

Review



Conceptualisations of COPD self-management: A narrative review of the research literature

Chronic Illness
1–15
© The Author(s) 2022
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/17423953221115441
journals.sagepub.com/home/chi



Sarah Delaney Delaney Delaney Delaney Delaney Delaney Delaney Delane Delaney Delane Delaney Delane Delaney Del

Abstract

Aim: To examine how self-management is conceptualised in the research literature on chronic obstructive pulmonary disease (COPD).

Methods: A narrative review was undertaken to search the research literature on COPD self-management. Ten databases (2000–2021) were searched for published texts. Sixty-two articles met the inclusion criteria. A thematic analysis was conducted of the literature.

Results: Three conceptualisations of COPD self-management were identified: I) a dominant medicocentric conceptualisation which represented self-management as medical in focus; 2) a less dominant experiential conceptualisation that viewed it as arising from the experiences of people living with COPD; and 3) a smaller body of literature that attempted to integrate medicocentric and experiential conceptualisations of self-management.

Discussion: The dominance of the medicocentric conceptualisation of self-management and the polarisation of medicocentric and experiential perspectives were striking. An integrated conceptualisation of self-management has the potential to unite these competing perspectives and promote collaborative relationships between individuals and professionals, so long as the underlying values informing it are made explicit. However, there is a dearth of literature on this approach and it would benefit from more attention. Methods such as Co-production and the Personal Outcomes Approach offer the potential to support an integrated perspective in clinical practice.

Keywords

Conceptualisations of self-management, self-management, chronic illness, chronic obstructive pulmonary disease, COPD

Received 3 December 2021; accepted 13 June 2022

Corresponding author:

Sarah Delaney, Health Research Charities Ireland, Digital Office Centre, 12 Camden Row, Dublin 8, Ireland D08 R9CN Email: delaneys@tcd.ie

¹Health Research Charities Ireland, Digital Office Centre, 12 Camden Row, Dublin, Ireland

²School of Nursing and Midwifery, Trinity College Dublin, 24 D'Olier Street, Dublin, Ireland

I. Introduction

I.I. COPD

COPD is a common and chronic illness of the lungs and airways that is due to chronic inflammation usually caused by "significant exposure to noxious particles or gases" including tobacco smoke. It is characterised by breathlessness, chronic airway obstruction, and chronic cough with sputum production.² These everyday symptoms can be punctuated by exacerbations triggered by bacterial and/or viral infections, environmental pollutants, or other unknown factors. Globally, it is estimated that the number of COPD cases was 384 million in 2010 with a global prevalence of 11.7 per cent and around three million deaths annually.³ This is expected to rise over the next 40 years. While chronic, COPD is treatable, although treatment is complex and varied. A central element in the treatment of COPD is the requirement for individuals to engage in extensive and complex self-management, which can be a protracted process requiring the mobilisation of considerable resources on the part of the individual with the illness.²

1.2. Self-management

Jones et al. have pointed out that definitions of self-management are varied and confusing and the term is often used interchangeably with other terms such as "self-care". For the purposes of clarity, in this review self-care is used to cover the whole span of health from maintaining wellness to preventing illness. Self-management is used to refer to activities triggered by illness and undertaken by people living with chronic illness to manage the experience of living with COPD every day.

Although self-management as a concept may have accompanied clinical medicine for much longer (especially in societies with fewer resources who are obliged to rely on selfmanagement as a way of dealing with chronic illness), it emerged in the literature. In the

1960s and 1970s from the development of the self-help, civil rights, feminist, and consumerist movements.^{6,7} Kendall et al. argued that there was an implied idea in these movements that individuals should be active participants in choosing the direction of their own health care.6 Lorig and Holman8 highlighted that this was reflected in the clinical medical literature in the 1970s through the work of Creer and colleagues on the rehabilitation of children with chronic illness.9 However, since the 1980s and 1990s, this recognition of the potential of self-management to improve the lives of patients was accompanied by increasing attention paid to the potential of self-management to reduce the impact of chronic illness on health service utilisation and associated costs. 7,10,11

The increasing focus on self-management in chronic illness policy and practice^{6,12,19} has been reflected in a growing body of clinical and research literature on COPD selfmanagement. In her 2013 review of the COPD self-management literature, Jonsdottir⁷ argued that self-management has become linked to a problem-solving approach that emphasised issues of cost-containment and minimal use of health services in an increasingly clinical view of what self-management "should" consist of. She pointed to the emergence of an authoritative ethos in the literature on chronic illness selfmanagement and asserted that conceptualisations of self-management in the literature are informed mainly by health care professionals, eclipsing the experience, knowledge and freedom of choice of people living with chronic illness. These predominant conceptualisations of self-management have been critiqued for focusing narrowly on standardised treatment regimens.^{2,7} This is especially striking given Schrijver et al.'s reporting of high rates of suboptimal adherence to formal self-management recommendations and interventions.²⁰

Jonsdottir⁷ highlighted the need for a "paradigm shift" to reorient clinician-centred conceptualisations of COPD self-management to a patient-centred perspective in which the experience of individuals with COPD is respected.

However, it is not clear to what extent this shift has taken place and whether it is evidenced in the literature. The current review is timely in that it presents a comprehensive and updated review of the quantitative and qualitative empirical literature on COPD self-management. The specific aim of this paper is to examine how self-management is conceptualised in the research literature on COPD self-management.

2. Methods

This narrative literature review used a systematic approach to searching the literature based on an adaptation of Kable et al.'s structured approach to documenting a search strategy for publication (see supplementary file 1).²¹ A subject librarian was consulted to develop the search strategy and search terms used. The following databases were searched: Medline, CINAHL, PsycINFO, Embase, Web Science, ASSIA. In addition, the following grey literature databases were searched: Open Grey, **Proquest** dissertations, LENUS. OpenAIRE. A search of relevant references in identified texts was also conducted. The search was limited to English language articles published from January 2000 to April 2021. Texts were included if they had a population of adults aged 18 and over with COPD, if they focused on COPD, and if they reported on self-management.

Texts were excluded if they did not focus on COPD, if they did not report on or conceptualise self-management, if they focused solely on dyspnoea self-management, and if they did not focus on adults aged 18 and over. Publications that were not empirical texts (such as theoretical and conceptual papers, study protocols, editorials, letters, book reviews, or non-systematic evidence summaries) were excluded, as were texts that reported on the same study as a prior publication. The search terms used in the search are set out in Table 1.

The search terms were used to search the databases with the article titles, abstracts, and body all searched. The search terms were tested to check that they effectively located the types of articles that were consistent with the inclusion criteria prior to conducting the search in all engines. The search was conducted sequentially using the search engines. This process and the search results are documented in supplementary file 2 accompanying this review.

Titles and abstracts were screened for relevance, after which full texts were screened for eligibility according to the inclusion and exclusion criteria set for this review. The reference management software EndNote was used to

Table 1.	. Search	terms	used in	the	review.

	Concept I Searched using OR	Concepts I and 2 combined using AND	Concept 2 Searched using OR
MESH Terms	Pulmonary Disease, Chronic Obstructive Chronic Obstructive Pulmonary Disease Chronic Obstructive Lung Disease		Self-Care Self-Management Self-Monitoring Self-Care Skills
Keywords	Chronic Obstructive NEAR 3 lung* OR airway* OR pulmonary* Chronic Obstructive Lung Disease Chronic Obstructive Airway Disease Chronic Obstructive Pulmonary Disease		Self-Manag* Self-Car* Self-Monitor* Self Manag* Self Car* Self Monitor*

ensure a systematic and structured approach to this process and to identify and remove duplicate texts. All articles included in this review are documented in a summary table in supplementary file 3 accompanying this review.

The number of records identified through database searching totalled 4325. Searches of the grey literature and reference lists yielded another 305 records. After removal of duplicates, title and abstract screening, and full text screening, a total of 62 articles were ultimately included in the review.

2.1. Thematic analysis of the texts

In order to identify key conceptualisations of selfmanagement in the literature on COPD selfmanagement, a thematic analysis was conducted of the texts according to Braun and Clarke's²² approach. After studying the content of the literature carefully, data were extracted from each publication regarding the authors and title, the aim of each text, type of text, study design, conceptualisation of self-management, and key findings. Key themes were then identified which were then grouped into three categories: 1) a category consisting of a conceptualisation of selfmanagement as compliance with a set of practices as defined by health researchers and health care professionals (otherwise known as a "medicocentric" conceptualisation management); 2) a conceptualisation that viewed self-management as referring to how people with COPD define and practice selfmanagement independently and on their own terms (an "experiential" conceptualisation of selfmanagement); and 3) a perspective that integrated elements of medicocentric and experiential conceptualisations of COPD self-management (an "integrated" conceptualisation management). A further thematic analysis²² was conducted of the findings from the qualitative studies within the experiential conceptualisation of self-management of COPD. Key findings were extracted, coded and collated into themes that represented the different aspects of experiences of self-management.

3. Results

3.1. Characteristics of included texts

The publications included in this review comprised a mix of intervention studies (35), correlational studies (8), qualitative studies (16), literature reviews (2), and a quantitative descriptive survey.

Twenty-six publications were published from 2016 to 2020, followed by 21 publications that were published between 2011 and 2015. Nine publications were published between 2006 and 2010, and six between 2000 and 2005. The majority of publications were multi-national.. Of those that originated in specific countries, the bulk of texts were from Canada, the United Kingdom, the USA, or Norway. It is notable that the majority of the studies identified through the systematic search strategy was from "Western" nations with majority Caucasian populations. The health systems across these countries encompass publicly funded insurance with limited co-pay (Canada), publicly funded through general taxation (Norway and the United Kingdom), and a combination of private insurance, federal and state programmes, and not-for-profit services (the USA). It is acknowledged that the high preponderance of studies arising from these countries means that conceptualisations of COPD self-management identified in this study will be influenced by a "Western" understanding of COPD selfmanagement. Notwithstanding this, however, a wide range of other countries were also represented in the literature, these were Australia. China, Denmark, Iceland, Iran, Ireland, The Netherlands, New Zealand, Pakistan, South Korea, Switzerland, Taiwan, and Turkey.

3.2. The medicocentric conceptualisation of COPD self-management

The predominant conceptualisation identified in the literature was one which represents selfmanagement as standardised, and prescribed, and arising from the point of view of health care researchers, professionals, and policy makers. Forty-eight texts took this perspective, including 1) intervention studies, ^{23,54} 2) correlational studies, ^{4,55,61} 3) qualitative studies, ^{62,67} 4) a descriptive survey study, ⁶⁸ and 5) an integrative literature review. ⁶⁹ This conceptualisation is termed 'medicocentric', referring to the norms, values, and mores of biomedicine. Biomedicine looks at health from the point of view of the medical aspects of illness.

Self-management was conceptualised as

existing in a state of optimum functioning and

quality of life, as defined by researchers and health care professionals. 4,23,27,29,38,40,63,65,69 This was reflected in the definitions used by the authors of included texts that espoused a medicocentric conceptualisation of COPD selfmanagement (notably, 16 texts did not present formal definition management). 23,27,32,34,37,41,45,46,48,52,54,58,59,61 Many of the authors referred to medical aspects in the definitions they used, including symptom management, self-monitoring, compliance with medical regimens and selfmanagement interventions, and with the recommendations health profescare sionals. 24,26,29,31,35,36,38,39,42,43,49,50,55,57,60,62,68

The concepts of patient education and behaviour change were also included in the definitions used by authors. ^{25,26,29,35,36,38,40,42,44,47,50,51,57,62,65} However, some also included social, emotional and functional domains, such as self-esteem, ability to function in social roles, relationships with others, and living with the social consequences of illness ^{4,24,25,29,31,36,38,40,42,43,50,57,62,67,69}

Similarly, within the main body of the medicocentric texts, emphasis was placed on the treatment of COPD, carrying out disease-specific medical regimens, managing symptoms, and adherence to treatment regimens. ²³,25,28,30,32,33,35,39,43,44,47,49,50,52,59,61,63, ^{66,69} There was a strong focus on education of people with COPD. ²³,29,31,35,37,41,43,44,46,52,54, ⁵⁷,62,65 Many of the publications that took a

medicocentric perspective also emphasised the role of lifestyle and behaviour change.^{28,} 32,34,36,38,39,41,42,44,45,47,50,51,53,54,57,65,67,69

The measures used in the studies that took a medicocentric perspective reflected this trend, tending to cluster around 1) healthrelated quality of life, ^{24,26,29,31,34,36,38,45,47,48,50}, 51,53,54,70,72 of health use care resources, 23,25,27,29,31,36,38,44,47,50,53,54,61,70,71 3) clinical or physiological r 26,28,30,33,36,38,41,47,49,51,52,54,56,60,70,71 measures, 4,24, and 4) selfand 4) efficacy, ^{31,33,36,38,40,41,43,46,48,50,51,54,57,60,70,71} concept based on the work of Bandura⁷³ and operationalised by Lorig and colleagues, ^{74,76} which is defined as 'the conviction that one can successfully execute the behaviour required to produce [given] outcomes'⁷³ p. 192. A minority of studies used other measures of the social and psychological aspects of self-management such as self-management or self-care behaviour, 4,50,54,60 or social and family support 54,55,57,58,60

Some studies also encompassed personcentred concepts such as empowerment, ⁵⁷ self-management as self-initiated and self-directed, ⁵⁵ and self-management as multi-dimensional and based on factors which cross the personal, medical, psychological, social and system domains. ^{4,54,60,77,78}

Two texts^{53,69} criticised conceptualisations of self-management that adopt a medicocentric view of what people with COPD should do to self-manage, with an absence of focus on shared decision-making between health care professionals and people with COPD. However, these were in the minority of texts that took the medicocentric perspective, and they still argued that people with COPD need to be encouraged to acquire and apply specific skills in self-management.

3.3. The experiential conceptualisation on self-management of COPD

The second perspective conceptualised selfmanagement as arising from experiences of living with and managing the illness. Nine studies took this perspective. Seven of these were qualitative in design. ^{79,85} A qualitative

systematic review² and an integrative literature review⁷ also took this approach.

The texts that took an experiential conceptualisation of COPD self-management used definitions of self-management that took a disease-specific view. These definitions focused on actions taken to minimise the impact of a chronic illness. 2,7,80,81 included self-monitoring symptom management, 2,86 compliance with inhaled medication or with the recommendations of health professionals, 7,86 adequate inhalation technique, 86 patient education, 80,85 and behaviour change. 2,81 Zeb et al. also included managing the physical consequences and psychological effects of the illness⁸⁵ in their definition. There was some evidence of person-centredness in the definitions used in two studies. Cicutto et al.86 included the active participation of the person in the definition they used for COPD-related selfmanagement. Chen et al.81 described selfmanagement as a "dynamic process in which people with COPD choose the behaviours that suit them and that help them maintain the stability of their health condition" (p. 263). Four studies did not provide a formal definition self-management self-care. 79,82,84 However, in contrast, in the main body of the texts that espoused conceptualisation of self-management based on the experiences of individuals living with the illness, COPD self-management was viewed as person-centred, dynamic, multi-faceted, and autonomous..^{2,7,79,82,84} The findings of the studies that espoused an experiential conceptualisation of self-management supported a view of self-management as defined by people with COPD based on their experience of living with the illness every day. 2,7,80,85 Several authors reported findings related to the struggle to live with the demands imposed by COPD, and the different strategies that participants used to manage the illness. These strategies were 1) pacing the body; 80,83,84 2) consciously planning activities according to the needs of the body; 80,83,84 3) pushing

oneself to the limits to lead as full a life as possible; 83,84 and 4) accepting help from families networks. 80,81,85 and social The management tasks involved in achieving balance were not just clinical, they also involved managing the spiritual, social and COPD.80,81,84,85 emotional aspects of Decision-making was also identified by some authors as a fundamental process in selfmanagement of COPD^{79,81} - where people with COPD made their own self-management decisions independently and autonomously.

Participants in five studies were reported as developing their self-management practice based on the creation of knowledge from a range of sources: health care professionals, their own experiences, family, friends, spiritual sources, and traditional and complementary healers..^{79,82,85} Seven of the studies also found that the self-management activity of people with COPD was rooted in personal knowledge gained from the experience of living with and managing COPD. 2,79,83,85 Three authors reported that this was done through a process of trial-and-error, 80,82,83 and Ehrlich et al. further reported that experiential knowledge was at least partly developed through risk-taking.⁸²

However, five authors also reported challenges and barriers to self-management faced by some people.^{2,80,83,85} Russell et al. and Apps et al. found that people with COPD sometimes lacked the information necessary to practice self-management.^{2,80} Apps et al. also found a lack of confidence in individuals' experiential knowledge management. 80 Three authors reported the use of avoidant strategies. Gullick and Stainton found that some of their participants restricted themselves and gave in to a shrinking life world.⁸⁴ Cooney et al. reported that some of their participants denied the symptoms of COPD, 83 and Zeb et al. found that participants in their study faced financial constraints on the ability to self-manage.⁸⁵

This experiential conceptualisation of selfmanagement denoted self-management as reflecting experiential knowledge and personal choice. However, this was not without limits, as demonstrated by the challenges and barriers to self-management identified in some of the studies.

3.4. Integrated conceptualisation of self-management

Notwithstanding the dominance of the medicocentric conceptualisation of COPD and the management, conceptual between medicocentric and experiential conceptualisations, some studies demonstrated attempts to integrate medicocentric perspectives on self-management with more personcentred approaches. Cicutto et al. 86 attempted to integrate a medicocentric perspective with an experiential conceptualisation of selfmanagement. Using a qualitative descriptive approach, they invited participants to share their experiences of self-management, but they did not explicitly explore the link between individuals' experiences and knowledge of self-management. They conceptualised self-management as both compliance with health professionals' recommendations about disease management strategies, and as a process arising out of the experience of living with the disease. Lomundal Steinsbekk^{70,71} reported on an intervention in their prospective observational studies that was co-designed by people with COPD and health professionals. The intervention consisted of educational sessions, and the content of the last four sessions was decided by the participants based on sharing their experiences of self-management. Jonsdottir et al. 72 explicitly took a partnership-based approach to the intervention in their randomised controlled trial. This consisted of both participant and family conversations about their experiences of living with and managing COPD, and an education and behaviour change focus. Self-management in this study was therefore conceptualised as integrating participants' experiences with behaviour change and education approaches. In their qualitative study of patient's experiences, needs and strategies to cope with COPD self-management, Sigurgeirsdottir et al.⁸⁷ also integrated medicocentric and experiential conceptualisations of self-management, placing their emphasis on the experiential. This led to a tension in their findings between reporting on patients' selfreported needs and lived experiences of COPD self-management and a tendency to assign moral value to self-management coping strategies, categorising them as 'helpful' or 'unhelpful'. The authors strove for a balance between the lived experiences of patients and a view that patients engaging in 'unhelpful' strategies need to be educated in appropriate self-management as defined by health care professionals.

4. Discussion

4.1. Summary of the main findings

The findings of this review show that the domconceptualisation of COPD management in the literature is a medicocentric one. This confirms the findings of Jonsdottir's ⁷ review of self-management programmes for people living with COPD, and is supported by work done on self-management in stroke, diabetes and colorectal cancer in 2017¹¹ and on obesity, type 2 diabetes mellitus, and COPD in 2018.88 Two of the studies that used medicocentric conceptualisation showed some evidence of person-centredness, however this was more evident in the studies that took the experiential perspective.

The experiential conceptualisation of COPD self-management was based on the assumption that people with COPD know themselves, their lives, and their bodies. There was a very small body of literature identified in this review that attempted to integrate medicocentric and experiential perspectives on COPD self-management. This integrated perspective was based on an understanding of self-management as collaborative, but also inherently nuanced,

complex and multi-dimensional. However, there were persistent underpinning conflicts in this conceptualisation about who should direct self-management.

4.2. Contextualising the findings in the wider literature

This medicocentric conceptualisation of selfmanagement grounds its legitimacy in a scientific evidence-base. However, authors such as Jonsdottir, Nolte and Osborne, 89 Hosseinzadeh and Shnaigat⁵⁰ have found that the evidence for the effectiveness of purely medicocentric self-management interventions is mixed. In the wider literature on chronic illness self-management, Holm⁹⁰ and Ellis et al. 11 have criticised the focus on outcome measures such as clinical health status, health service utilisation, behaviour change, and formalised quality of life measures for being used as a proxy for managing risk and associated costs. Ellis et al.11 and Greanev and Flaherty⁹¹ have linked this to a neoliberal agenda that focuses on creating moralised citizens that are judged for their capacity to become autonomous, proactive and responsible.

Holm,⁹⁰ Ellis et al.,¹¹ and Fletcher et al.⁹² have argued that the medicocentric conceptualisation of self-management is founded on a view of self-management as an ideal set of practices and knowledge with a concomitant expectation that patients should comply with the recommendations of health care professionals. Moreover, Ellis et al.¹¹ and Franklin et al.⁸⁸ have stated that this undermines the ideals of patient autonomy and choice that are often associated with self-management in the literature.

A number of authors such as Thorne et al.,⁹³ Kendall and Rogers,¹⁵ Kendall et al.⁶ and Hujala et al.⁹⁴ have pointed to a paradoxical view in the medicocentric conceptualisation of self-management of patients as at once responsible for their own health and compliant with the expectations of health care professionals. Greaney and Flaherty⁹¹ and Hujala

et al.⁹⁴ criticised this as the shifting of responsibility for self-management to people with chronic illness without a recognition of their autonomy in making self-management decisions. Ellis et al.¹¹ suggested that a further implication of the dominance of the medicocentric perspective is that the experiential knowledge of people with COPD is marginalised in favour of the legitimacy given to health care professionals' knowledge.

If this were the only perspective to be found in the literature, it could be argued that individuals with COPD have little or no say in how they self-manage their illness. However, authors of texts that took the experiential perspective such as Apps et al.80 and Chen et al.81 emphasised that patients viewed themselves as the decision makers about their selfmanagement even if this did not concur with the prescriptions of health professionals. This is supported by work conducted by van de Bovenkamp and Dwarswaard⁹⁵ and Ellis et al. 11 which emphasised patients' ability to act freely, make their own informed decisions, and engage in 'strategic non-compliance',11 (p.31), selectively applying medical advice to either suit their lifestyle or reduce the burden of following a treatment regimen. Kendall and Rogers¹⁵ have linked the experiential approach to a view of self-management as resistance to the dominance of biomedicine, either through individuals appropriating biomedical knowledge and applying it in the course of their day-to-day activities or championing other forms of knowledge that are routinely undervalued and pushed to the margins.

However, the experiential perspective is at risk of presenting too idealistic a picture of the freedom and autonomy of people with COPD as they self-manage. Kendall et al.⁶ critiqued discourses that emphasise self-management as emancipatory (see for example the work of Lorig and colleagues^{8,75,96,97)} and pointed out that emancipation through self-management is only possible when individuals are *supported* to self-manage in the way that they choose (p.93).

Jonsdottir⁷ called for a paradigm shift away from provider-centred models of care in COPD self-management in 2013, and it is concerning that in the current review the number of studies that took an experiential conceptualisation of self-management was relatively low in comparison with the bulk of literature espousing a medicocentric conceptualisation. The polarisation of the literature between medicocentric and experiential perspectives is also striking. However, the integrated conceptualisation of self-management offers a route to a more collaborative approach to chronic illness selfmanagement. This was recommended by Koch et al. 98 and Hujala et al., 94 who viewed self-management as shared between health care professionals and people with chronic illness in a relationship.

Overall, even when attempts to integrate medicocentric and experiential conceptualisations of self-management are made, there is a tension over who determines the course of selfmanagement. However, attempts to integrate medicocentric and experiential conceptualisations of self-management aim to address this tension. Fletcher et al., 92 recognising this, cautioned against the rejection of the concept of self-management on the basis of underlying inequalities and agendas. They argued that selfmanagement can be a positive practice, integrating the knowledge and expertise of health care professionals and the lived experience of people with COPD, provided that the underpinning inequalities and values informing it are made explicit.

4.3. Strengths and limitations of this review

This is the first in-depth review focusing exclusively on conceptualisations of COPD self-management in the literature. It builds on and updates previous work conducted by Russell et al.² and Jonsdottir⁷ exploring this topic. It expands our understanding of the key perspectives adopted by researchers and scholars in this field and how these give rise to different

conceptualisations of COPD self-management in the research literature. A valuable contribution is also made by this review to the body knowledge on chronic illness selfmanagement by focusing on COPD, an illness that is often stigmatised and overlooked. 12 This literature review benefits from the use of a systematic approach to literature searching. The heterogeneity of the included texts, bringing together quantitative and qualitative empirical studies, made comparison between the texts somewhat challenging. However, this heterogeneity contributed an added richness and depth to the review and allowed us to report a comprehensive analysis of the available literature.

5. Conclusion and implications for future research

The polarisation of the research literature into medicocentric and experiential conceptualisations of self-management has been addressed to a certain extent by the small body of research that attempts to integrate medicocentric and experiential conceptualisations of COPD selfmanagement into a united, holistic perspective. However, this integrated conceptualisation is very much in the minority. Future research and clinical practice needs to recognise it as unique, individualised, holistic, complex, and multi-dimensional. It is important to emphasise, however, that we do not mean that medicocentric self-management is in any way equivalent to mismanagement of COPD, rather we wish to highlight the importance of integrating medical and experiential approaches to COPD self-management.

There are two useful approaches that can help people with COPD engage in self-management based on an integration of their own experiential knowledge, and the clinical knowledge and expertise of health care professionals. The first is co-production, where people with COPD are recruited and resourced to take part in the design, development and implementation of self-management support. ⁹⁹ The second approach is

known as the Personal Outcomes Approach. This consists of a structured conversation between health care professionals and COPD patients and explores what matters to the person, eliciting their own knowledge and experience of self-management. The Personal Outcomes Network¹⁰⁰ website has collected training materials and resources on this approach. In this way, the best of the medicocentric perspective (such as knowledge of best practice in medical management of COPD at home) and the best of the experiential perspective (such as the recognition of the wealth of experience, knowledge, and skills of people with COPD) can be brought together to place the individual at the heart of self-management support and practice in a collaborative relationship with health care professionals. This would enrich not only individuals' practice of self-management, but also the knowledge and practice of health care professionals.

Acknowledgements

The authors would like to thank Mrs Jessica Eustace-Cook for her considerable support in the design of the search strategy for this review. The authors would also like to thank the anonymous reviewers who provided critical revision of the draft of this manuscript. SD would like to thank PC, SHM and Professor Geralyn Hynes for their supervision and guidance on the PhD study of which this review formed an important element.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Trinity College Dublin, (grant number 1252 PhD Studentship).

ORCID iDs

Sarah Delaney https://orcid.org/0000-0002-2143-4743

Patricia Cronin https://orcid.org/0000-0001-5806-120X

Supplemental material

Supplemental material for this article is available online.

References

- Global Initiative for Chronic Obstructive Lung Disease (GOLD). Global Strategy for the Diagnosis, Management, and Prevention of Chronic Obstructive Pulmonary Disease (2020 Report). Global Initiative for Chronic Obstructive Lung Disease, 2020.
- Russell S, Ogunbayo OJ, Newham JJ, et al. .
 Qualitative systematic review of barriers and facilitators to self-management of chronic obstructive pulmonary disease: views of patients and healthcare professionals. NPJ Prim Care Respir Med 2018; 28: 1–13.
- Global Initiative for Chronic Obstructive Lung Disease (GOLD). Global Strategy for the Diagnosis, Management, and Prevention of Chronic Obstructive Pulmonary Disease (2020 Report). Global Initiative for Chronic Obstructive Lung Disease, 2021.
- 4. Bringsvor HB, Skaug K, Langeland E, et al. Symptom burden and self-management in persons with chronic obstructive pulmonary disease. *International Journal of COPD* 2018; 13: 365–373.
- Jones MC, MacGillivray S, Kroll T, et al. A thematic analysis of the conceptualisation of self-care, self-management and selfmanagement support in the long-term conditions management literature. *J Nurs Healthc Chronic Illn* 2011; 3: 174–185.
- Kendall E, Ehrlich C, Sunderland N, et al. Self-managing versus self-management: reinvigorating the socio-political dimensions of selfmanagement. *Chronic Illn* 2011; 7: 87–98.
- Jonsdottir H. Self-management programmes for people living with chronic obstructive pulmonary disease: a call for a reconceptualisation. *J Clin Nurs* 2013; 22: 621–637.
- Lorig KR and Holman HR. Self-management education: history, definition, outcomes, and mechanisms. *Ann Behav Med* 2003; 26: 1–7.
- Creer T, Renne C, and Christian W. Behavioral contributions to rehabilitation

- and childhood asthma. *Rehabil Lit* 1976; 37: 226–232.
- Newbould J, Taylor D, and Bury M. Lay-led self-management in chronic illness: a review of the evidence. *Chronic Illn* 2006; 2: 249– 261.
- 11. Ellis J, Boger E, Latter S, et al. Conceptualisation of the 'good' self-manager: a qualitative investigation of stakeholder views on the self-management of long-term health conditions. *Soc Sci Med* 2017; 176: 25–33.
- 12. Health Service Executive. *National clinical* programme for respiratory. End-to-end COPD model of care. Dublin: Health Service Executive, 2019.
- Wilson PM. A policy analysis of the expert patient in the United Kingdom: self-care as an expression of pastoral power? *Health Soc Care Community* 2001; 9: 134–142.
- Wilson PM. The expert patient: an exploration of self-management in long term conditions. Hertfordshire: University of Hertfordshire, 2007.
- Kendall E and Rogers A. Extinguishing the social?: state sponsored self-care policy and the chronic disease self-management programme. *Disabil Soc* 2007; 22: 129–143.
- Lawn S, McMillan J, and Pulvirenti M. Chronic condition self-management: expectations of responsibility. *Patient Educ Couns* 2011; 84: e5–e8.
- Department of Health and Children. Tackling chronic disease: a policy framework for the management of chronic diseases. 2008.
- 18. Health Service Executive. *The health service executive chronic illness framework.* Dublin: Health Service Executive, 2008.
- 19. Chronic Conditions Working Group. Living well with a chronic condition: framework for self-management support national framework and implementation plan for self-management support for chronic conditions: COPD, asthma, diabetes and cardiovascular disease. Dublin: Health Service Executive (HSE), 2017.
- Schrijver J, Effing TW, Brusse-Keizer M, et al. Predictors of patient adherence to COPD self-management exacerbation action plans. Patient Educ Couns 2020; 104: 163–170.
- Kable AK, Pich J, and Maslin-Prothero SE. A structured approach to documenting a search

- strategy for publication: a 12 step guideline for authors. *Nurse Educ Today* 2012; 32: 878–886.
- Braun V and Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;
 77–101.
- Gallefoss F and Bakke PS. Cost-benefit and cost-effectiveness analysis of self-management in patients with COPD - A 1-year follow-up randomized, controlled trial. *Respir Med* 2002; 96: 424–431.
- Bourbeau J. Disease-specific self-management programs in patients with advanced chronic obstructive pulmonary disease - A comprehensive and critical evaluation. *Disease Management & Health Outcomes* 2003; 11: 311–319.
- Bourbeau J, Julien M, Maltais F, et al. Reduction of hospital utilization in patients with chronic obstructive pulmonary disease: a disease-specific self-management intervention. Arch Intern Med 2003: 163: 585–591.
- Monninkhof E, van der Valk P, van der Palen J, et al. Effects of a comprehensive selfmanagement programme in patients with chronic obstructive pulmonary disease. *Eur Respir J* 2003; 22: 815–820.
- Gadoury M-A, Schwartzman K, Rouleau M, et al. Self-management reduces both shortand long-term hospitalisation in COPD. *Eur Respir J* 2005; 26: 853–857.
- Kheirabadi GR, Keypour M, Attaran N, et al. Effect of add-on "self management and behavior modification" education on severity of COPD. *Tanaffos* 2008; 7: 23–30.
- 29. Labrecque M, Rabhi K, Laurin C, et al. Can a self-management education program for patients with chronic obstructive pulmonary disease improve quality of life? *Can Respir J* 2011; 18: e77–e81.
- Bentsen SB, Langeland E, and Holm AL. Evaluation of self-management interventions for chronic obstructive pulmonary disease. *J Nurs Manag* 2012; 20: 802–813.
- Taylor SJC, Sohanpal R, Bremner SA, et al. Self-management support for moderate-to-severe chronic obstructive pulmonary disease: a pilot randomised controlled trial. *British Journal of General Practice* 2012; 62: e687–ee95.
- 32. Benzo R, Vickers K, Ernst D, et al. Development and feasibility of a self-management intervention for chronic obstructive pulmonary disease

delivered with motivational interviewing strategies. *J Cardiopulm Rehabil Prev* 2013; 33: 113–123.

- 33. Mitchell KE, Johnson-Warrington V, Apps LD, et al. A self-management programme for COPD: a randomised controlled trial. *Eur Respir J* 2014; 44: 1538–1547.
- 34. Turner AP, Anderson JK, Wallace LM, et al. Evaluation of a self-management programme for patients with chronic obstructive pulmonary disease. *Chron Respir Dis* 2014; 11: 163–172.
- 35. Yu SH, Guo AM, and Zhang XJ. Effects of self-management education on quality of life of patients with chronic obstructive pulmonary disease. *International Journal of Nursing Sciences* 2014; 1: 53–57.
- Zwerink M, Brusse-Keizer M, van der Valk PDLPM, et al. Self management for patients with chronic obstructive pulmonary disease. Cochrane Database Syst Rev 2014; 3: CD002990.
- 37. Hardinge M, Rutter H, Velardo C, et al. Using a mobile health application to support self-management in chronic obstructive pulmonary disease: a six-month cohort study. *BMC Med Inform Decis Mak* 2015; 15: 46.
- Jordan RE, Majothi S, Heneghan NR, et al. Supported self-management for patients with moderate to severe chronic obstructive pulmonary disease (COPD): an evidence synthesis and economic analysis. *Health Technol Assess* 2015; 19: 1–515.
- 39. Majothi S, Jolly K, Heneghan NR, et al. Supported self-management for patients with COPD who have recently been discharged from hospital: a systematic review and meta-analysis. *Int J Chron Obstruct Pulmon Dis* 2015; 10: 853–867.
- Cannon D, Buys N, Sriram KB, et al. The effects of chronic obstructive pulmonary disease self-management interventions on improvement of quality of life in COPD patients: a meta-analysis. *Respir Med* 2016; 121: 81–90.
- 41. Johnson-Warrington V, Rees K, Gelder C, et al. Can a supported self-management program for COPD upon hospital discharge reduce readmissions? A randomized controlled trial. *Int J Chron Obstruct Pulmon Dis* 2016; 11: 1161–1169.
- 42. Jolly K, Majothi S, Sitch AJ, et al. Self-management of health care behaviors for

- COPD: a systematic review and meta-analysis. *International Journal of COPD* 2016; 11: 305–326.
- 43. Baker E and Fatoye F. Clinical and cost effectiveness of nurse-led self-management interventions for patients with copd in primary care: a systematic review. *Int J Nurs Stud* 2017; 71: 125–138.
- Murphy LA, Harrington P, Taylor SJC, et al. Clinical-effectiveness of self-management interventions in chronic obstructive pulmonary disease: an overview of reviews. *Chron Respir Dis* 2017; 14: 276–288.
- 45. Newham JJ, Presseau J, Heslop-Marshall K, et al. Features of self-management interventions for people with COPD associated with improved health-related quality of life and reduced emergency department visits: a systematic review and meta-analysis. *International Journal of COPD* 2017; 12: 1705–1720.
- 46. Ng WI and Smith GD. Effects of a self-management education program on self-efficacy in patients with COPD: a mixed-methods sequential explanatory designed study. *International Journal of COPD* 2017; 12: 2129–2139.
- 47. Wang T, Tan J-Y, Xiao LD, et al. Effectiveness of disease-specific self-management education on health outcomes in patients with chronic obstructive pulmonary disease: an updated systematic review and meta-analysis. *Patient Educ Couns* 2017; 100: 1432–1446.
- 48. Steurer-Stey C, Lana KD, Braun J, et al. Effects of the "living well with COPD" intervention in primary care: a comparative study. *Eur Respir J* 2018; 51: 1701375.
- Heidaripor N, Saeedinezhad F, and Kykha A. The effect of self-care training on spirometric indices in patients with chronic obstructive pulmonary disease: a clinical trial study. *Medical-Surgical Nursing Journal* 2019; 8: 1–6.
- 50. Hosseinzadeh H and Shnaigat M. Effectiveness of chronic obstructive pulmonary disease self-management interventions in primary care settings: a systematic review. Aust J Prim Health 2019; 25: 195–204.
- Liou HL, Huang YT, Lai ZY, et al. Improving self-care efficacy and quality of life with a selfmanagement program among patients with

- chronic obstructive pulmonary disease: a quasi-experimental study. *Nurs Health Sci* 2020; 22: 629–638.
- 52. Çevirme A and Gökçay G. The impact of an education-based intervention program (EBIP) on dyspnea and chronic self-care management among chronic obstructive pulmonary disease patients: a randomized controlled study. Saudi Med J 2020; 41: 1350–1358.
- 53. Gagné M, Lauzier S, Babineau-Therrien J, et al. COPD-Specific Self-Management support provided by trained educators in everyday practice is associated with improved quality of life, health-directed behaviors, and skill and technique acquisition: a convergent embedded mixed-methods study. *Patient* 2020; 13: 103–119.
- 54. Park SK, Bang CH, and Lee SH. Evaluating the effect of a smartphone app-based selfmanagement program for people with COPD: a randomized controlled trial. *Applied Nursing Research: ANR* 2020; 52: 151231.
- Kaşikçi MK and Alberto J. Family support, perceived self-efficacy and self-care behaviour of turkish patients with chronic obstructive pulmonary disease. *J Clin Nurs* 2007; 16: 1468–1478.
- Warwick M, Gallagher R, Chenoweth L, et al. Self-management and symptom monitoring among older adults with chronic obstructive pulmonary disease. *J Adv Nurs* 2010; 66: 784–793.
- Kwua-Yun W, Pei-Yi S, Sheng-Tzu Y, et al. Influence of family caregiver caring behavior on COPD Patients' self-care behavior in Taiwan. Respir Care 2012; 57: 263–272.
- Chen Z, Fan VS, Belza B, et al. Association between social support and self-care behaviors in adults with chronic obstructive pulmonary disease. *Ann Am Thorac Soc* 2017; 14: 1419–1427.
- 59. Khan A and Dickens AP, Adab P and Jordan RE. Self-management behaviour and support among primary care COPD patients: cross-sectional analysis of data from the Birmingham chronic obstructive pulmonary disease cohort. NPJ Prim Care Respir Med 2017; 27: 1–10.
- Park SK. Factors affecting self-care behavior in Koreans with COPD. Applied Nursing Research: ANR 2017; 38: 29–37.

- O'Conor R, Muellers K, Arvanitis M, et al. Effects of health literacy and cognitive abilities on COPD self-management behaviors: a prospective cohort study. *Respir Med* 2019; 160: 105360.
- 62. Stellefson M, Chaney BH, and Chaney JD. Using exploratory focus groups to inform the development of targeted copd selfmanagement education DVDs for rural patients. *Int J Telemed Appl* 2010: 450418.
- 63. Sheridan N, Kenealy T, Salmon E, et al. Helplessness, self-blame and faith may impact on self-managemen in COPD: a qualitative study. *Prim Care Respir J* 2011; 20: 307–314.
- 64. Mousing CA and Lomborg K. Self-care 3 months after attending chronic obstructive pulmonary disease patient education: a qualitative descriptive analysis. *Patient Prefer Adherence* 2012; 6: 19–25.
- Wortz K, Cade A, Menard JR, et al. A qualitative study of patients' goals and expectations for self-management of COPD. *Prim Care Respir J* 2012; 21: 384.
- 66. Korpershoek YJG, Vervoort SCJM, Nijssen LIT, et al. Factors influencing exacerbation-related self-management in patients with COPD: a qualitative study. *International Journal of COPD* 2016; 11: 2977–2990.
- 67. Molin KR, Langberg H, Lange P, et al. Disease self-management in patients with moderate COPD: a thematic analysis. *Eur Clin Respir J* 2020; 7: 1762376.
- Cicutto LC and Brooks D. Self-care approaches to managing chronic obstructive pulmonary disease: a provincial survey. *Respir Med* 2006; 100: 1540–1546.
- Disler RT, Gallagher RD, and Davidson PM. Factors influencing self-management in chronic obstructive pulmonary disease: an integrative review. *Int J Nurs Stud* 2012; 49: 230–242.
- Lomundal BK and Steinsbekk A.
 Observational studies of a one year self-management program and a two year pulmon-ary rehabilitation program in patients with COPD. *International Journal of COPD* 2007; 2: 617–624.
- 71. Lomundal BK and Steinsbekk A. Five-year follow-up of a one-year self-management program for patients with COPD. *International Journal of COPD* 2012; 7: 87–93.

72. Jonsdottir H, Amundadottir OR, Gudmundsson G, et al. Effectiveness of a partnership-based self-management programme for patients with mild and moderate chronic obstructive pulmonary disease: a pragmatic randomized controlled trial. *J Adv Nurs* 2015; 71: 2634–2649.

- Bandura A. Self-efficacy: toward a unifying theory of behavioural change. *Psychol Rev* 1977; 84: 191–215.
- Lorig K, Gonzalez V, and Laurent D. Chronic disease self-management course leader's manual. Palo Alto, CA: Stanford Patient Education Research Centre, 1999.
- 75. Lorig KR, Sobel DS, Stewart AL, et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalisation: a randomized trial. *Med Care* 1999; 37: 5–14.
- Lorig KR, Ritter P, Stewart AL, et al. Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Med Care* 2001; 39: 1217–1223.
- 77. Wang LH, Zhao Y, Chen LY, et al. The effect of a nurse-led self-management program on outcomes of patients with chronic obstructive pulmonary disease. *Clinical Respiratory Journal* 2020; 14: 148–157.
- 78. Bringsvor HB, Langeland E, Oftedal BF, et al. Self-management and health related quality of life in persons with chronic obstructive pulmonary disease. Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation 2019; 28: 2889–2899.
- 79. Chen K-H, Chen M-L, Lee S, et al. Self-management behaviours for patients with chronic obstructive pulmonary disease: a qualitative study. *J Adv Nurs* 2008; 64: 595–604.
- Apps LD, Harrison SL, Williams JEA, et al. How do informal self-care strategies evolve among patients with chronic obstructive pulmonary disease managed in primary care? A qualitative study. *International Journal of* COPD 2014; 9: 257–263.
- 81. Chen KH, Liu CY, Shyu YIL, et al. Living with chronic obstructive pulmonary disease: the process of self-managing chronic obstructive pulmonary disease. *The Journal of Nursing Research: JNR* 2016; 24: 262–271.

82. Ehrlich C, St John W, and Kendall E. 'Listening to my body' to 'Look after my body': a theory of information use for self-management of chronic obstructive pulmonary disease. *Journal of Nursing & Healthcare of Chronic Illnesses* 2010; 2: 262–270.

- Cooney A, Mee L, Casey D, et al. Life with chronic obstructive pulmonary disease: striving for 'controlled co-existence'. *J Clin Nurs* 2013; 22: 986–995.
- 84. Gullick J and Stainton MC. Living with chronic obstructive pulmonary disease: developing conscious body management in a shrinking life-world. J Adv Nurs 2008; 64: 605–614.
- 85. Zeb H, Younas A, Ahmed I, et al. Self-care experiences of Pakistani patients with COPD and the role of family in self-care: a phenomenological inquiry. *Health Soc Care Community* 2020; 29: e174–e183.
- Cicutto L, Brooks D, and Henderson K. Self-care issues from the perspective of individuals with chronic obstructive pulmonary disease. *Patient Educ Couns* 2004; 55: 168–176.
- 87. Sigurgeirsdottir J, Halldorsdottir S, Arnardottir RH, et al. COPD Patients' experiences, self-reported needs, and needs-driven strategies to cope with self-management. *International Journal of COPD* 2019; 14: 1033–1043.
- 88. Franklin M, Lewis S, Willis K, et al. Patients' and healthcare professionals' perceptions of self-management support interactions: systematic review and qualitative synthesis. *Chronic Illn* 2018; 14: 79–103.
- 89. Nolte S and Osborne RH. A systematic review of outcomes of chronic disease self-management interventions. *Qual Life Research* 2013; 22: 1805–1816.
- 90. Holm S. Justifying patient self-management evidence based medicine or the primacy of the first person perspective. *Medicine, Health Care and Philosophy* 2005; 8: 159–164.
- 91. Greaney AM and Flaherty S. Self-care as care left undone? The ethics of the self-care agenda in contemporary healthcare policy. *Nurs Philos* 2020; 21: e12291.
- 92. Fletcher S, Kulnik ST, Demain S, et al. The problem with self-management: problematising self-management and power using a Foucauldian lens in the context of stroke care and rehabilitation. *Plos One* 2019; 14: e0218517.

- Thorne SE, Ternulf Nyhlin K, and Paterson BL. Attitudes toward patient expertise in chronic illness. *Int J Nurs Stud* 2000; 37: 303–311.
- 94. Hujala A, Rijken M, Laulainen S, et al. People with multimorbidity: forgotten outsiders or dynamic self-managers? *J Health Organ Manag* 2014; 28: 696–712.
- van de Bovenkamp HM and Dwarswaard J. The complexity of shaping self-management in daily practice. *Health Expect* 2017; 20: 952–960.
- Lorig K. Self-management of chronic illness: a model for the future (self care and older adults). *Generations* 1993; 17: 11–14.

- 97. Lorig K, Ritter PL, and Plant K. A disease-specific self-help program compared with a generalised chronic disease self-help program for arthritis patients. *Arthritis RHeum* 2005; 53: 950–957.
- Koch T, Jenkin P, and Kralik D. Chronic illness self-management: locating the 'self'. J Adv Nurs 2004; 48: 484–492.
- 99. Curtice L and Greig N. How people with lived experience and people who work in services can have good conversations and build connections to co-produce wellbeing. Glasgow: The Health and Social Care Alliance, 2020.
- 100. Personal Outcomes Network. Key Resources.