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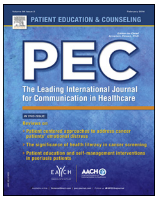

Review article

A scoping review of the literature on benefits and challenges of participating in patient education programs aimed at promoting self-management for people living with chronic illness

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ABSTRACT

Objective: To give a comprehensive overview of benefits and challenges from participating in group based patient education programs that are carried out by health care professionals and lay participants, aimed at promoting self-management for people living with chronic illness.
Methods: We searched 8 literature databases. Full text articles meeting the inclusion criteria were retrieved and reviewed. Arksey and O'Malley's framework for scoping studies guided the review process and thematic analysis was undertaken to synthesize extracted data.
Results: Of the 5935 titles identified, 47 articles were included in this review. The participants experienced the programs as beneficial according to less symptom distress and greater awareness of their own health, improved self-management strategies, peer support, learning and hope.
Conclusion: A substantial evidence base supports the conclusion that group based self-management patient education programs in different ways have been experienced as beneficial, but more research is needed.
Practice implications: The insights gained from this review can enable researchers, health care professionals, and participants to understand the complexity in evaluating self-management patient education programs, and constitute a basis for a more standardized and systematic evaluation. The results may also encourage health care professionals in planning and carrying out programs in cooperation with lay participants.

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1. Introduction

An increasing number of people are living with chronic illness, much due to longer life expectancy and improvements in medical treatment [1]. People whose life are affected by chronic conditions play a key role in taking care for themselves, and the self-management of chronic illness can be demanding [2,3]. They must face medical management of their condition, create and maintain new meaningful life roles regarding jobs, family and friends; and cope with the emotions of having a chronic condition [4]. The consequences of all the daily choices a person with chronic illness has to take in managing his or hers condition can affect health negatively [5].

In accordance with the pioneering work by Bodenheimer [2] and Lorig [3], self-management education focuses on skills the participants can use to identify and address problems related to living with a chronic illness. Self-management education programs are based on the view that greater confidence in the participant's capacity to make life-improving changes yields better clinical and other outcomes. There are a wide range of different types of self-management education programs. They vary in terms of content, form and how lay participants are involved in planning and carrying out the programs, often described as complex interventions [6,7]. However, despite long term focus on strengthening user involvement in developing health care services, this is not a common practice within the health care system [8,9]. Consequently, self-management education programs are most often initiated and carried out by health care professionals without involvement of lay participants [5,7,10–19].

Overall, the aim of self-management education programs is to enable the participants to understand the illness process, acquire skills related to medical management, as well as to provide education on how to live a complete life with illness. Several self-management education programs (e.g. American Chronic Disease Management Program, Expert Patient Programme in the United Kingdom and Learning and Mastery Courses in Norway) are based on the ideal that professional knowledge and patient experience are equally important, implying that health care professionals and lay participants cooperate in planning and carrying out the programs [20].

There is some evidence from a few systematic reviews of the literature that self-management education programs may improve knowledge of illness, health related quality of life and some psychosocial areas [5,7,10–19]. Most of the programs in these reviews had not involved lay participants in planning or carrying out the program. In addition, the interpretation of the findings is limited by heterogeneity of studies, in terms of population studied, type and duration of the programs, variety of outcomes measured and differences in timing of assessment. To date, no review has addressed the full scope of studies that have investigated different aspects of what participants have experienced and reported as beneficial and challenging in co-created patient education programs aimed at promoting self-management.

Therefore, the aim of this scoping review is to give a comprehensive overview of benefits and challenges from participating in group based patient education programs co-created and carried out by health care professionals and lay participants, aimed at promoting self-management for people living with chronic illness.

More specifically, the following questions are addressed:

1. What study aims, design, measures and outcomes are described in the literature?
2. Which type of patient education programs are described in the literature (aim, target groups, settings, modules and involvement of lay participants)?
3. What benefits and challenges are associated with participation in the programs from the perspective of the participants, as reported in the literature?

2. Methods

Due to the relative infancy of research on different aspects of what participants in patient education programs have experienced and reported as beneficial and challenging, the research questions were best answered by evidence from a range of data sources, and a scoping review was considered appropriate. Scoping reviews "*aim to rapidly identify the key concepts underpinning a research area and the main sources and types of evidence available, and can be undertaken as stand alone projects in their own right, especially where an area is complex or has not been reviewed comprehensively before*" [21]. Scoping reviews are relevant to disciplines with emerging evidence, because the researchers can incorporate a range of study designs, and generate findings that can complement the findings of clinical trials [22]. This scoping review followed the five-stage framework proposed by Arksey and O'Malley's [23] and further enhanced by Levac [22].

In stage 1, the study group defined our initial research questions. The study group consisted of two health care professionals with long experience from the field of practice (KF & TK), one person representing a patient association who has

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