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EXPERIENCES OF CAREGIVERS OF TERMINALLY-ILL
CANCER PATIENTS: A QUALITATIVE STUDY

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OF PURE MEDICAL RESEARCH**ABSTRACT**

Caregiving is considered a tough job as carers are challenged with care-related problems both from caregiving itself and the patients. In the Philippines, family members are usually seen doing the role for their patients. This study was conducted to determine the experiences and challenges in dealing with and addressing the needs of caregivers of terminally-ill cancer patients. Likewise, it explored the strategies caregivers do to manage the stress encountered in caring the terminally-ill cancer patients. A case study research method under qualitative research was followed in determining the experiences of five (5) caregivers from the selected barangays in Tacurong City, Sultan Kudarat. A self-constructed guide question served as the primary tool in gathering data from the respondents which was held in March 2019. Findings reveal that majority of the respondents took care of their patients for a short duration of 1-4 months. They provided the basic needs of the patients like bathing, feeding, giving medication and changing of diapers. Most of the patients were irritable, and the needed care was offered immediately by the caregivers. The respondents felt that their role as a caregiver is challenging due to lack of sleep. More to that are the financial difficulties due to the hospitalization and needs of their patients. The respondents have undergone the grieving and mourning process and gradually accepted the death of the patients. As a coping mechanism, the respondents spent their time with their families, and they consider God as their strength and support. Caregiving is indeed a complicated process, yet the caregivers can manage and surpass the challenges encountered while caring for their patients. Families with cancer patients should reflect on the challenges the caregivers go through, not only focusing on the patients as they also need physical, emotional, financial, spiritual and social support.

Background of the Study

Family is known as the basic unit of society. The Filipinos are very popular as family-centered individuals. For a family with a member diagnosed with cancer, this is a stressful matter. Everyone is getting involved to lighten the situation of the family member who has cancer. Some literature value the spirituality of families in accepting the depressing situation of losing someone at anytime.

According to an article published by LeSure and Chongkham-ang (2015), cancer and cancer treatment affect not only the patients but also their family members and caregivers. When giving care to persons with life-threatening illnesses such as cancer, caregivers are

confronted with physical and emotional challenges. Cancer is a generic term for a large group of diseases characterized by the growth of abnormal cells beyond their usual boundaries that can then invade adjoining parts of the body and spread to other organs. Other common terms used are malignant tumors and neoplasms [World Health Organization (WHO), 2017].

Most of the caregivers are women, and watching the deterioration of their sick family members also affects their quality of life. They support until the end-of-life of the terminally-ill patient, but they need to be recognized and cared for too (Goncalves, Novella, Rebeiro & Reigada, 2015).

Caregiving is a full-time job of providing care to a terminally-ill cancer patient and is a demanding task. It is a significant burden physically, emotionally, socially, spiritually, and mostly financially. The study provides baseline information to educate the community on the palliative care of terminally-ill cancer patients and the caring status of the caregivers.

This paper specifically explored the experiences of caregivers in dealing with and addressing the needs of their terminally-ill patients; the challenges encountered, and the strategies that caregivers employed to manage the stress encountered in the care of terminally-ill cancer patients.

Conceptual Framework

The study focused on determining the roles and experiences of caregivers who are attending to the health needs of terminally-ill cancer patients.

This enables understanding of the problem encountered by the caregivers. Also, information on the coping strategies employed by the caregivers is viewed as necessary in supporting the needs and concerns they faced.

Lee (2015) in her article: "The Effect of Stress and Burden on Caregivers of Individual with a Chronic Illness" utilized Lazarus and Folkman's (1984), Transactional Stress Theory. This theory has been extensively used in stress, burden, and coping research and has been the framework adopted to depict stress among caregivers across various chronic conditions such as in Cancer, Alzheimer's disease, stroke, multiple sclerosis, and Parkinson's disease.

The Transactional Stress Theory suggests that a stress reaction occurs under situations where the demands of the environment exceed the individuals' resources. In the presence of a threat, the individual will engage in both primary and secondary appraisal of perceived threats. Primary assessment is set into action when the individual appraises the harmful, threat or challenge encountered

and secondary appraisal or judgment regarding his or her available coping resources for managing the potential threat (Lazarus & Folkman, 1984). This was the theory adopted in this study to understand the phenomenon of caregiving for cancer patients.

METHODOLOGY

The study applied a qualitative research design and a case study method to explore the experiences of five (5) caregivers who took or are currently taking care of terminally-ill cancer patients purposively sampled from Tacurong City, province of Sultan Kudarat in Mindanao, Philippines last March 2019.

An in-depth interview with the five (5) caregivers was performed. According to a phenomenological study by Creswell (1998), 5-25 respondents are enough to obtain enough data to sufficiently describe the phenomenon of interest and address the research questions.

The caregivers of patients with terminal cancer cases (dead patients or currently suffering from cancer) were chosen regardless of gender, age, civil status, religion, and occupation; able to communicate verbally, and a parent, sibling, relative, guardian, friend or person who is not related to the patient but involved in the caring process of at least a month regardless of cancer cases.

The respondents were formally approached, explained the purpose of the research, and obtained their willingness to participate in the study through a signed consent for the interview. The guide questions were translated into the vernacular dialect of the caregivers for easy understanding and smooth verbal interaction with respondents. Probe questions drafted were reviewed by the research committee in the College of Nursing to conform with the university's ethical standards.

The guide questionnaire facilitated gathering of the socio-demographic data of the caregivers as to age, sex, civil status, occupation, relationship and length of care to a sick family member, patient's age, occupation, and monthly income; experiences of the caregivers in terms of activities of daily living, communication, challenges, thoughts and feelings as well as the stresses of having the responsibility.

Qualitative data gathered during the interview were recorded, collated, and transcribed. Analysis of the responses was done and formed by themes for better research result presentation and interpretation.

RESULTS AND DISCUSSION

The discussion focuses on (1) the experiences of the caregivers in terms of dealing and addressing the needs of their terminally-ill cancer patients, (2) the challenges encountered by the caregivers towards the delivery of care for terminally-ill cancer patients, (3) the strategies that caregivers do to manage the stress encountered in caring the terminally-ill cancer patients, and (4) the coping mechanisms of the caregivers after the death of their patients.

RESULTS

Case Study # 1: Ana

Ana is 53 years old, female, and married. The patient is her second child among her five children. Her son died on October 22, 2018 at the age of 25. She is a full-time housekeeper, and her husband is a farmer with a monthly income of Php 5,000 pesos only.

According to Ana, her son noticed a lump at his chest that kept on increasing by size in 2016, and they decided to have him checked by a physician. The patient underwent a biopsy procedure and had been diagnosed with lymphoma cancer in the same year. Her son did not drink alcoholic beverages, did not smoke and did not even go out at night to hang out with friends. But genetically, his late grandfather had colon cancer and his late third-degree cousin had lung cancer.

The physician advised them to have their son undergo chemotherapy, so they went to Southern Philippines Medical Center, Davao City and finished his six cycles of chemotherapy. They sacrificed their house and sold it for the treatment of her son. After the treatment, her son became well, and the lump at her son's chest was already gone. Her son should have a follow-up check-up after the chemotherapy, but her son refused to come back because he was already tired. Instead, he only asked to register him in a 24/7 food supplement organization for his maintenance, and he came back on his normal life.

But after 2 years, the nightmare of her son began again, he became weak, always had flu, and the lump that was gone for two years developed and grew at the lower part of his armpit and metastasized on the other parts of his body. They did not have it checked by a physician and relied only on food supplement that he used to take due to financial problem.

Ana took care of her son for three months of becoming terminally-ill. He was close to death and very weak. She has to attend to all the needs of her son like preparing his meals, bathing the patient, massaging his body, and giving him his medications like pain relievers. He seems to be so irritable, he always shouts and calls the respondent to attend to all his needs.

Ana pitied her suffering son and what she can do was to pray for her son's condition. According to Ana, her son felt self-pity. He even tried committing suicide several times to end his sufferings. They did not leave the patient alone in his room, and they watched him 24/7.

Ana encountered many problems and described it as "*perti kabudlay*" or "it is too difficult", especially with regards to financial matters and sleep patterns because whenever her son could not sleep she was not able to get some rest too. This was the everyday scenario in their house.

Two days before her son died, she had flu and did not address the needs of her son because she did not want her son to be infected. She blamed herself and stated, she did not now know that her son was going to die and she was not able to take care of her son at that period and she felt so bad. Her other children, husband, and other family members were there to help her to address the needs of her son before he died according to the respondent.

Ana had a hard time accepting that her son was already gone. She pitied her son because he was too young and he had many dreams. She got strength from her family and friends. Her son's death is still fresh to her. Everytime she sees her son's pictures, she cried. To ease the pain that she feels, she cries a lot and does the household chores to divert her feelings of missing her son.

Case Study # 2: Berna

Berna is 72 years old, female and a widow. The patient was her husband to whom she had 15 children. Her husband died last January 6, 2014 at the age of 74.

According to Berna, her husband was a farmer. He had vices like smoking and drinking alcohol. Her husband only suffered from cancer for a month. He experienced loss of appetite, abdominal distension, diarrhea, and body weakness. They admitted the patient at one of the hospitals in Tacurong City and undergone a colonoscopy procedure to get a biopsy sample. The result of the biopsy stated that the patient had colon cancer.

According to Berna, her husband did not want to get hospitalized because he felt that he could not last long and wished to stay at home and let all his family took care of him that was why his children made a way to go home.

The respondent was always at the side of the patient for a month of

being bedridden. As their daily routine together with her children, they were the one who fed him, bathed him, changed his diaper, exposed him to the sunlight on his wheelchair and giving him his medication. Whenever her husband needed something, he hardly called the respondent.

According to her, caring for a patient though at home is a tiring job due to lack of sleep and rest, and the patient always asked her and his children to fan him because he feels intense heat and pain inside his stomach.

With regards to financial aspects, the respondent did not have a problem with it because her children are providing funds for all the hospitalization, medications, and other needs of her husband. Even if the respondent did not get enough sleep and rest she thanked God of not having a health problem during the times that she took care of her husband.

The respondent described her job as a caregiver of her terminally-ill husband as *"syado kabudlay eh!"* or it means that it is tough, especially when her husband could not tolerate swallowing food anymore and they only blend fruits to feed him. The respondent also stated that if her children were not around watching her husband, she was not able to cope with the situation. Two (2) days before he died, his last will was to take a photo together with all his children and put it on a picture frame as a remembrance and it was granted.

When her husband died everyone in the family grieved and was filled with sadness. They even wished that the patient is still alive and lives with them although he is sick. The respondent got her strength from God, from her family and from her Senior Citizen family. She mourned for almost a year, as a diversional activity, she joined the Legion of Mary at the church and engaged herself to Senior citizen affairs.

Case Study # 3: Carla

Carla is 33 years old, female, and married. The patient was her eldest brother among her three (3) siblings. Her brother was single and died at the age of 29. Her late brother worked abroad as a seaman. An accident happened at the ship. The generator of the boat which was loaded with the chemicals exploded. He was locked inside the room and lost his consciousness. The captain brought him to a medical facility in Oakland City and underwent laboratory tests. They found out that he had lung cancer in 2015. He went back to the Philippines and underwent laser therapy in a hospital in Manila. After all the examinations, he went home in Tacurong City and planned to have chemotherapy in Davao City.

According to Carla, her brother being terminally-ill, suffered from muscle wasting, lack of sleep, restlessness and having a shortness of breath. Whatever he wanted or he needed, they attended it immediately because her brother was short-tempered. In attending the needs of her brother for almost four (4) months, she together with her mom and eldest daughter was the one who fed him, bathed him, gave him his medication, and strolled him around so he could divert the pain. The respondent was so anxious and did not know what she would feel for her brother.

In the entire duration of care, the respondent encountered problems like lack of sleep because the patient was restless. She had no time to do the household chores and to attend to her children because her time was focused on her brother. With regards to financial matters, they did not have a problem because her brother had enough savings for himself to spend for his hospitalization and medications. The respondent was there only to support him and take care of him.

According to her, it was really difficult to take care of a person with a disease compared to guarding an animal. Everything that the patient asks should be granted immediately. She did the bathing, wiping and washing of her brother after his bowel movement. The

respondent also stated that she developed phobia. Everytime she hears that someone in the family is in the hospital, she felt nervous. She does not want to go anymore at the hospital because she feels that her heart is crumpling. She developed nervousness because she witnessed the death and last breath of her brother.

According to Carla, before her brother died, they already accepted it that he is going to pass away. It was difficult for them to see him suffer everyday. After they lost her brother, she got her strength from her family and mourned for 2 months. She just prayed and strengthened her faith in God. That, it was just a trial that came in their life and will just pass.

Case Study # 4: Dina

Dina is a 28-year-old female and a single mom with two kids. She works as a cashier and earns Php 6,000 pesos per month. She is the fifth among her nine siblings. The patient was her mother, and she took care of her for two (2) months.

According to Dina, her mother always had a minor headache and had symptoms of flu. They did not have her checked by a physician. They only relied on over-the-counter medication. In August 2018, her mother underwent a CT Scan procedure and was found out that she had a brain cancer with a mild stroke.

According to her, being terminally-ill with brain cancer is manifested by headache and always having a feeling of not being well. Her mother needed to be always attended like feeding her on the right time, giving her medications, bathing her and all the care that she needed if possible.

In taking care of her mother, they did not have difficulties with it, because her mother was not irritable. When her head was aching, she just holds it with no complaints. The problem that she encountered was being financially hard-up. They were not financially stable especially in providing her medications and in feeding her because she has a mild stroke. Feeding her was quite difficult.

Dina pitied her mother and she was anxious about her mother's situation. She also experienced headache, flu, and dizziness due to lack of sleep. According to her, it was really difficult to take care of a patient with terminal cancer because she did not know what to do. Her mother could not talk and could not express what she wanted. Together with her siblings, they were able to provide all the necessary needs of their mother to the best they could. They were able to take turns in taking care of their mother so that each one can have a rest.

The respondent stated that *"kalain, kalian madulaan sang nanay, kung pwedi lang nga hindi lang sya mapatay, nga ara lang sya tani mabuhi lang sya"*. "It is a hideous feeling of losing a mother, and if it is possible that she will not die, I wish she is not. She is just here and alive."

Her mother died in August 2018. She grieved for a month. She got her strength and support from her siblings and children. As a coping mechanism, she just focused her attention on her children so that she will forget the death of her mother.

Case Study # 5: Elvira

Elvira is a 21-year-old, female and a single mom. She works as a vendor and earns a monthly income of Php 3,000 pesos. She is the second child among her four siblings. All siblings helped each other to provide and attend to the needed care of their mother. Her mother was a vendor and a farmer before.

According to the respondent, as a brief history of her mother's condition, her mother experienced heavy bleeding, so they consulted a physician and found out that she has ovarian cancer. In year 2014-2015, she was first admitted to one of the hospitals in

Davao City. She had her first treatment therapy which was the Brachytherapy (Internal Radiation Therapy) for 28 times at in Davao City. She also underwent 8 cycles of chemotherapy in one of the hospitals in Davao City, and another brachytherapy. After all the procedures there was still a tumor left. The size was like a 1 peso coin, so the physician conducted surgery, and the patient was declared free from tumor. After a year, she came back working at the farm and ate unhealthy and fatty foods which she believed caused her tumor to recur.

After 3 years, there was another struggle for her mother's life. The tumor that was gone came back and had already grown and developed at the lower part of her ovary. This caused the watery-like pus discharge coming from her vagina. When they first came back at the physician, it was seen through ultrasound that there was a 2.7 cm tumor that grew there. This time, she did not want to get any treatment. After 6 months the tumor almost tripled to its size that reached 7.6 cm, and that time they were relying everything to pain reliever and herbal medication.

When asked about her experience with her mother who had terminal cancer she said that the patient was in bed rest. It seems like there was no tomorrow, but she was fighting. According to her, aside from preparing her milk, feeding her, giving medication, bed bathing and attending all her needs, the most important care that she needed is love.

In communication, the respondent talked as lovely as she could at her mom but if the respondent could not attend immediately to her mother's needs, she was so irritable and angry. They were just shocked that her mother can throw the table and chairs even if she was terminally sick.

Dina's feelings about her mother's condition as a caregiver is *"kung ano ang gina batyag niya mabatyagan mo man ang kakapoy ng daw malooy kasiya"*. It means that she can feel the pain, tiredness, and pity for her mother but she did not want her mother to see it because her mother will become weaker, seeing them pitiful of her. According to the respondent, financial constraint posed as the major problem encountered as they just asked help from the Philippine Charity Sweepstakes Office (PCSO), Department of Social Welfare and Development (DSWD), barangay and her mother's siblings. According to her, the land inherited by her mother from her parents was already pawned to sustain her treatment. Second, she also got sick because of lack of sleep, dizziness, and stress. Her mother's stool seemed coming out from the vagina. She washed her even if it was so odorous and that caused her to lose her appetite.

According to Dina, it is really difficult to nurse a patient with terminal cancer. She acts and thinks like a child, and when she screams because of pain, she feels it too and she avoids to see her mother's situation. The patient also left her last will and it was painful on their side. She was trying to make conversation with her mother to divert her attention from pain and sometimes when her mother was upset she was blaming God. She even asked why her mother had to suffer. It was difficult to see her mother slowly dying. Some disciples of God went to their house and prayed for her mother to let her feel God's grace.

The respondent was able to take care of her mother, together with her siblings and father because she believed that her mother was able to take good care of her when she was little. The respondent also thinks that whenever she becomes sick like her mother, her child will take care of her too. The respondent thinks positively and just returning the favor to her mother. According to her, "God suffered for us, everyone has a problem too", that is why when she has vacant time she attends on a Sunday mass and put her siblings and child as her strength amidst trials in her life. She kept herself busy as a vendor and spent time with her child.

DISCUSSION

Relationship of the Caregiver to the Patient with Terminal Cancer

The findings of the study reveal that all of the respondents are closely related to the patients (2 are the children, 1 mother, 1 wife, and 1 sibling). Two of the respondents took care of their mothers, the other 3 respondents were the wife, mother, and sibling of the patients.

The findings imply that all of the respondents are immediate family members of the patients. According to Bellou and Gerogianni (2014), the family can satisfy the basic needs of the patient because at the same time family member can direct the patient to participate in self-care activities and can effectively face the complication of the illness.

As family members, they have the patience in dealing with the needs and irritability of the patients. They watched over the patient and showed concern all the time. In the psychological and emotional aspects of the patients, the respondents were able to assist and comfort them without any hesitation.

Challenging Roles as a Caregiver

According to the four (4) respondents, their role as caregiver was truly difficult, especially when attending to all the needs of the patients like bathing, feeding and changing a diaper because the patients were short-tempered whenever their needs are not attended immediately. It was also difficult for them due to lack of sleep, and they need to watch their patient 24 hours a day.

One of the respondents said that her son attempted to commit suicide due to self-pity and feeling of worthlessness. As a caregiver, witnessing such circumstances is very painful and stressful. The situation made her be more alert in watching the patient so that the same incident will not happen again.

Suicide is devastating, and the effects of death on family members and loved one of the person can be severe or far-reaching. Loved ones can be very afraid to talk about suicide for fear of judgment and condemnation- being blamed for the death of their family member. The extreme effects of suicide on the family member can be extreme isolation (Tracy, 2014).

On the other hand, one (1) respondent said that she did not have difficulties in caring for her mother because her mother was not irritable and did not complain of pain and whenever she felt the pain she just put her hands on her head and endure it.

The three (3) respondents said that they encountered problems, especially in financial matters, lack of sleep, tiredness and had experienced being sick taking care of their patients. The two (2) respondents did not have time to do other things because their time was focused on the patients. Only two respondents did not find finances as a problem. The following were the statements of the respondents about their challenges as caregivers:

"It is very difficult, if my son was not able to sleep, then I could not get some rest too, and in everyday living this was all we did to him."

"You can even feel shortness of breathing, and you did not know what you would feel for him."

"I developed a phobia, whenever I heard that someone in the family was in the hospital I felt nervous."

Despite the fatigue and restless days that the caregivers felt, the willingness to serve and provide care remained to them.

According to Hanratty, Holland, Jacoby, and Whitehead (2007), financial circumstances can play a significant contribution to quality of life for older people and maybe have a substantial influence on health and well-being at the end of life. Since most of the patients

and caregivers are not well-offed, some needs are not provided in their patients, especially the medical interventions that they need to undergo.

Sacrifices as Caregivers

One (1) of the respondents said that her responsibilities for her own family and children are sacrificed in lieu of the patient. Her mother who worked as an OFW sacrificed her work to provide care for their family member who was terminally-ill because of cancer.

One (1) of the respondents said that her children from abroad and from Manila sacrificed their work and came back home to grant the wish of their father to be complete and have their photo taken.

The other respondent said that their family already pawned their land properties to provide the needed care and treatment for her mother. One (1) of the respondents said that they sold their house and lot for the chemotherapy treatment of her son.

These experiences of the caregivers show that family members could not afford to see their patients suffer a lot, reason that they will exhaust all means to provide what the patients need.

Family members are usually the ones who provide the care needed by the patients on an unpaid basis. They sacrifice even their own financial, medical and social needs to do it (Grossfield, 2018).

Managing Pain after the Patient's Death

Four (4) of the respondents said that they spent their time with their family and devoted themselves to work and other social affairs to forget the painful experience of losing a loved one. One (1) of the respondents said she was offering all to God and thought it is just a trial.

According to Johnston and Johnston (1998), "coping is defined as what people do to try to minimize stress and is commonly seen in health psychology as problem-focused (to gather information), that is directed at reducing the threats and losses of the illness or emotional-focused (to express emotions), namely directed at reducing the negative emotional consequences and relationship-focused coping (to maintain relationship with others)."

This kind of coping strategies was beneficial to the respondents because they diverted their loneliness and sadness in the thing that could ease the pain. They also found happiness to it and found acceptance as time passes by.

Montilla, Marin, and Martin (2017) suggest that the main coping strategies one may explore are the following: searching family member, finding information, social or spiritual support, acceptance, and improved self-esteem. As a result, using this type of coping strategies can help us divert pain to other activities like talking to other and finding support to others, to find courage in every situation or challenge that may arise.

The Respondents

The age of the respondents ranges from 21-72 years old. All of them were female. Three (3) of them are married, and the other two (2) are both single mothers. They are engaged in business, a vendor, cashier, and a full-time housekeeper. Two (2) of them were college graduates, the other two (2) were high school graduates, and one (1) of them finished elementary level.

Younger caregivers may have a greater need for resource input than older carers and have greater effectiveness in obtaining the care. Younger carers also reportedly adopt more problem-focused coping than older carers. Nevertheless older carers are more likely to suffer age-related disability and ill health (Barclay, Farquhar, Grande & Todd, 2006).

The household size of the respondents ranges from 4 to 6 members

per family. Majority of the respondents had a short duration of caring for their loved one before they died. All of them are immediate members of the family.

According to Chin, et al (2011), the most commonly identified barriers to care for patients according to the caregivers included a lack of social support, insurance/financial concerns, and problems communicating with healthcare providers. In this study, insurance or financial matters was the primary constraint of the families in providing the needed medical services and physical demand of the patients. They could not afford to pay or hire the services of others as their alternate caregivers, so they too can take a break and regain strength.

Conclusion

Based on the findings of this study, it is concluded that the caregivers of terminally-ill cancer patients, experienced physical, psychological and financial difficulties as they care for their patients but were able to cope with the help of the family and their faith in religion. The similarities in the challenges encountered by the caregivers are brought about by almost the same experiences of patients who have cancer.

Recommendations

1. A seminar may be conducted for the caregivers and other family members of terminally-ill cancer patients especially after the chemotherapy procedure for proper knowledge and skills for taking care of the patient's needs.
2. Expand utilization of other governments support like DSWD for availing a PWD ID where discounts could be availed to ease medical expenses.
3. Local Government Unit may provide health services assistance for patients with terminal cancer cases, especially for the less fortunate ones.
4. Psychologist or Counselors may train the Barangay Health Workers to assist the caregivers in the delivery of care in the communities.

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