

Self-care 3 months after attending chronic obstructive pulmonary disease patient education: a qualitative descriptive analysis

Camilla Askov Mousing¹
Kirsten Lomborg²

¹School of Health Sciences, Randers School of Nursing, VIA University College, Randers, Denmark;

²Department of Public Health, Nursing Science, Aarhus University, Aarhus, Denmark

Purpose: The authors performed a qualitative descriptive analysis to explore how group patient education influences the self-care of patients with chronic obstructive pulmonary disease.

Patients and methods: In the period 2009–2010, eleven patients diagnosed with chronic obstructive pulmonary disease completed an 8-week group education program in a Danish community health center. The patients were interviewed 3 months after completion of the program.

Findings: Patients reported that their knowledge of chronic obstructive pulmonary disease had increased, that they had acquired tools to handle their symptoms, and that the social aspect of patient education had motivated them to utilize their new habits after finishing the course. The data indicate that patients need a period of adjustment (a “ripening period”): it took time for patients to integrate new habits and competencies into everyday life. Talking to health care professionals focused the patients’ attention on their newly acquired skills and the research interview made them more aware of their enhanced self-care.

Conclusion: Patients’ self-care may be enhanced through group education, even though the patients are not always able to see the immediate outcome. Some patients may require professional help to implement their newly acquired knowledge and skills in everyday life. A planned dialogue concentrating on self-care in everyday life 3 months after finishing the course may enhance patients’ awareness and appraisal of their newly acquired competencies.

Keywords: COPD, education program, patient knowledge, patient perspective, patient skills, ripening period

Introduction

This article explores patient perspective on the efficacy of an 8-week group patient education program in a Danish community health center. The program was specifically designed for patients diagnosed with chronic obstructive pulmonary disease (COPD). The authors focus on how the program influenced the ability of patients to perform self-care.

COPD represents a major public health problem worldwide and its burden is expected to increase in the next decade.¹ COPD is characterized by progressive, irreversible impairment of airflow through the lungs and airways. Symptoms include increased sputum production, shortness of breath, fatigue, and cough.² The importance of the patient’s role in treatment and the significance of self-care and self-management to optimize treatment and prevent further disease progression is recognized. Barlow et al³ concluded in a review that there is a growing body of evidence that, when compared with no intervention (eg, standard care), self-management approaches can provide benefits for participants. These benefits concern knowledge, performance of self-management behaviors, self-efficacy, and aspects of health status. A review by

Correspondence: Camilla Askov Mousing
VIA University College, Randers School
of Nursing, Jens Otto Krags Plads 3,
DK-8900 Randers C, Denmark
Tel +45 8755 2166
Email caac@viauc.dk

Coster and Norman⁴ of 30 Cochrane systematic reviews showed that assisting patients to become more knowledgeable about their condition, and providing them with basic skills to manage their illness on a daily basis, can result in physical and psychological patient benefits, and, in some cases, it can also reduce their dependence on service use. However, Coster and Norman's⁴ review concluded that there are too few well-controlled studies to draw consistent conclusions on the strength of the interventions for COPD or epilepsy or to identify the necessary components of successful programs. A Cochrane review by Effing et al⁵ concluded that COPD patient self-care ability training may reduce the number of hospitalizations for COPD. Effing et al⁵ showed that patients evaluated the fitness component of training positively. Patients had a perception of increased exercise capacity and were positive about the social aspect of group training. Nonetheless, research on patient education, COPD, and self-care indicates a conflict between the documented effect of patient education and patients' experiences in everyday life after attending patient education.⁵⁻⁷ Attention has been given to gaining insight into patients' perceptions of their situation.⁸ By listening to patients when they talk about their disease, health care personnel can gain knowledge and better understand the experience of living with COPD. Therefore, it seems relevant to study the effect of patient education from the perspective of the patient. The identification of patients' priorities concerning elements that enhance self-care can complement existing knowledge. This may help health care professionals develop new strategies and methods to strengthen COPD patients' ability to perform self-care activities.

In this study, self-care is defined as the patients' own resources and ability to live a healthy life in agreement with

their own preferences and wishes. The aim of the study was to obtain faithful and detailed descriptions that would reflect the view of patients living with COPD in everyday life after attending the 8-week group patient education program (Table 1).

Group sizes in the studied patient education program were seven, eight, and twelve participants. In Denmark, most health care services are free of charge. Accordingly, participation in patient education was financed by the municipal health services and included no user fees. Each session lasted 2 hours, and time was divided into two parts: education and physical fitness.

Methods

In the period 2009–2010, the authors conducted a qualitative descriptive analysis^{9,10} of semistructured individual and group interviews. This method offered the opportunity to analyze the interview data in layman's terms and to represent the patient perspective.

Sample

Six consecutively selected patients who had completed the 8-week group patient education program and who were capable of expressing themselves in an interview were invited to participate in an individual 1-hour interview. Five patients accepted. All participants from two subsequent COPD patient education groups (n = 15) were invited to participate in a 90-minute group interview. Six patients accepted and two group interviews were completed.

Data collection

Semistructured interviews were conducted 3 months after attending the patient education program, which included physical training and educational elements (see Table 1).

Table 1 Outline of the 8-week group patient education program

Session type	Content	Elements	Provider
Group	Disease education	Information about COPD, lung anatomy and physiology, pathology, medications, smoking cessation	Physician and specialist nurse
		Symptom management, management of breathlessness, prevention and management of exacerbations, reduction of anxiety, improvement of self-care ability, energy-conserving techniques, nutrition	Specialist nurse, nutritional adviser, physiotherapist, occupational therapist
		Motivation to stay active and information about the benefits of physical exercise	Physiotherapist
Individual	Physical training	Exercises aimed at improving endurance and strength, fitness training, breathing techniques, pursed-lip breathing, cough exercises, relaxation	Physiotherapist
	Goal setting	Individual goal setting	Occupational therapist
	Tests	6MWT, FEV ₁ , FVC, COPM, weight, BMI, oxygen saturation, blood pressure	Physiotherapist and occupational therapist

Abbreviations: 6MWT, 6-minute walk test; BMI, body mass index; COPD, chronic obstructive pulmonary disease; COPM, Canadian Occupational Performance Measure; FEV₁, forced expiratory volume in the first second; FVC, forced vital capacity.

The specific time frame for collecting data was chosen based on the following considerations: (a) after 3 months the patient education program would still be within patients' recent memory and (b) at this point patients had 3 months to integrate what they had learned into everyday life. Based on this, the authors expected that patients would be able to report how attending the group patient education had affected their everyday life with COPD. The five patients who accepted the invitation to participate in an individual interview were interviewed either at home ($n = 1$) or at the health center ($n = 4$), according to their preference. The authors strived to collect detailed accounts of these participants' thoughts, attitudes, beliefs, and knowledge. The six patients who accepted the invitation to participate in a group interview were interviewed in two groups of three. Group interviews took place at the health center. The primary goal of this method was to obtain data from group interaction during participants' discussion. Although groups and individual interviews are independent data collection methods, their combination can be advantageous to researchers, as complementary views of the subject of interest may be generated.¹¹ All interviews, individual and group, were audio recorded.

A semistructured interview guide (Table 2) was developed for use with both individual and group interviews. The interviewer's function was to encourage participants to talk freely about the topics in the interview guide and to tell their stories in their own words. Questions were open-ended; for example, patients were encouraged to describe a typical day before attending COPD patient education. The interview guide included suggestions for follow-up or probing questions that were designed to elicit more detailed information

when necessary, as described by Polit and Beck.¹² Even though the interviewer constantly challenged her own preliminary analytical data interpretation and the participants were encouraged to talk freely and to add other reflections, no new themes, statements, or remarks emerged during the last two interviews. Therefore, the interviewer had a clear sense of data saturation after five individual interviews and two group interviews.

All patients completed various medical testing of pulmonary function, as shown in Table 1. The results of these tests are not included in this study.

Ethical considerations

Permission to conduct the study was obtained from local administrators at the health center and the Danish Data Protection Agency (j. nr. 2010-41-4902). All participants were informed orally and in writing about the study, voluntary participation, confidentiality, and anonymity in the study report. All patients provided signed consent prior to participation.

Data analysis

The interviewer transcribed the audio-recorded interviews verbatim, including repetitions, notes on pauses, and emotional expressions such as laughter or sighing. The interviews were transcribed in Danish and the findings and citations were subsequently translated into English. Data were analyzed according to Sandelowski's^{9,10} description of the method in two phases: "getting a sense of the whole" and "developing a system." First, all interviews were read and reread to obtain a comprehensive image of each case. Second, line-by-line coding was conducted,

Table 2 Interview guide

Main questions	Probing questions
Can you describe your background knowledge of experiences of living with COPD before attending patient education?	Describe in your own words a typical day before attending COPD patient education
How was your everyday life with COPD before attending COPD patient education?	What concerns did you have about your condition?
In what ways has attending COPD patient education affected your everyday life?	Describe in your own words how attending the patient education program has influenced your everyday life
	Was your physical function affected?
	If so, in what ways?
	How did that affect your everyday life?
	Have you changed your everyday routines? If so, in what ways?
	What are your thoughts about the future with COPD?
	How do you handle COPD symptoms?
Regarding the organization and content of the patient education program, was there a particular theme in the program that you experienced to be the most important to your outcome?	In what ways were you able to influence the patient education program?
	What was the best part of attending patient education?
	Did you have any negative experiences of attending patient education?
	What do you think about the group sessions as part of the program?

Abbreviation: COPD, chronic obstructive pulmonary disease.

revealing 14 codes. These codes were subsequently synthesized and categorized into four major themes and related subthemes. Each theme was explored further using comparative analysis. The software program NVivo (v 8; QSR International Pty Ltd, Doncaster, Victoria, Australia) was used to sort and organize the data.¹³ Three of the four major themes were considered to be important for self-care in everyday life of patients with COPD; these three themes are described in the Results section.

Results

Study participants were eight females and three males aged between 51 and 75 years (median age, 67.1 years). Participants had suffered from COPD symptoms for 1–8 years and were diagnosed with moderate to severe COPD. Exploration of the participants' experiences of living with COPD revealed detailed information about their abilities to perform self-care after attending the COPD patient education program. Three themes were explored: (1) ability to handle COPD symptoms, (2) the social aspect of patient education, and (3) the time aspect (eg, "ripening period"). The last of these themes was considered the most surprising finding.

Ability to handle COPD symptoms

Most participants reported that information they learned about COPD pathology and medical treatment of COPD symptoms increased their insight into and knowledge of COPD. This increase in insight and knowledge had resulted in a sense of calm and a feeling of security with respect to understanding their symptoms. Participants said that the visual explanation of the disease and its symptoms with a poster was important for their learning process, as it enabled them to visualize their lungs and to understand what happened within the lungs during dyspnea attacks. The patient education program influenced the participants' thoughts about the future in a positive direction.

You have sort of imagined your lungs to be like ... ah ... a big lump of coal ... and absolutely useless, but as it turns out there are still a lot of opportunities. (Informant D)

The participants reported that they had learned to use breathing and relaxation techniques when dyspnea occurred. They explained that they became aware of their body signals and they focused on breathing techniques when coughing and during dyspnea attacks. Some of them felt that the acquired tools were now an integrated part of their lives.

I am very conscious about it. If I feel there is something on the way, I learned to take deep breaths and breathe out again through my mouth ... gently and easy does it [...] everything we learned at the health center is at the back of my mind, they helped us to handle it ... without feeling that it is a struggle ... that's how I feel, anyway. (Informant B)

Learning to handle COPD symptoms also involved being able to make plans and show cautiousness in everyday life. Being aware of potential exacerbating factors in everyday life enabled the patients to act appropriately. Participants explained that they had become more attentive to dust, smells, candles, heated rooms, and so forth, which in turn enabled them to take responsibility for their health and avoid aggravating factors.

Most participants reported influencing their dyspnea by staying in good physical shape. After only a few weeks of participation in the patient education program, some participants experienced progress, with gradual improvement in their walking skills to the point that they could walk home after a training session.

Well, to start with, I can walk now ... I am much faster now and can walk further without having to slow down.... So it has really helped me, that is for sure. (Informant D)

Before, I couldn't visit my mother, who lives on the other end of town – because it was uphill. Now I can walk all the way. The program has made me stronger and I know what to do if I have difficulty breathing. The program has changed my life. (Informant G)

The social aspect of patient education

Some participants reported that COPD had meant they could not fulfill their former role in their circle of acquaintances. Out of necessity they had to decline events or get-togethers, which gave them a feeling of great sacrifice. The patient education program gave participants the ability to meet other COPD patients, providing an opportunity where all participants could put themselves into one another's situation. They all knew what it was like to live with COPD and in that way they felt they were met with understanding. For example, they did not have to spend a lot of effort explaining what it felt like when they were "having a bad day." In the group they experienced a sense of connection to one another.

I felt like an outsider – outside a group of people that I have known for over 40 years and it was really distressing.... Yes,

I have been very upset about that, but now I am with others who don't ask me if anything is wrong – like when you suddenly have to sit down, can't manage any more – there are no questions asked – they feel like that themselves or perhaps even worse, yes. (Informant D)

All participants viewed the feeling of solidarity as an important factor in the patient education program. They looked forward to seeing one another again and enjoyed the feeling of sharing something mutual. This feeling of mutuality was a motivating factor both during the 8-week patient education program and afterwards, as eight participants continued to exercise in COPD groups once or twice weekly. Two participants continued exercising at a local gym instead, as their everyday life was not compatible with the training hours for the COPD groups. Only one participant did not continue exercising, because of poor public transportation that made it difficult to get to the training sessions.

You don't just stop going – there are people waiting for you ... no, you don't [...] and they are good friends and they mean a lot – and it is motivation I am talking about now. (Informant D)

Because you feel obliged to.... If I was on my own, it would be much easier to phone and say that I wasn't coming – but we keep an eye on each other, don't we? (Informant A)

The feeling of solidarity helped the participants maintain their new exercise habits, and the joint feeling gave them the opportunity to continue using one another's knowledge and expertise in other settings.

The time aspect: ripening period

The participants suggested that the general practitioner should recommend education programs to their patients at an earlier stage of COPD. By attending patient education early after the diagnosis of COPD, patients could look forward to improvements in everyday life in the years to come. Nine of the eleven participants expressed a belief that they would experience better years to come as a result of attending patient education.

There is no guarantee that we will live longer, but we will live better and will be able to take part ... yes, I think so. (Informant B)

To integrate new information and habits obtained from the patient education program into everyday life took time;

for some participants, the effect was not evident to them until attending the interview 3 months after finishing the program.

Most participants experienced an immediate benefit and were able to verbalize how the education program had improved their everyday life. Participants explained that they had acquired greater endurance and calmness and that they felt more secure handling their COPD-related cough and dyspnea. They had positive thoughts about the future with an everyday life full of newly integrated habits such as exercising, planning of daily activities, and attentiveness to their bodily signals and surroundings. Even though these participants reported an immediate experience of these positive effects, attention to these improvements increased during the interview session. Some participants felt that their benefit from the patient education program was clarified during the interview and that the interview opened their eyes to the outcome. They found it was helpful to talk about their everyday life with COPD either one-on-one or in small groups. Being interviewed made them aware of situations where they had changed their behavior and highlighted the significance and importance to their daily life.

We get a little down in the depths, and things like that ... it's not something I do every day ... but it has been there and I've used it [the knowledge and tools of patient education] ... without really thinking "what is it I'm doing?" (Informant B)

Three participants stated that attending patient education had not influenced their ability to perform self-care. Despite this, two of the three stated that they had initiated different activities during and after attending the patient education program. These initiatives included exercise, both with other COPD patients and with spouses. During the interview session one of the participants who questioned the influence of attending the patient education program suddenly exclaimed that attending had, in fact, made him change his smoking habits. It appeared that he had, among other things, reduced his daily number of cigarettes smoked from 80 to none. It appeared that the patients reported various new initiatives that made the researchers aware of their increased self-care abilities. Strikingly, the patients were not always able to identify these positive behavior changes themselves.

Discussion

In agreement with results from previous research,⁶ participants in the current study reported an increased knowledge

of COPD and its symptoms. Together with the acquisition of new tools to handle their symptoms in everyday life following the patient education program, this new knowledge improved the participants' self-care ability.

The social aspect

The examined education program was carried out as a group intervention. Results from the study showed that participants found it rewarding to interact with other COPD patients. That all participants expressed feeling relief at being able to interact with equals – people to whom they did not need to explain themselves – indicates that COPD patients spend a lot of energy explaining their symptoms and disease to others. This has been discussed in detail by Halding et al.^{14,15} In the current study, participants underlined the social aspect of interaction at the training sessions. For example, the opportunities available to chat with other participants between the exercise sessions and of being inspired by watching others work through the training. Thus, it appears that the social aspect of patient education not only increased patients' motivation for physical training but also their social fellowship with other COPD patients. In the current study, the participants valued this fellowship as an equally beneficial aspect of the training sessions. Because of the social interaction and the support among patients, the group aspect is considered to be important to the overall objective, adding a stimulating and even competitive aspect to the training, as described by Monninkhof et al⁶ and O'Shea et al.¹⁶ This implies that a lack of significant physiological improvements does not necessarily mean there is no benefit from the training session. A perception of improved function, even if it cannot be demonstrated quantitatively, may be important to patients diagnosed with COPD and should not be dismissed as worthless.¹⁷

Ripening period

This study demonstrates that patients need a ripening period following patient education. Bourbeau et al⁷ have stated that an isolated increase in knowledge is not enough to improve everyday life for patients with COPD. Rather, patients need to learn how to integrate the illness into everyday life. This study highlights a new aspect to the integrative process, suggesting that the interview dialogue itself can increase awareness among patients of the effects related to the patient education program. During the interview sessions in the current study, it became clear that the interviewer functioned as a mediator, encouraging the participants to tell their personal stories and consequently contributing to their realization of new narratives, as described by Bailey.¹⁸

Participants voiced two perceptions concerning the degree to which they felt that attending patient education had changed their everyday life with COPD. While eight participants stated that they had experienced great benefits from the patient education program, three stated that attending the education program had not influenced their daily life. These contradictory statements indicate that an effect of patient education may be achieved even when all patients do not recognize it. Although some patients were still unable to visualize the complete outcome of the training program after the interview process, they stated that the interview dialogue had initiated reconsideration of their personal outcome. This indicates that talking to health care professionals initiates reflexive behavior. By asking questions about everyday life with COPD, medical professionals may be able to lead the COPD patient to reflect upon their personal situation and outcome. Having this in mind, a 3-month post-training dialogue intervention may be important for patients to gain insight into their own situation and thereby maintain motivation and new habits.

It must be recognized that every patient is unique and will require different periods of time to acknowledge changes in self-care abilities and to integrate the newly acquired information and skills into everyday life. Therefore, follow-up initiatives should focus not only on maintaining the obtained knowledge and skills but also on patients' awareness of the education program's effect.

Study limitations

This study has some limitations. Because the health center staff contacted the patients and the interviewer had information only on patients who had completed an informed consent document, it was not possible to identify which of the patients attending the education program had declined to take part in the current study. The sample size was limited but there was reasonable variety seen in age and COPD stage among participants. The participants were eight female and three male patients. This gender distribution is different to that commonly found among COPD patients. In this study there were no gender differences in the patients' experience of attending patient education. Given the sample size, findings may be considered preliminary. Therefore, the authors suggest intervention studies be conducted in a larger and more representative group of COPD patients.

Conclusion

The patients in this study were positive about the education program. Attending patient education influenced their

self-care ability. The findings of this study indicate that patients with COPD need a ripening period to integrate what they learn from participating in an education program into everyday life. Talking to health care professionals may support this process of ripening. Therefore, the authors suggest follow-up consultations with health care personnel after patient education. Such consultations may also provide information for identifying patients who could benefit from additional follow-up interventions.

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Disclosure

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