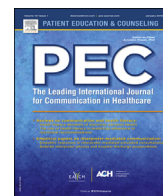




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# Patient participation during and after a self-management programme in primary healthcare – The experience of patients with chronic obstructive pulmonary disease or chronic heart failure

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### ABSTRACT

**Objective:** Patient participation is facilitated by patients' ability to take responsibility for and engage in health issues. Yet, there is limited research as to the promotion of these aspects of patient participation in long-term healthcare interactions. This paper describes patient participation as experienced by patients with chronic obstructive pulmonary disease (COPD) or chronic heart failure (CHF); the aim was to describe if and how a self-management programme in primary healthcare influenced patient participation.

**Methods:** Patients who had participated in a self-management programme were interviewed in nine focus groups (36 patients). Data was analysed using qualitative content analysis.

**Results:** Patients described equality in personal interactions, opportunities to share and discuss, and a willingness to share and learn to facilitate patient participation in a self-management programme. Consequently, patient participation was promoted by a match between the individuals' personal traits and the context.

**Conclusion:** Features facilitating patient participation by means of sharing and assimilating knowledge and insights should be included in self-management programmes and in the care for patients with COPD and CHF.

**Practice implications:** A self-management programme can complement regular primary care regarding enhanced understanding of one's disease and support patient participation and the patient's own resources in self-management.

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## 1. Introduction

It should be recognised that patients' preferences, abilities and experiences vary, and that opportunities for patient participation in healthcare interactions need to be flexible [1]. A healthcare that emphasises patient participation is known to also facilitate patients' ability to engage in self-management activities in everyday life [2,3]. Interventions should be tailored to enhance the individual patient's opportunities for participation [4,5].

There is a growing number of patients with long-term conditions, such as chronic obstructive pulmonary disease (COPD)

and chronic heart failure (CHF) [6]. These patients need self-efficacy to engage in symptom management, requiring the healthcare professionals to secure the patients recognise their primary role in maintaining physical functions and activities [7]. Therefore, patient participation need to be included in self-management interventions [8,9]. Living with COPD and CHF is characterised by multiple symptoms, of which many are similar, such as fatigue and respiratory difficulties [10]. Like most patient with long-term conditions, they are cared for in Primary Health Care (PHC): a first level contact that provide evidence based care, where diverse professions support the patient in preventive actions, like life style changes [6,11]. Consequently, health professionals in PHC have a key role in providing opportunities for COPD and CHF patients to optimize their everyday life [6].

Patient participation is advocated by the World Health Organisation, in particular in PHC [6]. However, different

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perspectives have been applied on patient participation [2]: to be interchangeable with shared decision making [12]; to be a relationship in nursing care [13]; or, from the perspectives of patients, a process that include mutual respect and equality [14,15]. Patients describe patient participation as a broad concept, that include dialogue; mutual sharing of knowledge; being included in the planning of care; establishing agreed health goals; and managing self-care [15], which is agreed upon by patients with COPD and CHF [16]. Patients with CHF have, among others, suggested that patient participation include a shared responsibility for self-management and rehabilitation [2,3], and to entail an active attitude [2].

While self-management interventions have the potential to impact on patients active participation [17], a further understanding of when interventions targeting patients with COPD or CHF influence patient participation is needed [18,19]. More specifically, interventions where knowledge is shared between patients as peers have not been fully explored, but would add knowledge with regards to facilitators and barriers to patient participation.

An intervention study including a self-management programme for patients with COPD and CHF was recently performed in Swedish PHC [20]. The programme, informed by Bandura's self-efficacy theory [16], was designed to increase self-efficacy in relation to fatigue and exercise, to decrease symptoms and limitations in functioning, and to increase overall health [20]. To meet the objectives, techniques such as performance mastery, modelling, interpretation of symptoms, and social persuasion, was used [21]. The three-month intervention included six group sessions (with three patients diagnosed with COPD and three patients with CHF in each group), where the patients could share their health issues and experiences of self-management. The groups were led by resident staff: a district nurse and a physiotherapist, with special training for this assignment. The patients' individual action plans, which included their current condition and health goals, formed the agenda for each group's sessions.

Recognising what patients suggest is patient participation, the programme could potentially enhance opportunities for: knowledge and skills to be shared, experiences of problems and goals to be recognised, ones health problems being addressed in a shared process, and enhancements in self-care ability [15,16]. The aim of this study was to describe if and how a self-management programme in primary healthcare influenced patient participation.

## 2. Methods

### 2.1. Design

This study had a qualitative design where the data, collected in focus group interviews (FGIs) [22], was analysed using qualitative content analysis [23]. FGIs were chosen due to prospects of collecting data in pre-existing temporary groups, created for the subject of interest, wherein the patients were familiar with discussing [22]. The participants were recruited from a multi-centre randomised controlled trial carried out between September 2013 and September 2015. Patients diagnosed with COPD or CHF, experiencing one or more of six symptoms (dyspnoea, fatigue, sleep difficulties, cough, tingling in hands or feet, or pain) were recruited, and randomised to participate either in a group intervention, or to receive regular care only, at their usual PHC centre (9 centres and a total of 14 intervention groups). For patients with COPD, an additional CHF diagnosis were allowed as well. Patients with a recent myocardial infarction (< 3 months); oxygen therapy; and patients with assessed cognitive impairment were excluded.

### 2.2. Participants and procedure

For this FGI study, a strategic sample [24] of nine intervention groups, from PHC centres in rural and urban areas, and intervention groups with leaders managing an intervention for the first time (n = 5 groups) and the second time (n = 4 groups), were included. Information about the study was provided to the patients either at their final group meeting in the self-management programme or sent by mail (n = 48). A total of 36 patients, that is 75% of the invited patients, agreed to take part in the FGIs (see Table 1). Reasons for declining participation were a perceived temporary deterioration in health, coinciding healthcare appointments, or a move from the area. As a result, each FGI group comprised 2–6 patients.

The FGIs took place less than a month after the self-management programme was completed. A research team not engaged in the intervention, performed the FGIs; the first author (KL) moderated the interviews and the second author (MH) took notes to verify the transcripts details. A study-specific semi-structured interview guide was used: pilot-tested in a separate FGI prior to the study, and found satisfactory. The patients were solicited to describe and discuss patient participation. An initial question about the meaning of the term "patient participation" as experienced by the patients themselves introduced the subject for discussion. The main question was then asked: When thinking about patient participation and the programme you have taken part in – what is your experience? Finally, a question was posed on experiences of, and reflections on, patient participation after the programme was completed. Hence, no definition of patient participation was presented, but the patients were free to ponder the concept from their own perspective. Probes were used only to trigger the patients to elaborate further on their experience, for example, "When you say . . . would you mind sharing what you think?" At FGI no. 7, the researchers recognised that the participants' discussions provided for an understanding of a common experience, and as no new data on patient participation emerged in the final two focus group interviews, a sufficient source for analysis was settled. The FGIs were digitally recorded (range 41–87 min, mean 73 min), and later transcribed verbatim, resulting in a total of 206 pages of single-spaced text. The Regional Ethical Review Board in Uppsala, Sweden, provided ethical approval for the study (number 2012/189).

### 2.3. Data analysis

The transcribed interviews were analysed using inductive and later deductive content analysis [23]. To become immersed in the data, and to get a sense of the whole, all authors read the interview transcripts. A naïve understanding was presented by KL, and discussed in the team of authors. A structured analysis was then performed, encompassing all FGI transcripts, by inductively identifying all aspects that related to patient participation in general. Corresponding meaning units were assembled and labelled with codes. The codes formed subcategories, by means of identifying and abstracting similar content with internal consistency, regarding the patient participation phenomena. These subcategories formed an unconstrained

**Table 1**  
Demographics of the participating patients.

	COPD	CHF
Women	15 patients	5 patients
Age mean (min–max)	73 (67–86)	75 (62–88)
Men	7 patients	9 patients
Age mean (min–max)	73 (57–83)	76 (69–85)

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