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How do informal self-care strategies evolve among patients with chronic obstructive pulmonary disease managed in primary care? A qualitative study

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Background: There is much description in the literature of how patients with chronic obstructive pulmonary disease (COPD) manage their breathlessness and engage in self-care activities; however, little of this is from the perspective of those with less severe disease, who are primarily managed in primary care. This study aimed to understand the self-care experiences of patients with COPD who are primarily managed in primary care, and to examine the challenges of engaging in such behaviors.

Methods: Semistructured interviews were carried out with 15 patients with COPD as part of a larger project evaluating a self-management intervention. Thematic analysis was supported by NVivo software (version 8, QSR International, Melbourne, Australia).

Results: Three main themes are described, ie, experiencing and understanding symptoms of COPD, current self-care activities, and the importance of family perceptions in managing COPD.

Conclusion: Self-care activities evolved spontaneously as participants experienced symptoms of COPD. However, there was a lack of awareness about whether these strategies would impact upon symptoms. Perceptions of COPD by family members posed a challenge to self-care for some participants. Health care professionals should elicit patients' prior disease experiences and utilize spontaneous attempts at disease management in future self-management. These findings have implications for promoting self-management and enhancing quality of life.

Keywords: chronic obstructive pulmonary disease, self-care, qualitative interviews, primary care

Introduction

Chronic obstructive pulmonary disease (COPD) is a progressive disease with a significant burden to the individual and society. Management of the condition is complex, but one important aim is to promote physical activity and minimize the impact on day-to-day functioning. Management can include smoking cessation, optimization of inhaled drug therapies, pulmonary rehabilitation, and strategies centered on the identification and treatment of exacerbations.

Self-care has been identified as a function that individuals must perform to maintain life, health, and well-being,¹ and more specifically applied to chronic illness, it has been defined by Riegel et al as "a process of maintaining health through health promoting practices and managing illness".² Self-management is often referred to more formally as a range of behaviors and skills necessary for

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disease management.³ These behaviors and skills are often considered as taught activities, whereas self-care could be considered as a function that occurs more automatically.¹ Supporting these behaviors has also been identified in the chronic care model⁴ to improve outcomes for those with long-term conditions.

Patients' individual experiences with the disease are important for developing the strategies to cope with increasing levels of breathlessness associated with COPD.⁵ A range of factors are considered important for influencing the adoption of self-management behaviors, including personal factors (for example, knowledge and social support) as well as contextual factors (for example, the physical environment, ie, air quality, mobility aids).⁵ Previous research, largely involving patients with moderate to severe COPD, suggests that patients experience a shift from an active to a more sedentary lifestyle and describes various strategies to adjust physically to the disease.^{6,7} "Planning, pacing and prioritizing" are described as behaviors adopted to compensate for this shift⁶ and are not unique to COPD.⁸ Early education and support has also been identified as important when adjusting to a new diagnosis of COPD, further stressing the importance of the health care relationship.^{9,10} However, much of this literature has focused on patients with moderate to severe COPD rather than mild disease.^{7,9-11} With increasing emphasis on the need to target interventions for those newly diagnosed or at mild stages of the disease, it is important to determine if the self-care experiences of those with milder levels of the disease share the same priorities for disease management. It has been stated that self-management should focus on solving what the patient perceives to be problematic.¹² However, what is less well known is how those with milder disease, who are primarily managed in the primary care setting, attempt to manage their disease and what the main challenges are to doing so. The literature currently lacks a description of self-care from the perspective of patients with less severe disease. If disease management strategies are to focus on this population, we need to have a better understanding of their perceptions of the problem.

This paper aims to address this gap in the literature by drawing on qualitative interviews with patients with less severe disease. It describes their perceptions of the impact of the condition and their corresponding attempts to manage the symptoms.

Materials and methods

This qualitative study was nested within a larger quantitative trial examining the effectiveness of a Self-management

Programme of Activity, Coping and Education (SPACE) for COPD. Details of the program are reported elsewhere.¹⁴

Participants

Patients were recruited from primary care COPD registers. Patients were eligible for the study if they had: a diagnosis of COPD confirmed by spirometry with a forced expiratory volume in 1 second/forced vital capacity (FEV₁/FVC) ratio of <70%; score 2–5 on the Medical Research Council Dyspnoea Scale (MRC);¹³ were not affected by neurological, locomotor, or cognitive problems that would prevent participation in an exercise program; and had not undertaken pulmonary rehabilitation in the previous 12 months. Participants randomized to the self-management arm of the trial were invited to attend an interview, having previously consented to the qualitative study. This was an opportunistic sample, and recruitment for the interviews stopped once it was felt that saturation had been met (n=15). One participant who earlier consented to the qualitative study later declined to attend an interview due to a lack of time. Demographics of those interviewed can be found in Table 1.

Data collection and analysis

Face-to-face, semistructured interviews took place after randomization in the randomized controlled trial but before participants had started the self-management program. Interviews were digitally recorded with participants' consent and transcribed verbatim. Interviews were carried out by one of two researchers (LDA, SLH) and took place either in the hospital or in the participant's own home as determined by the individual. The interview schedule was initially developed by researchers (LDA, SJS) and then reviewed for validity following the initial five interviews in which minor changes were made. Topics included perceptions of COPD, expectations, and understanding of self-management strategies.

The data were analyzed using thematic analysis which allows for identification of patterns in the data and rich descriptions,¹⁵ supported by the use of NVivo software (version 8, QSR International, Melbourne, Australia). Two researchers (LDA, SLH) carried out the initial coding of all transcripts. Analysis followed six stages as outlined by Braun and Clarke,¹⁵ ie, familiarization with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. A third researcher (JEAW) familiar with the study aims analyzed a subgroup of transcripts and all researchers met to ensure agreement about themes. A reflective log was kept during this process

Table 1 Baseline demographics of participants taking part in a baseline interview (n=15)

	Age	Sex	BMI	FEV ₁	FVC	MRC Dyspnoea Score	Employment	Social status	Smoking status	Disease duration (years)
1	55	Female	24.30	1.05	3.02	2	Retired	With partner	Previous	*
2	65	Male	27.20	2.10	6.05	4	Retired	Alone	Previous	*
3	78	Male	25.40	2.51	3.87	4	Retired	Supported living	Previous	3
4	82	Female	28.19	0.86	1.99	2	Retired	Alone	Never	2
5	56	Female	37.72	0.70	2.00	5	Retired	With partner	Previous	11
6	68	Female	29.70	1.55	2.95	2	Retired	With partner	Previous	7
7	60	Female	37.20	1.80	2.73	3	Working part-time	Alone	Previous	2
8	63	Female	30.90	1.54	2.62	2	Retired	With partner	Never	50
9	79	Male	23.50	2.12	2.30	3	Retired	With partner	Previous	28
10	70	Male	27.20	0.93	3.23	2	Retired	With partner	Previous	*
11	78	Female	25.53	1.65	2.28	2	Retired	With partner	Previous	*
12	61	Female	36.09	1.53	2.51	3	Working full-time	With partner	Current	8
13	82	Male	26.08	0.92	2.50	3	Retired	With family	Previous	2
14	69	Female	36.92	0.74	2.09	2	Retired	With partner	Previous	4
15	75	Male	24.20	0.78	3.05	4	Retired	With partner	Previous	30

Note: *Missing data.

Abbreviations: FEV₁, forced expiratory volume in 1 second; FVC, forced vital capacity; BMI, body mass index; MRC, Medical Research Council Dyspnoea Scale.

to ensure that themes remained grounded in the data set. Two large meta-themes emerged from the analysis: “the experience of COPD and the emergence of informal self-care strategies” and “expectations and understanding of formal self-management.” Due to space restraints and to allow for a richer description of self-care strategies, this paper focuses specifically on the first theme and describes patients’ experiences of living with COPD in three related subthemes. The second meta-theme will be published separately. A selection of illustrative, verbatim quotations are provided throughout in order to support the generalizations made from the data.

Ethics

Ethical approval was gained through the National Health Service research ethics committee (East Midlands). Written informed consent was gained from participants at the point of entering the larger self-management trial (ISRCTN33482179).

Results

The meta-theme “the impact of early experiences of COPD and informal self-management” is the main focus of this paper. It is constituted by three subthemes, ie, experiencing and understanding symptoms of COPD, current self-care activities, and the importance of family perceptions in managing COPD.

Experiencing and understanding symptoms of COPD

Shortness of breath was often the main symptom that disrupted daily tasks and prompted participants to make adaptations, plan more, or allow other family members to do tasks

for them. Participants reported feeling frustrated and confused about breathlessness and their condition more generally; something that was exacerbated by the feeling that there had been inadequate information provided to them by health care professionals. Six participants reported feeling unsure about the condition itself, its progression, and what to expect in the future. In particular, these participants felt that they lacked specific information about what to do in the event of an exacerbation, how to monitor symptoms, and when to act (see Table 2).

Feeling that their knowledge level was insufficient also had implications for how confident participants felt about

Table 2 Experiencing and understanding symptoms of COPD

Managing symptoms: “... is there a cure for this thing I should like to know and other thing is... is it like cancer, do you finish up dying from it or what?” P13

“... in one of the questions [in study questionnaire], would you know what to do if anything happened, something like that you know, now I ... I don't think I would know.” P14

“... there was no mention like that at the doctors about when you should, if you are poorly and you need to send for an ambulance, there was no mention of that.” P07

An acute event: “...at Christmas when I couldn't get rid of it myself... after 6 weeks... I said to him [Doctor] ‘it was nothing like a chest infection’ but he didn't say to me ‘you should have come before’ so I just presumed I did right... But then again, would it have got so bad if I'd gone earlier? So you don't know, do you?” P07

Advice about exercise: “I've been told to go for a 20 minute brisk walk a day, so suddenly out of the blue to be told to do that, well I said I can do 20 minutes stroll, I can do half hour stroll but 20 minutes brisk walk, are you walking with me?! ‘Oh no, no, don't do that’. They [GP] back off, they don't give me any more information.” P08

their medication use and what they should do in an acute event (see Table 2). Only two of our 15 participants recalled receiving specific advice from health care professionals about management strategies such as increasing exercise; however, in these cases, a lack of detail about what kinds of exercise to do had not led to any behavior change. These participants described receiving no further support or having any concerns allayed about whether increasing shortness of breath was harmful (see Table 2).

Despite this reported lack of understanding or knowledge, in the course of the interviews, participants described several “self-care” strategies that they had developed to limit the impact of the symptoms on their day-to-day lives.

Current self-care activities

Various strategies for limiting symptoms were described and included smoking cessation, adapting activities to accommodate breathlessness, pacing activities to conserve energy, taking more rest, and distraction from symptoms when they did occur. There was also some description of utilizing walking aids such as shopping trolleys or buggies as they were found to be effective (see Table 3).

All such strategies had been initiated by the participants without formal instruction in self-management techniques from professionals involved in their care. Often the adaptation of activities or strategies employed had evolved through the experiences they had of their illness so far. These strategies were

Table 3 Current self-care activities

“Well, I’ve started gardening, the little pots, I can’t do heavy work, you see so I’ve got all these pots in the back garden because to me, fresh air is very good and keeping moving for when I get older.” P01

Medication use: *“I’m not using my inhalers so much, either, you see, because, and I might be wrong on this, but I’m thinking if I don’t have to use the inhalers too much now, if I get worse, I’ve still got the inhalers to use before I have to go on the dreaded oxygen.” P01*

“...when I feel better I think ‘well do I really need the dinner one [inhaler]?’ To me I’m better leaving it off, just having morning and night and then when I’m bad again I can take that one at lunchtime extra.” P07

A lack of choice: *“I used to love dancing, I can’t you know, and going anywhere where there’s music now, no, no, because I want to get up and I can’t and it upsets us.” P05*

Actively involved: *“I don’t think I’ve given up anything. If anything wants doing I’ll have a go at doing it. I mean this has all been decorated by us, no, it’s just slower.”*

Influence of aging: *“At the back of my mind also is the fact that I am 79 years old, in all probability the body isn’t so responsive at that age than it would be for a younger person.” P03*

“... I think that some of it could be age related, I’ve thought this for a while. In fact, sometimes when I’m walking around at this speed [reference to walking test in assessment] I’m thinking should I be doing this at my age?” P09

introduced on a “trial and error” basis to adapt activities and try out different ways of managing symptoms, the end result being self-care activities that they felt confident worked.

As part of this self-care strategizing and informal management of their symptoms, participants also reported decisions about the use of medications and varying their use in response to symptoms. Inhalers were viewed as core to managing symptoms and participants would generally increase their use if shortness of breath felt worse. Participants also reported cutting down the use of their regular inhaler or nebulizer doses for fear of reliance or having “nowhere else to go” if their condition worsened. Participants were worried that their medications might not work as their disease progressed so they withheld doses in order that they had them to control their symptoms in the future (see Table 3). These views were limited to the regular use of inhalers: participants were more positive about using antibiotics and steroids in the event of an exacerbation if they felt that they had previously been beneficial. This discrepancy between the use of medicines during stable and acute episodes of the disease highlights how attitudes to medicines may differ over the course of the disease.

Participants differed in how much control they felt over the need to make changes in their lives. For half of the participants, changes were viewed as a necessity, that they had had “no choice” but to carry out certain activities less frequently or give them up entirely, ie, that the disease had forced the change. For other participants, the decision to adapt certain tasks was perceived as a proactive choice made in order to help themselves (see Table 3).

There were also differences in the ways participants interpreted the adaptations they were making. Loss of strength and fitness or the presence of fatigue, for some, could be attributed to getting older and not seen as a direct consequence of COPD. Participants felt that they would experience some of these symptoms without having been diagnosed with COPD. A reduced ability to engage in more physical activities was often attributed to the aging process regardless of whether they had developed a long-term health condition.

The final theme in the paper relates to the involvement of family members or partners in patients’ self-care. This was described as a challenge to self-care as participants report a dichotomy to social support whereby it was experienced as both creating conflict and being a positive source of support.

Importance of family perceptions in managing COPD

For most participants, the invisibility of their lung disease was an important consideration within their social environment.

Whilst one participant made attempts to hide her symptoms from her family when she was first diagnosed, many participants instead described the struggle of convincing their friends and family of the seriousness of their symptoms (see Table 4).

Friends and family were portrayed by participants as expecting more, in terms of household or caring duties, than they felt able to cope with. This often led to feelings of frustration and sometimes triggered conflict within relationships as participants attempted to restrict their activities whilst meeting the expectations of others around them. As described above, whilst participants would limit and avoid certain activities as a self-care strategy, such behavior could sometimes make it difficult to perform or live up to a certain role they themselves and others would have previously expected of them.

In contrast, some participants described receiving a degree of social support, which aided disease management strategies. One married participant, for example, described a successful working partnership with her husband where jobs were shared, allowing for more quality time to be spent together. For others, there was often a need for a more extensive transfer of jobs/roles to a partner or another family member. Whilst this transfer of responsibilities helped with symptom management, it was not always easy to tolerate as shifting roles again were experienced as having an impact on relationships. One male participant described a scenario where his wife had to dig a trench to prevent flooding (see Table 4). The change in roles in this case was emphasized by the sex of the participant and the transfer of a manual, and traditionally masculine, task to his female partner. Three participants who lived alone also reported sharing jobs with family members, though there was less conflict reported in these accounts.

Table 4 Family perceptions

Invisible disease: *"It's like a mental disease, in a sense there's nothing to see. A lot of people want to see a bandage on your head."* P01

"Because I don't look as though I'm ill, the upsetting thing is that people don't believe you, they think you're putting it on, sometimes even friends and family." P01

"when you're asked by your sister if you can look after her husband who's got multiple sclerosis and I said no I can't and she looked at me gone out and I thought 'you don't understand'." P01

Changing roles: *"I feel in my body, I feel as though I could but when I try, it just doesn't work. We were flooded up the top of the garden this winter and (wife) has had to dig a trench for me, I just couldn't do it myself. All sort of little things that were no problem once are now a big problem, to me anyway...as I say it's annoying to think is it me or all of a sudden, that's the problem. If it had come on slowly or if I'd have realised it was coming on I think it might have been easier."* P10

Discussion

This is the first study to focus on the experience of dyspnea and its resulting impact on activity and self-care in patients with predominantly mild to moderate COPD. There are clear parallels with studies exploring these issues in patients with severe COPD,^{9,10,16} showing that such losses and the associated distress may not be unique to the severe population and may be a core concern for anyone living with COPD who experiences reduction in activities of daily living due to breathlessness.

Participants independently initiated a range of self-management behaviors such as pacing, adapting activities, distraction, and utilizing social support, which has been described elsewhere.¹⁷ In this study, patients appeared to be unaware that they were performing self-management behaviors and instead described a lack of confidence about managing their symptoms as they did not feel confident about their current level of disease knowledge. Figure 1 outlines some of these behaviors, demonstrating the overlap between what may evolve naturally and what may require more support. Adaptive behaviors that occur more spontaneously should be further enhanced with taught skills to increase patients' confidence to manage their condition. This highlights the importance of health care professionals and the need for them to be clear with patients about how they can best manage their condition and what benefits they can expect from these techniques. Discussing patients' prior experiences with their condition and considering what self-care activities they have already engaged in may enable health care professionals to better capitalize on disease management activities in these patients. This may speed up the learning cycle that patients go through as they test and find actions to promote well-being. Such actions and the importance of disease experiences have previously been discussed in relation to "becoming an expert" in the self-management of chronic dyspnea.⁵ Although only time can provide patients with such experiences, ensuring effective and timely learning may help patients with this process. The role of health care professionals in instilling patient faith in treatment has been shown to aid participation in a disease management intervention.¹¹ This may be especially important in relation to adherence with medication since these findings demonstrate that patients may limit use of inhalers as a way of managing future progression of disease. Health care professionals are key, not only to maximizing self-care activity, but to ensuring that strategies invested in are likely to result in maximum benefit for the patient.

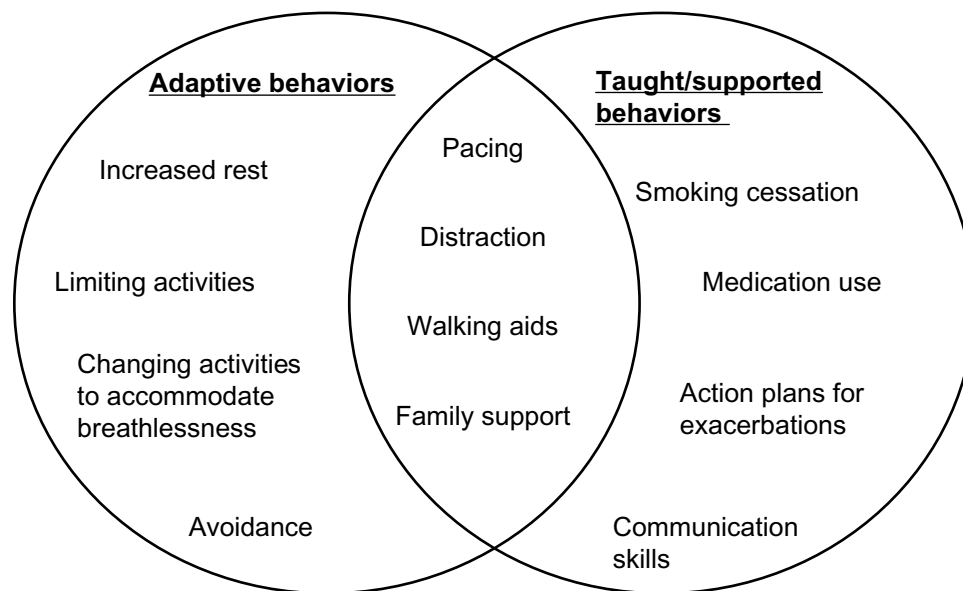


Figure 1 Adaptive self-care behaviors and behaviors that can be taught or supported by health care professionals.

Although many patients reported a reliance on family members to help with the management of their disease, there was also some conflict, as the invisibility of the disease challenged its acceptance by family members. This is a particularly interesting finding as research often focuses on the benefits of social support,^{7,10,11} although Williams highlights the issues of legitimacy and understanding of others when living with chronic lung disease.¹⁷ Participants interviewed here felt the burden of their symptoms and a need to engage in self-care, but felt this had not been acknowledged by family members around them. This seemingly unsympathetic response to patients' symptoms expressed by those closest to them perhaps in part stems from a general lack of knowledge regarding the seriousness of the disease.¹⁸ The patients taking part in these interviews were predominantly mild to moderate (with ten participants at MRC grades 2–3 and only one at MRC grade 5) and are unlikely to have experienced hospital admissions or severe exacerbations of their disease. As a result, family members may have yet to realize the significance of the disease.¹⁸

This study provides a description of living with and managing COPD from the perspective of a less severe population. The presence of an illness that affects activities of daily living may lead to a reappraisal of important activities for patients, in which autonomy is preserved as expectations are reframed according to current circumstances.¹⁹ It seems plausible to suggest that if patients feel confident and empowered about what they are doing to cope with their illness, this will encourage further positive behavior and buffer against distress as a result of the changes made. Participants spontaneously

engage in self-care activities when living with a condition that limits activities of daily living, and health care professionals should utilize these earlier experiences to better promote self-management.

There needs to be awareness among practitioners, not only of how COPD impacts on patients' activities of daily living and the family network, but also on the acceptance they feel of the adaptations they make. Early experiences of managing their condition are an important part of this picture and should be considered when designing or implementing self-management programs. Health care professionals should give advice, information, and guidance and should help patients reframe their expectations, acknowledging their current situation and enhancing autonomy.

Conclusion

This paper highlights the self-care behaviors and decision-making that patients actively and independently engage in when faced with limiting symptoms. Playing an active role or having higher levels of perceived control had been achieved by some but not others. What remains unknown, and is beyond the scope of this paper, is an understanding of which factors may influence self-management behaviors in COPD patients. Future research should examine factors that may optimize patients' participation in self-care.

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The authors report no conflicts of interest in relation to this paper.

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