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Self-management in chronic lung disease: what is missing?

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Shareable abstract (@ERSpublications)

Self-management is often effective in chronic respiratory disease and can improve symptoms and reduce healthcare burden. Yet patients rarely feature in the design or implementation of interventions; are patients as active partners the missing ingredient? <https://bit.ly/3LiqhVg>

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Abstract

Self-management, as a strategy to support those living with chronic respiratory conditions such as asthma and COPD, has been widely advocated in guidelines and adopted in practice. However, there can be a disconnect between the goals of patients and healthcare professionals. Goals and barriers to self-management are often compounded by the complex social, emotional and medical needs of patients. People living with chronic respiratory conditions also often have symptoms of anxiety and depression, which can impact on self-management. Self-management therefore requires patients and healthcare professionals to work together and it is essential to involve patients when designing, implementing and evaluating self-management interventions.

Patient preferences are clearly important and goal setting needs an individual, flexible and responsive approach from healthcare professionals, which aligns to a more personalised approach to management of treatable traits and the burden of disease. To achieve these goals, healthcare professionals need education to support patients in self-management and behaviour change. This approach should lead to shared decision-making and partnership working that puts the patient right at the centre of their care.

Introduction

Self-management is recognised globally as an important aspect of care and management for those with long-term conditions [1]. Various definitions of self-management exist, but it can be defined as the actions taken by a patient to manage their long-term condition and maintain a good quality of life [2]. It includes the person's ability to affect the cognitive, behavioural, and emotional responses necessary to maintain a satisfactory quality of life. Self-management interventions have been found to be effective in improving patients' quality of life and reducing the number of unscheduled healthcare visits, with interventions targeting mental health being especially effective [3]. Common issues highlighted in a major review of evidence for self-management included the need to balance support and autonomy in relationships; the need for social and emotional support and/or helpful peer support; and the importance of psychological support [3]. Self-management comprises a variety of complex and multifactorial interventions, which requires an individualised and personalised approach. This viewpoint explores factors that impact on the uptake of self-management and the gaps.

Mind the gap!

Self-management is a key element for helping patients with chronic lung disease to manage their condition and improve their quality of life. The development of self-management behaviours requires that healthcare professionals and patients "work together". However, different perspectives about barriers exist [4] and need to be identified. The self-management behaviours should be accepted by patients and not add excessively to disease burden.

The use of strategies and tools to support self-management can be useful, but they should be acceptable to patients and not add excessively to disease burden, potentially leading to poor adherence [5]. If healthcare professionals fail to consider such perspectives, then it will be difficult to engage patients fully with self-management strategies.



Barriers to the implementation of self-management support in chronic respiratory disease

For patients, barriers to self-management are often compounded by complex social, emotional, and medical needs. For example, identified barriers have been found to include health literacy [6]. Health literacy, the ability of an individual to gain knowledge and information to maintain and improve health, is an important factor in any interaction between a patient and healthcare practitioners. Limited health literacy can lead to lower levels of adherence [7].

A further barrier is anxiety and depression. Patients with psychological difficulties are often less able to self-manage symptoms [8], are less likely to be physically active [9] or to attend pulmonary rehabilitation (a key evidence-based intervention for people with chronic respiratory conditions) [10].

From a healthcare practitioner's perspective, barriers often include insufficient time, resources, or appropriate skills, including the ability to address patients' psychological needs [7, 10, 11]. Healthcare practitioners may lack confidence in the ability of patients to self-manage, which can lead to a lack of encouragement or implementation into practice [6].

How can healthcare professionals support the development of better self-management in chronic respiratory disease?

In COPD, cognitive behavioural therapy (CBT) approaches, delivered by respiratory nurses, have been shown to help address psychological difficulties. A large randomised controlled trial (RCT) of CBT in COPD found that CBT techniques delivered by respiratory nurses in a brief intervention improved symptoms of anxiety and reduced use of healthcare resources (emergency department visits and hospital admissions) [12]. Consideration of patients' psychological needs is important when supporting self-management.

It is essential when addressing self-management that we mediate patient and clinician goals, perhaps using peer support strategies, such as patient support groups. Peer support has been highlighted as beneficial in helping patients to engage in self-management, but is not always appreciated by clinicians [13]. To enable patients to engage in self-management, it is important to assess their motivation. Patient activation, described as knowledge, confidence and ability to self-manage chronic illness, is a way to assess a patient's ability to engage with self-management, it can be measured using the Patient Activation Measure and is useful when assessing patients' knowledge, confidence and ability to self-manage [14].

Educating healthcare professionals is a prerequisite for effective support for patients to engage in self-management. However, universities vary in the way they cover self-management, especially concerning specialist respiratory conditions [15, 16]. For patients in primary care, where most self-management programmes are initiated, specialist knowledge and skills can be variable and sometimes lacking [17]. Healthcare professionals also need training in behavioural change techniques and support mechanisms, which have been found to improve success in patient self-management [14, 18].

Delivery considerations

When considering resources and tools for self-management, they should be acceptable to patients and should not add to disease burden [19]. Recently, there has been a move to more digitally based approaches, but not all patients want or can adjust to such technologies. Nor has efficacy been proven [20]. Appropriate assessment and support for patients should be integral to self-management interventions, which need to be adapted to local needs and individual patient circumstances. One size does not fit all.

Factors such as health literacy, health beliefs, and social and economic factors need to be considered. Health inequalities (unfair and avoidable differences in health) among respiratory patients are wide and can influence a person's ability and willingness to self-manage. They are also often linked to anxiety, depression and general outlook on life. Self-management should not be regarded as a substitute for clinical support or interventions, but rather a way to increase a patient's confidence and autonomy in deciding what elements of self-management work best for them and when.

Identification of personal goals and potential burden of treatment should be part of the shared decision-making process between clinicians and patients to enable discussion and informed choices [21].

What is missing?

Patients' perspectives and inputs are essential when designing, implementing and evaluating self-management interventions [19, 22]. A recent study found that what matters to patients the most is often beyond immediate medical needs and supports the need for a patient-centred, holistic approach [22].

The traditional medical model approach focuses on managing a specific disease but with increases in life expectancy, comorbidities are more common, and an individualised and treatable traits approach is now often advocated [4]. To support patients with chronic respiratory disease, there is a need to ensure that shared treatment goals are similar or aligned to both patients and clinicians [23] and support patients to understand the relevance of being active partners in the management of their health condition.

For patients to participate in self-management, knowledge and understanding are important. Transfer of knowledge and skills to patients is part of the healthcare professional's therapeutic relationship, but to do this the clinicians themselves need to be educated and aware of the current evidence base.

What has been done to support self-management behaviours in chronic lung disease patients?

The European Lung Foundation (ELF) and European Multicentre Bronchiectasis Audit and Research Collaboration (EMBARC) have discussed how we can involve patients in their care by inputting into guidelines, clinical trials, and educational initiatives such as joint patient and clinician conferences [17]. There is also scope to consider such initiatives at a local and individual level by consulting with patient groups, individuals and their carers, as well as ensuring patient-centred goals are set and supported. To provide evidence on how effective this approach is, we need to be able to measure patient involvement in interventions. Early work on patient satisfaction assessment has evolved into patient-reported outcome measures (PROMS), for example the COPD Assessment Test [24], and the Living with Pulmonary Fibrosis Questionnaire [25]. PROMS are embedded in clinical trials to assess symptoms and quality of life. More recently the development of patient-reported experience measures (PREMS), with patients, has enabled a more focused patient perspective to be measured [26]. The unique nature of a PREM allows the patient voice and how the patient subjectively feels about their condition overall, including affective and or emotional responses, to be heard. Whilst useful, these tools are only part of the solution and their use is dependant on healthcare professionals supporting self-management and behaviour change.

Summary

When healthcare professionals support patients to self-manage, it is important to be aware of the potential disconnect between patients and healthcare professionals. Self-management is complex and requires an individualised and personalised approach. The patient is crucial to the success of such interventions and is a vital partner. A holistic approach is required from the healthcare professional, which includes physical, psychological, social, and emotional assessment. Patient preferences are important and goal setting needs an individual, flexible, and responsive approach, this in turn aligns to a more personalised approach to management of treatable traits and the burden of disease. Education of healthcare professionals regarding the disease and management are important, but equally self-management strategies and behaviour change are significant too. Such a comprehensive approach should lead to increased shared decision-making and partnership working. Let's advocate the development of self-management skills in our patients and staff.

Conflict of interest: K. Heslop-Marshall advises being a member of the NHS England Flexible learning Group (for patients), and a director of a company which is currently developing a digital self-management programme for patients with respiratory problems. All disclosures made outside the submitted work. The remaining authors have nothing to disclose.

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