

Original Article

Identifying Important Challenges of Coping with Female Breast Cancer among Iranian Spouses: A Qualitative Study

Marzieh Jahani Sayad Noveiri¹, Masoud Khodaveisi^{2*}, Farshid Shamsaei³, Zohreh Vanaki⁴, Leili Tapak⁵

Abstract

Objective: Breast cancer is a multidimensional crisis for women and their spouses that affects every aspect of their life. Coping with this disease requires investigating and resolving the challenges faced by all those affected by it. The present study was conducted to clarify these challenges on the basis of lived experiences of the spouses of women with breast cancer.

Method: The present qualitative research performed an interpretive phenomenological analysis in Iran. Purposive sampling was employed to select twenty spouses of women with breast cancer. The data collected through unstructured face-to-face interviews were analyzed using van Manen's method. To ensure the rigor of the study, Lincoln and Guba's criteria were evaluated in the qualitative process.

Results: Lived experiences of the spouses of the women with breast cancer in coping with challenges included the four themes of emotional confusion, shouldering the burden of care, psychophysical suffering caused by the disease and life without cohesion.

Conclusion: Spouses of the women with breast cancer in the Iranian community faced several challenges and issues. The socioeconomic support provided by supporting organizations and medical personnel appear to help moderate these challenges and improve coping in this group.

Key words: *Breast Cancer; Coping; Phenomenological; Qualitative Research; Spouses*

1. Department of Medical Surgery, School of Nursing and Midwifery, Guilan University of Medical Sciences, Rasht, Iran.
2. Chronic Diseases (Home Care) Research Center, Department of Community Health Nursing, Hamadan University of Medical Sciences, Hamadan, Iran.
3. Mother and Child Care Research Center, Hamadan University of Medical Sciences, Hamadan, Iran.
4. Department of Nursing, Faculty of Medical Sciences, Tarbiat Modares University, Tehran, Iran.
5. Department of Biostatistics, School of Public Health, Modeling of Noncommunicable Diseases Research Center, Hamadan University of Medical Sciences, Hamadan, Iran.

*Corresponding Author:

Address: Chronic Diseases (Home Care) Research Center, Department of Community Health Nursing, Hamadan University of Medical Sciences, Hamadan, Iran, Postal Code: 6517838698.

Tel: 98-81 38380535, Fax: 98-81 38380447, Email: khodaveisimasoud@yahoo.com, khodaveisi@umsha.ac.ir

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Breast cancer constitutes the most prevalent type of cancer in females and the second most common global cancer. With a reported number of new cases of breast cancer exceeding 2.1 million in 2018 (1,2), the incidence has been growing in numerous transition countries for decades and the highest rates have been observed in transition countries with a history of low incidence of breast cancer, such as South American, African and Asian countries. Recent estimates suggest more than 2 million new cases of breast cancer in 2018 (23% of all cancers) (3). In West Asian countries, the incidence of breast cancer is 45.3 per 100,000 women (2). In 2015, the prevalence rate of breast cancer was 24.5% in Iran (4). The mortality rates for this cancer are estimated as about 15.4% in developed countries, 13.6% in West Asian countries and 14.2% in Iran (2, 5).

Breast cancer is considered a crisis that is associated with psychological reactions such as rejection, denial, anger, stress and anxiety for women and their family members, especially their spouses. Its effects include unmet physical needs, emotional pressures, uncertainty, role and lifestyle changes due to women's specific roles in the family, fear of death and loneliness, anxiety in sexual relationships and financial problems (6, 7). Treatments such as surgery, radiotherapy and chemotherapy severely affect the role of women with breast cancer as a daughter, mother, mother-in-law or wife (8, 9). Women play different roles as a daughter, mother, mother-in-law or wife on the basis of their living conditions. Treatments and their side-effects cause different problems, including disfigurement, sexual dysfunction and failure to care for children (6, 9). The changes that occur following cancer can have a profound effect on the family, especially on the spouse, and require coping mechanisms for adapting to the new conditions. This process of coping is a complex issue that can present many challenges (10).

Coping is defined as learning behaviors that help survive the threats, and covers both successful and unsuccessful attempts to manage stress. In other words, it means being able to satisfy one's needs and desires in a given situation (11). Women's breast cancer is a really stressful situation for their male spouses, and requires coping with the new situation. Identifying the challenges facing women with breast cancer is essential to help their spouse cope with the emerging conditions. Despite the similarity of problems facing spouse and caregivers in different communities, the exact etiology of these problems should be investigated in the context of culture and community (12, 13). For instance, religion plays a key role in helping patients and their families adapt to their new conditions in Islamic and Arab communities (10).

Most people believe that men should assume the role of a supporter and head of the family, and help their wives in the family (14). Accordingly, Iranian husbands of patients with breast cancer are expected to play a proper

supportive role, given the importance of religion as part of the Iranian culture and the emphasis on men's supportive role in the family. Results of the Gonzalez-Robledo study in 2018 showed that breast cancer impacts men's lives in two ways: 1) Changes in their daily routine reflecting assumption of activities including, household chores, and physical and emotional support of their wives, and 2) supports that they provide for their wives in their search for and obtainment of medical care (15). The lack of supportive and therapeutic strategies for the families and spouses of women with breast cancer and differences in cultures, values and beliefs exacerbate their problems in Iran. Identifying the challenges facing these spouses is therefore crucial for helping them cope with these problems. Understanding the feelings and experiences of the patient's spouse as a caregiver in relation to the disease is of great importance in identifying the problems and challenges ahead in coping with the emerged circumstances.

Problems of family caregivers and spouses of women with breast cancer have been addressed in the literature (16, 17); nevertheless, to the best of the authors' knowledge, challenges facing spouses have not been investigated yet. Also, since understanding the feelings and experiences of the spouse, as a caregiver in relation to this disease, will be very important in providing nursing care and ultimately supporting them, it seems that a qualitative approach is the best way to understand the challenges facing spouses coping with the suffering of their wives from breast cancer. Faltmermeier (1997) writes that research with a qualitative approach to public health leads to an understanding of the experience and meaning of one's life in real life and creates new insights. Qualitative research is also able to assess the personal meaning of events and stressors and shows a person's perception of the meaning of illness in life, which is not possible by testing hypotheses (18). Exploring the experiences of the spouses of women with breast cancer can help identify their challenges and problems. The present study therefore adopted an interpretive phenomenological approach to determine the challenges facing these spouses in coping with the problems of their wives.

Materials and Methods

Study design

The present qualitative research employed an interpretive, hermeneutic and phenomenological approach to obtain a more profound understanding of human experiences through interpretation and description. The hermeneutic method and principles of the phenomenological philosophy of Heidegger assisted us in exploring the challenges facing the spouses of Iranian women with breast cancer.

Study participants and setting

Purposive sampling was performed to select twenty spouses of women with breast cancer from hospitals in

Hamadan and Rasht cities in Iran. The eligibility criteria comprised of psychophysical health, definitive diagnosis of breast cancer in the wife and living with the patient.

Data collection

Researchers conducted in-depth interviews based on the interview guides to gather information. They attended the medical centers to identify and interview the spouses of women with breast cancer. The unstructured interviews were performed in a private room in the hospitals. Researchers conducted the interviews from December 2018 to March 2019, and the sessions began with an open-ended question such as "Please tell me about the lived experiences of how you have coped with your wife's cancer" and "Please tell me any stories, thoughts, or feelings you may have experienced when coping with your wife's cancer". The sessions continued with follow-up questions such as "Please elaborate" and "Please clarify with an example". Spouses were encouraged during the interviews to explain their experiences of living with the patient. The interviews were digitally recorded and lasted about 30-60 minutes depending on the participant's condition. Participants' expressions and body language were documented by recording observation notes. Data reached saturation in interview 18, but the researcher conducted two more interviews to confirm data saturation. Researchers transcribed the interviews and categorized the data and organized them into themes, sub-themes and main categories. The first researcher was responsible for conducting interviews and transcribing them. The interviewer was a female, which was one of the limitations of the study. Interviews were coded and classified in collaboration with the research team. Also, during the research, the researcher benefitted from the opinions of external observers.

Data analysis

The data were analyzed based on the phenomenological method proposed by van Manen and through listening to all the recordings and comprehending the experiences of the participants. After transcribing all the digital recordings verbatim, the thematic statements associated with the experiences and directly related to the phenomenon were extracted using van Manen's method (19-21). The problems extracted were categorized as common themes among the statements of all the participants.

Interpretive phenomenological studies require the engagement of the researcher with the study question. The present study extracted and interpreted the themes by determining the experience of the spouses of women with breast cancer in coping with their wives' problems. The phenomenon was ultimately explained comprehensively by obtaining organized concepts. After simultaneously collecting and analyzing the data, the initial coding was performed and 4 subsequent interviews were conducted to complement the data. The lived experiences of the spouses of women with breast cancer were explained in the first 2 steps. The

transcribed interviews were analyzed based on activities 3 to 6 of van Manen's technique. According to activity 3, the whole text of every interview was reviewed several times. A holistic thematic analysis was then performed by shortly describing the entire interview in a few sentences or paragraphs. Afterwards, a selective approach was used to extract thematic statements. Transcriptions were therefore consistently reviewed to identify and highlight essential statements for revealing core concepts in the experiences of the spouses when adjusting to their wife's problems. After extracting general themes, similar ones were merged. According to activity 4, writing and rewriting was performed to explain the study phenomenon in written words. According to activity 5, efforts were made to acquire a more profound understanding of the phenomenon. The hermeneutic method was also employed, based on activity 6, to repeatedly refer to the entire text and part of it and analyze their connection. The extracted themes were then modified and reconstructed based on the similarities. Moreover, the data were managed in MAX-QDA.

Rigor of the study

The rigor of the present research was confirmed by evaluating credibility, dependability, transferability and confirmability as the qualitative criteria proposed by Lincoln and Guba. Credibility was ensured through recruiting subjects with diverse backgrounds in terms of hospital unit, age and duration of the challenging experience. Transferability was ensured by providing an in-depth description of the lived experiences of the spouses in two hospitals of different cities with different medical facilities. Dependability was confirmed through transcribing the lived experiences of the spouses and closely following the data analysis of the in-depth descriptions. Ultimately, confirmability was ensured by avoiding researcher bias through the use of raw participant data and data retention and re-review during data collection and analysis.

Ethical considerations

The Ethics Committees of Hamadan University of Medical Sciences, Hamadan, Iran, approved the present study (IR.UMSHA.REC.1397.606). All the participants were briefed on the study objectives using written and verbal information before their participation. They were assured of their voluntary participation, their right to withdraw from the study at their own discretion and the confidentiality of their information. All the participants were ultimately provided with a copy of the informed consent forms they signed.

Results

A total of 20 spouses of women with breast cancer, with an age ranging from 32 to 70 years and different levels of education, ranging from illiterate to bachelor's degree, living in the cities and villages of Guilan and Hamadan provinces, and belonging to different socioeconomic

classes and ethnicities took part in the present study. All the participating spouses were healthy and lived with their wives who had breast cancer for less than six months. The demographic information of the participants is presented in Table 1 and the qualitatively-extracted themes in Table 2. Analysis of the interviews led to the extraction of 13 sub-themes and four main themes. The concepts extracted by discussing the challenges facing the spouses of the patients included emotional confusion, shouldering the burden of care, life without cohesion and psychophysical suffering caused by the disease (Table 2).

First theme: Emotional confusion

The subthemes of this theme included neglect and abandonment, own emotional instability, conflict between hope and despair and facing the patient's emotions and frenzy.

The constant attention and care needed by the patients and expected from the spouses caused them to feel neglected by their wives. Deprivation from all their leisure and other activities and friends' company because of the patient's need for holistic care makes the spouses feel lonely. The emotional instability observed in the spouses in the face of their wives' disease manifested itself as feelings of guilt, remorse, being trapped in pain and suffering and a constant conflict between hope and despair.

Subtheme of neglect and abandonment

Participant No.10 said, "I stopped all my previous tasks and put them all aside, even the vegetables I grew in my orchard. I failed to pay attention to it. My orange orchard is infested with pests as I could not go and spray it. I have no fun and all my conversations and intimate chats are with her".

Subtheme of own emotional instability

Participant No.14 said, "It's true that whatever God wills happens, but you're always worried about the possibility of putting in insufficient effort and allowing something to go wrong. You have to make every effort, but there are always these stresses. "

Subtheme of conflict between hope and despair

Participant No.6 said, "Yet again we trust in God. God, do for us as you think fit. Thank God, I'm content".

Subtheme of facing the patient's emotions and frenzy

Participant No.1 said, "My wife's psychological problems caused me lots of difficulties. No one could help me treat her and I had no choice but to send her to her father's home. Her pain was initially severe and she needed to rest. She had also psychological problems".

Second theme: Shouldering the burden of care

The subthemes of this theme included the pressure caused by inadequate medical services, medical team's neglect of the spouse, suffering occupational and livelihood pressure and performing multiple roles .

Subtheme of the pressure caused by inadequate medical services and medical team's neglect of the spouse

The problems caused by the disease that face the patient's spouse included lack of support from insurance

organizations, exorbitant medical expenses, no access to proper healthcare services, lack of efficient medical teams, inadequate access to information and failure of the health system to pay attention to the patient's spouse as a member of the treatment team.

Participant No.4 said, "A patient with a special disease is not provided with the necessary services; for instance, the medical team was incomplete, especially after chemotherapy when we needed a nutritionist in the team to determine appropriate foods she should consume" .

Work and livelihood pressure and performing multiple roles

The high costs of treatment and lack of insurance support as well as interference of work with patient care caused numerous livelihood problems for the spouses of the women with breast cancer. These problems stopped the treatment process or even caused leaving the patient. After women develop the disease, their husbands should assume the responsibility of all the wives' roles in addition to their own roles as husband and father.

Participant No.11 said, "Having no financial support is dreadful. Having problems with radiotherapy caused patients to need public support, but the device doesn't meet the demand. There is also no insurance coverage for the costly private facilities".

Third theme: Life without cohesion

This theme consists of three subthemes: Transition from denial to acceptance, impact on personal, family, and social interactions, and a cold relationship.

Transition from denial to acceptance

All the spouses went through transition from denial to acceptance of the new conditions. This challenging transition differently affected the individual spouses. They ultimately resorted to coping strategies to raise their own and their wife's spirits.

Participant No.5 said, "We went to 4-5 weddings, parties and birthday celebrations to boost my wife's morale. We keep our spirits up".

Effects on personal, social and family interactions and a cold relationship

The spouses obviously experience diminishing personal, family and social interactions due to the patient's need for particular isolated treatments and also to create better emotional and mental surroundings for her. Some spouses also acknowledged that their relationship with the patient had gone cold after her diagnosis .

Participant No.4 said, "I went into a lot of trouble after chemotherapy; all of us, all the family, went into trouble, as the family should not get a latent disease or catch a cold to protect the patient. Family members may no longer contact you, and you are left alone with the patient" .

Fourth theme: Psychophysical suffering caused by the disease

This theme comprised 2 subthemes, i.e. spouse in physical torment and psychological effects on the spouse.

Spouses of the patients expressed constant worry about treatment failures and loss of their wife. The burden of care caused them numerous psychophysical problems in a way that the disease made them neglect themselves and their character.

Participant No.12 said, “I have been sick myself. I woke up with a headache at midnight. I went to a doctor and underwent a brain scan. It was fortunately nothing serious. They said nervous pressure had caused my headaches”.

Table 1. Demographic Information of Those Who Participated in the Study on “Identifying Important Challenges of Coping with Female Breast Cancer among Iranian Spouses”

Participant No.	Age (year)	Education	Profession	Duration of Breast Cancer (Months)	Place of Residence
1	42	High School Diploma	Supermarket	2	City (north of Iran)
2	54	Ninth Grade	Electrician	2	City (north of Iran)
3	50	Fifth Grade	Farmer	5	Village (north of Iran)
4	47	Associate Degree	Radiologist	6	City (north of Iran)
5	50	Primary School	Glazier	4	City (north of Iran)
6	55	illiterate	Laborer	2	Village (north of Iran)
7	49	Primary School	Taxi driver	4	City (north of Iran)
8	50	High School Diploma	House painter, sport coach, theater	5	City (north of Iran)
9	54	illiterate	Laborer (Plumber)	6	Village (north of Iran)
10	55	Associate Degree	Veterans' Foundation employee	3	City of Hamadan
11	45	Bachelor's Degree	Pharmaceutical company employee	3	City (north of Iran)
12	57	Primary School	Construction worker	2	Village (north of Iran)
13	67	Primary School	Farmer, orchardist	3	Village (north of Iran)
14	70	Bachelor's Degree	Retired from the Air Force	5	Suburban Hamadan
15	32	Bachelor's Degree	Curtain seller	6	City (north of Iran)
16	44	Bachelor's Degree	Employee	4	City of Hamadan
17	62	High School Diploma	Retired	5	City of Hamadan
18	54	illiterate	Farmer	5	Suburban Hamadan
19	57	Tenth grade	Shopkeeper	2	City of Hamadan
20	49	Primary School	Laborer	3	Village (north of Iran)

Table 2. Challenges Facing the Spouses of Women with Breast Cancer

Main Theme	Subtheme	Secondary Code	
Emotional confusion	Neglect and abandonment	A sense of solitude and isolation	
		Abandonment and rejection	
		Tolerating disease-induced hardships and crises	
	Own unstable emotions	Spouse feeling remorseful about inadequate support	Trapped in the disease
			Endless suffering and worry
		Conflict between hope and despair	Unpleasant feeling of guilt
			Dichotomous feelings about the prognosis of the disease
	Shouldering the burden of care	Facing the patient's emotions and frenzy	Despair and helplessness
			Trust in God
		Pressure caused by inadequate medical services	Facing the patient's behavior change
Patient's ill temper and nervousness			
		Relevant organizations' lack of support	
		Time spent seeking treatment	

	Doubt about the quality and effectiveness of medications
	Financial pressure of procuring medications
	Difficult access to rehabilitation and medical services
	Lack of access to disease-related information
	Treatment methods and decision-making challenges
	Improper access to counseling services
	Problems due to an inefficient medical team
Medical team's neglect of the spouse	Spouse's need for the medical team's support
	Forgetting the spouse in providing medical care
Suffering occupational and livelihood pressures	Disruption in occupational and professional activities
	Tolerating the pressures of livelihood
	Tolerating additional responsibilities
Performing multiple roles	Expecting services beyond the spouse's ability
	Denial of the disease
	Experience of intense and unpredictable crisis
	Efforts to accept the new circumstances
	Confusion in facing the disease conditions
	Anger and rage in accepting the disease
	Emotional reactions
	Coping with the existing circumstances
	Use of fun activities to help the patient
Transition from denial to acceptance	Distancing the patient from worries
	Non-disclosure of disease-related facts
	Use of positive cognitive beliefs
	Use of music therapy role-play
	Positive and negative effects of family communications
Life without cohesion	Avoiding sadness by trying to create happiness at home
	Supportive spouse
	Methods of coping with the spouse's disease
	The damages caused by interactions within the family
	Disruption in the family members' inner peace
	Children's behavior change
	Feeling that life is ruined
	Efforts to preserve the family's cohesion
	The effect of disease on social relationships
	Burnt-out family relationships
	Gradually avoiding the patient
	Impact on the emotional relationship between the patient and spouse
	Impact on marital duties
	Ignoring the patient's appearance
	Dealing with the spouse's feelings of loss
	Fear of the word "cancer"
	Psychological effects of the disease on the spouse
physical and psychological suffering of the disease	Physical effects of the disease on the spouse
	Deprivation from pleasures
	Cancer-induced physical pain
	Neglecting oneself
The effect on the spouse's psychological state	Disease as a barrier to the spouse's progress

Discussion

Results of this phenomenological study classified the challenges of Iranian spouses in coping with their wives' breast cancer into four themes. Studying these challenges and finding solutions for them can help these spouses adapt better to their wives' breast cancer as the first supporters of patients in the process of treatment and recovery. Addressing adaptation challenges and helping the spouses of women with breast cancer to better cope with the situation play a key role in the treatment and recovery of the patients.

One of the challenges of Iranian spouses in coping with their wives' breast cancer is confusion in the face of emotions. These spouses feel alone during the entire course of the disease, from diagnosis to treatment, and are unhappy about the medical personnel's and their own family's inadequate support. In addition, during the course of the disease, these spouses have to tolerate emotional and behavioral instability in their wives, who themselves have to endure sufferings of the disease (22). Couples are interdependent, and the patient's low mood and depression also affect the spouse (22). A qualitative study by Çömez in Turkey explained the experiences of the spouses of women with breast cancer as a crisis, and the spouses expressed their worries about their wives and fear of their death (23). Hasson-Ohayon reported anxiety, emotional despair and depression in spouses, as well as the inadequate support they received from their friends and family (24).

Shouldering the burden of care constituted a challenge for spouses of the Iranian women with breast cancer, who experienced numerous financial problems and pressures due to treatment costs. Their incomes were inadequate and their wives lost financial assistance in many cases. Moreover, research suggests the financial pressure that breast cancer in women exerts on their spouses (12, 25, 26). The other worrying issues for spouses and caregivers included lack of radiotherapy facilities in some medical centers, lack of support by insurance organizations and failure to assign a treatment team to the patients.

As a major concern of the spouses of Iranian women with breast cancer, health service justice refers to the fair distribution of healthcare services among different patients and groups of the community (27). Lack of access to information about various issues and events before and after the treatment constituted another challenge facing these spouses. Similarly, Çömez reported the need by the spouses for counseling and information (23).

Life without cohesion was a challenge facing the spouses of women with breast cancer. Numerous difficulties facing these spouses and their families, such as treatment-related and financial problems, behavioral and physical changes in the wives and excessive pressure on the family can disrupt the family's interactions and cohesion. As the head of the family, the spouse is expected to deal with this issue. According to

the present findings, all the participating spouses were required to make excessive efforts to maintain their family's cohesion. Similarly, a study by Neris and Zahelis reported the spouses' efforts to preserve their family's cohesion (28, 29).

The present research identified the psychophysical suffering caused by the disease as a challenge facing the spouses of women with breast cancer. These spouses had to withdraw from their personal activities to perform their different disease-related tasks and accept their newly-imposed roles. They eliminated or significantly reduced their leisure activities and interactions with friends and therefore suffered many psychophysical problems. Girgis *et al.* reported social and psychophysical disorders, disrupted social relationships and financial burden for the caregivers as the effects of cancer (30).

All such problems make the spouses feel lonely; as also discussed by Zahelis (29). In agreement with the present findings, Çömez also referred to the multiplicity of roles imposed on these spouses in the absence of their wives' contributions to life or due to her inefficiency (23). Failure to properly address these challenges causes complex problems in the relationship between couples, as well as physical and mental harm to male spouses. Given the key role of religion in Iran and the support expected from spouses in a family, the spouses of women with breast cancer are expected to support and accompany the patient and the family throughout the entire course of the disease. Nonetheless, there are challenges that prevent the spouses' coping and effective dealing with this crisis. Attention to the challenges faced by spouses can further empower them in coping with the situation and be proposed as a strategy to solve the problems of cancer patients. Creating sources of support and web-based training programs and phone counseling are among the simplest strategies to resolve some of these challenges, and addressing these issues requires the authorities' consideration of the issue. Using the lived experiences of the spouses of women with breast cancer to directly identify the challenges of coping with the disease was a strength of the present study. In this study, for more generalization, an attempt was made to use people living in different geographical areas. The results of this study are used in clinical and nursing education, so that through plans by the authorities to provide social and economic support and establish supportive institutions and organizations and through training of medical staff, many challenges that face spouses to adapt to the crisis can be solved. In this way, an effective step can be taken towards improving medical measures and care for patients and their spouses.

Limitation

This study was faced with a limitation. Although interpretive hermeneutic phenomenological studies address in-depth data about lived experiences and

complex textual factors that shape them, their generalizability is limited. Other limitations of this study included the self-censorship of spouses of women with breast cancer, who may not have been able to easily talk about some of their issues owing to the traditional context of the population and the possibility of following some rules of the Islamic society.

Conclusion

The present findings regarding the challenges facing twenty spouses of women with breast cancer showed that these spouses are faced with various challenges in adapting to their circumstances, and investigating these challenges and problems can help the spouses and patients cope more effectively with their conditions. Socioeconomic support planned by authorities, the establishment of supportive institutions and organizations and the improved training of medical teams can help resolve many of these challenges and are considered as effective steps toward improving medical care for patients with breast cancer and their spouses. In general, shifting focus toward the challenges that the spouses of these patients have to cope with and creating supportive care programs for them can help reduce their adaptation challenges.

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Conflict of Interest

None.

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