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Review Article

Reflections on the Experience of Community Health Nurses in Palliative Care: A Qualitative Approach

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ABSTRACT

There is a major demographic shift with increase in non-communicable diseases even in low- and middle-income countries. Many self-limiting illnesses are burdensome to people when they have limited access to health care system and poor family support. The aim of the study explores experiences of community health nurses in palliative care delivery in a primary health care setting. The study was conducted in Community Health Nursing Department, College of Nursing, CMC, Vellore. A qualitative research using a grounded theory approach was done which included in-depth interviews and focus group discussions from community health nursing faculty. This study used a deductive and inductive approach that stressed the process rather than the meaning of the studied phenomenon. The in-depth interviews lasted for 45 min–1 ½ h for each participant; focus group discussions were held in two sessions lasting for 2 ½ h. The group interviews were transcribed to verbatim. All transcripts were read multiple times to ensure correctness of the transcription by the authors to get an overall impression of the material before the initial coding. Authenticity, credibility, critical appraisal and integrity were demonstrated throughout the study. This study enlightens the experiences of the health care providers on palliative care delivery at the primary care setting and explores barriers, challenges and facilitators for delivery of good palliative home care. Totally, 15 subthemes were grouped under five major themes; community support, family support, acceptance of services, barriers and gaps in care. The in-depth interviews provided an insight into the experiences of the participants on successful collaborative services, caregivers fatigue and the barriers in providing services in the home care setting. Focus group discussion showed that a holistic approach to patient care in primary care setting is possible by community health nurses and a collaborative care from the secondary and tertiary care settings will bring down the non-compliance to the therapeutic regimen.

Keywords: Palliative care, Primary health care, Community health nurses, Qualitative study

INTRODUCTION

Incidence of non-communicable diseases is on the rise with a marked increase in cancer rates. The need for home-based palliative care has become the need of the hour. Palliative care improves the quality of life of patients and their families who are facing problems associated with life-threatening illness, whether physical, psychological or spiritual. Most of the palliative care services are available in cities and regional cancer institutes which make people in the rural areas inaccessible and consume a lot of time and energy.[1]

LMICs are predicted to bear 70% of global cancer cases by 2030. As LMICs industrialise, cancer incidence is predicted to rise 5-fold.[2] Poorer cure rates are anticipated in lower-income countries compared with high-income countries due to late presentation, lack of locally adapted protocols

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and limited resources.[3] Similarly, the provision of palliative care is woefully inadequate in LMIC, where the majority of palliative and end-of-life care is needed, due to later presentation, fewer curative options, ageing populations and rising cancer incidence.[4] The most recent iteration of the WHO Universal Health Coverage goals calls for the full spectrum of essential, quality health services, from health promotion to prevention, treatment, rehabilitation and palliative care.[5] The WHO's Global Report categorises India as lacking integrated palliative care.[6] The aim of this study was to analyse the experiences of the health care providers on palliative care delivery at the primary care setting and to explore barriers, challenges and facilitators for delivery of good palliative home care.

Study design

This qualitative research used a grounded theory approach which included in-depth interviews and focus group discussions.

MATERIALS AND METHODS

Grounded theory studies include all parts of the data as well as interpreted emerged codes, categories and main concerns to explore variations, similarities and differences. With this method, the analysis process proceeds as the researcher continuously writes theoretical drafts or memos.[7,8] This study used a deductive and inductive approach that stressed the process rather than the meaning of the studied phenomenon.

Setting

The study was conducted in Community Health Nursing Department, College of Nursing, CMC, Vellore. College of Nursing Community Health (CONCH) Department, Christian Medical College, Vellore, which provides a nurse, led primary health care services to the selected rural areas of Vellore District. CONCH provides care to 25 villages which covers a population of 65,000. Regular home visits, nurses' led clinics and referral services are rendered by the community health nurses. Special clinics such as eye, ENT and psychiatric clinic are also conducted in the villages as per the need with community participation and the assistance of other health care personnel. Health care workers are recruited from the villages, who are with good communication skills and willingness to provide primary health care for the villagers. They are trained in basic health care services and they act as a liaison between villagers and the health care system.

Participants

Two groups of community health nursing staff were recruited:

i. Community health nursing tutor who had completed their baccalaureate programme in nursing and is working in community health nursing department for a minimum of 5 years, who provide holistic home-based care
ii. Community health nursing faculty who had completed their post-graduate programme in community health nursing and is involved in organising, directing and providing home care services and teaching nursing students for a minimum of 10 years.

Inclusion criteria

The following criteria were included in the study:

- Community health nurses who had completed baccalaureate in nursing
- Community health nurses who had completed post-graduate programme specialising in community health nursing
- Who had worked minimum of 5 years in the community health nursing department.

Exclusion criteria

The following criteria were excluded from the study:

- Those who are not willing to be a part of the study
- Those who are on long leave and not available during the study.

Ethical consideration

The study was approved by the college of nursing research committee. The study was conducted after getting written informed consent from the participants.

Procedure

Primary data were obtained from four community health nursing faculty using open-ended semi-structured interview and five community health nursing tutors using focus group discussion.

Analysis

The group interviews were transcribed to verbatim. All transcripts were read multiple times to ensure correctness of the transcription by the authors to get an overall impression of the material before the initial coding. A qualitative descriptive approach was used for the analysis. Following this analytic approach, rigour was enhanced by focusing on the following strategies: (1) Authenticity was achieved by paying attention to the voices of participants and the ability to remain true to the phenomena under study, (2) credibility was achieved through multiple readings and reflection on field notes with the research team, (3) critical appraisal of every decision was made throughout the research process and (4) integrity was demonstrated by on-going reflection

and self-criticality of the researcher. All meaningful text units were identified and coded. The codes were subsequently grouped into relevant categories and at the end 15 themes were identified, which again were grouped into five main themes. Data were generated until no new themes emerged from the analysis.

RESULTS

The community health nursing department is rendering home-based comprehensive health care services for more than 3 decades; which includes palliative therapy at home for terminally ill patients. This study enlightens the experiences of the health care providers on palliative care delivery at the primary care setting and explores barriers, challenges and facilitators for delivery of good palliative home care. The major themes that emerged were community support, family support, acceptance of services, obstacles and gaps in care [Table 1].

Community support

The narratives of the participants make it clear that the patients and their relatives were grateful for the services provided through community health nurses and want to continue the services in their villages.

'*A patient's relative said that they are very thankful for the services provided by the community health nurse, as they walked extra mile to receive care from tertiary hospital (CMC) without a penny being spent on the hospitalisation*.'

The views of the participants also highlighted the importance of involvement of non-governmental organisations and other governmental services in caring for the bed bound patients.

'*the services provided by Sneha Deepam (a non-governmental organisation) was very helpful for my client in Melakuppam village, who had terminal stage cancer. As she had no one to take care of her, they provided a holistic care with utmost attention*.'

'*an effective collaboration with non-governmental organisations will bring down the non-compliance*'

Some felt that the helpless patients are often supported by people in the community. The villagers in the community feel socially responsible as they provide the destitute with food and money.

'*the shop keepers and kind hearted neighbours often come forward to provide them with food and administer medications on time*.'

Family support

The system of family in India is considered strong, stable and enduring. They share their joys and support each other during hard times. Interestingly, most of the participants shared that family support brings longevity in patients with terminally ill diseases. The ones who do not have a good family support seem to become depressed and face their end much earlier.

'*Usually the patients verbalise their inability to support their family due to their sickness and feel bad for being a burden to the family*.'

On the other side, lack of time and resources and nature of the family (nuclear) are said to be the causes for poor family support to the sick individuals.

'*Combined care of family and community will assure the patients and they feel that they are not left alone to endure the suffering, which reduces their burden and builds their confidence in coping*.'

Acceptance of services

India is a country of diverse culture and traditional beliefs. The choice of treatment modalities is intertwined with their religious and cultural beliefs. Some parts of the rural community still believe that diseases are caused due to wrath of God. The following participant's quote illustrates the impact of stigma and the financial burden over the disease.

'*many families cannot afford for palliative care because of financial constraints, while some feel that it is a wrath of God and treatment is helpless*'

'*there is resistance from the relatives in providing care because they consider them to be a burden and waste of money*.'

Barriers

The following participants' account affirms that the main obstacles for the palliative care in a primary health care setting are the accessibility, affordability, choice of alternative medicine and side effects of medical therapy.

'*I felt bad when he said not to waste money on him, as he's dying anyway…*'

'*though we are ready to take them to a tertiary care setting for treatment; they do not want to come as they are afraid of side effects of the treatment and they believe alternative medicine (siddha) has some relief over the illness*'

'*I have seen people use snake oil in massaging patients to relieve excruciating pain as there is no relief in other treatment modalities*'

Gaps in care

For many participants in the study; limitations in the nursing care were the gaps in providing continuity of care, at times they even found themselves helpless for the debilitated patients and the family.

'*I have tried all possible measures, she was sinking and I felt helpless…*'

'*I feel the referral system should be strengthened more to support poor patients from the community…. we refer only those who are not cared for and could not afford treatment*'

'*delay in getting appointment, consultation with various disciplines, financial constraints and multiple investigations make the patients tired and exhausted and make them discontinue the treatment*'

'*an effective complex referral services with existing governmental, non-governmental and inter-disciplinary services within institution and other agencies will benefit the terminally ill patients and their family at large*'

DISCUSSION

Due to ever-expanding population, rise in non-communicable diseases, unaffordable health care expenses and inaccessibility to health care services, there is a compelling need for community-based palliative care services. There are only a few community-based services available in India, among which not many institutions provide comprehensive care. The health care providers serve the community with available resources collaborating with other sectors. There is a profound need for a deeper insight into barriers and facilitators of these services for delivery of good palliative home care.

It is important that the health care professionals realise the barriers and challenges in providing care to the terminally ill patients in a primary health care setting so that a comprehensive home-based palliative care can be rendered. It is a challenge to all the professionals involved in palliative home care to balance between meeting the needs of the patients and matching the resources available.

The focus group discussion can be used as a factor of the development of views of the participants and can make new themes regarding the palliative care in primary health care setting. In our study, the group setting made new themes emerge but it also gave the community health nursing tutors a valuable feeling of shared experience and of being able to support each other in the interview situation. Interviews with community health nursing faculty gave us an insight into the caregivers experience and it gave us the opportunity to explore the barriers and challenges of the palliative care delivery. However, both positive and negative experiences emerged in the interviews. Some participants broke down emotionally when they recalled their experiences with the terminally ill patients.

In a qualitative study conducted by Neergaard *et al*.,[9] the relatives asked for health professionals who had the necessary knowledge, who were readily available to the patients and their families and more active in establishing personal contact with them. The study concludes stating that relatives experience insufficient palliative care mainly due to organisational and cultural problems among professionals. Palliative care in primary care in general needs improvement and attention should be drawn to the 'professionalisation' of the relatives and the need to strike a balance between their needs, wishes and resources in end-of-life care and bereavement. This study was in congruence with our study that many participants shared their positive experience of the families which were benefited by them. An empowered family and community will strengthen the patients physically and emotionally which brings longevity.

Second, it brought into light that adequate accessibility to the health care facilities and making the treatment affordable for everyone will bring down the non-compliance of the patients. Many could not access hospital services due to various reasons such as inadequate transportation facility, lack of person to accompany them, complicated referral system and financial concerns. Palliative care and hospice services improve patient-centred outcomes such as pain, depression and other symptoms; patient and family satisfaction and the receipt of care in the place that the patient chooses. Palliative care at primary level is needed to ensure equitable access to optimal care for seriously ill patients.[10]

Third, the focus group discussion reveals that community health nurses can provide effective home-based palliative care utilising all the available resources. As community health nurse takes up the extended role of a palliative care nurse in underserved population, she plays multiple roles in caring for the terminally ill patients in the community to provide a comprehensive palliative and end-of-life care to the patients and families. It has been suggested that family carers felt left out and had feelings of powerlessness when they did not manage to establish a relationship with the health care professionals. Health care professionals impart adequate knowledge to the patients and primary care providers so that they feel empowered to take care of the sick ones at home.[11]

Fourth, a collaborative interdisciplinary cancer care approach will bring cost-effectiveness to the health care industry and the patient as well. The existing referral system in this study is a multidisciplinary approach which leaves the patient more confused at times and tends to discontinue the treatment due to multiple appointments to different health care professionals. Moreover, the rapidly ageing population will increase the demand for palliative care services at home. Many observational studies have shown that home-based palliative care can be effectively delivered using interprofessional specialist palliative care teams; the teams better managed symptoms, improved quality of life and prevented late-life hospitalisations than usual care.[12] Expanding access to community-based palliative care is an

Table 1: Major themes and subthemes evolved in this study.

Themes	Subthemes
Community support	Community health nurses
	Collaboration with NGOs
	Support by neighbours and shop keepers
Family support	Unproductiveness
	Lack of time
	Caregiver burden
Acceptance of services	Cultural belief
	Stigma
	Financial burden
Barriers	Accessibility
	Affordability
	Alternative system of medicine
	Side effects
Gaps in care	Helplessness
	Nursing care limitations
	Referral system

important policy issue internationally because many patients prefer to die at home, hospitals are overcrowded and home care is often less expensive than hospital care.[13]

Fifth, health care professionals encounter compassion fatigue and emotional trauma as they journey with the patients through the end of life and grieve with their loved ones even after they are gone. Palliative care nurses are routinely exposed to pain, trauma and suffering as they witness on-going symptom management; however, the focus of care is on healthy end-of-life management rather than preservation of life. Identification of compassion fatigue for this profession helps facilitate the recognition of symptoms for a group that deals with patient suffering on a regular basis.[14] The analysis of a qualitative study on health providers delivering home-based palliative care suggests that similar care practices exist even among very diverse specialist teams with different models of care. Understanding the care practices can help to inform the development of other community-based teams. This strongly suggested the collaboration of primary care and specialist providers, intrateam communication, advocacy for patient preferences and importance of team building.[15]

This qualitative research has enabled the community health nurses to identify all potential factors inhibiting and enhancing home-based palliative care and in accessing health care facilities. This multidisciplinary cancer care between clinical teams and families, which is mostly expensive, had barriers and gaps in care which came in light as part of this study. The in-depth interviews provided insight into the experience of the participant on successful collaborative services, caregivers fatigue and the barriers in providing services at home care setting. Focus group discussion showed that a holistic approach to patient care in primary setting is possible by community health nurses and a collaborative care from the secondary and tertiary care setting brings down the non-compliance to the therapeutic regimen.

CONCLUSION

This study suggests that strengthening the referral system, upgrading the knowledge and extending the role of the community health nurses would help the primary health care delivery system function more efficiently. An interdisciplinary cancer care approach will bring down the financial burden of the patients and is a cost-effective method for health care industry. As compassion fatigue and burn out are more common among primary health care providers who care for terminally ill patients; a debriefing session and support system will help them to overcome their emotional distress.

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Declaration of patient consent

Patient's consent not required as there are no patients in this study.

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Conflicts of interest

There are no conflicts of interest.

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