



A qualitative study of patients' experiences of participating in SPACE for COPD: a Self-management Programme of Activity, Coping and Education

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ABSTRACT The aim of this study was to understand experiences of participation in a supported self-management programme for chronic obstructive pulmonary disease (COPD). There is a wealth of clinical trials examining the outcomes of self-management interventions for individuals with COPD, but current understanding regarding patients' perspectives of such complex interventions is limited. Further insight may help to tailor self-management interventions and maximise patient engagement.

Semi-structured interviews were conducted with individuals participating in a self-management programme, SPACE for COPD. Interviews took place at 6 weeks and 6 months following the programme. Data were analysed at each time point using inductive thematic analysis, and subsequently re-examined together.

40 interviews were undertaken and four themes emerged from the analysis: perceptions of the programme; lifestyle changes; social support; and disrupting factors and barriers to maintaining routines.

SPACE for COPD was acceptable to participants in this study. The importance of education and social support was emphasised at both time points studied, but there were challenges such as comorbidities, ill health of family members and limited maintenance of exercise behaviours over the longer term. Further consideration of the role of carers and partners may help to improve adherence to self-management programmes once healthcare professional support has stopped.



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Participants valued SPACE for COPD but met complex barriers to independently maintain healthy behaviour long-term <http://ow.ly/X7Ch30eMTVn>

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Introduction

The patient perspective is often neglected when examining the effects of self-management programmes for chronic obstructive pulmonary disease (COPD). There is a wealth of literature demonstrating benefits of self-management in reducing healthcare utilisation [1], increasing exercise performance [2, 3], improving knowledge [4] and enhancing health-related quality of life [5–7], alongside an increasing number of studies describing detrimental effects [8] or no impact of self-management programmes [9–11]. Inconsistencies in outcomes of complex interventions may be better understood by examining individuals' perceptions of, or experiences with these interventions. This may help inform the format, duration and content of self-management programmes for COPD as well as the degree of healthcare professional support needed.

An emerging body of literature highlights the importance of the individual's experience of living with their condition [12] and the importance of balancing life with disease management tasks [13] in the successful implementation of self-care strategies. Yet participants' experiences when attempting to improve the management of their condition by following a formal self-management programme are less well known, and self-management programmes can vary greatly in content and delivery. Disease knowledge has been identified by individuals in several studies as being important for continued self-management [13–16]; in particular a lack of knowledge about nonmedical management was expressed [16]. From the numerous trials evaluating self-management programmes for COPD only one has reported a qualitative evaluation performed post-intervention [17]. This found that the supervised exercise programme was the most important aspect of the intervention and participants were positive about both the exercise and education programmes they received. However, this intervention provided intensive support [9] with a weekly exercise programme for up to 2 years [9]. Therefore, further insights are needed regarding the perspectives of patients who receive interventions that offer less support. The SPACE for COPD (Self-management Programme of Activity, Coping and Education) programme [18] is an unsupervised programme in which participants receive a manual to follow independently with limited healthcare professional support. The unsupervised yet supported nature of this programme differs considerably from other approaches delivering self-management to COPD patients, where supervision over a longer period may be offered [9]. A recent randomised controlled trial (RCT) of this programme showed significant gains in exercise performance, knowledge, anxiety and dyspnoea at 6 weeks with some maintenance at 6 months [19]. This programme was a "lighter touch" approach. This qualitative study aims to consider how participants experienced this programme, which has potentially important implications for service development and future interventions.

Methods

Qualitative methods are an appropriate means by which to examine factors influencing the self-management of participants and allow individuals to describe their experiences. They can provide rich explanatory data and the opportunity to explore factors specifically pertinent to the patient [20].

This study was nested in a larger RCT examining the effectiveness of a self-management programme, which aimed to compare SPACE for COPD against usual care in primary care [19]. In the main trial patients were randomised to either usual general practice care or the SPACE for COPD programme, as described in box 1.

Patient selection and study setting

All participants were originally recruited from general practice COPD registers in Leicestershire (UK) and were invited to consider an interview if they had given consent to participate in the qualitative study at the beginning of the trial. Participants were invited to participate in an interview at the 6-week and 6-month follow-up if they were randomised to the self-management arm of the trial. This was an opportunistic sample.

Data collection

Baseline demographic and clinical data were collected at the initial RCT assessment as reported previously [19]. Face-to-face, semi-structured interviews lasting between 20 min and 51 min took place at the hospital or in the participant's own home, according to their preference. Data collection ended once data saturation was reached. Data collection ended in April 2012.

Interviews performed at 6 weeks explored participants' experiences of the intervention and perceptions of self-management and exercise. Interviews at 6 months explored participants' experience of continuing the intervention and explored barriers or facilitators experienced over this time period. Interviews were conducted by two researchers experienced in qualitative methodologies (LA and SH) and not involved in

Box 1 SPACE for COPD

The self-management programme described is structured around the SPACE for COPD (Self-management Programme of Activity, Coping and Education) manual. This is a 176-page manual that individuals follow independently at home.

The SPACE for COPD manual is structured across four sections containing educational material and a home exercise programme. The educational material included topics such as disease education, medications and breathing control, as well as goal-setting strategies, coping planning and case studies. The exercise programme consisted of a daily walking programme and resistance training of the upper and lower limbs using free weights three times a week. In addition, the manual included an action plan for management of exacerbations. All content was approved by the Plain English Campaign (New Mills, UK) and awarded the Crystal Mark.

Participants initially received a one-to-one introduction to the programme with a trained healthcare professional, which lasted 30-45 min. The consultations are underpinned by motivational interviewing techniques to explore readiness to change and enhance motivation to take up new behaviours relating to exercise and self-management. Education needs were discussed and initial goals explored and set using an action plan. The home exercise programme was outlined and use of the manual overall. Participants received a telephone call at 2 and 4 weeks to reinforce skills and encourage progress with the manual and home exercise programme. They had the option to call the healthcare professional if needed.

trial delivery. All interviews were digitally recorded, transcribed verbatim and entered into NVivo (version 10; QSR International, Doncaster, Australia) for analysis.

Data analysis

Data were analysed using inductive thematic analysis as it allows for identification of key patterns within the data [21]. This was supported by the use of NVivo software.

Interviews were analysed first by time point *i.e.* 6 weeks and 6 months. Following initial coding (by LA and SH) a thematic map was developed for each set of interviews and researchers met to discuss emerging themes and relationships. A third researcher (JW) familiar with the study aims analysed a subgroup of transcripts (n=3) and all researchers met to ensure agreement about themes and their description. Once

TABLE 1 Demographic profile of study participants

Age years	70.28±8.46
FEV₁ L	1.39±0.62
FVC L	2.79±0.71
Sex	
Male	19 (53)
Female	17 (47)
Marital status	
Married	24 (66.7)
Widowed	6 (16.7)
Partner	1 (2.8)
Divorced	3 (8.3)
Single	2 (5.6)
Employment status	
Retired	30 (83.3)
Working	5 (13.9)
Long-term sick leave	1 (2.8)
MRC grade	
2	20 (55.6)
3	9 (25.0)
4	4 (11.1)
5	3 (8.3)
Living with	
Partner/spouse	25 (69.4)
Alone	8 (22.2)
Family	3 (8.3)

Data are presented as mean±SD or n (%). FEV₁: forced expiratory volume in 1 s; FVC: forced vital capacity; MRC: Medical Research Council dyspnoea scale.

themes for each dataset were defined, comparisons and contrasts were made across the datasets, highlighting common themes across the time points as well as differing experiences between 6 weeks and 6 months. Themes were re-examined together to define second-order themes. A reflective log was kept during this process in which researchers made notes about key themes and important areas of interest to ensure that themes remained grounded in the dataset.

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.

Results

40 interviews were conducted with 36 participants; 16 were performed following the 6-week assessment and 24 at 6 months. Data saturation determined the end of data collection, therefore participants attending a follow-up appointment after this point had been reached would not have been approached for interview. Four participants took part at both time points. Participants' characteristics at baseline are described in table 1.

The findings from the interviews are organised according to the following four themes: perceptions of the programme; lifestyle changes; social support; and disrupting factors and barriers to maintaining routines.

Perceptions of the programme

On the whole, participants' comments regarding the SPACE for COPD programme were very positive. Participants described the content of the manual as easy to read and follow and were very satisfied with the breadth of content and the education it provided. Acknowledging that sometimes they would forget information they had read or been told about managing COPD, participants reported at 6 weeks that they could refer back to the manual and they could see it as a resource for the future as they meet new challenges with the disease.

"But safer, because you know it's there and you can fall back on it whenever you want to. You know if you're really bad and you think, oh what do I do, then you can just get the manual and have a look and it helps you... That's my little bible now [points to SPACE manual]." Female (ID189), 6 weeks

"I found the manual very well written, it was very well explained as it was written down and some parts didn't apply to me particularly, but it's nice to look through it and I felt breathless yesterday so I did look up the part on breathlessness, so it's quite useful as a reference actually." Female (ID174), 6 weeks

This was reiterated at 6 months where instances of participants returning to the manual for reminders and reassurance were described, although a small number of participants found they were using the manual less frequently or not at all. These participants expressed the feeling that they had completed the programme and were content with continuing their routines indefinitely. One participant referred to the use of a smaller leaflet provided to them by the primary care team.

"Maybe if I feel like I'm slacking I'll have a look at it, or if I don't feel very good about things. Because it just has got a sort of a reassuring theme going through it as well that lifts you up a little bit, you know." Male (ID752), 6 months

For many, the educational content was described as hugely valuable; however, one opposing view was expressed at 6 months where a participant described experiencing some anxiety resulting from the comprehensive level of the education, as they found it overwhelming.

"I didn't find a lot of it relevant with these sort of symptoms I have at the moment. I found it more anxiety-making than anything because it seemed to be mostly related to people who seem to be in a worse condition than me." Female (ID653), 6 months

All participants reported that they were satisfied with the healthcare professional support they received as part of the programme. Healthcare professional support was considered to be important and participants felt reassured by having someone they could contact by telephone if needed. At both time points, face-to-face contact with healthcare professionals was expressed as being beneficial, as it facilitated familiarisation with SPACE for COPD.

"A lot more confident that I can... that somebody's there [a health care professional] who I can talk to." Male (ID752), 6 weeks

“...sometimes when you're down...you know it's good to have that telephone number there...Because you've got someone on the other end that's got the expertise to tell you.” Male (ID639), 6 months

Lifestyle changes

Participants reported increased physical activity and exercise behaviour as well as altered medication use and the use of breathing control and chest clearance techniques. Other benefits described were decreased breathlessness, increased participation in valued activities, increased knowledge and understanding of COPD, improved energy levels and improvement in walking times.

“Very rarely get out of breath when I go out and I can even run to the bus now, which I couldn't before. Running to the bus was one of the things that really used to get me in a panic. I don't panic about things, anyway, now.” Female (ID124), 6 weeks

“At the moment the thought of actually dancing [motivates me] because I used to enjoy dancing also, not just the wife, so yeah, I can join in probably other activities as well of which I've not considered.” Male (ID204), 6 weeks

At 6 weeks, participants reported goals relating to walking times, engaging in daily tasks or aiming to return to a valued activity. At 6 months, their goals appeared to be more focused on extending walking times.

“I could have two or three stops getting myself to the car park and now I maybe stop, occasionally twice. And I'm thinking 'I'm going to get to the top this time'. And I will. So yes, setting goals is good for me.” Female (ID119), 6 weeks

“I try to do a bit what's in the manual about how far I can walk and then try and time it and progress perhaps probably not a next day, but a couple of days later try and go a little bit further in the same time.” Male (ID828), 6 months

As early as 6 weeks, participants reported translating these improvements in their exercise programme into other valued activities which may previously have been lost due to COPD. A sense of improved confidence was prominent in many of the interviews and participants reported considering other changes to their lifestyle or activities beyond the initial walking programme that had been introduced to them *via* SPACE for COPD. One participant discussed returning to dancing and another commented that she was considering having her grandchildren for school holidays, something with which she had previously felt unable to cope.

“He [son] said 'will your doctor allow you?' [to look after grandchildren] And I said, well I don't know it'll be up to the doctor really, if I feel I can do it, so I said, give me till Easter and we'll see...” Female (ID101), 6 weeks

The educational material was specifically mentioned in the 6-week interview. Prior low levels of knowledge appeared to impact upon participants' perception of their confidence in managing their condition, in particular with regards to medication use and what to do in an acute event [22]. By feeling more confident and informed to manage the condition, participants described perceiving positive behaviours, such as exercise, more favourably. They reported understanding what was beneficial for them (*e.g.* exercise) and described feeling confident to implement new behaviours (*e.g.* joining a gym facility or altering their diet).

“I've learnt more in the 6 weeks than I've known in 60 years. On the illness itself.” Female (ID189), 6 weeks

“Well, ... given me a push, haven't you with this? I mean I never would have plucked up the courage to go to the gym and say I want to join at my age. So, there you go, I mean it is because of this [SPACE for COPD programme] that I've, that I'm now joining in with things like this.” Female, aged 80 years (ID118), 6 weeks

At 6 months, individuals highlighted continuing exercise behaviours. Participants discussed the success of establishing an exercise routine earlier on in the intervention, monitoring their progress and continuing to be motivated.

“I got my Google Earth out to do my route and I've got distance and I know exactly what speed I'm going at.” Male (ID897), 6 months

Social support

Support from partners and family was described by participants as an important facilitator to engaging in an exercise programme at both 6 weeks and 6 months. This support appeared to be utilised for informational (advice), instrumental (help with tasks) and emotional reasons. Support described included advice about progressing their exercise programme, help with chores so that a participant could make time for exercise, having a walking partner or encouragement or reassurance when motivation to exercise was

waning. Healthcare professionals were often viewed as providing informational support, whereas family members or friends were more often described as providing practical or emotional forms of support.

“If it had been raining all morning and then I’ve started something else in the afternoon and it’s all brightened up, he [husband] said, ‘come on, I’ll carry on there, you go because it might rain’. You know, things like that. Sounds silly, getting the weather forecast up on the computer and all sorts he’s been doing. But it’s just somebody else involved in it, isn’t it?” Female (ID101), 6 weeks

“And my husband was very supportive so that’s important, if your family are supportive. I mean, they’re normally full of their own woes to bother with mine but (laughs) ... they were all quite keen that it [SPACE for COPD programme] would work out for me really. And even my son remembered to ring me and ask me how I’d got on.” Female (ID174), 6 weeks

Couples who felt they were accustomed to working together in general reported working in partnership with their spouse.

“It’s easier with the wife because we do lots of things all together, the gardening’s all done together. I mean when I’m working and she’s working we both do the cleaning and all that, because there’s only the two of us, we’ll do it between us, we work together like.” Male (ID147), 6 weeks

At 6 months, participants described feeling encouraged by others who noticed improvements in their abilities. This could be from healthcare professionals at outcome visits where performance on walking tests had improved, or from family and friends.

“...she [friend] said to me, you’re looking so much better and you’re walking better, why? And I said to her what I was doing ‘cos I’d kept it fairly quiet.” Female (ID527), 6 months

The availability of telephone support with the SPACE for COPD programme was seen as reassuring and provided opportunities for emotional support.

“[healthcare professional] especially on the phone when I’ve had a down week, and she’s been very good and say don’t worry about it, just leave everything off completely and ... then start again next week or when you feel better and to me that’s great ‘cos I ... I was beginning to feel oh I’ve let myself down ... but she made me feel that I hadn’t ... and it was lovely.” Female (ID527) 6 months

Disrupting factors and barriers to maintaining routines

At 6 weeks, barriers to participation included the weather, finding time or overcoming breathlessness.

“When it’s very cold, I’m not happy going out walking and when it’s windy I’m not very happy going out walking ... or too hot, I mean, you just hope the weather’s reasonable.” Female (ID174), 6 weeks

However, at 6 months, participants highlighted a wider range of more complex barriers and difficulties when trying to maintain their exercise programme. This included various disruptions to established routines and maintaining exercise regimes, including their own comorbidities, but also ill-health of spouses or family members or personal problems within the family. Participants described a re-evaluation of priorities in response to this, whereby non-COPD factors (such as a partner’s ill health) became their primary concern and subsequently led to reduced exercise behaviours.

“I mean all my other medical problems, it’s knocked the stuffing out of me a bit ... it was because of all my medical problems it just felt that I couldn’t concentrate on what I wanted to do regarding this programme.” Male (ID671), 6 months

“And it got in the way, and we were having various if you like personal problems in the sense that my youngest son was having a lot of legal problems right? And it was just family problems that got in the way, and trying to sort out all the accounts for the accountant and things like that. And frankly that took priority.” Male (ID794), 6 months

Discussion

Main findings

Following completion of the SPACE for COPD programme, participants cited the value of education and the confidence this had given them to better manage their condition. It was viewed as a resource for the future and participants enjoyed knowing they had something to refer back to. However, challenges to maintaining exercise behaviours were more pronounced at 6 months and interviews at this time point provided a rich description of the barriers faced by participants while following a self-management programme, such as illness within the family.

Education was highly valued by many participants; however, opposing opinions were expressed in a small number, highlighting how the approach may not suit all patients. One felt it was much more user-friendly to use a smaller leaflet in conjunction with his practice nurse. Another reported anxiety at 6 months from receiving such a large volume of education as they felt their illness had not been as debilitating for them. This participant was categorised as MRC grade 2 at baseline, and may have experienced milder symptoms at that point.

Participants reported confidence with adopting a walking programme as well as other lifestyle changes, yet this was not mirrored in outcome measures [19], demonstrating the complex nature of measuring these concepts. Our interviews showed a developing confidence at 6 weeks, which for some was still apparent at 6 months, although at 6 months it was also apparent that complex burdens and barriers may disrupt this confidence. This has been observed in other conditions in which self-management has failed to impact positively on self-efficacy for diabetes [23, 24], yet follow-up interviews have reported improved motivation and confidence as a result of the self-management programme [24] and highlighted the barrier of competing health and life concerns [23]. Other self-management programmes with qualitative evaluations show positive effects in wellbeing [17] and symptom control and pain [25], despite a lack of improvement in the corresponding primary outcome measures [9, 25].

As a “light” intervention, participants did not have regular face-to-face support from a healthcare professional, yet improvements in exercise capacity seen at 6 weeks were retained at 6 months [19]. A lack of direct healthcare professional support may have prompted participants to seek support in their own social environment and operate independently. In interviews at both time points, social support was a strong theme and was utilised for both practical and emotional support. It is often this level of support that is useful in maintenance phases of behaviour change, so there is clear value to this being established during the self-management programme and is an important component for learning and integrating new knowledge [26]. Social support encourages good self-management practices [26–28] and has been found to be beneficial in self-management programmes for stroke [29], COPD [14] and diabetes [24]. Although the 6-month interviews showed how reassuring this kind of support was, these later interviews provided an insight into the struggles that participants experienced when balancing other life events with disease management strategies; this echoes findings in COPD [14], diabetes [23] and angina [30]. In particular, exercise behaviour has been found to be the first strategy to be stopped by patients with COPD when difficulties are encountered [13]. Social support can be experienced from multiple sources (peers, healthcare professionals, family and friends) and for multiple purposes. However, the individual’s stage in the disease process can also influence their specific support and information needs, highlighting that this is not a “one size suits all” approach [26]. In fact, interventions that tailor to individual goals can lead to better outcomes in the daily living activities of older adults [31].

It is acknowledged in the literature that there is a dearth of studies highlighting patients’ needs and expectations regarding self-management [32], which is important in light of conflicting findings regarding the effectiveness of COPD self-management programmes, but in addition, information relating to the interventions that have been tested is lacking. Furthermore, how participants have experienced these interventions in COPD (*e.g.* what went well or what didn’t go well) is rarely described; this would inform service development.

To date, one study has described the patient experience of a COPD self-management programme [17]; in addition, it reported the value of exercise and education and improved confidence for participants. As we have found, this study highlighted the reassuring effect of contact with healthcare professionals, as has been found for other conditions [26, 29, 30].

A lack of information about COPD can be disruptive to effective self-care [22, 32]. This may not be solely due to a lack of information provided to patients. Some patients in primary care may feel ill-informed about the management of their condition, due to the socially complex nature of such discussions, which can limit the ability of both patients and healthcare professionals to utilise this discourse to maximum effect [33]. Furthermore, a qualitative study of nurses and allied healthcare professionals shows a lack of coherence about what self-management is and how to support it effectively [34], further limiting effective discourse. In addition, the provision of information to relatives is important, so as to provide adequate support to the patient [26] and to improve adherence to self-management programmes [14].

Strengths and limitations

A strength of this study is the valuable insight gained into the patient experience of participating in and maintaining a self-management programme, which has been underreported to date. The qualitative design used in this study allowed perceptions about the intervention to be explored and gave a richer description of the intervention and the post-intervention period, which would be difficult to gain from traditional

outcome data, such as health status or exercise performance measures. Participants were able to comment freely on what they found useful and, likewise, what they may not have enjoyed about the programme, although negative comments were rare in this dataset. However, participants often recalled experiences from several months ago, in particular in interviews at the later stage, and it must be considered that problems with recall or selective attention when discussing events are likely. A further limitation is that only participants who attended follow-up visits were invited for interview. This could introduce some bias, as completers of a programme are far more likely to be positive than those who do not complete it. This could be addressed in future work by inviting noncompleters of such programmes to participate, thus enabling us to consider the changes necessary to achieve behaviour change for a wide range of patients. This bias towards completers limits the transferability of these data to other self-management settings, although overall the data give us an indication of popular features of self-management programmes and the challenges for participants following the initial intervention period.

Only four participants in this qualitative study were able to take part in an interview at both time points. Due to staff constraints we were unable to recruit the same participants at both time points, so many of those interviewed at 6 months had been recruited to the study later. As a result, this may limit the interpretation of data, as we are limited in making comparisons between time points without interviews from the same individuals. Nevertheless, similar findings have been found across other chronic conditions. This feedback is valuable not only to the development of the SPACE for COPD programme, but also for the development of future self-management interventions.

Implications for future research, policy and practice

SPACE for COPD was feasible and acceptable to participants in this study. It combined initial support and instructions regarding an exercise programme with a manual resource that has been popular and valuable to participants. Further investigations into the support of carers and partners and facilitating their role may be important, as they were highlighted at both time points as a valuable source of support when adopting exercise behaviours. This source of support has been reported as important for many self-management practices across several conditions [14, 26–28], yet partners and carers were not specifically included and engaged in the delivery of this intervention. Support from healthcare professionals was found to be reassuring, both in this study and previously [17, 26, 29, 30], but what differs between these studies is the intensity and mode of provision of such support. This may require further exploration. A more focused examination of differences between those who respond and do not respond to such interventions, using interviews with both groups of participants may identify where self-management programmes may need to adapt to further increase adherence to such programmes.

Conclusion

The SPACE for COPD programme was well received by participants, and lower levels of healthcare professional support (compared to other interventions) were still favourably commented on as providing participants with reassurance. Education and social support were important for participants to engage in self-care behaviours and many readily utilised sources of support in their own environment. Comorbidities and other events in participants' social environment limited the continuation of exercise regimes.

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