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ORIGINAL ARTICLE

Palliative care in COPD—web survey in Sweden highlights the current situation for a vulnerable group of patients

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Abstract

Background. Chronic obstructive pulmonary disease (COPD) is a common cause of death. Despite the heavy symptom burden in late stages, these patients are relatively seldom referred to specialist palliative care.

Methods. A web-based survey concerning medical and organizational aspects of palliative care in COPD was distributed to respiratory physicians in Sweden. There were 93 respondents included in the study.

Results. Palliative care issues were regularly discussed with the patients according to a third of the respondents. About half of the respondents worked in settings where established routines for co-operation with palliative units were available at least to some extent. Less than half of the respondents (39%) were aware of current plans to develop palliative care, either as a co-operative effort or within the facility. Palliative care is focused on physical, psychological, social, and existential dimensions, and the proportions of respondents providing support within these dimensions, 'always' or 'often', were 83%, 36%, 32%, and 11%, respectively. Thus, to treat the physical dimensions was perceived as much more obvious than to address the other dimensions.

Conclusions. The survey indicates that the priorities and resources for palliative care in COPD are insufficient in Sweden. The data, despite limitations, reveal a lack of established team-work with specialized palliative care units and actual plans for such co-operation.

Key words: Care management, COPD, holistic care, palliative care, survey

Introduction

Chronic obstructive pulmonary disease (COPD) is a progressive, disabling, and life-limiting disease. In Sweden, 5%–15% of the population over 45 years of age is believed to suffer from COPD; the number of hospitalizations due to COPD has increased by 40%, and the number of deaths has doubled during the last decades (1,2). COPD is the only endemic modern Western illness where the number of deaths is still increasing (3,4). Shortness of breath, fatigue, and cough are the most troublesome and well-known symptoms, and living with COPD imposes limitations on

daily living (5–7). The available treatment regimens are mainly focused on physical symptoms and give only limited relief from these symptoms.

The comprehensive palliative care philosophy goes beyond the focus on physical symptoms, and, according to the World Health Organization (WHO), palliative care should comprise physical, psychological, social, and existential/spiritual dimensions throughout the continuum of the disease (8). The *physical* dimensions of COPD include severe breathlessness, acute exacerbations, cough, fatigue, anorexia and muscle wasting, osteoporosis, pain, increased risk for thrombosis, and heart failure (6,9–11). The

psychological burden is characterized by depression, anxiety, risk for cognitive impairment, and sleep disorders (10,12). The *social* consequences are mainly related to limitations in everyday life, affecting both the patient and the family (13,5), whereas the *existential* burden is a suffering connected to feelings of meaninglessness, guilt, and impending death (14-16). Thus, COPD in its advanced stages is definitely a disease requiring palliative care; still it is seldom discussed in a palliative context.

The comprehensive palliative care philosophy and the need for palliative care services are self-evident in advanced stages in cancer care, whereas this approach is not generally offered to COPD patients, despite the heavy symptom burden in the late stages of the disease.

Questionnaires have earlier been distributed in England, Wales, and Northern Ireland since it was unclear to what extent specialist palliative care was available for those with non-malignant lung diseases. The study revealed that patients with advanced COPD had less universal access to specialist palliative care services than patients with malignant lung diseases (17). Further, a self-assessment survey in the UK showed that 42% of the hospitals had formal palliative care arrangements for patients with COPD (18). The response rates for these studies were only 51% and 38%, respectively, which may reflect a less pronounced interest in these questions.

The aim of the study was to survey respiratory physicians' views of COPD as a potential palliative care diagnosis, where physical, psychological, social, and existential domains are addressed. A further aim was to survey the perceived availability of resources for palliative care and the trajectory through the health care system at the end of life in our setting, i.e. in Sweden.

Materials and methods

A web-based survey concerning palliative care in COPD was distributed by e-mail through the Swedish Society of Pulmonary Medicine (SLMF), initially to all members ($n = 259$) in Sweden in August 2011. The survey was distributed twice to the members with an interval of four weeks. The SLMF includes not only clinically active respiratory physicians but also retired members, other professionals within respiratory medicine, and supportive members. After exclusion of physicians who were retired or not in clinical work (but, e.g., within administrative positions, pharmaceutical companies) and exclusion of members who were not physicians, the response rate was calculated to be 41% (93 respondents). The address register for health and medical care personnel (HSRA) records in

2010 was used for comparison, and 222 clinically active respiratory physicians were identified, 126 men and 96 women. The web survey responses were returned anonymously, and neither respondents nor hospitals could be identified.

The survey consisted of five questions. The possible alternatives for the four first questions were: 'yes', 'partly', 'seldom', 'not at all', and 'do not know'. For the fifth question the alternatives were: 'always', 'sometimes', 'often', 'seldom', and 'not at all'. The questions were:

- (1) Do you consider any of your COPD patients as needing palliative care?
- (2) When a patient is considered as such, do you usually discuss palliative care with the patient and the family members?
- (3) Are there any established routines at your unit for patients with COPD to receive palliative care, if needed?
- (4) Are there any plans at your unit to develop, or further develop, palliative care services for patients with COPD?
- (5) According to WHO, palliative care is focused on physical, psychological, social, and existential dimensions. To what extent do you provide support in each of these dimensions?

Ethical considerations

The study was carried out in accordance with the ethical standards of the Helsinki Declaration (World Medical Association Declaration, 2000). Ethical approval of the study was obtained from the Regional Ethical Review Board in Gothenburg (Dnr: 209-11).

Results

The 93 respondents provided some demographic data such as gender, working place, working years within respiratory medicine, and whether they provided care for COPD patients or not. There was a predominance of male respondents and fewer female respondents compared to the general respiratory specialist gender ratio. There were, however, no significant gender differences in the patterns of the answers (Table I).

An absolute majority of the respondents provided care for patients whom they considered in need of palliative care (Table II). About one-third of the respondents discussed palliative care issues with their patients only partly or not at all. One of those who did not discuss palliative care commented: 'The patient is expected to realize that all medical efforts in COPD are palliative and thus palliation is not discussed as for cancer patients'. The optimal timing for palliative care discussions was commented on in

the web survey. There were different suggestions about when such discussions should take place, e.g. when the patient was hospitalized for intensive care, when the patient was listed for home care, after joint therapy conferences, or at the regular visits. One respondent stressed the need to discuss palliative care while the patient was still in a stable condition and not when the patient was admitted to hospital for an exacerbation.

About 53% of the respondents worked in settings where routines for co-operation with palliative units were available, although they were only partly established according to 24% of the respondents. As a spontaneous comment, several respondents (10%) emphasized the need for the availability of palliative at-home or in-patient services for COPD patients while still delivering profiled medicine respiratory care.

Almost 39% of the respondents were aware of current plans to develop palliative care, either as a co-operative effort or within the facility. There were more definitive plans according to 20% of the respondents and partly decided plans according to 19%. There were, however, no known plans for further development of palliative care services according to one-third of the respondents. Those respondents who had been working for 10 years or more as respiratory physicians were more likely to report plans to develop palliative care compared to those who had been working for 5 years or less (47% versus 13%) ($P < 0.05$, Fisher's exact test).

Since WHO's definition of palliative care focuses on physical, psychological, social, and existential/spiritual dimensions the final question addressed these issues.

The fact that a doctor should treat the physical dimensions was perceived as obvious in contrast to the psychological and social dimensions. Few of the respondents expressed the view that the existential/spiritual issues should be always or often addressed, and half of the respondents said that they seldom or never provided support in these dimensions, despite the poor prognosis in the late stages of the disease, as shown in Table III.

The open-ended comments showed that this last question is a broad issue and difficult to answer only by ticking a box in a questionnaire. Furthermore, it was perceived as a difficult task to separate these dimensions, and there is also a stated lack of time to address these issues in clinical practice. The cross-tabulation revealed that those who usually do not discuss palliative care with their patients and their families addressed neither the existential (0%) nor the psychological dimension (0%). Those who had worked less than 5 years in pulmonary medicine said that they never (9%) or seldom respond to an

existential/spiritual dimension, and none of them felt that they always do.

Discussion

Almost all of the physicians had patients in a palliative phase, and over two-thirds also did discuss palliative care issues with patients and their relatives. However, one-third of the physicians only partially or never discussed palliative care. This may be due to several reasons, e.g. the difficulty of prognosis in advanced COPD as well as predicting whether the patient will recover or not in an exacerbated phase of COPD (19). In studies from the UK there were even more notable figures, as 87% had no routines for initiating end-of-life discussions (17,20). Further, studies have shown that patients themselves are reluctant to discuss palliative care issues with their doctor (12,21). This may be due to the patients' own perception of COPD as a non-fatal disease, because most have suffered from COPD for a long time and have somewhat learned to live with the disease (19).

Only half of the physicians stated that they had established routines for working with palliative care units. Even fewer knew about any plans to develop further the palliative care for patients with COPD. There might be several reasons, e.g. lack of health staff members designated and responsible for palliative care of non-malignant respiratory diseases within the facility and collaborating with specialized palliative care medicine. Further, respiratory specialists might question if the palliative care services have sufficient competence in specific COPD issues. However, some health authorities in Sweden are now requiring excellence in palliative care of malignant as well as of non-malignant diseases, such as COPD, for those who are providing advanced care of patients in their homes (22).

In an early stage of COPD, it is reasonable for respiratory specialists or general practitioners within primary care to have sole responsibility for the patients, while at a later stage of the disease co-operation with palliative care services would most likely benefit the patient.

Studies have identified the obvious thresholds during the COPD disease course, i.e. when there is a risk of death within one year of complications to COPD, e.g. respiratory failure (23-25). Despite this knowledge, there seems to be a reluctance to initiate palliative care in time. Still, WHO emphasizes that palliative intervention preferably should be incorporated early in the course of the disease, along with disease-specific treatment. Palliative care services should be offered at least as a complement to specialist COPD care, if the symptom burden and

Table I. The study population (*n* = 93).

Gender ^a	
Female ^b	34%
Male ^b	66%
Health care providers	
University hospital	38%
Other health care providers	62%
Working years within pulmonary medicine ^a	
≤10	31%
>10	69%
Providing care for COPD patients	
Yes	96%
No	4%

^a Data incomplete for two study respondents.

^b Among all clinically active physicians 43% are female and 57% are male.

the emotional suffering are obvious, regardless of prognosis (26). As a comparison, early palliative care interventions have proven to improve quality of life and prolong survival for newly detected lung cancer patients (27). Moreover, in a recent study where the symptom burden was compared for hospitalized cancer and COPD patients, the frequency of distressing symptoms was comparable, but the symptoms were more difficult to relieve in COPD patients (28).

WHO strongly recommends team-based palliative care, ‘the third corner-stone’ (29). Team-based care seems to provide synergistic outcomes whether if the focus is on palliative care (3). The team members, with different professional profiles, create the possibility for improved management of complex symptoms and fulfilment of needs beyond medical ones. Effective and well-functioning team-work further creates trust as well as support for the team members themselves. Professionals within respiratory medicine who have the excellence and interest in palliative care

could be part of teams collaborating with palliative medicine and could support more integrated models of care for all patients in an end-of-life situation (2). Only a minority of COPD patients are treated by respiratory specialists; instead the majority of these patients receive medical help from primary care services. Although the survey was addressed to respiratory specialists, it still highlights considerable shortcomings as regards a palliative care approach for the COPD population. The cause has not been studied but may be related to insufficient chains of care for co-operative measures in advanced COPD and palliative care, the large number of COPD patients, and difficulties to communicate palliative care with the patient and the family, as well as a feeling of uncertainty and powerlessness for this vulnerable group.

COPD as a major cause of death is of course a well-known fact for COPD specialists, but as the medical trajectory is difficult to predict, co-operation with a palliative care team is rarely established. Further, there is still a widespread misconception: palliative care is believed to be limited to cancer care (30,31).

The psychological dimensions were only regarded as important by 36%. This is in good agreement with a comparative study of patients with lung cancer and patients with COPD, where the authors were able to demonstrate that COPD patients had more anxiety and depression, but were more seldom for treated (32). This is a great concern, as studies show that depression in COPD patients is highly related to mortality, hospital readmissions, and longer lengths of stay (33,34).

Barely one-third of the physicians considered the social dimensions important. This shortcoming may be related to a perceived lack of time, but may also be attributed to a lack of priority. Still, recent research highlights the need of chains of care and formalized co-operation between COPD and palliative care (31).

Among all aspects, the existential dimension of COPD care was the most neglected one: only 11%

Table II. Distribution of the responses to questions 1–4 in the web survey.

Questions	Yes <i>n</i> (%)	Partly <i>n</i> (%)	No <i>n</i> (%)	Do not know <i>n</i> (%)	Data incomplete <i>n</i>
1. Do you consider any of your COPD patients as being a palliative care patient?	85 (93%)	N/A	1 (1%)	5 (6%)	2
2. When a patient is considered as palliative, do you usually discuss palliative care with the patient and the family members?	63 (69%)	26 (28%)	5 (5%)	2 (2%)	1
3. Are there any established routines in your unit for patients with COPD to receive palliative care, if needed?	29 (32%)	24 (26%)	38 (41%)	2 (2%)	1
4. Are there any plans to develop, or further develop, palliative care services for patients with COPD?	18 (20%)	17 (19%)	27 (30%)	27 (30%)	4

Table III. Distribution of responses to question 5 in the web survey: 'According to WHO, palliative care is focused on physical, psychological, social, and existential dimensions. To what extent do you provide support in each of these dimensions?' $n = 93$.

	Always (%)	Often (%)	Sometimes (%)	Seldom (%)	Not at all (%)	Data incomplete
Physical	28	55	14	1	1	1
Psychological	4	32	48	13	3	1
Social	2	30	52	10	6	3
Existential	2	9	40	32	18	4

of the physicians considered support in existential issues to be a task for them, despite the high mortality rate of COPD patients, which activates thoughts of life and death issues and triggers existential anxiety (35). Study data show that these issues are of great importance to patients (13), but they are seldom addressed, possibly due to the lack of competence, lack of awareness, and a feeling of powerlessness. Still, existential discussions are probably addressed by the physicians, at least to some degree, even if they do not label them as being existential or spiritual (36).

The core question remains to be answered in a Swedish setting: should access to specialist palliative care be restricted to cancer care or should it be expanded also to include COPD? End-stage COPD is associated with a heavy symptom burden, not only from the respiratory system, but also in the form of pain, fatigue, weight loss, death anxiety, and depression, just like cancer diagnoses. Data indicate that an interactive and integrated process between COPD care and palliative care would benefit the patient and also optimize the resource utilization (37).

This web survey has its limitations since it is difficult to achieve adequate answers on such complex questions with only fixed-format questions and the possibility of adding open-ended comments. The interpretation of the survey was also impacted by the relatively low response rate (41%). A pessimistic view is that the low response rate at least partly reflects the limited interest in palliative care for COPD patients and the respondents might be those with an interest of palliative care. Despite the limitations of the study, it points to deficiencies in the palliative care of COPD patients.

Patients with COPD are a vulnerable, non-prioritized group as seen from the inadequate actions from the local authorities as well as from the health care services. Further initiatives must be taken to provide these patients with equal and decent care in the palliative phase of the disease. One way to establish these measures might be to increase education and information for health care providers as well as politicians about COPD. Patient organizations are also important to accomplish a sustainable change.

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