Original Article

Integrated primary palliative care model; facilitators and challenges of primary care/family physicians providing community-based palliative care

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Abstract

Introduction: Patients with advanced cancer often suffer from complex symptoms necessitating constant supervision and management. Primary care/family physicians act as an important bridge between the patients in the community and the specialists in the hospital ensuring continuity of care. **Materials and Methods:** The present paper explored the facilitators and challenges in providing home-based palliative care as perceived by the primary care/family physicians (PCP/FP). **Results**: 62 physicians reported that they were involved in palliative management of at least one cancer patient in the previous year. A significant number of GPs (34%) lacked confidence in providing this care because of patient complexity, inadequate training and insufficient resources. Other barriers included poor communication from specialists and treating teams. Factors facilitating provision of home-based palliative care included their willingness to help palliative care patients, their inclination to train in palliative care and enthusiasm to refer to guidelines while caring for patients. **Conclusion:** It is explicit in the paper that resources with respect to information sharing and communication, technical support and training are essential to empower the PCP/FP in providing community-based palliative care.

Keywords: Facilitators and challenges, primary care/family physicians, primary palliative care

Introduction

The country has evidenced a manifold shift in the acceptance of palliative care as an essential part of medical care. Now many institutions are integrating palliative care into specialities caring for patients with chronic life-threatening illnesses.[1,2] Only 10% of patients require specialist palliative care.[3] A large proportion of patients will benefit from home-based palliative care provided by the Primary Care/Family Physician (PCP/FP) due to their proximity and availability in the community. A survey conducted in India revealed that although 83% population preferred death at home, only 38% actually died at home at the end of life.[4] One of the major challenges in continuity of care in the community is that the health care system in the country lacks a structured liaison system with minimal or no formalised cross-referrals between specialists and the PCP/FP.[5] Often, PCP/FP are unfamiliar with important facts regarding physician-patient communication, medical decision making and attitudes about formal documents such as advance directives.[6,7] End-of-life discussions are particularly challenging because of their emotional and interpersonal intensity and often the lack of a structured communication can complicate the acceptance of end of life.[8,9]

The present paper has been written as a prologue to developing a community-based palliative care model by empowering PCP/FP

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in the community. In the existing unstructured health care system, we wanted to explore the facilitators and challenges in providing home-based palliative care as perceived by the PCP/FP. The results of this exploratory study will help us design interventions considering the challenges and use the facilitators as opportunities to overcome the challenges.

Methodology

Patients with advanced cancer, face many health-related challenges often complicated by intercurrent problems due to disease progression, adverse effects of disease directed treatment or side effects of supportive care medications provided for symptom control. Patients often have a difficult course warranting continuous monitoring and medical support. However, supporting a patient in the community is a major challenge as the country lacks a structured formalised liaison system between the specialists and the PCP/FP in the community. The project was conceived in the year 2018 with the intention of bridging the gap between the specialist in the hospital and PCP/FP in the community [Annexure 1 and 2], therein reach out to our patients who lived far from Tata Medical Center, Kolkata. The initial pilot work on liaison palliative care in the community showed some success that encouraged us to expand the network further. While we are expanding the service, we would like to know factors that may influence the maintenance and sustainability of community networking and use the facilitators as a tool to overcome the challenges in networking.

We conducted an exploratory study at Tata Medical Center, Kolkata between March 2018 and February 2019 to understand the facilitators and challenges in liaison networking with PCP/FP as perceived by the latter. The study also explored PCP/FP's perceptions of their role and highlighted facilitators and challenges in delivering primary palliative care within the community. We distributed the form to 165 PCP/FP in our database of whom 100 PCP/FP completed the survey. The survey forms were emailed to the PCP/FP or were completed by the PCP/FP during continued medical education (CME) programmes organised by the department. Involvement in the survey was voluntary and anonymous, and consent was inferred from survey completion.

The data were analysed using Microsoft excel and presented as frequencies and percentages.

Results

Successful liaison was established with 50.59% PCP/FP [Figure 1]. Out of 165 PCP/FP contacted for survey, 100 (60.61%), PCP/FPs completed the survey. About 62% of respondents mentioned that they had cared for palliative care patients in the preceding 12 months, however, only 34% respondents were confident providing care for palliative care patients. Common reasons for this included a lack of knowledge (32%) and confidence (34%), non-affordability of service (67%), poor out-of-hours support (89%) and poor communication from hospital services (87%) [Table 1]. Some of the facilitators included 46% PCP/FP were willing to support palliative care patients, 21% PCP/FP discussed advanced care plan with patient/family, 32% PCP/FP attempted treating palliative care patients by accessing websites and 75% PCP/FP were willing to be trained in primary palliative care [Table 2].

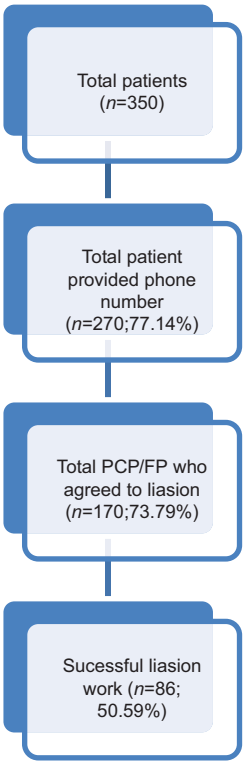

Figure 1: Primary Care/Family Physician contacted for liaison care

Discussion

Raina *et al.*, opine that unless the population needs have been addressed and comprehensive primary care is accessible to the universal population, the specialist care will remain a challenge in the country.[10,11] The recent innovation in care in the community is the introduction of patient-centred primary care (PCMC) model; a team-based health care delivery model that emphasises on the essence of care co-ordination and communication to improve patient care and ensure continuity of care. The structure and process used by the PCMC model will facilitate the PCP/FP to deliver a basic palliative/supportive approach for the patients in need.[12] Careful implementation of this model with support from palliative care specialists will ensure continuity of care in the community. The sustainability of the programme will depend on the political, social and economic commitment.[12]

PCP/FPs play a vital role in the continuum of care for patients in the community and help patient and family navigate through the journey of chronic life-threatening disease and terminal illness.[10] They form the core of patient and family care and an essential bridge between the patient in the community and the specialist

Table 1: Challenges in providing palliative care in the community by PCP/FP

	Frequency (100)	Percentage (%)
Has knowledge and skills in palliative care	32	32
Confidence in seeing palliative care patients in the preceding 12 months	34	34
Provided out-of-hours support to patients	21	21
Received correspondence from hospitals regarding goals of care and care plan	27	27
Clear information about goals of care by specialists	13	13
Knowledge about the existence of local palliative care service	15	15
Affordability of home visits	33	33

Table 2: Facilitators in providing palliative care in the community

	Frequency (*n*=100)	Percentage (%)
Home visits provided	49	49
Willingness to provide palliative care	46	46
Cared for palliative care patients in the preceding 12 months	62	62
Do you routinely discuss and/or develop advance care plans/end-of-life plans with your patients?	21	21
Do you use any other websites to access information when caring for patients with advanced cancer?	32	32
Would you be interested in receiving information on common symptom management for palliative care patients with advanced cancer?	75	75

in the hospital. The proximity of care and accessibility to care make PCP/FP the most essential part of community-based care. The PCP/FP knows the demographic profile of the patient and family, knows the social concerns in the family and will be able to navigate care keeping the background information of the family. The family physicians are in a better position to counsel the patient/family through the spectrum of the disease and support families in the bereavement phase. However, the transition is not without challenges, as the existing structure of the health care delivery system in the country is not commensurate with the growing need for community-based palliative care.[5] Also, lack of a systematic referral between specialists and PCP/FP acts as one of the essential barriers in seamless transition to community-based care in the country.

Consistent with other studies, the PCP/FP had experience of caring for palliative care patients in the preceding 12 months. Although they strongly felt that palliative care included some proportion of patients cared by them, they did not feel comfortable and confident in caring for such patients.[9,13] Some of the common reasons expressed were lack of experience or knowledge, poor interpersonal communication between health care providers, inability to provide 24-hours care, many did not do home visits.[14] There are multiple factors that act as barriers in care provision in the community such as personal barrier including lack of competence and emotional framework to care for terminally ill patients, lack of interpersonal communication and collaboration between health care professionals and unstructured health care delivery and lack of structured referral system between specialists and PCP/FP.[9]

To overcome these challenges, an integrated community palliative care model was suggested jointly by Indian Association of Palliative Care (IAPC) and Association of Family Physicians of India (AFPI). Subsequently, the associations jointly published a position paper[15] in 2018 emphasising the importance of incorporating primary palliative care into the routine clinical practice of PCP/FP and another paper in 2019[16] deliberating on the competency framework necessary for PCP/FP to provide primary palliative care in the community. The integrated model can have variations in its nature and application, however a systematic review investigating the integrated model identified five core aspects of a successful model.[17,18] These included good interpersonal communication, knowledge and skill enhancement, clearly defined roles and responsibilities, a streamlined referral and back referral between specialists and PCP/FP and assurance for continuous and coordinated support.[18] Collaborative care between specialists and PCP/FP have demonstrated better outcomes of symptom control, enhanced quality of life and increased likelihood of patient's preference to spend the last hours of their life at home.[18]

Way forward for streamlining the liaison primary palliative care at the institutional level and the country at large:

1. Improved communication between the specialist and PCP/FP: We plan to prepare a template for referral which will mention the necessary information related to the patient's disease, palliative care management, goals of care and contact details of specialists.
2. Improving access to information by developing a web-based application where the PCP/FP can access information on palliative care and management of symptoms.
3. Developing web-based modular training programmes for PCP/FP and skill-based training for PCP/FP who express interest.
4. The IAPC/AFPI has published competency framework for developing community-based palliative care for PCP/FP. The associations are collaborating to incorporate primary palliative care training in the post-graduate curriculum of family medicine under the National Board of Examinations.

Conclusion

Although a small sample size, the survey helped explore the facilitators and challenges in liaison primary palliative care. It is explicit in the paper that resource with respect to information sharing, interpersonal communication and technical support and training are essential to empower the PCP/FP in providing community-based palliative care. Professional development along with constant support from specialists can help PCP/FP gain confidence in assessment and management of symptoms and provide appropriate referrals. In conclusion, it can enable PCP/FPs to provide high-quality palliative care within the community and facilitate care at home as preferred by the patient.

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Conflict of interest

There is no conflict of interest.

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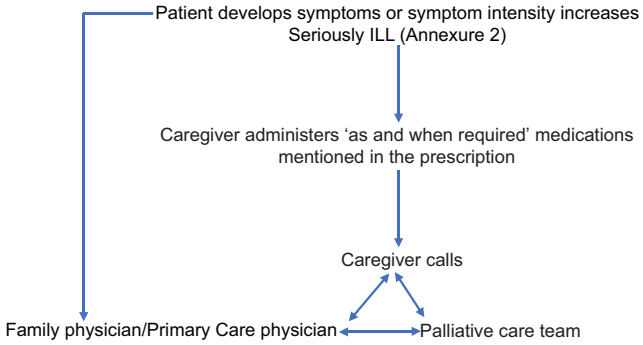
Annexure

Annexure 1: Flowchart depicting the liaison work



Annexure 2: Diagnosis of serious illness

1. Intractable symptoms: no reduction in symptoms despite 'as and when required' medications administered or dose increase
2. Patient's general condition deteriorates:
    1. Patient becomes drowsy or unresponsive
    2. Sudden onset breathlessness
    3. Agitated delirium or hypoactive delirium
    4. Convulsions
    5. New onset bleeding or massive bleed
    6. Sudden onset weakness or generalised fatigue
3. Suicidal ideation or attempt