



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

experience from living with chronic illness and (KFW), one co-researcher (MH) trained in research methods and with experience from living with chronic illness, and one researcher who were project investigator (US).

In stage 2, relevant studies were identified based on the research questions and purpose of the study. For this review, we conducted a systematic search of the following electronic databases from May 2008 to May 2015: MEDLINE, EMBASE, PsychINFO, AMED, CINAHL, SweMed+, ERIC, Cochrane Library Online. In each database, we searched for every term listed below in the database thesaurus and used the free text/key word method. Searches included the following terms; varying synonyms and related concepts; alone and in various combinations:

- Diagnose/health: chronic disease/illness, lung diseases, asthma, pain, fatigue syndrome, irritable bowel syndrome, osteoporosis, HIV infections, arthritis, diabetes mellitus, hypertension, myocardial ischemia, heart failure, stroke, neoplasms, fibromyalgia, mental disorders, obesity, pulmonary, COPD, cancer.
- Self-management education program: patient education, learning, teaching, health education, health promotion, counseling, self-management.
- Involvement of lay participant: user/patient/client/consumer participation, group processes, group structure, group dynamic, group intervention, peer group, sensitivity training groups, shared knowledge, insider knowledge, user/patient/client/consumer involvement, patient education course, lay led, peer led, patient led.

Inclusion criteria were research-based articles in English and Scandinavian in peer-reviewed journals that had investigated the benefits and challenges from participating in patient education programs aimed at promoting self-management for people older than 18 years of age, living with chronic illness. Furthermore, this had to be reported by the participants as well as planned and carried out by health care professionals and lay participants in cooperation. We also searched the reference lists of the included studies. The search strategy was deliberately broad, and we searched the databases with no language or study design restrictions to reduce the chance that relevant studies were missed and to prevent language bias. The search strategy was developed by the study group in collaboration with a librarian, and the searches were conducted by the first author (US).

Stage 3 entailed the process of study selection. This included reviewing abstracts and refining the search strategy and the inclusion and exclusion criteria. The search of the online databases yielded 5935 titles (Fig. 1). We excluded 5763 after reading the abstract, as they did not meet the inclusion criteria. Of those remaining, 172 were retained in full text; after reading the articles 113 were excluded from this subset, as they did not meet the inclusion criteria. The most common reasons for exclusion were that lay participants were not involved in planning or carrying out the programs, or this was not described (67/113), different form or content of the program (21/113), not reporting on benefits or challenges from participation as reported by participants (14/113), not chronic illness (3/113) or not research-based study (8/113). In summary, we retained 59 articles from this review. Of these, 12 studies were reviews of the literature; therefore 47 research-based studies were included for review. The first author (US) and co-researcher (MH) have, independently, screened all titles and abstracts and read all the full text articles. Disagreements about study inclusion were solved by discussion in the study group to reach consensus. These discussions have also helped us to clarify and revise the inclusion and exclusion criteria.

To evaluate the studies, we used the Mixed Method Appraisal Tool developed by Pace [24] for the critical appraisal of the quality

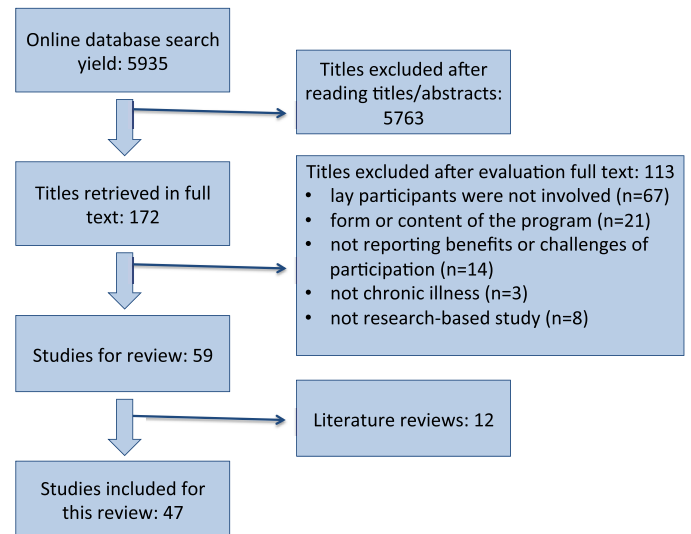


Fig. 1. Studies included in the review.

of qualitative, quantitative, and mixed methods research studies (Appendix A in Supplementary material). The quality assessment was conducted by two independent reviewers (US and MH), both familiar with qualitative and quantitative research.

Stage 4 entails charting the data of included studies. In an iterative process the first author (US) and co-researcher (MH) extracted information from each relevant publication about the aim, population, program, outcomes, role of lay participants, methods, results, and the author's conclusions.

Stage 5 entails collating, summarizing and reporting the results. In this review we made narrative summaries of both qualitative and quantitative results being assessed in parallel processes and finally included in a joint synthesis of results on a study level presented as themes [21,25]. This was a largely deductive process guided by our research questions and resulted in seven themes with descriptions of benefits and challenges. Characteristics of the studies and self-management education programs were also described. The summarizing of the data was mainly carried out by the first author (US) and co-researcher (MH), but validated by the co-authors (TK, KF and KFW) who examined the relevance and applicability of the categories.

3. Results

Results are presented under the following headings: characteristics of the studies, characteristics of the self-management patient education programs, benefits and challenges.

3.1. Characteristics of the studies

3.1.1. Aims and design

A total of 47 research-based studies were included in this scoping review. Of these studies, 15 were conducted in the USA, 12 in Norway, seven in the UK, five in Australia and two in Ireland. In addition, one study was conducted in the following countries: Argentina, Canada, Denmark, the Netherlands, Sweden and Turkey. Of the 47 research-based studies, 12 used qualitative methods [26–37], 28 used quantitative methods with randomized controlled design [38–51] or descriptive design [52–65], and seven studies used mixed methods [66–72]. Quantitative approaches relied heavily on questionnaires or surveys that evaluated physical-, social- and psychological domains, knowledge of conditions and treatments, self-efficacy, self-management

behaviors, coping and empowerment. Most of these studies with a quantitative design had evaluated effect, as reported by the participants, before and immediately after participation in a self-management education program [45,67,69], between one month and ten months [40,44,45,47–52,57,60–63,66,68,70], and one year [38,39,41–43,46,53–56,58,65]. Only one study had evaluated changes over five years after participation [59]. Qualitative methods included individual interviews and focus groups. The qualitative studies were mainly aimed at describing what participants in different programs had experienced helpful, useful or challenging.

3.1.2. Participant characteristics

A total of 7003 participants were included in the 47 research-based studies. Of the total number of participants, 2187 (31,2%) were men and 3162 (46,6%) were women. Gender was not reported in 7/47 (14,9%) studies, representing a total of 1654 (23,6%) participants of unknown gender. The mean age of the participants was 55,2 years (not including 20/47 (42,6%) studies that did not list mean age or age at all).

3.1.3. Classification of studies by chronic condition

A breakdown of the 47 studies by chronic condition is provided in Table 1. The largest number of studies included in this review focused on mental illness (13/47), followed by diabetes (8/47). Several studies did not focus on one condition, and had included participants across conditions (9/47).

3.1.4. Measures and outcomes

The reviewed research-based studies with a quantitative approach used a wide range of outcome measures that can be classified under the broad categories of physical-, social- and psychological domains, knowledge of conditions and treatments, self-efficacy, self-management behaviors, coping and empowerment. The most widely used and validated outcome measures with reference to the primary source are presented in Table 2. Where outcome measure is typically associated with a particular condition, these are noted in the Table.

3.2. Characteristics of the self-management patient education programs

The programs have diverse origins, aims, target groups, settings, modules and ways of involving lay participants in the planning and implementation of the programs. This is described in detail in Table 3.

3.2.1. Setting

The patient education programs in self-management were offered in a variety of settings. Most of the programs, 32/47 (68%)

took place in community settings such as senior centers, churches, libraries, and primary care, including traditional treatment settings such as community health centers, residential programs, self-help and peer support settings such as consumer-run drop-in centers and mental health support groups. The rest of the programs, 15/47 (32%) took place in hospital settings.

3.2.2. Target group and aim

The target group for the programs is people who are older than 18 years old, and are living with chronic illness. The most frequently reported program [26,27,33,35,38,39,42,43,49,51,60,61,63,65,66,69,120,121] was different variations based on the Chronic Disease Self-Management Program developed by Patient Education Research Center in Stanford University [3]. These varying programs aim to support the participants by increasing their confidence, improve their quality of life and aiding them in managing their condition more effectively. Nine of these were patient education programs in Norway [28,36,46,53–56,58,62]. The aim was to help the participants to achieve a healthier lifestyle and thereby improve their health related quality of life, and to gain knowledge about the disease and improve coping skills. The rest of the studies have investigated benefits and challenges from participating in a variety of other relevant self-management patient education programs [29–31,34,37,40,41,44,45,47,48,52,57,61,64,67,68,70–72]. Overall these programs aim to improve health behavior, self-esteem and/or psychological functioning to help the participants manage long-term illness and/or build a meaningful life.

3.3. Benefits and challenges

3.3.1. Peer support and mutual learning

The feeling of being “in the same boat as others” and realize that they were not alone, were reported as an beneficial experience that was immediate in several studies [28,30,68,69]:

“ . . . I thought it was such a great relief to see these people, you know, talking about their illnesses as well, and they knew what you were going through! And that made me come back . . . ” [35].

Receiving and sharing understanding with people with similar problems made the participants feel better and strengthened their self-confidence and identity [26,30]. Zangi et al. [37] found that meeting others who experienced the same emotions and challenges had strengthened the confidence in approaching challenges and recognizing their own feelings. The benefits from relating to others and share an understanding and being part of a group made them safe enough to approach and express their own feelings in the group [26,31,36,37,72]. Rogers et al. [33] reported that some of the participants found it easier to share with the group than with family and friends in an environment they felt they were not burdening others. For many participants, this was

Table 1
Classification of studies by chronic condition.

Condition	Number of studies	References
Rheumatic diseases	3	[34,37,38]
Multiple sclerosis	1	[27]
Chronic pain	1	[61]
Diabetes	8	[32,36,39,41,43,46,47,63]
Mental illness	13	[29–31,44,45,48,57,60,64,66–68,72]
Cancer	2	[40,52]
Heart disease	1	[65]
Chronic obstructive pulmonary disease	4	[35,49,55,59]
Overweight	4	[28,53,58,70]
HIV	1	[50]
Across conditions	9	[26,33,42,51,54,56,62,69,71]
Total	47	

Table 2
Typical outcome measures in the reviewed research-based studies.

Outcome	Condition	Outcome measure
Quality of life	Across conditions	Assessment of Quality of Life [73]
	Across conditions	EuroQol questionnaire (EQ-5D) [74]
	Across conditions	SF-36 [75]
	Across conditions	SF-12 [76]
	Across conditions	SF-8 [77]
Impact of Health Education	Diabetes	Audit of Diabetes–Dependent Quality of Life (ADDQoL) [78]
	Across conditions	Health Education Impact Questionnaire (heiQ) [79]
Health Literacy	Across conditions	The Health Literacy Questionnaire (HLQ) [80]
	Across conditions	General Perceived Self-Efficacy Scale (GSE) [81]
Self-Efficacy	Arthritis	Stanford Self-Efficacy measure [82]
	Depression	Depression Self-Efficacy Scale [83]
Social Support	Across conditions	MOS Social Support Survey [84]
	Across conditions	Social Network Index Questionnaire [85]
Impact of illness	Across conditions	Social Support Questionnaire 6 (SSQ-6) [86]
	Across conditions	Hospital Anxiety and Depression Scale (HADS) [87]
	Across conditions	Centers for Epidemiologic Studies Depression Scale (CES-D) [88,89]
	Across conditions	Patient Health Questionnaire (PHQ) [90]
	Across conditions	Brief Symptom Inventory (BSI) [91]
	Across conditions	The Rosenberg Self-Esteem Scale (RSES) [92,93]
	Across conditions	State-Trait Anxiety Inventory (STAI) [94]
	Across conditions	Health Distress Scale [95,96]
	Across conditions	Common Mental Disorders Questionnaire [97]
	Across conditions	Sickness Impact Profile (SIP) [98]
	Across conditions	General Health Questionnaire (GHQ-20) [99]
	Across conditions	Brief Illness Perception Questionnaire (BIPQ) [100]
	Across conditions	St.Georges Respiratory Questionnaire (SGRQ) [101]
	Lung/Heart Disease	McGill Pain Questionnaire [102]
	Pain	Pain catastrophizing Scale [103]
	Pain	Roland-Morris Disability Questionnaire [104–106]
	Disability	Patient Attitudes Toward and Ratings of Care for Depression scale (PARC-D 16) [107]
Depression	Diabetes Distress Scale [108]	
Diabetes	Diabetes Distress Screening Questionnaire [109]	
Diabetes		
Empowerment	Across conditions	The Empowerment Scale [110]
Self-Management behaviors	Diabetes	Diabetes Empowerment Scale (DES) [111]
	Across conditions	Patient Self-Advocacy Scale [112]
Recovery	Across conditions	Patient Activation Measure (PAM) [113]
	Across conditions	Recovery Assessment Scale [114]
Hope	Across conditions	The Hope Scale [115]
Sence of Coherence	Across conditions	Sence of Coherence Questionnaire (SOC-13) [116]
Coping	Across conditions	The Brief COPE Inventory [117]
Medication Adherence	Across conditions	Medication Adherence Report Scale (MARS) [118]
Cohesion	Across conditions	Perceived Cohesion Scale [119]

the first meeting with others with same health challenges or diagnosis, and the first time they found peers who were genuinely interested [34]:

“You know, it is so hard to have this illness . . . but it kind of grew smaller when I noticed that others have it too and that I may talk about it” [34].

The participants had learned new ways of perceiving situations, new possibilities and ways to appreciate life [27,30,72]. Meeting others had helped them to see their own life in a new light [34], and resulted in a shift in self-representation that allowed them greater self-acceptance and self-regard [26]:

“It’s helped me to gain more self-esteem. . . to be more independent. . . by learning that I am the boss of myself. I have got the right to choose what I want to do and what I don’t want to do. It helped me to love myself more and to know who I am.” [26].

Participation in the groups was perceived as an opportunity to learn from others experiences. Further, it gave meaning to their own illness experiences and an opportunity to share their own knowledge and practical advices [33–35,68,69].

3.3.2. Hope for the future

In several studies, participants reported that they felt more hopeful about their future. Four of these studies had investigated how hope for the future had changed after participating in a self-

management patient education program. The results showed a significant increase in hopefulness, also over time [57,67,68,122]. Findings from qualitative studies indicated that hearing positive stories from others elicited hope and optimism [31,68]. For example, participants thought it was important for the ‘beginners’ to see others who have managed to cope with the illness to give them hope [34].

3.3.3. Social support and network

One study had found a significant increase in having a social support system [67], and two studies had found no improvements in social support [57,122]. Additionally, two studies reported receiving social support as a predictor of quality of life [53], or as associated with higher quality of life [54].

A few studies reported that the participants gained new friends and felt less social isolated [27,30,67,69], or reported an increased number of people in their social network [47]:

“I got a lot of comfort in coming just knowing that there are other people having major issues like you. .you never felt alone because you knew everyone else had a problem as well” [69].

3.3.4. Impact on health and quality of life

Several studies had investigated changes in quality of life. Some of these studies had found significant improvement in quality of

Table 3
Characteristics of the programs.

Intervention and origin	Aim	Target group, setting	Modules, weeks/hours	Involvement of lay participant
CDSMP Chronic Disease Self Management program [26,27,32,33,35,38,39,42,43,49–51,60,61,63,65,66,69]. “Better choices, better health”, “Diabetes Self Management Education (DSME)” “The expert patient programme (EPP)” “Positive Self-Management Program (PSMP)” “The Chronic Pain Self-Management Programme (CPSMP)” “Living Life with a Chronic Condition” Origin: Stanford University, USA.	Develop skills to coordinate and manage health, help to keep active in their lives. Support people by increasing their confidence, improving their quality of life, helping them manage their condition more effectively.	People with different chronic health problems. Community settings such as senior centres, churches, libraries and hospitals.	A program Utilising the tenets of self-efficacy theory (Bandura, 1977), providing mastery experience, role modelling, persuasion and reinterpretation of physiological and affective states to assist participants in making changes. Covers generic topics including: an overview of self-management principles, exercise, pain management, relaxation techniques, dealing with depression, nutrition, communication with family and health professionals, and goal setting. Book: living a healthy life with chronic conditions, 4th ed. CD: relaxation for mind and body. 6 weeks, to groups of 8–16 participants, each session lasting for two or two and a half hours.	Led by peer educators who themselves have a chronic condition, or led jointly by peers and health professionals.
“Co-creating health (CCH)” based on the Expert Patient Programme (EPP), with the Self Management Programme (SMP) and The Advanced clinician Development Programme (ADP) [71]. UK	Both courses were designed to develop the skills for supporting patient self-management through deploying the same social learning processes during training delivery as would be employed by patients in learning to self management. Improve health behaviour.	People with long-term conditions. Community setting, patient course and clinician workshops	Initiative training of patients in self-management of their condition in group courses.	Lay-led.
The Diabetes Structured Education Courses for People with T2DM [41]. Argentina.	Improve health behaviour.	People with diabetes type 2, community setting.	Structured diabetes education programme. General concepts about disease, symptoms, glucose self-monitoring and good diabetes care. 4 weekly teaching units (90–120 min each), a reinforcement session at 6 months.	Implemented by trained peers with diabetes that also provided on-going peer support.
Learning and mastery/Educational lifestyle course [28,36,46,53–56,58,62]. Norway	To help the participants achieve a healthier lifestyle, and thereby improve their HRQoL. Increased knowledge about the disease and improved coping skills.	People with chronic illnesses or long-term ailments. At Patient Education Resource Centres in hospitals.	Educational lifestyle courses grounded in social cognitive theory and emphasizes participants' own work in uncovering unrecognized resources, strengthening self-concept, and coping skills. Reflecting the ideas of a salutogenic approach. The major subjects include available treatments and their intended and unintended consequences and necessary lifestyle changes. Core methods are participants' use of an individual action plan, guided reflection, and participation in self-help groups, as well as physical activity. 3–5 weeks of between 20 and 48 educational sessions. Some courses last 12 h or 40 h spread over 9–12 weeks.	Experienced users, former participants or representatives form user organisations take part in leading the course, or in the planning, implementation and evaluation, in developing the content of the course, or in sharing knowledge and personal experience as part of the content
“The recovery group project” [68]. USA.	To help participants build a life that is meaningful for them, and to help them improve their overall quality of life.	People with serious mental illnesses. Community mental health centres (CMHCs).	A program including opportunities to share recovery-related experiences, complete exercises to reinforce concepts, and engage in group problem solving. 6 weekly 2-h sessions.	The intervention led jointly by peer counsellors and professional counsellors.
“Diabetes Peer to Peer (P2P)” [47]. USA.	To consolidate social networking and reinforce group cohesion, with a central theme of improving health outcomes, as mediated by improved dynamics.	People with type 2 diabetes. Community setting.	Self management program including medical, nutrition, pharmacy and nursing, as well as non-smoking and exercise components. Information related to medications, the effects and the recognition and management of symptoms was also delivered.	Peer support as part of the program.

<p>“The Vitality Training (VTP)” [37]. Norway</p>	<p>To become aware of disease related emotions, thoughts and bodily experiences.</p>	<p>People with rheumatic diseases. Community setting.</p>	<p>Addresses a specific topic related to living with chronic illness. In addition, creative exercises, such as guided imagery, music, drawing, poetry and metaphors are used in order to encourage bodily and emotional learning processes. Reflection on own experiences is promoted through writing, sharing and listening to one another within the group. 10 sessions over a period of 4 months. Each session lasts for 4.5 h.</p>	<p>At least one of the tutors has user experience.</p>
<p>“Group Interventions for People with Co-occurring Disorders” [31]. Canada</p>	<p>To move participants forward in their recovery toward an active treatment stage in relation to their substance use, by means of discussion of pros and cons of substance use and other strategies.</p>	<p>People with co-occurring disorders (mental illness and addiction).</p>	<p>A peer support group led by persons with a co-occurring disorder. Weekly, 8 sessions per week, as an open- and time-unlimited group. Participants attended to any group sessions that they preferred as a part of their treatment.</p>	<p>The peer leaders involved in the peer-led group were patients who successfully completed the program who were taking part in leading the group. Peer leaders rotated across group sessions. Peer- group support as part of the content of the course.</p>
<p>“Shape up for Life” [70]. Australia</p>	<p>To manage obesity and cardio-metabolic risk factors.</p>	<p>People with metabolic syndrome. Community setting.</p>	<p>Lifestyle education program based upon national diet and physical activity (PA) recommendations. Practical strategies are used to aid in the uptake of dietary and physical activity recommendations and translate National guideline documents into ‘real life’. Covers the topics dietary and PA information based on national guidelines, behavioural self-management tools, food-label reading, supermarkets tour and cooking, exercise sessions, and peer-group support. 16-weeks.</p>	<p>Peer-driven.</p>
<p>“The NAMI FTF Education Program, family to family” [44]. USA</p>	<p>To help family members improve their wellbeing and coping capacities, and to better understand the experiences of their ill relative(s), the nature of mental illness, various aspects of the treatment system, and their own normative emotional reactions and conflicts.</p>	<p>People with mental illness. Community setting.</p>	<p>The program combines didactic, workshops, discussion, and experiential learning, emphasizing stress-coping and trauma recovery models of healing. Topics cover the program’s orientation to mental illness and family members, information about specific diagnoses and their treatments, basics of brain function per mental illness, treatment and recovery, problem-solving skills, review of medication and issues, first person experiences of mental illness, communication skills, self-care strategies, principles and potential of recovery, and mental health advocacy. 12 weeks classes.</p>	<p>Peer-led by trained peer instructors, taught by trained instructors who publicly disclose the fact that they are in recovery from mental illness.</p>
<p>“Building Recovery of Individual Dreams and Goals (BRIDGES)” [45,48,64]. USA</p>	<p>To meet the requests of consumers for practical information on the causes and treatment of mental illness and peer support.</p>	<p>People with mental illness, community setting.</p>	<p>A patient education course covering the topics: philosophy of recovery, psychiatric diagnoses, crisis planning and suicide prevention, building social support, medications and mental health treatment, psychiatric rehabilitation and employment, communication and problem-management skills, and self advocacy. 8-weeks.</p>	<p>The content of the program was constructed through a meeting between participating health care professionals and a group of COPD-patients. A patient with COPD participated in the running of all the classes.</p>
<p>“Self-management program (SMG)” [59]. Norway</p>	<p>To teach the participants basic problem-solving skills and gain knowledge of the nature of the disease. this included problem definition and generation of possible solutions in dialog with the other participants and the health care professionals.</p>	<p>Patients coping with COPD. Community setting.</p>	<p>Combined educational and exercise program with focus on coping and symptom management, physical activity and relaxation, how to exercise at home, therapy, and medications, nutrition, ergonomic posture and energy conservation during daily activity. Individual action plans and exchanging experiences and strategies. 16 sessions over 1 year.</p>	<p>The content of the program was constructed through a meeting between participating health care professionals and a group of COPD-patients. A patient with COPD participated in the running of all the classes.</p>

Table 3 (Continued)

Intervention and origin	Aim	Target group, setting	Modules, weeks/hours	Involvement of lay participant
“Wellness Education Group Intervention (WEGI)” [72]. USA	To improve quality of life through health promotion and disease prevention.	CSMI (Chronic severe mental illness), community setting.	Education program within a holistic framework and a fundamental principle that education is a form of empowerment. Workshops covering the topics: diet, stress, anxiety, recovery, depression, doctors visit, oral health, sleep, and financial health. 8-weeks.	Peer support through clubhouse-style programming.
“Person-Centred Health Education Group Intervention” [30]. Sweden	To increase the group members’ self-esteem and positive beliefs about themselves and to support them in improving skills to cope with life situations and develop relationships with other people.	Persistent Mental Illness. Community setting.	The sessions contained theoretical information about topics such as self-esteem and how to cope with difficulties and stressful situations, information from invited guests, and practical activities such as trips to various places in the community.	The content of the sessions were determined by the participants in collaboration with the group leaders and were based on the participants’ preferences. Peer-led.
“Wellness Recovery Action Planning (WRAP)” [29,57,67]. USA	To help people manage long-term illnesses.	People with various long-term illnesses, and people with serious mental illness. Community setting.	A program utilising instructional techniques to promote peer modelling by using personal examples from facilitators’ and participants’ own lives to illustrate key concepts of self-management. Lectures, group discussions, personal examples from the lives of the educators and participants, individual and group exercises, and voluntary homework assignments. 2.5 h, 8 weeks.	Peer-led.
“Healthy expressions” [40]. USA	To improve psychological functioning.	People with colorectal cancer, identified as psychologically distressed. Hospital setting.	A program covering the topics: fatigue management, interacting with the health care team, talking with family and friends about cancer, persistent physical symptoms, bowel management, sexuality, spirituality, emotional well-being, body image, and fear of recurrence. 12 one-hour sessions over 4 months.	Topics identified through a prior formative evaluation with 20 patients.
“Finally heard, believed and accepted” [34]. Ireland	To offer peer support.	Women with a long history of fibromyalgia. Community setting.	A program including lectures, group discussions, physiotherapy group exercises and individual treatments. Emphasising education and counselling instead of treatment of the symptoms. 17–20 days, divided into two or three intensive in-patient periods.	Peer support.
Daily group education programs in institution for stoma patients [52]. Turkey	To inform the patients and their relatives about stoma and stoma care.	People with Ileostomy, colostomy, urostomy. Hospital setting.	Care and management of stoma, surgery and complications. Education and social gathering in lectures given 1 day. Daily education and socialisation program at our institution.	Video presentation describing a stoma patients own family life with a stoma.

life over time [40,47,49,52,53,60,65], and some had found no changes [38,39,50,55,59,63] or a trend toward worse quality of life [46]. Analysis disclosed that participants with lower education [65], or who were married or who were living at rural districts, seemed to experience the most improvement in quality of life over time [52].

Overall, the results in these studies have demonstrated significantly changes in perception of illness consequences or less distress of common symptoms (depression, anxiety, pain, sleep) [40,44,55,60,61,63,64,68]. Steigman [48] found that participants with high levels of symptom distress showed greater gains than those with low distress or the control condition subjects with either high or low distress.

Participants in several studies experienced increased awareness of own condition and needs [26,28–31,37,67,69]. Awareness of triggers, warning signs, behavior patterns, use of medication and how to relate to health care professionals gave the participants more insight and made it easier to accept their health challenges, to participate more actively in care and take responsibility for their condition [29,31,37,69]. For example, Zangi [37] found that it was important to recognize oneself as both ill and healthy in the process of accepting ones health challenges:

“I got it confirmed that I really am a whole person in spite of being an ill person. I realize this, but it really makes a difference to work on it. I am not only a disease, I am so much more” [37].

3.3.5. Learning to manage own health challenges

Obtaining new knowledge is reported as one of the factors that can lead to lifestyle changes. Several studies have found improvements in self-management knowledge and skills [44,46,47,51,63,68] or participation as an opportunity to learn more about symptoms, medication and self-management behavior [32,36,66,67,70]. Some participants experienced that existing knowledge was reinforced or represented a useful ‘reminder’ of self-management techniques used in the past [27]. Others found that participating in a program taught them how to communicate more effectively with health care professionals [26,29,43,60]. Participants had expanded their view of wellness as an ongoing process, influenced by the support of others [67] and had learned how to plan daily activities in order to manage symptoms and preserve energy [26,27,68]. In addition, several studies showed that self-management education programs are efficient in improving confidence [29,66,68], sense of coherence [58], personal control [56], self-efficacy [29,43,45,63] and empowerment [44,45,48,122]. A few studies found no improvements in self-efficacy [54,61], and decreased empowerment [57].

Lifestyle changes occurred as a result of a changed understanding of their own role and responsibility [32,43,60,62,67,69]. Participants experienced that they were both expected to “take charge” and given the structured support to do so [29].

“What has changed is that before the course I thought my doctor had the responsibility for all this. But now I understand that it’s me. I have to make the decisions myself, and I feel that I have taken control. If the doctor was the one who had the responsibility, I would have eaten the wrong things because it wasn’t my responsibility, right. But now the responsibility is mine and I have to deal with the consequences” [32].

3.3.6. Cooperation between health care professionals and lay participants

Different terms were used to describe the lay-participants, for example peer leaders, peer educators, lay facilitators, volunteer lay tutors, experienced users, lay persons, facilitators with user experience, former patients participating, previously trained peers

or service users. How lay participants were involved in planning, carrying out and/or evaluating these programs varied from peer support as part of the program to structured cooperation between lay participants and health care professionals in planning, carrying out and evaluating the course. However, the results outlined that lay participants and health care professionals were able to support the participants in different ways [28,31,66,68,71]. For example, information given by health care professionals was highly appreciated by the participants, but the experiences and knowledge of lay participants were perceived as essential to make the information easier to understand [34]. Health care professionals were appreciated because of their understanding of the chronic conditions, their knowledge and insight into health-care services, counseling skills and medical expertise [27,71]. Many participants in these programs wanted information specific to their diagnosis by health care professionals, such as development in medical research [27]. Lay participants were appreciated because they were perceived to be sympathetic and easy to relate to [27,35]. Many participants felt that lay participants had greater empathy and were role models of successful coping. Furthermore, they added credibility to the program and information by sharing similar experiences as the participants as well as an unspoken understanding [26,66]. In overall, lay participants and health care professionals brought different qualities to the group that worked well together, as experienced by the participants:

“Well, one is the health care professional she could do the mechanics and the bones of the thing, and the other one had it . . . so it worked perfectly well” [71].

3.3.7. Challenging or negative experiences

Some participants reported unmet expectations [33,69], and participants from several studies reported feeling of loss and relapse after having ended the program [26,28,68,70]. Some participants reported that they had wanted more help to deal with underlying issues [70], and had needed follow-up sessions [36].

4. Discussion and conclusion

4.1. Discussion

This scoping review, based on 47 studies published between 2008 and 2015, is to our knowledge the first comprehensive review that include studies that have investigated benefits and challenges from participating in group based patient education programs, co-created and carried out by health care professionals and lay participants for people who are living with chronic illness. The studies were mostly carried out in developed countries throughout Europa and the United States of America. There was a large variety in the methodological approaches, and only one study evaluated changes after more than one year [59]. Totally 7003 participants were included, more women than men, with a mean age of 55,2 years. Most of the programs were diagnosis specific, only nine of the programs were generic. Most were implemented in different community- and hospital settings.

The programs were aimed at enabling 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. However, the programs varied in terms of origins, target groups, modules and the ways in which lay participants were involved in cooperation with health care professionals.

The participants experienced the programs as beneficial due to less symptom distress and greater awareness of their condition, improved self-management strategies, peer support, learning and hope. From the view of the participants, lay participants and health

care professionals contributed different qualities of support in the programs. For example, information given by health care professionals was highly appreciated, but the experiences and knowledge of lay participants were perceived as essential to make the information easier to understand. The programs yielded large variations in the reported outcomes of quality of life, social support and self-efficacy. Few studies reported challenges or negative experiences from participating in patient education programs.

Well-conducted research in this area is scarce. A few earlier reviews exist. Most of these included only randomized controlled trials focused on a few selected outcomes from diagnosis specific programs. However, we now find more high-quality research with different research designs that do suggest that these type of patient education programs can affect the experience of peer support and learning, health related outcomes and management of chronic illness. This suggests that the programs are an essential, integral part of modern illness management, health promotion and personal maintenance.

This study highlights the need for further evaluation efforts to adopt a comprehensive approach to measure outcomes in patient education programs. As evident in Table 2, the ways of measuring outcomes vary greatly, making it difficult to compare studies. Using robust and validated outcome measures will improve this field. Still, the significance of some outcomes or changes for the participants might not be adequately captured in the traditional survey measures, and/or there is lack of relevant outcome measures. For example, this is the case when it comes to measure 1) how people live with chronic illness [123], and 2) their experience of peer support and mutual learning.

As this review is based on studies with a variety of methods further studies should address the questions: what work, for whom, for how long and under what conditions. There is a paucity of information on the relationships between demographic characteristics (e.g. ethnicity, gender, family structure socioeconomic status and cultural heritage), and reported outcomes and experiences from participating in patient education programs. Much of what we know so far is based on Caucasian samples. More studies with samples from different cultural, ethnic or socioeconomic backgrounds are needed to investigate and explore differences in outcomes and perceptions in participants' experiences. Overall, more studies are needed to evaluate the long-term effects from different kinds of patient education programs. More research within this field are required to make the programs more likely to be implemented and replicable.

To investigate and evaluate patient education programs will always be complex. The Medical Research Council has recognized difficulties in the area of research and has produced guidance for complex interventions [6]. Studies that follow this guidance for complex interventions are more likely to be implemented and replicable, making the issue of what are the 'active ingredients' becomes less important as long as the program is transferable into other contexts [5].

This study shares limitations that are inherent to scoping studies in general, such as synthesizing qualitative and quantitative research in the same review [124], and balance between breadth and depth of analysis [125]. Our motivation for conducting this review was to lay the groundwork for a more standardized and systematic evaluation of group based patient education programs that are planned and carried out with health care professionals and lay participants in cooperation, aimed to promote self-management for people living with chronic illness. Therefore, we focused our attention on identifying both breadth and depth of benefits and challenges from participating in patient education programs. Despite this, this review may not have identified all articles published and grey literature. Searching other literature databases may have identified additional relevant studies, and relevant

studies in other languages than English or Scandinavian may have been excluded.

In terms of data extraction, our definition of patient education programs in self-management was broad to allow us to include a wide range of programs. In general, the cooperation between health care professionals and lay participants was modestly or not described in the studies we reviewed. Thus, we may have mistakenly excluded some studies. The focus has been aimed at getting an overview of relevant studies and different types of programs, and on summarizing knowledge on benefits and challenges, as reported by the participants in the programs. We have not summarized the state-of-art in patient education research. This question would have required a different type of review.

Ultimately, the validity and quality of knowledge synthesis relies on the quality of the individual studies included. The main aim of this study was to capture the breadth of studies evaluating patient education programs, rather than weighting articles in regard to method used or impact factor. However, two independent reviewers in the research team conducted quality assessment of the included studies (Appendix A in Supplementary material). Levac [22] and others point to a multidisciplinary team as a benefit for scoping studies. Our study group was not only multi-professional, but also included one person representing a patient association and one co-researcher with experience from living with chronic illness.

4.2. Conclusion

This scoping review has given overview of studies and different group-based self-management patient education programs for people living with chronic illness, and has highlighted the benefits and challenges as experienced by participants. A substantial evidence base supports the conclusion that participating in a group based patient education programs aimed at promoting self-management in different ways have been experienced as beneficial for the participants. The experienced benefits entail less symptom distress and greater awareness of one's condition and improved self-management strategies, peer support, learning and hope.

4.3. Practice implications

The results of this study support the conclusion that group based patient education programs aimed at promoting self-management for people living with chronic illness should be made available to a broader range of individuals. There are a great variety of different programs, which is good, because it is unlikely that 'one size fits all'. Different types of programs can meet the needs of a greatly varied population with different needs of support. There is a need of both disease specific and generic programs, in different settings as community and hospital, over short or longer time that will optimize the ability of the participants to effectively manage own health challenges over time. The results of this study should also encourage health care professionals to plan, carry out and evaluate programs in cooperation with lay participants.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.pec.2016.07.027>.

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