Patients with Breast Cancer: Care in the Eyes of their Caregivers

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Abstract

Previous quantitative studies have been conducted on breast cancer patients in terms of understanding and comprehending the nature of the disease. However, little is known about the lived experiences of caregivers of breast cancer patients. The study aimed to understand the lived experiences of caregivers of patients with breast cancer.

A Gadamerian-phenomenological approach and Van Manen methodological approach were used in the study. Data were collected using in-depth individual interviews. Researchers utilized unstructured which was aided with audio and/or video recorders. Seven participants included, who provide regular assistance in their activities of daily living, whose age from 21-65. Data transcription and analysis used van Manen’s hermeneutic phenomenological approach.

The meaning of lived experiences of caregivers of patients with breast cancer revealed thematic categories: caregivers being human, challenges as a caregiver thoughts and emotions emerging, lifting life above illness, caring as a choice, support despite challenges, strengthened relationship, light during darkness, escape amidst difficulties, accepting inevitable death, accepting a loss of a loved one.

It revealed that there is diversity in caregiving experiences among the participants despite going through the same situation, sharing nearly similar experiences of giving care to these patients. The study asserts that there is universality of the caregiving phenomenon across cultures similar or otherwise even with subsets of smaller cultures.

The study can potentially benefit any agencies or institutions that renders care to patient with cancer. This study can potentially add credence to their efforts of providing support mechanisms to the caregivers of breast cancer patients.

Keywords: Lived Experiences, Caregivers, Breast Cancer, Van Manen, Gadamerian, Hermeneutics.

Introduction

Cancer has been a prevailing chronic illness throughout the world and in the Philippines. It is a leading cause of death worldwide, accounting for 8.2 million deaths in 2012 (Ferlay, 2013). Particularly, breast cancer is the most common cancer among women and is ranked as the world’s 5th most common type of cancer, causing 521,000 deaths around the world (Bray, 2012). Cancer and cancer treatments not only affect the patient, but also the people who are responsible for the well-being of these patients. These people are usually families or caregivers who are faced with such daunting and exhaustive tasks such as helping the patient with medication, doctor’s consultation and many more.

A caregiver is a person whose role has traditionally included those activities that assist the client physically and psychologically while preserving the client’s dignities (Girgis, 2013). Caregivers may be spouses, partners, children, relatives, or friends who help the patient with activities of daily living and health care needs at home (Garnand, 2013). It also includes giving emotional and spiritual support, such as helping the patient deal with feelings and making hard decisions.

Further research was also needed in order to foster the caregivers of breast cancer patients’ experiences of living in hope, wherein nursing activities were required in order to facilitate the caregivers’ entering into the state of recollection. It was therefore for this reason that
this study was conducted in order to address the gap of previous studies that have been conducted.

Little is known about the lived experiences of caregivers of these breast cancer patients. LoBiondo-Wood (2013) cited in his survey that one of the top research priorities for oncology nursing research is the family and caregivers’ intervention that is why the researchers were able to raise our grand question “What are your experiences as a caregiver to a patient with breast cancer?” The researchers utilized the Van Manen methodology for gathering data and analysis. The Gadamerian hermeneutical approach as the underpinning philosophical perspective of the study.

The study aimed to describe the meaning of the lived experiences of caregivers of patients with breast cancer.

**Methods**

A hermeneutic phenomenological Gadamerian approach was used as the underpinning philosophical perspective to analyses and interpret the lived experiences of caregivers of patients with breast cancer. The purpose of this approach was to know and understand the lived experiences of caregivers in order “to gain information” or “to collect data” albeit seemingly an incorrect expression in a Gadamerian sense (Fleming, 2003), therefore the use of the term “gaining understanding” of the caregivers’ lived phenomenon prevailed throughout the research process. In addition, van Manen’s (1990) description of the life worlds were used to structure the meanings of the experiences, namely: lived body, lived time, lived space and lived relation.

**Setting and participants**

There were seven participants included and participated caregivers of patients with breast cancer, who provided regular assistance in their activities of daily living, whose age ranges from 18 to 65 years old, three participants were men and four participants were women regardless of their socio-economic status and how long they have assumed the role of being caregivers. Where there may be multiple caregivers of a particular breast cancer patient, they were be considered as participants for the purpose of maximum variation. They may be immediate family members or persons related to them by consanguinity. The researchers excluded caregivers with psychological illnesses or with altered cognitive function which was determined through an exploratory question prior to the content interview (see Appendix E). The number of participants depended on saturation. This study was conducted in Baguio City, La Union, and Pangasinan.

**Sampling**

The researchers utilized a purposive-convenience maximum variation sampling. Purposive means selecting a participant that generates useful data for our study (Burnard, 2004). It was utilized with the help of referral system to identify potential participants that passed in the researcher’s inclusion criteria through personal contacts and word-of-mouth (Kongsuwan W. Y., 2016). Maximum variation was also utilized sampling wherein it involves selecting caregivers who are caring for patients with breast cancer whether in the short or long-term basis and caregivers of either newly diagnosed or long before diagnosed patients with breast cancer.

**Data gathering tools**

The researchers utilized unstructured interviews in eliciting the lived experiences of the participants which was aided with audio and/or video recorders if allowed by the participants during the interview proper.

**Data gathering procedure**

The researchers submitted the proposal to the Saint Louis University Research Ethics Committee last December 2016. In the event that the Research Ethics Committee had disapproved the study, the researchers made the necessary revisions until approval. The researchers looked for caregivers of patients with breast cancer, which fit the inclusion criteria through referral systems. The researchers then administered an informed consent that protects the rights of the participants. Before obtaining the informed consent to the participants, the researchers explained what the research was all about, the risks and the benefits. The researchers informed the participants that they may refuse to participate in the study, or may withdraw at any point of time during the study. The main data gathering tool was through in-depth individual interview.
The researchers continued collecting data from the participants. The researchers conducted two follow up interviews in each participant and it was done within the study in order to facilitate the hermeneutic circle and engage the data in a guided approach. When there was enough information that seems to replicate or duplicate the themes and the ability to obtain additional new information has been attained, further interview was ceased. This was when coding may no longer be feasible as saturation has been achieved (Guest, 2006).

Data analysis

Following each interview, the researchers transcribed the acquired data into a script of the interview. The transcribers transcribed the interview using the following formatting: Arial 12-point face-font; one-inch top, bottom, right, and left margins; all texts began at the left-hand margin (no indents); the entire document was left justified.

The participant’s comments/responses began in the next line in the first column of the box. Audiotapes or video recordings were transcribed verbatim, that is word for word or exactly as said. It was included any nonverbal or background sounds like laughter, sighs, coughs, claps, snaps, gestures, facial expressions, pen licking, voice inflections, etc. Nonverbal sounds and gestures were typed in parentheses.

The transcribers and all researchers had proofread all transcriptions against the audio or video recording several times until all came to an agreement as to the accuracy of the transcription. The transcriber listened to the tape for three times against the transcript before it was submitted for appraisal by other researchers. All transcripts were audited for accuracy by all researchers.

Analysis of the data was achieved through the Max Van Manen phenomenological approach. The data analysis process involves the phases of immersion, theoretical and open coding, creation of categories and thematic analysis.

The researchers listened and viewed the recording through laptop and simultaneously transcribed. After the researchers watched the videos and transcribed the interview into its linguistic form, they are coded according to whether it was the first or second interview. First interviews were coded as colored blue and second interview were coded as colored orange.

We utilized simple topic coding wherein the text is labeled according to its context/subjects/theme. The transcripts are now ready for theming. First, we identify a basic theme that was derived from the textual data these are themes that are simple premises characteristic of the data. Second, we identify the organizing theme, these are clusters of basic themes of similar issues it summarizes the principal assumptions of a group of basic themes which are more revealing of what is going on in the texts. Lastly, we identify the global theme, this are super-ordinate themes that encompasses the principal metaphors in the data as a whole, under this are the four life worlds.

Strengths and limitations

An important limitation of the study is that only 7 participants took part, and most of them were their own relative or are related by blood. Although participants were recruited until saturation was achieved, more participants may have been recruited from a wider pool with close to similarities in characteristics as possible. While caregivers can be classified with more specific or definite categories, due to the availability of the study population that presented itself to the researchers at the time of looking for them, the researchers merely lumped all caregivers as a singular category.

Another limitation of the study is that these participants were not analyses with respect to the specific career and the dyadic relationship between the patients and their daughters, sons, and wives that might have had specific thoughts or perception in relation to the caring responsibilities and their role in the family as this could not be determined. The researchers’ own depth of experience with caregiving, and being novices with this process and the research approach may be biased, incomplete or to a larger extent not sufficiently sanguine.

The in-depth engagement in the text, the transparency in, and the level of expertise of the researcher students may demonstrate a simple but modest rigor of the study. The varied sources of viewpoints in this aspect added abundantly to the tone and tenet of this study. Another strength is its usefulness in relation to the paucity of research knowledge about the experience of caring mindfully in tertiary education.
Ethical considerations

Before the study was conducted, ethical principles were applied to ensure the rights of the participants. The researchers obtained an informed consent from the participants. The researchers assigned codenames or pseudonyms to the participants in order to observe confidentiality and prevent any external factors affecting the data’s credibility during the transcription of data. Credibility of the data was obtained through transcribing the data immediately right after interview to prevent a threat to history and through member checks wherein we validated all transcription of the data to the participants. The researchers applied the duty of beneficence in the study. The participants were given the autonomy to verbalize their experiences as well as their concerns.

The study did not provide monetary incentive to the participants to prevent distortion in the eliciting of lived experiences of the caregivers. To safeguard the collected data, the group assigned one member who was responsible in storing the information in a secure location. The research promoters of the group were the one who took over and gave necessary advices that was needed.

Trustworthiness of the study

To ensure the accuracy and reliability of the data collected, the researchers utilized several techniques to help improve accuracy, credibility, validity and transferability of the study. Member checking was done wherein participants were given their transcripts and the research reports that allowed the participants to agree or disagree with the researchers’ findings. In addition, credibility was built up through prolonged engagement in the text through transcribing the interview, translating and reading it more than three times and persistent observations during data collection. Transferability was achieved through a detailed report of the setting in which the study was conducted in order to compare the applicability of the findings for other possible settings. An audit trail was done wherein documented data, methods and decisions about the research was laid open to external scrutiny by the research promoters and contacted experts. Lastly, triangulation of data was employed in order to facilitate validation of the collected data through cross verification among the members of the research team.

Findings and discussion

Caregiving experience

People practically take on a caregiver role at some point in time as a part of filial duty especially in Asian cultures specifically in the Philippine context. To understand the meaning of experiences of participants caring for patients with breast cancer, describing the context is needed. Van Manen stated four life worlds in understanding these meanings.

Lived relation

This is described as the connection and relationship of the participants to the breast cancer patients. This theme is categorized in subthemes.

A. Caring as a choice

This involves the desire of the participants to assume responsibilities to takecare of the patients. This includes the purposes or reasons in taking care of the patients. The desire of participant to take the responsibility of being a caregiver is included here. Reasons mentioned by participants were, being a family member, the patient resides with them and lastly is the feeling of commitment of the participant to provide care to the patient being a her or his friend.

First, verbalized by participants was being part of the family. In one of the studies, it was described that family members play an important part in providing care and take on different roles as caregivers for patients with chronic diseases (Nolan 2001, Fisher & Weihs 2000, Gillick 2013). In the Filipino context, as experienced by the researchers, Filipino families are very family-oriented. For the caregivers, it is a natural thing to do. They assume the caregiver role because as a part of the family, we have a sense of responsibility towards the other members of the family. In addition, participants assume the caregiver role because no one among their family members can take care of the patient because most of them are busy in their own families.

Second of the reasons, was that participant assuming the caregiver role lives in the same house as person with breast cancer. Caregivers
feel that they are obliged to take care of patient because they feel that they need to help, because they co-habitate with them.

Last of the reasons, aside from assuming the caregiver role of a blood-related relationship is commitment. One of the participants verbalized that it was innate of her to assume being a caregiver due to her desire to rich out and offer her services to her friend even it is not demanded.

Fishbein & Azjen(1975) introduced the concept of behavioral intention which is the ultimate cause of behavior. Behavioral intention or the person’s motivation to engage in behavior was defined as the psychological construct through which attitudes influence a behavior (Fishbein & Azjen, 1975). Since the caregivers are related to the cancer patients either by blood or by a strong bond of friendship, this makes them have the motivation to assume the caregiver role. They are being motivated because they feel that they have the responsibility to take care of them as a personal subjective. And through this motivation, they perform the care giving roles accordingly.

The word “family” in the Philippines does not only include blood-related family members but further extends to non-blood related relationships. It is common among Filipino families that it is innate of us to help and fulfill their filial duties within their families. Another subtheme under lived relation is support despite challenges of being a caregiver.

**B. Support despite challenges**

In this area, support for the caregivers comes in various forms. Generally, support system pertains to anything that basically gave support to the caregiver. This may be identified as social support, emotional support or financial support. As shared by the participants, the researchers were able to identify and divide support into two, which are social support and physical support.

Social support is a recurrent phenomenon present in the caregiving experience wherein the other family member or relative uplifts feeling, other than in physical means, of the caregiver to lessen the burden of the caregiving experience. In terms of physical support, family members and friends have assisted their patients in their activities of daily living. Caregivers perceive physical support when a family relative or friend engages in an activity that lowers the burden of the caregiver while providing aid to the patient. One participant shared that the patient’s husband usually works during the day and comes home in the afternoon. Whenever he has free time or is off from work, he helps in the care of the patient with breast cancer. Another participant, Miss Orange, considers her sister as a support specially in performing other task towards the patient. Financial support was also important for the caregivers as it is necessary for the continual care for the patients with breast cancer. Financial support usually comes from family or relatives working abroad who are able to allay the expenses of treatment or their daily expenses or from the family themselves who are faced with the financial hardship.

**C. Strengthened relationship**

This refers to the event that happen when the participant and the patient develops a tight and fruitful relationship during the breast cancer experience until the recovery or survival or before the patient had their peaceful death and also before the occurrence of breast cancer to the patient.

Mr. Violet stated, “We showed more love with each other, become passionate to each other.” The relationship was a lot closer during the disease process. Mr. Violet also stated that they showed more strong feelings to each other other by spending time with each other more during the course of the disease. This behavior confirms that families realize that simply spending time with the patient was helpful not only to the patient but also to the caregivers as well (Peeranuch LeSeure and Supaporn Chongkham-ang, 2015).

In times of crises families tend to be closer with each other especially if there is sick family member. Asians are group-oriented. Filipinos tend to come together as a group or as a family to show a sign of support to the sick family member (Kawato, 1995). In times of crisis Filipino families try to depend on each other and members tend to build a closer bond to show a meaningful indication of support.

Among families, Filipinos are very expressive to what they feel. Whenever they experience problems or crises, they tend to voice it out to others especially to their family members. Filipinos have a way of sensing and feeling each other’s behavior or indirectly communicated.
intention through “pahiwatig” (implying) or “pakiramadaman” (a gut feeling).

D. Light during darkness

Spirituality is the belief on a higher power. In the Philippine context, many of its people strongly believe in a God as a giver of life and as a source of salvation from harm. Most Filipinos are Roman Catholic. The rest are scattered to other sects, dominions, religions and belief. Spirituality is belief in the union of a person to nature, or to other people, or to a Supreme Being. It is not limited to the beliefs but also to the traditional practices, rituals, and symbols of expressions their faith. Among all Asian countries, the Philippines is the only country with a predominantly Catholic population (Goh, 2005). Usually, Filipino Catholics search out for strength from Christian beliefs, practices and customs that aid them in dealing with every day challenges.

Spirituality greatly contributes in palliative care. As to this study, all the participants used the concept of spirituality in rendering care to their patient. The participants were all Christians but they belonged to different dominions like giving process. It also refers to the physical, emotional status and reactions felt by the participants toward the patients.

A. Caregivers being human

Caregivers as human beings are known to experience different emotions in different situations. The concept of ‘being human’ does not have a definite or universal definition but some literature defines being human as a means of preserving dignity through self-purpose, emotional and physical ties towards others (Togashi, 2014). Taking care of a loved one is something innate in life, living and existence of humankind (Bevis, 1981, Benner, 1984, Watson & Smith, 2002). It can be argued that caregiving is associated with the caregiver’s encounter regarding their limitations and inadequacies.

Caregivers provide nearly every form of support for their patient during the illness. Throughout this time, they experience hardships and difficulties because as human being, they become vulnerable to the stress or burden of caregiving. Being human is defined as someone who perceives and experiences different emotions such as fear, denial, sadness, feeling of shock, being optimistic and any other human Jehovah’s Witness, Mormon, and Roman Catholic. As Christians, being spiritual is believing in spirits and a higher power which is God, spirit is the essence of who they are as people and within that person they have a body, a mind and form relationships with people who are important to them (Lugton & McIntyre, 2005).

As a Christian, praying is a part of their spiritual belief. They believed that praying to God alleviates the suffering of someone and prayer can help the caregiver lessen the burden of care giving and to make the family relationship stronger (Herrera, Lee, Nanyongo, Laufman, & Torres-Vigil, 2009; Kloosterhouse & Ames, 2002; Pearce, 2005; Trelor, 2002). Spirituality helped family caregivers find meaning and purpose in stressful situations, sustaining their psychological wellbeing. Caregivers used religiousness or spirituality as a coping mechanism and a way of strengthening the relationship with the patient.

I. Lived body

This refers to the experiences of the participants within themselves during the care emotion commonly shared by humankind or society. As humans, caregivers suffer from various or different problems and they tend to cope with such experiences.

B. Challenges as a caregiver

These are the actions undertaken by the participants while caring for their patients. This involves necessary activities from the time of the diagnosis to the medical treatment until the recovery or demise of the patient with breast cancer.

Family caregivers in cancer care are individuals who provide uncompensated care and health-related assistance to a family member who has cancer (Effendy, et al., 2014) Most of the time, the caregivers usually stays with the patient. The activities done primarily by the caregivers were focused on assisting the patient in doing the activities of daily living such as bathing, feeding, preparing the things that they need, helping to clean their wound and accompanying her to the hospital. It is not only on the physical aspect of caring but also includes psychosocial aspects like sharing stories with the patient as a way of diverting the attention.
The holistic care given by the caregivers show how devoted they are to their patients. Even if they are being faced with a lot of challenges brought about these activities, they still continue to take care of their patients. Caregivers give holistic support; they want to give all their best so that their patient will be able to recover and survive the cancer. Motivation in giving care for the patient is towards the healing and recovery of the patient which affects the quality of care being given. After all the activities of the caregiver were done, feeling of relief and satisfaction during the care giving process is present when their family members or loved ones are able to survive cancer or lead to a peaceful death. Three subthemes occurred under this theme, these are: a) Characteristics of a caregiver, b) Perceptions and emotions of a caregiver, and c) Keeping my mind off it.

1 Characteristics of a caregiver

The characteristics of a caregiver are the participants’ traits while taking care of their patients and may influence the outcome of their caregiving experience. It differs from person to person and it can be positive or negative. This includes caregivers being zealous and resilient the term ‘resilience’ is used by Elnasseh et al. (2016) to refer to a psychological phenomenon that uses effective coping and adaptation strategies when faced with difficulties or adversities in life. Empathetic, empathy is defined by Olson and Kunyk (2004) as the ability to project understanding for both the patient’s feelings and the reasons for them. As caregivers, they understand what the patient is going through physically from the symptoms to the side effects of their treatment. Being optimistic, optimism is viewed as a state of being positive despite experiencing unfavorable events or difficulties. Caregivers who are optimistic see their positive actions produce a favorable outcome. It is also connected with less stress and less symptoms of depression meaning better mental condition for the caregiver (Elnasseh et al., 2016). LeSeure and Chongkham-ang (2015) observed that some caregivers tend to compare themselves with other people who are in worse situations.

A. Thoughts and emotions emerging

The perceptions of a caregiver are ways of understanding and interpreting something to create a mental impression and would be their attitudes towards caregiving. This affects their consciousness and their ability to provide the care they are supposed to give. Emotions are what the caregivers were feeling while taking care of their loved ones. Seven (7) subthemes further emerged, namely a) Fearful, b) Denial, c) Shock, d) Sadness, e) Guilt, f) Overwhelmed, g) Burdened.

Being fearful is one the unpleasant feeling that was experienced by our participants characterized by an anticipation of possible danger or by an anxious concern. Fear itself causes the participants to be in awe, panic, alarm, or dread while taking care of the cancer patients. In the studies of (May, 1950) & (Wolman, 1978) fear was defined as a temporary reaction and an emotional response to a specific real or unreal danger. Fear was the prevalent emotion experienced by the caregivers. It is connected with uncertainty of the future, the potential loss of a loved one, and a fear of cancer recurrence.

Being in shock is felt by the participants when the care giving experience becomes suddenly upsetting to them. Receiving the news that their loved one was diagnosed with cancer is a shock because the caregivers perceived that cancer was a life-threatening disease (LeSeure, 2015). Cancer is a life-threatening illness that affects not only the patient but also the caregiver and the family where he belongs.

Denial refers to the person’s tendency to fight off an unwanted event by not acknowledging that it is real. For Freud (1953), when a person experienced an unwanted event, they tend not to believe at first. Roing et al. (2008) defines denial as a feeling of grief and frustration at how bad the situation is and thinking of how did it even happen to them.

Guilt, some caregivers have feelings of guilt towards their ill loved ones and sometimes they even feel guilt for being healthy compared to their sick significant others (Otis-Green and Juarez, 2012). Hoffman (2000) views guilt as a feeling described as being regretful and tensed that emerges from the feeling of empathy for the
loved one and thinks that it is their fault for the loved one’s suffering.

overpowering thought or feeling. When a loved one’s condition gets worse, the caregivers may find their caregiving role as overwhelming (Otis-Green and Juarez, 2012). Caregivers’ daily activities were greatly affected due to the added amount of work and responsibilities that were formerly carried out by their loved ones due to their inability to provide for themselves.

Burdened and unburdened, feeling burdened is experienced by the participants when they feel that the care giving experience have caused them too much over load in work, duty, or responsibility and puts them in a difficult situation. Caregivers give holistic care to the breast cancer patients. The demands needed in the care giving process makes the participants feel burdened. The roles and responsibilities of a care giver become extended and difficult as the length of time is increased. The demands of caregiving often spawn additional stressors in caregivers’ lives, commonly referred to as caregiver burden. (Sautter, 2014)

The participant’s feeling of unburdened is associated with his religious belief. Despite of experiencing suffering and dwelling onto it, the participant found a positive meaning of losing his loved one because he knows that the patient is in the hand of the Lord. One of the techniques used by the participant is acceptance. The participant accepted the feeling of burden and surrendered it to the Lord. The participant’s emotion focused on regaining his self that he wanted to feel unburdened. It is very evident in the value of reciprocity, which is a practice still being used in modern Filipino society.

B. Lifting life above the illness

Lifting life above the illness for the participants is trying to find meaning in the caregiving experience despite of the overwhelming situations and emotions caregivers of breast cancer patients are going through. The participants managed to stay positive, have a closer relationship with the breast cancer patients and accept the inevitable death. These subthemes reflected are positivity, seeking for strength and searching for hope.

Being positive for the participant is when they are able to endure the experience and make it worthwhile. Being Positive states that instead of dwelling in sadness and sorrow for their life

Overwhelmed is typically defined as an and the patients’, some caregivers compared their situation to other peoples’ who had more problems (PeeranuchLeSeure,2015).

Seeking for strength, despite of the overwhelming experience that the caregivers are experiencing, looking for strength for the participant is when they are looking for source of power and solitude which makes them able to be strong not only for themselves but also for the participants. Looking for strength is the state of being strong physically, mentally, emotionally, and psychologically, it is dealing with problems in a determined and effective way.

Searching for hope, searching for hope is the state of wanting something to happen or be true. It is the chance that something good will happen despite of circumstance. Coping strategies needed in anticipating an event may often conflict with the strategies needed to anticipate the events’ non-occurrence. In their study, the spouses enjoyed thoughts of planning for a future with their partner, yet thoughts of planning for the future without their partner were forbidden, and quickly thrown out of their minds (Lazarus and Folkman, 1996). It states under Searching for Hope that Hope was tangible and important to the daily life of the caregivers. It gave the caregivers courage to support their loved one. “Hope is about making the best of a bad situation and moving on.” It states that hope was not only important for the caregivers to have a positive attitude, but the caregivers believed that it was also helpful for the patients (Peeranuch Le Seure 2015).

II. Lived space

This refers to an event during the participants’ experience where they had to search for haven where they can be free or just rest for a while after an exhaustive day. This may pertain to places, activities, or things they go to or perform to provide the space from taking care of their patients.

Participants find things they enjoy to do or company to be with to keep themselves away from the situation temporarily; this is to provide a refreshed mind when they go back to the caregiving process. These activities are helpful to them when they feel exhausted about their situation, about the situation of the patient.
A. Escape amidst difficulties

This refers when the participants temporarily get out of the situation temporarily because of the laborious and stressful demands of the care giving experience. Caregivers needed time to get out of the situation temporarily to maintain a well state of mind. A study discussed by (Chongkham-ang, 2015, p. 421) stresses that caregivers can feel negative emotions on the process of caregiving some of this are feeling of being overwhelmed, frustrated and exhausted; thus, getting their thoughts off an unpleasant situation had helped them regain balance in their mind and recover their strength. Sub themes identified were being a pet lover participant get away from the situation temporarily is through taking care of pets. Hobbies rules, another way on how the participant gets away from the situation temporarily is through cooking. For the participant, cooking becomes a diversional activity because the steps involved in cooking needs focus and attention to what they cook. Instead of focusing on the stress implied in caring for the cancer patient, the focus is being transferred to the activity of the participant such as cooking. Coffee break, another way on how the participants get away from the situation temporarily is through going out with friends. In the statement of Miss Green, she managed to have a time to go out with her friends to have coffee; she also added that having a different topic with friends had helped her divert her attention. Diversional activities, focusing on one thing gives redirection to the participant’s activities. Instead of focusing on so many things, the participant is able to limit their activities to focus on one particular activity. Keeping the mind out of the loss of the loved one It is in uncertain for the participants to not think about their patients during the course of the experience. But keeping the mind out of the loss of the loved one is done by the participants to get out of their stressful situation that happened when their patient die.

III. Lived time

Lived time is flow of the time in every moment of the experiences to both the care giver and the breast cancer patient. Lived time is further experienced in the following events.

A. Accepting the inevitable death

Accepting the inevitable death happens when the participants were able to accept the possibility of losing their loved one because of breast cancer. It is when the participants are able to endure the possibility of death brought about cancer without any protests.

Subthemes developed are; Hopeless and belief in life after death. Hopelessness is the feeling of something that is unreachable or impossible to meet, that nothing is going to resolve a certain problem or situation. Feeling of hopeless is sometimes accompanied by feeling of giving up. According to Han et al., (2013) hope is when a person is experiencing a tragedy and there is nothing, he/she can do to fix it.

In the Philippines, even though it cost them a lot of money they will still seek for more options because there are people who can lend them money like friends or family member/s. But even if the participant did her best and it was God’s will, there is nothing she can do because it is the plan of God and it is God who will decide as to what will be the person’s destiny. The best response of the participant is to accept the destiny of the patient that it is God’s will and there is nothing she can do.

Belief in life after death, belief that after a person dies, he or she would live in a concept of heaven or hell. It is a belief in the other life of a person after he or she passes away will be living with a God. According to Boyraz et al., (2015) life after death is categorized as approach acceptance in his study. Approach acceptance is religion-related dimension wherein if a person dies, a happy afterlife is about to come.

Hoping for a peaceful and pleasant life is what the participants would ask for their dying loved ones (Kongsuwan and Chaipetch, 2011). The participant believed that there is life after death, a peaceful life and place together with God. Suffering or burden or any other negative experiences or event is not present or would not happen in that life. The participant also thanked God for taking the patient’s suffering as well as the participant’s by ending the patient’s life because not only that the patent will suffer more if she lived with cancer but also the participant and the other family members.
B. Accepting the loss of a loved one

Accepting the loss of a loved one happens when the participants were able to face the fact that their loved ones already departed. This is a time when the participants were able to let go without any hindrance about the death of their loved one. This is when the participant believes that there is life after death and the notion that the death of a loved one is something that comes from the will of God. The third dimension is the escape acceptance. This is when the participant views the death of the breast cancer patient as a relief and as an escape from suffering.

The figure below summarizes the study’s findings through the themes explicated using Van Manen’s methodological approach. The circle represents the four life worlds under Van Manen specifically Lived Body, Lived Relation, Lived Space and Lived Time. Under these global themes, organizing themes have been identified which in turn show the basic themes of the lived experiences of the participants. The arrows represent interchangeability among the themes.

Implications

Implication for practice

The findings of the study give a valuable and reliable resource for nursing practice that involves exploration of caregiving experience of people taking care of patients with breast cancer. The meaning of the experience of caring for patients with breast cancer among participants presents a diverse attitude, perception and activities. It was presented under four life worlds by Van Manen, lived relation, lived space, lived time and lived body. Nurses in the global arena can reflect on these processes of the caregivers’ experiences. Caregiving experience for some participants maybe distressing, if not given appropriate attention, this can lead to psychological problems such as depression. Interventions such as counseling may be at help in preventing such catastrophic event among participants.

Implication for research

The findings also encourage researchers to stimulate an appreciation of cultural-specific studies about the caregiving experience. Global health organization and associations of reality. The reality that the patient is about to pass away, that there is no chance of the patient to be able to survive and that the only thing to do is to accept the situation. Also, to accept the oncologic care should strengthen policies to integrate care services concerning caregivers of patients with cancer. Further study is recommended to develop a practice model of care to address caregivers’ needs in general. The meanings of the experience could be used to develop a tool to measure the wellbeing of participants. Such tool could be used as an instrument to determine ultimate outcome of palliative care to cancer patients if necessary, especially involving significant others directly involve on their care.

Assertions

Caregivers of breast cancer patients undergo a multitude of experiences while caring for their patients. There appears to be a variety of how these caregivers express and portray their caregiving roles to their patients. Although varied, in the researcher’s point of view, these individual caregiver experiences when deciphered and deduced in a dialogical manner with the researchers’ and participants’ interpretation congregate into something common to all of them. The universality of understanding of these lived experiences seem to affirm Gadamer’s second central position or tenet that the participant who has lived the experience and the persons who understands their experience are connected by a collective human consciousness which makes understanding of the phenomenon of caring rather possible. This human consciousness of caring also appears to transcend across cultures and the religio-spiritual belief. There is a notion that caring as a phenomenon is a mutual experience between caregivers even if they belong to different traditions, in this study the Filipinos with subset cultures like the Ilocanos, Pangasinenses, and Tagalogs. This collective is similar to those espoused in the several literatures also portraying the caregiving phenomenon in other countries as discussed earlier. On another bearing of this study, the caregiving experience among this study’s participants also appear to have a communal human consciousness albeit the patient of breast cancer’s period of life, that of the time of cancer diagnosis to the patient’s
demise and even beyond the period of the family’s grieving phase.

**Figure 1.** Core phenomenology of caregivers of patients with breast cancer

*Caregivers being human* are the participants’ expressions of feelings and ways of behaving as outcomes of the usual and common life occurrences of a typical human interaction with another person needing caregiving. The *challenges as a caregiver* are the characteristics of the caregiver that makes them hard-wearing and ever-ready against the travails of caregiving. The *thoughts and emotions emerging* came forth as these were necessary to toughen the caregiver to face the hardships of burden the caregiving. The humanness also entails the caregiver to show human emotions like being fearful, being in denial, guilt, shock, being overwhelmed, being burdened and being likewise unburdened. Caregivers need to use strategies to support their ordeals. To *lift their life above illness* comprises being optimistic, seeking for strength, and searching for hope. These encumbrances the variety of techniques by which the caregivers would eventually fend for the remainder of their lives after the caregiving event. The gamut of emotions and feelings appear to be common reactions to similar life occurrences. There exists to be some semblance of synchronicity of these human sentiments with an analogous event or incident such as caring for a sick person. The relevant contention of reflection brought forth before a hermeneutic stand for the researchers is that whether these emotions are predictable human behaviors and therefore whether human emotions have been learned as a course of doing an action or where these emotions are unconscious products of understanding.

Another important fact is that caregivers need to have several activities to keep their mind away from the stress and strain of their experience. A host of activities like hobbies and a simple divisional activity appear to enhance their breathing room. Their special integrity is kept healthy by these activities. People need to have a space for themselves.

Caregiving as a phenomenon also entails that the social interaction between and among the caregiver, the patient and their families develop some form of affiliation be it a mere link or a deeper form of affiliation. This seem to be a logical consequence of human interaction where one’s point of view of life events or understandings are muddled together to become
a shared awareness and appreciation of the experience.

A corollary offshoot of the caregiving phenomenon especially with the course of the disease of patients with breast cancer is the acceptance of death or the eventual loss of the patient. It also looks as if these learned helplessness of being unable to control death of a loved one sooner or later develops one’s ability to survive the experience. People appear to learn these abilities to manage and cope with the loss may be because of the length of time it took them to care for a patient with breast cancer, the concept of the inevitability of death, or a relentless exposure to death and dying. From a hermeneutic point of view, the researchers feel that this may lead to a notion of learned resilience.

**Reflection**

In Gadamer’s form of phenomenology, the personal involvement of the researchers and those of the participants in the manner of interpretation that derives an understanding of the caregiving phenomenon cannot be disentangled from each other. In this study, the researchers feel that this is where Gadamer’s first intention of consciousness of prejudgment or preconceptions and prejudices emerges as transcendent rather than a usual germane point. The researchers as student nurses took care of a variety of patients in their clinical exposures. The research promoters had a long bout of supervising students caring for patients. These formed their prej udgments on the phenomenon.

**Recommendations**

This study worked as the starting point to further understand and interpret the lived experiences of the caregivers of patients with breast cancer in caring for their family members.

1. For health care providers, this can be a guide on health promotion activities such as dealing with caring for patients with breast cancer.

2. As for the field of nursing research, this study hoped to expand the findings that can be used in creating a guide for nursing practice, policymaking, and information dissemination.

3. This study can potentially add credence to their efforts of providing support mechanisms to the caregivers.

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