

Reluctance of patients with chronic obstructive pulmonary disease in its early stages and their families to participate in a partnership-based self-management trial: A search for explanation

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Abstract

Recruitment, the process of accessing, screening, selecting and retaining participants for research remains a challenge. In a randomized controlled trial, partnership-based self-management intervention for patients who have chronic obstructive pulmonary disease (COPD) in its initial stages, and their families, a theoretical framework developed for patients with an advanced COPD and their families was modified and implemented in a primary care context. In contrast to recruitment to the original study where 4% decline participation, in this study 25% of the potential patients declined participation. Although participants were encouraged to bring a family member, only 25% of them did so. The main reason for not being accompanied by a family member was that patients did not want anybody accompany them. Those who had quit smoking were more often accompanied by a family member compared to those who smoked. Reviewing the literature, the most compelling explanations for non-participation are shame and self-blame due to smoking, and that potential participants may not have envisioned any benefits from participating since they might not have realized that they had COPD. An alternative recruitment process needs to embrace the situation that potential participants find themselves in and which takes account of the issues at stake.

Keywords

Chronic obstructive pulmonary disease, families, recruitment, randomized controlled trial, self-management, shame

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Introduction

The effectiveness of healthcare intervention research is a major issue in health sciences.¹ To test the effectiveness of such studies, a sufficient number of participants is essential. Recruitment, the process of accessing, screening and selecting participants for a study, as well as retaining participants through the research, is a challenge. Recruitment in family intervention studies is an even greater task.¹

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Family-focused interventions in the context of chronic obstructive pulmonary disease (COPD) are scarce,² despite evidence of the effectiveness of family-based interventions for individuals with various chronic diseases and the complexity of COPD and the impact it has on families.^{3,4}

COPD is one of the most common chronic diseases worldwide and its prevalence is on the rise. COPD is primarily related to tobacco smoking.⁵ The disease develops incrementally over many years without people necessarily becoming aware of it. As such, the disease may progress to an advanced stage with irreversible health damage before the person finally seeks healthcare.⁶ Most effort in healthcare and research has been put into developing care for patients with advanced stages of COPD. The proportion of participants who do not accept invitations to self-management trials for people with COPD is around 40–50%.^{7,8}

In a randomized controlled trial (RCT), partnership to enhance self-management for patients who have COPD in its initial stages, and their families, a theoretical framework was implemented for a partnership-based nursing practice which had been developed for the patients' families and the patients who have an advanced lung disease.⁹ The patients were in principle recruited into the study but were asked to have a family member accompany them. One-quarter of potential patients declined to participate and one-third were excluded, giving a 41% recruitment rate. Moreover, only 25% of those participating in the study were accompanied by a family member. That changed the nature of this originally family-based RCT into a more patient-focused trial.

In this article, we attempt to understand why a considerable proportion of people with COPD in its early stages did not accept the invitation to participate in a partnership-based self-management programme for patients and family members.⁹ The characteristics of that study are contrasted with its predecessor, which was developed for patients with an advanced stage of COPD and their families.^{10,11}

Partnership-based self-management research programmes

Theoretical framework

The theoretical framework of *partnership as practice* is the foundation for the studies. It was originally developed for clients living with complex health problems.^{12,13} Then it was adjusted to the needs of

people with advanced COPD and their families^{10,11} and finally for people with COPD in its initial stages and their families.⁹ The partnership framework reflects a world view that transcends the binary view of health as the absence of disease and suggests a way to address the meaning of health circumstances with the lung disease. Creating the meaning of the health circumstances is regarded as a core issue to address in conjunction with other more conventional topics, for instance, those related to the physical and social conditions of patients. When holistically focusing on health problems related to the patients, predetermined goals or achievements are not laid out beforehand other than to understand and foster possibilities for enhancing the health experience. The Global Initiative for Chronic Obstructive Lung Disease (GOLD) clinical guidelines are the foundation for the disease treatment.⁵

A *dialogue* with participants is central in the partnership's theoretical framework. The dialogue is a process characterized by an unconditional positive regard, trust and respect for each individual's and family's values and ways of being. The dialogue is open, caring, mutually responsive and non-directive. Events and issues are comprehended in a context which gives them significance – meaning. The meaning *emerges* or *evolves* in a collaborative effort of all participants. In the dialogue, there are three suggestive themes for exploration: *family involvement*, *living with symptoms* and *access to healthcare*, with the primary goal being enhancement of the *health experience* in its entirety.

Distinctive characteristics of the studies

Comparison of the characteristics of the study of patients with COPD in its initial stages⁹ and the one with patients at an advanced stage of COPD and their families^{10,11} reveals that the main differences are the context of the studies, the seriousness of the health condition of the patients and the research designs (see Table 1), with consequent different emphases in the use of the theoretical framework.

Context. The context of the study of patients with advanced COPD was an already established outpatient clinic for lung patients at a tertiary hospital. Patients were invited to join the study when their health situation had become serious. They started attending the outpatient clinic, and receiving home visits and phone calls at the same time that they were invited to participate in the study. The patients continued receiving care after the study ended. The study

Table 1. Characteristics of patients and recruitment for the studies of partnership-based self-management for patients with COPD in its initial versus advanced stages and their families.

	Beginning COPD (N = 100 ^a)	Advanced COPD (N = 50)
	% (n)	% (n)
Description of research		
Design	Randomized controlled trial	Retrospective and prospective
	Qualitative	Qualitative
Study period	12 months	18 months
Invitation	Posted letters from patients' physician and a phone call from the research nurse	Face-to-face by a clinical nurse specialist
Context	University research institute	Outpatient hospital clinic and patients' homes
Structure	3–4 family conversations and one group meeting over 6 months	First weekly appointments, then indefinitely upon need
Data collection	Patients and family members	Patients
Patients		
<i>Stage of COPD</i>		
GOLD I and II	69 (69)	28 (14)
GOLD III and IV	31 (31)	72 (36)
Age (mean)	59 years	68 years
Gender		
Women	54 (54)	78 (39)
Men	46 (46)	22 (11)
Current smokers	60 (60)	28 (14)
Knowing existence of disease	24 (24)	100 (50)
Rejecting invitation	25 (72/291)	4 (2/52)
Exclusion	34 (100/291)	0 (0/52)
Retention		
	84 (100/119)	84 (42/50)
	1 quit	0 quit
	3 died	3 died
	1 too sick	5 too sick
	14 lost to follow up	
Family members		
Retention	60 (18/30)	Not documented
	12 lost to follow up	

COPD: chronic obstructive pulmonary disease; GOLD: Global Initiative for Chronic Obstructive Lung Disease.

^aIn this study, 119 patients started participation. Characteristics of patients are presented for those 100 who finished the study. An exception is the calculation of retention, where the number of those who started the participation was used (119 patients and 30 family members).

of people with COPD in its initial stages was conducted in a university research institute. The programme had a fixed schedule and a definite ending. Patients and families in the control group were offered a shortened version of the self-management programme at the end of the study.

Seriousness of COPD. The different stages of the COPD as well as higher age of the patients with an advanced disease required different emphases in the treatment sessions. For instance, the way and the extent to which living with symptoms were addressed varied

with regard to their severity, the individual recognition of their existence and their ramifications in daily life. For people with COPD in its early stages, the notion of bringing the progression of COPD to a halt might have prevailed, while for the person with an advanced disease the predominant emphasis could have been to optimize medical treatment and the possibilities for living a meaningful life.

The component *access to healthcare* was addressed differently between the studies. For a person with an advanced disease, the most important issue might have been to secure timely access to healthcare, while

Table 2. Motives of patients to include or not to include family members in the partnership-based self-management research for patients with COPD in its initial stages.

	Include ^a		Not include ^a
Help patient	27 (15)	Did not want to have anybody	74 (57)
Help family member	16 (9)	Did not have one	4 (3)
Know more about disease	35 (19)	No one had time	21 (16)
Contribute to science	22 (12)	No one willing to	1 (1)
Total	100 (55)	Total	100 (77)

COPD: chronic obstructive pulmonary disease.

^aPatients could mark more than one item.

for the person with the disease in its early stages, knowledge of and access to regular exercise and rehabilitation could have been of most importance.

Research designs. The research design in the study on patients with an advanced disease was retrospective and prospective with no control group. There was a qualitative study as well.¹¹ The inclusion criteria were GOLD stages II–IV as diagnosed in the medical record and repeated hospitalizations during the previous months.

The study on people with COPD in its initial stages had the RCT design. Potential participants were recruited from primary healthcare settings and the offices of private lung physicians, using the following diagnosis categories: J40-44, J96, Z71-72 and F17. Inclusion criteria were individuals aged 45 to 65 with mild and moderate COPD (grades II and III) as the primary disease. In the invitation letter, it was explained that the study was a clinical, family trial and that the participation of a close family member was requested.

Recruitment rates

One-quarter of potential participants rejected the invitation to the study on patients with COPD in its initial stages⁹ compared to a negligible proportion in the study on patients with an advanced disease.¹² The recruitment rate of family members was 25%. Family members of patients with an advanced disease were not participants in the study but joined patients at the treatment sessions.

Reasons given by patients with COPD in its early stages for not accompanying family members in the study

Half of the patients rejecting participation did not give a reason for the refusal (see Table 2). For those who gave a reason, the two most common ones were being

too sick and not having time. The two most common motives for being accompanied by a family member were that the family member wanted to know more about the disease and to help the patient. The main reason given by patients for *not* being accompanied by a family member was that they did not want to have anybody with them.

Explanations for low participation of patients and family members in the study with patients in the early stages of COPD

Although the recruitment rate in this intervention study is higher than that in some previous studies,^{7,8} the reasons that patients with COPD had for not participating in self-management research deserve scrutiny. Several possible explanations have been given, particularly the patients' characteristics, attitudes and experiences, acquaintanceship with healthcare professionals, and the nature of the intervention.¹

Nicotine addiction and the realization of COPD

The origins of COPD are predominately associated with cigarette smoking. The majority of people with COPD smoke or have smoked at some point in time.⁵ Addiction to nicotine means that the person's brain needs nicotine regularly and that he/she may smoke more than intended, despite indications and understanding of detrimental effects.¹⁴ The person may not acknowledge his/her own addiction or may minimize the threat that smoking has on health.³ Nevertheless the addiction dominates the person's life since the person does not control his/her smoking. This may be seen by people with COPD as a failure, both as regards not having self-control and not being able to live up to standards in society for a healthy life.¹⁵ In

this study, all participants had smoked at some point in time, and 60% were still smoking.⁹ Those who had quit smoking were more often accompanied by a family member compared with current smokers, which might suggest that being a smoker may hinder willingness to participate in self-management research.

In the study, one-quarter of the participants were unaware that they had COPD.⁹ Similar findings have been repeatedly reported elsewhere.^{16,17} Since the majority of the patients were at stages of COPD which were expected to give considerable symptoms, other issues were likely to come into play. Difficulties in recognizing the significance of having COPD and its accompanying long-term consequences have been described previously.¹⁸ A tendency has also been reported in people with COPD, even with an advanced stage of the disease, *not* to consider themselves as a 'person with COPD'.¹⁹ Symptoms of COPD, particularly breathing problems and restrictions in physical activity, develop gradually. Therefore, people may slowly adjust to the symptoms without recognizing them as indicators of COPD.^{6,20} Hence, people may view having COPD as 'a way of life',^{21,22} irrespective of a compromised health condition. The presence of acute symptoms, even a full-blown exacerbation, might ultimately lead to a situation where people with COPD are, for the first time, really confronted with their health problem.^{6,20,23}

Experiential aspects of patients with COPD

The experiences of people with COPD in its initial stages are gaining increasing attention, particularly shame and self-blame.^{20,23} Shame may be intensified by self-blame – a situation which is commonly associated with smoking^{24–27} – to the extent that these people may feel they have to deal with the disease on their own²⁰ and even refrain from participation in research programmes.¹⁹ Conversely, there are studies showing that being diagnosed with COPD stimulates patients to take actions to improve their health.^{18,20} Still, the influences of shame and self-blame might hinder the process of seeking assistance for smoking cessation as well as participating in a research programme where smoking and its consequences are the main focus.^{18,19}

Families

Family members of patients with COPD have been described as the 'hidden client',²⁸ despite indications of the impact that COPD has on families.^{3,4} Conversely,

support from family and friends of people may encourage those with COPD to live a smoke-free and healthier life.²⁰ The majority of the patients participating in this study did not want to be accompanied by a family member despite the convincing request that was made in the invitation letter. Non-participation by family members was quite disappointing, given the fact that studies of self-management programmes for families living with COPD are almost non-existent² and family-based interventions for individuals with several chronic diseases are effective.²⁹

Strained communication about COPD has been revealed in families, particularly when the disease is in its early stages and the symptoms are largely invisible.^{4,30} At this point in the disease process, patients may struggle to hide their symptoms from family members, while at the same time they may make efforts to convince the family members that the symptoms exist, for example, when unable to live up to expectations of performing household chores.³⁰ Addiction to nicotine may be difficult for family members to understand. Strong personal views on smoking may cause anger and frustration. Families blame people with COPD for the disease and for smoking, which leads to self-blame in the patients themselves.²⁷ Tension in families may last beyond the point in time when the patient has quit smoking and the smoking as such is no longer an issue,³ leading to limited success of family members in supporting each other.¹⁹

Acquaintanceship with healthcare practitioners

Recruitment may be influenced by whether potential participants are acquainted with the inviting physician/healthcare professional, and consequently it is subject to potential influence from that person, as well as the expectations of the potential participants of gains and losses in such relationships.³¹ To maximize our professional connections, we established collaboration with respected healthcare institutions, and the participants received an invitation letter from their lung/primary care physician.³² The extent to which that influenced participation is not known.

Reports on disquieting experiences with healthcare professionals in the context of smoking are numerous^{24,25,33} and may influence recruitment to research. There is a tendency for healthcare professionals to blame patients and to consider them responsible for their condition, to label them as smokers and

to repeatedly remind them of the connections between COPD and smoking even though they have stayed away from smoking for several years.^{26,34} Disturbing experiences of interacting with healthcare professionals may therefore interfere with potential participants' interest in participating in a self-management research. The extent to which that happened in this research is unknown.

Nature of the intervention

Participation in self-management programmes requires ongoing and active engagement, time and energy.³⁵ The participants in the experimental group were not only expected to be engaged in a comprehensive and time-consuming programme but to reveal their strengths and weaknesses to others, particularly in relation to current or previous smoking. In this study, the participants were also expected to understand new information and to consider an invitation to give up smoking, if they were still smoking. There was also an implied expectation that participants might change their approach to and expectations of important aspects of their daily life. An opportunity to consider influences on the progression of COPD was offered which was expected to motivate potential participants. However, plausible benefits might have looked quite different to those invited to join the study since they might not have been aware of any significant or potential health problems.³⁵ The partnership-based approach which was meant to non-judgmentally embrace the health situation of each participant/family may, therefore, not have come through in the invitation to the study.

Inconvenient timing, travel costs, location and being treated in a group are concerns that have been documented regarding non-participation in self-management research programmes,^{1,31} none of which seemed to matter to the potential participants in this research. In the few cases where participants indicated that travel costs would be a hindrance, they were offered reimbursement. The timing of appointments was made convenient to the participants and meetings were rescheduled as needed to adjust to individual needs and preferences. Mobility problems and ill health have been reported as barriers in some research programmes.¹⁹ Ill health was in fact an explanation which a few invited persons gave for non-participation. Most, however, should have been able to easily move around.

Alternatives to the recruitment process

The non-readiness of potential participants to participate in the RCT of initial stage patients with COPD and their families might lead one to conclude that since it was their choice not to participate, that decision should be respected and they should be left alone until a later time when the disease has progressed and they have become aware of it and its ramifications. However, the non-readiness may have been a consequence of the nature of the tobacco addiction to preserve "a *need* of the body [to continue to smoke], and an *automatic action* of the body, rather than merely an intellectual choice" (p. 9, italics in original).³ It is likely that several people with COPD in its initial stages do not realize how serious the disease is and what may be ahead for those having it. Consequently, we as healthcare professionals are obliged to continue to make efforts to reach out to them and invite them into research.

The most promising alternative recruitment process is to have face-to-face contact with potential participants where a respectful, trusting and welcoming approach is taken in person-centred conversations, instead of using a posted invitation letter.¹ There are, however, limited options to gain face-to-face access to individuals and families with a member who has COPD in its early stages. The primary reason is that the patients may not yet be regular clients of the healthcare system since the disease has not developed to a stage that requires stringent medical management. Still, recruiting participants face-to-face in regular appointments with physicians/other healthcare professionals either in primary care centres or lung physician offices is crucial. Under such circumstances, the potential participants would be seeking healthcare for an active health problem. The situation would be related to respiratory issues or connected to likely co-morbidities of COPD³⁶ for which a disease diagnosis with spirometry needs to be made. In cases where the person has a confirmed COPD diagnosis, the clinician would refer the patient to a research team that would simultaneously on-site, face-to-face, or in a telephone conversation present the study in more detail. Including the family in research would need to be raised in these conversations, preferably right at the beginning. An option might be to have one more step in the recruitment process, that is, to invite the family member later when the patient has become more capable and has a deeper understanding of his/her health circumstances.

Conclusion

A concerted effort needs to be made to develop an effective recruitment process of patients in self-management studies for people with COPD in its initial stages and their families. Recruitment efforts need to embrace the situation that potential participants find themselves in; to recognize the nature and consequences of nicotine addiction and its companions shame and self-blame. The fact that a considerable number of potential patients may not realize that they have COPD also needs to be acknowledged. The conflict that might exist between family members that may make patients unwilling to be accompanied by a family member needs to be accounted for in the recruitment process. Therefore, a stepwise recruitment process might be necessary.

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