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ORIGINAL ARTICLE

Validation and Reliability of a Family Resilience Assessment Questionnaire for Caregivers of Breast Cancer Patients Undergoing Chemotherapy

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Abstract

Background/Aim: Breast cancer, as the most prevalent non-communicable disease globally, imposes substantial emotional, economic and social burdens on patients and their families during chemotherapy treatment. Consequently, there is a critical need for instruments that assess family resilience. The aim of this study was to develop and evaluate a culturally appropriate family resilience assessment tool that explores the belief systems, organisational frameworks and communication strategies of families supporting breast cancer patients undergoing chemotherapy.

Methods: A pilot study was conducted involving 76 families of breast cancer patients undergoing chemotherapy. The inclusion criteria were: caregiving for a duration exceeding one month, being at least eighteen years of age, willingness to cooperate and literacy. Data collection occurred from September to December 2024, utilising convenience sampling techniques. The questionnaire comprised sociodemographic information and three dimensions of resilience—belief system (13 items), organisational pattern (8 items) and communication process (11 items). Validity was assessed using Pearson's product-moment correlation, while reliability was determined through Cronbach's alpha. Statistical analyses were executed using SPSS Version 26.0.

Results: Most participants were middle-aged (40–59 years) with high school education, have undergone six or more chemotherapy sessions, were unemployed and used national health insurance (BPJS). Reliability analysis showed good internal consistency (Cronbach's alpha > 0.7). One item was invalid due to a low correlation with the overall score, while the rest were valid.

Conclusion: The questionnaire is valid and reliable for assessing family resilience during chemotherapy care for breast cancer patients, supporting future studies and treatments to enhance patient outcomes and quality of life.

Key words: Breast neoplasms; Antineoplastic protocols; Family support; Resilience, psychological; Validity; Reliability; Reproducibility of results.

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Introduction

Breast cancer is one of the most prevalent non-communicable illnesses that affect women globally. According to the Global Cancer Observatory (GLOBOCAN) 2020 report, breast cancer is the leading cause of new cases globally, accounting for almost 2.3 million new cases

annually. One According to the Ministry of Health of the Republic of Indonesia (2021), breast cancer is one of the main causes of cancer-related mortality and morbidity in Indonesia.[1] Numerous physical, emotional and psychological challenges impact the quality of life for those receiving chemotherapy for breast cancer. In this situation, the family's role as caregivers becomes crucial in helping the patient through the course of therapy.[2–4]

Families of breast cancer patients receiving chemotherapy frequently deal with a number of challenging problems. They must become used to their new role as caretakers, which can lead to emotional strains associated with the patient's health, such as stress and worry. Furthermore, the high expense of therapy may become a major financial strain, putting further strain on the family.[5] Changes in family dynamics and heightened obligations can also strain relationships among family members, leading to emotions of exhaustion, annoyance and overload. The uncertainty surrounding the prognosis of cancer patients is one of the most significant issues that families deal with.[6]

Families of cancer patients suffer from worry, anxiety, sadness, role shifts and a reduction in income as a result of the high medical expenses associated with the uncertain recovery of their loved ones.[7] Families frequently encounter issues when they provide care for people with breast cancer. Families may experience anxiety and shock at the early stages of diagnosis. The mental and financial strain grows as therapy starts, leading to more stress and exhaustion.[8] Patients and their family are impacted by breast cancer on an emotional, social, financial, physical, spiritual and exhausting level.[9, 10] Insufficient clarity and assistance from medical professionals may make matters worse. Families may feel more anxious and powerless if they don't comprehend the illness and the course of therapy.[11]

Resilience is crucial for helping families adjust and continue to function when caring for breast cancer patients after chemotherapy.[12–15] Resilient families are more equipped to offer patients practical, emotional and informational support, which can greatly enhance their quality of life and treatment results.[16–21] On the other hand, families with low resilience typically struggle to cope with stress, which can result in emotional strain, a lack of communication and an atmosphere that is not supportive of the patient.[22–24]

Strong and culturally appropriate measuring techniques to quantify family resilience are still lacking, despite the growing recognition of the relevance of this factor in cancer care.[25] In the context of cancer patient treatment, available tools frequently emphasise individual resilience rather than family resilience as a whole.[25–27] Additionally, because of the various emotional, financial and unpredictable challenges that relatives of breast cancer patients face, psychometric tools have to be created especially for them.[28, 29]

A questionnaire was constructed to evaluate belief systems, organisational patterns and communication processes in this study and then the instrument's validity and reliability was examined. Giving meaning to challenges, having an optimistic perspective, transcendence and spirituality were all part of the belief system.[30] Social and economic resources, openness and flexibility are characteristics of organisational patterns. Clarity, emotional expressiveness and group problem-solving are all components of the communication process.[30] For the purpose of creating this model, the researchers created three surveys. As a result, the purpose of this study was to create and evaluate a family resilience tool that explores the belief systems, organisational frameworks and communication strategies of families supporting breast cancer patients undergoing chemotherapy.

Methods

Study design

This questionnaire's viability was assessed using a pilot study. Information was gathered from 76 relatives of patients with breast cancer receiving chemotherapy at facilities that satisfied the requirements. The following criteria needed be met in order to be eligible: families who are directly caring for a patient with breast cancer undergoing chemotherapy, such as husbands, kids, sons-in-law, or mothers; they must be over the age of 18, cooperative and willing to participate in the survey; and they must be able to read and write well. Among the exclusion criteria were relatives of patients with breast cancer who have never received chemotherapy and have communication difficulties.

Data collection techniques

The period of data collection in 2024 was September through December. Convenience sampling was the method employed in this study, which chooses samples according to research respondents' availability and ease of access.[31] Respondents who satisfied the study's inclusion requirements—adult family members who lived in the same home as the patient, were able to read and write and provided care for breast cancer patients receiving chemotherapy for longer than a month—were given an explanation of the study by the researchers. Respondents were requested to sign an informed consent form after meeting the exclusion criteria of residing in the same home but not having a family relationship. As a convenience sample technique, seventy-six questionnaires were given to families of patients with breast cancer receiving chemotherapy. Respondents completed it in an average of thirty to forty-five minutes. Because all of the statement items in the questionnaire were comprehended by the respondents, the first survey findings were deemed satisfactory. To make sure the respondents understood and filled out every statement item on the questionnaire, the researcher joined them while they filled it out. After then, 76 of the replies were examined.

Measurement variable

Three variables—belief system, organisational structure and communication process—were included in the created questionnaire. There were parameters for every variable. The belief system encompassed spirituality, transcendence, an optimistic perspective and providing meaning to challenges.[30] Openness, flexibility and social and financial resources are characteristics of organisational patterns. Clarity, emotional expression and cooperative problem-solving comprise the communication process.[30]

This study searched databases including *Scopus, PubMed, ScienceDirect, Medline, CINAHL, EBSCO* and others for literature on family resilience in caring for breast cancer patients receiving chemotherapy. When creating this tool, the researchers also consulted questionnaires from earlier investigations. The sociodemographic information of the participants (patients with breast cancer and their families) and the three dimensions of the questionnaire—belief systems (13 statement items), organisational patterns (eight statement items) and communication processes (eleven statement items)—made up the two sections of this survey.

Data analysis

The purpose of descriptive statistics was to provide an explanation of the respondents' overall characteristics. By comparing each statement item's score to the overall score, the validity test of the instrument was established. If a variable's score had a substantial correlation with the overall score, it was considered legitimate. For this connection, the Pearson product-moment correlation was employed. By comparing the estimated r with the table r, the validity test decision was determined. If the computed r was more than or equal to table r, the statement was considered legitimate; if it was less than or equal to table r, the instrument was considered invalid (table r = 0.227). Using Cronbach's alpha, the internal consistency of each questionnaire and its subscales was evaluated. The SPSS for Windows version 26.0 was used to examine the data that was gathered. If a measurement tool's Cronbach's alpha was more than 0.7,[32] it was considered trustworthy. The following was the interpretation if the dependability scale was divided into five groups with the same range:[33] Very low (Cronbach's alpha = 0.00-0.19) indicates that the measuring instrument was inconsistent and has very low reliability. Low dependability (Cronbach's alpha = 0.20–0.39) indicated that it has to be improved. Moderate dependability was reasonably satisfactory (Cronbach's alpha = 0.40–0.59). High reliability (Cronbach's alpha = 0.60–0.79) indicated that the measuring device was of good quality. Very high dependability (Cronbach's alpha = 0.80–1.00) indicates that the measuring instrument was excellent and reliable.

Results

Demographics

Participants were 76 patients receiving treatment for breast cancer at qualifying hospitals and their families. Of the patients, 68 (89.47 %) were between the ages of 40 and 59, which made up the majority. High school (62 (81.58 %)) was the most prevalent educational level. Foty-six (61.84 %) of the patients were jobless, making them the majority. Forty-three (56.58 %) of the patients had the most prevalent chemotherapy history of at least six.

The majority of family members, 44 (57.14 %), were between the ages of 40 and 59. There were 32 (42.11 %) men and 44 (57.89 %) women in

the household. The majority of individuals with breast cancer receiving chemotherapy had a connection with their husbands (32, 42.11 %), followed by their kids (29, 38.16 %). Nearly all of the financing for chemotherapy treatment came from BPJS, with 75 (98.68 %). The majority of the distribution of education levels (73, or 96.05 %) were ≤ high school. Sixty-five (85.53 %) of the participants said they had never heard of or been aware of family support education based on values. Table 1 provides an overview of the participants' sociodemographic characteristics.

Table 1: Socio-demographic characteristics of breast cancer patients and their families

Variables	Characteristics	Categories	n (%)	M ± SD
Breast cancer patient	Age (year)	Early adulthood (25–39 years)	2 (2.63)	50.87 ± 5.56
		Middle adulthood (40–59 years)	68 (89.47)	
		Late adulthood (60–74 years)	6 (7.89)	
	Education	≤ High school	62 (81.58)	
		≥ College	14 (18.42)	
	Employment	Not working	46 (60.53)	
		Entrepreneur	11 (14.47)	
		Private	12 (15.79)	
		Civil servant	7 (9.21)	
	The quantity of chemotherapy sessions	< 6	33 (43.42)	
		≥ 6	43 (56.58)	
Family	Age (year)	Emerging adulthood (18–24 years)	14 (18.18)	25.67 ± 13.12
		Early adulthood (25–39 years)	19 (24.68)	
		Middle adulthood (40–59 years)	44 (57.14)	
	Gender	Male	32 (42.11)	
		Female	44 (57.89)	
	Connection to the patient	Husband	32 (42.11)	
		Sibling	11 (14.47)	
		Child	29 (38.16)	
		Parent	4 (5.26)	
	Health funding sources	National health insurance (BPJS)	75 (98.68)	
		Making a personal payment	1 (1.32)	
	Education	≤ High school	73 (96.05)	
		≥ College	3 (3.95)	
	Marital status	Getting married	53 (69.74)	
		Not married yet	20 (26.32)	
		Widow/Widower	3 (3.95)	
	Experience in receiving education and family support previously	Ever	11 (14.47)	
		Never	65 (85.53)	
	Employment	Not working	20 (26.32)	
		Entrepreneur	26 (34.21)	
		Private	24 (31.58)	
		Civil servant	6 (7.89)	

M: mean; SD: standard deviation;

Validity of questionnaire

The organisational pattern factor was found to be valid (r count = 0.248-0.756; r table = 0.227) and the communication process factor was found to be valid (r count = 0.554-0.741; r table = 0.227). However, all items in the questionnaire statements on the belief system variable were found to be invalid (r count = 0.156-0.704; r table = 0.227), particularly in statement No 2, which gives a meaning of difficulty. The validity test's specific findings are described in Table 2.

Table 2: Validity test result

No	Variables	Questionnaire	Number of items	r count	Interpretation
1	Belief system	Giving meaning to difficulties	5	0.156-0.641	All items are not valid
		Positive perspective	3	0.595-0.679	All items are valid
		Transcendence and spirituality	5	0.549-0.763	All items are valid
2	Organisational structure	Flexibility	2	0.290-0.725	All items are valid
		Openness	4	0.601-0.756	All items are valid
		Social and economic resources	2	0.248-0.562	All items are valid
3	Communication process	Clarity	4	0.584-0.741	All items are valid
		Expression of emotions	3	0.554-0.695	All items are valid
		Collaborative problem-solving	4	0.632-0.801	All items are valid

Table 3: Reliability test result

No	Variables	Questionnaire	Number of items	Cronbach's alpha	Interpretation and level of reliability
1	Belief system	Giving meaning to difficulties	5	0.785	Reliable (high)
		Positive perspective	3	0.785	Reliable (high)
		Transcendence and spirituality	5	0.785	Reliable (high)
2	Organisational structure	Flexibility	2	0.740	Reliable (high)
		Openness	4	0.740	Reliable (high)
		Social and economic resources	2	0.740	Reliable (high)
3	Communication process	Clarity	4	0.908	Reliable (very high)
		Expression of emotions	3	0.908	Reliable (very high)
		Collaborative problem-solving	4	0.908	Reliable (very high)

Reliability of questionnaire

The reliability test findings for the instruments used in this study indicate that all of the questionnaires used to measure organisational patterns, communication processes and belief systems are deemed reliable (Cronbach's alpha coefficient = 0.740 - 0.908). High and very high reliability were among the levels of dependability that may be used to gauge the variables in the research, as determined by the Cronbach's alpha coefficient. The reliability test's specific findings are described in Table 3.

Discussion

The family resilience questionnaire's validity test is crucial for ensuring that it can effectively evaluate factors related to family support when caring for patients with breast cancer receiving chemotherapy. The questionnaire in this study, which measures belief systems, organisational patterns and communication processes, among other aspects of family resilience, has been validated by oncology, nursing and psychology specialists. The validity test findings demonstrate that every statement item in the questionnaire is consistent with the idea being assessed and may characterise a range of elements that affect a family's ability to withstand the difficulties associated with chemotherapy. This is in line with other research that highlights how crucial it is to evaluate family relations while managing chronic illnesses.[34, 35] The validated questionnaire provides a dependable instrument for clinical practice and research, enabling a systematic assessment of family involvement in patient care. The involvement of the family in enhancing the quality of life for patients with breast cancer may thus be measured with high confidence using this tool. Three factors were used to explain the questionnaire's items: belief system, organisational pattern and communication process.

Belief system

The questionnaire, which was based on the idea of family resilience and included three indicators—making sense of challenges, positive outlook, transcendence and spirituality—gives meaning to the support of known truth values and forms the basis for family attitudes in managing and supporting breast cancer patients undergoing chemotherapy.[30, 36–38] The presence of strong family beliefs correlates with an increase in patients' resilience in facing chemotherapy side effects.[39] Families that actively participate in creating meaning together are more resilient, which enhances patients' mental health and adherence to therapy.[40, 41] Utilising a 5-point Likert scale (Disagree = 0, Strongly disagree = 1, Neutral = 2, Agree = 3, Strongly agree = 4), the measure had 13 statements. The overall score was divided into two categories: good (≥ 26) and less good (≤ 25). It ran from 0 to 52.

Organisational pattern

Three indicators—flexibility, openness and social and economic resources—that measure family resilience served as the foundation for the development of the family rules questionnaire, which affects decision-making in day-to-day activities.[30, 36–38] Strong social support within the family and role flexibility are two factors that promote patient adherence to cancer therapy.[42] A five-point Likert scale was used to evaluate the instrument's eight items (disagree = 0, strongly disagree = 1, neutral = 2, agree = 3, strongly agree = 4). Two categories were created from the overall score, which varied from 0 to 32; category less good: < 15; category good: ≥ 16.

Communication process

The information-sharing survey between families and chemotherapy-treated breast cancer patients, which aims to promote love, cooperation and trust, was created using the idea of family resilience and included three indicators: emotional expression, clarity and cooperative problem-solving.[30, 36–38] Emotional support for patients can be improved and therapy adaption accelerated, via effective family communication.[43] A five-point Likert scale was used to evaluate the 11 items in the instrument (disagree = 0, strongly disagree = 1, neutral = 2, agree = 3, strongly agree = 4). The overall score fell into one of two categories and ran from 0 to 44; category good: ≥ 22 and category less good: ≤ 21.

Conclusion

The majority of the items on the organisational pattern and communication process variables were deemed valid and reliable, indicating that the questionnaire used to evaluate family resilience had excellent validity and reliability. This suggests that the questionnaire was capable of measuring the elements that contribute to family resilience when providing care for patients with breast cancer. The research findings have important ramifications for the creation of more focused family-based educational initiatives aimed at boosting patients' resilience when coping with breast cancer. This questionnaire can be a trustworthy tool for assessing the efficacy of family treatments in the future because of its validated validity and reliability. These findings also emphasise

how critical it is to improve the family support network by using a comprehensive strategy that takes into account communication, organisational styles and belief systems. In addition to promoting the more effective use of chemotherapy, this intervention is anticipated to enhance the quality of life for patients and their families.

Ethics

The Health Research Ethics Committee of Rumah Sakit Daerah K.R.M.T. Wongsonegoro Semarang, Jawa Tengah, Indonesia, has approved this study (decision No 161/Kom.EtikRSWN/XI/2024), dated November 2024.

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Conflicts of interest

The authors declare that there is no conflict of interest.

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Data access

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

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