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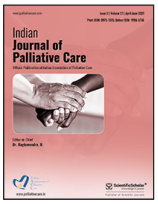

Original Article

Perspectives of Respiratory Physicians toward Need and Integration of Palliative Care in Advanced Respiratory Diseases

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ABSTRACT

Objectives: Patients with chronic life-limiting or advanced respiratory diseases often suffer from high symptom burden, requiring palliative care to alleviate symptoms, improve quality of life and restore dignity. The present study explored the perception of respiratory physicians and their current practice of integrating palliative care for adult patients with chronic advanced respiratory diseases.

Materials and Methods: An exploratory survey method using Google survey forms and SurveyMonkey was emailed to respiratory physicians between December 2020 and May 2021.

Results: One hundred and seventy-two respiratory physicians responded to the survey. The majority of respiratory physicians (n = 153; 88.9%) thought that early integration of palliative care early was beneficial. They did not feel referring to palliative care would result in loss of control on patient care (n = 107; 62.21%) and 66 (38.37%) strongly disagreed that the referral would result in a loss of hope in patients. Further exploration into the training needs of respiratory physicians revealed that 121 (70.35%) felt the need for training in end-of-life care.

Conclusion: Respiratory physicians in our study had an inclination toward palliative care integration into their routine clinical practice. A majority of them expressed the need to enhance their skills in palliative care. Therefore, concerted efforts at integration and a mutual exchange of knowledge between respiratory physicians and palliative care physicians will ensure that patients with advanced respiratory diseases are provided high-quality palliative care.

Keywords: Pulmonary disease, Chronic obstructive pulmonary disease, Palliative care, Pulmonologists

INTRODUCTION

Chronic life-limiting or advanced respiratory diseases are progressive and debilitating in nature and rank 3rd among the causes of life-limiting illnesses across the globe.[1] Chronic life-limiting or advanced respiratory diseases in India account for 32% of the global disability-adjusted life years (DALY).[2] There was a steep rise in the prevalence of chronic life-limiting or advanced respiratory diseases between 1990 and 2016, with chronic obstructive pulmonary disease (COPD) accounting for 29% and asthma for 9% of the cases in the country.[2] COPD and asthma contributed to a major proportion of deaths, as high as 10.9% and 8.7%, respectively.[2] They also accounted for the highest causes of disability-adjusted life years.[2] Non-malignant chronic respiratory diseases, in comparison with their malignant counterparts, are more indolent in nature, with acute exacerbations of symptoms requiring recurrent hospitalisations.[3] Patients suffer from a single worsening symptom or cluster of symptoms that impose limitations on activities of daily living,[4,5] which is further compounded by comorbidities.[6] Pain (54.4%), dyspnoea (84.2%), fatigue (81.4%), dry mouth (80.3%), insomnia (64%), depression (54.8%) and anxiety (52.5%) were among the most common and most distressing symptoms.[7] The physical and emotional distress affects both patients and caregivers

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alike, with caregivers particularly requiring recourse.[8] This demands a systematic screening of physical and psychosocial symptoms and incorporation of palliative care into routine clinical care.[5,7]

Palliative care focuses on mitigating symptoms through an interdisciplinary team and provides holistic care to patients and families as a unit. Studies have established the role of palliative care in reducing the burden of healthcare expenditure and improving the health of patients with life-limiting diseases.[9,10] Although patients receiving palliative care for chronic respiratory diseases are known to benefit from specialist palliative care inputs, many fail to receive it unless referred for terminal care.[10] Referral to palliative care is influenced by the attitude and knowledge that physicians have about palliative care.[11] Evidence suggests that clinicians associated palliative care with end of life and underestimated the proportion of their patients requiring palliative care.[12,13] Only a few physicians saw palliative care as something other than terminal or end-of-life care. Other reasons for hesitation in referrals were fear of upsetting their patients, stealing hope, unwilling to abandon their patients, seeing referral as an admission of failure, and not understanding the benefits of referral.[9]

Respiratory physicians serve as gatekeepers of referrals to palliative care. Their knowledge of facilitators and barriers in palliative care referral will influence the utilisation of the service. The present study explored the perception of respiratory physicians and the current practice of integration of palliative care for adult patients with chronic advanced respiratory diseases. It also attempted to learn the needs, facilitators, and barriers as perceived by respiratory physicians toward integration.

MATERIALS AND METHODS

Study design

Approval for the study was obtained from the Institutional Review Board of Tata Medical Center, Kolkata (reference number: 2020/TMC/207/IRB65). The study used an exploratory survey method. The participants included respiratory physicians providing care to adult patients in hospital and community settings. The survey questionnaire was emailed to respiratory physicians who were registered with the Indian Chest Society (ICS). The questionnaire was designed after a thorough literature search followed by the consensus of the respiratory physicians. The questionnaire comprised of multiple-choice questions. The survey was finalised after all the authors unanimously agreed on its readability, concept clarity, and user-friendliness. The survey was posted online and contained an inbuilt consent form. Google Forms and SurveyMonkey were the online portals used to conduct this survey. Information related to the study and informed consent form was provided on the first page of the survey form. Data were collected between December 2020 and May 2021.

Inclusion criteria

Eligible participants were respiratory physicians providing care to adult patients in hospital or community settings.

Study setting, sampling and data collection methods

The questionnaire either as Google Forms or SurveyMonkey was emailed to all the respiratory physicians registered with the ICS database. Since the consent form was inbuilt in the online questionnaire, the participants who agreed to participate had to click on the mandatory submit button (thus consenting to participate) to proceed with the study. The time taken to respond to the survey questionnaire was 10 min.

Data analysis

The data were collected and compiled using Google Forms and SurveyMonkey. The analysis was done using Epi Info (Version 7.2; CDC, Atlanta). The qualitative variables were expressed in terms of frequencies and percentages. The Kolmogorov–Smirnov test was employed to determine the data's normality. Normal quantitative data were depicted as mean and standard deviation and non-normal data as median and interquartile range.

Ethical consideration

Participation in the study was voluntary and only participants who clicked on the submit button after reading the consent form could proceed with the study. All fields were mandatory to respond to proceed to the submit button. Participants could withdraw at any time during the survey and the responses generated were null and void on withdrawal from the study. The investigator ensured the anonymity of participants by keeping all related identifiers such as names, places of work, and residential addresses confidential.

RESULTS

The survey was emailed to all respiratory physicians registered with the ICS database (n = 2400) of whom 172 physicians responded. Demographic details collected from the physicians revealed an average age of 44.7 years (SD = 10.4). In all, 119 (69.19%) of the respondents were male. One hundred and eighteen (68.6%) of the respondents had a postgraduate degree (MD) in respiratory or internal medicine followed by 23.88% of respondents with a diploma degree in respiratory medicine (n = 41). The median years of experience as a respiratory physician were 14 years (IQR – 7.50–23 years). The majority of the physicians (n = 91; 53.21%) worked in private hospitals or private practice.

The median number of patients with advanced respiratory diseases seen by the respiratory physicians (in the past 1 month) was 27.50 (IQR: 11.50–60). Only 13 (7.56%) physicians provided palliative care themselves. Only 58 (33.72%) of physicians had access to a specialist palliative care physician in their institution. However, 108 (62.79%) had access to a specialist palliative care

Table 1: Current provision of palliative care in the country.

Current provision of palliative care	Frequency	Percentage
Number of patients with advanced respiratory diseases seen during the past month (Median [IQR])	27.50 [11.50 to 60.00]	
In what percent of such patients have you been able to provide palliative care either yourself or through referral to a specialist palliative care physician?		
<10%	95	55.25
10% to 50%	49	28.49
50% to 75%	15	8.72
75% to 100%	13	7.56
Number of patients with lung cancer seen during the past month (Median [IQR])	4 [2 to 10]	
In what percent of such patients have you been able to provide palliative care either yourself or through referral to a specialist palliative care physician?		
<10%	79	47.31
10% to 50%	49	29.34
50% to 75%	21	12.57
75% to 100%	18	10.78
Do you have access to specialist palliative care in the same institution?		
Yes	58	33.72
No	114	66.28
Do you have access to specialist palliative care within a radius of 50 km?		
Yes	108	62.79
No	64	37.21
Have you used PARENTERAL morphine in your clinical practice?		
Yes	70	40.70
No	102	59.30
If yes, for what indication (n=70)		
Pain	20	28.57
Dyspnoea	44	62.86
Cough	59	84.29
Have you used ORAL morphine in your clinical practice?		
Yes	102	59.30
No	70	40.70
If yes, for what indication (n=102)		
Pain	81	79.41
Dyspnoea	48	47.06
Cough	29	28.43
Do you provide multidisciplinary care to patients with advanced respiratory disease?		
Yes	135	78.49
No	37	21.51
Who are part of this multidisciplinary team (n=135)		
Palliative care physician	61	45.19
Nurse	96	71.11
Medical Social Worker	49	36.30
Physiotherapist	105	77.78
Psychologist/Psychiatrist	81	60.00
Counsellor/volunteer	52	38.32
Others	4	2.96

physician within a 50 km radius. One hundred and thirty-five (78.48%) physicians involved a multidisciplinary team. Although, physiotherapists (n = 105; 77.78%) and psychologists/psychiatrists (n = 81; 60%) more often formed a part of their interdisciplinary team, 61 (45.19%) physicians referred their patients to palliative care physicians [Table 1].

The study explored their perception regarding the stage at which integrating palliative care would be appropriate. While 153 (88.95%) respiratory physicians perceived early integration of palliative care as beneficial, 42 (24.42%) felt the need for integration only for terminal care. The study further explored the perspectives of respiratory physicians regarding facilitators and barriers to integrating palliative care into the clinical care of patients with advanced respiratory diseases. The study revealed that respiratory physicians perceived integrating with palliative care as beneficial and felt comfortable discussing palliative care with their patients (n = 78; 45.35%) and did not feel referring to palliative care that would result in loss of control on patient care (n = 107; 62.21%). Sixty-six (38.37%) physicians strongly disagreed that the referral would result in a sense of abandonment or loss of hope in patients. A total of 114 (66.28%) shared an amicable partnership with the palliative care team, and 129 (75%) felt the need to upgrade their expertise in basic palliative care [Table 2].

The researchers were interested in learning about the training requirements in palliative care as expressed by respiratory physicians. Only 72 (41.86%) physicians had undergone some training in basic palliative care and only 28 (16.26%) and 23 (23.35%) physicians were confident in providing non-malignant and malignant palliative care, respectively. Furthermore, the study explored the areas of palliative care where the physicians expressed their needs for training. In all, 121 (70.35%) physicians expressed their need for training in pain and symptom management followed by end-of-life care (n = 113; 65.70%) and communication skills (n = 107; 62.21%) [Table 3].

DISCUSSION

Despite advancements in the management of respiratory diseases, many diseases still have a dismal prognosis. This

Table 2: Perceptions of Respiratory Physicians about the role of palliative care in advanced respiratory diseases.

Perception related questions	Strongly disagree		Disagree		Agree		Strongly agree	
	No[r]	%	No[r]	%	No[r]	%	No[r]	%
It is beneficial to work hand in hand with palliative care early on in the management of advanced respiratory diseases (for e.g., for symptom management or psychosocial or spiritual support)	3	1.74	2	1.16	14	8.14	153	88.95
It is useful to integrate palliative care when the respiratory distress is even after the use of all available therapeutic options	6	3.49	6	3.49	9	5.23	151	87.79
It is useful to integrate palliative care when the physical decline begins	7	4.07	9	5.23	18	10.47	138	80.23
It is useful to integrate palliative care when the need to discuss goals of care and advance care planning arises	3	1.74	6	3.49	22	12.79	141	81.98
It is important to integrate palliative care when the patient/family ask about or for palliative care	17	9.88	7	4.07	21	12.21	127	73.84
It is useful to integrate palliative care only when the patient is in the end of life.	103	59.88	17	9.88	10	5.81	42	24.42
Barriers								
Uncomfortable in discussing palliative care with my patients	78	45.35	31	18.02	41	23.84	22	12.79
Patients would have a sense of abandonment/loss of hope when referred to palliative care	66	38.37	26	15.12	37	21.51	43	25.00
Referral to palliative care will result in the loss of my autonomy in patient care	107	62.21	28	16.28	20	11.63	17	9.88
Lack of training and skills in providing palliative care	23	13.37	31	18.02	32	18.60	86	50.00
Unaware of palliative care service in the locality of my practice	81	47.09	24	13.95	20	11.63	47	27.33
I am unclear as to who needs palliative care	122	70.39	24	13.95	15	8.72	11	6.40
I am unclear as to when I should involve or integrate palliative care in advanced respiratory disease	106	61.63	28	16.26	20	11.63	18	10.47
Facilitators								
Confidence and good working relationship with the palliative care team	14	8.14	14	8.14	30	17.44	114	66.28
Good network palliative care team within the institution or area of practice	27	15.70	14	8.14	32	18.60	99	57.56
More training and up skilling in the provision of basic palliative care	10	5.81	7	4.07	26	15.12	129	75.43

No[r]: Number, %: Percentage

holds true for not only malignancy but also for non-malignant chronic respiratory diseases conditions such as severe COPD, interstitial lung disease, pulmonary hypertension, and neuromuscular disorders, leading to respiratory failure.[14] The trigger for palliative care integration is more disease-based rather than needs-based.[15] Some of these triggers include recurrent hospitalisations for acute exacerbation of symptoms, poor respiratory function, increasing symptom burden, deterioration in the functional status, increasing demand for advanced respiratory therapies and progressive recalcitrant disease.[15] Recent randomised controlled trials on early palliative care for patients with chronic life-limiting or advanced respiratory diseases have demonstrated significant reductions in breathlessness intensity, improvement in DALY, and alleviation of depressive symptoms.[16] Patients also reported improvement in confidence, function, and better control of their breathlessness.[16] Early introduction of palliative care is known to reduce hospital admissions, emergency visits, and utilisation of intensive care units.[17] It also aids in the fulfillment of patient's wishes to spend the final hours of life as well as the provision of opioids for symptom relief.[17] Palliative care integration improved their coping mechanisms by way of physical and emotional symptom alleviation, prognostic awareness, increased understanding of the care plan, and higher acceptance of advance care planning.[18,19]

Respiratory physicians play a pivotal role in providing palliative care for advanced respiratory diseases, so exploring their perceptions about palliative care integration, challenges in palliative care provision, and their need for training in palliative care, providing primary palliative and referral to specialists are important.[20] In our study respiratory physicians provided care to a high proportion of patients with advanced respiratory diseases, and almost half of them discussed palliative care with their patients and caregivers. However, only one-third were able to facilitate palliative care. This discordance in the numbers seen and referrals to palliative care could be influenced by factors such as inability to accurately predict the prognosis, time constraints, and limited resources.[21,22] The study also reported a lack of clarity in timing for initiating palliative care. However, our study revealed contrasting results. Respiratory physicians in

Table 3: Perceived need of training in palliative care among respiratory physicians.

Perceived need on training in palliative care	Frequency	Percentage
I have had some training in the basics of palliative care		
No	100	58.14
Yes	72	41.86
If yes, I am confident in offering basic palliative care to patients with advanced respiratory diseases? (n=72; 0-no confidence to 5- confident)		
0	1	1.39
1	1	1.39
2	13	18.06
3	16	22.22
4	18	25.00
5	23	31.94
Learning needs in Palliative care		
Pain and symptom management	121	70.35
End of life care	113	65.70
Communication skills	107	62.21
Ethical considerations in decisions of end of life	84	48.84

our study clearly delineated curative from palliative care and seemed to feel that palliative care should be integrated early. The other cause of discordance could come from patients or families who may be averse to discussing palliative care with their physician.[23,24] Furthermore, they perceive the condition as non-fatal due to the prolonged course of the disease that helps them adapt to it.[25] Whereas most respiratory physicians felt the need for early integration, they equally felt that it was essential to consider the patient/family's perspective for such a referral.[26,27]

Most respiratory physicians recognised the importance of early integration of palliative care for advanced respiratory diseases, and only a minority believed that palliative care could be provided at the end of life reveal an attitudinal shift. The findings corroborate with a study by Narsvage *et al.*[28] where the participants felt that early palliative care could facilitate communication in terms of patient/family preferences in an empathetic and supportive manner and aid in decision-making for end-of-life planning. Early integration ensures the preservation of hope and acts to guide patients and their families to realistically tackle the life-limiting illness.[28]

Almost all the participants felt comfortable referring their patients to palliative care, and this was a heartening response. They perceived this referral as positive and neither had any apprehensions of losing autonomy over their patients nor feared stealing hope from their patients. These results were contrary to the findings of a study that looked at referral patterns to palliative care by Australian oncologists.[29] In that study, oncologists did not feel it necessary to give a palliative care referral as they were confident in treating their patients' symptoms and perceived their care as non-inferior to a specialist palliative care service. In the study, oncologists had apprehensions about referring their patients due to a poor relationship with the service and perceived poor quality of service.[29] A physician will perceive a benefit in collaborating with the palliative care team if they expect or have experienced a positive interchange and if the benefits of this interchange outweigh the cost of the activity. The future collaborative behaviour will be enhanced by the value of this relationship.[30-32] Our physician participants' harmonious relationship with the specialist palliative care team and confidence in their care provision appeared to be the reasons for their perception, and these augered well for the future of respiratory palliative care in the country.

Some physicians in our study felt that they were constrained in their referrals due to the paucity of palliative care specialists either in their institution or proximity to practice. The nascence of the palliative care field, with most services concentrated in major oncology centres in the country and the focus of training being palliative oncology, can act as significant barriers for accepting referrals for non-malignant palliative care.[8]

Although most respiratory physicians mentioned the importance of opioids in pain management, dyspnoea, and cough, they still expressed the need to enhance their expertise in palliative care. Pain and symptom management were ranked highest among the topics followed by the issues around end-of-life care and communication skills. These were similar to findings from studies that explored the learning needs of general practitioners in primary palliative care.[33,34] Patients feel a sense of comfort and intimacy with respiratory physicians due to the prolonged period of encounters with their physicians.[35] This emphasises the importance of primary palliative care education for respiratory physicians to enhance their skills at providing primary palliative care and also based on standard referral criteria to know when to initiate palliative care and refer to specialists.[15]

Although this study adds to our understanding of clinical practice, there are several limitations to be aware of. Sampling bias was the key limiting factor, as we selected respiratory physicians from the ICS database. We could have missed the respiratory physicians who were not registered with them. The response rate was not clear from the study as we did not have a definite denominator, but the researchers made every effort to reach out to respiratory physicians through Google Forms, SurveyMonkey, and seminars. We sent the emails to the email ids of respiratory physicians and relied on the correctness of the email ids. This also could have contributed to the poor response. The survey was sent around the time of the COVID pandemic, which could have contributed to the

poor response from the study participants.[36] Other possible causes for the low response rate could be disincentivisation, discomfort in using online portals for surveys, or non-response from physicians who were not interested in palliative care.[37,38] There may also have been a possible bias in our responses as those physicians who saw the value in intergrating palliative care actually responded to the survey. Future studies could focus on comparing the perceptions and attitudes of respiratory physicians with exposure to palliative care against those having no exposure. Furthermore, future studies could explore the benefits and challenges of early palliative care for non-malignant respiratory diseases in a resource-constrained environment.

CONCLUSION

Although early palliative care is known to benefit patients with advanced respiratory diseases, which most of our respiratory physicians in the study also favoured, referral to palliative care in the country is still limited. Referral to palliative care will only occur if respiratory physicians perceive the referral as beneficial, available and easily accessible. Therefore, expanding specialist palliative care services beyond oncology and enhancing respiratory physicians' education in palliative care could potentially improve patient access to palliative care.

Declaration of patient consent

Institutional Review Board (IRB) permission obtained for the study.

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Conflicts of interest

There are no conflicts of interest.

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