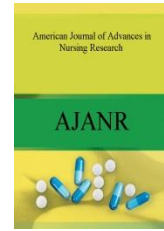




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NEEDS, CONCERNS AND LEVEL OF DISTRESS AMONG PATIENTS UNDERGOING PALLIATIVE CARE IN A SELECTED RURAL AREA, PATHANAMTHITTA DISTRICT, KERALA

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ABSTRACT

Palliative care is an approach that improves the quality of life of patients and their families who are facing the problem associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems. Assessment of needs, concerns and distress of palliative care patients is important as it affects their overall health. During our Community Health Nursing posting we identified that many patients who are receiving palliative care in their homes are suffering from physiological as well as psychological discomfort and in most of the houses, family members are considering the terminally ill as a burden. From this experience, we identified that it is essential to assess the needs, concerns and level of distress among patients undergoing palliative care. A quantitative non experimental research study was conducted to assess the needs, concerns and level of distress among patients undergoing palliative care in a selected rural area, Pathanamthitta district. This study is based on General systems theory by Von Ludwig Bertalanffy (1968). A total of 60 palliative care patients were selected as participants using purposive sampling technique. The tools used were baseline variable proforma, NEST interview schedule, and concern checklist and distress thermometer. The validity and reliability of the tools were established by using split half method and was further computed using Spearman's Brown Prophecy formula and was found to be reliable. The 'r' value for NEST interview was 0.78, Concerns checklist was 0.83 and Distress thermometer was 0.9 respectively. The results revealed that majority of palliative care patients, [190(79%)] had negative experience on need, 45(75%) of them had moderate level of concerns and 49(81.66%) had highest level of distress. There was a significant association between need scores of palliative care patients and selected baseline variable i.e., diagnosis ($\chi^2=8.19, p<0.05$). There was a significant positive correlation existing between needs and level of distress of palliative care patients ($r=0.4$) and concerns and level of distress of palliative care patients ($r=0.6$) at $p<0.05$ level of significance. It was concluded that the level of distress of palliative care patients increase as their needs and concerns increase. Hence the palliative care patients of Ayroor Panchayat, Pathanamthitta district need various interventional strategies to maintain their quality of life. This will encourage strict adherence to proper implementation of palliative care especially in rural area.



INTRODUCTION

“Watching a peaceful death of a human being reminds us of a falling star; one of a million lights in a vast sky that flares up for a brief moment only to disappear into the endless night forever.”

Dr. Elizabeth Kübler-Ross (Death and Dying, 1969)

Palliative care is a medical care focused on improving quality of life for patients and their families. It is a health care specialty that is both a philosophy of care and an organized, highly structured system for delivering care to persons with life-threatening illness from diagnosis till death and then into bereavement care for the family [1].

The WHO defined palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.” The goal of palliative care is, therefore, to improve the quality of life of both patients and families by responding to pain and other distressing physical symptoms, as well as to provide nursing care and psycho-social and spiritual support. This is why it is best administered by an interdisciplinary, multi-dimensional team, comprising doctors, nurses, counselors, social workers, and volunteers [2].

According to WHO, global health estimates there were approximately 54.6 million deaths worldwide in 2011 and over 29 million people died from diseases requiring palliative care. The estimated number of people in need of palliative care at the end of life is 20.4 million.³ The biggest proportion, 94%, corresponds to adults of which 69% are over 60 years old and 25% are 15 to 59 years old. Only 6% of all people in need of palliative care are children. Based on these estimates, each year in the world, around 377 adults out of 100,000 populations over 15 years old, and 63 children out of 100,000 populations under 15 years old will require palliative care at the end of life. In India, there were approximately 8,264,730 deaths reported in 2014. It is estimated that in India, total number of people who need palliative care is likely to be 5.4 million people a year. In Kerala there were approximately 7.0 deaths per 1,000 population reported in 2010. It is estimated that there may be a minimum of one lakh people needing palliative care [3].

India has a huge burden of suffering from life-limiting diseases. Less than 1% of its population has access to pain relief and palliative care. India is categorized as a developing country; however, over the past 20 years, increases in the aging population and

prevalence of advanced cancer are common. Cancer has been the leading cause of death worldwide for more than two decades [3].

Kerala is the only state with a policy which integrates palliative care with the public health system and is decentralized down to the primary care level. The state accounts for 80% of all palliative care services in the country but reaches 30% of those who need it [4].

Palliative care services can be provided in a range of settings including the home, hospices, aged care homes, hospitals and palliative care units. Home based palliative care services should be provided to a great extent, especially in rural areas of these services can be provided to the doorstep of the patients. Ideally, this is where people are most comfortable at the end of their lives, surrounded by their loved ones [5].

A cross-sectional study was conducted at the Surgery and Oncology Clinic between May - June 2014 in a tertiary hospital in Malaysia regarding the most prevalent unmet supportive care needs and quality of life of breast cancer patients. A total of 117 patients out of 133 breast cancer patients recruited by universal sampling were interviewed using a structured questionnaire. The results revealed that the highest unmet supportive care needs were observed in the psychological domain (Mean 53.31; SD \pm 21.79), followed by physical domain (Mean 38.16; SD \pm 27.15). Most prevalent unmet supportive care needs were uncertainty about the future (78.6 %), fears about the cancer spreading (76.1 %), feelings of sadness (69.2 %), feelings about death and dying (68.4 %), and concerns about those close to the patient (65.0 %) and feeling down or depressed (65.0 %). Multivariate linear analysis showed that early breast cancer survivors diagnosed at an advanced stage and with greater physical and psychological needs were significantly ($p < 0.05$) associated with poorer QOL [6].

A Systematic Review was carried out for screening Psychological Distress in Palliative Care by the Department of Psychiatry, University of Leeds, and Leeds, Mental Health Trust, U.K in 2008. This systematic review summarized the evidence for screening for psychological distress in a palliative care setting. They founded that Psychological distress is common in the terminally ill which is often under detected and undertreated and has significant impact on the individual and family [7].

Community nurses are the key persons for providing home based palliative care services. Community nurses help the patients in promoting, restoring and maintaining, maximum level of comfort, function, and health, including care toward a dignified death. Based on the above facts and figures and the investigators personal experiences, they realized that there are no proper assessment measures to identify the needs, concerns and level of distress of palliative patients

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Research article



especially in rural areas. Community nurses with other intersectional approaches can provide a wide variety of services by assessing the needs of patients requiring palliative care. Considering the above facts, the investigators felt that there is a strong need to find out the needs, concerns and level of distress among palliative care patients.

Statement of the problem

A descriptive study to assess the Needs, Concerns and Level of distress among patients undergoing palliative care in a selected rural area, Pathanamthitta District.

Objectives of the study

- To identify the needs of patients undergoing palliative care
- To assess the various concerns of patients undergoing palliative care
- To measure the level of distress among patients undergoing palliative care
- To find out the association between needs of patients undergoing palliative care and their selected baseline variables.
- To find out the association between concerns of patients undergoing palliative care and their selected baseline variables.
- To find out the association between level of distress of patients undergoing palliative care and their selected baseline variables.
- To find out the relationship between needs and level of distress of patients undergoing palliative care.
- To find out the relationship between concerns and level of distress of patients undergoing palliative care.

Operational definitions

Needs

In this study, it refers to something that is necessary for a palliative care patient to live a healthy life, which is measured as scores by NEST interview

Concerns

It refers to the level of worry or emotion a palliative care patient is having which is measured as the total score of Concerns checklist for this study.

Distress

It refers to an aversive state in which a palliative care patient is unable to completely adapt to stressors and their resulting stress and shows maladaptive behaviors, as measured by the scores on distress thermometer.

Assumption

Patients requiring palliative care may have

varied needs, concerns and distress levels.

Hypotheses

- H₁: There is a significant association between needs of palliative care patients and selected base line variables.
- H₂: There is a significant association between concerns of palliative care patients and selected base line variables.
- H₃: There is a significant association between level of distress of palliative care patients and selected base line variables.
- H₄: There is a significant relationship between needs and level of distress of patients undergoing palliative care.
- H₅: There is a significant relationship between concerns and level of distress of patients undergoing palliative care.

Conceptual / Theoretical Frame work: Ludwig Von Bertalanffy's General System Model (1968) was used as the theoretical framework of the study. According to this theory, a system is composed of interactive elements and makes each system distinct from environment in which it exists.⁸ The key elements of the System theory applied to this study consists of an **input** which is the preparatory phase in which the researchers collect the baseline proforma of the subjects such as age, sex, religion, education, occupation, income, marital status, diagnosis and living area and **throughput** which includes the NEST Interview schedule, Concern checklist and Distress thermometer in order to assess the needs, concerns and level of distress of palliative care patients and **output** which includes the level of needs, concerns and distress of palliative care patients.

RESEARCH METHODOLOGY

A Quantitative non experimental research approach with descriptive cross sectional survey design was adopted for this study. The study variables included the Needs, Concerns and Level of distress of patients undergoing palliative care. The baseline variables for the study were age, sex, religion, education, occupation, income, marital status, diagnosis and living area. The present study was conducted at selected wards of Ayroor Panchayat in Pathanamthitta district, Kerala. The target population for this study was clients requiring palliative care in Pathanamthitta district and accessible population were clients in selected wards, Ayroor Panchayat, Pathanamthitta district. 60 clients residing at a selected ward, Ayroor Panchayat, Pathanamthitta, who fulfilled the inclusion criteria, were selected as participants for the study and were selected by using purposive sampling technique. Clients who were residing in a rural community at a selected ward, with a history of a serious medical condition / a functional deficit and who were



present at the time of data collection and could speak and understand Malayalam were included. Clients who were not willing to participate in the study and who were cognitively impaired were excluded from the study.

Data collection tool:

The following tools were used for the study.

1. Baseline Proforma. This tool consisted of nine items to collect the baseline data regarding the client like age, sex, religion, education, occupation, income, marital status, living area and the diagnosis.

2. NEST Interview schedule: The Needs at the End-of-Life Screening Tool (NEST) is a comprehensive assessment and outcome measurement instrument. It consists of 13 questions related to Needs (social), Existential matters, Symptoms and Therapeutic matters. NEST is the first data-driven, comprehensive tool designed from an empirically validated framework and tested survey questions use in end-of-life care. The tool was developed by Linta L and Emmanuel.S in Chicago, USA in 2001. The reported reliability of the tool is $r = 0.7 - 0.99$. The total score of NEST interview is 10 and scores that ranges between 0-5 is considered as a positive experience and 6-10 is considered as a negative experience [9].

3. Concerns checklist: The tool was developed by Devlin J in 1984 under National Comprehensive Cancer Network at UK. The reported reliability score is $r = 0.750$. It consists of 14 questions to assess various concerns of patients undergoing palliative care and to evaluate the physical, economical, and social relationship among family members. The total score is 56 and the scores are categorized as lowest concerns (0-18), moderate concerns (19-37) and highest concerns (38-56) respectively [10].

4. The Distress Thermometer: It is the most widely used rapid screening tool for assessing psychological distress in people affected by cancer. The tool was developed by National Comprehensive Cancer Network (NCCN) and Hilling don Oncology and Palliative care team at London in 1998. The reported reliability score is $r = 0.8$. The total score is 10 and scores within the range of 0-4 is considered as the lowest level of distress, 5-7 moderate level of distress and 8-10 as the highest level of distress [11].

Validity & Reliability of the tool

The tools were given to 5 subject experts to get their consensus regarding the appropriateness of use of these tools in our setting. The content validity of the tools were established by the agreement of all five experts. The

tools were translated to the vernacular language and it was retranslated to English and the reliability of the translated tools were assessed. The reliability of tools were established by using split half method using Spearman's Brown Prophecy formula. Tools were found to be reliable and the r values were as follows: NEST interview- 0.78, Concerns checklist - 0.83 and Distress thermometer - 0.9.

Pilot study

The pilot study was conducted among 6 palliative care clients of Ayroor Panchayat on 30.1.17. The study was found to be feasible and also no modifications were needed in the tool or methodology after the pilot study. Hence the researchers proceeded for the main study.

Data collection process

The main study was conducted among 60 patients undergoing palliative care in a selected ward, Ayroor Panchayat, Pathanamthitta. After obtaining formal written permission from the Panchayat president Ayroor, participants were selected using purposive sampling technique. The data collection period was from 2.2.17 to 28.3.17. The patients were explained regarding the purpose of the study and written informed consent was taken. Confidentiality was assured to all the participants to get their cooperation. The investigators collected data by surveying the patients individually in their homes using the tools. It took 45 minutes to complete the data collection interviews for each subject. The obtained data were checked for completeness and coded for analysis.

Plan for data analysis

The data were organized, tabulated, summarized, and analyzed using descriptive and inferential statistics. The demographic variables, needs, concerns and distress scores of palliative care patients were analyzed by using frequency and percentage. Association of needs, concerns and distress scores of palliative care patients with selected baseline variables were assessed by Chi-square analysis. The correlation of needs and concern scores with level of distress of palliative care patients were analyzed by Spearman Brown Prophecy formula.

RESULTS

Section 1: Description of baseline variables of Palliative care patients

Majority of the participants were in the age group of 51-100 years i.e., 52(86.66%) and were females i.e., 38 (63.33%). Also 18 (30%) of them were illiterate and 47 (80%) of subjects were unemployed. Most of the subjects were having family income of Rs. 500-749 ie,



16(26.67%) and were married 55(91.67%). Majority of the subjects were having adequate living area 40(66.67%) and 39(65%) were Hindus.

The table 1 infers that the highest number of palliative care patients was having diagnosis of cancer 23(38.33%) and least number of subjects were affected by genitourinary system problems i.e., 1(1.66%).

Section 2: Need scores of palliative care patients.

The table 2 infers that 50(79%) of subjects had negative experience regarding needs and 101(58%) of subjects had negative experience regarding existential matters. In the area of symptoms, 104 (87%) of subjects had negative experience whereas in therapeutic matters, 133(74%) of subjects had positive experience

Section 3: Concern scores of palliative care patients

The table 3 infers that among 60 subjects, 45 (75%) of them had moderate level of concerns and 6 (10%) of the palliative care patients had lowest level of concerns.

Section 4: Distress scores of palliative care patients

The table 4 infers that among 60 subjects, 49 (81.66) of them had highest level of distress and 4 (6.7%) of the subjects had lowest level of distress.

Section 5: Association of need scores of palliative care patients with selected baseline variables.

There was a significant association between need scores of palliative care and diagnosis as the computed chi-square value was greater than the table value ($\chi^2=8.19, df=2$). There was no significant association of need scores of palliative care patients with other baseline variables such as age ($\chi^2=0.92, df=1$), sex ($\chi^2=0.13, df=1$), and education ($\chi^2=5.19, df=2$), occupation ($\chi^2=2.49, df=2$), income ($\chi^2=0.005, df=1$), and marital status ($\chi^2=3.60, df=1$), living area ($\chi^2=0.187, df=1$) and religion ($\chi^2=0.01, df=1$).

Section 6: Association of concerns scores of palliative care patients with selected baseline variables:

There was no significant association of concerns scores of palliative care patients with selected baseline variables such as age ($\chi^2=0.026, df=1$), sex ($\chi^2=0.93, df=1$), and education ($\chi^2=3.69, df=2$), occupation ($\chi^2=0.438, df=2$), income ($\chi^2=2.16, df=1$), and marital status ($\chi^2=1.32, df=1$), living area ($\chi^2=0.048, df=1$), religion ($\chi^2=0.31, df=1$), and diagnosis ($\chi^2=1.39, df=2$).

Section 7: Association of distress scores of palliative care patients with selected baseline variables:

There was no significant association of concerns scores of palliative care patients with selected baseline variables such as age ($\chi^2=1.40, df=1$), sex ($\chi^2=0.002, df=1$), and education ($\chi^2=3.68, df=2$), occupation ($\chi^2=0.38, df=2$), income ($\chi^2=1.04, df=1$), and marital status ($\chi^2=0.098, df=1$), living area ($\chi^2=0.64, df=1$), religion ($\chi^2=2.40, df=1$), and diagnosis ($\chi^2=2.004, df=2$).

Section 8: Correlation of need scores and the level of distress of palliative care patients

Table 5 shows that, there was a statistically significant positive correlation existing between need scores and level of distress of palliative care patients ($r=0.4$) at $p<0.05$ level of significance. Hence it is concluded that level of distress of palliative care patients increases as their needs increases.

Section 9: Correlation of level of concerns and level of distress of palliative care patients

Table 6 shows that, there was a statistically significant positive correlation existing between level of concern scores and level of distress of palliative care patients ($r=0.6$) at $p<0.05$ level of significance. Hence it is concluded that level of distress of palliative care patients increases as their needs increases.

Table 1. Distribution of Palliative care patients according to disease stages

N = 60

Sl no	Disease stages	Gender			
		Male	Percentage (%)	Female	Percentage (%)
1	CNS problems	1	4.34	6	16.21
2	CVS problems	2	8.69	8	21.62
3	Musculoskeletal system problems	3	13.04	4	10.81
4	Respiratory system problems	2	8.69	1	2.70
5	Physically handicapped	0	0	3	8.10
6	Endocrine system problems	1	4.34	2	5.40
7	Mentally handicapped	2	8.69	1	2.70
8	Cancer	11	47.8	12	32.43
9	GUS problems	1	4.34	0	0
	Total	23	100	37	100



Table 2. Frequency and Percentage distribution of Need scores of Palliative care patients. N=60

Sl. no	Area	Scores			
		Positive Experience[0-5]		Negative Experience[6-10]	
		Frequency	Percentage(%)	Frequency	Percentage(%)
1.	NEST Interview Schedule				
	• Needs	190	21	50	79
	• Existential Matters	139	42	101	58
	• Symptom	14	13	104	87
	• Therapeutic Matters	133	74	47	26

Table 3. Frequency and Percentage distribution of Concern scores of Palliative care patients. N=60

Sl. No	Area	Range	Frequency	Percentage(%)
1	Concerns	Low (0-18)	6	10
		Moderate(19-37)	45	75
		High(38-56)	9	15
Total			60	100

Table 4. Frequency and Percentage distribution of distress scores of Palliative care patients. N =60

Sl. No.	Area	Range	Scores	
			Frequency	Percentage(%)
1.	Distress	Lowest(0-4)	4	6.7
		Moderate(5-7)	7	11.7
		Highest(8-10)	49	81.66
Total			60	100

Table 5. Correlation of need scores and level of distress of palliative care patients. N=60

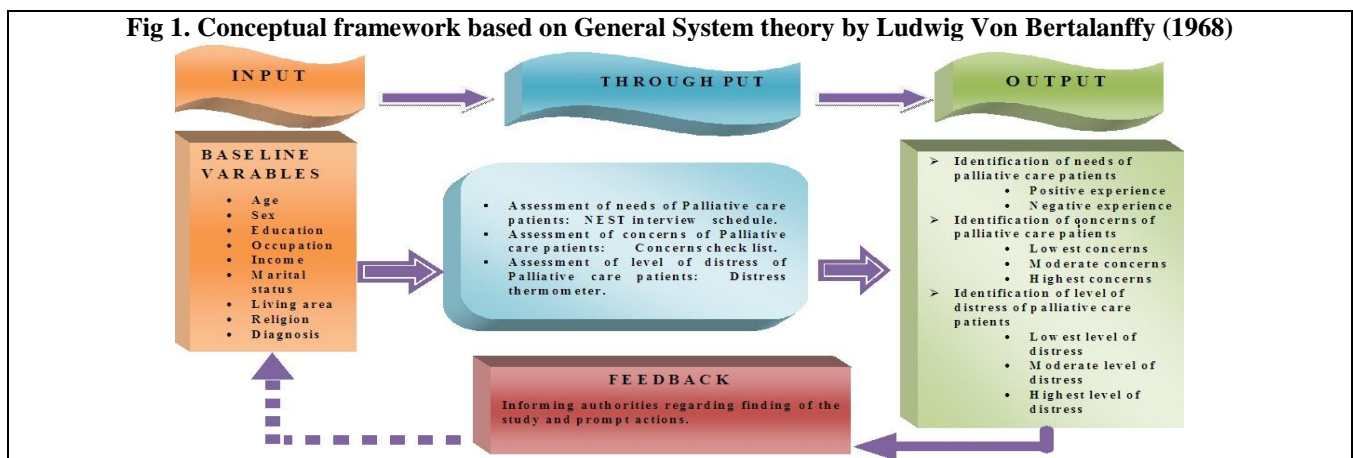
Sl. No.	Variables	Correlation coefficient 'r'	Test of significance 't'	Inference
1	Need scores and level of distress	0.4	3.32	Significant positive correlation

$p < 0.05, t^1 = 2.004, r^1 = 0.27$

Table 6. Correlation of level of concerns and level of distress of palliative care patients. N=60

Sl.no.	Variables	Correlation coefficient 'r'	Test of significance 't'	Inference
1	Concern scores and level of distress	0.6	5.71	Significant positive correlation

$p < 0.05, t^1 = 2.004, r^1 = 0.27$



DISCUSSION

Globally, the biggest proportion of people requiring palliative care corresponds to adults (i.e., 94%) of which 69% are over 60 years old and 25% are 15 to 59 years old. Only 6% of all people in need of palliative care are children. (WHO estimates, 2015). The distribution of adults in need of palliative care at the end of life by gender is 48% for females and 52% for males¹².

In the present study, majority of the subjects were in the age group 51-100 years i.e., 52(86.66%) and were females 38(63.3%). This reflects the increased sex ratio of females in Kerala. It was found that 39(65%) of subjects were belonging to Hindu religion and 55(91.6%) were married. 18(30%) of patients were illiterate and 40(66.67%) had an adequate living area. The distribution of adults in need of palliative care at the end of life according to World Bank country income groups is that 41% of the patients belong to upper middle income class, 29% of them in lower middle income class, 22% of them in high income class and 8% of them in low income class. In the present study, about 47(80%) were unemployed and 16 (26.6%) of patients had income between Rs 500-749.

WHO has classified the diseases requiring palliative care at the end of life into three categories: cancer, HIV/AIDS, and progressive non-malignant diseases. The proportion of adults in need of palliative care for cancer is relatively important for all regions. It ranges from 19.6% in the African Region to 41.5% in the Western Pacific Region. About 23(38.33%) of palliative care patients in the present study were having diagnosis of cancer.¹² This shows that there is increase in the number of patients requiring palliative care in India.

A descriptive cross-sectional survey was conducted among 124 patients, 100 nurses and 100 Domiciliary Care Providers (DCP) at National Cancer Referral Facility, Srilanka in 2014. The results revealed that 68% of patients reported that their most common need was pain relief followed by interpersonal relationship (60%) and majority (86%) confirmed that these needs were adequately met. 70% of the patients expressed full satisfaction with the psychological support they received. Only 54% of nurses surveyed expressed satisfaction with the care they provided and 94% of DCPs expressed the need to improve their knowledge and skills on palliative care.¹³

The need scores on NEST interview was interpreted as a positive and negative experience in the present study. The four sub components of NEST interview revealed that majority i.e., 50(79%) of palliative care patients had negative experience on needs. Regarding the existential matters, 101(58%) of palliative care patients had negative experience. In the area of symptoms, 104(87%) of palliative care patients had

negative experience whereas regarding therapeutic matters, 133(74%) of palliative care patients had positive experience.

About 45 (75%) of the palliative care patients in the present study had moderate level of concerns regarding various aspects such as the illness itself, feeling upset or distressed, the future, their job, finance, relationship with partner, relationship with others and the support they have etc.

A multicenter cross-sectional study in 88 terminally ill cancer patients receiving specialized inpatient palliative care was performed in Japan in 2004. The nurses explored patient existential concerns by asking several key questions, and recorded the answers that they considered typically described the patients' concerns. A total of 88 statements were subjected to content analysis. The categories and their prevalence were: relationship-related concerns (22%; isolation, concerns about family preparation, conflicts in relationship), loss of control (16%; physical control, cognitive control, control over future), burden on others (4.5%), loss of continuity (10%; loss of role, loss of enjoyable activity, loss of being oneself), uncompleted life task (6.8%), hope/hopelessness (17%), and acceptance/preparation (25%).¹⁴

The present study results revealed that among 60 participants, 49 (81.66%) of them had highest level of distress, 7(11.7%) had moderate level of distress and 4 (6.7%) of the participants had lowest level of distress.

A cross-sectional study was carried out in China in 2014 on Psychological distress in 153 elderly patients with cancer admitted to two tertiary hospitals were investigated using the convenience sampling method. Distress thermometer and the problem list, recommended by the National Comprehensive Cancer Network, and were used to assess the psychological distress and its specific manifestations. A self-designed questionnaire was used to collect demographic data. The results revealed that a total of 67 participants (43.8%) exhibited psychological distress to some degree. The analysis of the sub-categories in the problem list showed significant differences ($p < 0.001$). The highest scoring category was the emotional problems, followed by practical problems, physiological problems, and family problems. Among 34 items included in the statistical analysis, the top five were worry (73.9%), depression (55.6%), pain (54.2%), economic problems (52.3%), and fear (49.7%). Married participants, those with higher education and higher monthly income had significantly lower psychological distress score compared with single patients, those with lower education, and lower monthly income ($p < 0.05$).¹⁵

The study results show that the level of distress is more among Indian population when compared to other countries like China. Though there is increased magnitude



in India, the problems of palliative care remain almost same in India and China.

CONCLUSION

Transculturally, the needs, concerns and level of distress of palliative care patients are similar. The goal of palliative care should be to relieve the suffering of patients and their families by the comprehensive assessment and treatment of physical, psychosocial, and spiritual symptoms experienced by patients and to reduce their level of concerns and distress. All persons should have a right to palliative care at the end-of-life. The present study concluded that the level of distress of palliative care patients increases as their needs and concerns increases. The study results reinforce the

recasting of quality end-of-life care as a global public health and health systems problem, strengthen capacity to deliver quality end-of-life care and develop improved strategies to acquire information about the quality of end-of-life care. Future research works should focus on the role of community nurses and the need to develop several interventional strategies to address these needs.

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