



## Acceptance of home support and integrated care among advanced COPD patients who live outside large medical centers



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### ABSTRACT

**Background:** Poor self-management constitutes a risk factor for COPD deterioration. Patients from rural areas located at a considerable distance from large medical centers frequently need home-support in advanced stages of the disease. Integrated care has been proposed as a comprehensive model for appropriate treatment, coordination and holistic support. The aim of the study was to assess whether home visits provided by trained assistants are needed and accepted by advanced COPD patients living in rural areas a to evaluate whether an individual short educational program can actually improve such patients' knowledge of COPD and inhaler use.

**Methods:** Thirty patients with severe or very severe but stable COPD participated in one-month home-assistance interventions twice a week.

**Results:** The total value  $\geq 70$  of SGRQ (St George's Respiratory Questionnaire) was recorded in 18 (60%) patients. At the beginning of the study, the patients' knowledge of COPD and inhalation techniques was highly unsatisfactory. Significant improvement in all items ( $p = 0.00$ ) was obtained after the intervention. The risk for poor self-management was high. All patients had at least one 'factor' that indicated the need for home-support. A total of 240 visits (100%) were completed. Patients expressed high acceptance for home-based support delivered by medical assistants twice a week for one month. No patients opposed this kind of care and most of them expressed interest in receiving it in the future.

**Conclusions:** The results suggest a compelling need for home care and demonstrate full acceptance of this kind of support on the part of advanced COPD patients.

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## 1. Background

Chronic diseases have become a significant medical, economic and social problem in the majority of developed countries. Chronic obstructive pulmonary disease (COPD), which affects more than 300 million people worldwide, is the fourth most common cause of mortality and the third cause of increased morbidity and disability. It is particularly challenging in its advanced stages (Bousquet, Dahl, & Khaltaev, 2007). A considerable number of patients (including the so-called *frequent exacerbators*) deteriorate quickly, require frequent hospitalizations and generate the highest costs for health care budgets (Pasquale, Sun, & Song, 2012; Suissa, Dell'Aniello, & Ernst, 2012). There is an evidence that long-acting inhaled

therapy is effective in the prevention of exacerbations in a high proportion of patients (Kew, Dias, & Cates, 2014). Unfortunately, poor patients' compliance and insufficient self-management may offset this effect (Bourbeau et al., 2013; Effing et al., 2007; Walters, Turnock, Walters, & Wood-Baker, 2010; Wong, Carson, & Smith, 2012). Furthermore, patients with advanced COPD living in remote areas are typically reluctant to participate in educational self-management programs or rehabilitation sessions, especially when those are offered at a considerable distance from where they live.

In Poland (38 million inhabitants), like in other countries, COPD is one of the most prevalent chronic diseases. It is estimated that more than 2 million people are affected, including approximately 10–20% cases with an advanced stage of the disease (Bednarek, Maciejewski, Wozniak, Kuca, & Zielinski, 2008; Gibson, Loddenkemper, Lundbäck, & Sibille, 2013). This means that as many as 400,000 people with severe and very severe COPD may need complex care. As is the case in the majority of Central and Eastern

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European countries, there is no well-organized support for advanced COPD patients in Poland, which particularly affects those living in small cities and in rural areas. Usually, there is no close cooperation between physicians and nurses, and access to social support is limited. The situation is made worse by poor access to non-pharmacological management, including long-term oxygen therapy, pulmonary rehabilitation or psychological and dietary support. On the other hand, patients with advanced disease are commonly depressed, isolated and unmotivated to undertake any effort to improve their health status. Additionally, people with advanced COPD in small cities and rural areas are usually less educated and have a significantly lower socioeconomic status (Golec et al., 2014) that further worsens the already poor self-management of the disease.

Recently, Polish Respiratory Society has introduced a new integrated, nurse-coordinated and home-supported model of care for advanced COPD patients who do not adhere to their treatment regimens mostly due to poor self-management (Jassem et al., 2012; Jassem, Gorecka, et al., 2010; Jassem, Kozielski, et al., 2010). The model includes an electronic registry, which is also a medical file that allows for patient monitoring in accordance with the current standards (physicians' concerns), for the coordination of team action and control of patient's compliance (nurses' concerns), as well as for home support including physical and intellectual activation (home-assistants' and social workers' concerns). We expect that this model of care, which is a novel option for patients with advanced COPD, will reduce the exacerbation rate, improve the patients' quality of life and reduce hospitalization costs.

Home-based care in Poland for the past decade has focused on advanced cancer patients. In contrast to end-stage cancer patients, in advanced COPD patients the trajectory and prognosis of the disease are more unpredictable (Claessens et al., 2000; Murray, Kendall, Boyd, & Sheikh, 2005). In consequence, they may not need external (i.e. not family) support at home and may not accept it as willingly as cancer patients. Since the introduction of home support for COPD patients is a novel proposal, there is no information so far whether COPD patients will accept such a solution. It may be a particular concern in small cities and in rural areas, where people are commonly reluctant to accept new procedures or to trust unfamiliar people, including home care assistants.

In order to assess the feasibility of an integrated model of care in the above-mentioned areas, we designed a study of patients' needs and their acceptance of home support. This project was carried out over the period of one month in Chojnice, a small town of 40,000 inhabitants, and in the surrounding rural areas, where COPD patients are typically less educated, heavily nicotine addicted, and more prone to self-management problems.

The aim of the study was to assess whether home visits by trained assistants supporting patients' self-management and stimulating their physical and intellectual activity are needed and accepted by patients with advanced COPD. The secondary aim was to evaluate whether an individual short educational program can improve patients' knowledge of COPD and inhaler use. We also attempted to define the profile of an advanced COPD patient requiring home support.

## 2. Methods

### 2.1. Participants

Inclusion criteria for the study included severe or very severe COPD diagnosed according to the GOLD guidelines 2010 ([www.goldcopd.com](http://www.goldcopd.com)), whereas the exclusion criteria comprised the lack of informed consent, pregnancy, end stage of any chronic disease, severe dementia or disorders that significantly affected patients' compliance.

Patients were recruited between December 2010 and May 2011 from the pulmonary outpatient clinic at the Specialist Hospital in Chojnice (Pomerania, Poland). We recruited patients in a stable state who expressed their informed consent and met all the eligibility criteria. The study was approved by the Bioethics Committee of Medical University of Gdańsk, Poland (NKEBN/304/2010).

The scheduled duration of the study was one month. The initial assessment included evaluations by a physician and by a nurse coordinator

(Fig. 1). Participation in the study did not impact COPD or co-morbidity treatments (the latter if applicable), unless their deterioration or exacerbation was diagnosed.

Every patient was visited by a home-assistant for two hours twice a week over four weeks. Each visit included educational activities, inhalation control, a discussion of patients' current problems, simple physical exercises (controlled by pulse oximetry) and a conversation on any subject chosen by the patient (a structured schedule is available on request from the authors). In total, eight visits were planned for each patient. Patients' educational program implemented during each visit addressed the following issues: (1) epidemiology, COPD risk factors, general information on pathophysiology and diagnosis – two meetings; (2) diagnosis and treatment of nicotine addiction, negative impact of cigarette smoking on health – two meetings; (3) appropriate use of inhalers and nebulizers, the importance of rehabilitation – two meetings; (4) symptoms of exacerbation, rescue treatment – two meetings. Specific educational issues to be raised during a particular visit were printed on the reverse side of the report used by home assistants during visits.

Before the start of the study, home assistants (medical assistants' college graduates) participated in a training workshop (two sessions of approximately three hours each). They met pulmonologists, nurses, psychologists, priests and social workers, and could freely discuss their doubts with them.

During the entire study, psychological support was provided to both the patients and home assistants. Additionally, during the study two meetings for the whole staff were organized to address the current problems.

The need for home care for all patients was assessed by nurse coordinator. This included: (1) quality of life (QoL) assessment performed before the beginning of the study using the St. George Hospital Respiratory Questionnaire (SGRQ) validated for Polish patients (Kuzniar et al., 1999); (2) evaluation of patients' knowledge of COPD (Table 2) and (3) establishing risk factors for poor self-management. The latter included high scores (> 11) in the Beck Depression Inventory – Short Form, low income (disability pension, supplementary benefits, no income) and the lack of family support. Eventually, extremely high SGRQ scores ( $\geq 70$ ), the lack of basic knowledge of COPD and the presence of any of risk factor for poor self-management were considered as indicative of the need for home care.

In order to evaluate whether the individual short course delivered by home-assistants changed patients' knowledge of COPD and inhaler use, another assessment of their knowledge was performed by the nurse coordinator at the end of the study.

Patients' approval for home-based support was monitored by the nurse coordinator during the study and for one month after its completion. The final assessment was done using the 5-point Likert scale. All patients

### I. Preliminary stage

educational sessions for home assistants (2X)

patients' inclusion in the study by physician

### II. Intervention

assessment by physician, psychologist and nurse coordinator

home-based visits of medical assistants (8X)

discussion meetings with the entire staff (2X)

### III. Final stage

final discussion meeting with medical assistants

final assessment by nurse coordinator

Fig. 1. Study schedule.

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