Empowerment in people with COPD

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Background: Patient empowerment is recognized as an important aspect of chronic disease management. There is an increasing expectation that health providers engage patients as active participants in their own self-management. This engagement is crucial to the chronic care model as patients with COPD and their families manage the majority of the care in the community. Understanding what influences empowerment will help health care professionals to better engage in collaborative care planning and decision making that meet the needs of this new generation of health consumers.

Aim: The aim of the present study was to identify interventions or approaches that empower patients in the management of COPD.

Methods: An integrative review was undertaken following the preferred reporting items for systematic reviews and meta-analyses approach. Papers were included if they 1) provided a definition or conceptualization of empowerment, and 2) reported interventions or approaches fostering empowerment in patients with COPD. Thematic analysis was used to develop conceptual themes on patient empowerment in COPD. These conceptual themes were validated by a panel of specialists in COPD, chronic disease management, self-management, and patient education.

Results: Literature searching revealed 183 papers of which 15 studies conceptualized or defined empowerment interventions or approaches to support COPD management. These were grouped into the following five categories: pulmonary rehabilitation, social support, web-based interventions, approaches that support knowledge development, and the approach taken by the health care professional.

Conclusion: Pulmonary rehabilitation, knowledge acquisition, social support, telehealth and web-based interfaces, and collaboration with health care professionals empower patients to recognize their own strengths and to manage the impact of the condition. Patients' abilities to direct their own care are additionally influenced by physical debilitation, treatment complexity, economic status, and health literacy. Health care professional–patient relationships must shift to a more collaborative approach that recognizes the patient as an expert in their own condition and facilitates patients to determine their own plan of care and life goals.

Keywords: COPD, chronic disease, empowerment, peer support, telehealth care, self-efficacy, active participation

Introduction

COPD is a common and debilitating condition, with the majority of care being managed by patients and their families in the community.[1–4] Patient empowerment, or patients' ability to determine the approach in one's own life, is increasingly recognized as an important aspect of chronic disease management.[5–8]

Empowerment is at times difficult to define and conceptualize. As a process and an outcome, it is best understood within a specific context, for example, within empowerment for chronic disease management in COPD.[8] In this context, empowerment is most often conceptualized as a reciprocal relationship between the health professional and the client, in which the client develops skills, knowledge, and confidence to determine the focus of their own health care approach.[5,6,8] Four key models of empowerment influence chronic disease literature, such as Funnell et al,[9] Dowling et al,[8] Powers,[10] and Skelton.[11] The work by Funnell et al on empowerment in patients from culturally disadvantaged groups with diabetes focuses on empowerment through behavioral change based on the following principles:[9]

- Affirming that the person is responsible for and in control of daily self-management.
- Educating patients to promote informed decision making rather than adherence/compliance.
- Learning to set behavioral goals so that patients can make changes of their own choice.
- Integrating clinical, psychosocial, and behavioral aspects of self-management.
- Affirming the participants as experts on their own learning needs.
- Affirming the ability of participants to determine an approach to self-management that will work for them.
- Affirming the innate capacity of patients to identify and solve their own problems.
- Respecting cultural, ethnic, and religious beliefs of the target population.
- Creating opportunities for social support.
- Providing ongoing self-management support.[9]

The model of Dowling et al[8] presents a different focus with empowerment based on the patients' capacity for motivation to change, competence to communicate effectively, knowledge to problem solving, and active participation. While Dowling et al[8] argue strongly that these are positive and worthy causes, as a bystander, these still appear to imply that success is measured on patients' ability to comply and be competent in health professional defined behavioral changes, rather than empowerment through goals that meet self-determined priorities.[8] Skelton[11] alludes to this in arguing that often behind the notion of empowerment "lurks an older view that 'the professional knows best'". This claim is also implied by Powers[10] who argues that empowerment is often a strategy employed by one person over the another, and in health care, patients are only considered as empowered "if and only if they make correct choices as defined by the health care provider". In this view of empowerment,

health care professionals prescribe those parameters of behavioral change that are required for success.

In chronic disease literature, empowerment is commonly used interchangeably with self-management, active participation, or self-efficacy;[8,12] however, empowerment distinctly emphasizes self-determination.[12] Nonetheless, patients who are empowered are likely to have greater self-efficacy for self-management, known in COPD to improve symptom control, slow disease progression, and health-related quality of life.[13,14]

Traditional models of health care delivery have focused on the health care professional as the authoritative figure, with an obligation on the part of the patient to comply and adhere to therapeutic goals prescribed by this expert.[6] There is growing recognition, in chronic disease in particular, that patients should be supported as collaborative decision makers and empowered to determine the approach in one's own life, and therefore, their individual needs and priorities in health care.[6,12,15–17] This shift in perspective challenges health care professionals to relinquish the authoritative role in place of an equal partnership.[6]

Research questions

This review sought to describe those interventions or approaches that empower patients in the management of COPD. Understanding what influences empowerment will help health professionals to support patients in collaborative decision making.[18–20]

Specific questions asked in the review are as follows:

- What interventions or approaches empower patients in the management of COPD?
- What key factors support empowerment in this patient group?
- How do current clinical relationships facilitate empowerment in this patient group?

Method

An integrative approach following the preferred reporting items for systematic reviews and meta-analyses (PRISMA) approach[21] was used to understand the empirical and theoretical literature on patient empowerment in COPD.[22] This approach is particularly useful in undertaking a structured approach to a review of literature, while identifying the conceptual themes that contribute to the field of work.[22]

Eligibility criteria

Papers were included if they were published in peer reviewed journals, written in the English language, and published between 1995 and 31 March 2015. Papers written prior

to 1995 were excluded to ensure consistency with current clinical approaches.

Papers were included if they discussed interventions or approaches that are related to the development of empowerment in patients with COPD, and if they presented a definition of empowerment. Some papers did not always present a definition but did conceptualize empowerment in their discussion or approach, these papers were also included. Original research papers, systematic reviews, and reviews were considered. Opinion pieces and case studies were excluded from this review.

Information sources

The electronic databases MEDLINE, PsycINFO, CINAHL, and Google Scholar were searched using medical subject headings and keywords. Table 1 outlines the MEDLINE Ovid search strategy; this was translated into all other databases. The search terms and strategy were reviewed by a health informatics expert with the following appropriate derivatives used: "chronic obstructive pulmonary disease", "chronic obstructive airways disease", "COPD" OR "COAD", and "empowerment" OR "power" OR "empower" OR "patient participation" OR "patient driven" OR "active participation". The World Wide Web was searched using Google Scholar and Google search engine for related electronic documents. Journals held locally were hand searched for relevant articles.

Study selection

Papers were assessed for eligibility for inclusion by two independent investigators (RTD and JA) with consensus gained from a third independent investigator as necessary (DAD).

Data collection process

Data were extracted by a single investigator using a structured data extraction table (JA), and accuracy of data was verified by an independent investigator (RTD). The data extraction

Table 1 Example search strategy (MEDLINE Ovid)

	Search terms	Results from MEDLINE only
1	copd.mp. or COPD	35,246
2	coad.mp.	204
3	empowerment.mp. or "Power (Psychology)"/	14,834
4	empower$.mp.	13,883
5	Patient driven.mp. or Patient Participation/	18,730
6	Active participation.mp.	2,477
7	1 or 2	35,435
8	3 or 4 or 5 or 6	40,943
9	7 and 8	114
10	Remove duplicates	113
11	Met abstract review	38

table included author details, journal details, methodological approach, data utilized and data sources, any statement about empowerment, definition or conceptualization of empowerment, summary of findings, and conclusion.

Data analysis

Thematic analysis was used to develop conceptual themes on patient empowerment in COPD.[22] These conceptual themes were validated by a panel of specialists in COPD, chronic disease management, self-management, and patient education (RTD, DAD, SCI, and MH).

Results

Literature searching revealed 183 papers of which 82 met the inclusion criteria on title and abstract review (Figure 1). A further 67 were excluded after full-text review: 59 did not conceptualize or define empowerment, four included other diagnoses from which COPD responses could not be deciphered, and four were case studies or opinion pieces.

A total of 15 papers were included in the review and reported on eleven different studies[23–26] (two papers reported on one study[27,28]), two literature reviews[8,29] and one was a discussion paper (Table 2).[30] Ten of the studies were qualitative, including five interview studies, four focus group studies, and one using online data collection. One study was quantitative, using a quasi-experimental with matched control design and used a quantitative measure of empowerment.[23] Three of the qualitative studies were nested within large randomized controlled trials.[24–26] Papers were presented from the following countries and regions: Continental Europe,[29,31] UK and Republic of Ireland,[8,24,25,30–32] Scandinavia,[26–28,31,33] Australia,[34,35] Canada,[23] Russia,[31] People's Republic of China (Hong Kong),[31] Brazil,[29] and Iran.[36] The strong representation from the Western world, with exception to the USA, may influence an individualized view of empowerment and self-management.[14] A summary of the included studies can be found in Table 2.

Results from review of literature

The following interventions or approaches were assessed as contributing to empowerment in COPD: pulmonary rehabilitation, social support, approaches that support knowledge development, telemonitoring and web-based interventions, and the knowledge and attitude of the health care professional (Table 3).

Pulmonary rehabilitation

Pulmonary rehabilitation is a cornerstone of COPD management and is "an evidence-based, multidisciplinary, and
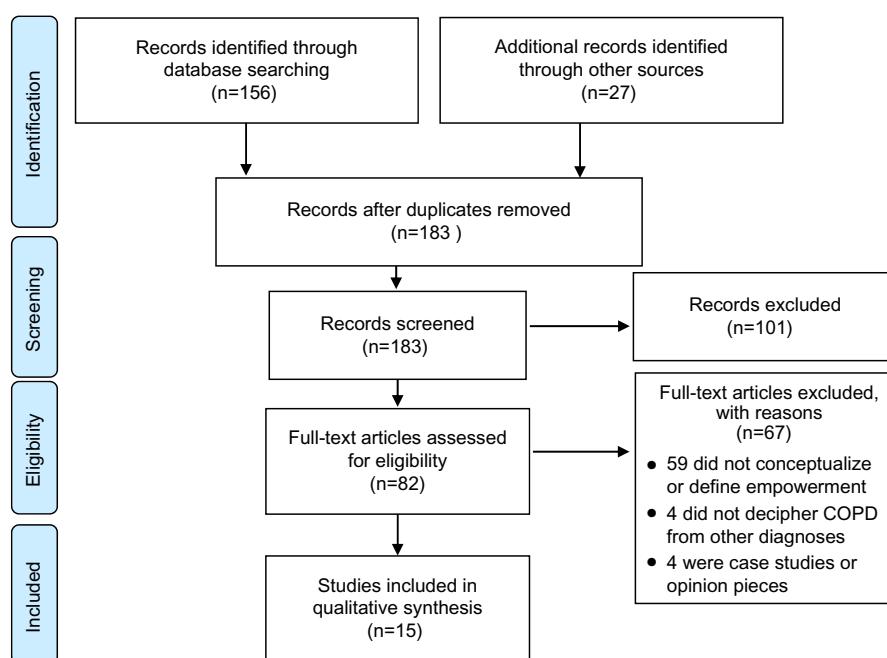
Figure 1 PRISM flow diagram.

comprehensive intervention"[37] framed within the chronic care model.[38] This multimodal approach includes exercise, self-management education, and behavioral components in an individualized plan designed to "reduce symptoms, optimize functional status, increase participation, and reduce health care costs".[37] Five studies (six papers) explored pulmonary rehabilitation as a key intervention in promoting empowerment, both overtly as an underlying framework and inadvertently as part of increasing patients' self-determination and confidence for engaging in activities of life.[8,24,29,32–34]

The Pulmonary Rehabilitation In Nurse-led Community Environments (PRINCE) study is a 5-year, two-armed randomized controlled study, clustered by general physician practice, in which participants either received Structured Education Pulmonary Rehabilitation Program (SEPRP) or usual care.[8,24] As part of this trial, the authors developed a model of empowerment in chronic illness as part of their initial concept analysis and also discussed empowerment in reporting the study outcomes.[8,24] The program used the transtheoretical model of behavioral change. Qualitative interviews with 16 patient participants with COPD revealed themes of a complex balance between treatment activities and retaining a life they wanted, adapting living to the limitations of breathlessness, and learning coping strategies to maintain independence. Having knowledge and knowing when to escalate treatment and access supports was a strong theme, as was having access to help to facilitate decision making. The SEPRP was noted to have changed patients' attitudes to

their disease with feelings of increased control and positive outlook.[24] A qualitative study on pulmonary rehabilitation experience by Denn[32] similarly noted that patients were empowered through increased physical confidence and in learning to cope with and accept their condition.

A study by Hellem et al[33] also used the transtheoretical model of behavioral change in their qualitative study exploring COPD patients' perceptions of the elements for success in an exercise maintenance program. The approach taken focused on health and beneficial change rather than disease cause and on recognizing patient strengths and ability for adjustment.[33] A key to empowerment was the physiotherapists' knowledge and ability to tailor the program to individuals' capabilities so that patients felt safe in this context and able to "exert themselves close to their limit". This was elucidated in the theme "the personal manner and empowering skills of the therapist" in which the patient felt recognized, valued, and taken seriously. The theme "regular appointments with someone who cares" additionally raised the importance of having a regular agreed time and an environment where they felt valued and part of a group. Negative experiences equally led patients to disengage.[33]

Milne et al[34] in their qualitative study exploring hope in patients following a home exercise program did not overtly target empowerment. However, their qualitative research undertaken after the program identified "hope through empowerment" as a key theme. This was related to increased self-confidence in their ability to cope and manage their

Table 2 Characteristics of included studies

Study	Participants and setting	Definition or conceptualization	Design	Key findings	Authors' conclusion
Casey et al[24]	16 patients with COPD, and 25 health professionals, Galway, Republic of Ireland.	"Operational definition" of empowerment in COPD that "… emphasized equality in the relationship between the health professional and the client, with the client viewed as an expert".	Qualitative study within the intervention arm of a cluster RCT. Descriptive qualitative interpretive design to analyze. Interviews with patients after completion of intervention. Grounded theory to analyze.	The concept analysis of empowerment provided an "operational definition of empowerment". The qualitative findings from the intervention arm suggest the participants felt better equipped with knowledge that improved their self-management and decision making. These findings also show that the participants were able to translate what they learnt from the program into their lives.	All participants had enjoyed the program; the involvement of different health professionals and the teaching strategies used were appropriate. The findings indicate that nurse-led primary care-based structured education programs have the potential to empower clients with COPD to better self-manage their chronic health condition.
Davies et al[31]	142 primary care clinicians and pulmonologists from seven countries the Netherlands, Russia, Norway, People's Republic of China (Hong Kong), Wales, Germany, and Poland.	Patient empowerment conceptualized as patients' feeling in control of their health.	Qualitative focus groups. Thematic analysis of transcribed focus groups.	The use of rescue packs varied across countries. Most participants considered these as useful in patient care. There was some concern that the use of rescue packs may delay critical medical assessment in some cases. Participants described "choosing the 'right' patient", one that they trust to use the rescue pack appropriately.	Clinicians do not feel it is appropriate to offer self-treatment rescue packs to all patients routinely without careful consideration of patient understanding of their illness and their capacity for self-management.
Denn[32]	Five clients with COPD, England, UK.	Empowerment conceptualized as patients' perception of control, coping, and confidence.	Qualitative focus groups. A focus group with five participants before and four participants after PR program. Thematic analysis.	Before the program, the main themes describe the participants' experience of living with the physical and emotional consequences of COPD. After the program, the three main themes included "comradeship", "empowerment", and the "concept of severity".	Pulmonary rehabilitation empowered participants to understand and cope with their condition. Peer support was important as it encouraged them to help each other.
de Sousa Pinto et al[29]	Literature review: eight studies included. Systematic review of meta-ethnography design.	Empowerment conceptualized as "self-efficacy", "control", and being able to recognize and overcome barriers.	Systematic review of appropriate databases. 3,306 papers from search results. Appropriate inclusion and exclusion criteria reported.	Patients in PR program feel supported by health professionals, their peer group, and their family. There is an element of education that facilitated knowledge of coping strategies. The program provided a time for the patient to consider and make changes to their life and management of their COPD. PR has benefits in physical and psychosocial domains.	The COPD patients' feedback revealed that PR promotes a better "way of life", well-being, and important behavioral changes toward health promotion.
Dowling et al[8]	Literature review of empowerment in chronic illness. Concept clarification and concept analysis.	"Empowerment in chronic illness is a process with both the nurse and client contributing to its evolvement".	Papers included in the review had reference to "empowerment" in the abstract.	Empowerment is a process. Circumstances that precede empowerment were identified from the nurse's and the client's perspective. For nurses, these circumstances were "feeling empowered", "communicating effectively", "surrendering control", and "focusing on goals". For clients, the circumstances that precede empowerment were a "motivation to change", "presence of client competency", "communicating effectively", "knowledge to problem solve", and "active participation".	The nurse must feel empowered, communicate effectively, and surrender control in the empowerment process. The client must be motivated to change and possess specific competencies to engage in the empowerment process. Both the nurse and client experience a transformation when empowered.

(*Continued*)

Table 2 (*Continued*)

Study	Participants and setting	Definition or conceptualization	Design	Key findings	Authors' conclusion
Fairbrother et al[25]	38 patients with COPD and 32 health professionals, Lothian, Scotland, UK.	Patient empowerment defined as a part of self-management where the patient is an active "partner in not a recipient of health care".	Qualitative study embedded in RCT. Semistructured interviews. Framework approach to transcribed data.	The core concept in the findings was "compliance-based self-management". The patient viewed telemonitoring as a useful tool in their management of the illness. Some described it an empowering tool. The professionals were concerned that some patients may become dependent on the technology and thought the empowering aspect was good but only if it lead to compliance with the health professionals plans.	Telemonitoring assisted many patients to embrace greater responsibility for their health, but the model of service provision remained clinician centered. A medical model of "compliant self-management" may paradoxically have promoted dependence on professionals.
Fotoukian et al[36]	15 older people with COPD, four family care-givers, and five health professionals, Tehran, Iran.	Empowerment defined as a process toward active participation in health management and capacity building.	Qualitative approach. In-depth semistructured interviews and field notes. Qualitative content analysis.	A number of barriers to empowerment were apparent: the disease process itself, complex treatments, the lack of resources (both fiscal and social support and within the health care system), feelings of fear, and hopelessness. Facilitators to empowerment have trust in the health professionals and previous experiences.	It seems that empowerment of the elderly with COPD was affected by many factors, which mainly rooted in social factors, health care systems, and personal resources.
Hellem et al[33]	Eleven people with COPD who maintained regular exercise, Oslo, Norway.	Empowerment defined as "… support and strength to influence one's own life situation".	Phenomenological approach. Focus group interview and in-depth interviews. Qualitative content analysis of transcribed verbatim.	Continued exercise habits were influenced by the individuals' perception of the disease and the success of any structured program they had attended, for example, PR. Successful maintenance of regular exercise occurred when the patient felt empowered by their therapists. Peer support was also a positive factor in exercise maintenance.	The management of chronic disease requires supervision, professional support, and ongoing communication between patients and practitioners to actively share responsibility across an entire continuum of care.
Huniche et al[26]	Eight participants with COPD, Denmark.	Empowerment defined "… in terms of the rights and abilities of individuals and communities, and the improvement of social conditions at the intersection of individual and community or organizational development".	Qualitative study embedded in RCT. Semistructured interviews. Thematic analysis.	The findings indicate how participants used the telehealth tools in monitoring and decision making, for example, when to exercise and when to seek medical assessment. The telehealth program was also a way of the participants choosing to improve their life and treatment of COPD. The findings also provided insight into how participants used planning daily tasks and their social network to cope in living with COPD.	The ways patients with COPD make use of home telemonitoring in the TELEKAT project points to the relevance of a return to the idea of empowerment rooted in ideologies of social action.
Milne et al[34]	Seven participants with COPD, Australia.	Empowerment conceptualized as perceived knowledge and control for self-care.	Interpretive phenomenological approach. In-depth interviews. Thematic analysis.	Participants experienced hope despite the "hopelessness" of no cure for their illness. The program encouraged hope by helping them reenvisage life living with their illness. Feeling empowered with information and coping mechanisms for their illness, for example, breathing techniques gave the participants hope. Hope was also facilitated by social supports, including their relationship with doctors and other health professionals.	Individuals who feel empowered are able to make informed decisions about their health care giving them a sense of control in the face of their prognosis and increasing their hope for a future. Although health professionals traditionally take control of health care, the agenda in maintenance programs should be support rather than control.

Author	Sample	Empowerment conceptualization	Method	Findings	Conclusions
Robinson et al[35]	21 community nurses from four community health centers, TAS, Australia.	Empowerment conceptualized in patient-centered self-management.	Qualitative, longitudinal action research. Nurses trained in mentoring. Data collected at monthly group discussion with nurses. Thematic analysis.	Nurses displayed changes in their "constructions of COPD", which lead them to rethink their approach to working with these clients from a "teaching and telling mode toward the more patient-centered approach", which was more holistic.	This study highlights that it is possible to support community nurses to take a lead role in the ongoing management of chronic disease in the community.
Sicotte et al[23]	46 participants, 23 per group, Montreal, QC, Canada.	Empowerment conceptualized and measured in terms of control and self-management.	Quasi-experimental retrospective and prospective design with matched control group. Both participants and care providers (nurses) provided data for satisfaction and empowerment. Quantitative analysis	No difference in satisfaction or empowerment between the control and the experimental group. However, the care providers "… positive assessments of improvements in patients' knowledge of how to manage their own illness and their ability to care for themselves, but …" were concerned about patient dependence on the tool. Quality of life declined in the control group but remained stable in the experimental group. Health care utilization results were "mixed" with reduced hospital admission in the experimental group.	Capturing the full potential of these new technologies will require a much more fundamental reorganization of work than just a simple deployment of the technology.
Smith and Kirkpatrick[30]	Excerpts from a solution focused brief therapy (SFBT) conversations, Aberdeen, Scotland, UK.	Empowerment conceptualized as patient autonomy and self-management.	Discussion paper using excerpts from SFBT conversations between nurses and patients.	Paper discusses the use of SFBT in COPD. This framework highlights strengths and wellness, rather that the deficits caused by an illness. It focuses on small, simple, positive steps toward change. And considers the patient as able to problem solve in direct opposition the idea that the health professionals have all the answers.	SFBT is a forward looking, minimalist way of helping people with COPD help themselves. It enables nurses and patients to share a collaborative relationship that helps focus on strengths and resources for achieving positive change.
Wentzer and Bygholm[27,28]	3,650 posts from online discussion forum: "Talks about COPD", Denmark.	"Empowerment is the discovery and development of one's inherent capacity to be responsible for one's own life and the patients are thus empowered when they are in possession of the knowledge, skills, and self-awareness necessary to identify and attain their own goals".	Qualitative textual analysis. Talks about COPD captured over an 18-month period.	In "Talks about COPD" the main two topics discussed were exercise and smoking. Participants encouraged each other to trust their health professionals' advice and continue to try fight against the illness by, for example, attending exercise programs. The users also acknowledged the difficulties in coming to terms with this illness and adjusting to the physical limits caused by the illness. The collective experience of the users is displayed. They share common experiences and interpretations of their experiences. In "Talks about COPD" the meta-narrative of the community was "about creating motivation: to believe in treatment recommendations, that is, changes in habits and lifestyle".	Online patient groups are a means to empower patients in relation to giving them the possibility of managing their illness, from collaboration with copatients and by guidance of professional health care information. The collaboration consists in information sharing and rituals of confirming each other's endeavors to follow health instructions. In spite of the potential of online communities of opening up health care to the critical voice of the public, the analysis points to a synthesis of the otherwise opposite positions of empowerment and compliance in patient care. On a collective level, the site is empowering the individual users to comply with "doctor's recommendations" as a group.

Abbreviations: COPD, chronic obstructive pulmonary disease; PR, pulmonary rehabilitation; RCT, randomized controlled trial; SFBT, solution focused brief therapy; TELEKAT, Telehomecare, chronic patients and the cooperating health system.

Table 3 Interventions or approaches that support patient empowerment in COPD

Intervention	Description	References
Pulmonary rehabilitation	Pulmonary rehabilitation or maintenance programs facilitate patient empowerment by providing means for patients to feel in control and manage the impact of symptoms on day-to-day life	8,24,29, 32–34
	Incorporating the concept of empowerment into the program led to a shift in the patient–health professional relationship necessary to facilitate empowerment.	24
	The physical activity improves capability in life and participants' confidence in physical ability.	32
	The health education and coping skills taught in these programs led patients to have more control in their lives and self-determination.	24,29,34
	Negative experiences in a program or a lack of motivation to take the opportunity to change habits are barriers to empowerment through pulmonary rehabilitation.	29,33
Approaches that support knowledge development	Knowledge development of condition and skills to manage symptoms provides basis for patients to engage in health and everyday decision making and management leading to empowerment.	8,24,25,29,34
Tele- and web-based interventions	Telemonitoring facilitates patient empowerment by providing useful information to aid everyday decision making and management of symptoms.	23,25,26
	Health care professionals' perception of patient dependence on the telemonitoring limiting access to tool.	23,25
	Online peer support provides access to a community of shared experiences facilitating empowerment.	27,28
Social support	Pulmonary rehabilitation programs can facilitate psychosocial support, which in turn provides encouragement and motivation leading to empowerment.	29,32–34
Knowledge and attitude of the health care professional	Training of health care professionals in particular approaches that encourage patient empowerment and self-determination.	30,35
	Positive and trusting relationships with health care professionals improve treatment and symptom management engagement and provide psychosocial support facilitating empowerment.	8,24,33,34,36
	Health care professional needs themselves to be empowered in their role to advocate for their patients.	8
	Access to tools that may facilitate empowerment, for example, rescue packs.	31
	Traditional authoritative approaches that require patients to adhere to predefined approaches limit patient empowerment.	25,36

breathlessness and therefore be able to live a normal life. Patients were able to manage the impact of their condition on their day-to-day life through knowledge of what COPD was and how to pace activities and use coping strategies. Coping mechanisms, in particular, were seen to give back self-control and self-determination. An important element of empowerment is in the ability for people to keep doing those things that they enjoy in life. Participants in the Milne et al[34] study were facilitated to learn how to adapt their hopes into achievable self-determined goals such as spending time with grandchildren and walking to the park. Increased confidence "in coping with episodes of breathlessness resulted in them feeling empowered, this in turn increased participants" hope to be able to enjoy a more "normal life".[35] Access to a more normal life was similarly highlighted in the PRINCE study.[24]

The positive benefits of self-determined, tailored goals of care were also raised in the systematic review of eight qualitative research studies on patient experience in pulmonary rehabilitation by de Sousa Pinto et al.[29] Being able to take back the control of life, not only in increased physical capability and mechanisms to cope with day-

to-day symptoms but also in the confidence to interpret symptoms and take a course of action and seek help when necessary.[29] Increased hope for the future was also a key to the empowerment outcome, with patients being provided with the resources and mechanisms to overcome and deal with barriers, thereby facilitating a positive outlook of a future in which the condition of the impact is managed.[29] Pulmonary rehabilitation, in particular, the support and education provided, facilitates "…the development of patients' empowerment".[29]

Empowerment through provided social support

Peer and social support has long been recognized as an important factor in the quality of life and self-management in COPD,[39,40] in addition to the emerging online peer support mentioned later. Empowerment through peer support was identified in three studies and one literature review looking at pulmonary rehabilitation.[29,32–34] The exercise maintenance program by Hellem et al[33] reported that the identification with peers gave patients a sense of normalcy that allowed them to engage freely in their activities without feeling the

need to hide their symptoms. Peer support and friendship in the exercise group were noted as markedly more important as a motivational factor than family and friends.[33] Similarly, in the focus group study by Denn,[32] patients often found their condition isolating and feeling embarrassed to show breathlessness in social settings. Participants in this study expressed a sense of relief and ease at exercising with others who experienced the same condition. The systematic review of de Sousa Pinto et al[29] similarly noted that patients felt able to express feelings and thoughts without recrimination or judgment during the group exercise. In the qualitative study by Milne et al,[34] social support through a variety of relationships, including health professionals, was identified as a crucial element in the maintenance and development of hope for the future. Relationships with friends and family were felt to encourage and motivate patients through increased sense of self-worth. While it is recognized that the social support from these studies was experienced within the context of pulmonary rehabilitation, the social interaction activity was highlighted specially as an important aspect of empowerment.

Approaches that support knowledge development

Knowledge development is recognized as a key factor that enables patients to make educated decisions about their care as part of collaborative decision making. While there were no studies that explored education as a sole intervention to improve empowerment, development of knowledge was raised as a key element in the pulmonary rehabilitation studies noted previously.[8,24,29,34] The PRINCE study[24] noted earlier raised the importance of developing knowledge as a key to empowerment, with specific knowledge of coping strategies that assisted patients to manage their condition to achieve the life they wanted.[24] Such knowledge also assisted patients to make informed decisions without panic, including knowing when to escalate treatment and access supports.[24] Knowledge was an important aspect of the SEPRP in changing patients' attitudes to their disease, with feelings of increased control and positive outlook.[24] Knowledge was also noted as a facilitator to active decision making and improved self-confidence found in the theme "hope through empowerment" in the qualitative study by Milne et al.[34] Similarly, Fairbrother et al[25] also noted that increased "knowledge and empowerment" was a key theme in patients being able to determine how they interpreted and responded to condition changes, and therefore, their ability to be active participants in their own care and life management.

Tele- and web-based interfaces

Tele- and web-based interfaces are increasingly recognized as vehicles to deliver information and promote patient engagement and peer interaction.[15,41,42] Limited literature was found that explored tele- and web-based interfaces with reference to empowerment in COPD directly, with three studies exploring telemonitoring[25,27,28] and one study exploring empowerment through online chat rooms.[29,30]

The telemonitoring study by Huniche et al[26] explored an integrated health care system for patients with COPD in which patients received a home telemonitoring, as well as home-based exercise prescription, and provision of a pedometer and Wii console.[26] Their study conceptualized empowerment as based in social action and self-help, with a renewed focus on patient perspectives of their goals in everyday life.[26] Some patients used telemonitoring measurements to temper daily activities and in deciding whether to seek help from a health professional.[26] Huniche et al[26] noted that patients felt "grateful for the easy and legitimate access to specialized health professionals" and reassured in knowing that their condition fluctuation was being monitored.

Fairbrother et al[25] similarly implemented a telemonitoring intervention for COPD in which patients entered symptom and oximetry scores into the system, as well as having access to telephone and home visits from a community respiratory team. In the post-randomized controlled trial qualitative study, participants voiced that the intervention provided them, for the first time, access to clinical data about their condition, which is crucial for collaborative decision making.[25] Access to this data allowed the patients to learn to recognize their normal symptoms, thereby increasing their confidence to undertake day-to-day activities and validation of their decisions to escalate treatment when unwell.[25] The participants, both patients and nurses, valued these tools as contributing to patient empowerment.[25] Sicotte et al[23] also reported a prospective interventional study that compared telemonitoring and telephone support with traditional homecare and found that empowerment, measured using quantitative questionnaire, was high in both the experimental and the comparison groups following the trial. Those receiving telemonitoring increased their use of consultations and phone calls for advice over the period.[23]

Health care professionals in two of these telemonitoring trials[23,25] raised concerns that the increased interaction with health care professionals was an indicator of fixation and increased dependence. However, a health care professional raising this issue also noted that one patient had substantially dropped acute service utilization, only having been admitted

once in 12 months over the duration of the telemonitoring intervention.[25] Additionally, patients in the same study noted that increased access to advice meant that they consulted earlier in deterioration and were more likely to start newly prescribed treatments, whereas previously they would have waited until condition deterioration warranted contact with health services to raise ongoing issues.[25] Increased consultation dependence through telemonitoring could in fact be reinterpreted as increased engagement in collaborative decision making. An argument supported by Huniche et al,[26] who support home telemonitoring as a promising approach to provide accurate and reliable data, enables patient to better manage their lives.[26]

Peer support through online social media groups has been increasingly recognized to improve social well-being, enhance self-management and self-efficacy, and provide a sense of belonging and normalcy across many chronic diseases.[15–17,43–47] Only the Danish study by Wentzer and Bygholm[27,28] explored empowerment specifically in COPD through online peer support. This study undertook a text analysis of discussion posts from an online COPD peer group. The main activities in the COPD group were knowledge sharing and shared experience and recognition, with sharing typically focused on smoking, exercise and coping techniques, and also more existential discussions of the burden of disease and challenges faced in dealing with COPD impact. Interestingly, while the authors noted that individuals experienced empowerment through this sharing, there remained a tone of compliance with participants reaffirming health care professional recommendations;[27,28] however, self-determination and engaging with health professionals recommendations should not be viewed as mutually exclusive.

Knowledge and attitude of the health care professional

Training of health care professionals, in particular, approaches that encourage patient empowerment and self-determination, were also raised as important. A study by Robinson et al[35] trained community-based nurses to use the transtheoretical model of behavioral change to promote self-management through motivational interviewing with patients with COPD. The qualitative study exploring the nurses' experiences found that there was a shift in the nurses' approach from a fatalistic and prescriptive to a patient-centered, facilitative, and consultative approach determined by the life goals set by the client.[35] Patients interpreted as noncompliant, depressed, and not willing to listen were recognized as facing an unpredictable and unrelenting condition, with nurses then changing

their focus to "do the best they can every day".[35] In the PRINCE study, there was a noted shift to a more collaborative relationship between patients and health care professionals, both in the programs ability to tailor activities to the need of the patient and in patients feeling empowered to ask their health professionals outside the program questions that are important to them.[24] A similar approach, solution focused brief therapy, is described in the discussion piece of Smith and Kirkpatrick.[30] This framework is designed to guide patients to consider self-determined positive futures and life desires with a focus on inherent patient strengths and wellness rather than pathology. Through this technique, patients are helped to see that change, and adaptation is possible, no matter what the symptom burden is.[30] Health care professionals were trained to adopt a position of "not knowing" with the patient as the expert and to avoid judgment and censure of patients for nonadherence, preferring to focus on a positive vision of change in the future.[30]

The influence of the health professional's approach was again raised in the multinational qualitative study by Davies et al.[31] This study does not present an intervention but rather clinicians' views on self-management of COPD exacerbation through at home rescue packs of antibiotics and steroids and empowerment as one possible outcome from this. From the comments of the clinicians, there was an acknowledgment that having medication at home might provide a sense of control over acute events and improve early treatment when access to health services was limited, but that this was only appropriate in a particular cohort of patients.[31] A mutually trusting relationship between the patient and the clinician was a factor in whether this opportunity would be given to patients, as was the viewpoint of the individual clinician, with some participants believing that antibiotics and steroids should never be used as a home-based rescue pack, and rather a consultation with the prescribing clinician is required. Time for adequate education was also raised as a barrier, with clinicians commenting that it was easier to have the patient make contact with them than to provide a rescue pack with detailed education for the patient to use at home. As noted by the authors, while these concerns are sound, they undermine the intent of self-management interventions to provide the patient with the knowledge, skill, and tools to manage symptoms, both acute and long term, and improve confidence in decision making. The authors further state that "There appears to be a gap between what is seen as a self-management intervention in the literature and what is available or actually implemented in routine care".[31]

The qualitative study by Milne et al[34] noted that positive relationships with health professionals, doctors in this case, had a marked impact on patients' hopes around their illness. Additionally, comfort was gained from the perception that the health professional understood the impact of the illness and given time for the patients to talk about their illness.[34] Negative relationships equally made patients feel isolated, unimportant, and with little hope for the future. Trust in health care providers was raised as a key theme in the qualitative study by Fotoukian et al[36] on the barriers and facilitators to empowerment in older Iranian patients with COPD. Positive relationships with health care professionals both endorsed the care provided and motivated patients to engage in treatment activities. Conversely, other participants noted that some health professionals did not appear to see empowerment, or the facilitation of self-management, as part of their role, and viewed this as an extra responsibility. It was voiced that the training of health professionals was required to enable them to support patients in collaborative condition management.[36]

Discussion

In recognizing the patient's empowerment as an important aspect of chronic disease management, this review sought to describe those interventions or approaches that sought to empower patients in the management of their COPD. Understanding what interventions or approaches facilitate empowerment and what influences patients ability to engage in care planning will help health professionals to better engage in collaborative care planning and to focus on their patients' individual care priorities.

Key findings

The review included 15 papers that conceptualized or defined empowerment as part of interventions or approaches to support COPD management and were grouped into the following five categories: pulmonary rehabilitation, approaches that support knowledge development, social support, web-based interventions, and the knowledge and attitude of the health care professional.

Pulmonary rehabilitation is recognized as a cornerstone of COPD management and was similarly found through this review to be an important approach and consistent theme in promoting patient empowerment.[8,24,29,32–34] The focus on increased function, coping strategies, and knowledge within this multimodal, individualized approach is closely aligned with empowerment literature.[5–8,24,29,32–34,37] Empowerment through self-determination was increased in pulmonary

rehabilitation through tailoring treatment approaches to the patients' own life goals and in increasing disease-specific knowledge necessary for collaborative decision making.[29,32,33] Development of coping strategies and increased confidence similarly allowed patients to manage the impact of their condition, thereby increasing social engagement and a positive outlook for the future.[8,24,29,32–34]

Knowledge development was also a key factor in patient empowerment throughout the discussions in the literature.[8,24,29,34] No studies explored education as a sole intervention, a likely finding given chronic disease management literature has long acknowledged the need for multimodal interventions that include a behavioral component in addition to education.[48–50] It is difficult to elucidate the distinct impact of education alone, for example, in the context of pulmonary rehabilitation goal setting and psychological coaching. However, knowledge development is acknowledged as essential in patients' abilities to interpret treatment approaches when engaging in collaborative decision making[8,24,29,34] and to respond to the change in condition.[8,24,29,34,51] Knowledge is integral to self-management and empowerment and should be viewed as something that develops through interactions with health care professionals and through the experience of living with their disease.[8,24,29,34]

A focus on a normal life and strength instead of pathology

Patients' ability to influence the approach to their COPD care is influenced by their physical debilitation, the complexity and unpredictable trajectory of COPD, the complexity of associated treatments, the lack of economic status to access necessary supports, and the lack of health literacy and COPD-specific knowledge.[36] Several interventions or approaches sought to focus on wellness, patient strength, and beneficial change, rather than the disease cause, using the transtheoretical model of behavioral change or focused brief therapy.[24,30,33,52] Patients were facilitated to consider possible positive futures and empowered to speak about their life desires.[24,30,33,52] In focusing on strengths, rather than pathology, patients recognized their natural strength and own capacity for adjustment, no matter what the symptom burden is. Adjusting the health care professional position to not knowing promoted a sense of power for patients to participate in collaborative decision making.[24,30,33,52]

A consistent theme throughout the review was facilitating patients to access a normal life and gain back self-control and self-determination to keep doing those things that brought

joy to life, such as spending time with grandchildren.[24,30,34] Coping strategies learnt during pulmonary rehabilitation were essential in managing the impact of breathlessness,[24,34] and both pulmonary rehabilitation and motivational interviewing were reported to facilitate patients to adapt previously unattainable hopes into achievable, self-determined goals.[24,30,34]

Telehealth care and web-based interventions

Tele- and web-based interfaces are increasingly recognized as vehicles to deliver information and promote patient engagement and peer interaction.[15,41] Telehealth care has been shown to significantly increase the quality of life and reduce emergency department presentations in chronic disease[53,54] and has the potential to provide patients with accurate and reliable data that would enable them to better manage the impact of the disease.[25,26] All the studies included in this review noted an increase in the interaction with health care professionals when telemonitoring interventions were in place.[23,25,26] Access to clinical data allowed the patients to learn to interpret daily fluctuations in symptoms and validated decisions to escalate treatment when unwell.[25,26] A key benefit of telemonitoring was that the ongoing monitoring gave patients a legitimate reason to connect with health care professionals outside of acute events, allowing for discussion on ongoing issues.[25,26] Health care professionals would never deem to make clinically based decisions without clear knowledge of the current condition, yet, patients are often required to engage in sage and appropriate decision making without the same privilege. Concerns raised over the increased dependency on telemonitoring access could also be reinterpreted as increased engagement in collaborative decision making, particularly in the context of reported reduced utilization of acute and emergency services in these studies.[25,27] While there is evidence that patients find telemonitoring useful, the economic utility of this change in approach remains unclear.[55,56]

Online peer support groups are recognized to improve social well-being, enhance self-management and self-efficacy, and provide a sense of belonging and normalcy across many chronic diseases.[15–17,43–47] Social support through a variety of relationships, including health professionals, was identified as a crucial element in the maintenance and development of hope.[34] Web-based interfaces will be an increasing adjunct to traditional face-to-face supports in the future,[16–18,49] suggesting an increased need for health professionals and health care services to participate in care delivered via this medium.

Defining empowerment in COPD

The term empowerment is commonly used interchangeably with self-management and self-care in discussing patients' involvement and decision making about their condition.[7] However, patient empowerment is distinctly different from self-management in that it additionally reflects self-determination about one's own care and future and recognizes that "knowing about an illness is not the same as knowing about a person's life and that, by default, patients are the primary decision-makers".[6]

Some might argue that increased confidence in the ability to manage COPD is in itself empowerment and would have a strong argument as described by Hellem et al "a strong sense of self-efficacy facilitates perseverance in efforts toward success".[33] Thereby, enabling patients to exert influence over their situation. However, in many current approaches, the emphasis remains on patients' confidence to adhere to health care professional mandated tasks, rather than true self-determination related to patient-defined life goals. The complexity of the definition and overlap in conceptualization of this term, with other key concepts, may in itself be one of the barriers to implement patient empowerment strategies.

Implications for practice

One of the findings of this review has been that health professionals have an important role in supporting empowerment through informed and collaborative decision making, a finding consistent within the broader literature.[6,27,28,57] Historically, health care professionals have occupied a position as the authoritative figure,[6] with patients required to comply with prescribed therapeutic goals to be considered as successful self-managers.[6]

Empowering patients to determine the approach and priorities in their own care requires a shift in patient–health care professional to allow for shared authority with their expert patients.[7,57] In doing this, the success is redefined "by the relationships they create with their patients, as well as outcomes achieved by their patients" in relation to patient-determined goals.[6] This collaborative approach translates to a marked shift from patients being assessed on their ability to make correct decisions that fit in with a health professional's defined plan of care to patients making decisions that align with their own goals and needs.[27,28]

It should be noted that empowerment and engagement with health care professional recommendations are not mutually exclusive, but rather patients should be empowered to make informed decisions about their own lives with relevance to their own life goals.

Limitations

The conceptualization and definition of empowerment are not without conflict. Several papers did not overtly define empowerment; however, it was felt that they did conceptualize or address empowerment in their approach. The inclusion of such papers did rely on the interpretation of the two independent investigators; however, this is consistent with data extract processes, and all conceptual themes were validated by a panel of specialists in COPD, chronic disease management, self-management, and patient education (RTD, DAD, SCI, and MH).

Few studies assessed the extent to which the interventions or approaches were successful at promoting patient empowerment. While empowerment is an important aspect of self-management of chronic disease, it is infrequently the focus of interventions or approaches to COPD care and is less frequently still assessed as an outcome. A further limitation is that there is an assumption that empowerment is always positive in patient care, which may not be the case for all people.

Future research should explore how interventions or approaches can better engage patients in self-determination of care and life goals and how training can facilitate health care professionals in undertaking more collaborative and consultative approaches to patient care.

Conclusion

Pulmonary rehabilitation, knowledge acquisition, social support, and collaboration with health care professionals empower patients to recognize their own strengths and to manage impact of the condition. Patients' abilities to direct their own care are additionally influenced by physical debilitation, treatment complexity, economic status, and health literacy. Health care professional–patient relationships must shift to a more collaborative approach that recognizes the patient as an expert in their own condition and facilitates patients to determine their own plan of care and life goals.

Disclosure

The authors report no conflicts of interest in this work.

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