End-of-Life Care: Differences in Perceptions on Between Patients and Family Members

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ABSTRACT

End-of-Life Care (ELC) has recently received attention from medical professionals due to the growing number of cancer patients. This descriptive relational study was conducted to determine the differences in perceptions of ELC between patients and family members in selected oncology clinics in Iloilo City. Patients and family members had different perspectives about ELC measures, including preserving life, allowing resuscitation, ventilator use, ICU admission, NGT feeding, parenteral nutrition, and dialysis. Family members tend to be more supportive of ELC measures than the patients. The monthly income and relationship with the patient have some bearing on how the family member perceived ELC. With the differences in their perception of ELC, advocating for advance directives is recommended. If allowed by the patient, family members closely involved in healthcare decision-making must also be included in the discussions to ensure congruence between the patient and family members.

Keywords: End-of-Life Care, Palliative Care, Hospice Care, Patient Decision Making

INTRODUCTION

Background and Rationale of the Study

The quality of End-of-life care has received growing impact over the past several years. Continuous monitoring through medical evaluations or administrative review is deemed essential to maintaining quality of care (Connor, 2004).

End-of-life care (ELC) refers to the healthcare of those individuals in the end stage of their disease which is on advanced stage. As a multidisciplinary approach, it requires numerous and complicated decisions, including queries on palliative treatment, patients' right to its autonomy, ethics, efficacy of extraordinary or hazardous medical interventions and even assessment of efficacy of continued routine medical interventions. Existing resources of the patients' family and the community's healthcare support may also impact ELC.

Although varied across culture, the interest in End-of-life-care appears in all

parts of the globe. In Canada, one specific example is the aging population which magnifies the demand for providing medical services for more people with prolonged multiple chronic health illnesses such as cancer. From today to the year 2056, it is projected that the deaths related to different illnesses or natural circumstances will double and 80 percent of which are rooted from end stage chronic diseases (Burge, 2014).

In Western countries, nursing home residents' multiple chronic diseases had been notable. Given that the patient's wants, and life-desires must be considered in ELC enrolment, the deterioration of cognitive function presents as a challenge. Giving importance to every patient's value and choice for ELC are the primary foundations of what is called Advanced Care Planning (APC) (Gjerberg, 2015). In Asian countries, Confucian culture continues to be dominant among the Chinese. The ELC is reliant on the ultimate responsibility of every son or daughter: (1) they are expected to watch their aging and/or dying parents and (2) they are expected to stay by their side until their last breath. This mentality and culture are inculcated among their younger generation (Yang, 2008). Interestingly, family members were found to have the enthusiasm to pay for the bills to prevent pain, promote peaceful death in their respective homes, as well as receive high quality care than their

patients (Malhotra, Farooqui, Kanesvaran, Bilger, & Finkelstein, 2015).

In the Philippines, ELC care began in 1980s among cancer patients. Malignant neoplasms maintain the third rank on the leading causes of mortality, after diseases of the cardiovascular system (National Statistics Office, 2010). The worsening of the physical and cognitive symptoms during management and treatment of terminally-ill cancer individuals hinders their own practice of autonomy – making them unable to verbalize their requests and wills on their final days. Their dependence to their respective families as a surrogate in making consent for critical decisions is recognized (Puchalski, 2000). Creutzfeldt (2015) emphasized that the family member's recognition to the choice of the cancer individual has been associated with high quality of ELC. With this, the family member plays the huge accountability in decision-making and is expected to be knowledgeable enough of the values, preferences, and advantages of the patient. Researches showed that surrogate decisions given by families are in line with patients' own preferences at a level the same with chance (Chan, 2004; Phillips, 2003; Covinsky, 2000; Marbella, 1998; and Layde, 1995).

Though multifactorial, most terminally ill cancer patients choose aggressive treatment. This is often derived from prolonged death, aggressive care, and financial instability. With the patient's inability to

communicate, their capacity to clear out wishes and their plan for own treatment preferences is hindered. Giving importance to the decisions and wishes of both groups is very essential to give a high-quality ELC; however, opposing preferences exist between the personal preferences of the patient and the family's choice. Thus, this study was conducted to identify the difference in perceptions of ELC care issues between patients and family members.

Objectives of the Study

This study aimed to compare the perception on End-of-life-care issues between patient and family members in selected Oncology clinics in Iloilo City.

Specifically, it aimed to:

1. describe the characteristics of the patient in terms of educational attainment, monthly income, and stage of cancer;

2. determine the characteristics of family members in terms of educational attainment and relationship to the patient;

3. determine if there is a relationship between the patient's characteristics and perception on End-of-Life Care;

4. determine if there is a relationship between the family member's characteristics and perception on End-of-Life Care; and

5. determine if there is a difference in the perception on End-of-Life Care

issues between the patient and family members in terms of 10-key areas.

Theoretical Framework

This study is anchored to the Family Systems Theory by Dominguez and Oetter (1996) which posits that family is the most significant component of the environmental influences in the quality of life of an individual. According to the proponents, this starts at birth where the child is influenced by the method and ways they are being cared of and supported. As we proceed to infancy, an individual begins to learn the basic concept of being part of the smallest unit of society. The family's impact to each member is a complex and reciprocal process, not linear. In a family, when a part is not functional, the other parts are being affected or impacted. The family is also in constant interaction with the healthcare team members who are directly caring for the individual family members.

Conceptual Framework

In this study, every patient is identified as an individual whose functioning is affected by a condition (cancer). The immediate family is presumed to be affected by this condition since members of the family compose the system. As a reaction to this stressor, patients and family members are seen to gain inputs from the healthcare team's existing condition or illness of the patient. This input is expected to be translated to

end-of-life care measures. Their perspective as a system with emotional boundaries is presumed to be congruent with each other.
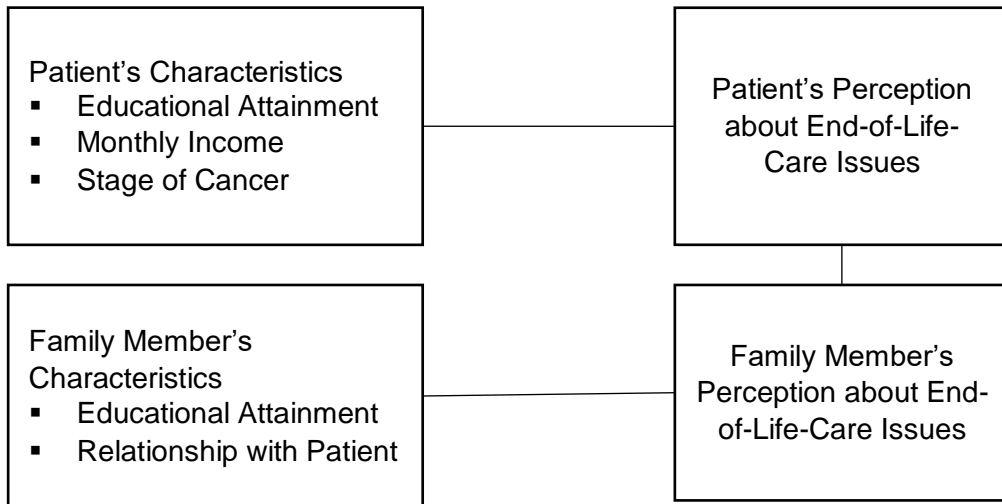

Figure 1. Paradigm of Research Variables

Definition of Variables

For the clarity of this study, the following terms are defined:

Characteristics. Characteristics refer to a trait unique to the individual. In this study, these refer to the characteristics of both the patient and family member. These include:

Educational Attainment. This refers to the highest degree the individual has attained. Responses were categorized as, Elementary Graduate, High School Graduate, and College Graduate.

Monthly Income. This refers to the amount of money received every month (in pesos). It will be categorized as follows: 'Low Income' if it is below Php 10,000.00, 'Average Income' if it is Php 10,001 to 20,000, and 'High Income' if it is 20,001 and above.

Stage of Cancer. This refers to the location, areas affected, and spread, and whether it is affecting other parts of the body of the terminally-ill patient. Responses will be categorized as Stage 1, 2, 3 or 4.

Relationship of the Family Member to the Patient. This refers to the state of being connected by both the patient and family member. Responses will be categorized as follows: First Degree Relative/ Immediate Family (Spouse, Parents, siblings or Children); Second Degree (Aunt/Uncle, Nephews/Nieces); Third Degree (Grandparents or Grandchildren); and others (In - Laws).

Perception on End-of-life-care. Perception is the process which involves the recognition and interpretation of the meaning of sensory stimuli. *End-of-life-care (ELC)* is a support provided for people who have been advised medically that their condition has poor prognosis and that they have only few months or years to live (National Health Services, United Kingdom, 2018). In this study, perception on End-of-Life Care refers to the recognition and interpretation of patient and family members on supporting end-of-life care measures. It was determined using a 10-item questionnaire which is answerable by three options: 'not want', 'undecided', and 'want'. The total number of responses 'want' was determined. It was categorized as 'does not support' if the total score is 6 and below and 'support' if the total score is 7 -10.

Significance of the Study

End-of-life-care (ELC) is gaining popularity in the medical arena due to the continuously growing cancer cases in the country and other chronic diseases. In the Philippines, cancer ranks as the third leading cause of mortality; hence, attention must be directed towards its management options. This study will benefit the following individuals and organizations:

Nurses. The findings of this study will serve as a basis for health education sessions by the nurses taking care of cancer patients. This will also help the nurse understand the involvement of the clientele and family members during interactions with the patient. The nurse can also help the patient identify coping strategies and set priorities to optimize quality of life. Furthermore, this study can guide nurses how to initiate therapeutic communications or conversations with consideration to their preference for advance directives and ELC.

Patients. Through the result of this study, the patients will be able to anticipate the difference, if there is any, on their own point of view and that of the family's decisions. Patients, as the recipients of our care, are not passive but rather active directors of their own care. This will also help them understand their own illnesses and prognosis in the same way, help them make choices regarding their own care.

Family Members. Understanding the distinction between their perception and of the patient is the key benefit that the family can gain from the findings of this study. Moreover, this will make them realize their major role when it comes to end-of- life decision-making process of their loved one such as ethical and legal issues surrounding dying and death.

Future Researches. The result of this study will be a basis or baseline information in identifying other needs of patients and their respective families in End-of-Life Care.

Delimitations of the Study

This descriptive relational study was conducted in outpatient medical

oncology clinics in Iloilo City. A one-shot survey design was utilized to gather the data needed to meet the objectives of the study. The study respondents are Ilonggo patients with Cancer and family members aging from 20 years old and above that are seeking consultation at the oncology clinics with cancer. The data were gathered from the family members who served as primary caregivers of the patient. The primary aim is to determine the difference of perception in ELC of both the patient and family members. Due to the conduct of the study in available medical oncology clinics, reproductive cancers may be understated.

RELATED LITERATURE AND STUDIES

Patient's Perspective of End-of-Life Care (ELC)

Researches demonstrate that ELC varies among families and patient's perspective. Three stereotyped trajectories of the remaining months and years of patients' lives are: (1) cancer experience, (2) organ failure occurrence, and (3) frailty and dementia among the elderly. With this, introducing End-of-Life Care may be delayed, or they may not receive any End-of-Life Care until very near death (Izumi, 2012). In Taiwan, a multi-group latent class analysis was utilized to determine the preferences for cardiopulmonary resuscitation, intensive care, advanced airway utilization, and intravenous nutritional support. Patient-caregiver agreement was poor and worsened over time. Agreement becomes evident only when both parties uniformly rejected life sustaining treatments. Open communication between the family and the patient is still strongly advocated (Tsang-Wu et al., 2017).

Family's Perspective on End-of-Life Care (ELC)

Without accurately understanding patients' ELC preferences, family members and other surrogates often project their own preferences to shape the ELC received by terminally ill patients. Understanding family surrogates' preferences and addressing any unrealistic expectations for their efficacy in restoring their loved one's life and function may counteract the trends toward increasingly aggressive and costly ELC over recent decades in the United States, Canada, and Taiwan (Tang et al., 2017). The patient-caregiver agreement on the utilization of life-sustaining treatment preferences is still unexamined. Despite recommendation that ELC should be personalized and tailored to the patient's preferences, these are often unknown. The majority

(40% - 79%) of patients needing ELC cannot make their own treatment decisions due to physical deterioration or mental incapacity, and only 5%-25% of seriously/terminally ill patients have advanced directives (Tsang-Wu, 2017).

METHODOLOGY

Research Design

This descriptive relational study utilized the one-shot survey design. This design allows description of a phenomenon for a specific period with consideration to the identified factors. In this study, the perspectives of the patients and their family members on End-of-Life Care (ELC) were explored among cancer patients.

Research Locale

The study was conducted in the medical oncology clinics in Iloilo City from January to March 2019.

Study Population and Sampling Procedure

This study involved patients and family members in the medical oncology clinics in Iloilo City. Purposive sampling technique was utilized using the following inclusion criteria: (1) legal age (above 18 years old), (2) had been diagnosed with cancer; and (3) without cognitive or mental-health related problems. The following inclusion criteria were utilized for the selection of family member: (a) legal age (above 18 years old), (2) related to the patient by blood; (3) had been caring for the patient and living with the patient.

Research Instrumentation

The data were gathered using a self-administered questionnaire. The questionnaire was divided into two parts:

Part 1. The questionnaire included inquiry on: (a) demographic data of the patient including educational attainment, monthly income, and stage of cancer and (b) characteristics of the family member in terms of educational attainment and relationship with patient.

Part 2 explored their perception of End-of-Life Care. A separate set of questionnaires was administered to the patient and family members. Two-way translation was utilized to ensure consistency of the English and Hiligaynon versions.

Validity and Reliability of the Questionnaire

The questionnaire was presented to a panel of experts in the field of research and nursing. All comments and recommendations of the panel were taken into consideration (content validity). For reliability, a pre-test was conducted among ten (10) patients and

family members. The same inclusion criteria were utilized. The respondents of the pre-test were not considered as part of the population. The reliability of the questionnaire was tested using Cronbach's alpha and the result is 0.892, indicating that it is suitable for use.

Data Collection Procedure

The permission of the oncologist and respective clinic heads were obtained before the conduct of the study. Upon approval, both the patient and family member who fulfilled the inclusion criteria were approached for participation in the study. When informed consent is already secured, the questionnaires were personally distributed to the respondents. It was immediately retrieved upon completion. The researcher was available to cater any queries and clarifications from the respondents.

Ethical Considerations

An informed consent was attached to the questionnaire. The objectives of the study were read and explained to the respondents. It was explained that the participation in the study is voluntary and that they may withdraw participation at any point of the study. The data gathered were solely used for research purposes only. The researcher has been present during the data gathering procedure to clarify any concerns from the respondents.

Data Processing and Statistical Analysis of the Data

The data were analyzed using the Statistical Package for Social Sciences (SPSS) version 25. Descriptive statistics, including frequency distribution tables, means, and percentages were used to summarize the data gathered from the study population. Cramer's V was used to determine the extent of the relationship between the nominal and ordinal variables. Cramer's V was used in all relational analysis as it can be used with any number of categories or levels (Frey, 2016). To test for the differences on the proportion who supports ELC measures between patients and family members, z test was used.

The values of Cramer's V were interpreted based on the following: Under 0.1 (Very Weak), 0.10-0.19 (Weak), 0.20-0.29 (Moderate), and 0.30 and over (Strong).

Gamma was used to analyze the relationship between the two (2) ordinal variables. For example, the relationship between monthly income and support on ELC (End-of-Life Care) was tested using Gamma. The results were interpreted using the following: 0.00-0.24 (No relationship), 0.25-0.49 (Weak relationship), 0.50-0.74 (Moderate relationship), and 0.75-1.00 (Strong relationship).

RESULTS AND DISCUSSION

Perception on End-of-Life Care

The table shows the summary of the perception of the patient and family members on ELC measures. As shown, most of both groups support ELC measures which means that they agree to at least 7 domains on ELC which were investigated by this study. However, it is notable that there was a higher proportion (83.7 %) of family members who supported ELC in contrast to the 65 percent of patients.

This indicates that both groups have supported ELC procedures such as cardiopulmonary resuscitation, emergency blood transfusion, and parenteral nutrition. However, the desire to execute these measures is strongly supported by the family members compared to the patients who experience the lifetime condition, cancer. This is contrary to the findings in a study conducted in Canada which revealed that majority of the patients and family members do not want to be kept alive on life support where there is little hope and meaning (Heyland et al., 2006).

Table 1
Distribution of Patients according to their Perception on End-of-Life Care

Perception on End-of-Life Care Measures	Patient		Family Members	
	f	%	f	%
Support (7 - 10)	52	65.0	67	83.7
Does Not Support (6 and below)	28	35.0	13	16.3
Total	**80**	**100.0**	**80**	**100.0**

Patient's Characteristics and Perception on End-of-Life Care

Educational Attainment and Perception on ELC. Based on educational attainment of the patient, there was almost the same fraction of elementary and college graduates (66.7 and 65.6 % respectively) who had high support on ELC. Gamma revealed that there was no relationship between the two variables. This means that regardless of their educational attainment, patients must be oriented comprehensively about ELC measure available to them as majority regardless of the group, supports ELC.

Monthly Income and Perception on ELC. To answer the question on the possible contribution of one's income to their perception on ELC, correlational analysis was also performed between the two (2) variables. It could be noticed that patients with income of Php 10,000 and below seemed to be equally divided on not supporting (48.1 %) and supporting (51.9 %) ELC measures. Statistically, the relationship turned out to be weak,

indicating that one's socioeconomic status only minimally influences one's perception on ELC. Although support tends to become higher among patients with higher income (a direct relationship), other factors need to be considered. Hence, clinicians and healthcare providers must continuously present options for ELC management to the patient regardless of their SES (socioeconomic status).

Stage of Cancer and Perception on ELC. The stages of cancer correspond to the severity and extent of damage of the cancer cells to the body. Based on the data, three-fourths of patients who had regional spread or stage 3 (77.8 %) and metastasis or stage 4 (77.8 %) supported ELC measures. They had the desire to extend their lives in a comfortable manner with pain medication. Interestingly, the proportion of those who highly supported ELC increases as one's stage of cancer also advanced (from 44.4 % to 77.8 %). This shows that as the patient's disease progress or as cancer was diagnosed late, patients opted for End-of-Life Care measures. It was also notable that the group with the highest proportion who gave low support on ELC was among those with Stage 1 cancer (44.4 %). Statistically, the relationship was weak (Gamma = 0.385). This means that the stage of cancer influences to a minimal extent how patients view ELC measures. Clinically, this would imply that education and talks about ELC measures should be discussed as soon as the patient is diagnosed.

Table 2

Relationship between Patient's Characteristics and End-of-Life Care

Patient's Characteristics	Perception on End-of-Life Care Measures					
	Support (7 – 10)		Does Not Support (0 – 6)		Total	
	f	%	f	%	f	%
Educational Attainment						
Elementary	4	66.7	2	33.3	6	100.0
High School	8	61.5	5	38.5	13	100.0
College	40	65.6	21	34.4	61	100.0
Total	52	65.0	28	35.0	80	100.0
Gamma = 0.049 (No relationship)						
Monthly Income						
10,000 and below	14	51.9	13	48.1	27	100.0
10,001 to 20,000	19	70.4	8	29.6	27	100.0
20,001 and above	19	73.1	7	26.9	26	100.0
Total	52	65.0	28	35.0	80	100.0
Gamma = 0.306 (Weak)						
Stage of Cancer						
Stage 1	4	44.4	5	55.6	9	100.0
Stage 2	18	56.3	14	43.8	32	100.0
Stage 3	21	77.8	6	22.2	27	100.0
Stage 4	9	75.0	3	25.0	12	100.0
Total	52	65.0	28	35.0	80	100.0
Gamma = 0.385 (Weak)						

Family Member's Characteristics and Perception on End-of-Life Care

The correlations between the characteristics of family members and their perception on End-of-Life Care were also investigated.

Educational Attainment and Perception on ELC. More than eight in every 10 family members who completed high school or college highly supported ELC (88.9 and 86.0 % respectively). On the other hand, elementary graduates had the highest proportion of respondents who did not support ELC (14.0 %). Gamma revealed a value of 0.185 which signifies that there is a weak relationship between the two (2) variables. Hence, one's educational attainment has minimal to no influence on their perception of ELC.

Relationship with Patient and Perception on ELC. Most of both groups (immediate and extended family) showed high support for ELC; however, there was a higher proportion among members of the extended family (91.4 %). Interestingly, the proportion of immediate family members who did support ELC was thrice as high as the fraction of extended family (24.4 and 8.6 %). Statistically, the relationship between both groups was moderate (Cramer's V= 0.207). Specifically, this means that the relationship with the cancer patient moderately support on ELC measures. Although both are supportive of ELC measures, extended families favor it more than the patients' immediate family. Immediate family members have seen the burden that they will carry for decisions made for their patients, hence, a greater proportion of them (24.4 %) do not favor ELC measures compared to the extended family counterpart (8.6 %).

Table 3
Relationship between Family Member's Characteristics and End-of-Life Care Measures

Family Member Characteristics	Perception on End-of-Life Care Measures				Total	
	Support (8 – 10)		Does Not Support (0 – 7)			
	f	%	f	%	f	%
Educational Attainment						
Elementary	2	40.0	3	60.0	5	100.0
High School	16	88.9	2	11.1	18	100.0
College	49	86.0	8	14.0	57	100.0
Total	67	83.8	13	16.3	80	100.0
Gamma = 0.329 (Weak)						
Relationship with Patient						
Immediate Family	34	75.6	11	24.4	45	100.0
Extended Family	32	91.4	3	8.6	35	100.0
Total	66	82.5	14	17.5	80	100.0
Cramer's V = 0.207 (Moderate)						

Difference in the Patient's and Family Member's Perception on End-of-Life Care

The data show the differences in the perception on End-of-Life Care measures between the patient and the family members. Among the ten (10) specific items, there were only three (3) items where there was no significant difference on the perception of two (2) parties: plan of care that focused on relieving pains, allowed the use of vasopressor drugs, and received blood transfusion. This means that regardless of the interventions, both the patient and the family members agree that ELC measures should be focused on pain relief. They are also willing to have vasopressor medications to be administered just to maintain the blood pressure of the patient within normal range. There is also no disagreement on the transfusion of blood as it is deemed by both parties to be an intervention for emergency.

Overall, the data show that the patient and family members shared a common interest in relieving pain and discomfort; however, they differed on the specific procedures that would be implemented. Oftentimes, family members were found to be medically aggressive, or hopeful compared to their patients. The close family ties, regardless of their relationship to the patient, was strongly evident even in medical decision-making. This gains support from the study of Yang (2008) where it was found out that the younger generation have an inculcated perspective that they should take care for their sick parents and other family members.

The findings supported the Family Systems Theory where several and varied outputs were generated from the experience of both the patient and family members when dealing with a cancer patient.

Table 4

Differences in the Patient's and Family Member's Perception on End-of-Life Care

End-of-Life Care Specific Items	Distribution of Patients and Family Members who supports End-of-Life-Care				z-value
	Patient		Family Members		
	f	%	f	%	
A course of treatment that focuses on preserving life as much as possible, even if it means having of more pain and discomfort.	48	60.0	67	83.8	3.464*
Plan of care that focuses on relieving pain and discomfort as much as possible.	77	96.3	79	98.8	1.016
Allow to be resuscitated to restore my breathing, if my heart stopped beating.	40	50.0	64	80.0	4.191*
To be attached to a machine to help me breathe, if I cannot be able to breathe on my own.	37	46.3	56	70.0	3.137*

Table 4 Continued

Allow the use of drugs to maintain my blood pressure in normal range such as vasopressors.	68	85.0	74	92.5	1.512
Admitted in the intensive care unit (ICU) to receive further care.	60	75.0	71	88.8	2.294*
Be fed by artificial means through nasogastric tube.	58	72.5	76	95.0	4.050*
Be fed by artificial means through intravenous nutritional support.	61	76.3	73	91.3	2.626*
Submit myself to a dialysis treatment, if my kidney function declines and uremia develop.	42	52.5	62	77.5	3.435*
Receive blood transfusion, if I will experience massive bleeding.	71	88.8	73	91.3	0.528

*Significant $z_{computed} > z_{critical} = 1.96$

CONCLUSIONS AND RECOMMENDATIONS

Based on the findings of the study, the following conclusions were drawn:

1. The patient's cancer site has a strong relationship with ELC. The family member's relationship with the patient has some influence on their perception of ELC.

2. More family members support ELC compared to the patients.

3. Monthly income and stage of cancer has a minimal influence on the perception of ELC while age and educational attainment have no bearing to the ELC.

4. The family member's relationship with the patient has some bearing on the perception of ELC while educational attainment has minimal influence on support on ELC.

5. The patient and family members both support plan of care that focuses on relieving pains, allows the use of vasopressor drugs, and receive blood transfusion. They have varying support on the course of treatment on preserving life, allowing resuscitative measures, attachment to ventilator, ICU admission, NGT feeding, parenteral nutrition, and dialysis treatment. This supports the Family System Theory which states that the family members may have varying outputs on a certain input to the system. In this study, they varied in their perception on ELC measures.

Recommendations

Based on the findings and conclusions of the study, the following are the recommendations:

1. Since it was found out that there is a difference on the perception on ELC between the patient and family members, health-related education sessions are recommended to be addressed to both parties. Despite being a patient advocate, the nurse is cognizant of the patriarchal nature of the Filipino culture and the influence of the family members on the healthcare decisions of the patient. Hence, involvement of the family in the healthcare decision-making is encouraged unless otherwise stated by the patient.

2. While there are limited evidences yet, this study has shown that there are several characteristics of either the patient or the family members which can influence their perception on ELC. This must be considered by healthcare professionals when counselling and caring for their patients who are terminally ill (i.e. those with cancer). Individual and combined counselling programs may be designed to allow both parties (patients and family members) to come up with a decision that will be a compromise for both parties.

3. The clinicians may use this study to become patient advocate by developing educational programs or interventions to facilitate open communication among family members. This will aid in achieving consensus in accord with the best interest of the patients and improve the quality of ELC.

4. Further studies are also encouraged to scenarios related to conflicts in aggressive care preferences between patients and family members. This will not serve as baseline information in identifying other needs of both groups but also strengthen the significance of advance directives by which patients can express their healthcare treatment preferences and authorize a person to make choices for them when they no longer decide for their own. Studies in the inpatient care setting is also recommended as this study focused on outpatient oncology visits only.

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