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

Short title: Integrated care in advanced COPD outside large medical centres

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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 centres 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 ≥ 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.

Key words: integrated care, advanced COPD, coordination, home assistance

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 J, Dahl R, Khaltaev N. 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 MK, Sun SX, Song F. 2012, Suissa S, Dell'Aniello S, Ernst P. 2012). There is an evidence that long-acting inhaled therapy is effective in the prevention of exacerbations in a high proportion of patients (Kew KM, Dias S, Cates CJ. 2014). Unfortunately, poor patients' compliance and insufficient self-management may offset this effect (Bourbeau J, Saad N, Jourbet A et al. (2013; Effing T, Monninkhof EM, van der Valk PD et al. 2007; Walters JA, Turnock AC, Walters EH, Wood-Baker R. 2010; Wong CX, Carson KV, Smith BJ. 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 M, Maciejewski J, Wozniak M et al. 2008; Gibson GJ, Loddenkemper R, Lundbäck B, Sibille Y. 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 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 M, Skórska C, Mackiewicz B 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 E, Batura-Gabriel H, Cofta S et al. 2012; Jassem E, Gorecka D, Krakowiak P et al. 2010; Jassem E, Kozielski J, Gorecka D 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 MT, Lynn J, Zhong Z et al. 2000; Murray SA, Kendall M, Boyd K, Sheikh A. 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.

Methods

Participants

Inclusion criteria for the study included severe or very severe COPD diagnosed according to the GOLD guidelines 2010 (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 approx. 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 (19); (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 (≥ 70), the lack of basic knowledge of COPD and the presence of any of risk factor for poor self-management was 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 were also asked whether they would accept such home-based support in the future. Three answers were possible: 'yes,' 'no' and 'I am not sure.'

Statistics

The mean and median values were used to express the results. The results obtained at the beginning and at the end of the study were compared using the Chi-square test. P-value <0.05 was considered statistically significant.

Results

Patients

Thirty six consecutive patients with severe or very severe COPD in the stable period of the disease diagnosed by the pulmonologist (MK) and confirmed by spirometry after the inhalation of SABA, were invited to participate in the study. Six patients were excluded – one did not sign the informed consent form, another one was excluded by the physician due to schizophrenia which made appropriate contact impossible, one moved to another locality, one resigned because his spouse opposed his participation in the study, and the remaining two resigned because the time of the study did not fit their life schedules. Finally, 30 patients were subjected to the analysis (Table 1), 11 of whom lived in a rural area.

Need for home care

The results of SGRQ were obtained from the whole group before the start of the study (Fig. 2). Mean values for symptoms, activity and impact, were 81, 81, and 63, respectively. The mean total score was 71 ± 14.3 and the median was 75 (range: 24–91). The total value ≥ 70 , expressing the need for home-support, was recorded in 18 (60%) patients.

Patients' knowledge of COPD was highly unsatisfactory at the beginning of the study (Table 2). Six patients (30%) were scored negative for any of the five items. Only one woman was able to give a correct answer to all COPD-related questions and to inhale appropriately. A significant improvement in all items was obtained after one month intervention (Table 2).

In the whole group, the risk for poor self-management was high. Only six patients (30%) were scored ≤ 11 in the Beck questionnaire, nine had very low incomes and seven had no support from the family. For each patient, there was at least one 'factor' indicating the need for home-support (Appendix 1).

Acceptance of home-based support

6 of the 36 patients invited to participate in program were excluded from the study group. One did not sign the informed consent form, which means at least a 3% non-acceptance. Patients who actually participated in the program accepted 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 (Fig. 2A). No patients opposed this kind of care and most of them expressed interest in receiving it in the future (Fig. 2B).

Discussion

The study demonstrated high acceptance of integrated care combined with home support among advanced COPD patients. Moreover, home support appeared to effectively address the patients' gaps in the knowledge of the disease and inhaler use.

The introduction of home assistants into the integrated model of care was expected to improve the self-management capacity of advanced COPD patients, to support their adherence to physicians' orders and drug intake compliance, to educate them, and to stimulate their physical and intellectual activity. A recent systematic review of nine randomized studies performed between 1987 and 2006, including almost 1,500 patients with various stages of the disease, demonstrated that regular home visits delivered by outreach respiratory nurses or

respiratory health workers substantially improved the quality of life of COPD patients (Wong CX, Carson KV, Smith BJ. 2012). However, this did not translate into a reduced rate of exacerbations that required hospitalization. On the other hand, an earlier study showed a 46% decrease in the number of readmissions due to exacerbations in patients with a high level of daily physical activity, enrolled in an integrated care program (Garcia-Aymerich J, Farrero E, Felez MA et al. 2003). Additionally, the study by Casas et al. (2006) demonstrated a significant difference in the exacerbation rate between patients given integrated care compared with those managed in a traditional way. Further, a study by Baumann et al. (2012) demonstrated that low-intensity long-term outpatient rehabilitation improved the quality of life and physical capacity in COPD patients. Hence, home assistance, including physical activity by medical assistants, may be effective in improving the course of COPD.

We assumed that patients from rural areas need home support due to their extremely low QoL, lack of knowledge of COPD and high risk for poor self-management induced by the level of depression, low income and being single.

Surprisingly, the results of SGRQ were poorer than in other groups of COPD patients. The quality of life assessed by this test in other European countries in large controlled clinical trials (conducted commonly in large centres) ranged between 32 and 43 (Jones PW, Brusselle G, Dal Negro RW et al. 2011; Seemungal TA, Donaldson GC, Bhowmik A et al 2000). A high proportion of patients with total scores ≥ 70 in the present study showed a particularly negative impact of COPD on their quality of life. It is highly likely that these results obtained from patients from rural areas reflected their poor self-management and compliance as well as inferior access to health care. Hence they confirm the need for home support among patients with advanced COPD who live in small cities and in rural areas. Furthermore, patients' knowledge of COPD was unsatisfactory. It may reflect a complex situation: lower educated

population in the studied area, older age and lower intellectual ability of individual patients, but also simply the lack of proper education in remote areas. Advanced COPD patients are rarely eager to improve their knowledge of the disease. The results of the study suggest that the educational program delivered during home visits significantly improved the patients' knowledge of COPD and the management of exacerbations (Table 2). Obviously, a one-month program is too short to give them a solid educational basis, and a continuous education would be required. However, we proved the usefulness of home-assistants as first-line educators. Our findings are in line with a Spanish study that demonstrated that even one year after the completion of a relevant program, patients who were given integrated care were significantly better educated than those treated 'conventionally' (Garcia-Aymerich J, Hernandez C, AlIonso A et al. 2007).

A meta-analysis of 14 studies demonstrated that appropriate self-management may decrease the risk of hospitalization due to COPD exacerbation (Effing TW, Bourbeau J, Vercoulen J et al. 2012). On the other hand, depression may increase three-year mortality in advanced COPD patients (Fan VS, Ramsey SD, Giardino ND et al 2008). Wong et al. (2008) demonstrated that being single was associated with an 18% higher readmission rate due to COPD exacerbations compared with individuals who have a supportive spouse. 23 out of 30 patients in our study had no support from their families. These findings may also confirm the need for home care delivered to depressive patients, to those with insufficient support from the family and those who poorly manage their disease. In our study, all patients had at least one reason for home care, while the majority showed a high need for home support.

Within one month of the study, all the scheduled visits (240) were completed. The results showed a high acceptance of home-based support delivered by medical assistants on the part of advanced COPD patients. They closely cooperated with the nurse coordinator and the chest

physician (Fig. 2). Patients declared that they would welcome a similar kind of care in the future.

In summary, the study showed that patients with advanced COPD who live in small cities and in rural areas have an extremely poor quality of life, are insufficiently educated regarding their disease and have low self-management skills. This suggests a pressing need for home care. However, there are no detailed criteria for the 'need of home support' in Poland and for that reason they should be developed in future studies. Moreover, advanced COPD patients highly appreciated home care delivered by medical assistants. Such staff may be easily recruited from among social support workers after an intensive educational training program in COPD.

Conflict of interest

No authors of this study have personal, professional, or financial conflict of interest to declare.

Funding

The study was supported by intramural grant ST-553 (Medical University of Gdansk, Poland)

Ethical approval

Ethical approval was given by the Bioethics Committee of Medical University of Gdansk, Poland (NKEBN/304/2010).

Highlights

- Poor self-management constitutes a risk factor for COPD deterioration. Patients from rural areas located at a considerable distance from large medical centres frequently need home-support in advanced stages of the disease.

- The home support for COPD patients is a novel proposal, 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.
- The need for home care for all patients was assessed by nurse coordinator
- Patients with advanced COPD expressed high acceptance for home-based support delivered by medical assistants twice a week for one month

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Figure 1. Study schedule

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

Table 1. Patient characteristics, n=30

Characteristic	Number
COPD	
severe	20 (75%)
very severe	10 (15%)
Sex	
males	21 (70%)
females	9 (30%)
Age	
Mean/median	66/64
Range	54 - 83
Comorbidities†	
>2	12 (40%)
>3	7 (23%)

† The most prevalent were arterial hypertension and heart diseases

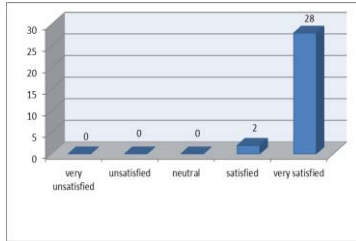
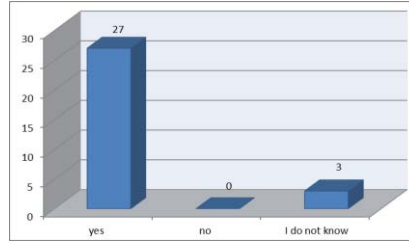
Figure 2. Assessment of the patients' acceptance of home-based visits**A****B**

Figure 2A. Acceptance of home-based care delivered during the study (*very unsatisfied, unsatisfied, neutral, satisfied, very satisfied*)

Figure 2B. Acceptance of home-based care in the future (*yes, no, I don't know*)

Table 2. Knowledge of COPD among advanced COPD patients

Question	Right answer (%)	Wrong answer (%)	Right answer (%)	Wrong answer (%)	P
	Before intervention		After intervention		
What is the name of your disease? (Q1)	3 (10)	27 (90)	27 (90)	3 (10)	0.00
What medicines are you using? (Q2)	10 (33)	20 (67)	21 (70)	9 (30)	0.04
What is a COPD exacerbation? (Q3)	2 (7)	28 (93)	18 (60)	12 (40)	0.00
What is the rescue medicine? (Q4)	18 (60)	12 (40)	28 (93)	2 (7)	0.00
Proper inhalation technique	18 (60)	12 (40)	29 (93)	1 (3)	0.00

(Q5)					
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Appendix 1. Need for home-support assessed by QoL, knowledge of COPD and risk factors for poor self-management

No	SG RQ	Q 1	Q 2	Q 3	Q 4	Q 5	B	I	F	G	A	FEV 1
1	72	2	1	2	1	1	30	3	2	M	56	37
2	75	2	1	2	1	2	11	2	2	M	70	25
3	52	2	2	2	2	2	12	3	2	M	72	40
4	68	2	2	2	2	2	14	2	1	M	75	37
5	70	2	2	2	2	1	18	2	2	F	60	41
6	75	2	2	2	2	2	5	3	1	M	55	44
7	88	2	2	2	2	1	33	2	2	M	79	40
8	71	2	2	2	1	1	19	2	2	M	65	44
9	53	2	2	2	2	2	13	2	1	M	67	44
10	87	2	1	2	1	1	20	2	2	F	59	44
11	24	2	1	2	1	2	13	2	2	F	66	44
12	90	2	1	2	2	1	9	3	1	M	54	20
13	64	2	2	2	1	2	14	2	2	M	83	25
14	77	2	2	2	1	1	4	5	2	M	58	41

15	67	1	1	1	1	1	8	3	2	M	61	50
16	85	2	2	2	1	1	28	4	2	M	57	51
17	43	2	2	2	2	1	20	2	2	M	64	44
18	77	2	2	2	1	2	20	4	1	M	59	46
19	67	2	1	2	1	1	16	2	2	F	63	53
20	74	2	1	2	1	1	28	2	2	M	62	17
21	78	2	2	2	2	2	20	3	1	F	79	41
22	87	2	2	2	2	1	11	2	2	M	71	26
23	71	2	2	2	1	2	9	2	2	M	83	33
24	78	1	2	2	1	1	21	2	2	F	61	14
25	65	2	2	2	1	1	17	3	2	M	64	25
26	82	2	2	2	1	2	18	3	2	F	74	23
27	87	2	2	2	1	1	3	2	2	M	71	16
28	80	2	2	1	2	1	16	2	1	F	69	26
29	67	2	1	2	2	2	13	3	2	M	57	20
30	81	1	1	2	1	1	19	3	2	F	57	17

SGRQ – St Georges Respiratory Questionnaire: total score

Q1-5 – questions from table 2: 1=yes, 2=no

B – Beck Depression Inventory (score)

I – income: 1=salary, 2=retirement pension, 3= disability pension, 4=supplementary benefit,
5=no income

F – family support: 1=yes, 2=no

G – gender: F=female, M=male

A – age

FEV1 – forced expiratory volume in 1 second: % of predictive value

Shaded area – high need of home support

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