of the explained variance. The first factor, internal stigma, refers to the shame and expectation of discrimination that prevents people from talking about their experiences and stops them seeking help.⁴² Caregivers are subject to a level of stigma.⁴¹ People used phrases or words especially in a tone that hurts caregivers' feeling.¹¹ The second factor, social isolation, refers to the lack of social connections, which can lead to loneliness in some people, while others can feel lonely without being socially isolated.⁴³ Caregivers refused to take patients out or to allow others to visit their family because these activities attract gossips and stigma.⁸ The third factor, perceived stigma, is the fear of being discriminated against or the fear of enacted stigma, which arises from society's beliefs.⁴⁴ The culture led caregivers to view cancer as incurable and as a death sentence, and it was associated with a negative stigma in society.¹⁰ Caregivers usually keep the cancer diagnosis to themselves to avoid perceived and actual stigma and solely assumed the caregiving role.⁸ The fourth factor, reactions, are actions taken in response to the family member diagnosed with breast cancer. After being informed about the diagnosis, close relatives and close acquaintances behaved differently, which triggered the caregivers' unfavourable reactions and caregivers accounted them as destructive factors to the spirit of the family.¹¹ The scale showed good internal consistency and test-retest reliability in the overall scale and the four dimensions as well. For the overall scale, there was also no evidence of any ceiling or floor effect.

According to the homogeneity test, we identified variables of age, family history of cancer, relationship with the patient, and communication with others about family member's disease have a significant difference in caregivers' affiliate stigma level. There were significant differences in affiliate stigma level across age subgroups, with caregivers aged 44 or younger having the lowest level. This may be because young people are easy to get information and knowledge related to breast cancer online. They may not deem breast cancer as an incurable disease. Besides, caregivers with family history of cancer have significantly higher affiliate stigma than those without family history of cancer. Caregivers without family history of cancer may consider cancer horrible and incurable while caregivers with family history of cancer have experience in dealing with the situation and may have already got used to some negative reactions from the society, thus taking the experience less serious. Additionally, partners of the patient reported higher level of affiliate stigma than others (e.g., children, parents, relatives). Since breast cancer is a couple disease and may affect the sex life with partners, and this might have partly explained the observation of the higher affiliate stigma in partners. In addition, all the partners in this study are male. Males tended to not to talk about their experience and seek social support as they thought these actions should not be part of their gender role.^{12,45} In the study, we also found a significant difference in affiliate stigma levels in the subgroups whether there was communication with others about family member's disease. Caregivers who communicated with others about their family member's disease might have higher social support, because they might

feel they have someone understand and empathize with them. Consistent with a previous study, communication with others and disclosure led to feeling accepted and secure and receiving understanding and support from friends and family. Participants were more willing to share when they felt less initial stigma and judgement. Communication reduces feelings of loneliness and social isolation, and increases empowerment as a way to break the affiliate stigma.⁴⁶ While it is possible that the longer term of caregiving experience might have diluted the negative feeling of stigma, it is also possible that caregivers with family history of cancer might interpret the items differently from those caregivers without family history of cancer. Further studies should examine the psychometric properties of the scale in different sub-populations.

We found strong evidence to the convergent validity of the scale as all the three tested hypotheses were supported in the current study.^{3,18,19,39} A negative correlation between affiliate stigma and social support was identified. The finding is consistent with previous studies,^{19,39,47} indicating that people who feel prejudice and discrimination may withdraw from their social circles and conceal their status. Caregivers with high level of social support most likely live in a friendly and open environment. Instead of looking down on caregivers or delivering socially stigmatising information, others are more likely to offer them help and understand their situation.¹⁹ Higher social support level enables caregivers to perform better in the caregiving process. Considering the 'face' concern in China, caregivers with high levels of affiliate stigma isolate themselves because they fear disclosure and possible discrimination. Instead, they keep the diagnosis to themselves, causing social distancing and limiting the social support they can receive.⁴⁸ Besides, those with higher levels of social support are more likely to receive more love and care, which may lead to higher levels of positive affect and lower levels of negative affect.⁴⁸ Self-esteem was negatively correlated with affiliate stigma in the current study. This is because people with higher level of esteem may pay more attention and be more sensitive to the negative perspectives from the society. Caregiving burden is positively associated with affiliate stigma level in the study, which is consistent with the findings of Mak et al.³ The higher burden they have, the higher affiliate stigma that they feel. The current findings were also in line with previous studies on family caregivers of people with mental illness, in which positive correlations of affiliate stigma with social support and caregiver burden were reported in a meta-analytic study. On the other hand, there was also difference as self-esteem was not significantly associated with affiliate stigma.⁴⁹

At the same time, internal stigma and social isolation are all correlated with self-esteem, social support and caregiving burden. However, the correlations between perceived stigma and social support, as well as between reactions and caregiving burden were non-significant. A potential reason for the non-significance of social support and reactions with caregiving burden is that in traditional Chinese culture, caring for a sick person is considered the responsibility of each family member, instead of considering the task as a burden.⁵⁰ Caregivers are usually family members or relatives in this study; thus, the patient is a significant person to the family members or relatives; as a result, the caregivers are willing to take care of the patient (i.e. their relatives). Therefore, the caregiving burden may not affect their reaction. Meanwhile, a potential reason for the non-significance of the link between perceived stigma and social support is that people who experience affiliate stigma may be more sensitive to others' behaviours due to cognitive biases. Caregivers create their own "subjective reality" from their perception, which may sometimes lead to perceptual distortion, inaccurate judgment, illogical interpretation, and irrationality.^{51,52} Hence, caregivers may sometimes misunderstand others' words or behaviours. This may account partially for the non-significance of perceived stigma with social support. Furthermore, caregivers with high levels of affiliate stigma are likely to have a sense of shame and inferiority due to their relationship with the affected family member.³ Affiliate stigma is a significant contributor to low self-esteem and social isolation, which may result in changes in social roles, acceptance and challenges related to employment.¹⁴ Therefore, an

accurate assessment of the affiliate stigma amongst caregivers of women with breast cancer is in the caregivers' best interest.

Test-retest reliability was examined through ICCs, and the finding showed the good test-retest reliability of the proposed scale (ICC > 0.74). Amongst the four existing scales that could be used to assess caregivers' affiliate stigma, all of them were without test-retest reliability.^{3,17-19} Therefore, this finding provides further evidence and support for the use of our scale in caregiving research and oncology practice.

Implications for nursing practice and research

Stigma is directly associated with caregivers' mental health. Affiliate stigma is positively associated with depression and anxiety in caregivers.⁵³ Caregivers feel themselves as inferior, endorse stigma in themselves, and have negative opinions toward themselves influencing their mental health, such as anxiety and depression.⁵³ Due to the feelings of shame and guilt driven by the fear of losing face, in order to avoid affiliate stigma, caregivers usually take avoidant behavior and keep a low profile, such as reducing contact with neighbors, friends and relatives, reducing going out with the patients, reducing interactions and communication with the patients, not to participating in activities related to the disease.⁵⁴ Given that affiliate stigma was associated with depression and anxiety, the reduction of affiliate stigma is needed to help caregivers improve their psychological distress. Therefore, appropriate interventions that can reduce affiliate stigma should be developed. Subsequently, improved outcomes for breast cancer patients may be gained as well. The scale developed in this study may provide a useful screening measure for identifying caregivers with a potentially stigmatised condition and provide those affected caregivers with appropriate psychological support. Specific recommendations could be provided for health care professionals or mental health workers on how to identify and address caregivers' affiliate stigma. Some initial intervention strategies could be proposed to help reduce affiliate stigma and its associated negative psychological impacts. For example, health care professionals can use the scale as a routine measure for caregivers of women with breast cancer to assess their levels of affiliate stigma for early detection and prevention. Tailored intervention for each of the four domains can also be developed to help caregivers with high stigma-domain score and use the scale as an outcome measure for interventional studies to reduce affiliate stigma. In addition, affiliate stigma may be salient amongst caregivers considering cultural beliefs towards breast cancer and their values of saving 'face' in the Chinese context. In order to protect their social image, caregivers often restrict disclosure, which potentially leads to loss of social support, increased stress and affiliate stigma. Furthermore, Bu et al.¹⁴ developed a stigma scale for women with breast cancer. Future studies can explore the level of stigma and their associated factors between patients and caregivers. Then, they can develop interventions to help these stigmatised families.

Strengths and limitations

Our study has several strengths. First, this is a multi-centre study that has enabled us to recruit participants living in different provinces in the middle region in China. These participants visited the selected five hospitals in Hunan and Jiangsu Provinces for medical service. Furthermore, we did not only invite the caregivers of newly diagnosed breast cancer patients but also those with long-term caregiving experience, thus ensuring a wide coverage of caregiving journey in the caregivers. These two characteristics imply that the study's findings have good generalisability. Second, the scale was developed with a rigorous procedure, with items generated from informants from the target population. Third, the scale was psychometrically tested in a large caregiver sample, thus enhancing the reliability and validity of the study findings.

Although this is a multi-centre study that employed a rigorous development and validation process, it is not without limitations. First,

we have employed the data-driven approach of EFA in determining the number of factors in the scale. Moreover, the observed variables can be influenced by extraneous factors such as response bias or measurement error. Therefore, further studies examining the factor structure of the scale by CFA are warranted. Besides, we used a common method, correlational analyses, to examine convergent validity of the scale in the study. The psychometric testing could be improved if we had measured other related variables of stigma in caregivers of women with breast cancer, such as psychological resilience, psychological distress, and quality of life, and tested the relationships among all the related variables in a framework using structural equation model.⁵⁵ In addition, other psychometric properties such as predictive validity of the scale should also be explored in future studies.

Conclusions

The newly developed 24-item scale offers a valid and reliable instrument for assessing the affiliate stigma experienced by caregivers of women with breast cancer in clinical and research settings. To the best of our knowledge, there has been no specific measurement of stigma amongst caregivers of breast cancer patients. The scale was tested and modified after qualitative interviews and two rounds of Delphi panels, thus capturing the spectrum of stigma relevant to caregivers of breast cancer patients. This study is a step forward for stigma-related studies amongst caregivers of cancer patients and provides a reference for developing effective interventions for those with potentially stigmatised conditions.

CRedit authorship contribution statement

Xiaofan Bu: Conceptualization, Methodology, Data collection, Data curation, Formal analysis, Writing. Xi Chen and Rongrong Fan: Methodology, Data collection, Data curation. Lu Luo, Ling Jiang and Xiangyu Liu: Conceptualization, Data collection, and Writing. Doris Y.P. Leung: Conceptualization, Methodology, Formal analysis, and Writing. All authors had full access to all the data in the study, and the corresponding author had final responsibility for the decision to submit for publication. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

Ethics statement

This study was approved by the ethics committee of Hunan Cancer Hospital (Quick review No. 34 in 2023) and was conducted in accordance with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. All participants provided written informed consent.

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Declaration of competing interest

The authors declare no conflict of interest. Dr. Doris Y.P. Leung, one of the corresponding authors, serves on the editorial board of the *Asia-Pacific Journal of Oncology Nursing*. The article underwent standard review procedures of the journal, with peer review conducted independently of Dr. Leung and their research groups.

Data availability statement

The data that support the findings of this study are available from the corresponding author, DYP L, upon reasonable request.

Declaration of generative AI and AI-assisted technologies in the writing process

No AI tools/services were used during the preparation of this work.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.apjon.2024.100652>.

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