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Informational and supportive needs of the family caregivers of women with breast cancer in a low resource context: A cross-sectional study

Abstract

Introduction: The present study was conducted to assess the needs of family caregivers in 2020 during the COVID-19 pandemic.

Participants and methods: Data were collected through purposive sampling from 103 participants and analysed by the Family Inventory of Needs (FIN) during the COVID-19 outbreak in 2020 (between July and September).

Results: Informational and supportive needs were high for most caregivers (76%), but they were scored unmet by higher than 30% of the family caregivers in items 8, 9, and 16 of informative dimensions and items 15, 17, and 18 supportive dimensions. Also, the illness stage was significantly associated with the score of unmet needs ($p = 0.03$).

Conclusions: Caregivers who live with women need more guidance and support. Considering the information and psycho-social needs of cancer caregivers may increase the satisfaction of health services and help improve the psychological well-being and quality of life of both patients and their caregivers.

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Key words: breast cancer, family caregivers, assessment of healthcare needs, low resource contexts, women

Introduction

The increasing incidence of breast cancer and its treatment costs among developing societies [1, 2] have a tremendous socioeconomic burden [3]. Decreased quality of life and longevity due to incompatibility and follow–up of the course of treatment and the problems of the patient's family and caregivers are the socioeconomic consequences of cancer [4, 5]. According to the World Health Organization (WHO), national cancer control programs aim to reduce cancer cases and deaths and improve cancer patients' quality

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of life [6]. Family caregivers are responsible for the prevention, treatment of illness or disability of family members, meeting their needs without payment, and positively impacting the community economy and health [7, 8]. Therefore, paying attention to these caregivers' needs and promoting their psychological well-being can be helpful in the patient's quality of life and rehabilitation [9, 10]. In addition to familial, occupational, and social responsibilities, family caregivers of cancer patients are subject to financial and patient care pressures, fear, and uncertainty about the disease's course [11, 12]. According to available reports, more than a third of adults do not have the necessary knowledge to manage their health and that of their families, and among them, the older people and groups with poor socioeconomic status are more associated than others [13].

Adequate information or health literacy is one of the critical factors influencing cancer care, especially when deciding on complex diagnostic and therapeutic processes [13]. Limited and imperfect information and not understanding cancer symptoms can prevent proper communication with professionals and discuss the benefits and risks of treatment choice [13]. In addition to increasing anxiety and depression and reducing the patient and family's well-being, poor cancer literacy is associated with misconceptions about the disease. It leads to less satisfaction with healthcare services and improper adherence to the treatment regimen [13].

Despite the importance of awareness and the role of family caregivers in facilitating cancer patients' treatment, it seems that less developed or low resource countries have not paid enough attention to this issue [9]. The available evidence indicates the health system's weakness in meeting caregivers' informational and communication needs [14]. The results of some existing studies suggest that a significant number of caregivers (53%) have at least three unmet needs and informational, psychological, and emotional needs were their most important concerns [15–17]. Needs assessment or awareness of the challenges of women caregivers with cancer is the first step and foundation of family-centred care programs [18]. Identification of gaps and barriers can help prioritize programs and improve services to this vulnerable group. The present study was conducted to assess the needs of family caregivers of Iranian women with breast cancer.

Participants and methods

Purpose and design

This descriptive-analytical study was conducted in Birjand, South Khorasan province, in 2020 (between July and September) during the COVID-19 pandemic. Structured interviews were performed in a separate place by considering required precautions and social distancing. Different regions surrounding South Khorasan have a small population (less than 100,000 people) and limited resources. In other parts of the province, cancer patients are referred to a speciality hospital in Birjand or other large cities for treatment.

Data collection

To collect the data, the first researcher referred to Birjand cancer hospital after receiving the code of ethics from the Research Council of X University of Medical Sciences (ethical code: IR.BUMS.REC.1399.401). Participants were family members of women with breast cancer who were providing primary or informal care. Inclusion criteria were caregivers aged over 18 years, mentally healthy (being able to comprehend questions), and Persian language speakers.

Measures

After explaining the study purpose and acquisition of written consent, data were collected through purposive sampling by structured interviews, the demographic characteristics questionnaire, and the Family Inventory of Needs [19–21]. Questions, in general, were about the patient's medical condition, care needs, communication with professionals, and the caregiver's own health needs and concerns. For the questionnaire to be used in this study, the questions were first translated and then re-translated (Table 1). A team of academic experts evaluated and approved the face and content validities of the questions. The questionnaire had two dimensions (the importance of caregivers' needs and unmet needs). The first dimension (importance of needs) consists of 20 questions that are graded on a five-point Likert scale (1: not essential, 2: less important, 3: relatively important, 4: essential, and 5: very important). The second dimension examines the level of fulfilment of the needs that have been essential for the person in the first dimension (scores 4–5). The second-dimension responses are graded into three categories: met (1), somewhat met (0.5), unmet (0). Overall unmet needs score was the average of scores in all questions. This instrument's validity and psychometrics have been confirmed in previous studies (Cronbach's alpha coefficients of the importance of needs and fulfilment of the needs are 0.92 and 0.96, respectively) [19]. The diagnostic and concurrent validities and power of distinction were also acceptable.

Data analysis

Data were analysed with SPSS22. The percentage of importance and non–fulfilment of needs was deter-

Table 1. The translated and re-translated questions

Q1. I feel that specialists are attentive to their patients
Q2. I ensure that the patient receives the finest care possible
Q3. My questions are answered honestly
Q4. Let me know what I need to do at home to assist the patient
Q5. The explanations they provide me are clear
Q6. Let me know any changes in the patient's condition
Q7. Let me know the specifics about the prognosis (course of the disease) of patients
Q8. Let me recognize the symptoms that manifest as a result of illness or treatment
Q9. Let me receive information about the possible consequences of the disease
Q10. Let me be informed of the patient's treatment regimen
Q11. I feel there is still hope
Q12. Let me know when a decision is made to change treatment plans
Q13. Let me know about the details of the service performed for the patient
Q14. Let me recognize why these actions are taken on behalf of the patient
Q15. Help me take care of the patient
Q16. Let me recognize when symptoms may manifest
Q17. Let me know people who can help solve problems
Q18. Let me know the names of the specialists who are involved in the care and treatment of the patient
Q19. Let me feel that specialists approve and accept me
Q20. I need someone to take care of me

mined with two categories of supportive and informational needs (Table 1). Finally, the appropriate regression model was determined at a significance level of 0.05 to assess the score of unmet needs. Independent variables were age, gender (female, male), university education (yes/no), marital status (married/single), employment status (employed/unemployed), the stage of illness (first stage, second stage, third stage, or metastasis), duration of illness, caregiver relationship (spouse, children, sisters). Variance inflation factor (VIF) and tolerance indices were used to ensure that the variables were not collinear. The reported research has been performed in compliance with the Declaration of Helsinki.

Results

Ten refused to cooperate with 140 selected participants, and some data (37 cases) were not analysed due to incompleteness, finally, data of 103 participants were analysed. More than half of the caregivers were female (32 spouses, 45 children, and 26 sisters). The mean age of caregivers was 36.58 ±14.28 years, and most of them lived with the patient (71.7%). In 12.1% of the cases, the time of cancer diagnosis was less than a month ago, and most of the women (63.6%) did not report disease progression or metastasis to other organs. The care time reported by most of the caregivers (43.4%) was between 20 and 40 hours per week. Most of the caregivers were married (68.7%) and had children (56.6%). About half of them (48.5%) were employed, and 39.4% had a university education.

At least 80% of participants evaluated the importance of caregivers' needs as essential in each supportive dimension question (Table 2). In the informative dimension, caregivers' needs were also scored as essential by at least 70% of the family caregivers. A total of 9.1%, 34.3%, and 32.3% of the individuals reported that support needs were unmet in questions 18, 17, and 15, respectively; however, informative needs were unmet at 37.4%. Correlation between the score of unmet needs and caregivers' characteristics have been presented in Table 3.

Exploring the association of the variables with the score of unmet needs (Table 4) shows that the fitted regression model is not suitable ($p = 0.30$ and $F = 1.20$), and these variables do not have tremendous power to predict changes in the response variable ($R^2 = 0.14$). The illness stage had a significant relationship to the unmet needs ($p = 0.03$). So, the higher the illness stage was, the lower the score of the meeting needs ($\beta = -0.23$).

Table 2. Percent of responses for each of the items of two questionnaires and dimensions

Needs	Questions	Not important	Less important	Relatively important	Important	Very important	Met	Somewhat met	Unmet
		The importance of caregivers' needs					Unmet needs		
Supportive	Q1	0%	1%	5.1%	17.2%	76.8%	48.5%	49.5%	2%
	Q2	0%	1%	5.1%	15.2%	78.8%	46.5%	51.5%	2%
	Q3	0%	0%	3%	14.1%	82.8%	44.4%	45.5%	10.1%
	Q11	0%	0%	1%	11.1%	87.9%	58.6%	36.4%	5.1%
	Q15	0%	5.1%	10.1%	28.3%	56.6%	25.3%	42.4%	32.3%
	Q17	0%	1%	4%	17.2%	77.8%	15.2%	50.5%	34.3%
	Q18	1%	1%	11.1%	27.3%	59.6%	55.6%	35.4%	9.1%
	Q19	0%	4%	15.2%	34.3%	46.5%	31.3%	60.6%	8.1%
	Q20	3%	4%	12.1%	29.3%	51.5%	31.3%	49.5%	19.2%
Informative	Q4	0%	0%	3%	21.2%	75.8%	25.3%	57.6%	17.2%
	Q5	0%	2%	1%	26%	70%	26.3%	59.6%	14.1%
	Q6	0 %	0%	2%	20.2%	77.8%	30.3%	53.5%	16.2%
	Q7	0%	0%	3%	17.2%	79.8%	32.3%	44.4%	23.2%
	Q8	1%	0%	1%	19.2%	78.8%	24.2%	44.4%	31.3%
	Q9	1%	0%	1%	26.3%	71.7%	28.3%	40.4%	31.3%
	Q10	0%	0%	2%	23.2%	74.7%	39.4%	51.5%	9.1%
	Q12	0%	2%	15.2%	30.3%	52.5%	35.4%	50.5%	14.1%
	Q13	0%	4%	20.2%	27.3%	48.5%	32.3%	57.6%	10.1%
	Q14	1%	1%	20.2%	39.4%	38.4%	25.3%	64.6%	10.1
	Q16	0%	0%	3%	15.2%	81.8%	18.2%	44.4%	37.4%

Table 3. Correlation between the score of unmet needs (questions 8, 9, 15, 16, 17) and caregivers characteristics

Caregiver characteristics	Q_{15}	Q_{17}	Q_{8}	Q_{9}	Q_{16}
Age	–0.007 (0.94)	0.007 (0.94)	–0.053 (0.60)	–0.184 (0.07)	0.016 (0.88)
Education	0.133 (0.19)	0.142 (0.16)	0.108 (0.29)	0.165 (0.10)	0.167 (0.10)
Care time	–0.055 (0.59)	–0.037 (0.72)	–0.040 (0.70)	–0.031 (0.76)	0.062 (0.54)
Gender	0.042 (0.66)	–0.081 (0.40)	0.017 (0.86)	0.062 (0.52)	0.018 (0.85)
Relation	0.060 (0.51)	–0.250 (0.006*)	–0.018 (0.84)	0.036 (0.69)	–0.014 (0.88)
Employment status	0.165 (0.09)	0.095 (0.32)	–0.069 (0.47)	–0.086 (0.37)	0.122 (0.20)
Location	–0.058 (0.54)	0.239 (0.013*)	0.001 (0.99)	0.141 (0.14)	0.135 (0.16)
Married	0.104 (0.28)	0.038 (0.70)	0.046 (0.63)	–0.102 (0.28)	0.141 (0.14)

*There is a significant correlation

Discussion

The study results show that the participants' informational needs were relatively more important because of the caregivers' perception of poor awareness and the influential role of this factor in cancer management. Appropriate information at the time of diagnosis or the onset of the disease and in the advanced stages (more complex symptoms and treatment) helps better manage the consequences and is very important in the quality of care and the course of treatment [22]. Most of the participants have been

Table 4. Regression analysis to exam the correlation of the variables with the score of unmet needs

Variables	#β	T+	P	VIF	Tolerance
Age	0.089	0.563	0.575	2.532	0.395
Gender (reference: women)	0.013	0.085	0.933	2.274	0.440
University education (reference: no)	0.091	0.780	0.438	1.372	0.729
Marital status (reference: single)	0.123	0.776	0.440	2.523	0.96
Employment status (reference: unemployed)	–0.002	–0.013	0.990	1.998	0.500
Stage of illness (reference: first stage)	–0.232	–2.196	0.031*	1.116	0.896
Duration of illness	0.102	0.905	0.368	1.271	0.787
Caregiver relationship (reference: spouse)					
Children	0.386	1.756	0.083	4.852	0.206
Sister	0.331	1.637	0.105	4.094	0.44

#Standardized regression coefficients; +Test of significance in regression; *Significant association in 0.05 significant level

living with the patient (71.7%), which might be why these caregivers' informational needs have been so important. In Iran and Asian countries, the spouse and children have an essential role in caring for the sick person, and family members must provide services to the sick member [23, 24]. In such a context, increasing awareness of the disease and cancer treatment methods and proper access to, support of, and communication with therapists in stressful situations can be effective in improving the quality of life of these caregivers and patient rehabilitation [13, 25].

Unlike other studies, this research did not find any association between age, sex, and social factors and the importance and non-fulfilment of caregivers' needs [26]. This difference may be due to the focus on one type of cancer (breast) in women. Also, cultural similarities in the participants and the acceptance and agreement of family members in caring for the sick member can be effective in this contradictory result [24]. In line with other studies, the present study results show that caregivers, who have a close relationship with cancer patients and spend more time with him/them, need more support [10, 23]. In other words, caregivers, who are emotionally attached to the patient, need more emotional and social support [16] because they are more likely to be harmed and endanger their physical and mental health. Unmet needs, increased time and pressure of care, the occurrence of stress and depression [27], and impaired immune function and cardiovascular system of the caregivers can also negatively affect patient care quality [9].

The relationship between the stage of illness and unmet needs was another significant result of this study. Individuals providing primary and palliative care for critically ill patients should be relatively aware of various medications and side effects. Therefore, they can establish an appropriate relationship with professionals and make rational decisions on the type and course of treatment [27, 28]. On the other hand, accepting that the patient is in the end stages of life will be very difficult and stressful for those who have a close and emotional relationship [27, 29]. Supportive and educational interventions proportional to the caregivers' needs may effectively reduce the psychosocial pressures of these people or increase their adaptability [18, 30].

Limitations of this cross-sectional study include a small population, although focusing on one type of cancer in the female population can help validate the results. Most Iranian patients and their families have severe concerns and stress about the cost of drugs, progress or recurrence, and fear of death. The healthcare professionals and staff often try to have suitable communication with patients. Some patients or their families from a closed context or particular ethnicity may not have the required acceptance of diagnosis and prognosis. Such conditions could be distressing for both caregivers (formal and informal) and cancer survivors. The study results may be helpful to similar contexts and deprived areas with limited resources.

Conclusions

Caregivers need to get information, communicate appropriately with professionals (tips for improving the quality of care), and receive support for managing challenges and stresses. People who live with women with cancer in less developed areas or who have a family history of malignancy are more likely to need guidance and support from others. Educational, psychological, and social interventions proportional to the caregiver's age, sex, and education may effectively reduce their problems. The study results propose several policies and practises implications. Considering the information and psycho-social needs of cancer caregivers may help them and cancer survivors to manage and deal with consequences. Satisfying those needs could increase the satisfaction of health services and help improve the psychological well–being and quality of life of both patients and their caregivers. Planning appropriate interventions is essential for providing information and psycho-social support in the community.

Declaration of conflict of interests

The authors declare no conflict of interest.

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