



The Suffering Experiences: Family Caregiver of Home Based Palliative Care in Malaysia

Wanda Kiyah George Albert^{1*}, Adi Fahrudin², Steward Lindong³, Husmiati Yusuf⁴

¹*Social Work Program, Faculty of Psychology and Education, Universiti Malaysia Sabah, Kota Kinabalu, Sabah, Malaysia;*
²*Department of Psychology, Faculty of Psychology, Universitas Bhayangkara Jakarta Raya, Indonesia, Associate Research Fellow, The Psychology and Social Health Research Unit Universiti Malaysia Sabah, Malaysia and Visiting Professor, Institute of Social Work Research, Japan College of Social Work, Tokyo, Japan;* ³*Hospital Chancellor Tuanku Muhriz, Universiti Kebangsaan Malaysia, Kuala Lumpur, Malaysia;* ⁴*National Research and Innovation Agency, Jakarta, Indonesia*

Abstract

Edited by: <https://publons.com/researcher/391987/mirko-spiroski/>

Citation: Albert WKG, Fahrudin A, Lindong S, Yusuf H. The Suffering Experiences: Family Caregiver of Home Based Palliative Care in Malaysia. Open Access Maced J Med Sci. 2022 Jun 15; 10(E):1623-1629. <https://doi.org/10.3889/oamjms.2022.8573>

Keywords: Family caregivers; Patients with cancer; Challenges; Caregiving

*Correspondence: Wanda Kiyah George Albert, Social Work Program, Faculty of Psychology and Education, Universiti Malaysia Sabah, Kota Kinabalu, Sabah, Malaysia. E-mail: wanda@ums.edu.my

Received: 09-Jan-2022

Revised: 14-Feb-2022

Accepted: 02-Mar-2022

Copyright: © 2022 Wanda Kiyah George Albert, Adi Fahrudin, Steward Lindong, Husmiati Yusuf

Funding: This research did not receive any financial support.

Competing Interests: The authors have declared that no competing interests exist.

Open Access: This is an open-access article distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 International License (CC BY-NC 4.0)

BACKGROUND: Caring for a family member who has advanced cancer and is nearing the end of their life comes with a slew of concerns and obstacles for the caregiver. A thorough understanding of the hardships and tribulations of caregiving may be a step toward resolving the issues that these patients' family caregivers confront.

AIM: The present study aimed to explore the suffering experienced faced by Malaysian family member who has advanced cancer and is nearing the end of their life.

MATERIALS: The present qualitative study was conducted through in-depth semi-structured interviews held with seven family caregivers of cancer patients selected through purposive sampling. Interviews continued until the saturation of data. All interviews were recorded, transcribed, and analyzed through conventional content analysis.

RESULTS: The codes extracted from interviews produced five main themes, including empathic suffering, powerless and hopeless suffering, predictive suffering, compliance suffering, and barriers' wrath, which collectively caused suffering for family caregivers.

CONCLUSION: Care provided in an atmosphere of suffering and discontent diminishes the caregiver's quality of life and quality of patient care. Health planners should therefore consider the challenges and sufferings faced by family caregivers and should seek to obviate them through plans.

Introduction

Suffering is a common sensation that all humans go through in their lives, particularly when they face stressful situations while caring for loved ones. During a major sickness, the agony is amplified. Family caregivers must deal not just with their loved one's illness, but also with the prospect of their loved one's death. For the quality of life, this end-of-life disease has a higher impact on family caregivers than it does on patients [1], [2], [3], [4], [5], [6], [7]. Family caregivers' quality of life ranged from medium to bad, particularly for those caring for end-stage acute cancer patients [6], [7], [8].

Families often become crucial providers of support and practical help during illness, especially in palliative care [7], [9], [10], [11]. More than half of carers in home-based palliative care settings have suffered since they handle a significant portion of the patient's care [7], [12], [13]. Suffering can be severe and terrible, leading to a desire for end-of-life care [9], [12], [14].

Patients and their family carers have been identified as being affected by the increased suffering experience [9], [15]. Caregivers often bear a burden that is greater than or equal to that faced by end-stage cancer patients. Even though family caregivers make significant contributions to care, they frequently feel neglected when their needs are overlooked by health-care professionals. The truth is that the family caregiver suffers just as much as the sick [16]. Secondary patients are family caregivers who must take care of their requirements while being monitored by healthcare providers [17]. The medical care provider frequently overlooks the requirements of the patient and caregivers to ensure that the patient's needs are satisfied [6], [18]. The experiences and suffering of caregivers of terminally ill cancer patients will be discussed in this study.

Concepts and types of suffering

When perceived risks to themselves and their integrity are not met with enough resources of coping methods, including personal or psychosocial strategies,

family caregivers suffer [14], [15]. To comprehend their suffering, the idea of holistic suffering, which includes physical, psychological, social, and spiritual elements, might be applied. The Psychosocial Suffering Model can be used to describe the relationship between suffering and interpersonal experience in terms of coping strategies and interpersonal experience in care [15], [18]. The psychosocial suffering model also describes the stress link between patients and caregivers, as well as patients, caregivers, and health-care providers, where one individual's stress affects the stress of others.

Several researchers have identified several types of family care suffering to better understand how carers suffer while performing their duties. Physical, psychological, social, and spiritual anguish are some of the problems that families face [10]. Caregivers' bodily symptoms and limitations are referred to as physical suffering, while anxiety, depression, sleep problems, confusion, concentration difficulties, nightmares, and substance misuse are referred to as psychological suffering [10], [17]. While social suffering refers to empathic suffering as a result of patients' distress, care burdens, family conflicts, and stress associated with health-care services. The suffering of end of life caregivers can be divided into four aspects:

- i. Physical aspect not aspects: Feeling the patient's bodily pain as well as the caregiver's physical pain.
- ii. Psychological aspect: Burden of care, want to be free of duties, receiving palliative care support, dread of the future.
- iii. Social aspects: Refers to a lack of social activities, social help, and open communication, as well as the resulting pain.
- iv. The spiritual aspect: Refers to the patient's belief in spirituality, death, and spirituality after death.

Materials and Methods

Study design

In this study that is a part of a large study as a doctoral thesis in social work, the descriptive exploratory study design was used.

Study setting

The present study participants included family caregivers of advanced cancer patients of home-based palliative care, selected through purposive sampling from a palliative care center in Kota Kinabalu Sabah.

Participant selection

Participants were purposively selected. They

were adult family members who were the primary caregivers of persons diagnosed with cancer. All provided written informed consent. We sampled for maximum variation, sampling for diversity across socio-demographic factors and relationship to the patient (sibling, parent, spouse, and children). Participants were considered eligible for inclusion in this study if they had a minimum age of 18, being a first-degree relative that lived with the patient and took care of him for at least eight out of 24 hours each day, being responsible for and competent in providing care for a cancer patient, having no history of mental diseases and having the ability to speak in Malay and English. All participants were informed about the study and were asked to sign informed consent. Verbal consent was obtained from the family member with cancer.

Data collection procedure

Data were collected between February 2017 and Jun 2018 using semi-structured in-depth interviews that continued until saturation of data. As agreed with participants, each interview was conducted in a quiet room in the hospital with the presence of a participant and the first researcher at the time agreed with the participant. With prior permission from participants, all interviews were recorded on an MP3 recorder. The interviews started with the question

"Can you tell us about your experience while caring for patients?" or "Can you share with us about the experience of suffering you experienced while caring for a patient?" and continued with more probing questions such as 'Could you please expand on that?' and 'Could you say more about that?' were asked based on the participants' response, to further enrich the information. Each interview lasted between 40 and 80 min. This cyclical process proceeded until data saturation was reached, at which point study participants realized no new information was being gathered [19]. This was accomplished by interviewing a total of nineteen family carers of cancer patients, with two more interviews undertaken for added assurance. In addition to interviews, field notes were obtained to complete the data collection.

Rigor

Dependability, credibility, conformability, and transferability criteria were utilized to evaluate trustworthiness in this study. Peer verification improved dependability [20], [21]. So that three experienced qualitative data analysts from outside the research team reviewed all interview transcripts, codes, and themes [22], [23]. Data collection from various sources (interviews and observation in the form of field notes taken during the researcher's attendance in clinical wards of the two medical centers), prolonged interaction with family caregivers, and discussion of the findings among the research team and some of the interviewees

all contributed to the credibility of the study. Initial codes were made available to participants to confirm and identify valid codes. Transferability was strengthened using a heterogeneous sample of the participants with optimal diversity (diversity in terms of hospital, and participants in terms of age, gender, and relation with the patient). Confirm ability was established using the memos to develop an audit trail of the research activities that occurred through the research process. For this purpose, all documents including interview texts, coding process, and extraction of themes were examined and confirmed by external check. Ethical considerations: The present study was approved by the ethics committee of Universiti Sains Malaysia (USM/ JEpem/17010061) and then conducted on obtaining a letter of introduction from the university and obtaining permissions from the palliative care. Informed written consents were obtained from all participants who were assured of the confidentiality of their data throughout the study and in the publication of the findings and of their right to withdraw from the study at any stage.

Research finding

The characteristics of family caregivers will be shown in Table 1.

Table 1: Characteristic of family caregiver

Total of caregiver	7 persons
Gender	
Men	2 persons
Women	5 persons
Age	
<40 years old	1 person
40–50 years old	1 person
50–60 years old	3 persons
>60 years old	2 persons
Marriage status	
Single/divorced	2 persons
Married	5 persons
Race	
Malay	2 persons
Chinese	1 person
Kadazan Dusun	3 persons
Bugis	1 person
Religion	
Islam	3 persons
Buddist	1 person
Christian	3 persons
Perhubungan dengan pesakit	
Spouse	2 persons
Parent	2 persons
Son/daughter	2 persons
Sibling	1 person
Time has taken care of	
<1 month	1 person
6 months -1 year	5 person
>1 year	1 person

Experience of suffering among family caregivers

After analyzing the data, 150 codes were obtained by filtering all the data for those relevant to the carers' suffering. Family caregivers in the home-based palliative care in Kota Kinabalu, Sabah is experienced empathic suffering, powerless and hopeless suffering, predictive suffering, compliance suffering, and barriers' wrath.

Empathic suffering

Empathy is the ability to understand another person's situation from their point of view and feelings. It is critical to engage in preventative maintenance operations. It can be one of the major causes of suffering. Empathy suffering is the pain that people experience because of putting themselves in such a predicament [18], [24]. The three categories of empathy described in this chapter are seeing, hearing, and anxiety empathy. Empathy through vision entails perceiving the patient's symptoms, such as pain, trouble breathing, dizziness, nausea, vomiting, weight loss, loss of appetite, weariness, and so on.

This involves witnessing patients lose function, such as the inability to walk, sit, move, eat, communicate, or sleep, as well as witnessing patients grow despondent after receiving a medical officer's diagnosis and prognosis. The concept of carers may be articulated in this scenario when people empathize with the suffering of end-stage cancer patients, but the help and support they can provide is limited. Witnessing your loved one's ability to go from being able to do everything to being unable to do anything affects the caregiver's emotions. An example of a family caregiver's experience is:

"It's hard to see he is in pain... at first Doctor said he had cancer and we were very surprised... did not think he would get cancer... I am very sad... the doctor said he will not live long... very sad after that." (Caregiver 1)

Empathy is harmed by the caregiver's fear about the patient's discomfort, stress, treatment side effects, and loss of nourishment, as well as caregiver anxiety if the patient refuses the treatment. Some caregivers are concerned about the patient's death phobia. Some caregivers worry about the patient's fear of death.

"I do not know how long she will be sick...I'm sad, i do not want to tell my sister about this. I just kept the matter a secret... but 1 day. I told my sister, and she was thinking about things the same only we touch little on this article very much because we are afraid I am afraid because maybe my sister will say: What do you think? Is mother going to die soon?" (Caregiver 3)

When caregivers receive bad news from a doctor, empathy for listening is activated. When it's rumored that the patient is nearing the end of his or her life, they're devastated. Serious blood results, illness progressing and spreading, further treatment, or coma are all outcomes. Hearing patients express a desire to die, a misery they can no longer take, and a desire to stop receiving therapy is extremely distressing.

"The hardest part is when he tells me about the pain that he feels. I can't see him in pain... sorry, I look at his condition. I hope I can get rid of the pain from his body and find where the pain is and get rid of the pain." (Caregiver 5)

Powerless and helpless suffering

The helpless caregiver is suffering as a result of the lack of secondary aid as well as moral support from other family members. Furthermore, caregivers' that are lack of understanding about how to cope with end stage cancer patients may feel hopelessness. This is because most family not trained as a professional. This scenario is exacerbated by a lack of moral support from other family members, resulting in their caretakers being neglected. This statement has been demonstrated using the following verbatim:

"I know they have stopped the treatment... I am also always by his side... but I do not know what to do... What else to say?" (Caregiver 2)
 "I am sometimes angry because I do not get support from other families who live close by... like not for any support or help to me. But I did not tell them that doing need to come... to me nda payah bah tell me what to do... You don't know what you need to do... what happened. I'm very disappointed with the other family for not helping." (Caregiver 6)

Suffering that can be predicted

This suffering happens before the loss. There are two sorts of losses: death-related losses and patient-related losses. The pain of prophecy caused by impending death can be separated into three categories: Perception, cognition, and emotion. Perception refers to the patient's awareness of his or her incurable sickness, the fact that stopping therapy extends life and knowing and seeing the patient's more chronic condition, which includes a lack of appetite, speech, and sleeps for the most part.

The caregiver's cognition refers to how he or she expresses various hopes and views. Many caretakers hope that the patients improve and that things return to normal. Some caretakers hope that patients will continue to fight and recover while being healthy, positive, and living longer. Denial, rejection, and acceptance are all aspects of cognition, in addition to expectations and beliefs. Grief is expected as a result of the death of a present or future patient. This is due to caregivers' inability to accept comments and move on without the presence of a patient. The following text exemplifies the anguish of this prophecy. The suffering of this prophecy can be seen through the following verbatim:

"I sleep next to mama every night... my sister always asks me to go back and take a rest. I'm reluctant to drive back... I won't always stay with mama... because when she is happy I am also happy... we can feel happy together... and when she feels sad she only shared the feeling with me... I want to stay with mama... sometimes I feel unwell and still... it doesn't matter... not for a long period... when she is

gone I won't feel guilty because I have done my best for mama." (Caregiver 3)

"I regret it now... why did I am not a nurse??... I have a lot of experience related to taking care of others... what can I do? I'm old... helpless in doing something like before." (Caregiver 5)

Compliance suffering

- a. This suffering of compliance is linked to the caregiver's burden of caring. The burden of companionship, the burden of functional help, the financial burden, and the burden of entertaining are the four categories of burdens that have been recognized. The burden to accompany the patient

Most caregivers should spend the majority of their time with the patient to provide moral support. This is because most patients are fearful and require company. As a result, the caregiver desires to be with the patient and provide care until the patient passes away. This load is reflected in the caregiver's 4 statements:

"This is my first experience taking care of him. I have a lot to learn. I need to learn how to take care of him, take care of him eating and drinking, bringing him to take shower... I need to take care of everything... I will also accompany him to encourage him to stay alive." (Caregiver 4)

- b. Burden to entertain
 Caregivers describe the challenges they face in keeping patients happy and not expressing their emotions in front of them. Even though the caregiver gives psychological support, many patients remain sad, and always grieve. The following is a statement from caregiver 7: "I do not want him to see me crying in front of him... so I do not want to show anything in front of him... somehow I want to see him happy. I will always take him anywhere like going shopping, gathering with family and eating... I know that I am the only one that next to him... if I was there with sad feeling... I think I might make him sad again." (Caregiver 7)

Barriers' wrath

The barriers' wrath when a caregiver confronts an external difficulty while caring, it is referred to as suffering. These obstacles are broken down into three categories: Patient-related barriers, family-related barriers, and health-care-related hurdles. In barriers relating to the patient, the caregiver expressed a high level of patient dependence on the caregiver, as well as the patient's incapacity to rely on others. Some patients require medical attention. Some patients require 24-h care, particularly when the patient's condition

deteriorates and the disease's symptoms become more complicated. This disorder has an impact on the patient's emotional and mental well-being; for example, the patient may become moody and desperate to continue therapy. Some patients express a desire to die because they are in unbearable pain and believe they become a burden to their families. Furthermore, concerns about patients' lack of appreciation were raised. This is because patients continue to complain despite the caregiver's attentive performance of their duties. Some patients do not consider and appreciate caregiver assistance. Caregiver 1 is affected by this situation:

"Sometimes it is difficult to take care of sick people. They are always moody and unstable... sometimes we have to do our best for them... but sometimes when they are not in a good mood, what we have done are all wrong... everything is not good... sometimes what I do is not appreciated by them..." (Caregiver 1)

"Do you know the range of his hemoglobin? It was 3... when I ask my son to go to the hospital... he was so angry and said that I need to understand his condition. He keeps on reminding me that his condition is critical... nothing will change if I bring him to the hospital... even if he goes to the hospital, his illness will not improve." (Caregiver 4)

Patients' families play a vital part in their care. Because each family member has different beliefs and opinions on numerous subjects, such as care goals, treatment alternatives, and level of involvement, there are barriers between them. When it comes to caring, there is conflict when some family members want the patient to fight for his or her life while others want the patient to leave quietly. Some family members will feel compelled to continue conventional treatment while others will advocate for attempting alternative treatments. Furthermore, when each family member has their recommendations, the matter becomes much more problematic. Some family members were not fully involved or did not care about the patient, according to the caregiver. Due to differences in their levels of family involvement, family members don't always talk.

The three concerns mentioned under the obstacles to healthcare include challenges connected to information, interaction, and institutions. Patient development and a lack of medical information are linked to information-related difficulties. Because they did not receive a thorough explanation of the matter from the relevant parties, caregivers expressed their concern about the negative effects of a treatment given to patients such as chemotherapy and morphine. Furthermore, many people are uninformed of their patients' most recent developments due to a lack of opportunities to meet with doctors who treat them.

A huge number of doctors treating patients also makes it difficult for caregivers to make references and have talked about the patient's condition because there

are lot of other cases and tasks for them to look into. When it comes to interaction concerns, it is about the pain that caregivers go through when they learn that the patient is nearing the end of his or her life. The patient's low life expectancy has come as a shock to many carers.

When doctors say there is not much that can be done or that there is no hope, the situation becomes even worse. This creates a sense of abandonment, as though doctors have abandoned their patients. The caregiver also believed the patient was left in the ward without receiving any medical attention. Loneliness and a lack of sensitivity in communication are exacerbated by dialogues that provide no hope, even in dire situations, adding to the caregiver's agony. Some caregivers are so overworked that they no longer want to hear unpleasant news about their patients. Less empathy is also portrayed in the subject of hurdle grieving.

Some carers believe that health-care professionals are unwilling to assist their patients. Some healthcare workers appear to be emotionless because they appear to be solely focused on performing their responsibilities rather than giving the patient their complete attention. When taking blood, for example, they conduct their task rapidly without paying heed to the patient's tension. Caregivers remark that some employees do not behave incorrectly because they do not listen to the circumstances and adapt their treatment accordingly. The following is the statement in response to this situation:

"My father and brother are also in the medical field, they are very firm in medical intervention. I told them that I was going to try something else I've talked to a lot of patients who have recovered by eating herbs... why don't we try...? but they prevent me to try other alternatives. I was disappointed with their attitude and very angry." (Caregiver 4)

"I feel disappointed with them... we have a brother jack... and if you do not want to spend time with him what is the meaning of having own siblings?" (Caregiver 2)

In terms of institutional difficulties, carers also complain about having to wait a long time for a doctor's visit. This is a difficult scenario because they must visit the hospital multiple times to see a doctor. The environment setting was also highly noisy, according to the family caregiver, making it impossible for the patient to sleep effectively. The caregiver in the palliative ward considered the ward as a place to wait for death. When they watched many people dying and dying in the ward, this situation emerged. Patients and caregivers alike are terrified by this illness.

"That does not mean the nurse here is not good... but they have other duties... they also can't afford to take care of them for 24 Hours." (Caregiver 5)

"I have asked for help with the same charity but could not... they said I have many things

like I should not subscribe to Astro, I should not have property or assets. The question is asked based on the application form. That's why I'm lazy to ask for help... I get angry when things are so questioned... do they think I don't need to think about myself? " (Caregiver 6)

Suffering among family caregivers is divided into four categories: Physical, psychological, social, and spiritual, as well as dimensions of existence or spirituality [15]. Caregivers' burdens, such as the burden of accompanying patients, the burden of functionality, the burden of finance, and the burden of entertaining, are consistent with the descriptions of various tasks performed by caregivers in providing support to the dying individual, such as caring for the patient's physical well-being, managing complex symptoms, arranging and managing care by other services, acting as the advocate for the patient, and decision-making [14], [25]. Suffering associated with caregiver burden is now referred to as compliance suffering, which arises when the caregiver's burden increases or when there is a conflict between the caregiver's different duties and responsibilities as a parent, employee, and caregiver. Continuous measurement of caregiver load is critical in sustaining caregivers' psychological well-being for this purpose.

In addition, caregivers confront a variety of problems from patients, families, and health-care professionals. This remark falls within the category of obstructive suffering. When the patient's medical and psychological state gets complex, when the patient's requirements conflict with the caregiver's demands, and when family members and caregivers disagree, caregivers are said to suffer.

Many studies have found differences of opinion between caregivers and patients for explaining diagnosis and prognosis [13], the use of life-sustaining treatment [16], places of care, and places for deaths [5]; Stajduhar, Allan, disagreements among family members on treatment options, particularly the type of treatment required for patients, add to treatment limitations [26]. Family reunions must be well-organized to solve this difficulty. Empathy has a crucial role in many care partnerships [24]. Caregivers must be able to communicate with and comprehend their patients [24]. Many caregivers suffer because of this empathetic link. Because carers are afflicted by mortality and losing patients in the future, suffering among caregivers exists before the loss of patients. They are constantly considering what will happen in the patient event's of absence and when the patient dies in the future [27], [28], which focuses on the five stages of grief (denial, anger, bargaining, depression, and acceptance), this chapter focuses on the three categories of grief: Perception, cognition, and emotion. Hearing news about terminal phase disease or seeing a patient's death is referred to as perception of this topic. Acceptance of the patient's loss refers to the

stress produced by the separation that occurs before the patient passes away [29]. As a result, attention and information about the patient's condition are needed at an early stage before the patient's death, besides offering support to the caregiver after the patient's loss during death. Caregivers often feel powerless and alone because they do not know what to do, say, or expect, and they do not have support from family, friends, or medical professionals. This encounter is linked to the patient's perception of suffering, that the patient is dying, and the caregiver's feelings of [30].

Conclusion

Finally, caregivers suffer in the same way that patients do. Their pain is undetected by health care providers and even by themselves. Caregivers suffer as a result of their empathy. Their pain is undetected by health care providers and even by themselves. Caregivers suffer as a result of their empathy. Every family member in the field of palliative care and medicine, as well as in the field of assisting professions such as social work, should have the ability to empathize. Caregivers' pain can be termed as silent suffering, and it hurts their quality of life. As a result, family members, healthcare practitioners, and persons in the helping profession should pay special attention to and support this group. Family caregivers should also receive training, information, and skills in coping with cancer patients who are nearing the end of their lives.

In addition, professionals in the helping professions, such as social workers and counselors who work in medical facilities, must provide emotional and psychosocial assistance. To avoid affecting their psychological well-being, family carers should be provided instruction in coping skills that can be utilized to deal with their pain. In addition, to make the care process easier, systems connected to patient medical information and practical support resources, particularly equipment, must be upgraded.

Author Contributions

This work was conducted in collaboration with all authors. Author WKAG and AF were planned, structured, wrote, revised, and rechecked the manuscript thoroughly. SL and HY improved the draft copy and revise and improve the manuscript thoroughly. All authors WKAG, AF, SL, and HY reviewed carefully and approved the final version of the manuscript.

References

- Balboni TA, Vanderwerker LC, Block SD, Paulk ME, Lathan CS, Peteet JR, *et al.* Religiosity and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. *J Clin Oncol.* 2007;25(5):555-60. <https://doi.org/10.1200/jco.2006.07.9046> PMID:17290065
- Fujinami R, Otis-Green S, Klein L, Sidhu R, Ferrell B. Quality of life of family caregivers and challenges faced in caring for patients with lung cancer. *Clin J Oncol Nurs.* 2012;16(6):E210-20. <https://doi.org/10.1188/12.cjon.e210-e220> PMID:23178364
- Morishita M, Kamibepu K. Quality of life and satisfaction with care among family caregivers of patients with recurrent or metastasized digestive cancer requiring palliative care. *Support Care Cancer.* 2014;22(10):2687-96. <https://doi.org/10.1007/s00520-014-2259-3> PMID:24789422
- Nguyen DL, Chao D, Ma G, Morgan T. Quality of life and factors predictive of burden among primary caregivers of chronic liver disease patients. *Ann Gastroenterol.* 2015;28(1):124-9. PMID:25608915
- Agar M, Currow DC, Shelby-James TM, Plummer J, Sanderson C, Abernethy AP. Preference for place of care and place of death in palliative care: Are these different questions? *Palliat Med.* 2008;22(7):787-95. <https://doi.org/10.1177/0269216308092287> PMID:18755830
- Kiyah W, Fahrudin A. Quality of life (QOL) assessment among advance cancer patient undergoing palliative treatment in Malaysia. *Asian Soc Work J.* 2017;2(2):26-35. <https://doi.org/10.47405/aswj.v2i2.18>
- Albert WK, Hatta ZA, Fahrudin A. The experience of family caregivers living with advanced cancer patients. *Asian Soc Work J.* 2017;2(1):53-63. <https://doi.org/10.47405/aswj.v2i1.14>
- Kim Y, Baker F, Spillers RL. Cancer caregivers' quality of life: Effects of gender, relationship, and appraisal. *J Pain Symptom Manage.* 2007;34(3):294-304. <https://doi.org/10.1016/j.jpainsymman.2006.11.012> PMID:17572056
- Dees M, Vernooij-Dassen M, Dekkers W, Van Weel C. Unbearable suffering of patients with a request for euthanasia or physician-assisted suicide: An integrative review. *Psychooncology.* 2010;19(4):339-52. <https://doi.org/10.1002/pon.1612> PMID:19771571
- Wilson KG, Chochinov HM, McPherson CJ, LeMay K, Allard P, Chary S, *et al.* Suffering with advanced cancer. *J Clin Oncol.* 2007;25(13):1691-7. <https://doi.org/10.1200/jco.2006.08.6801> PMID:17470861
- Hudson P, Payne S. Family caregivers and palliative care: Current status and agenda for the future. *J Palliat Med.* 2011;14(7):864-9. <https://doi.org/10.1089/jpm.2010.0413> PMID:21599532
- Al-Shahri MZ, Eldali AM, Al-Zahrani O. Prevalence and severity of suffering among patients with advanced cancer. *Support Care Cancer.* 2012;20(12):3137-40. <https://doi.org/10.1007/s00520-012-1443-6> PMID:22453792
- Tang ST, Liu TW, Lai MS, Liu LN, Chen CH, Koong SL. Congruence of knowledge, experiences, and preferences for disclosure of diagnosis and prognosis between terminally-ill cancer patients and their family caregivers in Taiwan. *Cancer Invest.* 2006;24(4):360-6. <https://doi.org/10.1080/07357900600705284> PMID:16777687
- Ruijs CD, Kerkhof AJ, van der Wal G, Onwuteaka-Philipsen BD. The broad spectrum of unbearable suffering in end-of-life cancer studied in dutch primary care. *BMC Palliat Care.* 2012;11(1):12. <https://doi.org/10.1186/1472-684x-11-12> PMID:22853448
- Wittenberg-Lyles E, Demiris G, Oliver DP, Burt S. Reciprocal suffering: Caregiver concerns during hospice care. *J Pain Symptom Manage.* 2011;41(2):383-93. <https://doi.org/10.1016/j.jpainsymman.2010.04.026> PMID:21146356
- Tang ST, Liu TW, Lai MS, McCorkle R. Discrepancy in the preferences of place of death between terminally ill cancer patients and their primary family caregivers in Taiwan. *Soc Sci Med.* 2005;61(7):1560-6. <https://doi.org/10.1016/j.socscimed.2005.02.006> PMID:16005787
- Given BA, Given CW, Sherwood PR. Family and caregiver needs over the course of the cancer trajectory. *J Support Oncol.* 2012;10(2):57-64. <https://doi.org/10.1016/j.suponc.2011.10.003> PMID:22222251
- Beng TS, Guan NC, Seang LK, Pathmawathi S, Ming MF, Jane LE, *et al.* The experiences of suffering of palliative care patients in Malaysia: A thematic analysis. *Am J Hosp Palliat Med.* 2014;31(1):45-56. <https://doi.org/10.1177/1049909112458721> PMID:22956340
- Creswell JW, Poth CN. *Qualitative Inquiry and Research Design: Choosing among Five Approaches.* Thousand Oaks, California: Sage Publications; 2016.
- Yin RK. *Case Study Research: Design and Methods.* 5th ed. Thousand Oaks, California: SAGE Publications Inc.; 2014.
- Yin RK. *Qualitative Research from Start to Finish.* New York: Guilford Press Publications; 2015.
- Patton MQ. *Qualitative Research and Evaluation Methods.* London: Sage; 2002.
- Miles MB, Huberman AM, Saldaña J. *Qualitative Data Analysis: A Methods Sourcebook.* 3rd ed. Beverly Hills, California: Sage; 2014.
- Reynolds WJ, Scott B. Empathy: A crucial component of the helping relationship. *J Psychiatr Ment Health Nurs.* 1999;6:363-70. <https://doi.org/10.1046/j.1365-2850.1999.00228.x>
- Stajduhar KI, Allan DE, Cohen SR, Heyland DK. Preferences for location of death of seriously ill hospitalized patients: Perspectives from Canadian patients and their family caregivers. *Palliat Med.* 2008;22:85-8. <https://doi.org/10.1177/0269216307084612>
- Breen CM, Abernethy AP, Abbott KH, Tulskey JA. Conflict associated with decisions to limit life-sustaining treatment in intensive care units. *J Gen Intern Med.* 2001;16:283-9. <https://doi.org/10.1046/j.1525-1497.2001.00419.x>
- Norinder M, Goliath I, Alvariza A. Patients' experiences of care and support at home after a family member's participation in an intervention during palliative care. *Palliat Support Care.* 2017;15(3):305-12. <https://doi.org/10.1017/s1478951516000729> PMID:27748224
- Kübler-Ross E. *On Death and Dying.* New York: The Macmillan Company; 1969.
- Kübler-Ross E. *Living with Death and Dying.* New York: Simon and Schuster; 2011.
- Milberg A, Strang P, Jakobsson M. Next of kin's experience of powerlessness and helplessness in palliative home care. *Support Care Cancer.* 2004;12(2):120-8. <https://doi.org/10.1007/s00520-003-0569-y> PMID:14685835