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Knowledge and attitude toward palliative care among health workers at health post level in Makawanpur district, Nepal

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Abstract

Introduction: Nepal has made some progress in palliative care. Need for palliative care is more in rural areas where primary health care workers deliver most of the care. Their knowledge and attitude toward palliative care is very important to deliver the service in rural areas. This study aimed to assess knowledge and attitude of health workers working at health post level toward palliative care.

Method: A cross-sectional descriptive study was carried out among 174 health workers working in health post of Makawanpur district. Census method was employed. Knowledge regarding palliative care was assessed by Palliative Care Knowledge Questionnaire-Basic (PCKQ-B), validated in India. Attitude related statements were adapted from previously conducted study in Palestine. Data were analyzed using descriptive statistics.

Result: A total of 174 health workers participated in the study; 126(72.41%) were females, 70(40.23%) were between ages 20-30 years, 65(37.36%) had clinical experience of less than 5 years and majority were ANMs. Only 68(39.08%) had fair level of knowledge and 63(36.21%) had poor attitude. Majority of respondents had better understanding regarding basic knowledge of palliative care than pain management, morphine use and bereavement care. Most of the respondents showed unfavourable attitude toward caring for dying patient

Conclusion: Primary health care workers have shown fair knowledge and poor attitude toward palliative care. This study emphasizes the need to introduce palliative care in the curriculum and training program of health workers to enhance their knowledge level and develop favourable attitude towards palliative care to better serve the rural population.

Keywords: Attitude; Community health worker; Knowledge; Palliative care

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Introduction

Palliative care need is increasing globally due to growth in population of elderly and burden of chronic non-communicable diseases as major cause of morbidity and mortality.[1] Nepal has seen some progress in the field of palliative care but only small portion of people who need the care actually receive it.[2] It is ethical and social imperative of health system to ensure quality palliative care to those who are in need.

Most people live in rural areas of Nepal, but palliative care services are limited mostly in urban areas.[3] Many living in rural areas who could benefit from the service lack access.[3,4] For most people living in rural area, home is the preferred place of death, preferring to die amidst their loved ones, deep cultural notion attached to it; however, many die at home with unnecessary pain and suffering.[4–7] It is, therefore, crucial to develop palliative care in their local community integrating with primary care through community-based approach.[4,8] Primary health workers of government service are the major providers of primary care in rural Nepal, who can play vital role in delivering palliative care in the local community.[4] Therefore, primary health workers' appropriate level of knowledge and positive attitude toward palliative care is pre-requisite to reach rural and disadvantaged population.

Limited studies are available in Nepal on primary health worker's knowledge and attitude on palliative care. Therefore, this study aimed to assess knowledge and attitude of health workers working at health post level toward palliative care and inform the existing gaps.

Method

A descriptive cross-sectional study was carried out among health workers of Makawanpur district, currently working at health post, over the period of October, November and December of 2023. Makawanpur district was selected purposively for this study as most of its regions have rural characteristics and there is an ongoing program on community based palliative care services throughout the district. There are 39 health posts in Makawanpur. Census method was employed to administer questionnaire. Approval for the study was obtained from the Institutional Review Committee (IRC) (Ref: chs2306131748) of Patan Academy of Health Sciences (PAHS), Lalitpur, Nepal.

Health workers with minimum of three months clinical experience after registration and present in the health post at the time of administering question were included in this study. Any health workers who had received training in palliative care, were excluded. Questionnaires were filled by the participants in the presence of the researcher.

Data were collected using self-administered questionnaires comprising three parts: Part I included information on socio-demographic characteristics, Part II tested the knowledge and Part III tested the attitude of the health workers. Palliative Care Knowledge Questionnaire-Basic (PCKQ-B) tool, developed and validated in India, was used to test the knowledge.[9] This section contained questionnaires related to background of palliative care, pain in palliative care, myths surrounding morphine use, colostomy care, communication, psychosocial and spiritual need and bereavement care. There were 22 questionnaires with three options (Yes, No and Don't Know). The right answer was graded as '1' and incorrect and don't know were graded as '0' with maximum score that could be attained being 22. The knowledge scores were classified into three categories as Poor knowledge (<=50%), Fair knowledge (51-75%), and Good knowledge (>=76%). [10]

Attitude related statements were adapted from previously conducted study. [10] It uses a five-point Likert scale ranging from 1= strongly disagree to 5= strongly agree which had 11 item rating scale with the highest score of 5 for each option with total possible score of 55. Five of the items were worded positively and six (1, 2, 4, 7, 10, 11) were worded negatively that needed reverse scoring. The total attitude scores were further classified into poor (<=50%), moderate (51-75%), and good (>=76%).

World Health Organization (WHO) guidelines for the translation and adaptation of instruments were followed.[11] The questionnaire adapted from previous studies, were translated into Nepali and back translated into English and revised with the input from experts working in palliative care discipline.[9,10] Pre-test of the Nepali version was carried out among five health workers to ensure clarity of questions and to eliminate any ambiguity before administering to the participants.

The information obtained was checked for completeness, coded and entered in Microsoft Excel 2007 and analyzed using Statistical Package for Social Sciences (SPSS) . Descriptive statistics frequency and percentage were used for the analysis of data.

Result

A total of 174 questionnaires were completed out of total 195 health workers working in Makawanpur district at the beginning of study period. Out of the 174 respondents, 70(40.23%) were between the ages 20-30 years; 17(9.77%) were above 50 years and 126(72.41%) were female. More than half of the respondents 103(58.62%) were Auxiliary Nurse Midwives (ANM) followed by 58(33.33%) being Auxiliary Health Workers (AHW). Among the respondents, 65(37.36%) had less than five years of clinical experience whereas nearly one-fourth 38(21.84%) had more than fifteen years of clinical experience, Table 1.

Table 1. Socio-demographic characteristics of health workers (N=174)

Characteristics		N(%)
Age	20-30 years	70(40.23%)
	31-40 years	62(35.63%)
	41-50 years	25(14.37%)
	>50 years	17(9.77%)
Gender	Male	48(27.59%)
	Female	126(72.41%)
Marital status	Single	28(16.09%)
	Married	146(83.91%)
Education	Diploma or less	104(59.77%)
	Bachelor	57(32.76%)
	Master	13(7.47%)
Job position	P.H. Inspector	5(2.87%)
	HA	8(4.60%)
	Sr. AHW	32(18.39%)
	Sr. ANM	52(29.31%)
	AHW	26(14.94%)
	ANM	51(29.31%)
Total duration of clinical experience	Less than 5 years	65(37.36%)
	5-10 years	61(35.06%)
	11-15 years	10(5.75%)
	Above 15 years	38(21.84%)

Majority of respondents 140(80.46%) agreed that care of the caregiver is equally important as patient's care. Regarding the need of palliative care, 157(90.23%) knew that patients with advanced cancer need palliative care while 142(81.61%) felt that it is the total care of chronically ill patients, 110(63.22%) were aware that palliative care could be applicable for HIV/AIDS patients, while 120(68.97%) were of the opinion that patient with chronic non-malignant diseases such as end-stage heart failure also require palliative care. The majority 143(82.18%) expressed that severity of pain determines method of pain treatment. Only 88(50.57%) respondents stated that opioid is the most effective drug for cancer pain. The majority 149(85.63%) were unaware of the concept of bereavement care, Table 2.

Sixty-seven (38.51%) health workers had poor knowledge level of palliative care, 68(39.08%) had fair knowledge and 39(22.41%) had good knowledge, Table 3.

Nearly two-thirds 128(73.56%) of participants agreed that palliative care is given only for dying patient. More than half 88(50.57%) of participants strongly agreed that involvement with the patient should be withdrawn when patient nears death. More than two-thirds 151(86.78%) of participants agreed that it is beneficial for chronically ill patients to verbalize his/her feelings. Nearly two-thirds 125(71.84%) of participants felt that the length of time required to give care to a dying person would frustrate them. Most 153(88.03%) of participants accepted that family should maintain a normal environment as far as possible for the dying person. More than half 110(63.22%) of the participants agreed that it was difficult to form a close relationship with the family of a dying member. More than half 109(62.65%) of participants acknowledged that caring for the patient's family should continue throughout the period of grief and bereavement. More than two-thirds 156(89.66%) thought that family should be involved in the physical care of the dying person. More than half 113(64.94%) of participants accepted that palliative care should extend to the family of dying person. Most 152(87.36%) of participants agreed that they would be afraid to become friends with chronically sick and dying person. Interestingly, 70(40.23%) of participants showed agreement that they would feel uncomfortable entering the room of a terminally ill person and found them crying, Table 4.

Sixty-three (36.21%) health workers had poor level of attitude towards palliative care, 60(34.48%) had moderate attitude, and 51(29.31%) had good attitude, Table 5.

Discussion

This study showed 22.41% of health workers had good knowledge about palliative care which is similar to the study conducted among Palestine nurses 20.8% while clinical nurses in Nepal in tertiary hospitals had lower level of knowledge.[10,12,13] Similar study in Jordan and Greece also reflected insufficient palliative care knowledge among nurses.[14,15] However, studies in India 46% and Ethiopia 59.7%, have shown comparatively better level of knowledge than this study.[16,17]

Table 2. Knowledge on palliative care of health workers measured by PCKQ-B (N=174)

SN	Statement	Yes	No	Don't Know
		N (%)	N (%)	N (%)
1	Taking care of caregiver is equally important as patient's care.	140(80.46%)	24(13.79%)	10(5.75%)
	When do you think palliative care is needed?			
2	Care of the patients with advanced cancer	157(90.23%)	10(5.75%)	7(4.02%)
3	Total care of chronically ill patients	142(81.61%)	21(12.07%)	11(6.32%)
4	HIV/AIDS patients	110(63.22%)	32(18.39%)	32(18.39%)
5	Chronic non-malignant diseases such as end-stage heart failure	120(68.97%)	27(15.52%)	27(15.52%)
6	Palliative care should start at the time of diagnosis of a life-threatening illness	106(60.92%)	45(25.86%)	23(13.22%)
	Pain in palliative care			
7	Is pain a vital sign?	148(85.06%)	20(11.49%)	6(3.45%)
8	Severity of pain determines method of pain treatment	143(82.18%)	20(11.49%)	11(6.32%)
9	Most effective drug for cancer pain is opioids	88(50.57%)	18(10.34%)	68(39.08%)
10	Use of placebos is appropriate in some types of pain	28(16.09%)	16(9.20%)	130(74.71%)
11	A patient on opioids including morphine does not need NSAIDs (e.g. diclofenac)/paracetamol)	78(44.83%)	36(20.69%)	60(34.48%)
	Morphine in palliative care			
12	Causes addiction in terminally ill patients	91(52.30%)	34(19.54%)	48(27.59%)
13	Causes death in all dying patients	41(23.56%)	85(48.85%)	48(27.59%)
14	Always causes nausea/vomiting	39(22.41%)	74(42.53%)	61(35.06%)
15	Are you aware of problems and practical care of patient with colostomy?	39(22.41%)	52(29.89%)	83(47.70%)
16	Oxygen supplementation may help in last difficult breaths.	157(90.23%)	13(7.47%)	4(2.30%)
	Communication of prognosis			
17	Prognosis should always be clearly communicated.	141(81.03%)	31(17.82%)	2(1.15%)
18	Prognosis should only be informed to family members.	69(39.66%)	105(60.34%)	0
	Psycho-socio-spiritual issues			
19	Role of health workers is to take care of physical aspect of disease only; psychosocial issues must be dealt by psychiatrist or other professionals.	47(27.01%)	120(68.97%)	7(4.02%)
20	Role of health workers is to take care of physical aspect of disease only; social issues must be dealt by social worker or other professionals.	39(22.41%)	121(69.54%)	14(8.05%)
	Bereavement care			
21	Do you know what bereavement is?	97(55.75%)	16(9.20%)	61(35.06%)
22	Are you aware of concept of bereavement care?	25(14.37%)	60(34.48%)	89(51.15%)

Table 3. Assessment of the health workers' knowledge levels of palliative care (N=174)

Knowledge Level	N(%)
Poor Knowledge	67(38.51)
Fair Knowledge	68(39.08)
Good Knowledge	39(22.41)
Total	174(100.00)

In this study, knowledge scores around different aspects of palliative care varied. Most health workers seemed to have good knowledge regarding communication of prognosis and category of patients that require palliative care, similar to the studies carried out in Greece, Jordan and Nigeria, while their responses regarding morphine use, pain management, colostomy care and bereavement care were relatively deficient.[14,15,18] However, other similar studies have shown that nurses have highest level of knowledge in pain management.[12,14] This could be due to attention in nursing education on pain management.

Majority of the respondents had better understanding on basics of palliative care; 90.23% of respondents agreed that palliative care was required for patients with metastatic cancers. In a study carried out in Nigeria, 93% and Oman, 93.2% of the participants were of the same opinion.[18,19] The possible reason for the similarity may be due to the existing belief that cancer causes uncontrolled pain and suffering mostly at the end-of-life. The study also revealed

Table 4. Assessment of the health workers' attitude of palliative care (N=174)

	Statement	Strongly Disagree	Disagree	Uncertain	Agree	Strongly Agree
		N(%)	N(%)	N(%)	N(%)	N(%)
1	Palliative care is given only for dying patient.	15(8.62)	27(15.52)	4(2.30)	90(51.72)	38(21.84)
2	As a patient nears death, we should withdraw involvement with the patient.	5(2.87)	4(2.30)	2(1.15)	75(43.10)	88(50.57)
3	It is beneficial for chronically ill patients to verbalize his/her feelings.	14(8.05)	9(5.17)	0(0.00)	90(51.72)	61(35.06)
4	The length of time required to give care to a dying person would frustrate me.	8(4.60)	29(16.67)	12(6.90)	78(44.83)	47(27.01)
5	Family should maintain as normal environment as possible for their dying member.	12(6.90)	7(4.02)	2(1.15)	79(45.40)	74(42.53)
6	The family should be involved in the physical care of the dying person.	14(8.05)	3(1.72)	1(0.57)	72(41.38)	84(48.28)
7	It is difficult to form a close relationship with the family of a dying member.	13(7.47)	26(14.94)	25(14.37)	83(47.70)	27(15.52)
8	Care for the patient's family should continue throughout the period of grief and bereavement.	11(6.32)	31(17.82)	23(13.22)	78(44.83)	31(17.82)
9	Care should extend to the family of dying person	13(7.47)	29(16.67)	19(10.92)	85(48.85)	28(16.09)
10	I am afraid to become friends with chronically sick and dying patients	5(2.87)	7(4.02)	10(5.75)	83(47.70)	69(39.66)
11	I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying.	19(10.92)	71(40.80)	14(8.05)	44(25.29)	26(14.94)

Table 5. Assessment of the health workers' attitude of palliative care (N=174)

Attitude Level	N(%)
Poor attitude	63(36.21%)
Moderate attitude	60(34.48%)
Good attitude	51(29.31%)
Total	**174(100%)**

that participants had good understanding regarding increased scope of palliative care for chronic non-malignant diseases such as end-stage heart failure 69.0%, chronically ill patients 81.61% and HIV/AIDS patients 63.22%, consistent with other studies.[19,20]

Likewise, many (82.18%) participants believed that the severity of pain determines the method of pain management. However, only half of the participants were aware of the effective drug for the management of cancer pain. The possible reason may be due to limited awareness of health workers about adequate pain assessment skills and opioid analgesics. Role of morphine is vital in pain management. Regarding participants' knowledge on morphine use, present study showed misconceptions among health workers, where 52.30% thought that it causes addiction in terminally ill patients, and 23.56% believed that it causes death in all dying patients. Such misconceptions are reported in other studies as well.[12,18] Many other studies have shown that even doctors and nurses have issues and fear regarding use of morphine.[18,21,22] Possible reason for this gap may be due to non-availability of morphine at health post level, lack of effective education and training on palliative care.

Regarding communication of prognosis to patients, most of them answered correctly 81.03%, similar to the studies carried out in Oman and Nigeria.[18,19] However, 39.66% thought prognosis should only be informed to family members, similar to the study from Oman.[19] Regarding psychosocial and spiritual issues, most of them were correct in answering that role of health workers is beyond taking care of physical aspect of disease; it is also fundamental to deal with psychosocial and spiritual issues as a concept of total care.

Bereavement care is one of the important aspects of palliative care and deserves special attention. Bereavement care is given for family after death of a patient to cope with the loss of loved ones.[23] When asked about bereavement knowledge, only 14.37% of health workers responded that they were aware. To contrast, 69% nurses of tertiary hospital in Madhya Pradesh, India were aware of the concept.[20] Participants of this study are the health workers who provide basic health services in the community;

therefore, they may have limited knowledge. Also, the variation may be due to difference in socio-culture and religious belief. Furthermore, present study also revealed that only 22.41% health workers understood well about the problems and practical care of patient with colostomy. Patient with colostomy seeking services more from the tertiary hospital than health post may contribute this knowledge gap.

Regarding attitude toward palliative care, 36.21% of health workers had poor attitude and 34.48% had moderate attitude. When comparing with the similar study conducted in Egypt, 62.9 % of nurses had a negative attitude toward palliative care.[24] However, finding was contrasted with other studies which showed higher attitude toward palliative care than this study.[10,12,13,16,17,25]

Though, majority of health workers in the current study showed poor attitude, the most favourable attitudes were seen in some areas of palliative care, such as family involvement in the physical care and the benefits of verbalizing the feelings of a dying person. Similar opinion has been observed in other studies.[10,12] The most unfavourable attitudes were seen in dealing with dying patient.

This study showed that 73.56% of health workers agreed that palliative care is given only for dying patient which is similar to the previous studies.[12,18,19] However, in a similar study in Palestine, 63.5% of nurses disagreed on the opinion.[10] Studies have shown that there are misperceptions equating palliative care with end-of-life care.[26] This study also reported that 63.2% of health workers found difficulty in forming a close relationship with the family of a dying member. This was in contrast to other studies in which most nurses seemed more comfortable in building such relationship.[10,12] Disparity in opinion may be due the differences in cultural values, norms, belief system and taboo related to death. Also, this may be due to health workers working in the health post are less likely to deal with terminally ill patients and lack effective communication skills.

Many previous studies have explained that level of education, work experience, training in palliative care and experience of caring for dying patient correlated with palliative care knowledge and attitude level.[10,12,16,20] Findings in this study were also consistent with these studies.

Lack of awareness, palliative care training programs and continuous medical education activities for health workers may be the possible reasons contributing for the deficiency of knowledge and attitude toward palliative care.

This study had some limitations. Since this study employed census method, there were limitations related to the study design. Due to lack of similar studies in community, comparison and discussion was difficult. Various studies have shown significant relationship between religion and ethnicity with the level of knowledge and experience of caring for dying family member or close relative with the level of attitude. However, this study fails to assess these variables. Therefore, this study recommends for further comprehensive community-based study in palliative care.

Conclusion

This study clearly showed the gaps in knowledge and attitude among health care workers working at primary levels toward palliative care. Health workers had adequate understanding on domains like philosophy and need of palliative care, which is encouraging but knowledge on important other aspects of palliative care like pain management, morphine use, communication, colstomy care and bereavement care seemed to be deficient. Regarding attitude toward palliative care, health workers had poor attitude towards caring for dying patient and issues around death. This study emphasizes the need to introduce and update study of comprehensive palliative care in the pre-service curriculum and in-service training of National health Training Centre of Department of Health Services for health workers to meet the changing health needs of rural and disadvantaged population of Nepal.

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Conflict of Interest

None

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Author Contribution

Concept, design, planning: KB, KPB, CL, RKG, PA, RG; Literature review: KB, KPB, RG; Data collection/ analysis: KB, CL, RKG; Draft manuscript: KB, KPB, CL, RKG, PA, RG; Revision of draft: KB, KPB, RG; Final manuscript: KB, KPB, CL, RKG, PA, RG; Accountability of the work: KB, KPB, CL, RKG, PA, RG.

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