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Self-management in bronchiectasis: The patients' perspective

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ABSTRACT

Aims: Self-management programmes for chronic disease are a high priority for health care providers. The content and method of delivery of self-management should give consideration to the specific requirements of the disease population. The aims of this study were to assess the physical and psychosocial impact of bronchiectasis, determine if patients with bronchiectasis are receptive to self-management and identify any obstacles or sources of support for a disease specific self-management programme. **Methods:** Thirty-two patients with a diagnosis of bronchiectasis attended four focus groups. Each focus group was videotaped and subjected to qualitative analysis using the grounded theory approach. **Results:** Bronchiectasis has an impact on a patient's physical and psychosocial well-being. Patients have the potential to self-manage with strategies including self-regulation of medication and airway clearance. Perceived obstacles to self-management include lack of information and confidence. Patients suggest that self-management could be promoted through disease specific information and appropriate health care procedures. **Conclusion:** Patients with bronchiectasis have their lives disrupted by this chronic condition, but they are receptive to self-management. This study has provided information from the patients' perspective of elements which need to be included in a disease specific self-management programme. (Word count: 191)

INTRODUCTION

Bronchiectasis is a chronic lung condition characterised by damage to the bronchial wall causing abnormal airway dilatation and poor clearance and pooling of mucus in the affected areas.[1] Symptoms include chronic cough, mucus production, dyspnoea, haemoptysis, malaise, weight loss and repeated exacerbations.[2] As this is a long-term condition patients have to cope with these symptoms over the course of their life. Patients with bronchiectasis may have a reduced quality of life and increased anxiety and depression.[3][4]

Current management of bronchiectasis includes antibiotic therapy, airway clearance, exercise and pulmonary rehabilitation and a range of inhaled medication.[2] The World Health Organisation advocates the addition of self-management programmes for long term conditions, like bronchiectasis, to enhance patient care.[5] Self management refers to how patients manage the day-to-day care over the length of their disease and includes adherence to medical treatments, actions to prevent ill health and promote good health, dealing with psychological and social needs and communication with health care practitioners.[6][7]

Self-management programmes offer the potential to include disease specific self-management strategies such as those available for asthma, chronic obstructive airways disease (COPD), and cystic fibrosis (CF).[8][9][10] There are no disease specific self-management strategies for bronchiectasis and the development of such a programme needs to ensure that the specific needs of the disease population are identified and included.[11] This focus group study was conducted to explore in depth the concept of self-management, from the patients' perspective. Focus groups have been used previously to assess the needs of patients and for developing new or

redefining services.[12] They have a high level of face validity because elements of the discussion can be immediately confirmed or disputed among the participants.

The specific aims of this study were to investigate the impact of bronchiectasis on the patient's physical and psychosocial functioning; identify if patients with bronchiectasis were engaging in self-management; identify any perceived obstacles to self-management; and identify perceived sources of support for self-management.

METHODS

Ethics

The local medical research ethics committee approved the study and the patients gave informed written consent.

Recruitment

Patients with bronchiectasis who regularly attend specialist respiratory clinics at Belfast City Hospital (n=39) were recruited to attend four focus groups; this number is often recommended to obtain theoretical saturation for homogenous groups. The focus groups were segmented according to gender and age (Figure 1). Inclusion criteria were: close proximity to the hospital, confirmation of diagnosis by computed tomography (CT) scan, and the presence of airways obstruction. Exclusion criteria were: oxygen dependency, colonisation of *Pseudomonas aeruginosa* / MRSA in sputum tests, communication difficulties, mobility problems, participation in a previous trial within 3 months, and a history of non-attendance. Characteristics of patients attending the focus groups are outlined in Table 1.

Table 1: Focus Group Profiles

	Group 1 Males, 18-64 yrs (n = 9)	Group 2 Females, 65+ yrs (n = 8)	Group 3 Males, 65+ yrs (n=5)	Group 4 Females, 18-64 yrs (n = 10)
Lung function category*	Mild, n = 0 Moderate, n = 4 Severe, n = 5 Very severe, n= 0	Mild, n = 0 Moderate, n = 2 Severe, n = 5 Very severe, n= 1	Mild, n = 0 Moderate, n = 3 Severe, n = 1 Very severe, n= 1	Mild, n = 0 Moderate, n = 8 Severe, n = 1 Very severe, n= 1
Antibiotic courses in previous 6 months	Median: 4 Range: 3 - 4	Median: 1.5 Range: 1 - 3	Median: 4 Range: 0 - 6	Median: 4 Range: 0 – 8
Respiratory clinic visits in previous 6 months	Median: 1 Range: 0 - 3	Median: 1 Range: 0 - 1	Median: 2 Range: 0 - 6	Median: 1 Range: 0 - 8
Number of hospital admissions in previous 6 months	1	3	1	1

* According to GOLD guidelines.[13]

Data collection

An experienced moderator facilitated the focus groups. The moderator had over ten years of experience of developing, organising and facilitating focus groups on a range of topics, and coding and analysing the resulting data. A structured schedule of topics was developed which was used to guide the discussion. The questions were reviewed by the moderator prior to conducting the focus groups and modified to ensure the questions were open-ended (Table 2). All four focus groups were videotaped.

Table 2: Schedule of topics for focus group study

1. What does self-management mean to you?
2. What aspects of your bronchiectasis are currently easy to self-manage?
3. What aspects of your bronchiectasis are currently difficult to self-manage?
4. How could self-management be improved in relation to information about medication, physiotherapy, nutrition, exercise and hospital admissions?
5. What contact do you currently have with the bronchiectasis service?
   - what is good about that contact?
   - what is not so good about that contact?
6. How could the bronchiectasis service help you manage your bronchiectasis better at home?
7. Are there other measures that could help you manage your bronchiectasis better at home e.g. childcare, care of elderly relatives, assistance from other agencies?
8. Why would you like to be able to self-manage?
9. What sorts of issues limit self-management generally?

ANALYSIS

Analysis of the focus groups was conducted in four stages; debriefing, transcription, selective coding, and triangulation. Saturation of subcategories was obtained by the fourth focus group.

Debriefing: A debrief was conducted the day after each focus group with the specialist physiotherapist and specialist nurse. Group norms and conflicting views were identified for each focus group. Topics discussed in each focus group were reviewed and compared to the previous group. The schedule of topics for the subsequent focus group was modified as appropriate, ensuring that any important additional issues were explored.

Transcription: The investigator manually transcribed the recordings of each focus group.

Selective coding: Coding was based on the grounded theory approach to qualitative analysis. Quotes relating to one topic were grouped together as subcategories and integrated under four main core categories, which related to the aims of the study. The four main core categories were (i) physical and psychosocial impact of bronchiectasis (ii) Self-management strategies used by patients with bronchiectasis (iii) Perceived obstacles to self-management of bronchiectasis and (iv) Perceived sources of support for self-management of bronchiectasis

Triangulation: A second researcher verified the core and subcategories. Member checking and a follow up questionnaire supported the results of the analysis.

RESULTS

Core category 1: Effect of bronchiectasis on physical and psychosocial functioning

Patients reported that bronchiectasis had an impact on their physical and psychosocial functioning (Table 3).

Table 3: Core category: Physical and psychosocial impact of bronchiectasis

Physical impact subcategories: Reduced ability to do house work, reduced ability to do leisure activities
Psychosocial impact subcategories: Depression, worry, annoyance, fear, nervousness, embarrassment, reduced confidence, low self-esteem, poor self-image, relocation, difficulty in planning events, altered relationships with family and work colleagues, increased time off work for hospital appointments and illness, increased holiday insurance

Reduced ability to do house work and leisure activities were consistent subcategories discussed in all four focus groups in relation to the physical impact of bronchiectasis, illustrated by the following quotes:

"I find if I am vacuuming just maybe a couple of square meters I would be out of puff and have to sit down…ten years ago I was able to build my own house" (Male, 18-64yrs)

"I play bowls but I've had to give up" (Male, 65+yrs)

Emotional issues related to having bronchiectasis, which were frequently due to symptoms, were consistently discussed in all four focus groups:

"When you have an exacerbation of this, it is a disgusting disease you know, and you have a poor self-image" (Male, 18-64yrs)

Socially patients home and working lives were affected by the bronchiectasis; one patient couldn't cope after having a bad exacerbation and had to live with her daughter for a period of time; another patient had to regularly take time of work:

"I seem to be having an awful lot of time of work…you can't guarantee that one week you're OK, and the next week you are maybe off again" (Female, 18-64yrs)

Core category 2: Self-management strategies

Some patients with bronchiectasis in this study perceived self-management as an approach independent from the health professional and others perceived self-management as a treatment regimen directed by a health professional, as illustrated by the following quotes:

"To me self-management began when I was first diagnosed. First of all finding out as much as I could about the condition, what it is, what causes, what possible causes of it. There are a number of causes of it some of them unknown. What sort of treatments, in terms of medication and self-help should I be looking to, and to do that I hit the Internet".
(Male, 18-64 yrs).

"Self-management to me means when I get up in the mornings I have to do postural drainage, and sort of clapping of the lungs" (Female 18-64 yrs).

Patients with bronchiectasis perceived they were engaging in a range of self-management strategies (Table 4).

Table 4: Core category: Self-management strategies currently used by patients with bronchiectasis

Adherence to medical treatments subcategories: Self-administration of intravenous antibiotics, having reserve oral antibiotics, performing airway clearance, using inhaled and nebulised therapies, receiving vaccinations
Prevention of ill health / promotion of good health subcategories: Monitoring of symptoms and signs, sending a sputum sample for testing, exercising, dietary changes, reducing alcohol intake, smoking cessation, avoidance of irritants, complementary and alternative medicine
Dealing with psychological and social needs subcategories: Attending a psychiatrist, acceptance, problem solving, attending an evening class, employing a housekeeper
Communication subcategories: Contacting the bronchiectasis multidisciplinary team, general practitioner, pharmacist, social services, ambulance service, insurance company

Subcategories consistent across all four focus groups included antibiotic therapy, performing airway clearance, having an exercise regimen, complementary and alternative medicine and problem solving as illustrated by the following quotes:

"I always think it is a good thing to have antibiotics in the house" (Female, 65+yrs)

"I do postural drainage every morning" (Female, 18-64yrs)

"Exercise is the biggest component of my self help there is no doubt about that"
(Male, 18-64yrs)

"I take a cod liver oil capsule every morning" (Male, 65+yrs)

"I'd a problem with the garden, lawn mowing. I've got a large garden but I bought a ride-on lawn mower" (Male 18-64 yrs)

Most patients were prescribed inhaled or nebulised therapy and the majority of patients agreed that it was important they received annual influenza vaccinations, with some having also received the pneumococcal vaccination. Nutritional advice appeared to be lacking in all four focus groups. Monitoring of bronchiectasis was evident by the patient's ability to differentiate symptoms between stable and exacerbation phases, but patients reported a wide variation in symptoms during an exacerbation. A small number of patients made a decision to avoid situations or stimulants that would irritate their bronchiectasis, as part of their self-management approach:

"I went to the pub quite a lot but now I don't. About once a week I would go because I just can't stick the smoke in the place" (Male, 18-64yrs)

Some patients had built up relationships with health care professionals including their GP and pharmacist. Having a named contact person at the bronchiectasis service was seen as useful.

Core Category 3: Obstacles to self-management

Patients with bronchiectasis perceived a number of obstacles to self-management and subcategories identified related to the condition or other health issues and psychological or social influences (Table 5).

Table 5: Core category: Perceived obstacles to self-management of bronchiectasis

Disease related obstacles subcategories: Disease severity / stability, health service policies, lack of information on disease process, side effects of treatment, complications of bronchiectasis, other medical conditions, advancing age
Psychological obstacles subcategories: Fear, lack of confidence, lack of competence, lack of motivation, lack of support
Social obstacles subcategories: Personal circumstances, lifestyle preferences, financial reasons, lack of time, adverse weather conditions

The most consistent obstacle to self-management, discussed in all four focus groups, was in relation to disease severity / stability. Patients did not initiate or continue self-management strategies if they had no symptoms or little change in their symptoms:

"I have been with the physios twice, but I have no regime of management…because I don't believe I've got a severe case of this (bronchiectasis)" (Male, 18-64 yrs)

Patients perceived that hospital and primary care practices caused a delay in medical treatment. Some patients felt there was an unnecessary long time lag between sending a sputum sample for testing and obtaining the results. Patients had difficulty getting reserve antibiotics, especially when going on holiday and others didn't like taking "a lot of" antibiotics as they experienced thrush as a side effect. Patients tended to be aware of the symptoms of bronchiectasis but some were unaware of what bronchiectasis was, its prognosis, how it affected the lungs and the significance of test results:

"The only thing ever I was told was, that's very good (spirometry). I don't know what very good would be…I always come away a wee bit frustrated" (Male, 65+ yrs)

Psychological influences tended to prevent patients from engaging in self-management or limited the effectiveness of self-management:

"Motivation's hard for me you know to get back to swimming" (Male, 18-64yrs)

"I say to myself when I'm doing it (postural drainage)…I wonder is this all useless, am I doing it right" (Female, 65+yrs)

Social obstacles to self-management influenced health care regimes, for example patients stopped their medical treatment in favour of holidays, or due to lack of time:

"I was going away…for a week so I had some wine every night…it just happened to be when I was on this six weeks course (of antibiotics), so I fell by the wayside" (Male, 65+yrs)

Core Category 4: Sources of support for self-management

Patients with bronchiectasis identified sources of support that would encourage them to self-manage (Table 6).

Table 6: Core category: Perceived sources of support for self-management of bronchiectasis

Health service resources subcategories: Information and guidance on the disease, accessibility to health care, medical reviews, familiar health care practitioner, experience of benefits of treatments, health service policies, government initiatives, accessibility to leisure facilities, home help, support groups
Family sources subcategories: Role within family, practical help from family, advice from family
Information sources subcategories: Medical literature, internet, newspapers
Self subcategory: Intuition

The most consistent sources of support for self-management, discussed in all four focus groups, were information and guidance on the disease and accessibility to health care. Patients were keen to have a greater knowledge about bronchiectasis and more open access to health care services as illustrated by the following quotations:

"If I understood more what to do you know I could try and help it myself. I don't want to come in to hospital" (Male, 18-64yrs)

"If there was some sort of support for a bronchiectasis patient who knows that they're running into trouble…there just seems to be delays all the time in trying to get you what you need at the time" (Female, 18-64yrs)

Some patients indicated that they would like to have reviews to ensure they were using self-management strategies correctly, and some patients indicated that they were more inclined to engage in self-management strategies if the benefits of treatment were evident. Close proximity to leisure facilities was identified as a factor that would encourage patients to engage in exercise as a self-management strategy. The initiative by the government for a smoking ban in public houses was also seen as a relevant factor in self-management.

The role of family was identified as important in self-management particularly in giving advice, providing support and assisting with treatment of the patient with bronchiectasis, especially airway clearance. The patient's position within the family, such as a single parent, increased willingness to participate in self-management to avoid admission to hospital.

"It's one of the reasons why I'm out every day cycling, why I force it because I have to just keep out of hospital…it keeps me focused" (Male, 18-64yrs)

Patients mentioned seeking information on bronchiectasis in medical books, and on the internet but it was observed that patients generally relied on health professionals to provide relevant educational material. Self-awareness or intuition was seen as an inbuilt source of support for self-management.

"I think by the time somebody would say to you you're not well you would know yourself" (Female, 65+yrs)

DISCUSSION

This study showed that patients with bronchiectasis have their lives disrupted by this long-term condition and patients are utilising self-management strategies. There are perceived obstacles to self-management but there are also perceived sources of support for self-management.

The emphasis on self-management of long-term conditions is growing and is seen as an essential part to enhancing care in the Chronic Care Model endorsed by the World Health Organisation [5]. This model suggests that patient's functional and clinical outcomes can be improved by informed and activated patients who self-manage, and by proactive healthcare providers. Access to necessary healthcare, self-management and decision support, and use of clinical information systems is central to the Chronic Care Model.

In this study, the patients had conflicting views on what self-management meant but self-management strategies generally involved using and adapting medical treatments that had been prescribed by health professionals. Patients appeared to monitor their condition and initiate or alter their treatment regimens during an exacerbation, for example, starting reserve antibiotics. They appeared to have no real problems communicating with health professionals when necessary, but lacked skills to self-manage psychological and social needs. The majority of patients appeared to be comfortable with the opportunity to self-manage, especially if it meant staying out of hospital but some patients lacked confidence and felt they would like assistance from community health care resources, or to be admitted to hospital if they were ill.

Existing research on self-management in respiratory conditions has been focused on asthma, chronic obstructive pulmonary disease and cystic fibrosis and has examined what motivates the patient to self-manage, the influence of education programmes on self-management, the

effectiveness of action plans to guide self-management, methods to control self-management of symptoms, and the impact of social factors on self-management.[14][15][16][17][18] There are no known studies on self-management in bronchiectasis, but the efficacy of some of the interventions self-managed by the patients has been investigated. Oral antibiotic therapy is frequently prescribed to patients with bronchiectasis and found to be effective in eradication of purulent secretions in this patient population.[19] Self-administration of intravenous antibiotics is available for patients with bronchiectasis and it is reported that patients prefer this method to hospital treatment as it promotes independence.[20] Home intravenous antibiotics may however increase medication costs as patients may report more exacerbations than previously, when the only alternative was admission to hospital for treatment.[21] Inhaled therapy is frequently prescribed to patients with bronchiectasis and in this study most of the patients were using bronchodilators on a regular basis.[22] It has been shown there is a significant response to bronchodilators in this patient population.[23] Patients with bronchiectasis often have an increase in sputum production and are advised to incorporate airway clearance techniques into their treatment regimen. Techniques may involve breathing exercises (the active cycle of breathing technique) or positive pressure adjuncts (PEP mask, flutter, acapella®). The bulk of existing literature on airway clearance techniques in bronchiectasis compares the efficacy of one technique with another.[24][25][26] Despite this reported clinical benefits of airway clearance include a reduced cough, a decrease in shortness of breath, an improvement in exercise capacity and a better quality of life.[27] Exercise, another popular self-management strategy in this study, is known to improve both physical and mental health in a wide range of chronic conditions and in patients with bronchiectasis a pulmonary rehabilitation programme has been shown to improve aerobic capacity, endurance exercise capacity and also inspiratory muscle strength.[28]

The use of complementary and alternative medicine (CAM) was a consistent self-management strategy used in all four focus groups with cod liver oil being the most frequently used product, followed by multivitamins, echinacea and evening primrose oil. Tai Chi was also practiced by one patient and acupuncture had been used by another patient. There are no studies investigating the efficacy of CAM in bronchiectasis, but studies in asthma and COPD have highlighted mixed results for effectiveness and safety.[29]

Obstacles to self-management highlighted some gender and age differences, although these were minimal between the groups. One of the mothers in a female focus group highlighted that a lack of time for airway clearance was one of her main obstacles for this self-management strategy. Motivation was identified as an obstacle to exercise in both younger groups, especially in relation to swimming. The younger groups (males and females, 18 – 64 yrs) also discussed side effects of treatment as obstacles to their self-management strategies; one man did not like taking antibiotics as he suffered from thrush as a result, and one woman only used her inhalers if she really needed them, as she had an irregular heart beat and perceived the inhaler could "kick that off". In older groups (males and females, 65+ yrs), age and lack of confidence were seen as obstacles to self-management. Age was seen as another barrier to exercise and lack of confidence made one lady worry if she was doing her airway clearance technique correctly and deterred one man self-administering his intravenous antibiotics. If the perceived obstacles to self-management were addressed through education, guidance and support from health professionals then the majority of patients with bronchiectasis could be encouraged to be more independent with many aspects of their care.

Patient perceptions in this study indicate that important elements to support self-management not only include health professionals but also the patient's families and themselves. The role of the health professional is seen as important for information and guidance on the condition and for review of self-management strategies. Patients would also like to have access to services at times of need.

The results of this study support a number of current models of health related behaviour. The models explain why some patients may self-manage better than others. The social learning theory considers a person's health related behaviour to be related to expectancy and value of a certain outcome.[30] Examples of this theory were seen in the study when the patients stated that they saw the advantage of adhering to medical treatments such as inhaled therapy or airway clearance to maintain status quo. Self-efficacy is important in Bandura's theory of social learning, which relates to patients believing they are competent to perform a specific task.[30] An example of self-efficacy is seen in this study when patients reported they felt competent to self-administer home intravenous antibiotic therapy. Fishbein's theory of reasoned action considers health related behaviour to be influenced by the individual's attitude and social expectations.[30] Examples of this theory were seen in the study when the patients stated they followed the advice given to them by family members because they believe it to be important.
The health belief model considers cues to action, whether external or internal, will predict health related behaviour.[30] Examples of this model were seen in the study when patients stated they followed the advice given in medical literature (external cue), or monitored their symptoms (internal cue) and sought help when an exacerbation occurred. Attribution theory considers past outcomes to the patient or other patients as relevant in health related behaviour.[30] It suggests

that feeling in control is important. Examples of this theory are seen in the study when the patients stated they avoided known irritants that aggravated their bronchiectasis.

There is no single theory that explains all health related behaviour of patients with bronchiectasis and the results from this study support several concepts. When developing a self-management programme it is important to consider theories of health related behaviour as they may predict variation in outcome. It is also important to consider that self-management programmes may not be equally effective in all respiratory conditions and assessment of the efficacy of self-management in bronchiectasis needs to be established.[31][32][33]

There are some limitations to this study. Focus groups by their nature are qualitative and thus the results are difficult to quantify. The majority of patients at the focus groups lived in a city and thus were able to access their GP and hospital services relatively easily. Patients living in rural areas may have different experiences, for example, in obtaining antibiotics. Patients who were more severely ill and on oxygen therapy may also have had different experiences of the bronchiectasis and also different needs.

CONCLUSION

This study has given a unique insight into the experience of patients with bronchiectasis, whose lives are disrupted by this chronic condition. The findings indicate that patients are utilising self-management strategies. There are a number of perceived obstacles to self-management but a there are also perceived sources of support for self-management. This study has provided information from the patients' perspective of elements which need to be included in a disease specific self-management programme.

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Figure 1: Focus group recruitment and profiles