



Original Research

Lived Experience's on Male Spouse of Patients with Lung Cancer in Indonesia

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Abstract

Patients with advanced lung cancer might have a higher number of supportive care needs, when a married, middle-aged woman is diagnosed with this disease, her spouses most often become the primary caregiver. However few studies have explored the lived experiences of Male Spouses. This study aimed to explore the lived experience of male caregivers among lung cancer patients. The phenomenological method is adopted to obtain the male lived experiences of caregivers." In-depth face-to-face interviews with the caregivers were the main source of data for this study. Five male caregivers completed the interview; all of the participant's spousal was diagnosed with lung cancer and are under a chemotherapy program. Content analysis of five participant interviews revealed four themes: (1) Facing difficulties, (2) Social activities interrupted, (3) a Sense of being responsible and needed and (4) Gaining support from family and God. This study explored the male caregiver lived experiences of five Indonesian patients with lung cancer. The findings pointed to the importance of considering multiple issues influencing male caregiver conditions while providing care.

INTRODUCTION

Lung cancer is one of the most frequent cancer diagnoses and one of the leading causes of cancer death around the world, with an estimated 1.8 million deaths (18%), followed by colorectal (9.4%), liver (8.3%), stomach (7.7%), and female breast (6.9%) cancers.^{1 2}

Patients with lung cancer commonly experience variability in symptoms as a result of complex pathogenesis and different multimodal therapies, they also need frequent health monitoring, which often contributes to heavy burden on their primary caregivers.²³ Family caregiving is

an integral and important part of health care system especially in lung cancer patient, they assist with patients' daily living activities, diet preparation, self-care regimens, physical symptom management, treatment administration, medication compliance, emotional and psychological support, financial management, and housework duties.^{4,5}

Families especially the spouse are mostly the main caregivers of patients with cancer, the needs of the families should be supported and be paid attention.⁶ Spouse or informal caregivers commonly experience physical, emotional, social and financial burden throughout the caregiving

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process.^{5,7} It has been well documented that family caregivers experiencing high levels of caregiving burden are at increased risk of a lower quality of life, depression and physical morbidity.⁸

Male caregivers are seemingly more likely to experience the typical symptoms of burnout, they also seem less inclined to seek out community service.⁹ Male spouses of women with cancer experience significant levels of distress and disruptions in their sleep, eating habits, and ability to work.¹⁰ The male spouses of cancer patients have deep feelings of suffering and struggling about their wives' illnesses, and they also feel difficulties in communication such as talking about the cancer with their wives.⁶

Few studies reported the experience of male caregivers on patients with chronic illnesses, and no study were found documented among patients with lung cancer in Indonesia thus the current study is needed to explore the experiences on male caregiver among lung cancer patients in Indonesia. This study aimed to explore the lived experience of male caregiver among lung cancer patients.

METHOD

Research design

The phenomenological method is adopted to obtain the male lived experiences of caregivers. The aim of the phenomenological method as to determine the meaning of an experience "for the persons who have had the experience and are able to provide a comprehensive description of it. From the individual descriptions, general or universal meanings are derived, in other words the essences and the experience." In-depth face-to-face interviews with the caregivers were the main source of data for this study¹¹. The semi-structured interview guideline below was created after discussions with 3 senior researchers that specialize in qualitative studies, palliative nursing, and lung cancer.

Before data collection, a pilot study was performed to confirm the appropriateness of the interview guideline.

The caregivers were encouraged to talk about anything pertinent in the way that they experienced caregiving.

1. Please describe your daily experiences after your spouse/mother was diagnosed with lung cancer patients?
2. Tell me about your changes after being a caregiver for your spouse/ mother?
3. Tell me about your difficulty fulfilling your spousal-caregiver role? Please explain.
4. Have you used any strategies to increase your competence in fulfilling your spousal-caregiver role? Please explain.

Participants

The Purposive sampling technique was used in this study, five male caregivers were recruited. The participants included 4 spouses' care givers and 1 participant is a son, their age was between 30 to 60 years. All caregiver passed the inclusion criteria for participants:

1. Being a male caregiver from patient with lung cancer.
2. Able to understand and converse in Bahasa Indonesia.
3. Willing to provide oral and informed written consent to participate in this study.
4. Willing to express their feeling, thoughts and share their experiences.

The following exclusion criteria were used: a lack of understanding regarding the purpose of the study by the patient or their family members and a participant likely to have difficulty participating in a face-to-face meeting due to their activities.

Ethical considerations

Data collection was conducted after retrieval of Institutional Review Board (IRB) approval (Number: 1.177/X/HREC/2019). Participants were enrolled from an oncology in The institution of teaching hospital dr Moewardi located in Central java, the written informed consent was obtained from each caregiver prior to participation in the study. Confidentiality was maintained by assigning pseudonyms to replace the actual names of individuals or places that were present on the demographic forms or written transcriptions of the interviews. No predicted physical risks were associated with participation in the study. However, psychological risks were anticipated. Participants were told in advance that they or the researcher could stop the interview at any time for any reason.

Data Collection and Analysis

The data was collected in dr Moewardi hospital, participant was drawn from special wards of oncology unit. Participation was voluntary, and written informed consent was obtained from all participants. After identified of sample, the investigator makes an appointment with the participant about time and location which has been provided. The location for mostly was in a private room at the hospital with the agreement of the participant and hospital. The data were collected from 15 January to 14 February 2019. The researchers collected data until saturation was achieved. Each participant was interviewed once. Each interview ranging from 1 to 2 hours.

The analysis of the data followed the phenomenological method adopted by Colaizzi's in their empirical studies on how individuals experience supervision and caring interactions, respectively¹². The data analysis followed the following procedure:

1. All the taped interviews were read and listened to numerous times until a feeling was acquired for them.
2. Significant statement relevant to lived experiences of male caregiver who take care female lung cancer patients were extracted from each transcript.
3. The formulated meaning was created from the significant statements. The researcher consulted his professor to verify that these formulated meaning were consistent with the significant statement.
4. Clusters of themes were identified and organized from the formulated meanings.
5. The descriptions of the lived experiences of male caregiver who take care female lung cancer patients were written as exhaustively as possible. The researcher made the comparison between transcript, sub-theme and themes several more times to validate the findings.
6. The description of concepts, sub-themes and themes were supported by the statements for further the validation of the study findings.
7. A final validating step was achieved by returning to each male caregiver to review the finding.

Trustworthiness

Processes were put in place to ensure credibility, dependability, confirmability, and transferability of the data analysis and findings.¹³ Credibility was established through prolonged engagement with the data and the writing of a personal account of the phenomenon, as well as through member checks and participant verification of the analysis. Dependability and confirmability were established through creation and maintenance of an audit trail and research journal throughout the study.¹⁴ The final themes were confirmed through an external review process with three professor whose expert in qualitative study. Prior to preparing the final report of the exhaustive text description, participants

verified the findings and assisted the researcher in clarifying the final description of their lived experience. The process of creating this rich description contributes to the potential transferability of the findings.¹⁵

RESULT

Five male caregivers completed the interview, all of the participants spousal was diagnosed with lung cancer and under chemotherapy program. The length of time since lung cancer diagnosed over than 6 months. Most participant were 30-60 years old. Content analysis of five participant interviews revealed four themes: (1) Facing with difficulties, (2) Social activities interrupted, (3) Sense of being responsibility and needed and (4) Gaining support from family and God.

Theme 1: Facing with difficulties

1. Sub theme 1: Afraid to lose

According to several participants, the cancer diagnosed was the serious problem. The family were afraid that the cancer can be easily kill the patients. This was evident by a participant said: "After my wife diagnosed with cancer I could not sleep and I feel that her life is not long." Even the development of cancer therapy can cure the cancer especially in early stage, cancer is still the most caused death in Indonesia, caregivers still believe that people diagnosed with cancer, their life in no longer anymore thus caregiver afraid that this condition will happen in their one's.

2. Sub theme 2: Having difficult to solve one's physical discomfort

Most of the caregivers did not know about how they solve the physical discomfort among lung cancer patients. This presented as problematic because they were forced to deal with their new

role as caregiver and at the same time the face that the patients always complaining pain. This was reported by a participant who said: "She always complained feeling pain and I don't know how to solve that problem, she also still complains some pain, queasy, vomiting, after the therapy. my mother condition is very weak and complaining pain... I just do some massage even there is no any significant effect." This condition is a challenge to the male caregiver. the lack of knowledge and new experience as caregiver create their difficulties dealing with that physical discomfort.

3. Sub theme 3: No one can take turn for caregiving

The study revealed that no one can take turn for caregiving, other family member has their own activity, thus the male caregiver is the only one choice to accompany the patient in Hospital. this was evident by a participant that said: "I have no choice except to accompany my wife, all family's member doesn't have time to take care of my wife, my children need to work."

Many of husband take the responsibility to be caregiver, due to their children already has their own life or married thus they could not leave their family to take care their mother. It makes no one can take turn for caregiving among male caregiver.

4. Sub theme 4: Having financial problem and leave job for caregiving.

The current study revealed that male caregivers caring for patients with lung cancer struggle financially. The majority of them stay far from the clinic and they don't have money for transport when they are supposed to go and collect treatment. all the participants interviewed none of them were financially stable and they all depend on their children or family

members This was supported by a participant who said: *"I have some financial problems; I could not work and earn money for our living cost and I need to sell my field to cover my financial needs."* Due to the demands of caring, male caregivers have less time to earn an income, the national health insurance only can cover the treatment but not all their living cost and transportation during their therapy. This create a condition that financial problems are mostly occur among male caregiver.

5. Sub theme 5: eave job for caregiving

The results of this study revealed that most caregivers have to leave job. This was confirmed by *participant saying: "I had to leave my job and need to stay at hospital to assist my wife." some changes occur in my life, especially in my daily activities, I could not work as usual." I could not work and need to accompany my mom every day.* Lack of time due to they have to spend all the time beside there one's make them could not work. The have to choose leave the job for caregiving or leave their one's. most of them achieved that they have to leave job for their one's.

Theme 2: Social activities interrupted

1. Sub theme 1: Need to stay in hospital for long time

The caregiver needs to accompany the participant with uncertainly condition, the treatment of lung cancer is taken longer time it makes the caregiver need to stay longer in Hospital. This confirmed by participant that; *" Her therapy is taking time; we need to stay in hospital for long time during the therapy. it is really hard for me."* Another participant who takes care of his mom also reported that; *" I need to accompany my mom, with uncertain my mom's condition."*

2. Sub theme 2: Leaving for hometown social activities

The study revealed that most caregivers their caregiving responsibilities greatly limited their social lives. they don't have time to go back home and do not have any assess to join the activities. This was confirmed with the participant saying; *" I could not join all social activities during my caring activities; they are so many activities in my home town. I already leave for that activity for five months start from my wife was diagnosed with cancer."*

Social life was seriously affected by the patient condition that caused the patient to stay in hospital the caregiver spending too much time taking care of her wife Finally, they could not join all activities in their hometown.

Theme 3: Sense of being responsibility and needed

1. Sub theme 1: Could not leave my wife alone

Most caregivers support for their wife who get lung cancer, their support is from their parents and family members as indicated during the interview sessions conducted. The support results from the fact that most of them are always stay beside patients and do not leave them for working, it was confirmed by a participant who said: *"I could not leave her alone to face this problem, it can be easier if we pass this condition together."* Another participant also supported by: *"I already take care of my wife more than 1 year. I always accompany during the treatment from the beginning my wife was diagnosed, this is my responsibility as her husband."*

Most participant believe that if they pass the condition together it will be

easier to them than they have to leave their wife alone.

2. Sub theme 2: be responsibility to their mother

Almost all the participants were required to assume full responsibility to provide the caregiving. a participant mentioned that dedication is one of reason for participant providing care. it was supported by a participant that report: *"When I was a baby my mom took care of me with love, now is my time to pay all of it. I only can do this for my mom as my dedication and my responsibility to my mother."*

3. Sub theme 3: My wife need support from me

Most of the participants engaged in self-encouragement to meet the needs of patients, the caregiver feel that they are vitally important to always support their wife. Participant said that: *"I could not leave my wife alone; she need support from me."* Another participant also feel that they have responsibility as husband the task is providing needs of their family including their wife: *"I have responsibility to take care of my wife because I am her husband."*

Theme 4: Gaining support from family and God

1. Sub theme: 4.1: Looking for help from God

All the participants are Muslim. In that religion all difficulty is an exam for human, and we believe that God will always give the best thing for us. It was supported by a participant that said: *"I believe the God will give the best thing for us."* Some participants mentioned that they were participating religious activity in Hospital and pray for their one's, a participant confirmed that: *"When the prayer time is coming, I always*

go to mosque and pray for my wife condition." they hoped that after they pray God will consider the best things for them.

2. Sub theme 2: Discuss problem with family members.

Participants described that facing difficulties together and good interaction were always helpful for the mutual feelings between them and their families. A participant confirmed that: *"I always share the difficulties with all my children; they all understand me and their mother condition."* The family members understand the condition of caregivers feeling thus they shared the responsibility together especially on finance and caring it was confirmed by participant that: *"All of my needs are provided by my son. When he come to hospital, we usually discuss any kind of treatment and needs for my wife."*

DISCUSSION

Male caregiver who takes care of lung cancer patients in this study encounter many difficulties and social interrupted. They face many difficulties such as: afraid to lose, having difficult to solve one's physical discomfort, No one can take turn for care giving, Having Financial problem, and Leave job for caregiving. this study confirmed the previous study that reported the caregivers commonly experience physical, emotional, social and financial burden throughout the caregiving process (Jabłoński et al. 2020; Lopes et al. 2018; See Jia Wen et al. 2022).

Most Caregivers in this study spoke at length about the effect caregiving had on their work, participant confirmed that due to they have to stay in hospital for long time they had to stay and leave the job and finally they do not have any income then it makes their difficulties are found in all male participants. They also need to provide caregiving tasks. Caregiving tasks typically involve assisting with activities of daily

living (e.g., eating, dressing, bathing, toileting, grooming, mobility), managing treatment and disease related symptoms, handling the behavioral problems and emotional reactions of the patient^{9,16,17}. although many tasks they have to provide to patient This study reported that all male caregivers committed to the care of their wives, as was demonstrated through their overall desire to provide care and stay around patient for long time.

Several participants believe that if they face difficulties, they can look for help from God. Prayer for Muslim people is the way of getting help from God. When the get closer to God then their stress also will decrease. It should be noted that religious faith often plays a vital role in the self-adjustment of the patient and family members. Spirituality has been shown to be important to caregivers of patients with lung cancer¹⁸. It supported by some studies that seven categories of spiritual needs were identified as present in patients and caregivers. These were the needs to relate to an Ultimate Other, have hope and gratitude, give and receive love, review beliefs, have meaning, and have needs met related to religiosity and preparation for death (Gibbs et al. 2020).

Gaining support from family member is also very important for caregiver, they can have same mutual feeling about their condition. It also explained that social support has been defined as a psychological phenomenon in which social interactions provide individuals with assistance or embed them in social relationships which are perceived to be loving, caring, and available¹⁹.

CONCLUSIONS

This study explored the male caregiver lived experiences of five Indonesian on patient with lung cancer. The findings pointed to the importance of considering multiple issues influencing male caregiver condition during providing care.

The findings of this study highlight several critical issues regarding male caregiver such as facing difficulties during their caring, and social interrupted that need improvement support from family, healthcare professionals and government (financial, emotional, instrumental and informational support), Therefore, an increase in awareness of these findings can help health administrators and healthcare professionals, such as nurses, to plan and design a comprehensive program to develop a support for male caregivers.

Although we achieved data saturation, participants were limited to all in patient in dr Moewardi Hospital. We recommend that future studies collect data from multiple hospitals to increase the richness of information acquired and to ascertain whether geographical factors influence the experiences of male caregiver on patients with advance lung cancer.

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