



The experience of caring for an advanced lung cancer spouse: Vulnerable journey of caregiving[☆]



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KEYWORDS

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Abstract

Objective: The aim of this study is to gain a deep understanding of the experience of carrying the role of spousal caregiver of an advanced lung cancer partner during treatment in hospital. **Methods:** A qualitative, descriptive phenomenology approach was applied to nine participants, who were chosen based on being in a vulnerable group: female, male, and elderly caregivers. Data collection was done using in-depth interviews. Colaizzi's method was applied in data analysis.

Results: The findings revealed three themes shared from the participants' perspectives and experiences about the caregiver role: changing roles in the family, sincerity in caring for an ill partner, and changes in closeness with the spouse.

Conclusion: Spousal caregivers have an important role in patient treatment and also need interventions to enable them to perform and adjust to the caregiver role.

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Introduction

The International Agency for Research on Cancer, World Health Organization, mentioned that lung cancer became

the leading cause of cancer-related death in Indonesia in 2012. Lung cancer diagnosis mostly were made when the disease were already in advanced stages and difficult to be cured.¹ Patients diagnosed with advanced lung cancer need supportive care related to physical deteriorations, burden of severe symptoms, and distress.¹⁻³

Sabo et al. mentioned that the caregiver role has mostly been taken by the spouse of the patient, among other family members.⁴ The spousal caregiver of a patient diagnosed with advanced lung cancer experiences stressors associated with poor prognosis, lack of capability in managing symptoms or problems, the change in roles caused by patient's health status, and grief caused by the chance of losing his

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or her partner.⁵⁻⁷ The partner with the caregiver role has to deal with higher psychological pressure, compared to non-partner or non-spousal caregiver.⁸

Friedemann and Buckwalter discussed about the extensive changes in family organizations, roles and functions of family members, working time, and social activities related to patient treatments.⁹ There are lot of things that need to be postponed because the spouse has to accompany the patient during treatments.¹⁰ Laursen et al. state that the spouse has the responsibility to balance the family life, to keep it running while at the same time has uncertain feelings and burdens.¹⁰ The spouse has to be responsible for all of the patient's activities in the home and accompanying the patient while being hospitalized even though they feel incapable of fulfilling the care role and receive little attentions and supports.^{9,10} The needs and health problems of spouse lung cancer caregivers could be missed by health professionals, while their emotional well-being and health status have an impact on the support given and patient adjustment.¹⁰ According to the situations, researchers have been interested in exploring a deeper understanding about "the experience of caring for a spouse with advanced lung cancer disease during treatment in hospital."

Method

Research design

A qualitative research design with a phenomenology approach was implemented in this research, to gain a deep understanding about the meaning of experience of caring for a spouse with advanced lung cancer, from an individual perspective.

Participant

Nine participants were involved in this research. Participant selected based on the inclusion criteria: (1) spouse of an advanced lung cancer patient; (2) identified as primary caregiver; (3) living together with the patient; (4) speak Indonesian language. Participants were excluded from this research if there were any conditions that affected the physical and psychological stability of participant, for example: patient with worsening conditions, or unstable health conditions.

Data collection

After receiving ethical clearance from the research committees of two national respiratory center hospitals, the Dr. H.A. Rotinsulu Hospital in Bandung and Persahabatan Hospital in Jakarta, the researchers collaborated with research facilitators, such as the head of the ward, to identify potential informants. The informant candidates were given flyers containing information about the research, then they decided to take part as a research subject. The researcher explained the purpose, advantage, and research procedure to the candidates. After giving consent, the informants were later interviewed. The instruments used were:

(1) researcher; (2) voice recorder; (3) structured-interview guideline; and (4) field notes.

Interviews were semi-structured and conducted using a standard set of open-ended questions. All interviews were held in the hospital area, which was convenient for and requested by participants, but separate from the patient's room to facilitate participants expressing their experiences and to minimize bias. Interviews were done by the researcher who had experience interviewing medical patients and their family members. Interviews lasted for 40–90 min and were digitally recorded. All participants were interviewed once, due to the limitation on participants' time and conditions.

Data analysis

Analysis data from interviews were done after data had been verbatim transcribed. Content analysis was used and based on similarities and difference found and how it was differed and resembled with one another. Data analysis was done using Colaizzi's method. Data saturation were already obtained on the sixth participants but researcher decided to continue to ensure redundancy and corroboration which also found up to the ninth participant.

Results

The demographic characteristics of the nine participants are listed in [Table 1](#). In the interviews, participants described their situations, worries, stressors, and thoughts about their experience as caregiver to their spouse with advanced lung cancer. Interviews were often tearful and full of emotional responses from participants.

This research has identified three themes corresponding to the experience of participants caring for a spouse with advanced lung cancer: changing roles in the family, sincerity in caring for an ill partner, changes in closeness with the spouse.

Theme 1: Changing roles in the family

This first theme originated from two categories, which were taking on a dual role and taking part in the fulfillment of the needs of an ill spouse. The researchers discovered that changing roles in the family had to be experienced by participants because of their partner's health status. The changing roles included a substitution in the ill spouse's role in domestic activities, the dual role as husband and wife together, and an increase in the participant's parts in providing for the needs of the ill spouse.

The first category is the dual role of participants in domestic activities, which were experienced by almost all male participants, and the role as breadwinner, experienced by 2 female participants. The involvement of male participants in carrying out household activities was revealed by 4 male participants namely P3, P5, P6, and P7. The role as the head and the breadwinner of the family was revealed by 2 female participants, namely P4 and P9. P6 and P4 spoke of the experience having dual roles in domestic activities:

Table 1 Participant demographic (N = 9).

	n (%)
Gender	
Male	5 (55.6)
Female	4 (44.4)
Age (years)	
30–39	1 (11.1)
40–49	2 (22.2)
50–59	3 (33.3)
60–69	3 (33.3)
Education level	
None	1 (11.1)
Primary school	3 (33.3)
High school	3 (33.3)
Undergraduate	1 (11.1)
Bachelor	1 (11.1)
Occupation	
Retail trader	3 (33.3)
Government employee	1 (11.1)
Retired government employee	1 (11.1)
Repair workshop	1 (11.1)
Entrepreneur	1 (11.1)
Housewife	2 (22.2)
Religion	
Muslim	8 (88.9)
Christian	1 (11.1)
Race/Ethnic	
Sundanese	5 (55.6)
Chinese descent	1 (11.1)
Javanese	1 (11.1)
Sumatran	1 (11.1)
Betawi	1 (11.1)
Length of time as a carer (months)	
<3 months	1 (11.1)
3–6 months	4 (44.4)
>6 months	4 (44.4)
Lung cancer type (spouse)	
NSCLC	9 (100)
SCLC	0 (0)
Lung cancer stage (spouse)	
Stage III	2 (22.2)
Stage IV	7 (77.8)
Performance status (spouse) WHO Scale	
2 WHO Scale	4 (44.4)
3 WHO Scale	5 (55.6)
Type of treatments	
Chemotherapy	7 (77.8)
Radiotherapy	1 (11.1)
Mixed	1 (11.1)

“Yes, I finally gave in ... (the participant laughed), yes, I even washed the clothes and everything what housewife usually did because she was too weak, lack of energy... thank God I helped ...” (P6, line 214–218)

“There was a difference. ... He was healthy before and able to work, there was income for me... but now I even hadn’t been able to vend and had income if it were not from the help of my children... it was given.” (P4, line 429–430)

The second category is taking part in the fulfillment of the needs of an ill spouse, which was experienced by all participants, both at home and in the hospital. P7 spoke about doing several activities related the needs of an ill partner:

“In the beginning, for example, changing her diapers was also done by me... and when She started learning to walk, I led her to the bathroom... things like that... Oh because she also loved to hear Quran recitations, I help turn on the cellular phone, ... yes ... everything that she wasn’t able to do herself of course I would help her ...” (P7, line 302–308)

Theme 2: Sincerity in caring for an ill partner

This theme comes from two categories, namely willingness to do things for their spouse and the presence of spiritual beliefs. This theme illustrates the acceptance of participants about their partner’s condition, and their role as caregiver for their ill partner, as well as the presence of spiritual beliefs that influenced participants in carrying out their roles. The first category, “willingness to do things for their spouse”, emerged from 5 participants: P2, P5, P6, P8, and P9.

“To take care of... I meant such as looking after, caring for, and everything else that was needed, should be sincerely done... never tired or bored...” (P8, line 414–419)

The second category “the presence of spiritual beliefs” enabling participants to be sincere in carrying out their role as caregiver was revealed by 4 participants: P1, P3, P4, and P7.

“... If Allah created something then it was no coincidence, there must be goodness from it including my situation caring for my wife in the hospital ... so ... there must be, there always be goodness from it...” (P7, line 653–658)

Theme 3: Changes in closeness with an ill partner

This theme comes from three categories, namely the ill partner as the main focus, an increase in togetherness, and changes in emotion of the ill partner. The first category, the ill partner as the main focus, emerged from 4 participants: P1, P4, P6, and P7.

“... I was more concerned about my wife, because I was afraid of her being more down, if I didn’t give enough attention. Furthermore, she was neglected by her parents ... they didn’t even care about her ...” (P1, line 448–456)

The second category, an increase in togetherness with the spouse, emerged from the statements of 3 participants: P4, P5, and P7.

“Yes, of course in the matter of physical closeness it is closer, because we used to meet only a few hours a day, only at bedtime, now it’s almost twenty-four hours together” (P7, line 531–542)

The category of emotional changes in a partner in a relationship was revealed by 3 participants, namely P2, P6, and P8.

“Actually, before he was sick, he was calmer, but maybe because of his condition, he was more emotional. ... just like ill person mostly behaved, easily felt offended. Because of his condition, he often have to attend to the outpatient clinic, and when he had been waiting a long time, already him complaining about it, I just remained silent ... he was never been like that all this time” (P8, line 261–264)

Discussion

Theme 1: Changing roles in the family

Several studies have mentioned that the Indonesian setting, with its cultural heterogeneity, religions, modernizations, and socioeconomic changes, has influenced male and female roles in marriage. Men are still considered to be the ideal dominant breadwinner, and women are still expected to manage household activities and in child rearing.^{11,12} After having the patient diagnosed, and being related to care of patients, partner of patient experienced drastic changes in life and roles in family.⁹

Partners of lung cancer patients are family members who most often carry out the role of accompanying and meeting patient needs.¹³ Several previous relevant studies explain the role of caregiver run by individuals has influenced the lives of these individuals.^{5,6,9,14} Caregivers’ unpreparedness to carry out the role of providing physical care needed by patients had troubled and burdened the caregivers to carry out the roles which was affecting their quality of life and their partner, and lack of health professionals and social supports received affected caregivers psychological distressed.⁸

The financial burden is known to be a factor that also plays a role in the psychological pressure experienced by the caregivers.⁸ This burden is related to increase expenses, reduced work hours, and loss of family income.^{6,8} P1 and P7 mentioned changes in their activities and lifestyles, including how participants were forced to leave their jobs to accompany an ill partner. Participants were also forced to leave their homes and families to accompany their partners when they undergo treatment at the hospital, leaving the role as mother while playing full role as caregiver to their partner, as revealed by P8. Participants also had limited activities outside home, due to the dependence of the ill partner, as expressed by P4.

Men and women who take on caregiver roles are known to have different responses to the role itself.^{9,15} There is social pressure that affects women and men to adopt the caregiver role. The changes in the role of women as caregivers are considered to be an addition to the role that women naturally possess, where women do personal care and household activities more than men, and men

generally feel social pressure to hold on to their ‘masculinity’.^{9,15} Male participants expressed efforts not to overthink and close their emotional reactions to things that were not commonly done before, as expressed by P5, P6, and P7. Fulfilling patient physical care, such as eating and drinking, personal hygiene, ambulation, and even elimination, were new activities carried out by P5, P6, and P7, because of their new role as patient caregiver. In this study, the male participants revealed their ability to eliminate masculinity issues linked to their role as the man in the family; instead, they were more concerned about the condition of their ill partner. Female participants, namely P2, P4, and P8, expressed their views about the obligation as wives to take care of their husbands. In particular, P8 conveyed that she did not prefer to use resources available to help in caring for her partner. She expressed persistence in performing a role as wife for as long as she was still capable.

All participants in this study felt that caring for a partner is a role that participants must carry out as a form of responsibility and belief regarding marriage; this enabled participants to manage the challenges in caring for their partners. Helping and supporting each other is considered by participants to be an appropriate thing to do in couple life. Caregivers who are middle-aged performed the role as caregiver for their partner with all the abilities they have, including physical abilities. Participants who are at this age choose not to be a burden to their family, in this case their children, as expressed by P5 and P6. P5 and P6 performed their role in fulfilling the physical needs of their spouses without assistance from family members or other resources, both at home and at the hospital.

Theme 2: Sincerity in caring for an ill partner

In general, family members who act as caregivers carry out their roles without getting proper training and have insufficient knowledge.^{9,10} When the disease is already in an advanced stage and difficult to cure, there are increasing and complex demands in carrying out the caregiver’s role, in terms physical and emotional. Effendy et al. mentioned that involvement in the care of an ill family member is part of the Indonesia culture; even when patients were being treated in the hospital, family members still helped the patient in meeting their physical, emotional, and medical needs, with social problems; in communicating with health professionals; and in the coordination of care.¹⁶ The fear of losing a partner, and witnessing the decline of an ill partner’s physical condition and suffering, created strength for the caregivers to continue carrying out their role and face the challenges related to the physical condition and care of the patient. Female caregivers are closer to their partners emotionally and are more willing to sacrifice their social life and strive to use as little help as possible from others, even though such assistance is available.^{16,17}

Mosher et al.⁶ explained that not much is known about family coping strategies to deal with existing physical and psychological problems related to caregiving, but religious and cognitive approaches are strategies that are more accepted by families. Participants in this study believe that what participants face in their role as caregivers came from

God, as expressed by P1, P3, P4, and P7. P1 believes that God will enable him when trials and difficulties are given, in the terms of his spouse's illness and conditions he faces today. Every trial God gives to a person is believed by P1 to be accompanied by the strength to endure. P1 further states that everything is determined by God, and being closer to God becomes the source of strength to undergo the burden of what has happened.

P3 and P4 revealed that they sincerely their existing conditions and spouses with a severe illness. Both participants realized that, as humans, they could not dictate God's will toward their lives and their partners. P7 believes that everything that happened was, of course, permitted by God, not as a coincidence, and God will provide wisdom. The spiritual beliefs possessed by all participants have enabled them to continue caring for their partners and adapting to their new circumstances and roles.

Theme 3: Changes in closeness with an ill partner

Individuals who act as a spousal caregiver are responsible for various activities related to the care of their ill partners both at home and hospital, that will lead the caregiver to experience higher stress. Caregivers experience physical and psychological challenges and burdens related to caregiving.¹⁴ Caring for a partner with a severe illness has an extensive mental effect on the individual who acts as a caregiver and influences the shared life and the relationship between individuals who act as caregivers and their ill partners, during hospitalization.¹⁰ Milbury et al.¹⁴ added that the burden of caregiving is problematic for both patients and caregivers, and people who act as caregivers run the risk of experiencing health problems and distress over a long period of time that affects the quality of care and psychological support provided, as well as the patient's adjustment to his or her condition.

The diagnosis of cancer and the consequences of life-threatening diseases disrupt self-perception, spirituality, attitude toward life, relationships, individual assumptions, value systems, and, prevent a sense of life-survival meaning.¹⁸ This situation is shown in the participants' observing an ill partner experiencing emotional change, as revealed by P2, P6, and P8. Laursen¹⁰ mentioned that the emotional status of the caregiver, in this case the spouse of the patient, plays an important role in adjusting the patient to the conditions of the disease. P6 and P8 revealed the efforts made to deal with the changing emotional status of their partners. P8 mentioned a preference to remain silent and not respond to any patient's emotional reactions, to suppress advancement of the disease, when obstacles were placed in the patient's care and troubled physical conditions were met. P8 and P6 both indicated that changes in emotional status of the patient came from disease conditions that must be understood.

Attachments security accompanied with respect to the ill partners, which is reflected on a sense of comfort to be close and interdependent, has been consistently related to the strength of autonomous reasons for caregivers in care providing. It is found to have more benefits in caregiving and life satisfaction.¹⁹ Participants express practice of caregiving has increased physical togetherness between participants

and partners, and view positively by participants as a new opportunity, as expressed by P7.

Conflict of interests

The authors declare no conflict of interest.

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