

Integrated care for patients with advanced chronic obstructive pulmonary disease: a new approach to organization

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KEY WORDS

chronic obstructive pulmonary disease, integrated care, volunteer work

ABSTRACT

Chronic obstructive pulmonary disease (COPD) affects approximately 10% of the population aged above 40 years. In advanced COPD (forced expiratory volume in 1 second <50% of the predicted value), patients suffer from severe pulmonary symptoms including dyspnea, chronic cough, poor exercise tolerance, which are commonly associated with systemic disorders, such as osteoporosis, loss of fat-free body mass, fatigue, anxiety, and depression. Moreover, patients with advanced COPD experience annually an average of 2 to 3 episodes of exacerbations requiring hospitalization. We present here a model of integrated care based on the cooperation between medical staff, social workers, volunteers and patients and their families. The essential components of this model are intensive education, treatment supervision, and support in self-management as well as coping with the disease and its consequences. It is expected that these measures will result in a decreased number of exacerbations requiring hospitalization, improved disease course, and better quality of life.

Introduction The estimated number of patients with advanced chronic obstructive pulmonary disease (COPD) is about 400,000.¹ This group includes those with a forced expiratory volume in 1 second below 50% of the predicted value. These patients usually suffer from severe dyspnea, persistent cough (frequently productive), and significantly decreased exercise tolerance.² Furthermore, many patients complain of depression and anxiety.³ Increasing social isolation, difficulty in walking and performing everyday activities, as well as deterioration in cognitive function result in poorer quality of life similar to that observed in patients with advanced lung cancer.^{4,5} Poor patient compliance and prescription non-adherence are the main factors that negatively affect the course of COPD.⁶ Studies showed that inadequate treatment may cause frequent

exacerbations, sometimes requiring hospitalization. Severe aggravation does not only produce detrimental effects but also unfavorably affects prognosis. Of note, survival among patients with COPD is not better than that of patients with advanced lung cancer.^{7,8} Moreover, unlike in cancer patients, it is much more difficult to predict the final phase of life in those with COPD.^{9,10} It is frequently prolonged and, apart from medical aspects, it is determined by depression, social isolation, and lack of integrated care that would combine social, psycho-spiritual, palliative, and hospice care.¹¹

Integrated care system In 2002, the World Health Organization (WHO) proposed integrated care programs for chronically ill patients.¹² The new models of care are designed to prevent

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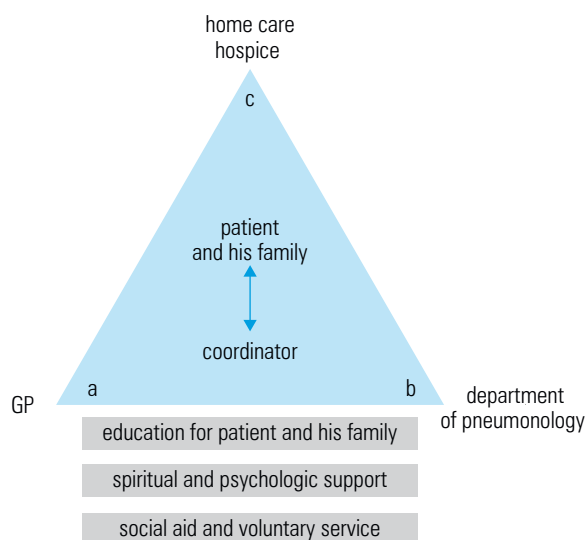


FIGURE 1 A model for palliative care in patients with advanced COPD. Palliative care in patients with advanced COPD should comprise 3 most important components – education, spiritual/psychological support, and social support. Coordinators (e.g., medical assistants) would be responsible for entering patient data into an electronic database, organizing education courses for patients and their families, and coordinating social, psychological, and spiritual care services in the stable phase. If stable, patients would remain under the care of their GP. In case of exacerbation requiring hospital admission, coordinators would be responsible for the organization of hospital care (in case of any difficulty). In this phase, patients would receive treatment in a pulmonary ward or clinic. In end-stage COPD, coordinators would be responsible for the organization of home or palliative care (if necessary) for patients and their families.

Abbreviations: COPD – chronic obstructive pulmonary disease, GP – general practitioner

disease progression, for example through prevention of unfavorable events such as exacerbation. The cornerstone of the integrated care system is education of patients and their families to strengthen their abilities to cope with the disease and associated limitations. An important aspect of integrated care is close cooperation between medical and nursing personnel and between health care professionals and patients and their relatives. The proposed model of care comprises also social assistance and care (volunteer work, social workers in the neighborhood, social care organizations).

Education International recommendations regarding the diagnosis and treatment of COPD emphasize the importance of education in patient management.¹³

Studies on the risk factors associated with exacerbation of COPD revealed that some of them can be modified if cooperation with the patient and his family is good and the level of patient knowledge about COPD is high.¹⁴ These factors are pneumological care, appropriate use of bronchodilators (inhalators), and physical activity.¹⁴

Current evidence shows that a 1-hour education course once a week for 8 consecutive weeks leads to a decrease in hospitalization rate by almost 40%.¹⁵ Positive effects of education are also observed with regards to relatives and

caregivers.¹⁶ Web-based interfaces appear to provide new opportunities for education and quick communication between patients and medical personnel.^{17,18}

Ability to cope with the disease and associated limitations

The ability to cope with the disease and associated limitations is defined as an ability to comply with prescription medication regimen, readiness to modify lifestyle, and improvement in the emotional state and life activity.¹⁹ A review of 14 studies (unfortunately randomization was used only in few) shows that interventions aimed at improving the coping abilities of patients with advanced COPD may significantly reduce the number of hospital readmissions and the degree of dyspnea using the Borg scale.¹⁹

Better knowledge about COPD, appropriate use of medication and inhalers, and, what is especially important, improved ability to detect an exacerbation early and treat it correctly were reported in a study based on an integrated care model proposed by the WHO.²⁰ In the study, patients who had been admitted with COPD exacerbation were randomly assigned to usual or integrated care at the time of discharge. At 1-year follow-up, the 2 groups differed significantly in prescription adherence, especially regarding inhalers. In the integrated care group, 86% of subjects used inhalers correctly compared with only 24% in the usual care group.²⁰ A previous study of the same investigators revealed at 24 months that the proportion of subjects who did not require hospital readmission was significantly higher in the first compared with the second group (55% vs. 33%; $P = 0.02$).²¹

A proposed model of care in patients with advanced chronic obstructive pulmonary disease in Poland

We believe that the first step to organize care for patients with advanced COPD is to establish regional databases that would provide an overview of the problem, thus allowing to plan appropriate care (FIGURE 1).

Role of the medical coordinator Databases of patients with advanced COPD should be created in reference centers such as clinics or pulmonary wards. Databases should be managed by medical coordinators who would be also responsible for the organization of education for patients and their families (referring patients to appropriate COPD education programs, fixing appointments, etc.) and for the organization of social care (coordinating nonmedical aid, ensuring contact with volunteers or medical assistants), and emotional/spiritual support (organizing psychological and spiritual care). Coordinator's tasks, performed in cooperation with adequately trained nurses or social workers, would also include a phone call to a patient once a month regarding inhaler use and symptom control. In case of aggravation requiring readmission, coordinators would organize pa-

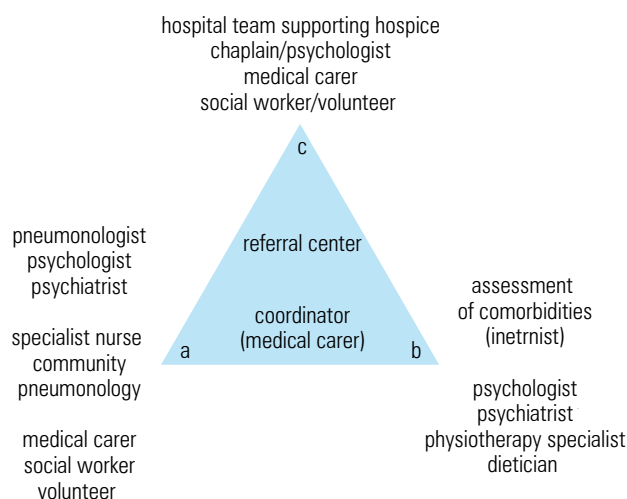


FIGURE 2 A model for integrated care in patients with advanced COPD

a GPs would consult specialists about the health condition of patients with advanced COPD. Nursing and auxiliary personnel (depending on the resources) would keep regular contact with patients and inform GPs about patient compliance and their need of support

b during hospital stay, patients would receive detailed information about their health condition including COPD and comorbidities, medical advice for stable phase, and guidelines for the management of COPD exacerbation. Hospital stay would also provide an opportunity to instruct patients about diet and physical activity

c in end-stage COPD, apart from spiritual, psychological, and social support, symptomatic treatment would be the most important part of the management

Abbreviations: see [FIGURE 1](#)

tient hospital stay in agreement with the general practitioner (GP).

Role of the general practitioner In an integrated care model, GPs would be responsible for providing permanent medical care for patients with advanced COPD ([FIGURES 2](#) and [3](#)). In the stable phase, patients would visit a GP for a check-up 4 times a year. After each hospital stay (in case of exacerbation) in a reference center, the patient, his family, and GP would receive detailed information about the current health status (COPD and comorbidities), medical advice about the stable phase, and guidelines for the management of COPD exacerbation. In case of exacerbation that does not require hospital stay, the patient would receive medical advice from a pulmonologist once a year (during 1 of the 4 planned visits). In case of COPD that is difficult to manage (persistent dyspnea, cough, cachexia), the patient would be consulted by a specialist in palliative medicine or, in case of depression, by a psychiatrist (or other specialists depending on an individual patient's need). Moreover, GPs in cooperation with social nurses (general and pulmonary), would monitor the course of treatment (especially the correct use of inhalers and inhaler adherence) and patient and family compliance with medical recommendations. In smaller centers, appropriately trained medical assistants and volunteers could be in direct contact with the patient.²²

Education There is an urgent need to design national educational programs that would be more comprehensive than the existing ones. Apart from knowledge about COPD, its management, inhaler use, and early detection of exacerbation, such programs should offer advice on how to modify lifestyle (e.g., how to quit smoking, increase physical activity, change diet) and how to cope with everyday life activities.²³ New education programs should be prepared for the families of patients with COPD that would also cover information on volunteer activity.

Spiritual and social support Patients with advanced COPD have poor quality of life.²⁴ They gradually lose self-management and mental abilities, which leads to social isolation and, in many cases, to poor relationships with the family.^{25,26} Moreover, many patients with advanced COPD experience depression and anxiety.²⁷ Similarly to patients with end-stage cancer, they need psychological and spiritual support. In many cases, material social support and the presence of a caring person are the best approach to improve the quality of life of patients and their relatives. These tasks can be performed by volunteers and social workers. Patients with end-stage COPD should receive home or hospice care.²⁸ Hospital palliative care support teams can also be helpful. Apart from palliative medicine, social, psychological, and spiritual care are also part of integrated care at the end of life. At this stage, volunteer work can support all nonmedical aspects of care for patients and their relatives. When a patient dies, both volunteers and social workers can continue to care for a bereaved family.²⁹

Implementation of the program in Poland We are currently implementing the presented concepts of palliative care of patients with advanced COPD in 2 Polish cities – Gdańsk and Zabrze. We have encountered various difficulties related mainly to the city size, organization and possibilities in the field of lung disease treatment, involvement of city councils and local health care services, or organization of voluntary work. The city of Zabrze can serve as an example. There is a university hospital with the pulmonology department. The hospital staff is involved in the implementation of palliative care in COPD; the program coordinator works in the same hospital; a hospital ambulance is available for the program procedures; a hospital physiotherapist has joined the program. There is also an outpatient pulmonary clinic and the clinic for home oxygen treatment, where patients who require hospitalization can be placed. The medical doctors from this hospital are prepared for program implementation and the educational part of the program is supported by the City Council, while organizational procedures are conducted in cooperation with the City Council's Department of Health.

The heads of health clinics in the city have been informed about the program, and an information

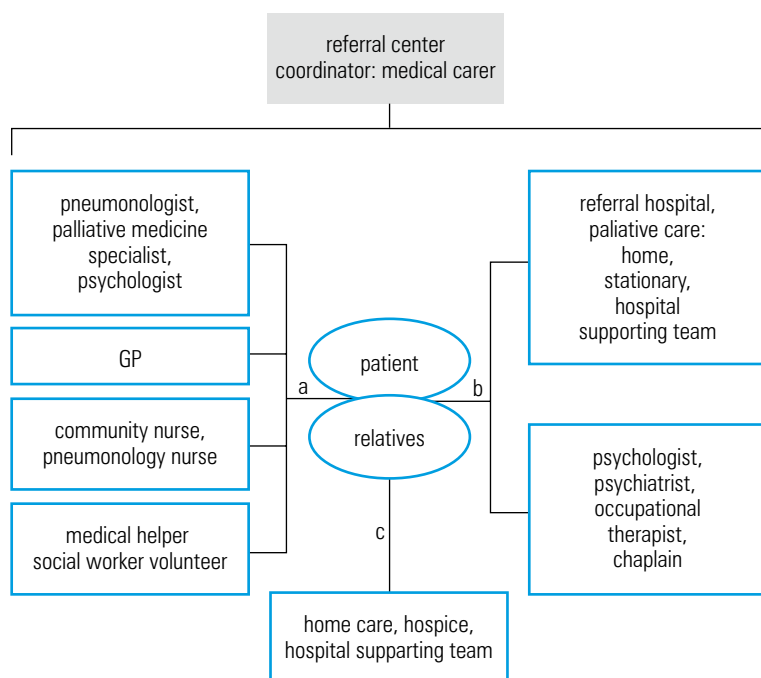


FIGURE 3 A model for integrated care in patients with advanced COPD; relationship between the patient, his family, and a team of palliative caregivers
a COPD, stabilization
b COPD, exacerbations
c COPD, end-of-life phase
 Abbreviations: see **FIGURE 1**

meeting has been organized. The City Council has launched an educational website where the program participants can obtain information about COPD and the program itself. Currently, a toll-free number is being set up for the medical staff of the coordinating hospital and for the program participants, i.e., patients, their families, and health workers. A brochure about COPD for patients and their families has been published. A database of patients with severe/extremely severe COPD is going to be created based on the records of health clinics.

It must be remembered that it is the patient who decides whether to participate in the program and he/she has to give his/her consent to send their personal information to the coordinator. Although consent forms have been distributed, few patients have applied. We believe that the main problem lies in the health clinics, which is difficult to understand because participation in the program is free for the clinic and patients remain under its supervision. In the nearest future, we are going to distribute information via the local press and television to reach wider audience among medical doctors and patients.

Another factor that hinders program implementation is not sufficient number of volunteers in the city to meet all the requirements of palliative care. The basis of the program are active, motivated volunteers. The coordinator will handle the organization of voluntary work. There is a great need for new volunteers. We hope that there will be a lot of students at the Medical University of Silesia in Zabrze that will willingly participate in the training scheduled to start in the fall, 2010, and organized by the University with the help of the Hospice Foundation from Gdańsk.

Program implementation depends to a large extent on social activity and logistic support of

the local government. So far, we have not received any support from the National Health Fund although this may change in the future when we obtain some positive results. We also hope to find other sponsors to support the program.

Conclusion We encourage the readers of the present article to voice their opinion about the organization of care for patients with advanced COPD. Please send your opinions to the following email address: klinika.alergologii@amg.gda.pl with "copd.care" in the subject line.

We hope that your suggestions will contribute to the preparation of the guidelines for integrated care and palliative care in patients with advanced COPD and other chronic respiratory diseases. This final initiative has been proposed by Professor Władysław Pierzchała, the President of the Polish Respiratory Society.

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Zintegrowany system opieki nad chorymi z zaawansowaną przewlekłą obturacyjną chorobą płuc: nowy schemat organizacyjny

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SŁOWA KLUCZOWE

przewlekła
obturacyjna choroba
płuc, wolontariat,
zintegrowana opieka

STRESZCZENIE

Przewlekła obturacyjna choroba płuc (POChP) dotyczy około 10% osób >40. rż. W zaawansowanych postaciach choroby (natężona objętość wydechu pierwszosekundowa <50% wartości należytnej) występują nasilone objawy ze strony układu oddechowego: duszność, kaszel i zła tolerancja wysiłku, którym z reguły towarzyszą zmiany ogólnoustrojowe, takie jak osteoporoza, utrata beztłuszczowej masy ciała, zespół wyczerpania, lęk i depresja. Ponadto średnio 2–3 razy w roku u chorych na zaawansowaną POChP pojawiają się zaostrzenia wymagające leczenia szpitalnego. Autorzy artykułu przedstawiają model zintegrowanej opieki nad chorym, opierający się na współdziałaniu personelu lekarskiego, pracowników socjalnych i wolontariuszy z chorym i jego bliskimi. Istotnymi elementami modelu są: intensywna edukacja, nadzorowanie leczenia oraz wspieranie chorego i jego bliskich w radzeniu sobie z chorobą i jej konsekwencjami. Pozwoli to najprawdopodobniej na zmniejszenie liczby zaostrzeń wymagających leczenia szpitalnego oraz umożliwi poprawę przebiegu choroby i jakości życia chorych.

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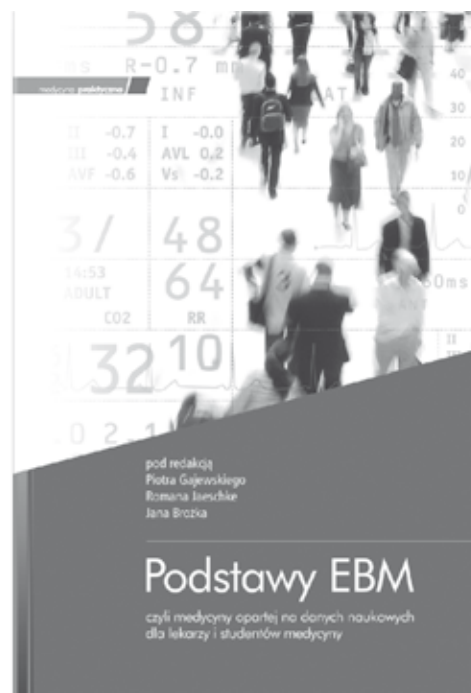
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