

## Self-Care Strategies for Managing Respiratory Illness in South-East Toronto: Life Histories of Chinese and Caribbean Immigrants\*

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This article reports on a qualitative study of ten Caribbean Canadians and sixteen Cantonese-speaking Canadians with respiratory illness. The data were gathered through life history interviews conducted during 1998 in South-East Toronto. After an overview of the literature, the study design is presented. The results focus on the techniques these immigrants use to manage their illness. The article concludes with a discussion of implications for research and policy.

Respiratory illness is one of the most common chronic health problems. There has been a significant world-wide increase in morbidity and mortality rates from asthma (Gottlieb et al. 1995). Respiratory illness causes a substantial financial burden on the health care system. In addition to medical costs, the personal suffering and productivity lost due to illness have societal costs as well.

Recent research has shown that respiratory symptoms are significantly higher among poorer children, those in the inner city, and among minority populations (Ernst et al. 1995; Gottlieb et al. 1995; Wing 1993). Immigrants from outside North America and Europe constitute over twenty percent of Metro Toronto residents, yet relatively little is known about their experience of respiratory illness. In Regent Park, a large public housing site in South-East Toronto, respi-

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ratory illness accounted for 9.3% of all hospital admissions in 1995 (Glazier et al. 1995). With its significant impact on our health care system, and its disproportionate representation in marginalized segments of society, respiratory illness presents an important topic for research.

An ecological assessment of factors related to health outcomes has contributed to the development of a new framework for understanding health (Boothroyd and Eberle 1990; Premier's Council on Health Strategy 1991; Renaud 1993). This population health framework was adopted in 1994 by the Federal, Provincial, Territorial Ministers of Health (Health Canada 1994). In addition to the importance of genetics and biological factors, evidence consistently has pointed to the significance of the social, psychological, economic, and environmental correlates of health (for example, Evans and Stoddart 1990; Marmot et al 1987; Mustard and Frank 1991; Health and Welfare Canada 1986; Premier's Council on Health, Well-Being and Social Justice 1993; Renaud and Bouchard 1994). These factors have been defined as the determinants of health.

Income and social factors have been identified as the most important determinants of health (Health Canada 1994). Other research has highlighted the importance of the social environment, including job-related factors and unemployment, family and social networks, prenatal and early childhood conditions. In addition to social and economic determinants, physical environment is also a key factor (Health Canada 1994).

This determinants of health framework can also be applied to understanding how people select strategies to manage their health. The resources individuals have to deal with their illness are accessed from their location in the social, cultural, geographic and economic environment. Only when people are allowed to tell their life stories can the full dimensions of these factors become visible.

This study builds on a pilot study of 19 residents of South-East Toronto who had breathing problems themselves or who had children with breathing problems. Of those interviewed, five were immigrants to Canada. Environmental factors were identified as a major cause of their breathing problems. These included the following: Toronto's cold, damp climate, dusty and poorly ventilated work environments in factories, and pollutants in the home, (for example, sewage backups in public housing). Many of the things which people identified as triggering their breathing problems could be avoided (for example, household sprays and chemicals, dust, animals, exercise, cigarette smoke). In addition to medication, a common management strategy involved avoiding triggers to the disease. A number of the immigrant participants described folk remedies that had been used in their home countries (Cossam et al 1996). There is, however, a lack of information on the use of alternative therapies among asthmatics (Blanc et al 1997). We felt that these remedies should be more thoroughly researched and documented. This article is the result of that exploration.

There are several key themes that typically emerge when one is studying the experience of chronic illness. These issues include the following: how medical crises are prevented or managed and how symptoms are controlled (Strauss 1975;

Clarke 1996). Research has highlighted the importance of the geographic environment as well as the social context in which illness is experienced (Dych 1995). By restricting our study to South-East Toronto, we could control some of the geographic variability. It also allowed us to explore in greater depth regional issues influencing the management of respiratory illness.

## Method

We conducted life history interviews with 26 immigrants (16 Cantonese-speakers and 10 immigrants from the Caribbean) in South-East Toronto experiencing respiratory health problems. South-East Toronto was chosen as the focus of our research for three major reasons:

- Active community members had identified respiratory health as a key problem in their community. They approached university faculty to assist them with research on this topic. Over a three year period, joint meetings with community members, service providers and academics had served to build a working relationship.
- Recent research has identified South-East Toronto as experiencing disproportionate rates of hospitalisation due to respiratory illness (Glazier et al. 1995).
- South-East Toronto is among the most economically disadvantaged and multicultural communities in Canada.

We are interested in how disadvantaged groups experience and cope with respiratory illness. In addition, we are particularly interested in techniques used within poorer immigrant communities. For the purpose of this study we focused on two case study immigrant groups: Cantonese-speakers and English-speakers from the Caribbean. These two groups were chosen for four reasons: the community health centres have identified particular respiratory health needs in these immigrant groups; we wished to compare and contrast traditional, culturally specific coping strategies such as traditional medicines and herbs; we wished to minimise the heterogeneity of the sample by limiting the population to two groups; and our community health centre partners already had positive relationships with these communities, therefore recruitment was easier.

We chose to use qualitative techniques in our study because we felt relatively little was known about illness-management techniques among Cantonese-speaking Canadians and Caribbean Canadians. We believe a questionnaire would fail to uncover the whole range of techniques used in these communities. Life histories are a popular qualitative research technique of particular value to investigate the less dominant voices in the world, such as women and minority members (Smith 1994; Fontana and Frey 1994).

Recruitment occurred through referrals from local service providers, leaflet

postings, and announcements in the ethno-specific media. We also did a number of presentations at community centres, English as a Second Language classes, and local gathering places. Several of our respondents were referred from other interviewees. Recruitment and interviews were done by a Cantonese-speaking Canadian graduate student and a Caribbean Canadian graduate student in their respective communities. These research assistants were integral to the project. They provided access to the community and promoted greater openness during the interviews. In addition, they provided culturally appropriate interpretation of the text during the analysis process. The interviews focused on the respondents' experience of respiratory illness, using the following listed questions as probes to stimulate the discussion:

- When did you first develop breathing problems?
- Have your breathing problems changed throughout your life (including pre/post immigration to Canada)?
- How do your breathing problems change throughout the day?
- How have you managed your breathing problems?
- Is there anything that would help you manage your breathing problems?

The life history interviews were recorded and transcribed. The interviews in Cantonese were translated before they were transcribed into English. Four transcripts were independently coded by each of the five authors. The themes that emerged were then used as a tentative framework with which to code the remaining transcripts. Additional codes were added until saturation was reached. Once analysis was complete, all authors reviewed the article to assess if the interpretations were appropriate and grounded in the data (Charmaz 1983).

Of the ten Caribbean Canadian immigrants, three were men and seven were women. Two of the Caribbean Canadian sample were mothers of children with asthma and seven respondents had asthma themselves. One respondent had chronic upper respiratory symptoms, although she was unclear whether these symptoms were due to allergies or sinus problems. The majority of these respondents were in their thirties or forties although one elderly woman was included.

Sixteen Cantonese-speaking Canadians were included in our sample. Five respondents had children with Asthma and one interviewee cared for an asthmatic grandchild. The remaining ten respondents had respiratory illness themselves, one of whom also had a child with asthma. Among the ten adults there were three major diagnoses: three respondents had asthma, two had chronic bronchitis and five had undiagnosed problems with chronic coughing. Of the Cantonese-speaking adults with respiratory illness, six were seniors and four were in their thirties or forties.

## **Results**

The immigrants in this study used an extensive range of strategies for managing their illness. These self-management strategies included the use of Western and traditional medicine, avoiding triggers and managing the environment, diet, exercise and educating themselves.

### **Use of Western Medicine**

Western prescription medicine was the most prevalent strategy for managing respiratory illness. All but one Caribbean Canadian respondent used a puffer. That respondent had upper respiratory symptoms, not asthma. She used prescribed nose drops. Among the 16 Cantonese-speaking Canadians, ten were using puffers and four were using a variety of prescribed medicine. Only two respondents were not currently using prescribed Western medicine. Most respondents relied on puffers for relief of acute symptoms.

Some respondents had great confidence in the efficacy of their medication. A Caribbean Canadian woman stated “Certain medication, if I don’t take them I will dies....”. An elderly Cantonese-speaking old woman stated:

“I have to take many kinds of medication. It’s like an addiction . . . I know I’m in trouble if I don’t take the medication. I can’t breathe if I don’t use the spray. I have all kinds of medication in my purse. Sometimes I have to use the spray more often when my breathing is bad. Sometimes it’s every two hours”.

Some respondents knew a great deal about their medication. In describing a prescribed medication, one Cantonese-speaking mother informed the interviewer that “this is to regulate and enlarge his trachea”. In contrast, many respondents described their puffer by colour only and did not know the name. One Cantonese-speaking respondent, when asked what kind of pills he was taking stated “I don’t know what kind of pills. I don’t understand English. The doctor didn’t tell me”. Several respondents were unclear or misinformed about when and how to use the puffer. One mother was administering the puffer every hour to her child, which is potentially dangerous.

A Caribbean Canadian man reported that getting the correct medication was often contingent on finding a good doctor. After several futile visits to different doctors he accidentally found an excellent doctor.

“When I described the symptoms she knew exactly what it was, she could actually tell me how I was feeling and she could prescribe exactly the right thing. So accessing the medicine is not a problem, it’s being lucky enough to be in the right place at the right time to see the right person”.

Cantonese-speaking respondents were more likely than the Caribbean Canadian respondents to mention the use of antibiotics. One respondent felt they were very helpful, whether or not they were prescribed. "When he is really bad, I give him antibiotics too ... It's his father's prescription ... The doctors said he doesn't need the antibiotics ... I guess I'm too impatient, seeing him suffering".

Several Cantonese-speakers and Caribbean Canadian respondents also used over-the-counter medications such as decongestants and cough medicines. One Caribbean Canadian respondent commented "Well, before it was really miserable ... because when I go to parties and stuff, I have to make sure that I take my Sudafed before I leave home. Because I would be so clogged up...". In the Caribbean Canadian community, Vicks was used in a variety of ways: on their nose to help stop sneezing, in a humidifier to relieve sleeplessness or as a rub to improve breathing. Vitamins were also used as a preventative measure by members of both communities.

While there was not a great deal of difference within the two communities on the types of Western medication used, the folk cures varied significantly between the two cultures. In both communities, however, these folk cures were recommended to the respondents by many other people. It appears that folk medications are well known in the communities.

### **Folk Medicine use among Caribbean Canadians**

Only one of the ten Caribbean Canadian respondents had not used any traditional or folk medicine and most used it regularly. Of those who had developed their respiratory illness before they had immigrated, most had used traditional medicines in their country of origin. Only a few took prescription drugs before their arrival.

In the Caribbean Canadian community, Bush tea is one of the most prevalent techniques used to manage respiratory illness. Bush, also called Cold Bush, is a medication made from boiled herbs and consumed as a tea. The ingredients vary slightly from country to country but the most common herbs include the following: cerissy bush, marijuana, orange or lime bush, round-the-world, search-me-heart, leaf-of-life and sour sop leaf. Elders appeared to be keeper of this traditional form of medicine. Many respondents received the bush from older relatives in the Islands. One woman commented "Oh, my mom will boil cold bush and all these medicines and send it for them (the children) ... I don't know the name of some of them ... (It is an) old people's remedy".

Consumption of Bush tea was thought of as a preventative strategy. One woman reported that she drinks it "whenever I want. I don't wait 'til I have the attack. I use it in the morning ... The attacks don't come as often as they used to and you know, you breathe more freely and easier ...". Although the majority of participants believed in the effectiveness of traditional medicines, in an acute attack they turn to Western medication for relief.

Other traditional medicines mentioned include onions and honey, garlic and honey, coconut oil (both for consumption and as a rub), peppermint oil (added to hot water and inhaled), nutmeg tea and castor oil. Some respondents commented that they disliked the appearance and taste of the traditional medications and found the prescribed drugs easier to take.

### **Folk Medicine use among Cantonese-Speaking Canadians**

Among the 16 Cantonese-speaking Canadians, there were only three who had never used Chinese traditional medicine. An additional two respondents had used it in the past but had since stopped. Nine of the respondents are currently using both Western and traditional medicine and two were only using Chinese medicine. In general, there was a belief that Chinese medicine is helpful, however its relative merit in comparison to Western medicine is still debated. One mother stated, “sometimes I don’t give her the puffer, I give her some Chinese medicine. Chinese medicine can clear her symptoms better”. In contrast, a father of young asthmatic stated, “Chinese medicine isn’t as effective as Western medicine. When her asthma and her coughing became worse she needs to take Western medicine”.

One of the most frequently cited treatments for respiratory problems were special soups, particularly alligator soup. One respondent stated, “this is in our culture to prepare those soups”. Many respondents thought that these soups may improve the immune system. One mother of an asthmatic pre-schooler stated,

“Some people suggested I make some soup as tonic for her. It seems to have helped her symptoms. Her health is better. It’s not as easy for her to catch a cold or ‘flu now. Her immune system may be better. Even her coughing is not as severe as before”.

In contrast, one parent when asked about alligator meat, found it “not that effective. Or maybe if one believes in it psychologically, it may have some effect”. One soup recipe included ginseng, quail and lotus seed and another included dates and black beans.

Chinese cough syrups and pills were used and thought to be effective by several respondents. As one elderly woman reported, “I asked the drug store in Chinatown here what I could have for throat infection. They showed me these tablets ... so I bought them to try. I took them and I felt better right away”. Other traditional medicine mentioned include fish oils, aloe vera, bee pollen and royal jelly.

A 62 year old man with chronic bronchitis reported another strategy for managing his illness.

“I use massage as a treatment. I put my hands together and put them on

my chest ... (I) massage the chest to the left and back 36 times. Then ... the stomach 36 times ... Use enough force to massage, such that the massaged areas get warm. After ... put both hands to press down on the abdomen two minutes. Afterward, put both hands to the lower back and massage the back in a sweeping downward movement”.

### **Avoiding Triggers and Managing Environment**

In both groups, avoidance of cigarette smoke was a key strategy to minimise respiratory symptoms. This ranged from not allowing smoking in the house to avoiding public places where people could be smoking. Another major trigger appeared to be dust. Many respondents reported that they cleaned and vacuumed their house often. Some respondents were careful to use non-toxic cleaners. “I use things like vinegar instead of aerosol sprays”. Other strategies included removing carpets in the home, forbidding pets and toys with furs, and avoiding feather pillows and duvets.

Inadequate moisture in indoor air was also cited as a problem, particularly for those prone to nose bleeds and bad coughs. Several respondents had humidifiers installed or used large fish tanks to improve the humidity. Air quality was enhanced through air filters or opening the windows to improve the ventilation. One Caribbean Canadian respondent thought her cool mist humidifier was particularly helpful. “I run that all night ... because the cool air just opens it up (her breathing passages)”.

To many respondents, it was important to control their apartment or house’s temperature to minimise the respiratory symptoms. Several of those who lived in apartments where this was not possible found it very frustrating. “You always have to leave a window open or leave it cracked. When we were living in Regent Park the rooms were so small and you don’t have enough space and it’s not properly ventilated”. In the winter, this respondent needed to put towels around the doors to keep out the drafts.

Many people find a combination of these strategies beneficial. As one Caribbean Canadian respondent said, “Yes, my asthma, you could say it was under control up to an extent. I have an air cleaner, I took off all the carpeting. Everything changed. If I stay in here, I’m fine. Go down the street and I have a problem. I can’t do without the inhaler”.

As indicated in the above quote, many respondents found it more difficult to control the external environment. Some interviewees found the extremes of temperature particularly problematic. A major self-care strategy was to avoid time outside. As one Caribbean Canadian mother with four asthmatic children stated,

“Oh well, for me what I do, like when it’s too hot, if I don’t have to go outside with them I don’t. When it’s too cold, if I don’t have to take

them out, I don't. Just for the precaution, because for me when I find that it's too hot or when it's too cold it triggers it off, for some reason, I don't know why".

Other respondents had problems on hazy days. For those who do spend time outside, a variety of preventative strategies were used. These strategies included covering one's nose in cold weather, dressing warmly, avoiding getting damp, resting frequently to prevent over-exertion and drying oneself quickly after a swim. Three of the ten Caribbean Canadian respondents reported that returning to the Caribbean dramatically improved their symptoms.

### **Diet**

In both communities some interviewees mentioned the importance of avoiding certain foods and eating others to minimise respiratory symptoms. Several respondents tried to eat primarily at home. "You basically give them their own food and try not to eat out too much at other places". Several Caribbean respondents had severe food allergies and therefore needed to be especially vigilant. Some respondents emphasised the need to eat a variety of healthy food including green vegetables, fruit, yams, plantains, a lot of curry, but to avoid eating too much meat. Financial difficulties further hamper attempts to eat well. As one Caribbean Canadian mother commented,

"It was the same thing when we used the food bank. Some people will say 'well, if you're hungry you'd eat anything'. I remember one lady got annoyed at me because I had to use about three different ones to end up with the things that I want ... But she didn't understand at the time".

In addition to consumption of alligator soup discussed above, other special diet considerations in the Cantonese-speaking community include avoiding chicken. "A person is not supposed to eat chicken either. That's what Chinese people say. Chinese doctors also say no chicken". A traditional Chinese belief is that ice water or very cold drinks exacerbate coughing and respiratory symptoms. Therefore, some respondents avoided cold drinks. One respondent mentioned avoiding too much fruit. Another felt that a little of everything was nutritious. Two respondents discussed the traditional Chinese belief in the hot and cold nature of foods. One elderly asthmatic woman stated that she does not eat foods that are "cold in nature, like watercress or bean curd products".

### **Exercise**

In both communities some people regularly exercised and others did not. Two

Caribbean men participated in sports to control their asthma as well as to maintain general good health. A Cantonese-speaking woman took her asthmatic son swimming twice a day in the summer “to get him some exercise and get him stronger”. An older Cantonese-speaking man performed a daily exercise he believes improves his breathing and circulation. “Standing, I stretch my arms forcefully to the side and then quickly bring them back to the centre. This helps to increase fresh air in my respiratory symptom”. Other Chinese respondents reported doing Tai Chi or walking briskly.

In contrast, many respondents were almost house-bound, particularly in winter, and did not report doing any exercise. One Caribbean Canadian woman was exhausted due to her asthma. She stated, “I can’t stand up straight. I can’t leave the house”.

### **Educating Oneself**

Almost all the respondents had invested a great deal of effort learning about the disease and management strategies. Many respondents turned to friends and family members for information and traditional cures. Most interviewees also expected their doctor to provide information. Some respondents were satisfied with the information they received. One Cantonese-speaking respondent stated, “My knowledge is like what the doctors know. The doctor wants me to know as much as he does”. Other respondents, such as this Caribbean woman, were much less satisfied and felt the need to pursue information elsewhere. “I had to find out on my own. Nobody tells you. If they tell you, you’re not going to take it. I realise don’t just pop anything that the doctor gives you until you find out”. Some respondents turn to written material. For example, one Cantonese-speaker receives a newsletter from the Lung Association. There was a general belief that information on the disease was important, yet it was difficult to access.

No matter what combination of self-care strategies the respondents used, they consistently were vigilant to assess whether an attack was coming. Particularly among parents of asthmatic children, the need for constant awareness was underscored. One Cantonese-speaking respondent changed from full-time to part-time work in order to monitor her child’s symptoms and assure that he did not need to walk to school. A Caribbean Canadian mother commented, “He doesn’t eat and from that I know it’s coming on. Cause he’s a child who loves his mouth and tummy ... all these signs I notice. Then I take him to the doctor, but only if the medication isn’t working the way it should”.

## **Summary and Conclusions**

The coping techniques that were identified suggest that there is a rich collection of resources in the community for managing breathing problems. In this study,

the principle strategies used for managing respiratory illness are Western medicine, traditional and/or folk medicine, avoiding triggers and managing the environment, diet, exercise and educating oneself. Although both communities reported extensive use of folk medicine, the types of traditional medicine varied dramatically.

These findings can be contrasted with a recent qualitative study of non-immigrant adults with asthma (Clark and Nothwehr 1997). The 29 respondents in Clark and Nothwehr's (1997) focus group study were living in or near a Mid-Western U.S. college town. Ninety percent of the samples were white, with the remainder being African American (Nothwehr 1998). The themes that emerged from Clark and Nothwehr's (1997) study were similar to our findings with respect to the strategies of using Western medicine, avoiding triggers and managing the environment, exercise and educating oneself. The two strategies that we found in our sample that were not discussed in the American study were folk medicines and diet. With the exception of a general belief in eating healthily, none of the diet or folk medicine strategies were reported by their respondents (Nothwehr 1998). These elements appear to be the strategies uniquely rooted in the immigrants' experiences and cultures. Consequently, further ethno-specific research is needed on these topics in particular.

Qualitative studies are not designed to be representative nor generalizable. However, our findings do indicate areas for future research that may have important implications for policy development.

Our findings on the use of herbal products and over the counter medicine support the need for further research on the subject. In many communities, the use of non-prescription medication is relatively common (Blanc et al. 1997). While some studies have begun to look at the topic of Chinese medicine (for example, Borchers et al 1997), more research is needed in the area. Bush tea, which was used extensively by the Caribbean respondents, provides an important, and neglected, area for future research.

There needs to be some recognition by the health care system that traditional medicines are widely used and often preferred. Present strategies of ignoring this fact are problematic. In order for a holistic health care plan to be developed, it is necessary to consistently explore with patients what alternative therapies are being used. With this knowledge, links between the traditional and Western health care systems can be constructed.

The respondents' wish for more information indicates a need for easily accessible information, in both Cantonese and English, on respiratory illness, and recommended medical and self-care management strategies. This recommendation supports earlier demands for language specific medical information (Ontario Ministry of Health 1994, 1995). A review of community-based asthma intervention programs for inner-city children suggests that three factors can enhance their effectiveness:

- Community settings such as churches, public schools and community-based

clinics should be used as sites for workshops and other interventions.

- Health professionals need to be educated on asthma management.
- There needs to be a multi-faceted approach to address housing, social and medical access problems of this population (Butz et al 1994).

Furthermore, these model programs had minority members recruiting and/or administering the intervention. Ethno-specific self-care management workshops based on these principles seems very promising for both the children and the adults in this study.

More research is needed on the relationship between diet and respiratory illness. The traditional Chinese belief that drinking ice water or cold drinks may induce or exacerbate asthma was recently supported in a clinical trial (Lin and Hsieh 1997). Our research revealed foods that the respondents thought were beneficial (for example, alligator meat) and others thought to be harmful (for example, chicken).

Immigrant communities should be provided with more culturally sensitive and language-specific health care provision. To achieve this goal, it is important that policies improve access of immigrant physicians and nurses to Canadian professional accreditation (Ontario Ministry of Health 1994, 1995).

Several respondents reported that they were almost house-bound by their illness. While most had developed adequate strategies for managing their indoor environment, controlling their illness outside was more problematic. Coalitions of community members, service providers and policy makers need to continue their work on improving the environmental air quality in inner-city Toronto.

The respondents in this study spent a great deal of time and energy managing their respiratory illness. They have developed an impressive array of strategies for minimising the disease's negative consequences for their lives. The wealth of information gained from these life history interviews will be helpful in informing future research. The study also illustrates that asthma sufferers have vital information essential in improving community-based care. The findings indicate the need to understand respiratory health and illness from a broader ecological perspective including socio-cultural, economic and environmental factors.

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