# **Research** paper

# Using community-based participatory research (CBPR) with ethno-cultural groups as a tool to develop culturally and linguistically appropriate asthma educational material

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#### What is known on this subject

- Many newcomers to Canada experience limited access to care services and present certain difficulties in understanding information about asthma.
- Limited understanding of the English language, cultural differences, and lack of basic and health-related literacy mean that newcomers to Canada are more likely to misunderstand the appropriate management of their asthma.
- Cultural, linguistic and systematic barriers have been linked to a lack of adequate access to crucial information, as well as to delays in seeking care for asthma symptoms.

#### What this paper adds

- Our study assessed attitudes, beliefs, practices and awareness in relation to asthma among newcomers from four different communities within the Greater Vancouver Area in order to develop educational material that would be culturally sensitive and geared towards the patient.
- The knowledge gained will enable us to further understand the relationship between culture, language, and the management and care of asthma.
- We encourage the use of a participatory approach wherein community events and social gatherings are used as practical communication methods to enhance an ethno-cultural community's awareness about the prevention and management of asthma.

## ABSTRACT

Educational interventions for new immigrants are usually developed without any input from the individuals involved. We examined how communitybased participatory research could act as a tool in the development of patient-related educational material to enhance the self-management of asthma within these communities.

Concept development focus groups were used to uncover participants' specific beliefs, issues, and concerns about asthma and its management. The analysis included systematically reading and reviewing the notes taken by the moderators, establishing categories of themes, and sorting responses into thematic categories. A total of 29 adult asthma patients of Latin American, Chinese, Iranian and Punjabi descent volunteered to participate in patientoriented group sessions. The purpose of these sessions was to gather input for the production of a series of asthma-related educational video clips and comprehensive pamphlets that were not only developed in a community's specific language, but also reflected its cultural beliefs and practices.

We found that focus group methodology is a useful strategy for developing culturally and content

relevant educational interventions for members of new immigrant groups that are typically underrepresented in research about asthma and related issues in Canada. In an aim to fully understand the cultural and linguistic issues relevant to asthma patients from the target communities, we integrated and applied common concerns and barriers identified during the group discussions in the development of educational material.

We uncovered elements that could be applied when broadening the narrow concepts of the healthrelated educational interventions, including factors that are beyond the healthcare system's original focus on the management of asthma in underserved communities. This allowed us to describe a range of research and extension activities suitable for participatory health education development that are both culturally and linguistically appropriate.

**Keywords**: asthma, culture, educational materials, language, new immigrant population

# Introduction

In recent years, there has been increased awareness of the need for a more community-based participatory research (CBPR) approach within the domain of health research (Buysse et al, 2003; Nguyen et al, 2006). This shift is mostly related to the fact that researchers have recognised the value of including the intended beneficiaries in the actual planning, implementation and evaluation of research (Horowitz et al, 2009). CBPR in health research is considered as a partnership approach that involves groups such as community members and researchers throughout the entire research process (Green et al, 1995; Israel et al, 2003). As such, CBPR aims to represent the social and cultural dynamics of the community and integrate the knowledge gained through actions to improve the health and well-being of community members (Israel and Schurman, 1990; Hatch et al, 1993). Even if this mandate has resulted in an increased application of CBPR, in reality much of the literature on CBPR addresses issues among mainstream populations (Levine et al, 1992). However, partnerships should in theory focus on issues and concerns identified by all segments of the community and create processes that enable all parties to participate and share influence in the research (Lantz et al, 2005).

There are very few reports that evaluate the process of conducting research using a participatory approach among minority and newcomer communities in Canada in relation to chronic diseases, such as asthma (Gazmararian et al, 2003; Raynor et al, 2004). However, a recent study describes lessons learned regarding how this approach was employed to develop culturally sensitive asthma management interventions for lowincome Puerto-Rican families (Martin et al, 2010). Similarly, our study used CBPR with minority groups to respond to the following research questions. How do researchers and community participants work together, make decisions and develop meaningful educational materials? What are the benefits and challenges of doing this type of research for patients, researchers and practitioners? What information can be gained through reflection on this type of research process in order to guide the development of culturally and linguistically appropriate educational materials on issues related to asthma? We believe a better understanding of these questions enables us to ensure the effectiveness of educational interventions that aim to improve patients' knowledge and health literacy about asthma and its management in newcomer and ethno-cultural communities in Canada.

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## Background

Many studies have reported under-diagnosis and under-treatment as important features of asthma management in ethnic minorities (Arif et al. 2005; Netuveli et al. 2005; FitzGerald et al. 2006; Mosnaim et al, 2006; Cabana et al, 2007; Inkelas et al, 2008; Poureslami et al, 2011a). Other studies have shown how exposure to environmental allergens (e.g. cockroach, pollen and dust-mite antigens) and higher smoking rates among minorities influence the risk of developing asthma (Pachter et al, 2002; Canadian Lung Association, 2007; Poureslami et al, 2007c; Salari and Burchard, 2007), as well as subsequent outcomes for asthma (Davis et al, 2006). As a result, research has suggested that improving one's understanding of environmental and behavioural factors is one means of improving the health status of asthmatic patients (Melia et al, 1988; Williams et al, 1998; Lahdensuo, 1999; Chapman et al, 2000; Evans et al, 2002; US Department of Health and Human Services, 2003; Asthma and Allergy Foundation of America (AAFA), 2005a,b; Paasche-Orlow et al, 2005; Asthma Society of Canada, 2008a, b).

According to recent Canadian studies, newcomers to Canada experience a lack of access to the health information that they need (Enarson and Ait-Khaled, 1999; Dunn and Dyck, 2000; Oxman-Martinez and Hanley, 2005; Fuller-Thomson et al, 2006; Health Canada, 2006; Replanski, 2006; FitzGerald et al, 2007, Salari and Burchard, 2007; Poureslami et al, 2009), and difficulty in understanding information about asthma (Williams et al, 1998; Chen et al, 2002; Health Canada, 2004), mainly due to a lack of familiarity with English, competing cultural frameworks, lack of health literacy, and literacy issues in general (Enarson and Ait-Khaled, 1999; Litonjua et al, 1999; Sawyer and Shah, 2004; Oxman-Martinez and Hanley, 2005; Zanchetta and Poureslami, 2006; Poureslami et al, 2007c; Canadian Public Health Association, 2009). In part, for these reasons, newcomers are at increased risk of having less well-controlled asthma (Fuller-Thomson et al, 2006; Halm et al, 2006; Smeeton et al, 2007; Poureslami et al, 2011a). There is a need to identify whether lack of access to proper health information, and consequently reduced use of asthma-related care services among newcomer communities, is the result of information that is culturally and linguistically inappropriate (Poureslami et al, 2007a,b; Canadian Public Health Association, 2009; Poureslami et al, 2009), or if the information has not been developed with the direct involvement of community members, and consequently does not adequately meet the unique needs, challenges and priorities of these subgroups (Litonjua et al, 1999; Raynor et al, 2004; Zanchetta and Poureslami, 2006; Poureslami et al, 2007c). Studies also indicate a crucial need to identify the best communication approach to educate adults from ethnic minority groups about asthma and its control and management (Hatton, 1992; Santanello *et al*, 1997; Forbis and Aligne, 2002; Rudd *et al*, 2004; Agency for Healthcare Regional Quality, 2007; Cabana *et al*, 2007; Smeeton *et al*, 2007).

In this article, we present the results of a CBPR study of asthma prevention and management that used qualitative methods. Community has been defined as an aggregate of people who come together around a mutual engagement in an endeavour. Ways of doing things, ways of talking, beliefs and values are practices that emerge in these communities (Lave and Wenger, 1991). In our study, we define community as a gathering of individuals with a common bond, in which they can freely express their thoughts, gain support, and connect with community resources. We recognise that individuals typically negotiate overlapping memberships in various communities (e.g. family, friendship and workplace), and many of them are important in understanding the dynamics of social interaction.

This is an exploratory research study that describes how a patient's attitudes, beliefs and values influence asthma management in the urban areas of the Greater Vancouver Area (GVA). The goal of this study was to use focus groups (Hussein and Partridge, 2002; Nguyen *et al*, 2006) to further understand the links between culture, language and asthma management in order to develop culturally and linguistically appropriate patient education material. We called our approach *concept development focus groups*, as we aimed to capture cultural concepts and nuances that are embedded in the language.

## Methods

## Project design

Using a CBPR approach (Glaser and Strauss, 1967; Murphy et al, 2007; Kwan et al, 2008) we collected qualitative data from Chinese, Latin American, Punjabi and Iranian patients with asthma during four focus group sessions in 2008. This approach was consistent with earlier work by Greenhalgh et al (1998), who used focus groups to explore the health beliefs and folk models of diabetes among British Bangladeshis. We used purposive sample methods because we sought to interview subjects with certain characteristics, such as sharing a similar language, a similar country of origin, and similar condition, in this case asthma. There were two main purposes for which a CBPR approach was used in this study. One was to generate baseline data related to patients' beliefs, values and practices with regard to asthma,

and the other was to apply the knowledge gained to develop culturally and linguistically appropriate asthma health education material. With the understanding that culture is neither seamless nor static, we sought to discover some of the values and beliefs held by patients from different ethno-cultural communities (Greenhalgh *et al*, 1998, see table on p. 979). Therefore we encouraged patients from the target ethno-cultural communities to participate with us in the processes of developing asthma education material (see also Martin *et al*, 2010).

Focus groups are reported to have been used with success in the development and piloting of health education utilising appropriate content and language (Duke and Omi, 1991; Nguyen et al, 2006). In this study, concept development focus groups, as a major feature of CBPR, were used to explore both the broad and specific concerns of the participants about asthma and its management. Concept development focus groups have been shown to be a practical approach for identifying how people from minority groups consider prevention, control and management of chronic diseases (Dutta-Begman, 2004; Mosnaim et al, 2006; Poureslami et al, 2011a). In addition, this approach is reported to have advantages over other methods of eliciting information that could be used when developing educational materials for patients with low levels of literacy (Frey and Fontana, 1991; Lasch, 2000; Nguyen et al, 2006).

#### Participants

Our study focused on four ethnic communities in the GVA, namely Chinese, Latin Americans, Punjabis and Iranians. In this area, these ethnic groups represent over 54% of all newcomers (Canada Statistics, 2001; Vancouver Coast Health, 2005; Ivan, 2006), and are considered to be among the fastest growing cultural communities in Canada (Fuller-Thomson et al, 2006; Ivan, 2006; Replanski, 2006). However, they are underrepresented in research on asthma and related issues (Mosnaim et al, 2006; McLeod et al, 2007; Poureslami et al, 2007c; Smeeton et al, 2007). Selection criteria included age, residency, belonging to the cultural communities targeted by the study, and having been diagnosed with asthma. Participants were asked to bring a letter from their doctor or prescribed medications indicating that they had a diagnosis of asthma.

Participants were recruited with the help of health brokers, who served as gatekeepers for this study, from the immigrant-serving agencies in the GVA, as well as by posting flyers in physicians' offices within the same communities, or in walk-in clinics in immigrantdominated neighbourhoods. The research team has established trusting relationships with immigrantserving agencies in the GVA. These agencies acted as community collaborators in our previous studies (Poureslami *et al*, 2007a,b,c, 2011a). We selected the health brokers, who were mainly trained nurses or social workers, in each agency, and they were responsible for providing access to care services for members of their own communities.

## The focus groups

Each focus group was led by a bilingual-bicultural professional focus group moderator from the same community, who had no other connection to the project. The moderators were selected based on the recommendations received from community leaders, and they received relevant training before conducting the group sessions. During the training, the moderators and research coordinator reviewed the focus group's questions, how best to present questions to the group and ways to motivate each participant to engage in the discussion. The aim was to ensure that every participant would be sufficiently motivated to contribute to the discussion, and that personal experiences related to asthma would be highlighted. At the end, the team, including the coordinator and moderators, reflected on the process of the group sessions and how to conduct the sessions with a similar approach to collect practical data. There were four experienced moderators. They met with the research coordinator before each session to ensure that the group meeting was well organised. Each session had six to nine participants and lasted for 90 minutes. The moderators facilitated the sessions, organised group discussions and attempted to keep the participants focused on the questions (Lasch, 2000; Nguyen et al, 2006).

Two weeks before the sessions, the patients were contacted by phone and asked to suggest a convenient time and place for conducting the focus groups. We provided flexible times and places and made decisions about the sessions according to the patients' preference, convenience and availability. In compliance with the requirements of the University of British Columbia Human Ethics Board, the written consent form was developed in the target communities' native languages, and was read and signed by each patient. For those who had difficulty reading the consent form, it was explained orally by the moderator and signed by each patient before the discussion began. In addition, patients were asked to agree to the use of audiotaping to produce a permanent record of the focus group sessions. The moderators helped the patients with any questions about or difficulties with the consent form. During the sessions, in addition to the moderators, the study coordinator also attended in order to observe the discussions and clarify any unanswered questions and concerns. After the sessions, the moderators transcribed the audiotapes for in-depth analysis and translated the focus group data into English. The moderators took information gleaned from the focus group and developed a synthesis of the discussion. In addition to audiotaping, the moderators took detailed notes and reported their observations. After receiving all of the information from the moderators, the research team analysed the data.

Questions and issues derived from our literature review and from key-informant contributions, as well as input from immigrant community members, helped to guide and focus the discussion in each group. The emphasis was on patients' beliefs, values, attitudes and practices with regard to asthma (Pachter et al, 2002), as well as the challenges that they faced in accessing and using services in Canada, and their relationship and communication with their care provider. Each focus group began with the moderator explaining the purpose of audiotaping, the aims and goals of the group discussions and how the session would be conducted. The group sessions were conducted in the community languages. When leading the discussion, the moderator focused on the same issues with each group. These were as follows:

- 1. general daily life concerns about their asthma
- 2. the perceived value of individuals taking specific action to protect their health or manage their asthma
- perceptions about the quality and availability of medical care in the community
- 4. knowledge of and attitudes to asthma and its triggers
- 5. knowledge of and attitudes to asthma management (i.e. how to prevent an asthma attack)
- 6. description of their condition when experiencing an asthma attack
- 7. perceived barriers to and difficulties in communicating with care providers
- 8. perceived difficulty in accessing, understanding and using asthma-related information.

We had successfully used this focus group method in our previous research in order to develop health literacy and health knowledge measures as well as educational material related to diabetes, and to better understand the use of government-sponsored health services (Poureslami *et al*, 2007a,b,c, 2011a). We offered the participants a fee to pay for local travel, parking and childcare, in order to maximise participation.

#### Data analysis

We applied three steps for data analysis in order to identify specific themes:

1. systematically reading the translated transcripts, reviewing the moderators' notes on the non-verbal

content and comparing and contrasting the responses of the participants within and across groups in order to document emerging themes

- 2. establishing categories of themes
- 3. sorting responses into thematic categories (Glaser and Strauss, 1967; Raynor *et al*, 2004; Nguyen *et al*, 2006).

Using this approach, we were able to identify several commonalities and disparities within and between different cultural groups, which are described in detail in a separate report (Poureslami *et al*, 2011a). For the purposes of this paper, we have extracted key overlapping thematic categories from the Iranian, Chinese, Punjabi and Latin American focus group sessions.

## Results

The community brokers and collaborating physicians introduced 32 patients, of whom 29 individuals (13 men and 16 women) agreed to participate. These included six Iranians, six Chinese, nine Punjabis and eight Latin Americans. The overlapping results of the group discussions and the quotations that exemplified them served as the basis for developing the preliminary content of the asthma education material. We considered four broad themes in this regard:

- 1. cultural beliefs, values and attitudes related to asthma and its self-management
- 2. overall knowledge about asthma and its triggers and symptoms
- 3. cultural, language and systematic barriers in accessing and using necessary asthma services
- communication issues with care providers, including misunderstandings about asthma information and the use of asthma medications and/or treatment regimen.

In the following sections, we describe some examples of how we interwove the above-mentioned themes when developing asthma educational material.

### Communication with care provider

Language and cultural barriers were identified by almost all patients as major problems when trying to communicate with care providers in Canada. It is interesting to note that some patients in this study indicated that their inability to manage asthma was linked to a perception that they were not receiving enough information from their physician about their disease or its treatment, and therefore they were less likely to take medication as prescribed. Patients also indicated that they were more likely to follow their doctor's directives if they liked and trusted the physician, if the doctor communicated in their mother tongue and if they felt that the physician had taken the time to listen to them and to understand the challenges associated with asthma. In view of these findings, and to incorporate the patients' cultural beliefs and practices, we invited two well-known physicians (one male and one female) from each of the target communities to provide necessary information in knowledge video clips that we developed in the community languages about asthma and its management. We also included some of the concerns raised by the participants, such as how to use medications and how to follow the treatment regimen.

# Misconceptions about asthma and its management

Like the general asthma population in Canada, patients in this study had universal concerns about asthma treatment (Boulet et al, 1994, Pachter et al, 2002; FitzGerald et al, 2006). They expressed a fear of adverse effects of medication, a belief that the medication was not helpful or that it was unnecessary and a perception that they should only use medication when they experienced symptoms. Participants also mentioned concerns about the diminishing effectiveness of medication over time, as well as being fearful of addiction or dependence. In order to provide patients with information about these misconceptions, we involved community members (e.g. patients and their family members) in developing plain-language pamphlets and drama-format video clips (i.e. 'community' videos). While considering the most appealing cultural beliefs and practices, the community videos were designed to address misunderstandings and false impressions about asthma and its management, and how to deal with them.

Another important finding in terms of language and cultural differences was that most of the participants described their feelings of fear and hopelessness when trying to seek medical care, because of language and cultural issues. As observed by other researchers, language and cultural barriers may also lead to a poor exchange of information, inadequate treatment and worse healthcare outcomes (Enarson and Ait-Khaled, 1999; Forbis and Aligne, 2002; Health Canada, 2004, 2006; Nayar, 2006; Nayar and Sandhu, 2006; Zanchetta and Poureslami, 2006). In this study, many of the participants explained that one of the reasons why people from their communities were reluctant to seek preventive treatment and did not take daily medications to control persistent asthma was because, according to their cultural belief, they only tried to visit the doctor or take medications when they felt that they were really sick and suffering (Pachter et al, 2002; Halm et al, 2006). This was a crucial issue that we considered in our educational videos, and therefore we responded by promoting the patient–doctor relationship, advising patients to visit their doctor regularly and to take their medications even in the absence of symptoms. In our educational material (including videos and pamphlets), we attempted to cover different views and beliefs held by care providers and their patients about health and well-being, and how they could both overcome communication problems.

Our previous study of diabetes in Latin American communities (Poureslami et al, 2009), as well as an analysis of access to government-based health services for Iranian, Chinese and Punjabi communities in their native language (Poureslami et al, 2007a, b), illustrated that when information is provided in an audio-visual format, it will be more effectively understood by ethnocultural communities than if the information is provided in print format. The main reason, as indicated by our participants and also reported elsewhere (Forbis and Aligne, 2002; Sawyer and Shah, 2004), is that printed material is normally developed using a mainstream perspective, and is produced in either English or French. Materials are then translated into the community's native language, thereby failing to reflect the cultural and linguistic issues of the community. In response, we developed the material in both audiovisual and written formats through the direct involvement of the community and the end users to provide culturally and linguistically appropriate information geared towards effectively changing health behaviour. Unlike the ways in which the majority of educational material is developed for multicultural communities, we sought to initially develop material in the language and from the cultural perspective of the community, and then translate the material into English.

Using the information gathered through the focus groups in addition to the educational videos and pamphlets, we also created pictorial instruments to assess the ethno-cultural communities' asthma knowledge and health literacy, which we are currently testing in a randomised controlled trial (RCT). We have collected initial normative data from selected individuals within the target communities in an effort to identify differences in asthma knowledge and health literacy according to gender, cultural group, socio-economic status, and urban/rural and other subgroups within the target communities in the GVA. Although we focused on overlapping themes that emerged within all four ethno-cultural groups, it is important to emphasise that there were some specific issues within each cultural group that added variation to the study's findings. For example, the Chinese participants were concerned about the spatial design of the patient education material. In one case they were uncomfortable with a gate that we used in the video, indicating that they felt the actors looked boxed in and isolated. Therefore we adapted the spatial design in the video based upon their specific request. We also found that a common perception among the Chinese community was that asthma is a communicable disease. This belief was addressed in the educational material.

In addition, we found that the practice of smoking was culturally embedded. Iranian participants explained that they preferred not to smoke in front of elders, Punjabi participants noted that smoking clashed with their religious beliefs, and Chinese participants said that smoking tended to be promoted by the Chinese government. Some Chinese participants were ashamed to use an inhaler in public because they were concerned that others would believe they had tuberculosis. These were perceptions that we found useful to challenge in the educational material. When we enquired about keeping pets at home, most of the Iranian and Chinese participants tended to state that they did not normally have pets at home, whereas Latinos and Punjabis more typically had a dog in their home. Therefore these cultural norms were included in the educational material directed at each specific ethno-cultural community. The cost of medication was of serious concern to Punjabi participants. Therefore they often indicated that they brought medication from home (i.e. their country of origin) because it was cheaper and could last for up to a year. It was most likely that their low level of education and socio-economic status was related to their aversion to purchasing asthma medication (or any other kind of medication) in Canada. This aspect of their belief system, which was mainly observed among Punjabi patients, was thus addressed in the educational videos. For instance, one of the community videos shows that the patient's cousin, who had recently come back from their home country, brought some asthma medications as a gift for the patient and their family members.

## Discussion

Our study engaged urban patients with asthma from four ethnic communities in concept development focus group discussions designed to elicit information that could be used in the development and implementation of a community-specific asthma education intervention. We used qualitative research methods to identify the structural parameters of situations in which ethnic-minority adult patients are at risk of health inequalities because of limited access to and use of health services. In Canada, for example, only 1 in 10 immigrants speaks either English or French as their first language (Statistics Canada, 2005). As a result, the specialised language and vocabulary used, in both written and spoken form, to convey health information (Institute of Medicine, 2008) can be difficult to understand for those with low levels of literacy in their native tongue and/or English and French. The goal was to translate the information obtained into educational material that is culturally and linguistically appropriate.

The focus group methodology was chosen because it provided a way of both involving participants and uniting researchers with community concerns.

The use of qualitative methods to collect social marketing information and to develop recommendations for decision makers is well documented (Morgan, 1996). However, because very few models of educational interventions for asthma patients exist, researchers have started to use focus groups to gain insight into the information needs of adults with asthma (Cortes et al, 2004; Nguyen et al, 2006). Drawing on the cultural expertise of the facilitators as well as community input gathered during focus groups, we developed the asthma material in each community's native language, and then translated it into English so that it would be accessible by members of the younger, second generation of the target communities, who might prefer to use English. We asked the participants to narrate asthma-related stories, to vote on the best ones and, in consultation with medical experts, to incorporate them into a script that they would later perform. We were interested in other aspects of communication, so we also drew on community knowledge to ensure that humour, for example, was used in a culturally appropriate way. The final translation was then verified with the participants. Approaching the translation process in this way ensured that the educational material was embedded within the cultural logic of each community. For example, in one case we learned that touching pets was not a common cultural practice among the Punjabi or Chinese community participants, and that Iranian community participants preferred to see a doctor from outside their community, so we adapted the material accordingly. We then sent all of the final drawings and video clips to community key informants and the study facilitators, and asked them for feedback. The final step involved a consultation with our advisory panel, which consisted of healthcare providers, such as primary care doctors and respirologists, researchers and focus group facilitators.

This study identified several issues which, if addressed, could help policy makers to better allocate resources and healthcare professionals to provide better care. Of particular policy relevance were the findings relating to participants' experiences of and opinions about accessing health information and care services. These findings support the views of the Canadian Expert Panel on Health Literacy, which described 'access' as 'mediated by education, culture and language, by communication skills of professionals, by the nature of materials and messages, and by the settings in which health-related supports are provided' (Canadian Public Health Association, 2009 p. 1). We disseminated the study findings through presentations and written reports to knowledge users, which included policy makers and healthcare decision makers, about the link between culture, language and health outcomes. In December 2010, we participated in a Pan Canadian Health Literacy Expert Panel and presented our study findings, which are being integrated into their report to be released in summer 2011. In addition, our research team planned to meet the British Columbia Ministry of Health Services and Minority Health in order to disseminate our findings and present an executive summary and recommendations on how to improve the health of new immigrants with asthma.

The participants in this study unanimously stated that it would be a practical approach, when talking about asthma and relevant issues, to include newcomers who had some difficulty in reading English, but who had received information from a doctor and audio-visual communication support through television or video. Once it was widely understood and accepted within the communities, health education material that had been developed by direct involvement of the community members (Raynor et al, 2004) could be used to monitor individual patients' progress in the self-management of their asthma, to enable them to make more enlightened decisions about their condition and communicate more effectively with their care providers (Poureslami et al, 2007a, 2011a). Based on these parameters, we established and followed three guidelines when developing our educational material. First, at each step of the development of the material, we made an effort to become better acquainted with the beliefs and perceptions of the target communities about asthma and its management. For instance, patients clearly articulated their concern about medication-related side-effects, the cost of medications, and fears of dying alone from an asthma attack. Second, we sought to understand the patients' knowledge of asthma symptoms, the triggers of asthma, and the signs of an asthma attack. With this in mind, the patients in the study talked about several issues that affected their health. They also discussed how difficult it was to merely discuss poor asthma management without talking about the issues related to side-effects, cost and access to services. Finally, it was clear that the patients in the study might have received some health information from their caregivers on how to manage their asthma. We wanted to do more than merely increase their knowledge, as we wanted to understand the importance of supporting their ability to act. Therefore we aligned our educational material with a definition of critical health literacy (Nutbeam, 2000; Lee et al, 2004), which requires a combination of more advanced cognitive and social skills in order to be better suited to critical analysis of the information. This critical analysis can be used to exercise better control over one's life and the situations that one encounters (Nutbeam, 2000). The depth of the data collected in this study allowed us to clearly see how the patients, as well as their families, were managing their asthma and how their beliefs and perceptions affected their actions (Gazmararian et al, 2003; Indian Cultural Association of Pittsburgh, 2006). The focus groups promoted critical dialogue and encouraged consensus building among the patients, which resulted in a process of conversation that shed light on the exact nature and logic of their beliefs and practices and how they could relate them to asthma. It thus became our goal to generate knowledge that could affirm the patients' intense struggle to manage their asthma. The aim of the educational material that we developed was therefore to enhance the patients' capacity to actively participate in self-management practices.

Furthermore, our focus groups allowed us to collect descriptions of the fears and concerns encountered by patients with asthma that might not be attainable with deductive quantitative methods, and to include their perspectives, expectations, experiences, meanings and expectations in our educational material. Local representatives of the Punjabi-, Mandarin- and Cantonesespeaking communities in Vancouver, including asthma patients and their family members, have now cowritten subsequent versions of story scripts and acted in the video clips in order to ensure cultural sensitivity. We chose to translate the materials into these three communities' languages because they are newcomer groups that have been reported to have a higher prevalence of asthma (Fuller-Thomson et al, 2006; Wang et al, 2008; Gershon et al, 2010). As a result, we were funded by the Canadian Institute for Health Research (CIHR) to address the barriers to care for people with asthma in these communities. This CIHRfunded study was titled 'Asthma and Health Literacy in Newcomer Communities in the Greater Vancouver Area (GVA): A Population-Based Qualitative Study'.

The video story lines reflect the cultural practices related to asthma prevention and control typical of the target communities. We were able to incorporate relevant scenarios into our video clips. For example, we produced a clip that shows a patient attempting to use controller medications only when his asthma is worsening, and avoiding the use of preventive medications when the symptoms are not apparent. In another clip, we showed a patient who thought that his condition was not serious enough to warrant daily medications. We then incorporated necessary information in our community and knowledge videos about the importance of regular daily use of medications as well as the use of preventive inhalers in accordance with what had been prescribed by a physician, even in the absence of symptoms. In addition, we encouraged patients to adhere to their treatment plan as prescribed by their treating physician.

Based on the findings of this study, we have also created culturally appropriate asthma-related printed material, such as pamphlets, and pictorial measurement tools. We developed the material in the distinctive language of each of the communities, with the direct involvement of patients, key informants and community members. It is noted that pictures closely linked to written or spoken text can, when compared with text alone, significantly increase engagement with, and recall of, health education information (Hatton, 1992; Austin et al, 1995; Dowse, 2004; Dowse and Ehlers, 2005). However, in other Canadian printed educational material, it has been shown that visual images do not represent the increasingly multicultural population of our societies (Simich, 2009), and therefore we aimed to fill this gap in the area of asthma care and management with marginalised newcomer communities in Canada. Our study demonstrates the effectiveness of culturally and linguistically appropriate material about patient awareness and intention to manage asthma. The results of our study indicate that language and culture can be important barriers to accessing, understanding and using asthma information and the healthcare system. Appropriately developed educational materials can help to increase knowledge about asthma over time. For example, there was a particularly strong response with regard to improvement of inhaler techniques. To date, we have conducted a clinical trial with 43 Punjabi patients and 42 Chinese patients, and we have obtained promising results, which will be reported elsewhere (Poureslami et al, 2011b). We discovered that when patients improved their health literacy, their knowledge of asthma symptoms and self-management practices increased significantly. Therefore healthcare providers need to understand and acknowledge these factors as major determinants of health, and apply them in their practice. In the future we shall continue to formally evaluate and monitor the relevance of culturally appropriate educational material for improving knowledge and practices with regard to asthma. Therefore subsequent studies will be conducted to determine whether increased awareness is associated with an improvement in health outcomes and asthma management.

# Limitations of the study

Some specific health beliefs emerged within each community, and our sample size was not large enough to generalise the cultural norms and health behaviours of certain communities. Moreover, we did not separate focus groups on the basis of gender, and thus we could not address issues of powerlessness among the women in our study. We view this as a major limitation because the men often spoke over the women, rendering them voiceless. This was particularly apparent within the Iranian and Punjabi focus groups. Future research that addresses this issue is needed, and should include collaboration with male and female champions as well as a focus on developing gender-specific materials. We also recognise that we did not address how those with low health literacy experience shame and thus would conceal their struggles when sharing mainstream health information with others. We suspect that this might be an issue in non-English-speaking ethno-cultural groups. Further research is needed to address how gender and shame interact in different ethno-cultural populations, influencing how individuals understand and use health information (Parikh et al, 1996). Similarly to other studies that have used CBPR when developing asthma management interventions (Martin et al, 2010), our study entailed a considerable time commitment of approximately five years. This process involves the complexity of building diverse relationships between members of medical, academic and local communities, which requires an arduous time commitment and the practice of patience.

## Conclusions

This study provides important insights for developing further research about the relationships between language, culture and asthma prevention and management. In addition, it provides insights into the use of patient focus groups as a practical approach for enhancing the ethno-cultural communities' awareness of the condition. The goal of the study was to translate the information that we obtained from patients and key informants into educational material that is culturally and linguistically appropriate. We argue that language and cultural barriers, as reported by other researchers, may lead to a poor exchange of information, inadequate treatment and worse healthcare outcomes. The implications of these findings are important when taking language into consideration, and cultural discordance between healthcare provider and patient has been shown by several researchers to be associated with lower patient compliance and poor health outcomes.

We also found that one of the benefits of using concept development focus groups is that a broader community understanding and individual response can be achieved. Furthermore, by organising the groups according to their language and ethnic background, cultural influences on the outcomes of respiratory health in general and asthma in particular can be identified. A clear example of one of these universal understandings is the belief stated by some of the participants that they were willing to use controller medications if their breathing was deteriorating, but that they preferred to avoid using them if symptoms were not apparent, because they believed that their illness was not serious enough to require daily medications. As a result, their asthma might be unstable because they did not adhere to their treatment plans. Many patients did not easily accept the belief that the daily use of controller medications was essential for controlling their asthma, and some were convinced that the risks or inconvenience of using asthma medications might outweigh their health benefits. These findings indicate that there is a lack of appropriate communication between the patients in this study and their care providers. In common with the general asthma population in Canada (FitzGerald et al, 2006; Fuller-Thomson et al, 2006; Gershon et al, 2010), patients in this study expressed their concerns about communication with care providers with regard to their condition. The implications of these findings are serious when taking into consideration the fact that language and cultural discordance between healthcare provider and patient has been shown by several researchers to be associated with lower patient compliance and poor health outcomes (Gazmararian et al, 2003; Arif et al, 2005; Cabana et al, 2007).

Different studies have indicated that culturally and linguistically appropriate patient education about asthma self-management is effective in improving objective measures of lung function, frequency of asthma symptoms, and healthcare utilisation (Enarson and Ait-Khaled, 1999; Cortes et al, 2004; Raynor et al, 2004; Fuller-Thomson et al, 2006; Halm et al, 2006). The data generated by this study enabled us to expand narrow concepts and functional approaches to health education interventions to include social and cultural factors outside the care practitioners' original focus in the management of asthma in underserved communities. In addition, the focus groups inspired our team of researchers to develop and test an educational intervention that supported the ability of these communities to participate in culturally driven self-management approaches.

As with most qualitative studies, our findings are tentative and the samples are not representative of the target populations. Although we have been careful not to make cultural generalisations, we have noticed that the information shared by the patients who participated in this study is rich enough to develop educational material that would be culturally and linguistically relevant and appropriate. The use of patient-oriented focus groups allowed us to identify several challenges (Dunn and Dyck, 2000; Forbis and Aligne, 2002; Halm *et al*, 2006; Health Canada, 2006) related to access that are relevant not only to the target communities, but also to other ethno-cultural groups in GVA and Canada in general. In addition, we gained valuable insights into the cultural beliefs and values, language issues, attitudes, concerns, meanings and perspectives of the target communities that could be applied to the management of other chronic diseases among newcomer groups to Canada.

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#### CONFLICTS OF INTEREST

None.

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