RESEARCH ARTICLE

Family caregivers' perspective of caring for cancer patients during radiotherapy: A qualitative study

Lingga Curnia Dewi[1], Ika Nur Pratiwi[2], Lailatun Nimah[3], Vimala Ramoo[4]

Abstract

Objective: To explore the perspective of family caregivers of cancer patients undergoing radiotherapy.

Method: The descriptive, qualitative study was conducted at the Indonesia Cancer Foundation, Surabaya, Indonesia, in July and August 2019, and comprised family caregivers of cancer patients undergoing radiotherapy. Data was collected using in-depth semi-structured interviews which were recorded, transcribed and analysed using conventional content analysis.

Results: Of the 26 caregivers aged 24-65 years, 16(62%) were men, 19(73%) were married, and 14(56%) had close relationships with the patients. Among the patients, 4(15.4%) had breast cancer, 2(7.6%) had nasopharyngeal cancer and 20(77%) had cervical cancer. The themes identified were uncertainty, disintegration and burden.

Conclusion: Caregivers of cancer patients tended to have both physical and emotional challenges.

Keywords: Caregivers, Adaptation, Psychological, Neoplasms, Cancer, Radiotherapy. (JPMA 73: S-18 [Suppl. 2]; 2023)

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Introduction

In recent days, the number of family caregivers who deliver care for cancer patients has increased, and so has the severity of the care.[1,2] While they care for a patient with cancer, family caregivers may face numerous challenges, such as communication styles, work performances and disruption of their social roles.[3] Studies showed that family caregivers need emotional support and other support system from health providers. The support includes appropriate information of caring for cancer patients.[4,5] Furthermore, family caregivers experience challenges for uncertainty, anxiety in seeing the worsening of the disease, and even financial and health problems.[6] Furthermore, another study has mentioned that family caregivers need to receive intensive counselling due to difficulties that may cause stress, frustration and alteration of health issues.[7-10] Proper understanding of family caregivers is important during the caring process of cancer patients in any stage of cancer and specifically during the treatment phase.[11,12]

Family caregivers could be the main foundation of support for cancer patients. Various issues related to their caregiving experiences, such as financial difficulties, stress, anxiety, depression, and poor health status, have been reported.[13,14] This can lead to a decrease in the quality of life (QOL) of family caregivers due to important changes in family and social roles.[15,16]

The current study was planned to investigate family caregivers' perspective on caring for cancer patients during radiotherapy.

Subjects and methods

The descriptive, qualitative study was conducted in July and August 2019 at the Indonesia Cancer Foundation, Surabaya, which is the largest cancer home care in Indonesia. After approval from the ethics review committee of the Faculty of Nursing, Universitas Airlangga, the sample was raised using purposive sampling technique and individual were enrolled till data saturation.

Those enrolled were adult family caregivers of either gender providing care to cancer patients undergoing radiotherapy. The subject had a minimum age of 20 years, were never diagnosed with mental issues, and were able to speak the Indonesian language. Informed verbal consent was obtained from all the subjects. Those not meeting the inclusion criteria were excluded.

Data was collected through semi-structured in-depth interviews. Each interview was conducted in a private room within the health facility. All interviews were recorded on a tape recorder. Each interview lasted 30-60 minutes. Written notes were also taken during the interviews.

The recorded interviews were transcribed and reviewed by the principal investigator. Data was analysed using conventional content analysis.

Results

Of the 26 caregivers aged 24-65 years, 16(62%) were men, 19(73%) were married, and 14(56%) had close relationships with the patients. Among the patients, 4(15.4%) had breast cancer, 2(7.6%) had nasopharyngeal cancer and 20(77%) had cervical cancer (Table 1).

[1-3]Department of Nursing, Universitas Airlangga, East Java, Indonesia; [4] Department of Nursing, University of Malaya, Kuala Lumpur, Malaysia.

Correspondence: Lingga Curnia Dewi. email: lingga.curnia@fkp.unair.ac.id

Table-1: Characteristics of the caregivers (n=26).

Characteristics	Category	n (%)
Gender	Male	16 (62)
	Female	10 (38)
Marital status	Married	19 (73)
	Single	7 (27)
Age (Years)	20-30	2 (8)
	30-40	6 (23)
	40-50	12 (46)
	>50	6 (23)
Employment status	Employed	20 (77)
	Unemployed	6 (23)
Level of education	Elementary school	0 (0)
	Junior High School	4 (15)
	Senior High School	15 (58)
	Diploma	7 (27)
Monthly income	< Rp 4.000.000	22 (85)
	>Rp 4.000.000	4 (15)
Living arrangement	Same household as patients	15 (58)
	Not same household as patients	11 (42)
Relationship with patient	Spouse	14 (54)
	Others	12 (46)
Types of cancer in patients	Breast cancer	4 (15)
	Cervical cancer	20 (77)
	Nasopharyngeal cancer	2 (8)

Table-2: The themes, categorised and illustration quotes**.**

Themes	Main Category	Quotes
Uncertainty	Feeling vulnerability	A man (44 years old), the husband of a patient, 'My life is a totally risky. I'm always thinking the worse.' A husband of the patient (35 years old), 'I'm disseminated with the perspective view of my wife condition. It will be getting better or worse? What should I do?'
Disintegration	Hopelessness	A daughter of patient aged 31 years old, 'I feel depressed at this state. I cannot expect to do anything. I could not forget my mother, or take care of her like I should.' The wife of a patient (35 years old), 'I cannot go anywhere freely or visit my friends and relatives. I felt I had to be by his side. All my thoughts are in this place of treatment now.' A 31-year-old daughter of a patient, 'No one knows me well. Sometimes I think they don't understand that I have another life too.'
Burden	Exhausted	A husband of the patient (48 years old), 'Sometimes, I feel tired. The treatment never ending, but I should believe in God. This is the best way.'

The themes identified were uncertainty, disintegration and burden. Caregivers dealt with uncertainty and responsibility. Coping strategy concerning the patient's side effects during radiotherapy was also a challenge (Table 2).

Discussion

The caregivers expressed their own cancer-related stressors, as well as the countless changes the families experienced along the journey of the patient being diagnosed with cancer, undergoing treatment and issues related to survival. Similar studies mentioned that the caregivers could have stress coming from emotional disruption of the experiences and other issues.[17-18] In the current study, maintaining positive perspective was dependent on the caregivers' spirituality and community support.

In dealing with complex problems and daily challenges, appropriate interventions for caregivers comprise emotional control, positive support, clarity of information as well as counselling.[19,20] In addition, the ability to adapt is a crucial factor in the face of increasing demands that may threaten emotional health.[21,22]

Interventions should be designed according to the needs and desires of the caregivers to provide meaning and potential benefits in cancer experiences and positive coping attributes, like in terms of spirituality, reviewing the experience, staying focussed on the condition, and remaining a strong person.[1-23]

The findings of the current study emphasise the importance of the need for understandable and meaningful communication and shared decision-making with healthcare providers who actively involve patients and caregivers. This interaction must be complemented by the help of written information that is understandable to avoid limitations in reading and health literacy.

The current study did not calculate the sample size, which is a limitation. Also, the participants were directly recruited if they met the inclusion criteria due to the limitation of the specific population.

Despite the limitations, however, the current findings indicate the necessity of a comprehensive understanding on the part of professional healthcare providers of the perspective of family caregivers of cancer patients.

Conclusion

The cancer experience often has an impact on the family caregivers. Understanding the perspective of the caregivers is necessary to design appropriate interventions for them.

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