

Research paper

Responsibility for COPD self-management in ethno-cultural communities: the role of patient, family member, care provider and the system

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What is known on this subject

- Some patients from ethno-cultural communities may have a lower understanding of how to properly manage their COPD and may experience multiple barriers to accessing health information.
- Available healthcare resources for COPD such as professionally translated 'one size fits all' educational materials are not culturally applicable across all ethnic minority groups in the Greater Vancouver area.
- Limited access to care services as well as inadequate knowledge of the disease can cause poor management and misconceptions about COPD.
- In Canada there are currently no COPD-related educational materials developed with an awareness of ethnicity-related issues at an appropriate health literate level or with community involvement in information development.

What this paper adds

- Successful self-management strategies in chronic diseases go beyond basic patient education and must also include processes that allow for patient empowerment.
- Involvement of family members in chronic illness care is vital and has the potential to impact positively on patients' self-management performance.

ABSTRACT

In chronic obstructive pulmonary disease (COPD), patient education is one of the fundamental components of successful self-management. However in most instances patient education is limited to the transfer of information about COPD, its causes and its treatment. Moreover, among patients who have received health information regarding their

disease, a number do not continue disease management at home or outside of the healthcare setting. This is in part due to misunderstanding instructions given by care providers. Additional issues arise when patients and care providers do not share a common language. Developing information materials in English and then simply translating them

into either written or video formats is not effective because the materials do not incorporate patients' cultural beliefs, views or perceptions.

This study investigated how patients with COPD, from new immigrant communities in British Columbia, Canada, received and utilised information about their condition and its management as a basis for developing appropriate educational materials. We applied a community-based participatory approach in learning about the cultural beliefs and perspectives influencing patients' self-management practice. Family members and home caregivers were also encouraged to become involved in the material development and learning process. Qualitative focus groups and individual interviews were conducted with a total of 46 COPD patients ($n=30$) and their family members ($n=16$) from Chinese (Mandarin and Cantonese), Filipino, Korean, English, and Farsi ethnic minority communities in the Greater Vancouver Area between May 2013 and March 2014.

Findings were summarised into five themes: current knowledge and practices of COPD self-management; trusted sources of health information; insufficient care received from doctors; information they wish to receive; barriers to accessing health information. Data analysis of these themes showed that it is essential to consider diverse cultural beliefs and practices when developing self-management educational materials for patients from ethno-cultural communities. Our findings suggest that engaging patients in all stages of development may increase patient efficacy and motivation to apply and use information, as well as ensuring that materials developed are relevant and appropriate for minority groups.

Keywords: COPD self-management, cultural beliefs and practices, educational materials development, immigrant communities, participatory approach

Introduction

Background

Chronic obstructive pulmonary disease (COPD) is a disease of the respiratory system defined as irreversible airflow obstruction. It is the third most common cause of death in the world (Lozano *et al*, 2012; Kim and Criner, 2013). It is one of the leading causes of death worldwide and is one of the few chronic diseases where mortality and hospitalisation rates are increasing (Ernst *et al*, 2000; Chapman *et al*, 2003; Buist *et al*, 2008). Education, self-management, and access to appropriate medications are essential in preventing complications and in improvements in quality of life. Access to plain language health information materials has been shown to play an important role in improving patients COPD knowledge and self-efficacy to manage their illness (Scott *et al*, 2010).

Members of minority ethnic groups may not have the same level of access to health information as patients from mainstream communities if they do not speak or read the country's official language. In Canada, health information resources reach only a small proportion of minority ethnic communities as many information materials are developed only in either English or French (the country's two official languages). Smoking is very common among members of these groups and there is a high incidence of COPD (Chapman *et al*, 2003; Evans *et al*, 2010). Language or literacy limitations and cultural issues

may influence these patients' awareness of COPD and how to control and self-manage it (Oxman-Martinez and Hanley, 2005). Translated materials are not necessarily effective as they may not present health information in culturally appropriate formats (Caidi, 2008). Even when they are able to access care, patients who are members of minority ethnic groups may not adhere to treatment regimens and may have limited understanding of their condition due to language limitations and cultural issues (George *et al*, 2007; Karliner *et al*, 2007; Restrepo *et al*, 2008). Family involvement is another crucial factor in the self-management of COPD in many ethno-cultural communities (Holm *et al*, 2009). About 30% of people living with a chronic condition rely on a family member for use of medication and care at home. Thus it is important to involve home caregivers when planning educational materials about self-management (Kanervisto *et al*, 2007; Rosland, 2009; Poureslami *et al*, 2012).

Little work has been done in Canada to examine the impact of health information materials about COPD for patients who are members of minority ethnic groups (Monninkhof *et al*, 2003; Coulter and Ellins, 2006). To the best of our knowledge, there is no published article in the literature reporting a study that has developed COPD educational materials at an appropriate health literacy level, considered culture-related issues, or engaged patients and family caregivers in the development of such information materials in Canada. Ethnic minority patients are more likely than members of other groups to have poorly controlled COPD (FitzGerald *et al*, 2007; Ng *et al*, 2012). This project

sought to address the needs of members of minority ethnic groups by developing appropriate educational materials about COPD. The objectives were to: (i) assess knowledge, attitudes, and beliefs related to COPD self-management practices within the target communities; (ii) investigate access and utilisation patterns of COPD-related information and care services among participant groups; (iii) examine the feasibility of involving family caregivers in the learning process and self-management practices. We aimed to identify the link between culture, beliefs and COPD self-management in order to help us to develop culturally and linguistically appropriate patient educational materials.

Methods

Project design

A community-based participatory approach (CBPR) was used to collect qualitative data from COPD patients in Chinese (Mandarin and Cantonese), Filipino, Korean, English and Farsi communities living in the Greater Vancouver Area (GVA) (Lantz *et al*, 2005; Horowitz *et al*, 2009; Poureslami *et al*, 2011, 2014). CBPR facilitates partnership among key-stakeholders such as community members and key-informants, professionals and researchers throughout the entire research process, as well as the representation of social and cultural dynamics of the community and application of knowledge gained to improve the health and wellbeing of community members (Kidd and Byram, 1979; Krishnaswamy, 2004; Murphy *et al*, 2007; Poureslami *et al*, 2012). In our study, CBPR enabled us to involve patients, family caregivers and professionals in all aspects of the design and implementation of the project. Focus group and interview questions were developed with direct involvement of community key-informants and professionals working with the target communities. Patients were also asked to provide feedback and their thoughts on the drafts of the educational materials during focus group sessions and individual interviews. A network was built and the research team established trusting relationships with community organisations, key-informants and professionals in the GVA.

Initial drafts of the educational materials were developed by COPD health professionals, as explained below, prior to the focus groups and interviews. To ensure that we developed materials which could help our targeted COPD patients learn more about self-management practices, we conducted a number of patient-oriented focus group sessions and individual interviews to check the understandability, relevance and cultural acceptability of our materials. Data collection was undertaken through five focus group

sessions (37 participants in total with six to nine in each session) and nine individual interviews, covering a total of 30 patients and 16 family members. Individual interviews were conducted with participants who were unable to join the group discussions due to time, location or severity of their disease (e.g. needing to use an oxygen tank) but still showed interest in contributing to the study. Each participant was only required to attend one focus group or interview. During the sessions we encouraged participation and involvement of family members in the discussions. Patients were asked questions on how they normally obtain and acquire health information related to their COPD, their views and comments on initial drafts of the educational materials, barriers to accessing health information, concerns about COPD self-management, and how cultural beliefs and perceptions relate to their disease management. Identical questions were used for both focus group discussions and individual interviews. As our main goal was to create educational materials which could be helpful in aiding COPD patients from the target communities better manage their disease at home, no demographic information was collected. Focus group sessions lasted roughly 90 minutes; the interviews were roughly an hour.

Development of educational materials

Initial materials included: proper use of their medication (inhalers), steps to manage exacerbations (lung attacks) at home, and light exercises and breathing techniques that could be easily done at home. The English written print materials were developed by the COPD Best Practice & Evaluation Working Group at Vancouver Coastal Health, which we sought as a professional consultant group, with input and involvement of healthcare providers working in the community. The materials were then translated into the target languages by community facilitators, which were further reviewed by the study team, health professionals and community key-informants for accuracy and scientific soundness before being reviewed by COPD patients in the focus group sessions and individual interviews. A graphic artist drew pictures for each step of inhaler use, showing pictures that featured ethnic-specific community faces, different genders and elderly people. Patients and their family caregivers were asked to advise on the format of educational materials (videos and pamphlets) and the information they wished to receive. Further content of the inhaler videos and pamphlets was reviewed and developed through direct involvement of patients, family caregivers, community key-informants and health practitioners to ensure cultural and linguistic acceptability. The instructional knowledge videos were derived

from pictorial pamphlets using the same informational content in a different presentation format.

After the materials were developed, we pilot-tested the videos and pamphlets with selected COPD patients and their family members from the target communities. During the pilot testing, participants were asked to review and comment on the materials and help us to improve them in terms of readability, accuracy, understandability and relevance to their cultural beliefs and practices. Also, as part of the project procedures and during the home visits, all patients and their family members received necessary information from community facilitators on how to correctly use COPD medications, the necessity of using their medications as prescribed by their physician, when to call their doctor or emergency services for their COPD symptoms and exacerbations, avoiding smoking, and maintaining daily exercise and walking habits as well as keeping a healthy diet.

Ethics

The study was conducted at a university-based research centre. It was approved by the University of British Columbia Office of Research Ethics. All subjects signed a written consent form in their native language that explained detailed information on the project, its aims, the patient's involvement and requirements prior to the study. Consent forms were translated by community facilitators, and patients were asked to sign only if they fully understood and agreed to participate.

Community facilitators and project team

A total of 15 bilingual-bicultural community facilitators were recruited and selected based on suggestions and recommendations received from members of the six minority ethnic groups. The facilitators participated in initial training to ensure their interactions with the patients were consistent, and that they recorded the response of the patients by writing down their verbatim words and explanations to avoid any data collection bias. During the training, facilitators and the research coordinator reviewed the focus group questions, how best to present these to each group, and ways of motivating participants to engage in discussion. They met periodically before each session to ensure that the data collection process was well organised. In addition to community facilitators, we also involved a professional video maker and a respiratory educator to help in the development of educational materials.

To build rapport, ensure good communication, gain the patient's trust and give value to the language

in which they communicated, patients were interviewed in their native languages. To improve the possibility of capturing the best of their views and feedback about the materials, we also involved the family caregivers in the interview and material review process in all community groups. The community facilitators delivered the study questions orally and noted the patients' and family members' comments, questions and concerns on the answer sheet, as well as their responses to open-ended questions. The English-speaking project manager attended all interviews to reduce the likelihood of observational errors and took notes of the patients' comments and demonstration of inhaler technique while the facilitators were conducting the interviews. During the interviews, the manager asked facilitators to clarify some questions or procedures with patients and family members. The facilitators asked patients the questions for clarification and translated their responses, which were then noted down by both the facilitators and manager. At the conclusion of each session, the notes were reviewed by the team, including the manager and facilitators, for clarity, precision, necessary adjustments and reflections.

Participants

Our study began with exploration focus groups and in-person interview sessions that were conducted with patients from the target communities, namely Chinese (Mandarin and Cantonese), Koreans, Filipinos and Iranians, in addition to English-speaking. Our intention was to assess patients' attitudes, beliefs, practices and knowledge related to COPD self-management during patient-oriented focus groups and personal interviews in each of the target communities. We applied a convenience sampling method and recruited 46 individuals: 30 were COPD patients and 16 were family caregivers. Eligibility criteria were a physician diagnosis of COPD, at least 21 years of age, been an immigrant to Canada, belonged to the cultural communities targeted by the study, and resided in the GVA during the study period. Participants were asked to bring along their prescribed medications to the interview or focus groups to review inhaler techniques.

Participants were recruited with the help of collaborating organisations (e.g. professionals at VCH community organisations and British Columbia Lung Association), specialty and primary care doctors and respiratory therapists. Professional collaborators and care providers identified eligible patients according to the study criteria. If a patient showed interest in participating, he/she was asked to contact our centre to speak with a facilitator who communicated in their native language. In order to capture participants who might not have access to our collaborating specialty doctors and family physicians, we also advertised in

local community newspapers and used radio broadcasting in the target communities.

Data analysis

For data analysis we applied three steps in order to identify specific themes: (i) systematically reading transcripts, reviewing notes on non-verbal content (provided by the facilitators), and comparing and contrasting responses of participants within and across groups to document emerging themes; (ii) establishing categories and coding themes; (iii) sorting responses into thematic categories.

Findings

The results of this qualitative research revealed that participating patients showed interest in learning how to find relevant and useful information and services

about their chronic disease in their community language. In general, disease-related knowledge and awareness about COPD symptoms and how to manage them were low among patients in the target communities. Language and cultural barriers, lack of understanding care provider instruction on self-management, and concern about side effects of medications were identified by almost all patients as major problems when trying to communicate with care providers about managing their COPD. Tables 1 to 4 summarise the content of qualitative data and quotes reported by the patients about their knowledge, beliefs, perceptions, attitudes, concerns and practices related to COPD management. Furthermore, in common with English-speaking COPD patients in Canada, patients in this study had universal challenges and concerns regarding COPD medications, treatment and access to proper services, which are summarised in Table 5. These findings reveal and support the importance of developing culturally and linguistically appropriate COPD educational materials.

Table 1

Quotes from COPD patients in respect to current knowledge and practices of COPD self-management

'I know I cannot fully recover from this disease, and I know that there are things to prevent it from getting worse...I do tai chi, because it helps with my lungs and breathing.' – Cantonese

'I believe the current way of taking medication is a waste. Not all of it goes into the body, and I think injecting it into the body is more direct, therefore better.' – Cantonese

'I don't want to take traditional medicine because it may counter with my prescribed Western medicines.' – Cantonese

'If something like [exacerbation] happens, there's nothing you can do. The best thing is to call 911 then use an oxygen mask.' – Cantonese

'I don't think my COPD is as serious as what my doctor says.' – Mandarin

Table 2

Quotes from COPD patients in respect to trusted sources of health information

'[The pharmacist] explains to me how to use the medication. Pharmacists are good.' – Cantonese

'The stuff taught at the rehab programme is very useful.' – Cantonese

'We don't have any access to special COPD educational resources in Farsi and the only resources we have access to are Farsi magazines that don't include much information regarding health issues. Although some of our younger family members try to find information from the internet as well.' – Farsi

'I bought a Chinese book in Taiwan that helped with my cough and phlegm.' – Cantonese

'I saw a Mandarin TV program for COPD that talked about lungs and lung diseases and taught breathing exercises.' – Cantonese

Table 3

Quotes from COPD patients in respect to insufficient care received from doctors

‘For [the doctor], it’s better to see me quickly. Not even five minutes to see a disease.’ – Cantonese

‘I thought that she was so busy I shouldn’t bother her. When I go to the pharmacist to get the medication, they will show me how to use it.’ – Cantonese

‘They just told me to take medication, that’s all!’ – Cantonese

‘I don’t know the function or the purpose of the inhalers I’m taking, I’m only taking them because to follow doctor’s orders.’ – Cantonese

‘I think doctors here only get paid when they write your name down on the paper. You can’t stay in the office for that long.’ – Cantonese

‘When I had a question for my family doctor, he told me to ask my specialist or the pharmacist.’ – Filipino

‘My specialist and family doctor say different things...I think my family doctor should improve on his knowledge about COPD.’ – Farsi

‘I want my family doctor to spend more time during their visit to provide them with more information, to answer their question regarding my sickness, have better relationship with the patient, and can visit my specialist whenever I need to instead of waiting for months.’ – Farsi

Table 4

Quotes made by COPD patients in respect to information they wish to receive

‘I think my doctor should assign COPD classes for patients to attend at the hospital.’ – Cantonese

‘For me, Advair and Airomir is the same unless you can explain why it is called this name. I’ve seen some Chinese names for English medication. This might be more useful then medications can have a Chinese name that reflects the use of the medication. To me, the English name means nothing.’ – Cantonese

‘I think that when you are first diagnosed with COPD, the information you need should be simple and help me understand how to benefit my life. For example, diet and what should be limited...for example, if I take this medication, I can’t eat grapefruit.’ – Cantonese

‘I don’t know any numbers to call for help so it is important to include some numbers like hotlines and help lines for his COPD.’ – Cantonese

‘Walking exercises, action plan and diet plan that’s good for COPD.’ – Cantonese

‘It would be better if patients receive information from their family doctors rather than other people like the nurses or pharmacists, because patients trust their family doctors more.’ – Farsi

Current knowledge and practices of COPD self-management

Knowledge of COPD and its self-management for all the target communities was relatively low. In general, patients were not adequately informed about the disease, the symptoms or actions they need to take when facing exacerbation. Farsi-speaking patients were not aware of the importance of early diagnosis of COPD and how crucial it was to start treatment

according to their physician’s recommendation. Despite having symptoms such as coughing up phlegm and breathlessness and being diagnosed with COPD, Farsi patients did not perceive themselves as having COPD. To them, COPD was like a typical cold but had a longer recovery time. Korean patients stated that they were unsure of whether they had COPD or asthma due to being given different diagnoses from care providers. As a male Korean patient stated: ‘I’m still not so sure that I have COPD because it can be

Table 5

Quotes made by COPD patients in respect to barriers to accessing health information

'I got called in by phone to go to the rehab programme, but I refused to go because at the time I received the call was in the winter, but I was interested to go.' – Cantonese

'The rehab programme does not have the translated version...The problem is in English.' – Cantonese

'I am not able to find [more information] or know more.' – Cantonese

'I book a doctor's appointment with her once a year and get the prescription for the medicine [but if I have information that I am unclear, I would have to wait for a year].' – Cantonese

confused with asthma. I checked with a couple of different hospitals to make sure whether I have COPD or asthma.'

In contrast, Cantonese COPD patients were more knowledgeable in terms of their disease and self-management practices. For example, patients knew that exercise was important, to eat in moderation, and to take medications accordingly. Moreover, two Cantonese male patients had attended a COPD pulmonary rehabilitation programme previously and used the materials received to manage their COPD. 'I was taught which to inhale first [inhaler] in rehab. I did not know before, and after going to rehab, I started knowing. After a year, my flare-up [exacerbation] symptoms started to diminish.' Very few patients from the targeted communities had received verbal or written information on what to do in a case of emergency. Other types of traditional self-management practices mentioned by participants in all language groups included tai chi to help with lungs and breathing, salt water to clear up phlegm in the morning, wearing a scarf to keep warm and quitting smoking. Table 1 includes more comments made by participants regarding current knowledge and COPD practices.

Trusted sources of health information

The internet, most often in their native language, was a commonly cited source by all community groups as a means for acquiring COPD-related information. A Korean-speaking patient mentioned that he used a trusted website in his native language which provided him with confirmation and more detailed explanations on his disease: 'I went to a Korean website and typed COPD. I got lots of information. I even printed it out. If there is another meeting in the future I can bring them. They [the internet] said red ginseng is really good for COPD patients. However, I can't eat red ginseng because I have high blood pressure.'

Cantonese patients also used the internet as a source of further information on the self-management of COPD. A Cantonese male participant said: 'I use

Google and type in the English but go to Chinese sites.' Other sources were identified by the participants, for instance, Chinese patients sought treatment from Traditional Chinese Medicine practitioners as a secondary provider. 'The Chinese doctor told me to drink ginseng and ganoderma [herbal drink]... the inhalers are just for inhaling. Going to the Chinese doctor is to maintain the health of my lungs... I think that eating [sic] Chinese medicine serves as a supplement to the inhalers.' Many Chinese COPD patients learn instructions on inhaler techniques through their local pharmacist. 'The pharmacist doesn't have more time but they will definitely tell you until you understand. Their responsibility is very strong. The doctor is different, they will just tell you to take the medication home and not tell you that much. The pharmacist is very important.'

Filipino patients also felt that the pharmacist had more time to explain inhaler use than family doctors. One female Filipino patient used the British Columbia Nurses hotline (a telephone line providing health information staffed by nurses in British Columbia) to obtain information for her COPD. A male Farsi-speaking patient identified that he would like to receive information through a nurse hotline available in his native language and communicate with a care provider over the phone. Table 2 contains more narratives by participants in relation to other trusted sources of health information.

Insufficient care received from doctors

Most patients did not trust their family doctors and indicated that doctors did not listen to their concerns or understand their needs, and only provided similar instruction and the same medication for everyone with COPD. They further indicated that their doctor had never fully explained to them what COPD was, how it was developed, or how to properly manage it. They reported that physicians prescribed inhalers but never explained how to use them. In the words of a Cantonese COPD patient: 'Usually the pharmacist

does it [information and instructions for the inhaler]. The doctors in Canada don't spend time with you, they are always in a rush.' Farsi-speaking patients indicated that reputation and knowledge of the doctor was more important than language; patients who did not trust their family doctors tried to find well-known and knowledgeable doctors. The ideal would be a well-known physician from their own community who was knowledgeable. One male Cantonese patient also stated: 'Honestly, for family doctors they don't know much about COPD. You need to see the lung specialist. Family doctors are family doctors.'

The participating patients also stated that they normally tried to find other sources of health information for their needs to fill this knowledge gap. In the Farsi community, a majority of patients informed us that family doctors in Canada are not as caring compared to doctors in their home-country. Subjects reported that doctors in Canada were said not to provide enough time and resources for the needs of the patient. A male Mandarin patient said: 'My family doctor is very busy and I do not feel confident enough to ask him for any health information because he never has time to explain.' Many also stated that it is harder to see a specialist through the healthcare referral system due to long waiting times. Hence they preferred to go back to Iran to consult with a healthcare professional. Korean COPD patients, likewise, found that doctors in Canada need to be prompted with questions or direct requests to obtain necessary services and information. Along the same lines, a Farsi-speaking male patient indicated: 'It would be better if GPs spent more time with COPD patients giving them more information, should talk to patient directly even if old [sic]'. Additional quotes mentioned by participants regarding communication issues with their official care providers can be found in Table 3.

Information they wish to receive

Various topics of information that the patients would like to receive on self-management of COPD included but were not limited to: types of exercises, a diet plan specific for COPD, side effects of medications, smoking cessation, and the use of an action plan. A proper diet was very important for Cantonese COPD patients: 'Yes, for example if you cough, it would be the cause [sic] of oily food. Cold food is also a factor. I don't like to eat cold food. Cold food is not good [for COPD]. It is easy to cough after eating cold food.' In many situations and especially in the Cantonese community, the spouse or family member of the patient is the one who looks after the patient and is involved in the disease management. The wife of a Cantonese patient stated that she makes different types of soups for the patient daily and would like to learn more about a diet

plan for COPD patients. Another spouse said: 'Yes [to learn more about diet], because I only cook what he wants to eat right now. I don't know what types of foods are good for the lungs and what is not...The family doctor told us that whatever my husband wants to eat, just make it for him...I only know that you cannot eat anything fried from the family doctor.'

Obtaining correct information on the side effects of COPD medications was also important for Chinese patients. Patients were aware that this information was provided in the instruction leaflet that comes along with the medications but thought that a health-care provider such as a pharmacist or doctor should explain the side effects verbally to the patient upon use. One Cantonese patient said: 'I think side effects should be mentioned because the manufacturer has included this in their instructions. I think side effects should be mentioned because most people would not read the information provided by the manufacturer.' More information is summarised in Table 4.

Barriers to accessing health information

As stated above, patients in the focus groups and individual interviews showed interest in learning more about their disease and how to manage it. Yet many barriers to obtaining health information were cited by our participants. Language was stated as a main barrier to successfully accessing and receiving information and services for COPD. A Cantonese-speaking patient said: 'I can't speak English and my son went with me. The problem is that I can't speak English.' Likewise, Farsi-speaking patients also complained about the lack of available translators and interpreters in the healthcare system when visiting a doctor or the hospital.

Other barriers contributing to lack of access to health information included such information being unavailable in the doctor's office, inconvenient timings to attend the pulmonary rehabilitation programme for COPD, reliance on family members to accompany to sessions, and other obligations. Timely access to a respiratory physician was the most frequently mentioned concern for patients. Chinese-, Filipino- and Farsi-speaking patients stated that in Canada it is difficult to see a specialist for COPD as you need a referral from the family physician and sometimes this can be a lengthy process. COPD patients are also relatively older and many have comorbid illnesses. This can cause physical limitations and restraints. The wife of a Cantonese-speaking patient said she had to escort her husband to the pulmonary rehabilitation programme, since he could not go there on his own: the patient uses a walker and needs an oxygen tank daily, even when going out. She observed that it was 'a hassle for him to

bus' and that arranging for a HandyDart (shared ride service) is costly. 'If the cars come to pick him up, we have to pay. He doesn't want that. Are there any programmes that are free or that we can apply for it to be free? He doesn't want to go if it costs money.'

Discussion

Most research to improve self-management among ethno-cultural communities has been limited to enhancing disease-related knowledge (Johnson *et al*, 2004; Caidi, 2008; Harris *et al*, 2008). Improving knowledge is necessary, but is insufficient alone to empower patients to gain the necessary skills to properly manage COPD (Coulter *et al*, 2006). Education alone will not necessarily lead to behavioural modification, and previous research has shown substantial improvements in disease management among mainstream patients while improving self-confidence and applying behaviour modification strategies (Worth and Dhein, 2004; Harris *et al*, 2008; Labrecque *et al*, 2011; Almagro and Castro, 2013). Patients need to learn how to integrate self-management skills into their daily treatment routine. Lifestyle, culture and language are important factors in self-management, particularly when these differ from the majority. In ethno-cultural communities, a patient's ability to comprehend their physician's instructions and the potential for improved adherence to their treatment regimens is shaped by cultural factors and the support he/she receives from the family members that extends beyond education level, language proficiency or socio-economic status (Johnson *et al*, 2004; Monninkhof *et al*, 2004). The challenge of limited ability to recall information in elderly subjects (due to possible cognitive impairment) is amplified when patients with limited English proficiency may have more difficulty comprehending medical information and treatments prescribed by a care provider who communicates in English (Bourbeau *et al*, 2004; Coulter *et al*, 2006; Karliner *et al*, 2007; Johnson *et al*, 2011). Such individuals are consequently more likely to be non-adherent due to misunderstanding instructions given by physicians and other healthcare providers (Karliner *et al*, 2007; Press *et al*, 2011). This factor may be associated with greater mortality and morbidity than their mainstream counterparts (Dransfield and Bailey, 2006; Khan *et al*, 2008; Shaya *et al*, 2009). Considering the limitations of educating COPD patients from ethnic minority groups identified by other studies, we applied a community-based approach that involved patients, their family members, professionals and key-community stakeholders in all stages of our project.

We used a communication approach trusted most by the target ethno-cultural communities, namely

using COPD-related information materials developed and presented by individuals who communicated in their native language. We created a trustful environment and encouraged patients and their family members to not only help us further develop our materials, by providing their feedback about the materials, but also to talk about their own concerns, challenges and barriers that they may encounter while accessing and using health information and care services to manage their chronic disease. We received promising support from the patients and their family members related to the development of educational materials.

Previous research has attempted to enhance patients' access to relevant and appropriate education materials about COPD and how to manage symptoms and exacerbations, applied different interventions such as using peer educational programmes, psychosocial support group strengthening, conduct home monitoring, address barriers and facilitators of self-management (e.g. disease-related skills), and improve self-efficacy (Bourbeau *et al*, 2004; Worth and Dhein, 2004; Almagro and Castro, 2013). While such interventions showed modest improvements in disease management among mainstream patients, their efficacy among COPD patients from ethno-cultural communities has not been systematically studied. More important is the presence of self-efficacy among patients to perform the recommended treatment regimen.

Proper communication with patients from ethno-cultural communities, in particular older adults, and improving their access to culturally and linguistically relevant health information materials are, therefore, key to successful disease management and health outcomes (Anderson *et al*, 2003; Flores, 2005; Poureslami *et al*, 2007). Patients in this study stated that they utilised health services in recent years but had never fully received information about COPD: its symptoms, triggers, medication and self-management practices including how to manage a lung attack (exacerbation) in their native language. Information was usually presented verbally and no patients from our study had ever been provided with a written action plan for COPD. Most of them did not even know what an action plan was, had never heard of it and had no idea how to use it. There were various misinterpretations and doubts on how to properly manage their COPD. Family physicians were the first source of health information but were lacking in assistance: while family doctors were identified as the most trusted source to receive disease-related information, they were also identified as a major barrier to understanding the nature of illness and what steps they could take to manage it, mainly due to lack of proper communication between patients and their care providers. Patients felt that their family physician did not have sufficient knowledge on their specific disease. Those who conveyed this concern went on to find other

relevant sources of help such as websites, family members, other healthcare professionals or their pharmacist. Patients from the different communities reported that sometimes they came across questions and queries they would like to discuss with their doctor but often forgot by the time they were able to meet a physician. It was recommended to include a 'notes' section on the side so that patients could write down the information they would like to discuss during appointments. We applied the quotes shared by patients and their family caregivers (some of which are summarised in Tables 1 to 5) in the development of information written materials and video clips in the target languages. This provided necessary information to COPD patients about how to correctly use their inhaler medications, how to control COPD exacerbations, how to avoid smoking and other tips to self-manage their disease.

We noticed that many patients did not use their COPD inhalers correctly, or follow their doctor's instructions properly, mainly among older participants who indicated having difficulty understanding their physician's treatment regimen. Many participants indicated that when they obtained relevant educational information – provided by trusted people (community members and physicians who speak the same language) or when family caregivers accompanied them to visit the doctor – they were more likely to follow the instructions received from their doctor and aimed to better manage their chronic illness. This indicates that when patients receive information that is culturally and linguistically relevant, their understanding of self-management concepts and physician instructions improve. We believe that patients can be perceived as 'experts' in their own disease management if they are empowered by practical skills to manage their illness. Therefore we fully involved patients in the study as collaborators to produce educational materials, because they were the end-users and consumers of healthcare information and services. This ensured that the information created was applicable to patients and met the real needs of ethno-cultural communities. This approach also facilitates patients' collaboration in the project and willingness to follow the recommended procedures with confidence, and promotes patients getting actively involved in the learning process on how to self-manage their chronic disease.

Due to possible cognitive decline and some activity limitations of COPD patients in our study (as reported by the patients or their family members), we observed active and useful involvement of family members (mainly the spouse) in COPD management: taking daily medication, treatment dosage modification, diet intake, exercise and other physical activities. In some cases, and among male participants from the Farsi and Korean communities in particular, we observed that

the patient's wife or adult children decided on or recommended a reduction in COPD medication use (dosage modification), limit of physical activities and certain diet intake for the patient. This finding may suggest that in these newcomer communities the concept of health and wellbeing may not be an individualised issue and it seems the decision to manage chronic disease is made by collective agreement between patient, immediate (informal) caregiver at home and other family members. Other studies have identified family members as the best supporters and primary caregivers in chronic illness (Kanervisto *et al*, 2007). Educational programmes for COPD management for ethno-cultural communities need to involve family members in addition to the patient in the learning process. Further investigation with larger sample sizes could also explore the role of spouses or other family caregivers in medically related skill-based learning for COPD patients in different ethno-cultural groups.

Conclusion

Studies in Canada and elsewhere have attempted to increase patient awareness and action to manage COPD exacerbations; applying educational programs to help patients to identify and manage triggers, home visits, identify barriers to self-management, and improve self-efficacy (van Eeden and Burns, 2008; Hernandez *et al*, 2009; Simpson and Jones, 2013). We applied all these approaches in our community-based participatory research and generated remarkable knowledge in terms of patients' self-efficacy and self-management practices, which could be applied in developing culturally and linguistically appropriate COPD educational materials. The learning approach we employed in our study not only facilitated the patients' active participation in the education development process but also helped them to better understand their disease and its management. This finding suggests that the interaction of language, cultural beliefs and practices, access to relevant educational materials, and involvement of family members in the learning process may influence a COPD patient's ability to accurately manage his/her chronic condition at home.

Practical implications

COPD in minority communities is managed within the family context. These patients may feel misunderstood and diminished by their care provider or the health system due to language and cultural barriers that occur when trying to obtain health information. Our findings add to the literature suggesting that succinct, culturally and linguistically appropriate

educational interventions that involve family members in the learning process can be used as a practical approach to effectively improve patients' ability to manage their COPD. Health educators and professionals involved in COPD patient care need to address ethno-cultural issues in their interventions and practices. In addition, health promotion researchers need to tailor the information materials so that patients are able to develop and strengthen their sense of self-efficacy to manage their chronic disease. Investment in development of patient educational approaches, like our method, can be inexpensively used by a large number of inadequately educated patients from ethno-cultural communities who have COPD and need to learn self-management skills, and will extend opportunities beyond current patient education methods.

CONFLICTS OF INTEREST

None.

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