“Swinging Pendulum”: Lives of Family Members Caring for A Dying Relative

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ABSTRACT

Among cultures which place emphasis on the centrality of family in ones lives, the care for the dying patient is more often than not delegated on family members. Given this context, it is interesting to note that few research have been done on the experiences of these individuals who provide care to their dying relatives.

This research aims to understand the lives of these informal carers as they provide care to their dying relatives. After securing clearance from an IRB, seven (5) informants, deemed as co-researchers, were recruited and agreed to participate in this study. The co-researchers where selected based on a pre-set criteria and the number were reached based on theoretical saturation. Multiple individual in-depth face-to-face interviews were done to create the individual narratives which was later reflectively analysed.

Interpretive phenomenology as espoused by van Manen served as the philosophical underpinning of the study. Consequently, the proposed analytic technique of van Manen was utilized as the process of reflective analysis.

After the process of reflective analysis, three (3) themes were gathered, namely: Ambivalence in anticipation, Courage in uncertainty, Meaning in suffering. These themes represent for the co-researchers their lives as they care for their dying relatives. Further, these themes reflects for the co-researchers a phenomenon of living moment-to-moment, unsure of what tomorrow will bring, patiently waiting for their relative to cross over. For them, there seems to be a constant struggle of finding a reason for being and a sense of what has happened, what is happening and what could happen to their dying relative and their family after their death. This essence can be symbolically represented by a swinging pendulum, constantly in motion trying to situate ambivalence in their anticipation, looking for courage amidst uncertainty and finding for meaning in their experience of suffering.

The insights suggest that there is a need for constant dialogue among family members and health care providers as they assumed the role of primary caregivers. Further continued emotional, moral and spiritual support is implied during this transition as well as follow-ups when the families are at the home setting.

INTRODUCTION

In the advanced stage of a life-limiting illness it may be apparent that despite the best care, curing the disease may not be possible anymore. Aggressive attempts may prove futile as these may even become financially draining and physically and emotionally exhausting both for the patient and the family. Nevertheless, care does not come to a halt. In the final stages of many terminal illnesses, care priorities tend to shift. The continuum of care assumes a special form and shifts its focus from curative into palliative. The goal is set on relief of symptoms, especially pain, and emotional stress making sure that the patient will be as comfortable as possible (Krau, 2016). As for the family, the focus of care is to see to it that a loved one's final moments are spent as quality family time, making sure that every moment counts as a memorable experience rather than a distressing nightmare. This holistic approach of addressing the needs of the patient, as well as the welfare of the family are the focus of the care modality termed as palliative care.

End of Life Care (EoLC) is a portion of palliative care that is specifically focused on care of the dying patient (Kraus, 2016). The UK Department of Health (2008) defined EoLC as the care provided to help all clients with progressive and terminal illness for them to live optimally until death, and which includes supportive and palliative care that aims to help meet the needs of both the client and his family until the last phase of life. Pain management, symptomatic relief and provision of psychological, social, spiritual and practical support are integral components of this care modality.

Providing care and comfort during the most difficult times generally generates a rewarding altruistic experience. Jean Watson (1979) described human care and eventually came up with her Ten (10) Carative Factors, which includes the formation of humanistic-altruistic system of values which relates caregiving and satisfaction through the sense of giving. Outside the professional aspects of healthcare, caregiving takes place in the context of established family and friendship relationships and from here the concept of informal care emerged. Gordon (1998) defined informal care as care given to the sick and the elderly by people who have no formal or structured training as preparation for the caregiving task. In most cases, the immediate family members instinctively assume the role of the family caregiver since caring is a family affair especially in the face of a life-limiting illness. Filipinos are known for their tight family relationships and illnesses, especially those with terminal prognosis, highlight this cohesion.

In the end-of-life, care priority shifts into palliative approach, Patients and relatives prefer to keep the patient at home and death at home would be more preferable (Higginson & Sen-Gupta 2000; Gott, et al, 2004). Care provided by the family at home is also considered as a demonstration of love (Gott et al, 2004). This care is more desirable since it comes with familiarity, ease, and less intrusion during this vulnerable period compared to the institutional setting. Since home is synonymous with love, warmth, memories and basically life, it is a more desirable place to continue care at the end of life since further stay in the hospital comes with greater financial consequences and both patients and relatives perceive this burden that will persist even after the patient dies.

However, the idea of caring for someone at home may not be a readily-welcome option for everyone since it is dependent on important considerations such as the ability of the family to cope with the demands and their readiness for a major change in life situations. For example, family caregivers need to learn how to provide physical care, ranging from basic skills (Bee et al, 2009) such as feeding, bathing, oral care, etc., up to the advanced nursing procedures such as tracheostomy care, stoma management, etc. This is quite a handful of task for them, considering that they have no formal trainings for these tasks. No formal preparatory training is available to equip the family members in assuming the responsibility of being a family caregiver. Assumption of this role resembles a leap of faith and family members who become the lay carers tread this new journey with ambivalence as they are driven with altruism yet struggling with uncertainties.

For a formal carer (a person who underwent professional and structured training) like a registered nurse, the patient-caregiver relationship may be of casual and professional nature initially, but given the magnitude and chronicity of the illness, paralleled by the time spent together may lead to personal attachments between the patient and the nurse (Owen, 2007). The same vulnerability increases exponentially for family members who are tasked to be the family caregiver due to their emotional bond with the patient. Since caregiving spontaneously emerges out from empathy, family carers tend to become emotionally involved hence their susceptibility (Gaugler, et al, 2005).

Results of the literature review presented in this section reveal varying perspectives in the end of life. Caregiving in the end of life elicited antipodal meanings (burden vs. reward) in different countries, with a multitude of references citing it in their own sociocultural context. The

researcher recognized that there is an obvious scarcity in related studies in the Philippines showcasing the said phenomenon within the Filipino context. Caring is innate in the Filipino psyche and the "Filipino Brand of Care" is of unique reputation (Martinez, 2014) sought after by many; however, our limited access to structured palliative care (Lynch et al, 2013), leading to poor caregiver support, with financial challenges (Aoun et al, 2005) and misconceptions making things more complicated, tips the scale towards the unpleasant meanings of EoLC associated with caregiver burden and burnout.

It is interesting to note that related literatures in the Philippine setting are scanty, with most of them designed as a quantitative inquiry. Published phenomenological, most especially interpretive studies are sparser. The researcher recognizes this literature gap in the meanings placed on End-of-Life Caregiving, especially in the Philippine setting as there are limited studies available, hence this qualitative inquiry.

This paper sought to understand the essence of caregiving in the end-of-life among family members who do not have a medical/clinical background or formal training for the caregiving task. The investigator aimed to understand the lived experience of family caregivers, as well as the effects of the caregiving experience to them as end-of life drew near. How do you go on a long, painful journey with little or no support? How do you give more, with so little that you have? What does the experience mean to them?

METHODOLOGY

A. Philosophical Underpinning

Qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret the meanings of the phenomenon as perceived by people. Talbot (1994) further discussed that it explores real-life situations as they occur naturally. Qualitative research is intended to penetrate to the deeper significance that the subject of the research ascribes to the topic being researched. It involves an interpretive, naturalistic approach to its subject matter and uses an inductive analysis as it discover and explore a phenomenon rather than deductively determining them through testing of predetermined hypotheses, as in the case of a quantitative study. In this chapter, the entirety of the methodology of the researcher's qualitative investigation will be presented.

Research Design

Research designs serves as the investigator's blueprint on how data should be collected and analyzed to answer the specified problem. It also lays out the strategies that researchers undertake to acquire precise and objective information that will provide the evidences needed (Polit and Beck, 2004). To obtain rich and in-depth understanding of the phenomenon being studied, phenomenological method was used for this qualitative inquiry. The meaning/s placed on experience (interpretation) was explored and understood the way the study subject sees and concretely describes it (De Castro, 2003), making the participants "co-researchers". This term will be discussed in the succeeding paragraphs.

Interpretative Phenomenology

Contrary to the Husserlian descriptive phenomenology which aims look for the eidetic structures (or universal essence) among those who experience the same phenomenon under study, Interpretive Phenomenology seeks to understand the contextual meanings entrenched in the everyday world. These meanings are oftentimes obscure to the participants but can be deciphered from their narratives (Lopez and Willis, 2004). Moreover, interpretive phenomenology intends to explore meanings in the context of sociocultural, historical, political and other factors within the subject's life world (Smith, 1987). World, in the phenomenological sense as described by Leonard (1989), does not pertain to mere nature or environment, but on the meaningful set of relationships, practices, and language inherited from the culture one is born to. He also noted that from a phenomenological perspective, a person is a capable of putting meanings and values on things. As Heidegger (1927/1962) puts it, to be human is to interpret; hence every experience entails an interpretation perceived through the lens of the person's background and situation. Given these philosophical viewpoints, the researcher concurs with Heidegger's (1962) proposition that phenomenological inquiries should also look at the invariable influence of the subject's life world in the meanings he/places on certain phenomena, including the decisions they make. Unlike Husserl's descriptive inquiry, interpretive phenomenology acknowledges the presuppositions arising from what is considered an expert knowledge of the researcher, which may even tilt the rudder towards a

more substantial inquiry of co-creating meanings with the study subjects (hence the term "co-researchers"), since this pre understanding kick starts the desire to pursue the study on the first place.

B. Ethical Standard

Ethical considerations are basic principles relevant to conduct research. They are necessary when human beings are involved because people have the right to self-determination and treatment as an autonomous agent. They have the freedom to participate or not in a research project (Polit & Hungler 1999). This study espoused ethical standards throughout its process of inquiry. Respect for human dignity was upheld with utmost importance and was exercised by undertaking the following measures:

1. Sought approval of the Ethics Review Committee prior to the commencement of the inquiry.
2. Informed consent was secured from the prospective co-researchers on the premise of adequate explanation and reiteration of the study objectives, the possible risks involved, the extent of their participation, guarantee of identity anonymity and information confidentiality. The researcher also ascertained that the co-researchers fully understood that they may voluntarily withdraw at any point of the study without any consequential interrogation, need for explanation or strain. Finally, the possibility that the research might be published in a local or international journal was also disclosed.
3. Aliases were used to conceal the co-researchers' identity and their narratives were kept confidential and unidentifiable with them.
4. Access to their identity information and their narratives was restricted. Only the researcher and the research adviser has the full privilege in retrieving these files, including recorded audio files, consents, memory cards, audio recorder, etc. These files will also be kept secured in a locked cabinet, with the key always with the researcher's custody.
5. Closed-loop to Spiral process of validation and counter validation and final approval of the content of the study was observed
6. Storage materials and hard files of collected information and narratives will be disposed a year after completion of the study.

C. Selection of Participants

This paper explored the lived experience of family caregivers who took care of patients with advanced illness beyond cure. The researcher worked with five (5) co-researchers based on the following criteria: (1) Family members (parents, spouse, siblings, children) of patients afflicted with advanced to terminal stage cancer; (2) With end-of-life caregiving experience up to 6 months after the death of the patient / care recipient; and (3) They are willing and able to describe and share their caregiving experience and the meaning they placed on it. For this study, purposive sampling was used based on the afore-mentioned inclusion criteria and this study included selected participants within Metro Manila and bordering provinces.

D. Ways of Gathering the Narratives

Data collection in qualitative studies is unique from its quantitative counterpart. According to Polit and Beck (2004), data collection in qualitative studies is more spontaneous compared to quantitative research and topics are further explored according to the set of information emerging from the interview.

Conroy (2003), purported in her Hermeneutic Principles of Research (HPR) that other innovative means of data collection that will foster engaged participants are recommended, such as narrative-telling (story-telling), dialogue, reflection, elaborating meanings, etc. Adhering to this recommendation, the investigator conducted informal interviews and preliminary visits as needed so that the participants will feel more comfortable and at ease. When the participants appeared to be more acquainted and interactive, the researcher engaged in-depth interviews to facilitate story-telling.

A voice-recording hand-held device was used to record the conversation for easy replay and transcription. Prior to the actual interaction, participants were informed that the said device will be used to ensure that the exact verbatim will be noted down. A simple interview guide was kept handy to guide the flow of the conversation. The interview started with a grand tour question followed by supplemental questions which were deemed necessary for continuity and elaboration. To facilitate the narration of the lived experience of the family caregivers, the interview was formally started with an open-ended question, followed by a series of sub-questions to guide the participants in expressing their thoughts.

Recorded conversations were transcribed and processed thereafter. Results of the initial interview were presented back to the participants for validation and further revision until the exhaustive description was achieved. Finally, researcher synthesized the meanings which family caregivers placed on their EoLC experience through inductive process.

E. Process of Reflective Analysis

Electronically-recorded narratives were carefully transcribed. Afterwards, the researcher adapted the step-by-step process designed by Van Manen, elaborated by Taylor et al in 2007, as follows: *"(1) Turning to the nature of the lived experiences; (2) investigating the experiences as it is lived rather than how it is conceptualized by the researcher; (3) reflecting on the essential themes which characterize the phenomenon; (4) describing the phenomenon through the art of writing and rewriting; (5) maintaining a strong and oriented relation to the phenomenon; (6) balancing the research context by considering the parts and the whole"*

Van Manen's proposed approach unveils themes from the experience, which he appears to be interchangeably mentioning as phenomenon (Dowling, 2005). His approach attempts to grasp and comprehend the essence of the phenomena or experience under study, hence merging the features of both interpretive and descriptive inquiry. To achieve this objective, an immersive attention to the data gathered is essential through repeated appraisal of both the recorded and transcribed narratives, with specific focus on identified significant statements. By repeatedly listening and analyzing the recorded interview, essence and themes will surface and become prominent to the researcher. He proposed doing this process as follows:

1. Preliminary listening to the entire audiotape recording. Listening to the whole conversation and narratives help the researcher grasp the meanings as each statement is analyzed.
2. Next, standing out crucial statements are sorted and singled out.
3. Each compelling statement selected is analyzed individually.

Reflection and interpretation revolved around the emerging themes. The repetitive process of deduction and induction was pursued until the main essence of caregiving in the end-of-life was synthesized. The by-product was presented back to the co-researcher for validation

and counter-validation. After the themes and the main essence have undergone the exhaustive process of deduction, induction, and synthesis, the researcher returned to the co-researchers for inter-subjective confirmation of the essence and themes' validity (Polit & Beck, 2008; Speziale & Carpenter, 2007; Taylor et al, 2007; Dowling, 2005; Colaizzi, 1978).

F. Maintaining Rigor

Qualitative research should exhibit trustworthiness and this is achieved by the extent to which the study questions tap the participants' experience and not merely their theoretical knowledge about it (Streubert and Carpenter, 2011). Primarily, criteria-eligible participants were selected purposively. Next, the co-researchers were to talk freely about their experience. Follow up questions were limited to general leads so as to help participants express their thoughts. Leading questions were avoided so as not to unconsciously impose the researcher's own biases. Moreover, the researcher allowed the participants to express both their positive and negative experience of the phenomenon under study. Negative descriptions "is helpful in establishing authenticity and trustworthiness of the data" (Streubert and Carpenter, 2011). To further ensure the trustworthiness of the analyzed data, verbatim transcription of digitally-recorded conversations was done. Repeated proof-reading and cross-checking with the hired transcriptionist was observed to eliminate typographical or transcription-related errors.

The researcher also acknowledges the existing first-hand pre-understanding of the phenomenon, as stated in the earlier part of this chapter. Awareness of this potential bias is important in order not to compromise the credibility of the study, although this pre-understanding is essential in exploring deeper meanings and arriving at a co-created universal essence. Participant validation was also utilized wherein the researcher will present the exhaustive descriptions back to the study participants to validate if these reflected their experiences. This iterative process went on until the exhaustive description was attained and data saturation was achieved. As part of the audit trail, the selection of significant statements, formulation of meanings, identification of emerging themes, and the implementation of entire research methodology was closely discussed with the research adviser.

RESULT AND RESONANCE

Results

Verbatim accounts obtained through interview were analyzed by extracting the elements each significant statement holds. These elements identified by the researcher outlines the intrinsic meaning of the experience. Afterwards, these elements were clustered and then coded based on the idea that they collectively form. This chapter will discuss the results of the reflective analysis revealing the essential themes and eventually leading to the construction of the eidetic insight.

Thematic analysis enables the researcher to examine the content for recurrent patterns that link the data gathered. This iterative process is important in synthesizing the shared meanings co-created by the study participants as the analysis of themes tends to be expansive and evolving. With this process, the following themes were identified: *Ambivalence in Anticipation*, *Courage in Uncertainty*, and *Meaning in Suffering*.

I. Ambivalence in Anticipation

Cancer is a dreadful illness everyone silently hopes not to have an encounter with, either directly or indirectly. Unfortunately, cancer may afflict anyone at any point of time. The disclosure of this terminal illness of a loved one placed the co-researchers in a spiraling course of unpleasant emotions. This emotional roller-coaster in which the co-researchers went through is discussed on this theme. It includes concepts on *Conglomerated Responses*, *Fear in Anticipation*, *Ambivalence in the Course of Action and Capitulation*.

“Halo-halo na... (It’s all mixed up)”

It all starts with trepidation over the results of the diagnostic workup: patients and their families wait anxiously for the reports to come in. Anxiety lingers and increases during the waiting period. Co-researcher Lioness remembered accompanying her mother (the patient) on her multiple outpatient visits. They have a strong family history of cancer and she had suspicions that her mother’s breast lumps are not to be shrugged off. They had family discussions about the

possibilities concerning the histopathological tests of her breast masses. There were also regrets that diagnostic tests should have been done earlier.

Finally, the undesirable news was revealed: the suspicious mass was confirmed to be malignant. Co-researchers claimed that they were not expecting the diagnosis. They were shocked and frightened while trying to reconcile the situation to reality:

“Na shock” (shocked), Courie.

The co-researchers went through a repetitive cycle of disbelief, shock, fear, and dread as they attempt to process the information they received. A once dreaded situation taking place right before one’s eyes usually catch people off-guard and unprepared. The disclosure of a dreaded illness may prove to be too much to handle:

“Syempre napaiyak kami...nag iyakan kami (we broke into tears) , Gallany

This torrent of unpleasant emotions persisted for some time. As soon as they were able to gradually process the information, they could not help but weep every so often.

“Kapag sinabing cancer, mahirap na (It will be difficult if it’s cancer)”

To somehow re-establish control over a situation, people seek to understand its cause, its course, and the possible outcomes so that the succeeding series of actions can be contemplated and executed. However, this process of anticipation generates anxiety as cancer is generally embraced as a life-limiting illness despite the emergence of various treatment modalities and protocols. Since cancer has a very unfavorable outcome, this anxiety triggers a myriad of responses, mainly unpleasant ones, as people equate cancer with a lifelong journey of misery.

Living with cancer is almost always perceived as a long and tormenting journey while fighting a losing battle. Auda easily described the entirety of it as:

“Sobrang sakit, sobrang hirap (It’s so painful. So hard)”

Apparently, there was a pre-conceived notion that the illness would be beyond acceptable management with a definite deteriorating progress. Co-researcher Courie seemed to know how things would end up:

“Tsaka alam ko naman kasi talagang yung cancer, dun na din yan pupunta (I already knew that cancer will eventually lead to death)”, Valerie

At this point, people usually attempt to analyze the situation and anticipate the possible scenarios in order to prepare themselves for what is going to happen next, as well as on how they will respond. Having an almost uniform perception of the course and prognosis of cancer, the co-researchers seem to be anticipating the worst cases on their ill loved one:

“Hinahanda na lang (namin sarili namin) (We just set our minds to be prepared)” Courie

Anticipation as a coping response came with a disadvantage. It generated excessive anxieties when triggered by both specific and nonspecific situations. Co-researcher Lioness even remembered being restless whenever she would receive text messages or calls from her siblings or their neighbors asking her to skip classes and promptly head home to attend to her sick mother. It appears that there was a constant reminder that death is imminent.

“Aware kami na parang pag sinabing cancer magastos sya (We are aware that cancer is costly)”, Auda

Cancer treatment and comfort measures are already expected to be really expensive. The co-researchers were aware that cancer entails funneling of precious, limited resources. This added burden posed further anticipatory and actual anxieties over our co-researchers.

“Naguguluhan pa din po ako. Di ko maintindihan (I am still confused. I don’t understand)”

Having been aware of the course of the illness, eventual outcome, cost, and other things, accepting the reality remained to be a struggle. There were questions as to why their family was not spared, of all the people. She could not help but be saddened by this reality. Co-researcher Lioness also encountered difficulty processing the situation:

“Naguguluhan pa din po ako. Di ko maintindihan (I am still confused. I don’t understand)”

Having empathy for people who suffer from cancer causes one to feel sorry about the illness. This grief increases exponentially whenever the afflicted patient is a loved one, much

more, an immediate family member. This misery seems to be directly proportional to the degree of closeness and blood relations between the patient and the empathizer:

“Masakit din po...syempre masakit kasi nanay ko po yun (It’s painful, of course. She’s my mother)”

This shock and disbelief caused intrapersonal and interpersonal disruption among the family members. Moreover, this gave them a hard time accepting the reality and embracing the situation. There was also an initial uncertainty with the next course of action among the co-researchers, making things more complicated than it already was. Co-researcher Valerie claimed that she was perplexed and undecided on what to do next:

“Mahirap mag desisyon (ng susunod na steps) (It’s hard to decide on what to do next)”

There was also indecisiveness with co-researcher Valerie whether to continue with the treatment and management. Due to the terminal stage of the disease, aggressive approaches may just turn out to be futile and at the same time, uncomfortable and inconvenient both for the patient and the carers.

“Tinanggap na lang po namin (We just accepted it)”

When the emotional outbursts started to dissipate, the co-researchers eventually decided to accept the reality. They knew that they had to embrace the situation for them to be able to move forward and do what must be done. Co-researcher Lioness claimed that she just accepted the tried to understand that things are different now:

“Tinanggap ko na lang din po...Intidihin na ganito na po talaga yung sitwasyon namin (I just accepted it, anyway... to understand that this is our situation now)”

It was hard at first, but along the way they started to make good strides in their progress and eventually learned how to just make do with the situation. Acceptance, no matter how reluctant it may be, was a pre-requisite before they could make that crucial decision of assuming the caregiving role. Co-researcher Lioness knew that she ought to fill in the role:

“Dapat gawin ko to... (I have to do this)”

There was a courageous assumption of the role, as co-researcher Valerie recognized that she was preordained for the role.

“Iniisip ko na ako yun (nakalaan mag alaga) (I thought I am destined to be the caregiver)”

They were headed for a long, challenging journey ahead, hence they must be ready. Co-researcher Auda started off with mental conditioning:

“Si-net ko yung mind ko na kailangan kong maging handa (I set my mind to be ready)”

This mental preparation was crucial in their assumption of the role. It was not an easy task, but the decision was already made. The present reality may not be as desirable as they would have wanted, but there was no profit in mere whining void of action. The co-researcher demonstrated their willingness to ensure that all medical attention and comfort measures will be continued.

This deteriorating course of cancer draws a myriad of responses from the co-researchers. Upon disclosure of the diagnosis and eventually its terminal prognosis, shock and disbelief disrupts them for a time as they struggle to process the information overloading their senses and reasoning. As reality sinks in, fear and anxiety ensue as the co-researchers start to realize that they are indeed afflicted by the fearsome situation. In the process, worst case scenarios are fearfully anticipated due to the illness’ life-limiting nature. There was also confusion and uncertainty over their succeeding course of actions. Despite this, the co-researchers choose to make that important yet difficult decision of accepting the present reality and embrace the caregiving role no matter what was at stake.

II. Courage in Uncertainty

Assuming the caregiving role in the end-of-life seemed to be the most rational response since the co-researchers involved in this study are immediate family members. The role is unbelievably challenging and required extraordinary commitment. The co-researchers somehow seemed to have an idea of this sacrifice. This selfless service will be discussed in this theme, and will include concepts, namely *Ambivalent Acquiescence, Taxing Tasks, Selflessly Unreserved, Recurrent Compunction, and Courage in Uncertainty.*

“Pikit mata...lakasan ng loob... (With eyes closed... be courageous)”

As the family recovers from the undesirable impact of the shocking revelation of the diagnosis and the eventual prognosis, they seemed to have come into their senses and muster the courage to respond. Their attempt to convince and reassure themselves that they could take on the challenges ahead was observable. They knew that they had to stand up and shake the fear off. Living with fear as a constant companion is by itself a difficult situation, yet inadequate to hinder the volunteering family member from providing end-of-life care. As per co-researcher Auda:

“Pikit mata na kung anong kailangang gawin, gawin (With eyes closed, just do whatever needs to be done)”

Despite the very unwelcoming news that the patient and the family has to live with, it is interesting to note that family members assumed the responsibility of being the caregiver anyway. What lies ahead may be uncertain and tough but doing nothing was not part of their options. They knew they had to step up because much was at stake. Gallany claimed that she could not bear standing on the side lines and watch helplessly:

“Di pwedeng pababayaang ko yan (I will not forsake him)”, Gallany

The role was viewed as something that must be accepted courageously and wholeheartedly. There was a sense of obligation and a necessity to respond, as stated by Lioness:

“Dapat gawin ko ito (I ought to do this)”, Lioness

The co-researchers shared the readiness for the task ahead. They had high hopes that they would be able to fill in the tall order of the caregiving role. Even as the challenges and the drastic shift of everyone's situation were acknowledged to be taxing, the co-researchers' almost instinctive response to the question of who will take up the role was evident. Family members knew it by instinct that they have to be that caregiver. They believe that they have to step up and act despite the uncertainties that lie ahead.

“Sobrang Sakit. Sobrang Hirap (So painful. So difficult)”

Over time, the co-researchers, who have already assumed the caregiver's role, came to realize the immense complexity of the situation. Their first-hand experience continues to give

them realizations that the journey is indeed life-changing. The role required them to embrace both subtle and drastic changes in their lifestyle and patterns. As co-researcher Lioness puts it:

“Medyo po nalulungkot na ang laki na ng pinagbago ng buhay ko (I’m still quite sad that my life has changed drastically)”

Committing on the life-changing journey is one thing; embarking on and pursuing it is a different story. Co-researcher Auda realized that the responsibility is indeed tough:

“Yun pala yung mas mahirap...na kailangan na kami na mismo yung hands-on na mag aalaga sa kanya (So that was the harder part...that we ourselves needed to be hands-on in taking care of him)”

Caregiving in the end-of-life at home involves round-the-clock care and attention. That requires exceptional physical endurance since there are no definite break times nor defined relievers. Constant presence and immediate attention to needs are fundamental to this role in order to ensure comfort and relief of the terminally-ill patient. However, despite the nobility of this role, its demands may push one’s physical capacity to its limit. Due to the anticipation of immediately attending to whatever needs that the patient may have, or partly because of many things that pre-occupy their thoughts, sleep deprivation is common among them:

“Walang tulog (sleepless)”, Valerie

Aside from the lack of decent sleep, loss of appetite, or simply the inability to eat uninterruptedly, results to weight loss. Altogether, these physical wear eventually takes its toll among the co-researchers. Effects were described as physical exhaustion and irritability. As per Courie:

“Minsan nagagalit din ako kasi napapagod din ako (Sometimes I get upset because I get exhausted, too)”

“Parang pagod na pagod na rin ako (It seems like I am so exhausted)”

On top of the physical demands of the caregiving role, there are upshots on the co-researchers’ thoughts and emotions. To start with, there is constant anticipation of the worst outcomes of the disease prognosis, as discussed in the prior essential theme. The fear and the

anticipatory grieving persisted throughout the end-of-life care journey. The dread of the inevitable endpoint kept on bothering them. Co-researcher Courie put it into words:

“Lalo na nung umuwi kami sa bahay natakot ako. Kasi mamaya yung katabi ko baka kako di na humihinga (I was scared, especially when we went home. I might find him breathless next to me)”, Courie

Co-researcher Valerie even encountered the dilemma of making the tough call concerning her patient’s advance directive, to which she admitted to have felt guilty about:

“Nako-konsensya din ako (na pumirma ng DNR) (I feel guilty signing the DNR)”

Moreover, the everyday hurdles of the caregiving tasks, as well as the unavoidable decision-making crossroads posted constant assault to the co-researchers’ emotional wellbeing. As for the day-by-day routines, there were times when their sick family member displaced their pique on them. The co-researchers could not help but be affected and hurt yet they knew the reason for their patient’s irrational behaviour stemming from frustration.

Witnessing a dearly loved one fight a losing battle daily also adds up to the pain they experience. At this point, the physical exhaustion and the emotional burden are piling up, making the caregiving role more challenging. Interestingly, however, there was still a wishful desire to relieve the patient from the suffering:

“Ayoko na siyang mahirapan (I don’t want her to suffer anymore)”, Valerie

In the long run, the co-researchers appear to have worn down emotionally. There were times when they felt emotional exhaustion and getting fed up. There were times when they would get irritable and emotional out of fatigue. They would sometimes feel frustrated and unintentionally display signs of exhaustion. They were aware that they sometimes lose their patience yet the outward manifestation was kept discreet and somewhat filtered. Sometimes, emotions just leaked out of their guards that they just cried for no readily determined reasons.

Their need for support and burden share was also observable. It may have been demonstrated in various ways but their subtle message could be deciphered. One co-researcher felt that she had not been receiving enough tangible support from her family in caring for her ill husband. Another co-researcher mentioned that she owes her ability to fulfil her caregiver role to

her brother; had it not been with her brother, she was not sure if she would have made it. Most notably, Co-researcher Valerie somehow regresses whenever her siblings visited her in her ill sister's home. She admitted to have cried and clung on to them, as if she was looking for comfort and consolation:

“Pag nakikita ko sila parang gustong gusto ko magsumbong (I feel like asking for rescue whenever I see them)”, Valerie

She would feel consoled and somehow reassured just by having her siblings visit her. Though they were not really actively involved in caregiving, their presence meant so much for the co-researcher.

“Umikot yung mundo ko sa kanya (My world revolved around him)”

In order to accomplish the responsibility, our co-researchers made a commitment to embark on the journey together with the patient. It was more than a sacred vow of responsibility; it was a demonstration of love. A tall order awaits; hence they had to make sure that they can size up to the measure of the task. They had to make sacrifices. These sacrifices include prioritizing their patient over studies, or choosing the role over work promotions. Co-researcher Auda was a dedicated and decorated employee, yet she had to file for an indefinite leave for a greater cause:

“Leave muna sa work para mabantayan yung kapatid ko (I filed for indefinite leave so that I can look after of my brother)”, Auda

The responsibility was so special that it requires the virtue of strength and endurance. There seems to be no room for weakness, nor any sign of it to be seen by the patient because the co-researchers believed that their vulnerable side would be the last thing that their sick loved one needs to see, hence a facade of strength and reliability should be displayed instead.

Putting up a wall to cover any trace of weakness seems to leave them keeping things to themselves. This adaptive response tends to create an imagined sense of being alone in their duties and this contributes to the weight of the role itself. Co-researchers Courie and Valerie mentioned that they opt to keep some sensitive information to themselves to avoid unwanted stress to the patient. As self-suppression translates into selflessness, the co-researchers desire to

somehow spare their patient from all the possible hurts and stressors. In the process they ended up more hurt yet they had to be extra cautious in their display of emotions lest their ill loved one would notice their grief.

This self-suppression was evident but their purpose was to direct their focus on their ill loved one's welfare instead. This selflessness goes as far as deprivation of their basic physiological needs, sacrificing their pastimes, and even choosing the responsibility over their own personal aspirations and current endeavours. This genuine compassion and love enables them to understand the patient's experience deeper and somehow experience a fraction of how the patient feels, even it meant leaving more room for their patient's emotional displacement:

“Naiintindihan ko kahit sumisigaw sya (I understand him even when he's yelling)” Gallany

The co-researchers were so entrenched in their caregiving role that they had almost, if not completely, taken their own welfare for granted. While treading the journey with their patient as they live with death, they almost forgot to look after and live for themselves, according to Auda:

“Umikot yung mundo ko sa kanya (My world revolved around him)”

“Parang hindi ko na rin alam kung paano magsisimula (I don't know how to start over again)”

This was especially true whenever they would have unusual times off away from the patient, such as when someone would look after their patient for them to have a little break. Even after the death of their sibling, co-researcher Auda and Valerie encountered difficulty in returning to their usual lives before the cancer struck their families.

“Di ko talaga alam ang gagawin ko (I really don't know what to do)”

The caregiving role is not an easy task; doing it in the end-of-life stage would require so much from the caregiver. Despite knowing that the role must be embraced wholeheartedly, a hint of slight reluctance in the form of self-doubt can be traced. This compunction loomed and persisted throughout their caregiving experience in the end of life.

There always was reluctance due to the uncertainty on what to do on certain situations, and whether care is done correctly since our co-researchers have no formal or structured healthcare backgrounds or even trainings (hence the term *Family caregiver*), making the caregiving role more challenging:

“Di ko naman naiintindihan lahat yun kasi wala naman akong background sa ganun (healthcare profession) (I don’t understand everything since I did not have background on the healthcare profession)”, Auda.

Since they had no prior experience or preparations, the caregiving task triggers anxiety and other unpleasant emotions. There were times when they would be baffled and perturbed as various situations were beyond their mental preparations:

“Sana nga wag na magka aberya...para di ako mataranta na naman (I hope things will not go wrong so that I won’t get rattled again)”, Courie.

Due to this lack of structured preparatory trainings, they resorted to observational and experiential learning. There was neither positive validation nor corrective coaching in the care they render, hence the trial-and-error approach. This method may be practical due to financial and logistic scarcity, yet the unnecessary and lingering stress that comes with it aggravates the burden.

“Kailangang tapangan. Nandyan na eh (I have to be brave. It has already come)”

The co-researchers admitted that they somehow felt hesitant and fretful as they lived each day with their loved one’s death inevitable. The fear was still there. However, they had to persevere, anyway:

“Kailangang tapangan. Nandyan na eh (I have to be brave. It has already come)”, Gallany
Natatakot ako, pero kailangan kong lakasan loob ko (I am scared but I have to be brave)” Auda
“Pinipilit ko pong magpakatatag (I have to remain strong)”, Lioness

Every moment counts. Since they were not prepared for the task and they do not have the luxury of time, they could not afford to stay weak and helpless. It was deemed necessary to remain strong for their loved one depends on them. When their back was against the wall, they had to push back and continue the fight. They had to be resourceful and think of ways on how to make the most out of the remaining opportunities. Everyday might be their last moment with their patient; that is why availing the best possible care on time even in the end-of-life stage is still in their best interest

The promise of going all-in was evident even if it meant increasing costs and inflating debt. It did not matter because their loved one's welfare is far more important than its financial implications:

“Kahit ipangutang namin basta lang gumaling sya (Even if we have to borrow money, as long as he gets well)” Auda

Cancer treatment and management is lengthy and expensive. Depletion of resources is a very common story among cancer patients and their families. However, the status of their financial condition was kept from their patient's awareness, lest the addition of unnecessary worry.

Because of this emerging concern, our co-researchers had to find other means in order to sustain the treatment and afford comfort measures. Austerity measures and exclusion of other simple luxuries were assimilated to their already modified daily routines. They also tried availing the government and the non-government organizations' assistance programs, such as the Philippine Charity Sweepstakes Office (PCSO) Medical Assistance Program (MAP) and the Philippine Cancer Society financial aid.

This is very exhausting since the said institutions accommodate and serve a very huge number of people seeking financial and logistic support. Anyone requesting for assistance should be at their office's registration area as early as 5 AM and it would usually take a full whole day before all steps are completed and guarantee letters (GLs) are released. There are times when a person requesting for aid is asked to return on a particular day due to incomplete or insufficient requirements. Once they go back on their scheduled date, they had to undergo all the tedious steps all over again. In summary, availing financial assistance entails long queues, hunger, sleep deficiency, uncomfortable waiting areas, and tiresome series of steps.

With regards to their depleting resources, our co-researchers had to learn simple to complex nursing procedures for them to be able to take care of their patient. However, because of their lack of formal educational or vocational background on caregiving, there were instances where they had to resort to observational and experiential learning:

“Tingnan mo kung ano yung mga ginagawa ng nurse na magagawa mo (You have to observe what the nurses do that you can perform as well)”, Gallany.

Every day was not easy but the co-researchers were persistent; the harder the task, the stronger they should be. The road trodden was tough, but their pledge to hold nothing back was stronger. It was an all-out effort. They wanted to convey to the patient that he/she is not alone in his/her journey for they would walk with the patient all the way as they live with inevitable death. This was a vow:

“Magiging all out kami na we will be there for him kahit na gaano kahirap yung pagdadaan (We will be there for him all-out regardless of the hardships that we will go through)”, Auda

Even though the enormity of the responsibility appeared to be disproportionate to their preparations, even if there are any, their caregiving commitment remained unfaltering. They remained true to their word no matter what the cost, material or non-material, may be.

Caregiving in a terminal illness is a very challenging responsibility. This is very much different from the typical experience of taking care of a sick family member. Unlike cancer, other non-terminal illness somehow guarantees recovery which makes the caregiving role easier. Recovery is very likely; therefore, caregiving can easily be associated with rewards. As for cancer, they knew what the situation really was and what will happen soon.

The journey is as painful as the revelation of the dreaded diagnosis and the anticipated outcome of the illness. There were many occasions where the co-researchers realized that not only that having a family diagnosed with cancer is painful, but the day-to-day adjustments is of proportional, if not greater, difficulty

These repetitive encounters with the various undesirable scenarios brought about by the deteriorating course of cancer draw a relentless myriad of responses from the co-researchers. Responses vary from fear and anxiety in anticipation of the worst, uncertainty with the safety and accuracy of the care provided, and their constant dilemma as they struggle to remain strong and resilient in order for them to effectively perform their roles and the responsibilities. Family caregivers continuously experience these various emotions from the moment the diagnosis was disclosed and this pattern persist throughout the caregiving experience until the terminal phase of the disease. As the prognosis advances to its terminal phase, feelings of ambivalence resurface. Family carers continue to experience a repetitive cycle of plethoric difficulties.

III. Meaning in Suffering

Amidst the torrential outpouring of unpleasant emotions and downpour of seemingly unending difficulties, the co-researchers eventually started to find meaning and purpose. Although the process of acceptance and moving forward took a while, they were able to see the positive aspect of the experience of their end-of-life caregiving role. This theme showcases the following concepts: *Questions the Reasons, Privilege for a payback, Finding Purpose and Meaning, Sourcing Support, and Surrender and Submission*

“Naitanong ko na lang sa Diyos (I questioned God)”

Living with death, or more elaborately, living everyday while dealing with the inevitable reality that cancer is real and death is imminent, turned out to be a daily struggle. As laid out in the prior section, the diagnosis and its terminal prognosis exposed the family members acting as family caregivers to difficulties of varying kinds and degrees. The co-researchers seemed to be stuck in a loop of interconnected challenges to their physical, psychological, social, and spiritual being. Moving forward and finally making a progressive decision concerning patient care and role assumptions were wearisome.

Acceptance was more than just a one-time decision. It is a daily encounter with ambivalence; a daily struggle between the disbelief of affliction versus relinquishing the nearly-paralyzing pain and just make do with the situation in hand. While in her anger stage, Co-researcher Auda admitted that she once became indignant with a handful of questions over the situation:

“Nag question ako. Nagalit ako (I asked questions. I got mad)

”

There was also a progression to the bargaining stage, as co-researcher Auda desired for an ability to change the situation towards a different turn of events:

“If only I had the power na baguhin yung sitwasyon (If only I had the power to change the situation)”

The co-researchers who received the discouraging news concerning the diagnosis and the eventual prognosis went through a great deal of sadness and possibly anticipatory grieving. This foresight of perceived worst outcomes emanates from their mental picture of the situation, and in

this case, of a loved one's terminal illness. At this point, the reality cannot be denied nor bargained for anything else anymore. There was nothing left to do but to face their immediate reality. Depression insidiously seeped in as they realized that nothing could be done to revert the situation. Before and while co-researcher Courie was caring for her terminally-ill husband, she admitted being extremely sad over her situation up to the point of depression:

“Parang nadi depress din ako na (It seemed like I’m getting depressed)”

Prior to their acceptance, the co-researchers endured this loop of sadness and anticipatory grieving. Nevertheless, they displayed the ability to proceed to the next stage despite still being troubled by their anticipatory grieving. It seemed that sorrow, hurt, disbelief, understanding, or the lack thereof, were just temporary stopovers eventually leading them to acceptance. Assumption of a very demanding role would require acceptance of things that could not be changed and carrying out measures while they still matter.

Part of acceptance is the acknowledgement that things are beyond one's control now. Acknowledging their limited comprehension of the situation, co-researchers resorted to the belief that only the God knows the entirety of the bigger picture and they could only see but a fraction of it. As co-researcher Auda puts it:

“Only God knows kung ano mangyayari (Only God knows what’s going to happen)”

Yielding enables one to deal with the immediate reality and make use of all available options. It is noteworthy, however, that this form of surrender is not of the hopeless kind. The co-researchers still upheld their entreaty, believing that the likelihood of recovery could not be completely dismissed:

“Alam kong darating yung time na gagaling sya (I know she will get well in time)”, Lioness.

This optimism was noted among the narratives of the co-researchers. This attitude seems to be a universal phenomenon among them amidst the unfavorable circumstances and uncertain outcomes.

“I’d Rather Be Here than Anywhere Else”

Although the hopeful desire for the patient to recover still lingers, co-researchers gradually reached the transcendence of accepting the situation even if this petition ends up unfavorably. There seems to be an interesting connection between the acceptance of the terminal situation and just letting things run its course. A submissive attitude was observed among the family caregivers:

“Kung kaylan Niya gustong bawiin, wala tayong magagawa (There’s nothing we can do whenever He wants to take something back)”, Valerie

Eventually approaching the acceptance stage, there was an assent, complemented by the optimism that things are temporal. This temporality was believed to have a reciprocal promising turn of events. Some questions may have been left unanswered and bitter truths may not make sense, yet there was acquiescence:

“Siguro talagang ganun kaya tinanggap na din naming (Maybe it’s just like that so we accepted it)”, Courie.

Learning to accept the prognosis helps them fulfill their roles and meet the demands that come with such responsibility. Co-researchers sought meaning and purpose in a reality that they could not fully comprehend:

“Baka yun talaga nakaplano; para mag alaga sa kanya (maybe that’s the plan, that I would take care of her)”, Valerie.

The meaning and purpose apparently involves being the responsible carer in the end-of-life phase despite having no formal educational or vocational background, or even preparatory trainings, as elaborated in the previous theme. All they needed was their love for the person to drive that courage into action:

“Kaya kong gawin kasi mahal ko yung kapatid ko (I can do it because I love my brother)” Auda.

“Di naman po ako nagsisi na ganito po yung sitwasyon ko (I have no regrets with my situation)”

Amidst the morass, a clear message was deciphered by the co-researchers: everything may not be good, but there is something good in everything. Caregiving in the end of life revealed a myriad of unexpected opportunities to be thankful for. Though painful as it is, caregiving in the terminal stage of illness was somehow viewed as an opportunity for payback:

“Parang return na rin po ito sa pag aalaga nya sa amin (It’s our way of reciprocating her care)”, Lioness.

As if bargaining against time and making up for all the lost times, an all-out sacrifice was deemed as a noble gesture of returning all the favor and making the last remaining chances count:

“Chance na bumawi sa kanya (Chance to make up with him)”, Auda.

No matter what lies ahead, the vow to walk with the patient all the way was observable:

“Nag promise talaga ako sa kanya (I did make a promise to him)”, Auda

They could have asked for more time with their beloved patient, but the longing was set aside in exchange for the selfless desire for the patient to be taken out of the torment. The bailout was something they were and will be thankful for:

“Thank God kasi di Niya na rin pinatagal yung hirap ng kapatid ko (Thank God because He did not prolong my brother’s suffering)”, Auda.

Caregiving in the end of life also opened avenues for them to demonstrate their unconditional love as a spouse or as a sibling.

“A privilege and opportunity to show how much I love my family”

Moreover, the situation seems to have forged them to be a better version of themselves as they become someone and something they were not: an family caregiver who only capitalized on courage and hope. They were able to give without holding anything back. Their own personal weaknesses were superseded by a newfound strength which emerged out of necessity. According to co-researcher Auda:

“Sobrang maselan ako pero kinaya ko na alagaan sya (I used to be picky but I was able to take care of him)”

Despite being unable to understand some medical terms and procedures, the compelling need to adjust enabled them to learn important basic nursing care such as intravenous and administration of medications either via peripheral or implantable central venous access device, turning to sides, catheter insertion, tube care, ostomy care, etc. Co-researcher Gallany claims that she puts in extra work in making sure she learns what the nurses could do:

“Pinagaaralan ko lahat (I make sure to learn everything)”

The caregiving role required them to be proactive in hands-on care round the clock, both in the hospital and at home. Providing comfort measures were their main intention to make sure that the final moments are not distressing for the patients. Moreover, they also had to learn the more technical aspects of care in the form of nursing procedures since they had to be prepared and able for anything even if they are at home with the patient and no immediate medical support is available. No sense of powerlessness could be hinted; In fact, there was striking pattern of transcendence across the co-researchers.

“Wala naman akong regrets (I have no regrets)”

The co-researchers could have pled for another one to take over their role instead, or they could have bargained for a completely different situation; instead they desired for the ability to carry on their tasks effectively. They were aware that it would never be easy. Safe and accurate care was crucial for the patient’s life quality and dignified death. In the process, they learned how to overcome uncertainties and accomplish every single task that had to be done. The co-researchers were able to satisfactorily fill their role without compunction as their purpose outweighs their perceived inability. As per co-researcher Gallany:

“Wala akong iniisip kundi pagsilbihan sya (I don’t think of anything else but to serve him)”

At the latter part of their caregiving time, the co-researchers learned acceptance. The only regret mentioned was if the best care was rendered or if it could have been better. They did not want to settle for anything else less than the best care. Co-researcher Auda looked back and reflected:

“Sana I could have done better (I wish I could have done better)”

Selflessness through the pursuit of excellent care seems to persist among the co-researchers. These family caregivers’ ability to surpass their perceived and actual intrapersonal boundaries enabled them to effectively handle their roles.

“...Makakasama, makakatulong man lang? (A companion or a helper, at least?)”

The situation seemed to be an eye-opener to the co-researchers; they got to see what they consider as the essential truths and realized important lessons in life. Being trapped unprepared in a horrendous situation they did not ask for nor imagine, acceptance and bravery may not thrive. Nevertheless, they managed to overcome the daily hurdles through their newfound strength. Moreover, the fortitude they drew from their support systems, comprised of their family members and friends, was unequivocal.

Support was described in various ways and stretches. It may start from a simple check on how the family caregiver was doing, as mentioned by co-researcher Auda:

“Marami naman akong kaibigan na nangangamusta... nagdasal (I have many friends asking how I am doing...they pray for me)”

A simple visit, with prayers and words of encouragement were also appreciated and recognized as a fundamental component of their ability to manage:

“May laging pumupuntang ka church...Lagi nila akong pinagpi pray (People from our church always come...and they pray for me)”, Valerie.

More importantly, an immediate family’s display of staunch reliability provided the much needed support, as pointed out by co-researcher Auda:

“Nasuportahan naman (ako sa responsibilidad bilang tagapag alaga) kasi dalawa naman kami ng kapatid ko (nagtutulong) (I feel supported in my responsibility as a caregiver since my brother is helping me)”

A family member who helped with the tasks and shared with the day by day responsibilities provided a much-needed boost for the family caregiver. This assistance was very important for the carer because the role proves to be too much to be handled alone. It served as a

mitigating factor to the end-of-life caregiving stress. Family appears to provide a respite for them. According to co-researcher Valerie:

“Pag nakikita ko sila parang gustong gusto ko magsumbong (I feel like asking for rescue whenever I see them)”

There were times when there was a longing for a helping hand in the responsibilities. The very taxing responsibility grows harder with time. This yearning may be outspoken:

“Kaya kako, bakit parang nagiisa lang din ... Bakit mga anak ko kako parang di nila ako tinututuhungan “Why does it seem that I am alone...why don’t my children help me”

There were also times when this desire to be helped out and supported was subtle. Co-researcher Valerie recalls an instance when she wanted to just vent out to her family:

“Pagod ba ‘to o gusto ko ng makakasama, makakatulong man lang? (Is this fatigue or do I just want a companion, or a helper, at least?)”

As discussed in the previous theme, she confessed a feeling of loneliness and an indirect request for support. This was manifested in her sudden, unprovoked cries whenever relatives would visit, as if she was regressing and asking for back up. The presence of a consistent support system, either by a family member, friends, or even church folks, is consciously and unconsciously, valued by the co-researchers

“Basta’t hayaan ko lang po na i-drive Niya po yung buhay ko (Just let Him drive my life)”

There was a discernible pattern among the co-researchers as to their ultimate source of strength. They all profess clinging on to God in every step of the way and their ability to find meaning and purpose amidst the situation they were not prepared for seemed to be expedited by this dependence. Co-researcher Auda claimed that their situation taught them that they could only rely on God and one’s own self:

“Wala kang ibang aasahan kundi ang sarili mo at si Lord (you have no one to rely on except for yourself and God)”

Recognizing the disproportion between the task and the expenses versus their role readiness and capabilities, they knew that they could not have done it alone by themselves. They acknowledge a higher power and a higher being sustaining them all throughout. This expression of spirituality allowed them demonstrate their faith by believing that terminal cancer and all its effects are all but challenges designed to bring out the best in everyone and in everything.

First, the reframing of the perception that terminal cancer and end-of-life caregiving are just a complex of challenges designed to accomplish a greater good no matter how unpleasant the means may be. As per co-researcher Lioness:

“Challenge lang to sa akin ni Lord (This is just God’s challenge for me)”

Next, faith in the form of optimism and positivity was also evident among the co-researchers. The situation was less than encouraging, but there was an assurance from within that things will get better soon. An unrelenting faith and stalwart perseverance were believed to yield their favorable outcomes in due time. The complete surrender and daily leap of faith was necessary for the ordained purpose and meaning to come to their full measure. This constant seeking allowed the co-researchers to grasp important lessons on hope, faith, reliance, reliability, essence of time, and love. Finding purpose and meaning was believed to be connected to their ability to reconnect with God. The experience allowed the co-researchers to have more time for reflection and soul-searching. Co-researcher Lioness claimed that her mother’s terminal illness enabled her to seek God more:

“Nung nagkasakit po si mama parang mas dun po ako nagkaroon ng time kay Lord (I seemed to have more time with the Lord when mother got sick)”

Despite finding themselves ensnared to an unfavourable situation with a dreadful outcome, the co-researchers were able to find meaning and purpose. Challenges were overcome in small, daily successes. Every dead end revealed opportunities for breakthroughs. Breaking barriers and accomplishing all necessary tasks that come with the caregiving role took the co-researchers to a new level of personhood.

The terminal illness caused ambivalence among the co-researchers. Their ambivalence stemmed from their dilemma as they transitioned between anger, bargaining, depression and acceptance. Moreover, the caregiver role proved to be a life-altering decision on top of the illness’ impact on their lives. The transition between these stages was a struggle itself and the co-

researchers had to deal with this on a daily basis. However, there was not a trace of hopelessness nor powerlessness. Furthermore, their eventual acquiescence and acceptance empowered them to find meaning and purpose in their experience as they live with death and provide care in the end-of-life

Thematic Resonance

Thematic resonance presents how the significant insights gathered from the process of reflective analysis situate itself in the contemporary nursing knowledge. It does not affirm, negate, rationalize, nor provide reason for the results; rather, it presents how these insights fit on what is already known in the topic. This section will discuss the appraised literatures to further explore and appreciate the phenomenon under study.

I. Ambivalence in Anticipation

Almost by default, family members assume the caregiving role whenever a loved one falls ill. Cancer seems to make things more dramatic and complicated with its poor prognosis. With a rational knowledge of its trajectory, family caregivers, hereby termed as family caregivers, go through a plethora of mostly unpleasant reactions to the illness. Even when shock and disbelief start to dissipate, the ambiguity of the situation results to uncertainties in their next course of actions, role, and expectations.

Cancer remains to be one of the leading causes of morbidity and mortality locally and globally. Due to its chronicity and poor survival rate, its diagnosis triggers a plethora of responses. Cancer does not only disrupt and devastate the diagnosed patient. Family members are equally affected as well (Kim & Given, 2008). There is a consensus among related literatures, underlining the multidimensional implications of this life-limiting illness associated with caregiving. In her study on spouses of breast cancer patients, Reodica (2011) described the myriad of emotions to which cancer caregivers go through. There are mixed responses and roller-coaster of emotions as family members process a surreal report.

Initial responses to the diagnosis and the terminal prognosis result from their shock and disbelief. Due to the unfavorable prognosis and the downward trajectory of the disease, family members lose sense of control. Anticipation as an attempt to regain a sense of control seems to

yield the opposite outcome: cancer equating with distressing symptoms and eventual death elicits negative appraisals of the situation. Instead of serving an adaptive purpose, anticipation turns into anticipatory grief. Anticipatory grief was described by ThereRando in 1988 (which she preferred to call anticipatory mourning) as a multidimensional, complex process in response to a loss during a terminal illness of a loved one. Nielsen et al (2016) further shed light on this topic with his study showing high levels of pre-loss grief among family caregivers of cancer patients. Losses are related to either impending death, or non-death events, such as deterioration, life pattern alteration, restrictions, and uncertainties about the future (Rando, 1988).

Cancer is almost always equated with prolonged suffering and eventual mortality. Literature suggests the complicated, contagion effect of cancer to physical, emotional, psychosocial, and financial wellbeing of the patient and of their family caregiver. The constant fear of death is prevalent among the co-researchers and is a significant predictor of higher caregiver burden (O'Hara et al., 2010). This is consistent with other literatures, such as that of Hudson et al (2011) which profiled that significant proportion of family caregivers of patients on palliative care experience recurrent patterns of anxiety. A loved one's death triggers fear and anxiety, and the degree of closeness and emotional bond amplifies this unpleasant emotion.

While still struck with shock and disbelief, family members will need to take action despite the ambiguous appraisal of their current reality. Contrasting emotional responses dominate at this point. Ambivalence, as described by the co-researchers of this study, stem from their uncertainty on the succeeding series of actions. Learning about the diagnosis entails a series of situations where every decision-making is crucial. Cancer care is complex and costly; hence subsequent course of actions should be thoroughly appraised and consulted with each involved family member (Nambayan & Lu, 2015; Manalo, 2013). With the patient's best possible care and comfort in mind, family members will maximize all resources and options. This process is usually long and exhaustive, especially if financial constraints are taken into consideration.

It is considered a filial duty to volunteer as the person responsible for their family member's care and failure to do so may result to undesirable societal perception of their behavior. However, in the study of Smith in 2009, family caregivers of terminally ill cancer patients concurred that love and concern was their motivation for caring, regardless of the challenges and perceived burden. In a study of Kotronoulas et al (2012), family members are required to assume multiple roles, and consequently, make significant adjustments in their lives,

in order to gratify the complex demands of their cancer patients. Family members were not expecting the diagnosis; hence, their unpreparedness for the burden of caregiving, most especially at home-based end-of-life care (EoLC) (Saleh & O'Neill, 2018). As they assume a new identity, family caregivers desire to receive every single detail that would help them in their role (Zapart et al., 2007). This need for continuous supply of supportive information on various aspects of the disease, including, but not limited to, the disease course, plan of care, symptom control and physical care, is consistent with existing literatures, such as those of Wikes et al (2000), Harrop et al (2014), and Zapart et al (2007). Ironically, the healthcare team seems to be mainly focused on the patient and hardly ever, consider involving the family caregivers in the continuity of care (McLaughlin et al., 2011). It is important to note, however, that the said study was intended to explore the perceptions of family caregivers of patient's with Parkinson's disease (PD). Nevertheless, the similarity of PD's and cancer's chronic and debilitating course clusters them under the same category for this study's research aim.

Linderholm and Friedrichsen (2010) pointed out that despite these antipodal perceptions, family caregivers of cancer decedents share the imperative to project an impression of security and strength. Showing signs of breakdown or inefficiencies are a taboo. This abiding dilemma further contributes to the ambivalence that family caregivers constantly deal with. A randomized clinical trial (RCT) of Bultz et al in 2000 shed light on how cancer patients draw strength from their significant others. This is especially true whenever the coping abilities of diagnosed cancer patients are yet to gain traction. Out of their caring instinct (Coristine et al., 2003) and familial bond (Mok et al., 2003), family members choose to capitulate and instead do what is necessary, disregarding their unpreparedness and ambivalence.

Acknowledgment of the current situation and the new realities that they have to live with is crucial since there is already an alteration in their life and family dynamics (Bowden-Tucker, 2012). Acceptance is a pre requisite to their caregiving role. This argument resonates with the results of the study of Kim et al in 2007, signifying that coming to acceptance of the new situation relates to a more effective adaptation and role performance. In order to strategize a comprehensive plan aimed towards optimal patient care, Mehta et al (2010) accentuated that accepting the caregiving responsibility is a vital factor. In the same study, it was found that family caregivers of patients on pain management at home were able to satisfactorily perform

practical and intermediate aspects of caregiving once they were able to accept their family's current situation and the corresponding roles.

II. Courage in Uncertainty

At any given point of the illness trajectory, feelings of ambivalence continue to resurface. Family caregivers continue to circle the loop of suffering that presents in varying forms and degree. Their travail takes its toll to a certain, limited degree. Amidst the hardships and inadequacies, a resilient courage emerges to go beyond one's personal needs and move towards selflessness.

Assumption of the caregiving role emanates from the family centrality in every Filipino (Manalo, 2017). In the Philippines where care is integral in the family bond (Martinez, 2014), caregiving is innate, and this caring nature is evoked most especially during a terminal illness. Once a loved one is diagnosed with a terminal illness, family members recognize the imperative to immediately take responsibility of the patient's care. They are quick to count themselves in and be part of the patient's lifelong journey especially that their time is running short. This desire to be included in the patient's care is described by Linderholm & Friedrichsen (2010) in their study involving family caregivers of cancer decedents. This desire to be acknowledged and involved in the patient care plan is also describe in a similar study in 2011 by McLaughlin et al. Although their study focused on family caregivers of patients with Parkinson's Disease, the context of illness chronicity and complexity demonstrated comparable result.

Cancer caregiving requires complex care. At any stage, cancer patients require holistic and comprehensive care from trained professionals. Similarly, family caregivers serve as an important cornerstone of palliative and end-of-life care (McGuire et al., 2012) to ensure the continuity of care. According to Aoun et al in 2005, successful palliative care requires the substantial contribution and participation of family members to ensure the continuity of care even after the patient is discharged. However, complex care may be too much for lay people and their readiness versus their competence for the role may not be congruent. Research on cancer patients and their family caregivers, such as those of Harding & Higginson (2003) and Bee et al (2009), conferred that there are inadequate preparatory trainings offered to the identified family member who will be responsible for the patient's care. While there may be few structured supportive programs available, these are not optimally utilized by the family caregivers (Harding

et al., 2012; Hudson et al., 2004) for a number of reasons: Their current competence and needs were not integrated to the discharge planning (Lindholm and Friedrichsen, (2010); (2) contents of the program may have an emotive nature (Hudson et al., 2004) to which the family caregivers may not wish to entertain, lest they will feel more vulnerable; and (3) healthcare professionals are not trained to support and educate them enough to make them feel significant (Giles & Miyasaki, 2009)

As the battle with cancer endures, family caregivers eventually come to realize the details of the new reality. Realizing that the role and its responsibilities prove to be enormous and life-altering (Bowden-Tucker, 2012) they find themselves ambivalent towards the new role (Brobäck and Berterö, 2003). Their ambivalence manifests as feeling of insufficiency in their adjustment to the role and altered patterns and feelings of uncertainty, both in their role performance and in their patient's day-to-day condition. This makes the continuation of palliative care at home more challenging and distressing in the long run.

Due to the complex nature of cancer, caregiving in the end-of-life (EoL) is almost perceived as synonymous with multifarious responsibilities, mostly exhausting and taxing. The adverse effects of caregiving, particularly in the EoL stage, have been outlined by numerous studies such as those of Jack & O'Brien (2010), and Robinson et al (2012). In a systematic review conducted by Stenberg et al in 2010, there were numerous problems reported that comes with the caregiving responsibilities. These negative aspects range from physical, psychosocial, emotional, and financial domains.

Palliative care at home requires round the clock readiness to attend to the patient's needs. As a result, sleep deprivation is a staple complaint among family caregivers (Northouse et al., 2012). An incompletely subdued fear of deterioration and eventual death may also cause sleep disturbances, hence the feeling of fatigue and energy drain over time.

Exhaustion was also related to various factors aside from altered sleep pattern. In the study of O'Hara et al (2010) on family caregivers of cancer patients, the increasing dependence of patients for their activities of daily living (ADL) demands is directly related to exhaustion and burnout. Although these basic ADLs, such as bathing, hygiene, feeding, and toileting are simple and do not require technical nursing expertise, these are still physically exhausting activities. Moreover, due to the patient's decline in function and independence, together with other complicating details such as tubes, ostomies, drains, pressure injuries, stumps, etc., simple tasks

may otherwise become complex. Other reports include back pain, weight loss, and muscle strain (Jo et al., 2007)

Negative aspects of caregiving also include emotional torment. An elaborate array of literature on how cancer affects the various aspects of the patient's personhood have been published to date. Kim and Given (2008) stressed out that family members are equally affected by the multi-aspect effects of cancer. This result is especially observable among Filipino families due to the strong sense of family centrality where personal and emotional connections are part of their culture. Filipinos are known to be driven by empathy. This empathic nature of the Filipinos enables them to be more effective in their caregiving role. However, one setback of this innate characteristic is their exposure to the nearly same level of emotional torment, while simultaneously balancing their physical, psychosocial, and financial problems associated with their caregiving role. This puts additional stress to family caregivers, eventually leading to caregiver burden.

The constant fear of witnessing a loved one deteriorate and their imminent death consciously and subconsciously affects the role performance of the family caregivers. Dumont et al (2006) associated this lingering fear of declined functioning and terminal outcome with increasing caregiver burden. Furthermore, Northouse et al. (2000) found that the patient's distress affects their caregivers' perception of their caregiving effectiveness. Deterioration is somehow perceived as an outcome of poor care, making them question their competence and whether they were doing things correctly.

Eventually, as the entire weight of the caregiving in the end of life comes to its full measure, the role slowly transforms into a distressing experience. Adverse effects eventually take their toll on family caregivers. Numerous studies expose how the carer's needs are underexplored and profiled. (Soothill, 2001; Caress et al., 2009; Linderholm & Friedrichsen, 2010). It is even uncertain whether these needs are definitively addressed by existing support programs (Harrop et al., 2014), due to the lack of methodologically rigorous evaluation studies (Harding and Higginson, 2003; Hudson, 2004; Hudson, 2006). In fact, studies converge on their findings that caregivers have significant unmet needs related to their caregiving role. In a related study, Giles & Miyasaki, 2009, showed that family caregivers feel alone, isolated, and left out on their own. Overall, there is an evident lack of longitudinal and empirical studies on how to prevent the adverse events of EoL caregiving (Grande et al., 2009).

Caregiving in the end of life is very demanding. This entails enormous sacrifices on the part of the person in charge of the patient's care. Over time, family caregivers find themselves struggling to balance their caregiving responsibilities with their personal interests (Kotronoulas et al., 2012). With the patient's best interest as the priority, the family caregivers can often ignore their own needs, leading to unfavorable health outcomes (Clemmer et al., 2008). What was seen as important at this stage was to support the ill person in both practical and emotional terms. By placing the ill person's need over their own, the tendency is for family caregivers to ignore or hide the recognition of their own forthcoming loss. This may have enabled them to continue in the family caregiving role for a time, but it also has reduced their ability to prepare for the death of their loved one.

They usually resist acknowledging their own personal needs in exchange of striving to become a better caregiver and be able to balance the patient's needs and wishes (Robinson et al., 2012). In the process, this abnegation results to other adverse effects on the carer's emotional well-being, as described in previous literatures. In their descriptive, correlational study in 2002, Cameron et al links higher emotional distress with cancer carer's inability to participate in his / her valued activities and interests. Since the caregiving tasks require so much time and effort, family caregivers would concentrate their depleting physical and mental reserves on their responsibilities, leaving them unable, or even remorseful, to take some time off for their leisure. Personal or social time may be viewed as merely a secondary priority. This social isolation is also mentioned in the study of Goldstein et al (2004) and Zapart et al (2007) where cancer and palliative caregivers who have limited social networks and altered lifestyle patterns reported higher caregiver burden.

Aoun et al., (2005) linked the largely unmet needs of the cancer caregivers to the dearth of evidence-based programs aimed at mitigating the adverse effects of the role. This finding strongly associates with the study of Lynch et al in 2013 which revealed the weak and selectively accessible palliative care services in the Philippines. This care modality is mostly institutionalized and lacks congruity among healthcare facilities. Since palliative care is still yet to gain strong national traction legislatively and executively, there is considerably little, or even misconceived, knowledge about palliative care. Due to this prevalent inaccessibility to professional palliative care services, and the consequent nescience, carers resort to experiential learning and mostly via trial-and-error approaches (Stajduhar et al., 2013). Lack of

tangible professional support and feedback mechanisms leave the family caregivers attrited as they struggle to continue providing complex care despite the worry of additional discomfort or injury. Uncertainty with the basic care skills expected of them draws recurrent guilt whether they were doing things correctly. The fear of doing more harm than good was always present. Brobäck & Berterö (2003) described this as feelings of insufficiency where family caregivers constantly feel uncertain with their task, leading to poor perceptions of self-efficacy.

Alongside the sparse palliative care services, there is also a scarcity in published literatures on research-based carer support interventions in the Philippines. Only selected healthcare facilities offer palliative care services, hence the inadequacy of published research. The need for a national policy and healthcare programs that will address the overall welfare of the family members acting as family caregivers is evident. Even for other countries with an already established and structured palliative care system (including hospice and end of life care), recommendations for further needs assessment and research-based intervention development are part of their quality improvement processes. Their focus also includes reducing the negative aspects of caregiving and provide basis for cost-effective resource allocation. (Aoun et al, 2005).

This healthcare paradigm has significant advantages in the Philippine healthcare setting since there are no tangible carer support programs to date. Moreover, the limited healthcare budget has direct effects on its markedly reduced healthcare workforce. The intricate interplay of the lack of a robust palliative care program, limited access to relatively unaffordable palliative care services, and the significant patient-to-hospital/healthcare professionals disproportion, leaves caregivers unaided and unsupported. It is highly-recommended that the government should aggressively devise and implement a carer support program since family caregivers are replacing skilled health workers in the delivery of complex care in cancer.

Helplessness is not an option upon recognition of the need for a responsible caregiver. Since time is running out, family members strive to make use of the remaining times with the patient. The need to remain reliable is so ingrained that family caregivers refuse acknowledging their own needs over their patient's. They must not show any sign of breakdown or at least exhaustion lest they become a source of discouragement (Linderholm and Friedrichsen, 2010). This is consistent with the study of Northouse in 2000 which pointed out that caregiver symptoms (role adjustments problems) affect their appraisal of how they effectively perform their caregiving role. Hence, family caregivers needed to demonstrate courage and dependability

for them to effectively carry out their tasks, instill hope, and improve their patient's quality of life.

Cancer care comes with considerable financial costs. From diagnosis, to treatment, and up to palliation, financial implications have been a source of stress and burden among family caregivers (Gardiner et al., 2014). Co-researchers of this study acknowledged the effect of cancer care in their finances. Depletion of resources is common report among them. In order to sustain palliative care at home and not to make the patient feel forsaken, family caregivers would maximize all possible sources of funds. Financial resources are extracted from their family savings, properties, loans and even aids from government and non-governments entities. Obtaining financial assistance from these sources is physically exhausting and time-consuming. Family caregivers recognize this as an additional cause of stress, especially when their debts start to accumulate beyond their perceived ability to pay. The study of Nijboer et al (1999) and Guada et al (2011) provided evidence that low socioeconomic status further complicates the adverse effects of end of life caregiving. Consequently, the family caregivers' quality of life is significantly lower among those with socioeconomic deprivation (Iqbal et al., 2010). Nevertheless, worrying on payment and their own quality of life are of lesser priority compared to the more urgent concerns on how to afford the best possible care and comfort measures in the end of life.

In congruence with other studies on Filipino culture of care, this study suggests that filial bond seems to be the most important factor in the role assumption. It is interesting to note that family members assume the caregiving role despite having no formal educational background or prior competency. However, willingness to take part in the patient's cancer journey entails immense responsibility and implications. Symptoms management and personal care needs were identified as significant stressors (Brazil et al., 2010). Daily activities associated with these aspects vary from practical caregiving to more complex tasks, such as medication administration, assessment and identification of warning signs, symptom relief, safety, and comfort measures (Wikes et al., 2000). Caregiving strain appears to increase proportionally with the patient's dependency on caregiver as end of life draws near (Jack & O'Brien, 2010). In the study of Kalnins (2006) family caregivers of terminally ill cancer and stroke patients reported the explicit need for supportive education, especially on practical caregiving. This finding resonates with the

research of Lai & Thomson (2011), when they studied the family caregivers of elderly patients with several comorbidities and varying levels of dependency.

Consequences of self-deprivation and neglect of family caregivers accumulate over time. They have complex needs that usually get unnoticed as most of the attention and resources are funneled towards the patient. Failure to address the caregivers adversely affects the caregiving outcomes. Patient's long-term adjustment to the illness is negatively affected by the family caregiver's role adjustment problems (Northouse, 2000). Similarly, the study of Park et al (2010) on 1662 family caregivers of cancer decedents revealed that unmet needs adversely influenced the quality of care delivered.

III. Meaning in Suffering

Ultimately, the co-researchers were able to find meaning and purpose in their ordeal. Making sense of their situation was a difficult and gradual. Family caregivers suffered the adverse effects of cancer caregiving in an enduring pattern before they discovered the rewards and benefits of their experience. Their need for holistic support to alleviate the deleterious effect of end-of-life caregiving is evident. Interestingly though, regardless of the amount of actual or perceived support received, family and spirituality was of great importance in shaping the meanings they derived from the experience

The unequivocal need for caregiver support is already mentioned in several literatures (Harding and Higginson, 2003; Kalnins, 2006). There seems to be a contradicting view on the adequacy of existing programs aimed at supporting family caregivers. Harding et al (2012) pointed out that numerous interventional studies on how to support family caregivers are already circulating. Perhaps, this result applies to western countries where palliative care has strong local activity (Group 3B) and integration to mainstream service provision (Group 4), according to the global palliative care level map by Lynch et al (2013). Despite the presence of evidence-based interventions, such as those of Bultz et al (2000), Hudson (2004), Hudson (2006), these programs' structure, contextual feasibility, and access or delivery are still areas to be focused on and streamlined. Palliative care as a comprehensive service is yet to gain national coverage and accessibility in the Philippines. Hudson et al (2004) and Bee et al (2009) argued the insufficiency of available support programs for family caregivers. In the same paper, Lynch et al (2013) labeled Philippines with Category 3A (Isolated Provision) in terms of perceived palliative care

development. This category indicates patchy scope and modestly supported palliative care services, with funding often donor-dependent. It is important to note that supportive care for family caregivers strongly emanates from an established palliative care service.

Moreover, the chronicity of the illness depletes financial resources; hence even if palliative care services are available it may not be fully utilized. Families will have to settle with what they have after having spent most of their resources on their patient's diagnostic and treatment expenses. This means that family members take over a completely unfamiliar role as they take charge of their loved one's care despite having neither prior technical preparations nor supportive trainings. In the course of their caregiving experience, family caregivers feel alone and left on their own without adequate information or training on caregiving (Giles & Miyasaki, 2009; Hasson et al., 2009). Experiential learning bears physical, psychosocial and emotional downsides (Stajduhar et al., 2013). Without a professional team actively assisting them and providing feedback, family caregivers experience recurrent uncertainty, compunction, and guilt, all of which contributes to the caregiving burden.

Positive reinforcements predict life satisfaction among caregivers (Kaufman et al., 2010). For family caregivers to effectively and satisfactorily perform their role, they need to be reassured that they are not alone and that they are a significant part of the patient's care. Corrective measures should be implemented with gentleness and respect; otherwise they may feel guilty or incompetent. They need to be encouraged that they are doing a good job. Literatures have pointed out the importance of boosting the family caregiver's morale as a form of emotional support, optimizing patient care and role effectiveness (Hudson et al., 2008), and improving quality of life and satisfaction (Kaufman et al., 2010)

In a study of Lai & Thomson in 2011, they examined the difference between actual vs. the caregivers' perceived adequacy of social support. They found out that the perceived adequacy, rather than the actual amount of social support, predicted lesser caregiver burden. This finding provides a framework in addressing caregiver burden, especially when palliative care services could not be afforded or even accessed. The presence of family and friends is an excellent source of emotional support. The inclusion of family members and social networks (friends, relatives, etc.) in the comprehensive plan of end of life care at home is extremely important, especially in the Philippine setting. Manalo (2013) discussed the pivotal role of the family in the shared decision-making process concerning their patient's care. They provide

invaluable emotional, financial, and respite support, both for the patient and the family caregiver. Moreover, Varona et al (2007) underlined the buffering effect of social support in perceived caregiver burden. In a quantitative study involving caregivers of patients with lung cancer, Haley et al (2003) linked social activities, visits from family and friends, and larger social networks with lesser depression and greater life satisfaction.

The ability to care for a terminally-ill loved one generates feelings of satisfaction (Haley et al., 2003; Wong & Ussher, 2009). In a study to determine how the family caregivers of terminally ill cancer patients cope, Hudson (2006) discovered that in contrast to the already known negative aspects, there were strong positive emotions associated with the opportunity given to them. The role enabled them to demonstrate their love through care (Smith, 2009). Their ability to handle and master the role generates pride and satisfaction (Jo et al., 2007). Keeping their promise was precious, especially when it was a commitment made to a dying loved one. According to Funk et al (2010), caregiving in the end of life was described by family caregivers as positive and rewarding. The role generated a sense of accomplishment as they were able to handle an extremely challenging responsibility. According to them, family caregivers found strength and comfort as they discovered a sense of meaning in their role, enabling them to cope. Meaning was associated with the privilege to reciprocate the care and affection they once received from the patient. This payback was considered their final sendoff offering as the patient prepares for eventual death.

Another positive benefit of the caregiving experience is the formation of deeper sense of connection and togetherness (Seal et al., 2014). Caregiving in the advanced stage of illness means following the patient in every step of the way and being an immediate responder to every need (Brannstrom et al., 2007). Since time was not a luxury as the patient's life draws to an end, moments spent together were considered priceless. Further undermining end of life caregiving's positive facets, family caregivers even claimed that if they had to do the same thing again, they would not hesitate to do so (Linderholm and Friedrichsen, 2010). The positive rewards of caregiving help create meanings that enable family caregivers to generate a sense of purpose out of the hardships and loss they went through (Wong & Ussher, 2009).

As discussed earlier in this chapter, acceptance of the current situation and how it will alter lifestyle patterns and family dynamics is crucial. This enables strategic planning on optimal patient care. While questions on why such things had to happen resurface every now and then,

family caregivers resort to their spiritual connection to a higher being / power for anchor of faith and hope. Religion (or spirituality) is considered an important factor in benefit finding and discovering meanings of life experiences, as stated in the study of Donovan et al (2011). In a systematic literature review by Becker et al in 2007, only a fifth of the studies appraised differentiated religion from spirituality. Although technically distinct in terms of expression and definition, scientific papers use both words interchangeably since concepts of religion and spirituality in the research context still requires further juxtaposition. For this paper's purpose, religion and spirituality will convey the same meaning and will be used interchangeably.

Surrender and submission to God characterizes a good death (Manalo, 2017) among Filipinos. As end of life comes near, coming at peace with God is a priority. Likewise, reconciliation with family and friends is among every dying person's wish in preparation for death. Since Filipinos are mostly Christians, (believing in God, regardless of denomination or order), religion plays an important role in their lives, illness, and death, as well as in every decision concerning these aspects (Nambayan & Lu, 2015). Therefore, to ascertain a dignified death that patients and families desire, spiritual care should remain among the priority intervention of healthcare providers, particularly nurses (Doorenboss et al., 2010). Moreover, religion positively relates to grief and bereavement (Becker et al., 2007). Spiritual care aimed at helping to understand the illness and how to cope with the situation yielded higher satisfaction among family caregivers of seriously ill patients, as cited in the study of Hanson et al in 2008. Therefore, religion and spirituality complements their attempt in finding purpose and meaning (Donovan et al., 2011) in their experience despite the hardships and losses. It enables them to cope effectively during and even after their end of life caregiving experience.

IMPLICATIONS AND DIRECTIONS FOR FUTURE RESEARCH

Implications

This study depicts the emotional journey to which family caregivers embark on when they took the caregiving role in terminal illness. Upon diagnosis, the myriad of emotions starts to revolve and tasked family members confer their ambivalence in the anticipation of major life changes, crucial decisions, new role assumption, and altered family dynamics. Since cancer

affects the family as well, it is suggested that the disclosure of diagnosis, treatment options, and prognosis be done on a multi-disciplinary team conference together with the family. Their active involvement in the team's plan of care will give them access to necessary emotional supports that will somehow alleviate their unpleasant responses to their new situation. This multi-disciplinary team may include doctors, nurses, social workers, and psychiatrists. Since family members are already considered as equal care recipients, the healthcare team should not merely include them in the care provision to the patient. It is essential to include their mental, psychosocial, and emotional wellness in the team's care plan. Counseling, mental hygiene, and emotional wellness programs are just some of the measures that may be explored for this purpose. Further, communication skills with emphasis on conveying empathy and sensitivity are excellent trainings that the healthcare team should undergo.

The explicit need for professional support among family caregivers is also accentuated in this study. As mentioned earlier, family caregivers desire information on the diagnosis, prognosis, and treatment options. To support them in their new role, they will need structured programs that will help them in the practical and technical aspects of caregiving. Patient and family empowerment through their active engagement in the actual care is a widely-used approach in preparing lay persons for independent caregiving. Systematic demonstration and return-demonstration provides opportunity for them to learn with lesser fear since the supervision of a healthcare professional offers continuing assurance. This resembles training in a controlled environment with the presence of a mentor. Positive reinforcements and corrective feedbacks will also improve their caregiving competence, while boosting their confidence in their ability to handle the role.

There is a stark difference in the perspectives of patient care when healthcare in the Philippines is to be compared to other countries. Not all healthcare facilities move with the philosophy of patient and family partnership through their active participation in care and care-related decisions. Seemingly, patient care is focused on attending to a passive, "sick patient" until they recover. Family members are like spectators on the side line, waiting anxiously on how things will turn out. Whether patients will improve or continue to deteriorate (which will either prompt them to be transferred to other cheaper facilities or go home against advice), the hospital's responsibility does not appear to go beyond the patient's hospital stay. Prior to discharge, family members who will assume the caregiving role are inadequately prepared for

their role. Not all facilities have structured program for information and skill acquisition support that will make home caregiving less strenuous. Care recipients (both the patient and their families) are left on their own. Hospitals, therefore, should be more aggressive in integrating patient/family empowerment and continuity of care in their services. This should not be merely confined to offering private duty services, but rather, the empowerment to care for themselves and their family members at home. This may range from simple, practical caregiving tasks to more complex skills (oxygenation, suctioning, tube feeding, wound care, ostomy management, etc.)

As life draws to an end, the focus of care tilts toward palliation where the goal is to provide comfort and relief while making sure that the last remaining moments are lived with quality and dignity. However, cancer care, including the palliative modality, can be costly and healthcare programs in the Philippines have limited coverage due to political and economic factors. Resources are most likely depleted at the illness' terminal stage as well. With death nearing and financial drain to consider, patients and/or their families will resort to be discharged even against medical advice. EoLC is continued at home where family members are primarily in charge of taking care of the patient. Its involvement in every details requiring decision indicates the significance people place on their families. Out of this intricate structure comes the voluntary assumption of the caregiving role. This study emphasized the promising contributions of family members in the end of life. Although they are recognized as the critical piece in palliative care at home, the attention seems to be exclusively focused on the patient's needs. This leaves the family members, now acting as family caregivers, unattended, vulnerable, and deprived. This study provides evidence that the inclusion of family caregivers as equal recipients of care will maximize their contributions on EoLC. The researcher believes that this is an economically practical and cost-effective investment that will offer short and long term solutions for the financial and caregiving-related challenges. One specific intervention is to design training sessions for family caregivers regarding basic nursing care prior to discharge.

Likewise, the nursing profession can also make good use of this study's result, as well as those of the related studies reviewed. Patient education should not be limited to verbal teachings, brochures, or pamphlets. Enhancing the curriculum to include patient and family engagement for a more active, hands-on role in their care is an upgrade to our profession's current state. This is a very encouraging embodiment of the nurse's educator-advocate function. Further, a follow

through mechanism via structured hospital-wide patient/family involvement programs will strengthen this educator-advocate function of nurses.

This study was able to shed light on the profound dearth of affordable and accessible national program on palliative care and how its provision can positively affect EoLC at home. Even with the encouraging progress over the last decades, there is still a long way to go, especially in gaining government-initiated funding and implementing tangible services. Until then, taking care of those who take care of others is a win-win solution for all the concerned parties (government, hospitals, healthcare professionals, patients, and their families). Policies that will create comprehensive and nationally-accessible support programs for them will optimize available financial and human resources. The researcher considers this as a sustainable and culturally congruent solution, compatible with the inherent set of morals, values, and faith that Filipinos are known for. The Philippines may not be endowed with a hefty national budget, nor substantial allocations on healthcare compared to other countries yet, but we can tap a sustainable resource unique among the Filipinos. We have our families unconditionally demonstrating their affection through selfless care. Their unpaid contributions make up for the lack of attention to healthcare and so this is the appropriate time to start involving them in the care delivery, both as providers and recipients

Another significant insight in this study is that towards the end of the trajectory of their experience as caregiver of a dying relative, they will begin to find meaning in their ordeal. However, for them the process of finding meaning is influenced by the availability of support coming from all possible sources (their need for information and instructions was already explicated in this chapter). One interesting finding is how the family caregivers value the comfort of social support coming from their family and friends. It is suggested that the family caregivers should have other family members, or even willing friends, with them that will assume active participation in EoLC. This will provide respite for the main family caregiver in order for them to attend to their personal needs and dissipate the stress buildup. This option can be discussed with the patient to ensure his / her willingness to involve people other than the immediate family in his / her care. Again, this will be traced back to the suggested creation of multi-disciplinary care programs that recognize the invaluable contributions of social networks.

The integral role of religion and spirituality in EoLC was also discussed in this paper. Spirituality seems to be a deeply ingrained trait evoked by crises such as, for this paper's

purpose, cancer. Since Filipinos are known for their resilient faith, the inclusion of spiritual care will supply the missing, and often neglected, piece in the holistic care of patients and families. Hospitals should involve spiritual services in their multi-disciplinary care approach. The availability of spiritual support in every institution is expected to contribute dramatic improvements in coping and meaning finding among patients and their family caregivers. A wary strategic formulation is, however, necessary to ensure respectful considerations since there are different religions and sects / orders already in existence. Spiritual care can be a sensitive topic in both ways; care recipients may not be appropriately addressed, or it may not be able to adequately provide the desired quality of care. The researcher, therefore, advocates for close coordination with religious authorities for this matter.

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