

Exploring Education and Training Needs in Palliative Care among Family Physicians in Mumbai: A Qualitative Study

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Abstract

Context: Patients with chronic life-limiting conditions on palliative care (PC) prefer to be treated at home. Medical care by family physicians (FPs) reduces demand on costly and busy hospital facilities. Working of PC team in collaboration with FPs is thus helpful in home-based management of patients. **Aims:** This study aimed at exploring the extent of knowledge of FPs about PC and the need for additional training. **Settings and Design:** Semi-structured interviews were conducted with ten FPs from two suburbs of Mumbai, currently served by home care services of a tertiary cancer care center. **Subjects and Methods:** Data were digitally recorded, transcribed, and analyzed using exploratory analysis followed by content analysis to develop thematic codes. **Results and Conclusions:** FPs perceive PC as symptom control and psychological support helpful in managing patients with advanced life-limiting illnesses. Further training would help them in PC provision. Such training programs should preferably focus on symptom management and communication skills. There is a need for further research in designing a training module for FPs to get better understanding of the principles of PC.

Keywords: Family physicians, palliative care, training needs

INTRODUCTION

Palliative care (PC) encompasses assessment and relief of suffering of all kinds including pain, other physical and psychological symptoms, and social distress along the entire course of the patient's disease process.^[1] PC has been shown to improve patient outcomes, including mortality, when integrated with disease-modifying therapy.^[2] Despite the documented benefits, however, access to comprehensive, integrated PC remains limited in most developing countries, where the global burden of chronic disease is greatest.^[3] India is the world's largest democracy, the second most populous country in the world (1.21 billion people according to the figures of the 2015 census), and the tenth largest economy (with a gross domestic product of US\$ 7.965 trillion) in 2015.^[4] Of this, only 1.2% is spent over public health sector against a global mean of 5.4%.^[5] India accounts for 21% of the world's global burden of diseases, death rate being 7.43 deaths/1,000, and the noncommunicable diseases including coronary heart disease, hypertension, diabetes mellitus, chronic obstructive pulmonary disease, liver diseases, HIV/AIDS, cancer form the major bulk of causes of death in India (World Health Rankings).^[6] Hence, there is an increasing need of awareness and availability of PC

in India. According to the World Health Organization (WHO), India has the largest private health sector in the world. Today, there are approximately 1,125,000 practitioners of different systems registered with various medical councils in the country such as the Medical Council of India, various state medical councils, and councils for alternative medicine. Of them, only 125,000 are in government service (including those in central health services, the armed forces, railways, and state insurance), which leaves about a million doctors floating around in the private sector, not to mention tens of thousands of additional unqualified and unregistered medical practitioners.^[7] Mumbai is one of the major metropolitan cities in India, and according to the Census 2015 statistics, population wise, it ranks 1st with a population of 21,043,000.^[4] According to the Mumbai Human Development Report 2015, physician density in Mumbai is 0.599 physicians/1000 population, whereas the

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How to cite this article: Damani A, Ghoshal A, Dighe M, Dhiliwal S, Muckaden M. Exploring education and training needs in palliative care among family physicians in Mumbai: A qualitative study. *Indian J Palliat Care* 2018;24:139-44.

Access this article online

Quick Response Code:



Website:
www.jpalliativecare.com

DOI:
10.4103/IJPC.IJPC_216_17

hospital bed density is 0.9 beds/1000 population. Mumbai has a vast supply of public and private health-care services. The services range from the superspecialty, tertiary-level care hospitals to the community-based family physicians (FPs).^[8]

Providing quality health care in patients suffering from chronic life-limiting conditions is important and PC forms an important element of the same. In such a scenario, the FPs can work in collaboration with the PC team for management of patients who are on PC at home. FPs play a vital role in caring for patients in the final phase of their lives.^[9,10] There are studies about home being the most preferred place of death for patients suffering from chronic life-limiting illnesses. Although it is important to respect patient's autonomy, decision for care can be influenced by many other factors such as prognostic uncertainty, caregiver preferences, and availability of health-care facilities in the community.^[11] For provision of a complete and holistic care for the patients with regard to medical, psychological, social, and spiritual aspects at the end of life, it is important to ensure that the FPs providing the end-of-life care to the patients need to be skillful enough to do this job and for this they should be aware about the principles of PC and have good communication skills. Hence, it is important for them to have a formal training with a specific focus on PC and communication at end of life.

Qualitative researches provide insight into PC needs, knowledge, and preferences, identify the causes of suffering, and guide local responses to recognized needs.^[12,13] However, few published accounts describe PC needs, knowledge, and preferences and fewer still detail efforts to translate identified needs into programmatic action and describe effective models of PC service delivery, particularly community- and home-based models that integrate PC with health services. Our study aimed at exploring the current knowledge and perceptions of the FPs in Mumbai in PC and to find the need of a training program in PC for them. This study would act as the basis for designing a training module for the FPs in PC.

SUBJECTS AND METHODS

To explore the perceptions, knowledge, and need for PC training among the FPs, we invited them for semi-structured interviews through exploratory qualitative research.^[14] The sample was selected using purposive sampling techniques, with FPs who have looked after patients who were registered with home care services in our tertiary cancer care center and have been in contact with our team at least once.^[15] The FPs were selected from the home care database of four different suburbs of Mumbai.

The qualitative method used was based on exploratory approach to data analysis in which theories are generated from the data.^[14] Participants were interviewed at each site by one of the study investigators (A. D.) and asked to discuss the PC infrastructure and service delivery practices at their practice. Transcripts were reviewed with participants for comment and clarification by going back to the interviewee. PC policy documents, clinical encounter forms, data

recording tools, and training materials were reviewed by the investigator prior to participant interviews to provide context. To minimize the influence of PC documents on responses, these materials were not provided to the participants before or during study interviews. Preliminary study findings were shared at a dissemination meeting to refine our understanding and representation of perspectives expressed by participants during interviews.

We planned to interview a sample of individuals, comprising of participants from each of the four home care divisions. We devised this sampling strategy to capture a diverse range of perspectives regarding PC services and experiences with serious chronic illness in Mumbai. With this strategy in place, we recruited and interviewed a consecutive sample of FPs. We approached potential participants face to face at health facilities to maximize the efficiency of the recruitment process, given the accessibility of the target population at health facilities and the cost and logistical limitations involved with alternative recruitment approaches (e.g., telephone and paper flier). While study investigators helped recruit interview participants, they had not met any participants prior to the time of the interview. Based on thematic saturation, recruitment was stopped at ten participants after an interim analysis revealed that saturation of major themes had been achieved. No participant declined study participation.

A study investigator (A. D.), with formal training in research methodology, conducted the participant interviews. We obtained written informed consent from all participants prior to commencing interviews. As part of the informed consent process and prior to the structured interviews, the study investigators explained the rationale for the study but did not disclose personal information regarding their interests in the research topic or their assumptions about possible study findings. All interviews were conducted in private areas of the FP, at a time, which was convenient for them, after taking a prior appointment with the FP. A single session lasted approximately 30–45 min. The investigator led each interview session and read questions aloud sequentially, allowing enough time to fully capture participant responses and adhering to the format of the interview instrument as it progressed through the following sections which were audio recorded: physician demographics, knowledge about their diagnosis and treatment, medical care preferences; and psychosocial support and relevant information—needs, preferences, and on-going sources of support. The interviews were audiotaped and transcribed immediately after each interview. The investigator then transcribed English-translated responses verbatim. No repeat interviews were carried out at any time during the study period. The interviewer checked each transcription against the tapes and then read them for accuracy.

Data analyses and reporting

Qualitative analysis was conducted on the transcripts of the interviews by the investigator. The interviews produced a multitude of interesting topics. In the analysis, the investigator aimed at clarifying the material in such a way that it could be

translated into the proper areas of focus needed for creating a training module for the FPs.

For qualitative data, we employed content analysis methodology to develop thematic codes. The study investigators coded participant responses together and reconciled differences by consensus. We calculated frequencies and simple proportions for all thematic codes generated, including root and child codes. We then used this information to develop taxonomy of themes, providing a structure to interpret participants' experiences with illness and to describe PC knowledge and preferences among all interviewed. All analyses were done by NVivo qualitative data analysis Software; QSR International Pty Ltd. Version 11.4.1, 2015.^[16] The results of structured interviews are reported in accordance with the Consolidated Criteria for Reporting Qualitative Research.^[17]

RESULTS

Characteristics of interview participants

We interviewed ten FPs. Participants interviewed were, on an average, 51 years old (ranging from 40 years to 70 years) and three (30%) were women. Most of them (6 [60%]) were Bachelor of Medicine, Bachelor of Surgery doctors of modern medicine; while four (40%) were Bachelor of Ayurveda Medicine and Surgery doctors practicing traditional Indian medicine alongside. All of them take part in continuing medical education (CME) to maintain competence and learn about new and developing areas of their field.

Psychosocial needs and support reported by interview participants

In response to questions about desired psychosocial services, participants frequently mentioned self-care needs. Most participants cited a need for motivation, receiving training in self-care, or having break from duty to reduce burnout. Many mentioned lack of formal training and support services as important barriers to their well-being:

Participants reported psychosocial needs and sources of psychosocial support ($n = 36$) as follows:

“I was told to lead a well-balanced life, which I can't do because of time constraints. There is nobody in the locality to share my work” (Participant 2).

“(My mental health is) getting compromised. I was earlier happy to be in the clinic with the patients coming over regularly and developed friendship with many of them. But seeing them dyeing makes me feel bad” (Participant 6).

“What I need most in my life is a break; I have always wanted to have a break. I would like help with that” (Participant 1).

Most participants interviewed reported a desire for emotional support.

“There are people who still don't understand-neighbours, family. And I am finding it difficult as I can't share my story with anybody” (Participant 9).

All participants interviewed reported receiving some form of psychosocial support, which was needed. Most of them described receiving psychosocial support from fellow colleagues. This most frequently consisted of emotional support, but often also included dining and get-together parties. They noted that often close friends, or nursing staffs, were important sources of professional support. Several participants reported that they had received support in the form of information and training from the Internet.

Community religious leaders and organizations provided many with psychosocial support.

Palliative care knowledge

With respect to knowledge about the subject, most participants interviewed could describe the nature of the principles, or indications for PC. The most frequent gaps in knowledge existed for symptom management and usage as well as availability of morphine.

“My patient has some sores on the chest, oedema in the legs, and some shortness of breath, and some bad pains. I don't know if I can use Morphine for him” (Participant 7).

Despite attending many workshops on PC, few participants had received formal clinical training or had learned about communication skills in PC. Most of them identified training in PC as a major need as they cater patients with chronic life-limiting illnesses and basic training in PC would empower them to provide better patient care.

We interviewed one key stakeholder, the president of the general practitioner (GP) organization in Mumbai. He reported being familiar with the concept of PC, even those working for organizations providing psychosocial support without an explicit PC mission. He was aware that international PC guidelines existed and that they are updated regularly. However, most of them are not practicing in PC exclusively and had not seen the updated guidelines and noted that they had not yet been fully disseminated at the district level. He noted that additional training was needed for all levels of PC providers.

Preferences for palliative care setting and models of service delivery

Participants were asked to select one or more settings where they would most like to receive PC training from and to explain the rationale for their selections. Their responses most frequently included hospital-based clinical teaching with CME accreditation, community-based teaching at a nearby health post or health center, and internet-based teaching; only one response favored intensive PC training provided in a designated ward (a notion approximating the idea of a hospice). Most participants reported wanting the need for CME accreditation of state or central medical council in PC training courses.

“If I can get a training with CME accreditation that would be good because I'm not being able to go to my clinic for the day for this training and I have many other duties that I am missing at home” (Participant 3).

“Assuming I will be certified; will I be able to provide palliative care independently? I haven’t done that before” (Participant 4).

While most participants expressed a preference for home-based care for their patients, hospital care was still important to many, particularly who felt that the illness was serious or required higher level care, and patients who expressed a distrust of the level of expertise that would be provided in a health center or in their home. For others, the convenience of receiving care in an easily accessible place was most important. Several participants noted that travel to the hospital could be difficult, time-consuming, and disruptive to worsening health status. One of them summarized the conflicts between accessing health care at home versus hospice or hospital in this way:

“It would be good to have health care close to where my patient lives, because then I would be able to take care of him either directly in person or I can even speak with the treating physician about palliative treatment intent over phone. Then I would be able to take care of my family” (Participant 6).

All participants expressed that PC should be widely accessible and integrated with inpatient and outpatient clinical services.

“Palliative care should be part of the routine services, not a separate project. It is part of essential healthcare delivery” (Stakeholder 7).

Health-care providers who have worked in public facilities noted that the integration of PC with other clinical services proved difficult because of limited health worker time and training. Most favored a model in which a mobile PC team combined home-based care—where symptom assessment and psychosocial support would be provided by home-based care volunteers or health workers in the community—with a dedicated hospital-based PC clinic or inpatient service for very sick or complex patients. They stated that a major success of PC in Mumbai was the linking of PC in the home, the community, and health facilities. All of them noted that trained health workers and home-based care volunteers had been crucial in making PC, and health care in general, accessible to vulnerable patients in Mumbai.

Future palliative care priorities

Opinions about future PC priorities varied widely among the participants. The key stakeholder felt that the integration of PC into national policy would assure its eventual implementation in all districts. Health workers should be allocated in the development and scale up of new models of PC service delivery, particularly mobile teams. Psychosocial services should be provided to further integrate clinical and nonclinical PC services and reinforce the existing referral systems between these services. Most of them noted that improving coordination—both among PC-relevant governmental and nongovernmental organizations and across tiers of the public health system—should be a priority for future PC activities. All of them cited a lack of consistent funding for PC activities, amidst competing health priorities, as a threat to the sustainability and scale up of PC services.

“When donors provide money for certain activities, priorities shift and old plans can be forgotten. We need to have money (for palliative care) that is stable from year to year” (Stakeholder 5).

DISCUSSION

We present the results of the first PC needs analysis, to our knowledge, among the FPs from urban Mumbai in India. We report a high prevalence of psychosocial needs among the physicians indicating a large need for PC training. Early results from the study suggest that comprehensive PC can be provided and integrated with disease-modifying treatment even in the most challenging settings by creating a network of hospital, clinic, and home-based services that include psychosocial support incorporating physician assistance.

In urban Mumbai, and India, there have been few published evaluations of needs analysis among GPs practicing PC though the rationale behind such a study has been highlighted many times.^[18] We describe an innovative city-based network of FPs, integral to the health and well-being of the residents in the metropolis.

The need to increase the number of health professionals involved in palliative and end-of-life care has become a priority of PC policies across the developed world and hospitals will play an increasingly prominent role in providing that care.^[19] In developed nations, much of PC in the hospital setting is provided by “generalist” PC providers, that is clinicians who do not have specialist training in PC, but who routinely manage patients at the end of life. In the United Kingdom, a recent policy has highlighted the importance of training and education for generalist providers if they are to provide effective PC.^[20] However, difficulties incorporating PC into a generalist workload have been reported, as has defining the role of PC outside the specialist setting.^[21,22] A recent study by Gott *et al.*^[23] reported significant challenges in generalists working in England and New Zealand. Difficulties with defining the nature and limits of generalist PC, as well as negotiating partnership working, were reported; these reveal a significant gap between PC provision as enshrined in policy and the reality reported by frontline staff.

Similarly, findings reported here show that various barriers exist to the provision and management of PC, not least a need for more education and training. Participants felt that they did not always feel adequately prepared to conduct very sensitive discussions around prognosis and goals of care with patients and their families and expressed a need for additional training in PC. In a recently published review from the UK, education and training were identified as important facilitators of collaborative working within the PC workforce, with many studies identifying education for generalists as a priority.^[24] Examples of successful education models for generalists included study days for home care staff,^[25] practice-based education and decision-making support for GPs,^[26] and educational inductions for PC partnership models involving GPs and practice nurses.^[27] One study reported shared learning

practices involving specialists and generalists; as part of the evolution of joint working between heart failure and specialist PC staff, heart failure nurses attended formal education events organized by specialist PC services and vice versa, which was successful in facilitating shared learning.^[28] Shared teaching can demonstrate core skills needed in the delivery of care such as negotiation, clarification, context setting, and evaluation, drawing upon “real life” case studies from clinical practice.^[29] Similarly, in terms of diffusing education and training into practice, there is evidence that using digital media learning can enhance understanding and application of theory to practice. However, the use of online learning in PC should be matched against the need to practice skills, particularly in relation to sensitive communication and interprofessional interactions.^[29]

Our data suggest that nursing and medical staff in the hospital setting rarely view providing PC as part of their role. While traditionally acute hospitals have been places where people go to be “cured,” ensuring people have a “good death” is now a crucial part of their remit. It could be suggested that viewing of death as a “failure” is largely behind the problem of missed opportunities for communication and discussion in advance of the dying phase. The outcome is that often crisis-driven decision-making pervades the care of the individuals at the end of life and wider service delivery.^[30] Nurses, in similar ways to doctors, tend to feel unprepared for situations, which require them to respond to questions and discussions about death and dying.^[31] If positive transitions to PC approaches are to occur, clarity about when the end of life is near is required. Christakis^[32] argues that a reemphasis on prognostication—which he defines as the process of “foretelling,” that is, forming an expert opinion about the possible trajectory of an illness and then using excellent communication skills to discuss this with the individual concerned and their family—is vital if care and treatment options are to be realized and better end-of-life care is to be achieved. Uncertainty in prognostication, however, is just one issue affecting communication in the whole arena of death, dying, and bereavement; “getting it right” in these sensitive areas remains a considerable challenge. The wider literature has shown^[30] that while education and training is important, it is only part of the picture. Effecting clinician behavioral change is highly complex. Evidence has suggested that education alone may be insufficient to effect cultural change among health professionals, so initiatives that more effectively moderate attitudes and behavior need to be explored.^[33]

Participants in this study felt that the use of care pathways was important in improving the quality of care, particularly with respect to recognizing the point of transition to a PC approach. However, the relationship between the use of “tools” and standardized protocols and quality PC has been identified as in need of further examination.^[33] Rycroft-Malone draws upon a wide range of practical and methodological approaches and offers a useful practical tool to aid those involved in implementing and evaluating the impact of interventions within complex health-care environments.^[34]

Undoubtedly, more work is required to examine and clarify the interplay of setting, pervading culture, type of health professional, and nature of any educational intervention to effect sustained behavioral change.^[35]

CONCLUSIONS

There is a clear need to develop and implement educational interventions to support generalist PC providers who work in private hospital/clinics for better initiation of transition and better quality of palliative care delivery. Support for staff to do this needs to encompass not only education and training for “generalist” PC providers tailored specifically to the unique nature of their job settings, but also a critical consideration of how to address the further significant barriers of the unique “cure-orientated” culture of physician mind-sets. Ensuring that this happens will require a significant cultural change within the current scenario, and there is an urgent need to commit resources to education and training initiatives that support clinicians in this regard. In the absence of concerted efforts to effect change, patients and their families will continue to be denied opportunities to make decisions about one of the most critical periods in life.

Limitations

The study was done in urban Mumbai and might not represent FP practices elsewhere in the country.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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