ทัศนคติและความต้องการของผู้ดูแลในการดูแลผู้ป่วยมะเร็งแบบประคับประคอง ณ โรงพยาบาลพระมงกุฎเกล้า

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วัตถุประสงค์: ศึกษาทัศนคติและความต้องการของผู้ดูแลในการดูแลผู้ป่วยมะเร็งแบบประคับประคอง

แบบวิจัย: การศึกษาแบบผสมผสานร่วมกัน

วัสดุและวิธีการ: มีผู้เข้าร่วมวิจัยเป็นผู้ดูแลผู้ป่วยมะเร็งแบบประคับประคองจำนวน 25 คน ระหว่างเดือนมีนาคมถึงพฤษภาคม 2562 ซึ่งได้รับการสัมภาษณ์แบบกึ่งโครงสร้าง 3 ประเด็น คือ (1) เหตุผลและความคิดเห็นในการดูแลผู้ป่วย (2) ปัญหาและความต้องการของผู้ดูแลในการดูแลผู้ป่วย (3) การแก้ปัญหาเบื้องต้นของผู้ดูแล ข้อมูลถูกเข้ารหัสและวิเคราะห์โดยใช้วิธีการวิเคราะห์เฉพาะประเด็น ผู้เขียนได้ศึกษาลักษณะทางประชากรศาสตร์ของผู้ดูแลผู้ป่วย รวมทั้งปัญหาและความต้องการการดูแลแบบประคับประคอง โดยใช้แบบสอบถามความต้องการการดูแลแบบประคับประคองของผู้ดูแล (The Problems and Needs in Palliative Care Questionnaire-caregiver form: PNPC-c) ฉบับภาษาไทย และวิเคราะห์ข้อมูลทัศนคติและการแก้ปัญหาโดยใช้สถิติเชิงพรรณนา

ผลการศึกษา: อายุเฉลี่ยของผู้ดูแลเท่ากับ 52.45 ปี มีบทบาทในการดูแลโดยเฉลี่ย 3.45 ปีและมากกว่าครึ่งหนึ่งใช้เวลาดูแลมากกว่า 12 ชั่วโมงต่อวัน โดยส่วนใหญ่จะมีผู้ช่วยดูแล จากการสัมภาษณ์พบว่าผู้ดูแลมีปัญหาในการดูแลแตกต่างกันไป โดยปัญหาที่พบมากที่สุดคือ ความกลัวต่ออนาคตที่ไม่แน่นอน ความเข้าใจในโรคของผู้ป่วย และปัญหาทางจิตใจและอารมณ์ตามลำดับ โดยมีแนวทางการแก้ไขปัญหาด้วยตนเองคือการหาวิธีผ่อนคลายความเครียด รวมไปถึงการได้รับการช่วยเหลือสนับสนุนจากผู้อื่น ครอบครัว และบุคลากรทางการแพทย์ทั้งข้อมูล ช่วยเหลือดูแล และดูแลสภาพจิตใจของผู้ดูแล

สรุป: ทัศนคติและความต้องการของผู้ดูแลในการดูแลผู้ป่วยมีหลากหลายปัญหาที่อาจจะยังค้นพบเพิ่มได้ แนวทางการแก้ไขปัญหาสามารถแก้ไขได้โดยจากตัวผู้ดูแลเอง ความยืดหยุ่น ทัศนคติ สภาวะจิตใจ และการช่วยเหลือสนับสนุนจากผู้อื่น ครอบครัว และบุคลากรทางการแพทย์

คำสำคัญ: ผู้ดูแล, การดูแลแบบประคับประคอง, ความต้องการ, ปัญหาในการดูแล

Caregivers' Attitudes and Needs in Palliative Care Cancer Patients in Phramongkutklao Hospital

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Abstract

Objective: The study aimed to explore the attitudes and needs toward being a caregiver for palliative care of patients with cancer.

Design: The study employed a concurrent mixed-method design.

Materials and Methods: Data were collected from 25 caregivers of patients with cancer using semi-structured interviews from March to May 2019. Three aspects were explored: (1) attitudes of caregivers in palliative care of patients with cancer (2) problems and needs in palliative care of patients with cancer, and (3) problem solvings of caregivers. Data were gathered until saturation was reached then coded and analyzed. The problems and needs in palliative care by caregivers were analyzed using bivariate analysis. The results of problems and resolutions were analyzed, coded, and interpreted using qualitative analytic techniques to arrive at several common overarching themes.

Results: The mean age of caregivers was 52.45 years. An average caregiving role was 3.45 years with more than one half giving care > 12 hours daily. From interviews, variable problems were identified. The most common problems were fear regarding the future, distressing symptoms, pain, and emotional problems. Moreover, the problem solving of caregivers involved themselves and others, knowledge, attitude, activities, assistance, and psychological support.

Conclusion: The care of patients with cancer presents a series of problems for caregivers many of which remain undetected. Additionally, the problem solving of caregivers involved themselves and others, resilience, coping, knowledge, attitude, activities, assistance, and psychological support.

Keywords: palliative, caregivers, needs, problems

Introduction

Patients with cancer are increasing globally. In 2008, 12.7 million new cancer cases emerged and 7.6 million cases died from cancer.[1] In 2018, 9.6 million died from cancer.[2] In Thailand, 61,082[3] died from cancer in 2011 and the trend increases every year.[3] The many treatments include surgery, chemotherapy, and radiotherapy, or a combination of treatments. Palliative care is specialized medical care for people living with an incurable disease, active, progressive, advanced disease, who have little or no prospect of cure and are expected to die. The goal is to improve the quality of life for both the patient and the family.

In palliative care, attention is usually concentrated on the patient and the family stays in the background.[4] The spouse, who is closest to the patient, usually bears most of the caregiving burden. From the patient's perspective, family caregivers are "fellow sufferers"[5] and rightfully so. In recent years, the World Health Organization has included the health and well-being of family members and caregivers working with a patient in their concept of palliative care.[6] A formal caregiver usually refers to paid care services provided by a healthcare institution or individual for a person in need. Informal care refers to unpaid care provided by family, close relatives, friends, and neighbors. Both forms of caregiving involve a spectrum of tasks, but informal caregivers seldom receive enough training for these tasks. Formal caregivers are trained in the field.[7] Caregivers in Thailand are often family members or informal caregivers.[8] Family members play an important role in the care of patients with cancer and are often unprepared for the combination of physiological and mental changes[9] such as depression, anxiety, fatigue, and sleeping disorder. When caregivers are inflexible and cannot adapt to the patient, the burden of the caregivers will affect their emotional health, and the quality of care.[10] The caregivers' burden of patients with cancer is associated with several poor health outcomes, including increased depression and anxiety, poorer health behavior and increased mortality.[11-14] Spouses of patients with Alzheimer's disease reported poorer mental and physical health than the general population.[15] Understanding the factors associated with increased caregiver burdens in this group would allow clinicians to more easily identify and target these caregivers for interventions to address caregiver problems, needs coping skills reducing the related risk of poor health outcomes.

Materials and Methods

This study employed a concurrent mixed-method design. The present study was undertaken in the Oncology Clinic of Phramongkutklao Hospital from March to May of 2019 after obtaining approval from the Ethics Committee Board of the Institutional Review Board of the Royal Thai Army Medical Department (IRBTA).

This study took place in a tertiary care setting. The research participants comprised caregivers of patients with cancer, who were able to understand the items of the questionnaire; Problems and Needs in Palliative Care Questionnaire-Caregiver Form (PNPC-c) and did not receive earnings from caring. They were also well informed and provided their consent to be included. The sample size was adequate to reach a sufficient level of "saturation", a term describing a point beyond which no new concepts will arise as a result of further interviews.

Interviews averaging 30 minutes, were conducted over three months. Sixty-seven questions divided into 11 items represented the most important issues of the problems and needs of caregivers in providing palliative care for a cancer patient. The Problems and Needs in Palliative Care Questionnaire-Caregiver Form (PNPC-c)[16] was utilized for patients and caregivers to comprehend and answer in about 15 minutes. The PNPC-c constitutes a checklist designed to present a comprehensive picture of the problems experienced by caregivers and their perceived subsequent needs for care. The instruments were translated to Thai by Suphasiri Chiangta.[17] The reliability of the instrument is 0.93 and 0.95. The validity is 1 and 0.95.[16] There are 3 levels of scores in each question; 3 is a problem and needs, 2 is sometimes, 1 is not a problem, and no needs. Higher scores indicated a higher need for help.

All basic characteristics of data and PNPC-c questionnaires were collected from caregivers, and all interviews were recorded by audiotape. For qualitative data, Open codes were created and analyzed using the investigator triangulation method. The codes were purely data driven. After that, the codes were discussed, modified, and merged by all authors, and final revised codes were developed afterwards. Emerging concepts were extracted and analyzed using a thematic analysis approach. After demographic data collection, three aspects were explored: (1) attitude of caregivers in palliative care of patients with cancer, (2) problems and needs in palliative care of patients with cancer, and (3) problem solving of caregivers. Data were gathered until saturation was reached.

Results

1. Descriptive Statistics: Demographic Characteristics

Twenty-five caregivers of patients with cancer were involved and participated in this study. The mean age of caregivers was 52.45 years (range, 30 to 67 years) and 80% were women. The majority of caregivers in this study were the primary caregivers for their parents (n = 11, 44%) followed by spouse (n = 7, 28%) and grandchildren (n = 4, 16%). Approximately one half (52%) of the caregivers were single, ten (40%) were married and two (8%) were separated. Twenty-one caregivers (84%) held a bachelor's degree and above. An average caregiving role totaled 3.45 years and more than one half spent >12 hours giving care daily.

2. Problems and Needs of Caregivers

The most frequent problems experienced by 80% of caregivers are listed in a ''top 20'' (Table 2). One issue stood out from the rest: Fear of an unpredictable future. Accepting the patient's disease (76%), The meaning of death (54%), and the caregiver's physical symptoms: Muscle pains or painful joints (52%) and Fatigue (76%): were further common problems. The other issues in this top 20 list were reported to be ''somewhat of a problem'' by many caregivers.

3. Thematic Analysis

Attitude and caregivers' needs in palliative care of patients with cancer could be divided into two major themes: 1) Resilience and coping strategies to provide a caregiving role; and (2) methods of problem solvings.

Resilience and Coping Strategies to Continue in the Caregiving Role

Long term care of patients with cancer entails challenging behaviors which were always problematic when managing care including related physical and mental problems. When no way could be found to deal with the problem, the caregivers experienced exhaustion leading to using costly hospital and emergency services. The interviews revealed that maintaining positive reasons and attitudes in the caring role, reframing, acceptance and intentional activities of resilience and coping strategies by the caregivers helped them to continue in their role.

Most caregivers identified themselves as family members, parents, spouse, children and grandchildren. These participants enjoyed close relationships with their patients and gave their reasons for caring as affection, gratitude and reciprocity. This made the caregivers more willing to continue in their caregiving role. Moreover, their relationship encompassed positive reinforcement towards the caregiving role and strengthened their relationships to be better able to face with problems for their beloved patients. They explained as described below.

"That's the way it is in our families. It's like, if you can do it (care for a sick parent), then you do it. If you can't, then you're going to leave your job, or whatever. But our family comes first. Our parents come first."

"On top of all is keeping them comfortable, keeping the whole family comfortable on what exactly is going on with them and what we can do to make them feel better in their last days"

In addition, the reason given for nonrelative acting as caregivers to maintain their role is love. The long relationship occurring in Thai society also links these patient-caregiver relationships as relatives.

"I have taken care of him for a long time; it's a bond we have with each other."

When asked about problems and needs towards being a caregiver, most participants said that they now can cope with the problems they experienced. A lack of understanding of the disease caused problems at first when they did not understand the symptoms and how to handle them. However, once they understood and accepted the signs and symptoms, they could reframe their perception and become able to care for the patient.

"I don't know how you do it, but if somehow in the medical profession could explain to the public better what palliative care entails, it would take away some of the fear and the stigma."

"It is the physician who should at least inform parents about advanced directives and why it is important to plan. I would dare not initiate the discussion with my parents. When the physician tells them, they may consider it."

Methods of Problem Solving

One of the most consistent themes that emerged during the interviews was the notion that quality of life, the make-up of which varied among patients, was more important than prolonging life.

The concern for caregivers' problems was expressed and indicated a real need for services, including regular assistance with patient care, pain and medication management advice, psychological support, and respite care.

"I feel that the caregivers themselves deserve a break. I feel my sister carried the entire burden for about 2 or 3 years now. So that's what I wanted to speak on. The people that are the caregivers, where do they get a break? When you want to scream, where do you go?"

God, religion, and spirituality were spoken of as essential components of the coping process for patients and families throughout every phase of life and death. The state of a person's relationship with God was seen as a mediator of personal distress or peace.

"I have been meditating and praying for an hour every night. It makes my mind calm and cheerful."

Whether representing a means to adapt to a difficult situation or a continued pattern of the previous observance, it did not appear that religion or spirituality affected treatment choices or how aggressive patients, or caregivers were with their illness. In most respects, spirituality was seen more as a means towards understanding, rather than guidance.

"The soul never dies. The body is just like the jacket you are putting on."

Some participants had no time for self-care that caused stress in the caregiving role, so they reorganize their time to pay attention to activities other than patient care.

"When I'm tired or discouraged, I try to live happily. I have a dog as a friend, I play with it, I grow trees; it helps me to relax."

Discussion

This study demonstrated that caregivers were the closest contact of the patients with cancer, constantly responsible for the care of the patient, a fact that has also been reported in other studies.[18] Caregivers' problems most frequently concerned they are coping with the situation mentally, their fears, and existential/spiritual questions. These came together with stress-related physical symptoms. Other researchers found that caregivers had a greater prevalence of affective disorders than patients.[19, 20]

One requirement of caregivers and patients at home is pain alleviation. The majority of caregivers noted that their patients suffered mainly from pain and they faced difficulty managing it. Such difficulty has also been confirmed by other studies.[21] Recent studies[22,23] have evaluated the administration of strong opioids among patients with cancer and concluded that fentanyl in the transdermal patch formulation can be used effectively and safely for pain management among patients with cancer while additionally being easy for caregivers to use.

Fear concerning the patient's future was the most frequent spiritual problem caregivers encountered. Most caregivers managed to solve their problems, such as lack of autonomy and bad mood, which they developed during the period they cared for the patient with cancer, by themselves.

Caregivers also indicated a wish for more professional attention to problems in the quality of care: coordinating care, accessing care provision, and having the opportunity to consult another doctor. Many caregivers would like more information to be given in writing. Caregivers are confronted with a new and emotionally challenging situation, which makes asking the right questions on the spot difficult. The situation also reduces a caregiver's capability to process new information, and it may be necessary to offer information several times before the family can understand and assimilate it.[24]

The findings of the present study agree with those presented in the literature[25] reporting that anxiety and depression were common among patients and their caregivers. These feelings might represent a reaction to the disease, or they might result from it. These feelings are effectively managed with psychopharmacologic and psychotherapeutic approaches. Modern antidepressants and sleeping pills are better tolerated and might be safely administered or be withdrawn when the symptoms regress.[26]

Another issue that is scarcely reported in the literature is the presence of spiritual or religious problems.[27] Questionnaires measuring the quality of life usually focus on the medical problems that caregivers face and it would be generally unusual to discuss spiritual issues between researchers, patients, and caregivers.

The findings demonstrated that reframing and accepting the illness, adaptability dealing with stress use of intentional activities were effective ways to reduce the burden of care and maintain the care for patients exhibiting mental deterioration. Religion and spirituality are significant resources in adapting to stressful life events. Moreover, assistance from family members, health care services, and social support are keys to caring for patients. The support of the family members in terms of assisting the care, emotional support, and financial resources also reduces the burden of care. Medical service support can also help caregivers gain knowledge, experience, trust in caregiving, and encourage them in the caregiving role. The knowledge and understanding gained from caring for these patients also produced positive effects on the caregivers themselves as they could share with others in the community.

Conclusion

The care of patients with cancer presents a series of problems for caregivers as many remain undetected: fear of an unpredictable future, accepting the patient's disease, fatigue, depressed mood, difficulty in showing emotion. The diagnosis and acknowledgement of these problems by health workers might contribute to offering practical help and finding solutions to assist with the difficult tasks of these caregivers. Illness and death are and will be an inevitable and integral part of human life. How we recognize and manage the needs of patients experiencing a terminal disease and those of their family members demonstrates the degree of society's maturity. The difference in duration of caregiving maybe affects the attitudes of caregivers

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Table 1. Basic Characteristics

Characteristics	N (%)
Caregivers Age, mean 52.45 years	
Gender	
Women	20 (80.0)
Men	5 (20.0)
Relationship to patient	
Son/daughter	5/6 (44)
Spouse	7 (28)
Grandchildren	4 (16)
Daughter-in-law	3 (12)
Others	0 (0)
Marital status	
Single	13 (52)
Married	10 (40)
Separated	2 (8)
Education level	
Primary school	3 (12)
Secondary school	1 (4)
Bachelor degree	19 (76)
Higher than a bachelor's degree	2 (8)
Health status	
Healthy	8 (32)
Ill	13 (52)
Never checked	4 (16)
Time spent caregiving per day (hours)	
<8	6 (24)
8-12	4 (16)
>12	15 (60)
Duration of caregiving, mean 3.45 years	
Care assistant	
Yes	19 (76)
No	7 (28)
Sleep time (hours)	

Characteristics	N (%)
<6	6 (24)
6-8	13 (52)
>8	6 (24)

Table 2. Top 20 Problems and Needs for Palliative Care (N = 25)

Top 20 Problems (‘‘yes’’ and‘‘somewhat’’)	N	%	Top 20 Needs for More Attention	N	%
Fear of an unpredictable future	20	80	Knowing what physical signs I should notice	17	68
Accepting the patient’s disease	19	76	Fear of an unpredictable future	15	60
Fatigue	19	76	How I should handle the patient’s pain?	15	60
Depressed mood	17	68	Lack of information in writing (inability to reread information)	15	60
Difficulty in showing emotion	16	64	Difficulty in coordinating the care of different professionals	14	56
Hope for the future	16	64	Extra expenditure because of the disease	14	56
How I should handle the patient’s pain?	16	64	Difficulty in getting access to help from agencies/professional organizations	13	52
Anxiety for my health	15	60	Difficulty in getting a second opinion from another doctor	13	52
The meaning of death	14	56	Insufficient adjustment of hospital care to the home situation	13	52
Activities to relax	14	56	The possibility of choosing another care provider	11	44
Knowing what physical signs, I should notice	13	52	Changing tasks and responsibilities in the family	11	44
Not wanting to leave the patient alone	13	52	Hope for the future	11	44
Muscle pains or painful joints	13	52	Difficulty in showing emotion	11	44
Sleeping problems	12	48	Anxiety for my health	10	40
Asking for help	12	48	Activities to relax	10	40
Making decisions	12	48	How I can help the patient to fill the days?	9	36
Experiencing difficulty in remembering what I was told	12	48	Accepting the patient’s disease	9	36
Difficulty in coordinating the care of different professionals	11	44	The insecurity of the availability of a hospital bed if needed (acutely)	9	36
Difficulty in seeing any positive aspects of the situation	11	44	The contact with (one of) my children	9	36
Continuing doing the things I do for others	11	44	Reduced income because of the disease	9	36

Table 3 Theme and Codes of the Participants After the Interview.

Themes	Codes
Resilience and coping strategies to continue caregiving role	Love, gratitude, reciprocity, good relationship Knowledge of patients and their caregiving
Methods of problem solving	Assistance, psychologic support, family members, health care provider Religious beliefs including mindfulness, physical activity, and hobbies

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