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Original Research Article

Knowledge and attitudes of patients with gynaecologic cancer on palliative care in a low-middle income region

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ABSTRACT

Background: Palliative care improves the symptom burden of women with gynecologic malignancies either when they are admitted or treated in an outpatient. This study aims to evaluate the knowledge and attitudes of gynecologic cancer patients regarding palliative care, with the potential to identify barriers to delivering high-quality palliative care services. The results may be used by policymakers in developing strategies for the delivery of effective palliative care services.
Methods: This is a cross-sectional study design using a validated, self-administered questionnaire. Level of knowledge of the respondents was determined based on the number of correct responses. Attitude of the respondents was assessed using a 5-item Likert scale with its corresponding descriptive equivalent and computation of weighted means. The association between patients' knowledge and attitude were determined using Pearson's moment correlation coefficient.
Results: Between July and December 2020, a total of 67 patients participated in this study. The mean score of the participants' knowledge was 8.78 (67%) which is of adequate knowledge. The majority of the participants' computed weighted mean for attitude ranges from 3.31 to 3.52 which indicates appropriate attitude. Most participants responded correctly about the goals of palliative care that it would address any psychological issues (83.58 %) and stress (77.61%) brought up by serious illness and it can help the patients in dealing with the side effects of their medical treatments (82.09%). Unfortunately, more than half of the participants (62.69%) believed that palliative care is specifically for cancer patients and half of them (50.75%) responded that patients must be in the hospital to receive palliative care. The study also showed that the knowledge of the respondents is not correlated with appropriate attitude (p-value>0.05).
Conclusions: This study shows that gynecologic cancer patients have a good level of knowledge of palliative care and have a generally positive attitude toward accepting palliative care. No significant correlation between knowledge and attitudes was established in this study.

Keywords: End-of-life care, Gynecologic cancer, Palliative care, Supportive care, Symptom relief

INTRODUCTION

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering using early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.[1] It is estimated that 20 million people worldwide are to require palliative care at the end of life (EOL) every year and more than 4 million people will benefit from palliative care but knowledge and attitudes of the general population especially the patient towards palliative care is very minimal as per various studies.[2-4] Gynaecologic cancer patients are to suffer more from significant symptom burden, from the time of diagnosis, during treatment and to both end-of-life care and remission. Recent studies shows that palliative care improves symptom burden of women with gynaecologic malignancies, such as pain, anorexia, fatigue, nausea, anxiety and shortness of breath, either when they are admitted or treated in an outpatient palliative care clinic.[5,6] The palliative care service is an exclusive form of holistic treatment which interconnects sufferers and their families with doctors at hospitals, as well as the community irrespective of age, religious differences and social status.[7] It is imperative to relieve, and ease the pain (physical, mental and spiritual) of the sufferer and offer a support system; hence, it is equally important to educate the public and patients regarding the role of palliative care and what services are provided since it is often mistaken for end-of life or hospice care.[8] Ideally, palliative care services should be provided from the time of diagnosis of life-threatening illness, alongside potentially curative treatment such as chemotherapy or radiotherapy which may positively influence the course of illness. and may include end-of-life or terminal care.[9]

The concept of palliative care and the awareness of available facilities in the general population is very much lacking especially in setting of third world countries hence, assessing the knowledge and attitudes of the patient would create awareness about palliative care by doing methods that would interest the public thru various media, internet and health education materials and that hospitals would be equipped to cater patients' palliative care needs and to assist them to get through palliative care that would eventually bridge the gap between the public and palliative care institutions.

Currently, most health care systems are not set up in a way that makes it easier for people to receive palliative care or to die where they would wish and most countries don't have policies or integrated palliative care services. A recent study done by McCarthy et al, shows that most of the public is unfamiliar with palliative care which may have a negative implication with regards to equitable access to health care services and to the quality of care provided to the dying and bereaved.[10]

The increasing frequency of chronic non-communicable diseases such as cancer as major cause of morbidity and mortality in developing countries has emphasized the need to identify knowledge, acceptance and understanding of the patient regarding the benefits and services when dealing with palliative care. In the Philippines, cancer is the third leading cause of morbidity and mortality and is ranked 78th out of 80 countries as worst place to die in the 2015 quality of death study index because of impaired health and medication literacy among patients that they may resist or be unaware of the need for early treatment and palliation.[11]

According to the 2015 Philippine cancer facts and estimates, the top three gynaecologic cancers affecting Filipino women are cervical, ovarian and endometrial cancer with incidence rate of 16, 5.9 and 5.6 per 100,000 respectively with cervical cancer as the most common and leading cause of mortality and when in advanced stage would require a judicious and cost-effective palliative care.[12] Palliative care has been misinterpreted and often neglected by the society since its main definition and scope are not merely understood by the general population. This study would evaluate the knowledge and attitudes of gynaecologic cancer patients that could be used by policy makers in developing strategies that would improve the acceptability of quality palliative care and service delivery to patients with terminal illnesses. We focus on gynaecologic cancer patients, to help them access palliative care by implementing targeted education and policy campaigns on benefits of palliative care and to manage their future needs, expectations and resourcing of end-of-life care. Ultimately, to establish baseline understanding of patients towards palliative care that will serve as a basis of future studies and interventions aimed in identifying barriers towards delivering quality palliative care services.

METHODS

This is a cross-sectional study design with the use of a validated, self-administered and interview guided questionnaire. All diagnosed gynaecologic cancer patients who were admitted for chemotherapy or on medical management and sought consult at the outpatient department gynaecologic oncology clinic and who met the inclusion criteria were eligible to participate. Software generated simple random sampling was done to enroll participants in the study. Knowledge section was based on Palliative care knowledge scale (PaCKS) while questions for attitudes were lifted from different studies. Content validity of both knowledge and attitude were verified by one medical oncologist, one psychiatrist and one radio-oncologic nurse. Questionnaires were piloted to 30 participants. Reliability testing was done using Cronbach's alpha coefficient with a value of 0.93 which indicates an excellent internal consistency to measure knowledge and attitudes of respondents.

A total of 67 participants were included in this study by using the prevalence rate of gynaecologic malignancy in Asia which is 12% and computed at 95% confidence interval using Open Epi sample size calculator. Participants were asked to answer self-administered and interview-guided questionnaires. The interview was performed by a single research assistant assigned to all study participants to avoid interview bias. Informed consent was obtained from the population study and the questionnaire was handed out on the day of recruitment when respondents were properly identified.

The respondents were informed about the objectives and the purpose of the study on the first page of the survey questionnaire. A written consent form for approval of their participation in the study was also included. Instructions were provided in the survey form. All data collected from questionnaires were coded with the use of a coding manual that made the data suitable for analysis. Microsoft Excel v 2010 was the main data management tool in the study. Data analyzed using IBM SPSS Statistics 19 © 2010.

Data collected were analyzed using statistical tools. Percentages were used to analyze data gathered for the demographics of patients. Tables were utilized in order to represent data collected during the study. Knowledge score was determined among respondents. The number of correct responses were tallied, and scores range from 0 to 13. "I don't know" responses were scored as incorrect and mean average score of the participants was determined and a value of <50 % represents poor knowledge while a mean average score of >50 % represents good knowledge.

The attitude was assessed using a 5-item Likert scale (ranging from strongly agree (3.25-4) to strongly disagree (1-1.72)), using their descriptive equivalent by computing their weighted means. Association testing was done using Pearson's -moment correlation coefficient to determine the direction and magnitude of relationship between participant's knowledge and attitude towards palliative care.

RESULTS

Between July and December 2020, a total of 67 patients participated in this study, with a majority age group of 40 to 59 years old. The majority of the patients (64 %) originated from the region of study and the rest were from the nearby province. Forty-three percent (43%) of them are high school graduates and are currently unemployed. Forty-four percent (44.78%) are Roman Catholic and more than fifty percent (56.72 %) has a monthly income of less than 10, 000 pesos. Half of the participants (50.75%) are diagnosed with cervical cancer and 44.78% are diagnosed at stage II of their disease. Table 1 presents a socio-demographic profile of participants.

Table 2 shows the knowledge of patients on palliative care. Correct answers are in bold. Most participants responded correctly about the goals of palliative care that it would address any psychological issues (83.58 %) and stress (77.61%) brought up by serious illness and it can help the patients in dealing with the side effects of their medical treatments (82.09%). Forty seven percent answered that they should not give up their primary attending physician and the same percentage of respondents believe that palliative care is not exclusively for people who are at the last six months of their life. Unfortunately, more than half of the participants (62.69%) believed that palliative care is specifically for cancer patients and half of them (50.75%) responded that patient must be in the hospital to receive palliative care. Interestingly, almost half of the participants (47.76%) thought that palliative care is only for adult patients but they recognized that it's a team-based approach to care (79.10%) and its goal is to help people better understand their treatment options.

Surprisingly, there's a small difference between the respondents who answered correctly (47.76%) that palliative care doesn't encourage people to stop treatments aimed at curing their illness compared to those who believed otherwise (40.3%). Furthermore, 83.58% of the respondents answered that palliative care improves a person's ability to participate in daily activities and helps the whole family to cope with a serious illness. The mean average score of the participants is 8.78/13 (67.5%) representative of a good knowledge.

Table 3 presents the attitudes of participants on palliative care. Based on the computed weighted mean, the participants strongly agree that it is crucial for family members and significant others to remain at the bedside until death occurs (3.52), that they would avail of palliative care services upon diagnosis of a terminal illness (3.33), they should always be told of their condition and the process of death and dying should be discussed openly (3.37) and palliative care would lead to patient's satisfaction and dignified death (3.31).

Table 4 shows the correlation of level of knowledge to attitude of gynaecologic cancer patients on palliative care. Based on correlation analysis there is no significant relationship between knowledge and attitude with a p-value of more than 0.05.

Table 1: Socio-demographic profile of participants.

Socio-demographic	N	%
Age (in years)		
18-29	2	2.99
30-39	10	14.93
40-49	20	29.85
50-59	20	29.85
60-69	13	19.40
70-79	2	2.99
Province		
Benguet (Region of study)	30	44.78
Mt. Province (Region of study	12	17.91
Pangasinan (nearby)	18	26.87
Ilocos Sur (nearby)	1	1.49
Nueva Ecija (nearby)	2	2.99
Laguna (nearby)	3	4.47

Continued.

Socio-demographic	N	%
Kalinga (Region of study)	1	1.49
Educational attainment		
Have not attended formal education	2	2.99
Elementary graduate	6	8.96
High school graduate	29	43.28
Vocational graduate	3	4.48
College graduate	22	32.84
Post graduate education	5	7.46
Occupation		
None	29	43.28
Housewife	14	20.90
Teacher	3	4.48
Farming	6	8.96
Housekeeper	5	7.46
PWD	1	1.49
Caregiver	2	2.99
Self-employed	2	2.99
Branch coordinator	3	4.48
Others	2	2.98
Religion		
Roman catholic	44	65.67
Born again Christian	7	10.45
Baptist	5	7.46
Pentecost	1	1.49
Seventh day Adventist	3	4.48
Anglican	2	2.99
Iglesia ni Cristo	1	1.49
Protestant	2	2.99
Others	2	2.99
Monthly income		
less than 10,000	38	56.72
10, 000-30,000	27	40.30
30,000-70,000	2	2.99
70,000-140,000		0.00
More than 140,000		0.00
Type of cancer		
Cervical	34	50.75
Uterine/Endometrial	15	22.39
Ovarian	17	25.37
Gestational trophoblastic neoplasia	1	1.49
Stage		
I	15	22.38
II	30	44.78
III	18	26.87
IV	4	5.97

Table 2: Knowledge of gynaecologic cancer patients on palliative care (PaCKS).

	True	%	False	%	I don't know	%
A goal of palliative care is to address any psychological issue brought up by serious illness	56	83.58	0	0.00	11	16.42
Stress from serious illness can be addressed by palliative care	52	77.61	5	7.46	10	14.93
Palliative care can help people manage the side effects of their medical treatments.	55	82.09	3	4.48	9	13.43

Continued.

	True	%	False	%	I don't know	%
When people receive palliative care, they must give up their other doctors.	25	37.31	32	47.76	10	14.93
Palliative care is exclusively for people who are in the last 6 months of life	22	32.84	32	47.76	13	19.40
Palliative care is specifically for people with cancer	42	62.69	18	26.87	7	10.45
Palliative care must be in the hospital to receive palliative care	34	50.75	27	40.30	6	8.96
Palliative care is designed specifically for older adults.	32	47.76	24	35.82	11	16.42
Palliative care is a team-based approach to care.	53	79.10	8	11.94	6	8.96
A goal of palliative care is to help people better understand their treatment options.	54	80.60	6	8.96	7	10.45
Palliative care encourages people to stop treatments aimed at curing their illness	27	40.30	32	47.76	8	11.94
A goal of palliative care is to improve a person's ability to participate in daily activities	56	83.58	7	10.45	4	5.97
Palliative care helps the whole family cope with a serious illness.	56	83.58	5	7.46	6	8.96

Table 3: Attitude of gynaecologic patients on palliative cancer.

Attitude	WM (weighted mean)	Descriptive equivalent
It is crucial for family members and significant others to remain at the bedside until death occurs	3.52	Strongly agree
I would avail of palliative care services upon diagnosis of a terminal illness	3.33	Strongly agree
Patients receiving palliative care must always be told of their condition and the process of death and dying should be discussed openly.	3.37	Strongly agree
Palliative care would lead to patient's satisfaction and dignified death	3.31	Strongly agree

Table 4: Correlation of level of knowledge to attitude of gynaecologic cancer patients on palliative care.

		Knowledge	Attitude
Knowledge	Pearson correlation	1	0.359
	Sig. (2-tailed)		0.553
	N	13	4
Attitude	Pearson correlation	0.359	1
	Sig. (2-tailed)	0.553	
	N	4	4

DISCUSSION

Improved knowledge of palliative care would lead to a better understanding and involvement in responding to the different needs and concerns of the patient in palliative care.[13] In this study, there was generally a good level of knowledge among the participants which contradicted most recent studies that show a lack of knowledge among the general public regarding palliative care. Reasons such as working in a medical field or the experience of a close friend or family member increase knowledge on palliative care.[13,14] The impact of being a woman, as seen in this study population has already been established as having a higher level of knowledge of palliative care.[2,15] A good level of knowledge may also be attributed to the fact that most gynaecologic cancer patients have: a) higher rates of access and referral to palliative care because of high symptom burden among patients; b) the relative lack of systemic therapy options for patients with resistant gynaecologic cancers; and c) early palliative care referral among gynaecologic oncologists.[16]

Despite having a good level of knowledge, the respondents have an incorrect understanding that palliative care is specifically for cancer and adult patients and that patients must be hospitalized to receive palliative care. This may indicate that there is a general tendency to identify palliative care goals as giving comfort and dignity at the end of life to elderly cancer patients only. This is in contrast to the World Health Organization's advocacy that palliative care should not only improve the quality of life of patients but also of their families and be available from diagnosis regardless of condition or age.[1,2] Due to their understanding that one must be admitted to receive palliative care, people might choose to stay at home because of the added cost of being treated at the hospital, when in fact, palliative care should be available at both basic levels such as patient's homes and specialized levels such as cancer centres. These misconceptions may lead to a delayed and missed opportunity for early access and referral for palliative care services.[17,18]

The patient's knowledge of health services will drive utilization and consumers need to know what a service is and how it is relevant to their situation before they seek it out or accept it.[19] Even though patients are somewhat knowledgeable about palliative care, patients still are not able to make fully informed treatment decisions when they are unfamiliar with the service or misunderstand key aspects of this type of care hence brief educational interventions can help address these gaps by providing accurate and comprehensive information thru videos or information page.[19]

There's a positive attitude of patients towards palliative care as reflected by their weighted means which agrees with most studies.[20-23] The majority of the societies are not good at discussing death and find that the issue is upsetting and difficult to confront.[16] In the Philippines, one's perspective is based on cultural values and beliefs related to religion, family, and interpersonal harmony. Family is the basic social and economic unit of Filipino kinship and in times of illness, the extended family provides support and assistance which may be attributed to inherent values of strong respect for the elderly, a strong reliance on family as decision-makers in cases of illness, and strong expectations of care by the family.[24,25]

The primary goals in gynaecologic cancer care are to enable patients to use positive coping mechanisms and sustain their adherence to therapy through a positive attitude. Religion which holds a central place in the life of Filipinos may play an important role in this finding in palliative healthcare by obtaining comfort and strength from their religious beliefs that motivate the individual to seek out a support group that can provide help when necessary and may offer a perspective to the individual to develop attitudes that enable the person to face stressful life conditions.[21,22,24] In cases of end-terminal diseases, peaceful death has been advocated with the presence of family support, acceptance of the burden, belief in God and dying as a time to surrender self.[25]

Early involvement of specialized palliative care services for patients especially with gynaecologic malignancy improves their quality of life, increases satisfaction with care, limits overall costs, and may be associated with prolonged survival.[8] Negative attitudes toward palliative care among patients and caregivers are often cited by physicians as a reason for late referrals to palliative care services; hence palliative care should be offered to the patient and to their immediate care givers starting from the time of diagnosis.[23] A significant correlation between the level of knowledge and attitude in this study has not been established, which is inconsistent with recent studies showing a positive relationship between knowledge and attitude, indicating that a higher level of knowledge could lead to a more positive attitude towards palliative care.[26-28] According to KAP (Knowledge, Attitude, and Practice) theory, there is a progressive relationship among knowledge, attitudes, and behavior, as knowledge is the foundation of behavior change, while belief and attitudes are the driving forces behind behavior change, however, this theory does not apply to this study.[29]

Various factors such as gender, religious beliefs, educational attainment, and place of residence whether urban or rural, along with their proximity to a hospital may affect one's knowledge and attitude. This implies that good knowledge does not necessarily equate to a good attitude, and a positive attitude does not inherently imply good knowledge. In some instances, patients and their caregivers may be familiar with the term palliative care but often have only a partial understanding of their disease and treatment strategies.

The Filipino perspective on death and dying is influenced by cultural values and beliefs characterized by tough-natured optimism. They tend to view palliative care as a means of prolonging the life of a seriously ill family member and do not give up hope for recovery. This may result in additional costs and burdens on the family, exhausting all of their resources. Knowledge and its correlation to attitudes toward palliative care may vary by social norms, including a reluctance among the general public to discuss death and dying, which can lead to hesitance in utilizing such care despite awareness of it. In general, there is consensus that the knowledge and attitudes of patients are crucial for improving access to services and for empowering more patients and communities in palliative care. Since knowledge plays a causal role in attitude and behavioral consistency, a better understanding and involvement of oneself in addressing the diverse needs and concerns of patients regarding palliative care is important.

CONCLUSION

This study shows that patients have a good level of knowledge of palliative care but other misconceptions regarding its scope and services offered may lead to delayed or non-access to palliative care during the early trajectory of serious illnesses. Even if participants are somewhat knowledgeable about palliative care, patients will not be able to make full treatment decisions if they are unfamiliar with the services available and have an insufficient understanding of the key aspects of this type of care. Hence, comprehensive information dissemination programs that would address palliative care knowledge gaps and quality service delivery to the patients are needed. In general, respondents have a positive attitude in accepting palliative care which may relate to Filipino cultural values and beliefs as influenced by their religion, family and interpersonal harmony, and their acceptance of peaceful death. No significant correlation between knowledge and attitude was established in this study.

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