

# **UNDERSTANDING SELF-MANAGEMENT OF CHRONIC DISEASE IN THE SOUTH ASIAN COMMUNITY**

**A Literature Review of Barriers and Enablers**

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Prepared by:  
Jeet Sivia, Project Lead  
Health and Business Analytics, Fraser Health



# EXECUTIVE SUMMARY

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## Introduction

It is widely known that South Asian migrants are at considerably greater risk of developing chronic diseases such as type 2 diabetes (T2D) and cardiovascular disease. In addition, chronic disease-related complications are also more frequent in this group and occur much earlier than in non-South Asians.

While research has demonstrated a genetic predisposition to these conditions, the majority of the increase is due to factors such as the aging population, and lifestyle factors such as obesity, diet and sedentary routines. Such conditions cannot be cured and are normally managed with pharmacological treatments; patient education and lifestyle modification have been shown to reduce the burden of diabetes as well as other related chronic conditions the person may develop. The ability to affect patient outcomes in these areas has led to the development of evidence-based interventions such as standardized education, professional skill development and materials, and self-management approaches.

Self-management, although shown to be effective in Caucasian populations, is highly demanding on the patient and its success is dependent on an informed patient and a fertile patient-provider relationship. However, little is known about how such strategies could be applied and adapted to the South Asian community, including the patient, families and family physicians.

## Purpose

The purpose of this report is to synthesize the peer-reviewed and grey literature for evidence on understanding self-management incentives and requirements in the South Asian community in order to learn:

- the cultural, social and personal beliefs of South Asians towards chronic diseases such as type 2 diabetes and cardiovascular disease;
- the attitudes and practices of South Asians towards self-management of chronic disease; and
- the factors (enablers, requirements and barriers) that should be considered in the development of culturally sensitive chronic disease self-management interventions.

## Methods

A literature scan of the main electronic databases (see Methods section of report for additional information) was undertaken from 1990 to the present for articles related to the self-management topic for South Asian migrants living in developed countries.

## Results

### Demographics:

- According to the Canada 2006 Census, the South Asian population totalled 181,895, or 13% of the total Fraser Health population.

- Between 2001 and 2006, the Fraser Health South Asian ethnic population grew by 34% while the total Fraser Health population grew by 8%.
- The majority of the Fraser Health South Asian population resides in the Surrey Local Health Area (LHA), representing 32% of Surrey LHA's total population.
- Punjabi is by far the most dominant mother tongue and the language most often spoken at home among South Asians.

#### **Epidemiology:**

- South Asian migrants have considerably higher rates of T2D (and cardiovascular disease) compared with Caucasians of European origin.
- The age of onset for T2D is much lower for South Asians.
- South Asians have significantly higher rates of insulin resistance.

#### **Cultural aspects associated with chronic disease:**

##### Diet

- Considerable dietary and food diversity exists among South Asians depending on their religion, country/area of origin, age and level of acculturation.
- Religious and food beliefs play an important role in food choices and practices.
- Many believe that simply eating a vegetarian diet equates to a "healthy diet" rather than ensuring that diets with higher nutritional value. (vegetables), decreased carbohydrate consumption and food prepared using low-fat cooking ingredients are also important.
- Lower awareness of nutritional content of foods and diet is common among certain subgroups.
- Healthy dietary behaviours are often ignored for the social norms of hospitality.
- There is a need for the development of targeted South Asian-specific dietary behavioural models -very few exist at this time.

##### Physical Activity

- Social norms of modesty and gender roles often override physical activity, especially for Muslim women and older adults.
- Cultural and religious factors impacting certain subgroups need to be overcome, such as through women-only facilities and culturally appropriate services for the elderly.
- Interventions to increase physical activity need to be both individual and community-based. For example, South Asians need personal advice on physical activity dealing with barriers such as time and motivation.
- Studies show evidence of change in attitudes and receptivity towards physical activity - this provides unique opportunities for targeted interventions in this area.
- Appropriate physical activity needs to be incorporated into everyday life events.

### Health Beliefs

- Heredity/family history of chronic illness - thus illness is thought to be inevitable if a family member has the disease.
- Illness is attributed to external factors such as fate, stress and cold weather and less likely to personal factors
- The need for self-management/monitoring is not commonly seen as necessary in the absence of symptoms.
- There is passive participation in self-management and strong reliance on the health care providers.
- There is very little preventive or promotional outlook about chronic disease prior to diagnosis.
- Interventions that target perceptions of disease may be beneficial in risk-reduction and self-care among South Asians.

### Language and Health Literacy

- English fluency and health literacy are major public health and clinical challenges in South Asians.
- English fluency and health literacy greatly impact South Asians' ability to engage in health-inducing practices including access to and use of health care services.
- Language fluency allows patients to build deeper relationships with their care providers.
- Interventions need to use clear and multiple forms of communication and delivery methods to increase literacy.

### Awareness of Disease

- Knowledge about disease and their risks varies among South Asians but is generally lower than that of Caucasians.
- Many South Asians - especially those unable to speak the local language, those with low education levels, new immigrants, women and the elderly - have minimal understanding about the key elements of diabetes care.
- Those with good knowledge feel more empowered, in control and less threatened by their disease.
- Poor access, irregular care and missed appointments are highly correlated with patient efficacy and awareness.

### Attitudes Toward Treatment

- The concept of fate and inevitability of chronic disease may drive the lack of urgency seen in South Asians towards care-seeking behaviours.
- Self-regulation of care plans and medications is common among South Asians.
- Interventions targeted at modifying perceptions of external factors may be beneficial in improving self-management care.

### Relationships with Care Providers

- South Asians generally have good satisfaction with health care workers, including family physicians.
- Patients' cultural values and beliefs place their relationship as "receiver" of care and advice and not as equal partners in their care plans.

- Evidence shows that during clinician/patient visits, clinicians usually centre their focus on routine tasks of monitoring, with little feedback or discussion of patients' issues or concerns. This did not change with patients' ability to speak English.
- Cultural differences between patients and care providers have more impact on the patient/provider relationship than does language.

### **Self-management in South Asians:**

- South Asian migrants have lower access and utilization of overall health care services, including care related to chronic disease.
- South Asians generally have lower levels of chronic disease self-care than Caucasians.
- Studies assessing culturally based self-management aspects among South Asian migrants are sparse.
- Self-management is highly influenced by a patient's proximal factors, such as attitudes, social influences and support, intentions, self-efficacy and feeling a sense of control over disease, and by distal factors, such as cultural, religious and socioeconomic factors. These factors impact self-management through
  - o the patient's perception that chronic disease such as T2D is inevitable and little can be done to address its impact and potential complications;
  - o making uninformed decisions about balancing the intake of foods and complementary medicines in order to minimize the side effects of pharmaceuticals and/or blood sugar levels;
  - o reliance on lay knowledge networks resulting from language and service inequity;
  - o low knowledge of disease and its management;
  - o passive attitude about receiving care;
  - o lack of self-care models suited to or tested on South Asians; and
  - o the patient's ability to access self-management care and services due to structural factor challenges such as transportation, distance and time of appointment.
- Most self-management interventions targeting South Asians have been educational, and these have shown improvements in patient knowledge.
- Most of these interventions have been of short duration, and very few have shown long-term sustainable and culturally appropriate generalizable results.
- Numerous principles and strategies have been proposed to make self-management more culturally applicable in order to increase uptake and impact. Some of these include
  - o addressing deep-rooted factors that tackle cultural, religious, social and psychological characteristics;
  - o thorough involvement of target community in planning, implementation and evaluation of interventions;
  - o Tailored approach built on in-depth knowledge of targeted groups (i.e., patient profiling); and
  - o mainstreaming services to South Asians and involving primary care practitioners in a collaborative, integrated approach to building client and care-provider capacity for self-management.

## Conclusions

This literature review clearly suggests health and self-management inequity in South Asians. This can be addressed through the provision of culturally and linguistically competent care strategies that support self-management. Solutions to tackle self-management capacity in Fraser Health need to address a wide range of issues and not just language fluency. There needs to be a focus on successful partnerships between health care providers, patients, carers and the community. The main findings of this literature scan are

- **Limited linguistic and literacy capacity among South Asians**  
Literacy and language fluency are integral to self-management, and the literature suggests low levels of both in South Asians. Building linguistic and literacy competence of high-risk subgroups will likely entail developing culturally acceptable, evidence-based health education techniques to reach high-risk South Asians.
- **Limited knowledge of disease and self-care among South Asians**  
Knowledge of disease and self-care varies considerably among South Asians. Improvements in knowledge, understanding and management of chronic disease will require a multi-pronged approach, including multi-media resources, and use of bilingual care providers to enable more direct communication with patients and their concerns.
- **Ingrained health beliefs and attitudes related to disease**  
This review has highlighted the role of culture, religion and gender on beliefs about health and health-inducing behaviours. Interventions can use these beliefs as a resource to bring about positive attitudinal and behavioural changes.
- **Significant heterogeneity and diversity among South Asians**  
There is considerable diversity among this ethnic group along the lines of religion, place of origin, language, gender roles, levels of acculturation, educational levels and length of residency. Understanding this intra-ethnic diversity is important for motivating individuals to consider, initiate and maintain self-management practices.
- **Structural barriers impact the most vulnerable South Asians**  
For South Asians women with little or no education, the elderly and recent immigrants, structural and material barriers (such as limited mobility, limited financial support, gender inequalities, transportation and distance to services) are just as important as cultural/religious/linguistic-based barriers for engaging in self-management and other health-seeking behaviours.
- **Need for cultural adaptation of interventions**  
The literature reveals the application of a wide array of strategies for adapting interventions to take into account the cultural context of target groups - from the use of link workers, diabetes nurses, interpreters, ethnic case workers, peer-educators, to the use of community venues and places of worship and overcoming structural barriers by providing taxis to participants, etc. The key is to ensure that the community is fully involved from planning to evaluation.

- **Cultural competency of care providers**  
Increasing the cultural competency of health care practitioners is considered an important strategy in reducing disparities in health status and health care use among South Asians. This entails increasing their knowledge, attitudes and skills about multicultural care in order to facilitate more meaningful interactions with their clients.
- **Mainstreaming of new and existing initiatives**  
Given that targeted intervention can take considerable time, resources and effort, it is imperative that in parallel to this process, mainstream initiatives are developed and implemented with South Asian ethnic groups' input and expertise. This ensures that South Asians with lengthy residence in Canada and those that are well acculturated receive appropriate care.
- **Implement best practice checklists for planning and service provision**  
Given the both inconsistent and limited level of promotion, prevention and self-management services for South Asians, the literature suggests improved coordination and delivery of community-based services and increasing primary health care capacity for prevention, early detection, early intervention and chronic disease self-management.
- **Scarcity of research evidence and diversity of studies**
  - Limited studies on self-management and studies that evaluate generalizable interventions. Most of the evidence is from the UK.
  - Lack of theoretical frameworks on this topic, and as a result, almost all studies lacked the planning and assessment of interventions underpinned by theories. This is important given the dynamic and fluid nature of both culture and ethnicity over time.
  - Most of the interventions reviewed were short-term, suggesting RCTs of long-term duration are required to evaluate the effectiveness of initiatives beyond the typical 6 to 12 month duration.
  - The studies reviewed in this literature search were diverse and multi-faceted in terms of the target audience, age groups, setting, nature of interventions, scale and duration.
- **Lack of ethnic-based data**  
Currently, very little demographic, utilization and health-related data exist for South Asians. Quality data are needed for planning, implementing and evaluating interventions and health outcomes. Targeted approaches are difficult to implement without adequate levels of ethnic-based data.

# TABLE OF CONTENTS

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<b>EXECUTIVE SUMMARY</b> .....	i-vi
<b>1. INTRODUCTION</b> .....	1
<b>2. METHODS</b> .....	3
<b>3. THE SOUTH ASIAN POPULATION IN FRASER HEALTH</b> .....	5
<b>4. CHRONIC DISEASE EPIDEMIOLOGY</b> .....	8
<b>5. CULTURAL ASPECTS ASSOCIATED WITH CHRONIC DISEASE</b> .....	16
DIET .....	16
PHYSICAL ACTIVITY.....	19
HEALTH BELIEFS AND ILLNESS PERCEPTIONS .....	21
LANGUAGE AND LITERACY .....	22
AWARENESS OF DISEASE .....	24
PSYCHOSOCIAL AND GENDER-BASED ELEMENTS .....	25
ACCESS TO HEALTH INFORMATION.....	26
ATTITUDES TOWARD TREATMENT .....	27
RELATIONSHIPS WITH CARE PROVIDERS .....	28
<b>6. CHRONIC DISEASE CARE &amp; MANAGEMENT</b> .....	30
SELF-MANAGEMENT IN SOUTH ASIANS .....	31
SELF-MANAGEMENT AND CULTURALLY-APPROPRIATE EDUCATIONAL INTERVENTIONS .....	37
PRIMARY CARE INTERVENTIONS.....	40
<b>7. CONCLUSIONS</b> .....	47
<b>8. REFERENCES</b> .....	50

# 1. INTRODUCTION

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## **Purpose**

This report scans the peer-reviewed and grey literature for evidence on understanding self-management incentives and requirements in the South Asian community in order to learn

- the cultural, social and personal beliefs of South Asians towards chronic diseases such as type 2 diabetes and cardiovascular disease;
- the attitudes and practices of South Asians towards self-management of chronic disease; and
- the factors (enablers, requirements and barriers) that should be considered in the development of culturally sensitive chronic disease self-management interventions.

## **Background**

The prevalence and incidence of chronic diseases, especially cardio-vascular disease and diabetes, is high and rising in the South Asian population. While research has demonstrated a genetic predisposition to these conditions, the majority of the increase is due to factors such as the aging population, and lifestyle factors such as obesity, diet and sedentary routines. Such conditions cannot be cured and are normally managed with pharmacological treatments, but patient education and lifestyle modification (weight reduction, exercise and diet) have been shown to reduce the burden of diabetes as well as other related chronic conditions the person may develop. The ability to affect patient outcomes in these areas has led to the development of evidence-based interventions such as standardized education, professional skill development and materials, and self-management approaches.

The sustained uptake of self-management concepts and approaches by their target populations presents significant challenges. Understanding the impact of cultural context is becoming increasingly important, as British Columbia (BC) moves aggressively forward with its Primary Care and Integrated Community Care strategy. This strategy is predicated on widespread adoption of self-management activities, with patients actively participating in their care and the health of the community. Little is understood, however, about how such strategies could be applied and adapted to the South Asian community, including the patient, families and family physicians.

Gaining a fuller understanding of the South Asian communities' chronic care needs, their attitudes towards self-management and the incentives that may be effective in facilitating uptake of self-management approaches is necessary to demonstrating health system utilization pattern changes and achieving successful health-related outcomes for this population group.

## Why South Asians?

The South Asian population is being targeted for the following reasons:

1. South Asians have significantly greater risk of morbidity and mortality from type 2 diabetes and cardiovascular disease.
2. South Asians face considerable service and care inequities including uptake of health-promoting and health-managing opportunities.
3. South Asians are the largest ethnic group in Fraser Health, representing 13% of the total Fraser Health population, and this population is growing at a much faster rate than the total Fraser Health population.

Increasing research evidence on South Asian migrants living in Western countries, such as the United Kingdom (UK), the United States (US) and Canada, suggests this ethnic group to be at greater risk for morbidity and mortality from chronic diseases such as type 2 diabetes and cardiovascular disease as compared to the native white population.<sup>1,2,3</sup> Risk of diabetes also increases over time from the point of migration from South Asia.<sup>2</sup> Diabetes-related complications are also more frequent in this group and occur much earlier than in non-South Asians.<sup>4</sup>

Studies have shown that both environmental and genetic factors play important roles in the increased incidence of diabetes in this group.<sup>6,7</sup> They tend to have higher abdominal adiposity and insulin resistance, two important correlates of diabetes in this group.<sup>8</sup> The situation becomes even more serious given that knowledge of the risks associated with diagnosed and undiagnosed diabetes as well as its risk factors is poor among South Asians.<sup>9,10</sup> This is partially due to their underutilization of diabetes-related services resulting from two significant barriers: language challenges<sup>11,12</sup> and the lack of culturally sensitive services and programs.<sup>13</sup> South Asians have lower rates of secondary service use and lower hospitalization rates from type 2 diabetes compared to whites, despite having a higher prevalence of type 2 diabetes.<sup>14</sup>

People of South Asian decent living in Fraser Health represent the largest ethnic minority group. According to the 2006 Canadian Census, there were approximately 182,000 people of South Asian ethnicity residing in Fraser Health, representing 13% of the total Fraser Health population. Identifying the unique risk factors is important in the development of tailored strategies for the identification, prevention and management of type 2 diabetes since South Asians represent a significant and growing population in Fraser Health.

The adoption of self-management, or self-care, skills is necessary to improve outcomes for people with type 2 diabetes and cardiovascular disease. Chronic disease management programs continue to grow; however, care associated with chronic diseases such as type 2 diabetes and cardiovascular disease is both demanding and complex, requiring pharmaceuticals, regular review, behaviour modification and the development of self-management skills.

Successful management of diabetes requires that we understand the lifestyle, cultural beliefs and attitudes, religion, family and social networks of clients being treated. Understanding which interventions are most effective and suitable in this ethnic group, given the health status disparity from chronic disease, could guide the development of culturally appropriate disease management programs.

## 2. METHODS

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The focus of the review was the international literature (grey and peer-reviewed) from 1990 to present. The following databases were searched and the number of potential journals found for review (n):

- CINAHL (n=28)
- Medline (n=44)
- Embase (n=87)
- PsycInfo (n=10)
- Cochrane Library (n=3)

Further, the reference sections of most journals were hand-searched for other relevant publications.

The search was based on the following areas of inquiry:

Search Topic: Understanding self-management incentives/requirements in the South Asian community.

Search Questions: What are the cultural, social and personal beliefs of South Asians towards chronic diseases such as type 2 diabetes and cardiovascular disease?

What are their attitudes and practices towards self-management of these chronic diseases?

What factors (enablers, requirements and barriers) should be considered in the development of culturally sensitive chronic disease self-management interventions?

The literature search was based on the following inclusion and exclusion criteria.

Inclusion Criteria:

1. Studies and publications related to South Asian ethnic populations
2. Age = adults (20 and over)
3. Studies based on the Search Terms, Words and Phrases listed below
4. Published in the English language
5. Published between Jan 1, 1990, and May 2011

Exclusion Criteria:

1. Studies not related to diabetes or cardiovascular disease
2. Studies focusing on prevalence data

## Search Terms, Words and Phrases:

### Population Terms

ethnic*	immigra*	south asian
indo*	indo canadi*	east india*
minorit*	racial	india*
sikh*	hindu*	muslim*, moslim
islam*	pakistan*	gujarat*, gujerat*
sri lanka*	bangladesh*	ethno-cultural,
ethno cultural	panjabi*, punjabi*	Indian sub-continent

### Disease Terms

chronic disease	chronic illness	pre-diabetic
diabet*, Diabetes Mellitus	cardiovascular	heart
stroke	coronary	ischemic
hypertension, blood pressure	insulin resist*	renal disease*
myocardi* infarct*	metabolic, Metabolic syndrome*	
hyperinsulemuia	atherosclerosis	

### Risk Factor Terms

obes*	smok*	tobacco us*
alcohol*	weight	BMI
body mass index	waist circumference	risk*
barrier*	cultural barrier*	dyslipidemia
impaired glucose intolerance	impaired fasting glucose	blood glucose
adipos*	abdominal obesity	language
anthropometrics	glucose	cholesterol
truncal obesity, central obesity	abdominal adiposity	

### Behaviour Terms

diet*	nutri*	food*
eat*	tradition*	prepar*
cook*	cuisine*	physical activit*
alcohol consumption	inactiv*	itness
urbanization	vegetarian	lifestyle, life style
factor*	belief*	religious
attitude*	knowledge	self efficacy
self-efficacy	practice*	literacy
habit*		

### Intervention/Practice Terms

self manag*, self-manag*	self care, self-care	self manag*
model	self-manag* model	self care model*
self-care model*	prevent*	promot*educat*
policy	interven*	behaviour*
behavior*	empower*	skill*
community development	community interven*	information
campaign*	cultural*	culturally
sensitive	culturally appropriate*	culturally
competent	disease management	treatment*
care plan*	costs, cost analysis	structured
lifestyle modification*	social support*	

### 3. THE SOUTH ASIAN POPULATION IN FRASER HEALTH

*People of South Asian origin* refers to those with ancestral links to the countries of India, Pakistan, Bangladesh and Sri Lanka. In 2006, visible minorities totalled about one third of the total Fraser Health population (Table 1). South Asians were the largest ethnic minority in Fraser Health with a 2006 population count of 181,195, which represented approximately 13% of total Fraser Health population.

**Table 1. Visible Minority Population, by Count and Proportion of Total Population, Fraser Health and BC, 2006 Census**

Visible Minority	Fraser Health		BC	
	Count	% of Total	Count	% of Total
South Asian	181,895	12.8%	262,290	6.4%
Chinese	126,285	8.9%	407,225	10.0%
Filipino	37,660	2.7%	88,080	2.2%
Korean	31,125	2.2%	50,495	1.2%
Southeast Asian	18,390	1.3%	40,690	1.0%
Black	14,150	1.0%	28,315	0.7%
Latin American	13,350	0.9%	28,960	0.7%
West Asian	11,955	0.8%	29,810	0.7%
Japanese	10,930	0.8%	35,060	0.9%
Arab	4,245	0.3%	8,635	0.2%
Total visible minority	463,145	32.7%	1,008,855	24.8%
Total Population	1,416,635	100%	4,074,380	100%

Source: Statistics Canada

**Table 2. Population Growth, by Visible Minority, Fraser Health, 2001–2006 Census**

Visible Minority	2001	2006	2001–2006
	Count	Count	% Growth
South Asian	136,280	181,895	33.5%
Chinese	107,185	126,285	17.8%
Filipino	25,690	37,660	46.6%
Korean	20,255	31,125	53.7%
Southeast Asian	13,810	18,390	33.2%
Black	12,290	14,150	15.1%
Latin American	10,880	13,350	22.7%
West Asian	8,535	11,955	40.1%
Japanese	9,890	10,930	10.5%
Arab	3,200	4,245	32.7%
Total visible minority	355,710	463,145	30.2%
Total Population	1,314,630	1,416,635	7.8%

Source: Statistics Canada

The South Asian population is growing much faster than the overall Fraser Health population. From 2001 to 2006, the South Asian population grew by 33.5% while the total Fraser Health population increased by 7.8% (Table 2).

**Table 3. South Asian and Total Population by Local Health Area, Fraser Health, 2006 Census**

Local Health Area	South Asian Count	Total Count	South Asian as % of Total
Surrey	105,945	334,430	31.7%
Abbotsford	23,615	122,800	19.2%
Burnaby	16,760	200,855	8.3%
Delta	14,210	96,750	14.7%
Coquitlam	7,660	195,745	3.9%
New Westminster	4,725	57,850	8.2%
Maple Ridge	2,750	84,030	3.3%
Mission	2,335	38,560	6.1%
Langley	1,840	116,900	1.6%
S.Surrey / W.Rock	1,820	76,440	2.4%
Chilliwack	655	76,415	0.9%
Hope	55	7,915	0.7%
Agassiz-Harrison	25	7,940	0.3%
Fraser Health	182,395	1,416,630	12.9%
British Columbia	265,595	4,074,380	6.5%

Source: Statistics Canada

As seen in Table 3, the Surrey Local Health Area accounted for a total of 105,945 people, or 58% of the total South Asian population residing in Fraser Health. A further 23,615 or 13% of the total South Asian population were in the Abbotsford LHA. Nearly one-third of Surrey LHA's population comprises South Asians, followed by 19% in Abbotsford and 15% in Delta.

**Table 4. South Asian Population by Mother Tongue and Language Most Often Spoken at Home, Fraser Health, 2006 Census**

Language Type	Mother Tongue	Home Language
Punjabi (Punjabi)	116,335	90,225
Hindi	17,055	8,880
Urdu	5,080	3,610
Gujarati	3,640	1,720
Tamil	1,345	955
Sindhi	1,035	385
Bengali	720	415
Malayalam	565	205
Sinhala (Sinhalese)	485	155
Pashto	460	305
Total Indo-Aryan languages	157,675	106,855

Source: Statistics Canada

In the 2006 Canadian Census, approximately 158,000 of the total Fraser Health population identified their mother tongue (for example, the language first spoken) as one of the Indo-Aryan languages. Of this group, nearly three quarters (or 116,335 total) acknowledged Punjabi as their mother tongue. Hindi was next at approximately 11%.

The language most often spoken at home is another indicator providing additional context for Canadians of South Asian origin. Data from the 2006 Canadian Census show that approximately 90,000 people in Fraser Health spoke Punjabi most often at home, followed by Hindi (8,880) and Urdu (3,610).

These data on mother tongue and language most often spoken at home reflect the heterogeneity of the people making up the four countries of South Asia. For example, people from Sri Lanka and the southern parts of India speak Tamil. Bengali is the main language of Bangladesh with Urdu and Punjabi as the two primary languages of Pakistan. Gujarati is spoken in the north-western Indian state of Gujarat. Gujaratis have mainly settled in the urban centres of Ontario and in the eastern United States. Punjabis' ancestral area is the northern Indian state of Punjab. As the language and population data in the tables suggest, the largest proportion of the South Asian population in Canada is Punjabi Sikhs from Punjab.

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## 4. CHRONIC DISEASE EPIDEMIOLOGY

In their 2010 Annual Report, the Canadian Heart and Stroke Foundation warned of a “perfect storm” of risk and demographics impacting certain population groups within Canada.

“In a very short time, the face of heart disease in Canada has changed to include groups that have historically been immune to the threats of heart disease,” says Dr. Beth Abramson, cardiologist and spokesperson for the Heart and Stroke Foundation. “But the combination of new groups at-risk of heart disease and the explosion of unhealthy habits across Canada have accelerated the impact of these threats which are now converging and erasing the progress we've made in treating heart disease over the last 50 years.”<sup>15</sup> ( page 2)

The report highlights that between 1994 and 2005, rates of high blood pressure among Canadians young and old increased by 77%, rates of diabetes by 45% and rates of obesity by 18% - all major risk factors for heart disease. For example, among those 35 to 49 years of age, the prevalence of high blood pressure increased 127%, diabetes by 64% and obesity by 20%.

The Annual Report identified the new at-risk populations as follows:

- young Canadian adults, age 20 to 30
- women, age 35 to 45
- boomers, age 50 to 64
- Aboriginal peoples, and
- *some of Canada's growing ethno-cultural communities*

The last point is reinforced by studies from around the globe that suggest that people of South Asian ethnic origin are at higher risk of type 2 diabetes and other related chronic diseases, such as cardiovascular and renal diseases, irrespective of their religion, diet or socioeconomic status.<sup>16</sup> This scenario persists regardless of the country of choice for immigration among South Asians.<sup>17</sup> Literature has suggested that some of the reasons for this excessive risk are genetic, environmental, behavioural, socioeconomic and differences in access to health care.<sup>7,18</sup> Studies also suggest that type 2 diabetes and its risk factors manifest differently in this group than in the host populations: It is occurring at a younger age and at a much lower body mass index.<sup>19</sup>

The prevalence of type 2 diabetes in South Asians is estimated to be 2 to 5 times higher than the white Europeans in the UK and in other European countries.<sup>6,8, 20</sup> Diabetes-related complications are also more frequent in this group and occur much earlier than in non-South Asians.<sup>21,22</sup> This elevated risk of cardiovascular disease and diabetes among South Asians is seen across the globe, irrespective

of the length of time in host country or the level of risk with the host population (see Table 5).<sup>4</sup>

**Table 5. Coronary Heart Disease Mortality in South Asian Migrants**

Country	Years	Groups	Age	CHD Mortality Ratio
Singapore	1980–86	S.Asian vs Chinese	30–69	3.8
Fiji	1980	S.Asian vs Melanesian	40–59	3.0
Trinidad	1977–86	S.Asian vs African	35–69	2.4
South Africa	1985	S.Asian vs European	35–74	1.4
England	1979–83	S.Asian vs European	20–69	1.4

Source: Cappuccio, 1997

A recent study comparing the prevalence of diabetes in Canadian recent immigrants (having immigrated sometime between 1985 and 2000) with Canadians that are long-term residents showed that South Asians' prevalence was approximately 12% compared to about 6% for long-term residents.<sup>2</sup> South Asian recent immigrants had the highest prevalence of diabetes compared with all other Canadian ethnic groups. An earlier study comparing Canadians of European, South Asian and Chinese origins showed that South Asians had significantly higher mortality rates from ischemic heart disease and diabetes than the other ethnic groups.<sup>23</sup> Another Canadian study found higher rates of established diabetes and cardiovascular disease in the South Asian ethnic group compared with Canadians of European and Chinese origin despite lower carotid atherosclerosis in South Asians.<sup>24</sup>

Some of the earliest studies assessing health differences of South Asian immigrants with the rest of the general population come from the UK<sup>25</sup> where South Asians represent close to 4% (or about 2 million total) of the total population.<sup>17</sup> The majority of the UK studies have shown that the excess mortality seen in South Asians is mostly explained by the increased risk of cardiovascular disease and type 2 diabetes.<sup>26, 27</sup>

While the majority of people represented in South Asian studies tend to be first-generation immigrants, research evidence suggests that increased risk for coronary heart disease and diabetes is also seen in second-generation individuals<sup>17</sup> with most of this risk occurring at younger ages.<sup>28, 29</sup> Hughes, Raval and Raftery (1989) reported a difference of nearly five years in the mean age for myocardial infarction among South Asian men versus the general UK population.<sup>30</sup>

### **Higher Prevalence of Type 2 Diabetes in South Asians**

To date, Canadian studies addressing the prevalence of type 2 diabetes or its risk factors in Canadians of South Asian origin are limited. Three studies, mentioned above, identified higher prevalence of type 2 diabetes in this ethnic group.<sup>2, 23, 24</sup> The Creatore et al. study estimated the prevalence of type 2 diabetes by the

country of origin in South Asian recent immigrants and showed the highest rates for Sri Lanka and lower rates for Pakistan and India (Table 6).

**Table 6. Age-adjusted Prevalence of Diabetes in 2005 Among Recent Immigrants from South Asia and Among Long-term Residents of Ontario**

Country of Origin	Men	Women
India	10%	10%
Pakistan	11%	12%
Sri Lanka	17%	16%
Bangladesh	---	---
South Asians, All	12%	12%
Ontario Long-term Residents	6%	6%

Source: Creatore et al., 2010

The Anand et al. study reported a prevalence of 6.2% among South Asians based on a small sample of diabetics.<sup>24</sup> A study by Davachi et al. (2005) explored the prevalence of type 2 diabetes risk factors and the development of a screening and awareness program aimed at Canadians of South Asian origin.<sup>12</sup> This study addressed an important limitation of self-reported studies by directly measuring most anthropometric factors such as height, weight, waist circumference and blood glucose tests, and concluded that a high level of risk factors associated with type 2 diabetes exists among South Asians.

Perez (2002) compared the health status and health behaviour of immigrants to Canada versus those born in Canada using data from the 2000/01 Canadian Community Health Survey (Cycle 2.1).<sup>31</sup> He concluded that immigrants tend to be healthier than non-immigrants, but this pattern reverses with time spent in Canada.

Studies from the US have reported higher rates of diabetes among South Asians. A recent study by Misra et al. (2009) estimated diabetes prevalence at 17.4% for those aged 18 years and above, a higher prevalence than previously reported for this age group.<sup>21</sup> Jonnalagadda and Diwan (2005) reported diabetes in 18% of 226 Asian Indians aged 50 years and above with average time residing in the US of 25 years.<sup>32</sup> Similar prevalence of diabetes mellitus (18.3%) was reported in a study in the Atlanta metro area of Georgia.<sup>33</sup>

Studies from the UK have shown three to four times higher prevalence rates of type 2 diabetes in South Asians compared with the general population.<sup>11</sup> The Southhall Diabetes Survey in West London was one of the first and largest house-to-house studies done to ascertain the difference in known prevalence of diabetes between this group and Europeans in a suburb with a substantial immigrant population.<sup>26</sup> This study found approximately a fivefold higher prevalence of diabetes in South Asians than in Europeans in the 40 to 64 year age group. At about the same time, these differences in diabetes prevalence were confirmed by the Coventry Study, considered to be methodologically sound given its large sample size and the use of study participants from a wide range of ages.<sup>34</sup> This house-to-house survey in a low socioeconomic area with a high concentration of

South Asians reported the adjusted diabetes prevalence for people aged 20 and over in South Asian men to be 11.2% and women to be 8.9%, compared with white men at 2.8% and white women at 4.3%. Another study of low socioeconomic individuals in the 35 to 79 year age group in Manchester, England, showed surprisingly high prevalence of diabetes among Europeans (20%) and even higher rates among Pakistanis (33%).<sup>35</sup>

**Table 7. Sample of Published Studies on Prevalence of Type 2 Diabetes**

Year	Setting	Size	Age Range	Diabetes Prevalence (%)			Authors
				Europeans	S.Asians	African/Caribbeans	
1991	Coventry	9,903	20+	3.2–4.7	11.2–12.4	---	Simmons et al.
1991	Southall, London	3,753	40–69	2.3–4.8	16.1–19.9	14.6	McKeigue et al.
1997	London	1,578	40–59	5–7	20–25	15–18	Cappuccio et al.
1998	Newcastle	1,504	25–74	7.1	21.4	---	Unwin et al.
2001	Manchester	981	35–79	8.1–22.7	15.7–48.1	15.7–29.5	Riste et al.
2010	Ontario	Million+	20+	5–6%	12%	---	Creatore et al.

McKeigue, Shah and Marmot (1991), in another large study conducted in West London about five years after the Coventry Study, reported the prevalence of diabetes to be 4.3 times higher in South Asians compared with the European group in the 40 years and older population.<sup>20</sup> These authors also reported prevalence within the South Asian ethnic group as follows: Sikh (20%), Punjabi Hindu (19%), Gujarati Hindu (22%) and Muslim (19%).

*The Health Survey for England 2004: Health of Ethnic Minorities*, a recent survey by the Department of Health, reported that South Asian men and women were more likely to develop type 2 diabetes - nearly three times more than the general population of England.<sup>36</sup> This survey provided data on another important aspect of ethnicity-based studies: differences in the prevalence of diabetes and ischemic heart disease as well as their determinants *within* this group in countries other than their ancestral homeland. For example, prevalence of type 2 diabetes was highest in Pakistanis (approximately 45% in women and 26% in men aged 55 years and above), followed by Indians (25% in men and 20% in women) and Bangladeshis (30% in men and 13% in women).

## Risk Factors

Most chronic diseases have common risk factors and determinants and this is especially true for cardiovascular disease and diabetes mellitus. Behavioural factors - such as poor diet, physical inactivity and tobacco use - and biomedical risk factors - such as excess weight, high blood pressure, high blood cholesterol and insulin resistance - are well-established factors associated with these two chronic diseases.

This section provides an overview of the distribution of biomedical risk factors for type 2 diabetes among South Asians while the next section previews the broader social and cultural aetiological factors that uniquely impact not only the behavioural risk factors identified above but also whether chronic disease related health care services are accessed and utilized.

Evidence suggests that the impact of classical risk factors associated with diabetes and cardiovascular disease materialize differently and do not fully explain their increased risk in South Asians.<sup>1, 24</sup> For example, Patel et al. (2001) concluded that obesity was not strongly associated with the metabolic syndrome in this group but the waist-to-hip ratio was.<sup>37</sup> Migration is also seen as a key determinant of increased risk of chronic disease in South Asians, especially since migration has not led to increased risk of chronic disease among other ethnic groups, such as the Afro-Caribbean people.<sup>38</sup>

Research evidence on ethnic studies suggests that some ethnic groups - for example, South Asians and Hispanics - are predisposed to developing type 2 diabetes and cardiovascular disease at a much higher rate than the white Caucasian ethnic population.<sup>34,39</sup> This increased risk is seen in South Asians wherever they have immigrated (for example, in Europe, North America, Australia or other Asian countries such as Singapore) and is primarily attributed to higher insulin resistance and clustering of other metabolic factors referred to as the insulin resistance syndrome or the metabolic syndrome.

The metabolic syndrome consists of insulin resistance, dyslipidemia, hypertension and obesity as the main risk factors and conveys a substantial risk for cardiovascular disease and type 2 diabetes.<sup>36,40,41</sup> The prevalence of the individual risk factors as well as the clustering of the metabolic syndrome components is higher in South Asians.<sup>42</sup> UK studies have reported higher rates of abdominal obesity, glucose intolerance and hyperinsulemia in this group compared with the host white population.<sup>20,25,40</sup> Up to 50% of South Asian adults are estimated to be insulin resistant.<sup>43</sup> They have higher concentrations of plasma triglycerides and lower concentrations of high-density lipoprotein cholesterol compared with whites.<sup>7,44</sup>

Another unique aspect of the insulin resistance syndrome applicable to South Asians is that it manifests in this ethnic group at a much younger age.<sup>21,45</sup> A study done by Dickenson, Colagiuri, Faramus, Petocz and Brand-Miller (2002) on young adults aged 18 to 35 years from five ethnic groups showed that South Asians had the highest level of insulin resistance.<sup>46</sup> Whincup et al. (2002) demonstrated greater insulin resistance in South Asian children compared with white UK children even after adjusting for central obesity.<sup>8</sup>

Insulin resistance is perceived to be the single most important component of the metabolic syndrome and the best predictor of type 2 diabetes among South Asians.<sup>17</sup> South Asians are known to have the highest insulin resistance among major ethnic groups.<sup>47</sup> A large cohort investigation by McKeigue et al. (1988) showed a much higher level of insulin resistance in South Asian immigrants compared with the local white Caucasians with similar living conditions and social environments and with little or no excess obesity.<sup>25</sup> A smaller US study comparing South Asian immigrants with whites of European ancestry showed a higher level of insulin resistance in this group.<sup>48</sup> Anand et al. (2000) reported the highest prevalence of insulin resistance among Canadians of South Asian origin compared with Canadians of European and Chinese origin.<sup>24</sup>

Adiposity is considered a key correlate of insulin resistance, with South Asians being more prone to higher percentages of body fat than other ethnic populations.<sup>37,49</sup> This increased body fat is manifested through higher truncal or abdominal obesity and lower muscle mass.<sup>17,50</sup>

Central obesity, or abdominal obesity, refers to the collection of body fat in the upper body (waist and trunk) instead of the hips and thighs. It is measured by the waist to hip ratio (WHR) and reflects a key factor in the distribution of body fat and body profiles in South Asians versus the white Caucasians.<sup>51</sup> As seen in Table 5, South Asians in general are shorter and have thinner limbs and lower muscle mass but tend to be centrally obese and have higher waist-to-hip ratios despite lower or average BMIs.<sup>43,52</sup> In an early and important study by McKeigue et al. (1991), the authors concluded that central obesity in South Asians in the UK was strongly associated with insulin resistance even though they were no more obese than Europeans. In a more recent Canadian study, Anand et al. (2000) showed that Canadians of South Asian origin were lighter than Europeans but heavier than the Chinese.<sup>24</sup> South Asians and Europeans had a higher amount of abdominal adiposity compared with Chinese based on WHR. These findings are contradictory with American, Afro-Caribbean and European populations in which insulin resistance is associated with general obesity.<sup>20</sup>

**Table 8. Body Profile of South Asians and Their Association with Insulin Resistance**

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Shorter height
Lower BMI
Excess body fat*
Abdominal obesity*
High waist-to-hip ratio
Normal waist circumference
Higher intra-abdominal fat
High truncal subcutaneous fat*

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\*positive association with insulin resistance

Source: Misra, Misra, Wijesuriya and Banerjee, 2007; Misra and Vikram, 2004

Abdominal obesity and a high proportion of body fat are associated with insulin resistance, type 2 diabetes<sup>19,37</sup>, atherosclerosis and heart disease and is inversely

associated with physical activity and intake of carbohydrates and trans fatty lipids.<sup>53</sup>

Given the body type and lower BMIs of South Asians, the waist-to-hip ratio (WHR) is considered a better predictor of obesity in this group since it is more sensitive to the measurement of abdominal obesity.<sup>54</sup> This line of reasoning argues that, especially for this group, obesity could be redefined as excess in body fat and not excess in body weight.<sup>55</sup>

Studies have shown that compared with white Caucasian groups, South Asians have a higher percentage of body fat at a lower BMI<sup>20,36</sup>, which is an important risk factor for insulin resistance.<sup>42,46</sup> Consequently, the use of BMI in South Asians greatly underestimates the risk of diabetes and other diseases given that their BMI range is typically lower than Europeans.<sup>17</sup> For example, an individual of European ancestry with a BMI of 30 or higher is estimated to have similar morbidities as a person of South Asian origin with BMI of 27.5 or higher.<sup>17</sup>

The traditional BMI cut-off values based on the World Health Organization's (WHO) criteria primarily originated from studies of European populations<sup>36,49</sup>; however, a growing body of research questions the applicability of these cut-offs to non-European population groups. Studies have suggested that due to certain genetic and environmental characteristics associated with the South Asian ethnic group, the risk of chronic disease in this ethnic group becomes more evident at lower BMI values.<sup>36,54</sup>

## **Genetic Predisposition**

While environmental conditions (economic, social and lifestyle) are considered to play a major role in the development of chronic diseases such as type 2 diabetes, data from migrant studies suggests a strong interaction between genetic and environmental factors.<sup>50</sup> This is especially true in the development of type 2 diabetes in South Asians given that they are believed to have an increased susceptibility to insulin resistance and central obesity, especially if combined with Western-style living.<sup>17,50</sup>

Neonatal studies have suggested that South Asian babies are born smaller but are much fatter than Caucasian babies, and this phenotype tends to be present in childhood and could signal the adult body shape of South Asians as described earlier.<sup>56</sup> A retrospective study in Southern India reported that the risk of coronary heart disease was associated with size at birth such that people with low birth weight and small head circumference were at higher risk of coronary heart disease later in life.<sup>57</sup>

The *thrifty phenotype* is another hypothesis which suggests that, given South Asians' socio-economic status, babies tend to face under-nutrition in fetal and infant spans followed by over-nutrition in later years, which predisposes individuals to chronic diseases such as diabetes.<sup>51</sup> A recent investigation demonstrated that low birth weight babies with increased over-nutrition in later years were associated with greater prevalence of insulin resistance.<sup>58</sup>

The familial aggregation of type 2 diabetes tends to be much higher in this group. Results from one UK study show that 45% of South Asians had a first degree relative with diabetes versus 36% for Europeans.<sup>59</sup> The same study showed that about 10% of South Asians had parents who were both diabetic compared with only 1% for Europeans. Data about the offspring with both parents having type 2 diabetes show that about 55 to 60% of South Asian offspring had diabetes or impaired glucose tolerance—a proportion much higher than offspring of diabetic parents who were European.<sup>59</sup>

## 5. CULTURAL ASPECTS ASSOCIATED WITH CHRONIC DISEASE

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Social, cultural and environmental factors play a significant role in the risk of developing and managing chronic conditions such as type 2 diabetes and cardiovascular disease. In order to develop culturally-appropriate self-management interventions, it is necessary to understand factors such as health beliefs, attitudes, customs, knowledge levels, and other cultural practices that may affect people's acceptance and ability to play an active role in managing their disease. This section summarizes the literature on factors such as beliefs about diet and physical activity, language, literacy level, gender roles, cultural values attached to health and wellbeing, as well as stereotypes and attitudes held by care providers about South Asians.

### **Diet**

The dietary practices of South Asians are influenced by a range of factors such as religion, customs, food beliefs, socioeconomic status, length of stay in the host country, region of migration, acculturation, age and gender. Studies have shown that religious and cultural factors have a significant impact on South Asians' food choices.<sup>60</sup> Generally, South Asians with higher education and income, longer length of stay in host country and younger ages tend to adopt the Western diet much sooner than their counterparts.<sup>61</sup> A thorough knowledge of the underlying food choices and reasons for acceptance/non-acceptance of foods and related dietary practices are all critical aspects for health care workers to understand in order to provide culturally appropriate dietary food strategies.

### **Food Beliefs**

Religious and cultural factors have an overriding significance for South Asian food choices. For example, religious-based fasting is common in some faiths. During the month of Ramadan, Muslims refrain from eating, drinking and smoking from sunrise to sunset. Fasting is obligatory for all Muslims except pre-puberty children, menstruating women, the elderly, pregnant women and those with chronic illness. Further, Muslims are given instructions on diet and are forbidden to eat pork, while beef, lamb and chicken can only be consumed if the animal is slaughtered in a particular way to make it *halal*. Hindus also fast for special religious events, whereas fasting among Sikhs is uncommon. Hindus do not consume beef because the cow is considered sacred. Many Hindus tend to be vegetarian.

Humeral views of food, illness and health including the hot/cold concept are common among South Asians. South Asians perceive food as hot and cold, strong and weak, and digestible and indigestible, which signifies the food's impact on the body. A study by Greenhalgh, Helman and Chowdhury(1998) of British Bangladeshis concluded that foods were grouped into perceived strength (nourishing energy) and digestibility.<sup>62</sup> For example, strong foods, seen as energy giving include sugar, meat, butter, solid fat and spices, and weak foods include

rice and cereals. Strong foods were seen as health-giving and essential for the healthy body and a necessity for the festive seasons. Raw/grilled/boiled foods were viewed as indigestible and not suitable for the elderly and children.

These cultural and religious beliefs and restrictions can influence the feasibility of a balanced diet. For example, foods of equivalent nutritional content are not assumed to be interchangeable in the view of South Asian diabetics.<sup>60</sup> And practices such as fasting can be harmful to the wellbeing of patients on oral medication or insulin therapy.

### **Traditional Diets**

Traditionally, South Asians have higher carbohydrate intake, both in their home countries (about 60–67% of energy intake) and in countries of migration.<sup>43,63</sup> Evidence shows that customs in raw ingredients and cooking methods are retained to a high degree after migration.<sup>60</sup> Although considerable regional variations exist among the South Asian groups, the traditional diet of South Asians consists of large amounts of starchy staples, such as white rice and bread in the form of *chapatti*, *roti* or *paratha*. These staples are eaten with vegetables, beans, lentils or meat. The majority of the Indian snacks and desserts are either deep fried and/or contain a high concentration of sugar or salt. People originating from Pakistan and North-West India use wheat as their staple and have a *chapatti*-based diet. Ghee (clarified butter) and regular butter are widely used in cooking among this group. A Canadian study compared the consumption of carbohydrates and HDL cholesterol levels in four population groups and concluded that South Asians consumed the most carbohydrates, followed by Europeans, Aboriginals and Chinese, and that higher carbohydrate consumption was associated with lower HDL cholesterol levels.<sup>64</sup>

One significant factor attributable to higher consumption of carbohydrates is the fact that many South Asians are vegetarian.<sup>43</sup> Evidence suggests that South Asian vegetarians have higher BMI, higher body fat, increased truncal obesity and lower consumption of fibre compared with white vegetarians.<sup>43</sup>

Diet, consisting of higher and faulty fat intake, higher carbohydrate intake but lower protein intake, is considered a major factor in South Asians' increased susceptibility to diabetes, cardiovascular disease and other associated diseases.<sup>65,66,67</sup> An association between higher carbohydrate intake and hyperinsulinemia in South Asians has been reported.<sup>23,39</sup> A higher dietary fat intake is associated with insulin resistance and obesity.<sup>67,68,69</sup> Reduced fibre consumption and an increase in the consumption of refined carbohydrates are associated with increased risk of developing type 2 diabetes.<sup>39</sup>

### **Dietary Acculturation**

Studies show that a longer duration of residence in the host country is associated with higher rates of smoking, lower physical activity and higher BMI.<sup>32</sup> Evidence suggests that South Asians—and all migrants to Western countries in general—tend to adopt the Western, cholesterol-rich diet after migration<sup>32,70</sup>, with an increase in caloric intake.<sup>39</sup> This 'dietary acculturation' includes reduced vegetarian status and increase in animal fat, sodium and simple sugar consumption.<sup>50</sup>

Younger migrants are more likely to change their dietary habits to more energy-dense foods.<sup>50,71</sup> Raj, Ganganna and Bowering compared the dietary habits of South Asians in the US among those that were recent residents (less than 10 years in the US) and long-time residents (more than 10 years in the US) and concluded that fatty and high energy foods were common among both groups and tended to be concentrated at social gatherings, festivals and religious ceremonies.<sup>72</sup> Consumption of fruit juices, alcoholic beverages and other processed foods such as chips and colas had increased in both groups while the consumption of traditional foods had decreased. A decade long study of South Asian women in the UK revealed that their fat intake had become similar to that of the general population.<sup>73</sup>

In another study, Lip et al. (1995) compared the food purchasing habits of whites, blacks and South Asians in England and concluded that South Asians purchased the highest quantity of fatty foods compared with the other two groups.<sup>68</sup> They also observed frying as a common food preparation method, compared with grilling or poaching for whites and blacks. Consequently, a significant proportion of the fat consumed by South Asians comes from cooking fat that lacks the longer chain fatty acids<sup>7,70</sup> needed for normal insulin action.<sup>67</sup> In the UK, South Asian children are known to consume fewer fruits and vegetables than white children.<sup>8</sup>

Having said that, studies have shown that food and food preparation practices among migrants are retained and are often resistant to change given that they are symbolic of cultural and religious beliefs.<sup>60</sup>

### **Implications for Health Education/Health Promotion and Dietary Change**

Many factors play a role in food choices, including individual needs and broader heterogeneity of South Asians. As a result, approaches to healthy eating education should not be constrained by fixed ethnic stereotypes.<sup>60</sup>

A study by Astin, Atkin and Darr (2008) found that white European families were better equipped to share information on dietary changes and thus were more likely to adopt healthier eating habits.<sup>74</sup> In larger South Asian households, patients had less involvement in food preparation, given that the larger size of South Asian families could likely make it more difficult to prioritize the dietary needs of patients. In addition, given that food preparations are typically done by females in South Asian households, usually the mother or elder daughter-in-law in the case of extended families, they may have little or no contact with health professionals due to language barriers and/or gender-based rules and stigmas. Thus food preparers and food purchasers must be involved with any lifestyle change and self-management care plan of patients.

A study by Mohan et al. (2008) of South Asians with coronary heart disease (CHD) concluded that unhealthy dietary habits persisted even after CHD diagnosis, with preferences for foods rich in fat, sugar and salt<sup>76</sup> although patients acknowledged the need for healthier choices, the changes often lacked consistency, especially at social and religious gatherings. A typical strategy used by men was to choose to eat less rather than compromise on the preferred taste, ingredients or preparation.<sup>74</sup>

## KEY POINTS

- There is considerable dietary and food diversity among South Asians depending on their religion, country/area of origin, age and acculturation.
- Religious and food beliefs play an important role in food choices and practices.
- There is a lower awareness of the nutritional content of foods and diet.
- Healthy dietary behaviours are often ignored for the social norms of hospitality.
- Many South Asians believe that simply eating a vegetarian diet equates to a healthy diet, rather than ensuring that diets with higher nutritional value (vegetables), decreased carbohydrate consumption and food prepared using low-fat cooking ingredients are also important.
- Younger generations of South Asian migrants are more likely to adopt the dietary habits of the mainstream population. This has been associated with a less healthy diet that is higher in energy, fat and salt.
- Dietary interventions must involve persons who shop for groceries and those who cook, thus targeting the entire household, including children.
- Interventions should be tailored to specific subgroups and it should be ensured that cultural and religious acceptability, gender and family dynamics are addressed.
- Trained and qualified community workers and other professionals that are able to reinforce changes in knowledge, attitudes and behaviours should be used.
- Places of worship and other community gathering venues that use religious leaders, chiefs and other community leaders to facilitate uptake and acceptability should be used.
- South Asian-specific dietary behavioural models should be developed—very few exist at this time.

## Physical Activity

Physical activity is associated with reduced complications and mortality from type 2 diabetes and cardiovascular disease.<sup>75,77</sup> In addition, levels of physical activity are inversely related with waist circumference, BMI and insulin resistance in South Asians.<sup>77</sup>

Studies have shown that physical activity levels are significantly lower in South Asians compared with other ethnic groups.<sup>3,40,78,79</sup> A systematic literature review of 17 studies assessing physical activity all showed lower levels in South Asians.<sup>80</sup>

South Asian women are especially prone to reduced physical activity.<sup>3</sup> High rates of physical inactivity in both sexes among Canadians of South Asian origin were reported by Davachi et al. (2005).<sup>12</sup> Evidence about why these differences occur is

limited. Factors associated with migration, language difficulties, gender roles, religious and cultural modesty, cultural attitudes and values all contribute to lower levels of participation in sports and physical activity among South Asians.<sup>81,82</sup>

South Asian diabetic patients interviewed by Lawton. indicated that time dedicated towards family obligations (such as child minding, assisting with family business, etc.) and towards traditional household activities (such as cooking, cleaning and child minding) took precedence over their own health-related activities such as exercise. Generally, these types of activities are perceived as a form of physical activity by this group whereas whites view engagement in recreational activities as being active.<sup>81</sup> Another study assessing physical activity of South Asian women diagnosed with coronary heart disease and diabetes found that women expressed lack of knowledge about their conditions and were uncertain about the benefits of exercise to their illness and the type of activity most suitable for their conditions.<sup>3</sup> In the same study, motivation for exercise and physical activity among women varied by age: Improving body image and appearance motivated younger women while being mobile and active motivated older women. Thus, engagement in physical activity was often not for the purposes of disease management<sup>83</sup> - an important concept for care providers to understand when developing care plans.

For women, exercising in public places is viewed as culturally inappropriate, especially if it involves displaying their bodies, such as in community swimming pools or if the sessions constitute mixed-gender activities.<sup>10,71,83</sup> Thus, South Asian women will often indicate preference for women-only sessions and other culturally appropriate programs in their communities.<sup>18,79</sup>

Walking is seen as a popular and more feasible form of physical activity by South Asian women given its non-threatening nature and easy incorporation into daily schedules.<sup>3</sup> Physical activity regiments geared towards moderate activity, versus regiments stressing vigorous activity, are better received by South Asian women.<sup>3</sup>

Additional factors associated with lower levels of physical activity, especially among new immigrants, are fear of racism and lack of access to recreational facilities resulting from financial and transportation challenges.<sup>77</sup> This is further complicated by their inability to speak the local language.<sup>81</sup>

While many of the barriers associated with physical activity and healthy behaviours—such as time constraints, existing chronic health conditions, motivation, family support, weather, lack of facilities, etc.—are common among all ethnic groups<sup>82</sup>, the level and capacity to overcome these constraints differ for South Asians.

### KEY POINTS

- Social norms of modesty and gender roles often override physical activity especially for Muslim women and older adults.
- Cultural factors impacting certain subgroups need to be overcome, such as through women-only facilities and special services for the elderly.
- Interventions to increase physical activity need to be both individual and

community-based. For example, South Asians need personal advice on physical activity dealing with barriers such as time and motivation.

- Studies show evidence of change in attitudes and receptivity towards physical activity—this provides unique opportunities for targeted interventions in this area.
- Appropriate physical activity needs to be incorporated into everyday life events.
- Increasing the cultural and religious appropriateness of physical activity interventions is critical.

## Health Beliefs and Illness Perceptions

Illness beliefs have been shown to influence a range of outcomes, such as dietary change, physical activity, help-seeking behaviour, motivation to change and self-management.<sup>84</sup>

How South Asians view health and the diagnosis of a disease is often contradictory to established views held by modern medicine. On the whole, South Asians are more likely than whites to contextualize their illness in relation to external factors such as fate, stress, heredity and cold weather and less likely to personal factors.<sup>79,84</sup>

Typically, South Asian patients react to diagnosis in two ways: either as an expression of shock and difficulty accepting it, or as an attitude of resignation and sense of inevitability, the latter being attributed to fate or the will of God.<sup>10,13,85,86</sup> South Asians are less likely to believe that they have control over their illness, and as a result, are less likely to engage in risk-reducing behaviour.<sup>85</sup> In a recent qualitative study<sup>87</sup> of Punjabi Sikh patients from British Columbia showed that “many patients expressed shock and disbelief about their diagnosis”( p. 3137). All expressed the importance and role of religion and *kismet* (fate) in attempting to understand their diagnosis. In contrast, white Europeans predominately believe that good health is obtained by being proactive and engaging in positive practices about diet and physical activity.<sup>62</sup> Further, illness and physical weakness are seen as part of aging, with diseases such as diabetes further weakening the body.<sup>14,79,88</sup> South Asians perceive these physical changes as signals that the body requires rest, which can lead to further reduction in physical activity levels.<sup>79</sup>

In a study of older Sikhs with coronary heart disease, King, Leblanc, Sanguins and Mather (2006) noted that Sikhs have a limited understanding of coronary heart disease (CHD) as a chronic illness.<sup>89</sup> They were more receptive to dealing with the acute phase of illness than the chronic management of disease and risk-reduction requiring attention over the long term.

One common factor which illustrates South Asians’ belief that they have little control over their disease is the role of stress. In a systematic review exploring the role of stress and perceptions of disease, 41% of studies identified stress as the most important cause of CHD while 31% of studies cited lifestyle behaviours.<sup>90</sup> A

study by Darr et al. (2008) of South Asian CHD patients showed that stress, worry, tension and overwork were the most frequently cited causes of heart disease.<sup>84</sup> Nearly one half (44%) of coronary heart disease patients from a US study cited stress as the most common risk factor.<sup>91</sup> Among men, the most commonly cited causes of stress were financial stress, job and employment uncertainties, social pressures and expectations to ensure family and children success, and among women, stress was attributed to isolation, lack of informal support, language barriers and inability to access essential services.<sup>76,92</sup>

Racism is a well-established source of stress among ethnic migrants and is commonly identified in many UK South Asian studies, especially those involving Muslim participants.<sup>92</sup> This concept remains mostly unexplored in the Canadian context.

### KEY POINTS

- Heredity/family history—thus the disease is thought to be inevitable if a family member has the disease.
- Illness is attributed to external factors such as fate, stress and cold weather and less likely to personal factors.
- There is a need for self-management/monitoring not commonly seen as necessary in the absence of symptoms.
- There is passive participation in self-management and strong reliance on the health care providers.
- There is very little preventive or promotional outlook about chronic disease prior to diagnosis.
- Interventions that target perceptions of disease may be beneficial in risk-reduction and self-care among South Asians.

## Language and Literacy

Language is cited as a key cultural barrier contributing to disparity in health access and utilization.<sup>3,10,94</sup> Language fluency is a critical factor in, first, gaining entry into the health care system; second, for establishing an ongoing relationship with care providers; and third, for acquiring necessary health care services and other health-related information pertaining to disease management.<sup>86</sup> Language has a positive effect on keeping appointments, adhering to medications and other therapies, and providing a better outlook of positive health for clients.<sup>95</sup> Studies have shown that English fluency, rather than ethnicity, has a stronger influence on health care use.<sup>96</sup>

The basic idea behind health literacy is simple: A person's ability to learn about and engage in his or her health is positively correlated with improved health outcomes.<sup>97</sup> According to a 2006 Canadian health literacy survey, about 60% of immigrants fall below the Level 3 (considered to be the minimum level for coping

with the needs of everyday life) compared to 37% of the Canadian-born population.<sup>97</sup>

The trend towards increased chronic disease self-management requires that patients and their carers have a good understanding of disease, treatment options and written medical information, are able to follow written care plans and are able to participate as informed partners in their decision-making and ongoing communication about their disease.

English fluency and literacy are cited as major contributors to the lower use of health care services among South Asians.<sup>10,79,82</sup> In one study, 60% of Southeast Asian respondents in San Diego identified language as a major barrier in acquiring health care services.<sup>98</sup> Among South Asian women, language was identified as a significant barrier in attending health and physical activity promoting sessions.<sup>3</sup> In another study, authors cited language as a barrier among South Asian patients for their difficulty in remembering names of medications related to diabetes management and for showing little interest in attending diabetes clinics held in the community.<sup>10</sup> Language difficulties tend to be less prevalent in younger South Asians than the elderly.<sup>14</sup> This seems logical given that younger people will likely assimilate faster into their new environments than older immigrants.

Literacy levels in both English and their native language are low in South Asians, and these levels vary considerably by country of origin, religion, age and gender of immigrant groups. The groups most likely to face language and literacy challenges include recent immigrants, especially from areas of Bangladesh, Pakistan and Punjab (India), women of Muslim and Sikh faiths, and the elderly. In one study, fewer than one third of Bangladeshi and Pakistani women were able to read English and over one half were illiterate in their own language.<sup>99</sup>

One strategy South Asians often utilize to overcome the language and literacy barrier is using family members, children and/or other relatives as translators and interpreters for both health care visits and written materials.<sup>10,61,94</sup> While there is considerable benefit to the use of interpreters, South Asian clients also identified numerous concerns associated with this approach, including lack of privacy, lack and unreliability of interpreter availability, feeling of dependence, patient's discomfort discussing certain topics or diseases in front of their family members or relatives, and interpreter error or mistranslation of prescription doses.<sup>86,94</sup> Clients also noted that when interpreters are used, physicians tend to be less communicative and are more likely to ignore clients' questions,<sup>95</sup> perhaps a time-saving strategy on behalf of the care provider given that appointments requiring interpreters are considerably longer than those without interpreters.<sup>86</sup>

Simich<sup>97</sup> identified three key elements of a practical health literacy approach for immigrants:

- Use plain language: using engaging, consistent messages targeted at specific audiences.
- Use good translation practices: This entails practitioners being trained in the provision of services to low-literate people and that cultural experts are used in the development and delivery of educational resources.
- Use multiple visual tools such as pictures, theatre and videos.

Simich<sup>97</sup> suggested that the most promising practices combine good written materials, direct oral communication by a trained practitioner or a health educator who is linguistically and culturally competent, and delivery of multiple visual messages through a variety of public outreach sites such as community health centres, ethnic associations, places of worship and ethnic media resources.

### KEY POINTS

- English fluency and health literacy are major public health and clinical challenges to South Asians.
- English fluency and health literacy greatly impact South Asians' ability to engage in health inducing practices including access to and use of health care services.
- Chronic disease self-management requires engaged and informed patients, with education being an important component of self-care.
- Clear and multiple forms of communication and delivery methods should be used to increase literacy.
- Language fluency allows patients to build deeper relationships with their care providers.

### Awareness of Disease

Studies have shown that South Asians have lower levels of general knowledge and awareness of disease and this is considered a significant barrier to effective control, prevention and self-management of chronic disease.<sup>100,101</sup> This lower awareness is also associated with delayed diagnosis and delayed access to treatment and care<sup>102</sup> and is more prevalent in South Asians with lower income and education levels, recent immigrants, women, the elderly and those unable to speak the local language.

In one UK study with multi-faith and country-based South Asian participants, exploring causes of disease, showed that Pakistani-Muslims were least likely to be knowledgeable about the causes of their heart disease.<sup>84</sup> This group also contained the largest proportion of participants unable to speak English. Darr et al. also suggested that this low awareness of disease impacts South Asians' ability to make sense of new diagnosis or engage in any health behaviour program.<sup>84</sup> This also likely contributes to South Asians' perception of fate or inevitability as the cause of chronic disease.

A recent study of South Asians from the Chicago area found significant knowledge gaps related to CHD, with the majority of the participants indicating that heart attacks could not be prevented.<sup>91</sup> In this study, only 38% of the participants knew at least one of these to be a risk factor for CHD: cholesterol, blood pressure and diabetes. Lower education level and English fluency were closely associated with lower knowledge about CHD and its risk factors.

Raleigh and Clifford<sup>67</sup> found that South Asian diabetes patients with lower knowledge scores were less likely to have received eye care, foot care, blood pressure checks, education and general support compared with patients with higher knowledge scores. In the same study, these patients lacked confidence in the overall health benefits of ongoing diabetes care and were less likely to believe that they had good control over their disease.

### KEY POINTS

- Knowledge about disease and their risks vary among South Asians but is generally lower than that of whites.
- Many South Asians—especially those unable to speak the local language, those with low education levels, new immigrants, women and the elderly—have a minimal understanding about the key elements of diabetes care.
- Those with good knowledge feel more empowered, more in control and less threatened by their disease.
- Poor access, irregular care and missed appointments are highly correlated with patient efficacy and awareness.

## Psychosocial and Gender-based Elements

Psychosocial and gender-based factors are known to impact patients' adoption of and ability to engage in risk reduction and the uptake of self-care practices.<sup>32</sup>

Many traditional, social and gender norms applicable to South Asian females can potentially limit their ability to engage in healthy practices and the use of timely care. Newly immigrated women with low education levels are more likely to remain housebound, prioritize family over independence<sup>61</sup> and face increased levels of stressors such as isolation, lack of autonomy and vulnerability that places them at greater risk of delays in their disease diagnosis and poor uptake of care and other health-enhancing behaviours.

A study exploring gender-based challenges facing Sikh older women with coronary heart disease showed that the social issues of isolation, lack of autonomy and increased vulnerability were all important factors in their poor management of disease risk and in behavioural change.<sup>89</sup> Saving face and projecting a certain image are deeply rooted cultural values that prevent women from sharing their health issues. The study also identified factors such as child care responsibilities, lack of transport options and poor health as other isolating factors. Because most of these women did not work outside the home, they lacked autonomy and faced integration and acculturation challenges given their low literacy levels and limited English language skills. These obstacles also greatly prevented these women from obtaining health-related information on their illness and self-care.

The immigration criteria under which Sikh women from South Asia were admitted to Canada were as dependents under the family reunification policy. These women

were typically from rural areas of Punjab with little education, minimal employable skills and lacking English fluency. These factors, along with the fact that Sikh women come from a patriarchal system, predisposes them to a greater degree of isolation and disadvantage when dealing with a chronic illness.

### **Social Support**

Social support is positively associated with psychological and physical wellbeing and with health enhancing behaviours and health care service use.<sup>85,103</sup> Patients with low social support are more likely to engage in unhealthier diets, low physical activity levels and other practices that negatively affect health.<sup>32</sup> Although the South Asian community is interconnected and is known for high levels of social cohesion, social supports tend to be lower than in the white community.<sup>85</sup> This may likely be from factors such as distance from extended family, lower literacy and awareness of disease and the overall lack of information available in South Asian languages.<sup>85</sup> A Canadian study<sup>89</sup> found that interpersonal connections and support were limited for those not employed, those with limited English fluency and those who immigrated later in life. The authors concluded the Sikh community is reluctant to share their personal health information with each other and that the participants' willingness to share this information with other community members in order to seek social support is very limited.

There is abundant evidence that higher levels of social support are correlated with improved self-management and better health outcomes. Support has been assessed from a variety of sources, including spouses, family, friends and neighbours, and colleagues.

#### **KEY POINTS**

- South Asian women face considerable gender-based obstacles when living with chronic disease.
- South Asian women face greater levels of isolation, dependency and vulnerability.
- To reach women and other South Asians facing language, literacy and other cultural barriers, the following interventions are necessary:
  - Using alternative media forms, especially verbal and pictorial
  - Using places of worship such as Gurdwaras and temples to reach women and the elderly
  - Using ethnic media and television networks to provide culturally relevant material using South Asian care providers

### **Access to Health Information**

Health information that is timely, accurate, culturally relevant and presented at the literacy level of the recipient is essential for first understanding and then for properly managing care plans. Linguistic barriers represent a significant obstacle

in the provision of health information to patients.<sup>74,104,105</sup> As a result, children, rather than the patient and patient's spouse, usually become the primary providers and translators of health information.

Language barriers can potentially prevent detailed interactions among practitioners, patients and their spouses. A UK study by Astin et al. (2008), comparing South Asians and white European cardiac patients, illustrated that while it was typical for spouses to accompany and participate in conversations about care with the practitioners, this was not the case with South Asians, especially for females and other family members who could not speak English.<sup>74</sup> As a result, three-way conversations between the patient, spouse and health care worker were limited. This dependency for information from secondary sources, typically spouses or children, not only reduces the comprehensiveness of the message being conveyed by the practitioner, but also minimizes the patient's ability to engage in meaningful discussions about his or her care and/or illness. It was found to be common for spouses and children acting as interpreters to withhold information about the seriousness of their condition from patients in order for them to be not alarmed or distressed about their illness.

Family involvement in care plans and in other health-related decisions is common among South Asians.<sup>106</sup> This is contradictory to the modern medical culture favouring individualistic relationships between clients and care providers.<sup>106</sup> South Asians also perceive that responsibility for the management of health conditions remains with the health care provider.<sup>10,79</sup> The role of health care professionals is to articulate the care plans to their clients and the role of clients is to follow these orders.<sup>10</sup>

### **Attitudes Toward Treatment**

Patients who attribute their illness to external causes such as fate, stress and climate are less likely to engage in health-enhancing practices. This could take the form of missed appointments, not adhering to medications or care plans and using lay persons as sources of health information.

A recent US study<sup>32</sup> exploring health behaviours of older South Asian immigrants with an average residency of 25 years in the US showed that a substantial proportion of respondents did not engage in relevant health behaviours. The study found that:

- 30% of respondents did little to no physical activity,
- 30% consumed high-fat diets, and
- 74% consumed low-fibre diets.

This is true despite the fact that 31% had hypertension and 18% were diabetics. Many of these respondents (41%) were vegetarian.

Generally, South Asians' adoption of particular lifestyle changes is strongly linked to their own underlying health beliefs and causes of illness, as discussed earlier.<sup>84</sup> For example, Lawton et al.'s 2008 study of Indian and Pakistani type 2 diabetes patients noted that despite acknowledging the importance of taking hypoglycaemic agents, less than half of the respondents reported taking medications as prescribed.<sup>107</sup> Self-regulation or adjusting the amount of prescriptions was

common without prior consultation with their physicians. Many felt that it was unnecessary to continue taking medicines once they felt well, or if they noticed any side effects, during fasting sessions or during certain meals. Some respondents attributed their type 2 diabetes to existing ailments such as asthma and pneumonia. This can lead to adjusting or minimizing their prescriptions dosages to not conflict with prescriptions for these conditions. Reducing food intake and taking medicines only when the condition worsened (for example, high blood sugar or blood pressure) were common practices.

In another small qualitative study of South Asians in Australia with CHD showed that patients seemed to put off their visits to the doctor and had a passive attitude towards help-seeking behaviour, and many did not follow instructions and advice from doctors.<sup>76</sup>

### KEY POINTS

- The concept of fate and inevitability of chronic disease may drive the lack of urgency seen in South Asians towards care-seeking behaviours.
- Self-regulation of care plans and medications is common among South Asians.
- Interventions targeted at modifying perceptions of external factors may be beneficial in improving self-management care.

## Relationships with Care Providers

Delivering good care has always been a cornerstone of health care policy, with primary care providers playing a key role, as they are often the first point of contact with the health care system. In some cases, the personal attitudes and values of care providers around group differences can impact how this care is delivered. Nunez and Robertson (2006) described a client's primary care encounter as an interaction of three cultures (the care practitioner's, the client's and that conveyed by the Western medical model).<sup>106</sup> In this process, a client's cultural input is often not recognized or is dismissed as irrelevant,<sup>86,108</sup> given that health care providers are strongly influenced or socialized by their profession. Spector (2004) argued that the views of professionals trained in the modern medical model are potentially so rigid that they may dismiss South Asians' strong beliefs and reliance on alternative forms of interventions, such as homeopathic and naturopathic medicine.<sup>109</sup>

An important component of this disparity is the potential lack of cultural knowledge and the potential cultural insensitivity of health professionals about their clients.<sup>98,110</sup> This often occurs when care providers face language barriers, engage in stereotypes and generalizations or misinterpret culturally dense messages.<sup>98</sup> Abundant evidence exists suggesting that the needs of clients would be improved if the care providers were better informed and sensitive to clients' cultural and

social orientations, beliefs, knowledge and attitudes about health and wellbeing.<sup>10,86</sup>

A UK study concluded that South Asian diabetic patients had little or no support or input in establishing their care plans.<sup>10</sup> Ethnic minority patients were often left feeling insecure and helpless with the lack of control or input over their health decisions, which is contradictory to the self-care approach suggesting that high level patient involvement, awareness and knowledge are critical components in managing disease.<sup>10</sup> Where interpreters were used, South Asian patients felt that consultation times were too brief, resulting in inadequate information exchange for the client. In another study, patients were frustrated by the lack of explanation by primary care providers about their diagnosis and care plans.<sup>111</sup> Patients, especially women, felt that their input or concerns were not taken seriously.<sup>111</sup> Conversely, practitioners reported that appointments using interpreters were typically longer than others.<sup>10</sup>

#### KEY POINTS

- South Asians generally have good satisfaction with health care workers, including family physicians.
- A patient's cultural values and beliefs make him or her a receiver of care and advice and not an equal partner in his or her care management.
- A study by Rhodes et al. of UK Bangladeshi patients showed that clinical visits were centred around routine tasks of monitoring, with little feedback or discussion of patients' issues or concerns. This did not change with patients' ability to speak English.
- Cultural differences between patients and care providers have more impact on the patient/provider relationship than does language.

## 6. CHRONIC DISEASE CARE AND MANAGEMENT

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Chronic disease management programs continue to grow in order to improve the quality, efficiency and targeting of care for patients with chronic disease. Care associated with chronic diseases such as type 2 diabetes and cardiovascular disease is complex, requiring pharmaceuticals, regular review, behaviour modification and the development of self-management skills. A limited number of publications have documented the effectiveness of disease management in South Asian migrant populations. Understanding which interventions are most effective and suitable in this ethnic group given the health status disparity from chronic disease could guide the development of culturally appropriate disease management programs.

Effective management of chronic illness and disease is complex and requires significant participation by patients and their families. Arguably, successful management of chronic conditions depends on adequate self-care. According to Bodenheimer et al., self-management by individuals with a chronic condition is not an option: individuals with long-term chronic conditions must become partners in their own care because they have the day-to-day, primary responsibility to manage their disease or condition in collaboration with their physician.<sup>111</sup> As clinicians may be present for only a fraction of a patient's life, nearly all outcomes are mediated through patient behaviour. Exercise, proper nutrition and using medications appropriately are integral to minimize disease progression and improve overall well-being.

Self-management of type 2 diabetes has been positively associated with most biomedical and knowledge-based outcomes. A systematic review of 72 randomized controlled trials assessing the effectiveness of type 2 diabetes self-management indicated that positive outcomes were seen in the following areas: knowledge gain, glucose checks, glycaemic control, dietary habits, weight and lipid profiles.<sup>112</sup> None of the studies in this review demonstrated any long-term outcomes. Additional studies have also shown the effectiveness of type 2 diabetes self-management with better glycaemic, metabolic, blood pressure and weight control in non-South Asian populations.<sup>112,113</sup>

Historically, education-based interventions have been the most frequently implemented strategies, using information-based resources and training to improve self-management practices.<sup>114</sup> Literature suggests that while improvement in knowledge is important, it alone is usually not enough to facilitate an ongoing lifestyle shift. As a result, the practitioners and academics have turned to psychological, behavioural and sociological models to better understand the relationship between outcomes such as self-management and its determinants.

Two of these models, the Personal Model and the Attitudes-Social support self-Efficacy (ASE) Model have explored the relationship between self-management and patients' beliefs, emotions, knowledge, experiences and perceptions about the cause, seriousness and treatment effectiveness of chronic disease.<sup>115,116</sup> These models suggest that self-management is primarily influenced by patient's attitudes, social influences, self-efficacy and intentions.<sup>115</sup> In other words, individuals'

understanding of their chronic condition and their partnership in the treatment and management process is critical to self-management. Research on Caucasians suggests that the variables with the strongest association with self-management are treatment effectiveness, social support and self-efficacy.<sup>115</sup> Significant literature exists showing the association between self-efficacy with diabetes care in the areas of diet, exercise and glucose monitoring.<sup>117</sup> Studies have also shown that patients who feel that their condition is controllable are better at managing their chronic disease and are more likely to engage in diet and exercise improvements and in glucose monitoring.<sup>117</sup> Thus, practitioners can take two potential approaches when considering self-care interventions:

- build interventions around the illness perceptions identified as important by the target group, or
- aim to alter target group's illness perceptions in order to facilitate better self-care practices.

These proximal factors - such as people's perceptions, beliefs, attitudes, self-efficacy and intentions about a disease - are further influenced by the broader distal factors such as age, sex, socioeconomic status, religion, ethnicity and culture. Ethnic and, more importantly, cultural factors form the critical background context through which individuals navigate, and exert a great deal of influence on how patients perceive and practise self-management.<sup>118</sup>

Although the concept of culture applies across standard social categories (e.g., race, gender and sexual orientation), most research on illness modification has focused on gender and ethnicity. Ethnic group membership is a marker for many psychosocial processes - identity, group pride and discrimination - that are embedded in a socio-historical context. These shared characteristics help to shape people's perceptions about their surroundings, the role of family and community, and their place in society, which includes interaction with the medical community. The disproportionate burden of diabetes among ethnic minority groups supports the need for chronic disease management to be delivered in a cultural context that is familiar and accessible. It is critical to understand how cultural differences influence the way messages about chronic disease are received and how these differences contribute to self-care practices.<sup>89</sup>

## **Self-management in South Asians**

While research evidence on Caucasian groups clearly shows that self-management and biochemical outcomes such as blood glucose levels and behavioural interventions targeting diet, physical activity and general efficacy have been effective,<sup>114,120</sup> such evidence remains relatively unknown in South Asians. South Asians, and minority ethnic groups generally, are under-represented in trials of self-management programs. Majority of the South Asian studies on this topic have either explored the influence of cultural factors on chronic disease and management or the type of barriers impacting self-management.

Quantifying the degree of chronic disease self-management in South Asians has been difficult given the lack of studies comparing this ethnic group with others. For example, in this literature search, only two studies quantitatively compared the level of self-care among South Asians with other ethnic groups. In the more recent study comparing Europeans, South Asians and Pacific Islanders in New Zealand,

no difference in diabetes self care among South Asians and Europeans was found but Pacific Islanders had statistically lower levels of self care compared with the other two ethnic groups.<sup>117</sup> This study also found that self-efficacy was consistently associated with self care, but not glycaemic control. In the earlier observational study consisting of a large sample size (n=500), awareness and self-management of diabetes was assessed on U.K. South Asian and Caucasian patients attending diabetic clinics within a set period.<sup>121</sup> Compared with Caucasians, South Asians reported statistically significantly lower levels in the following areas:

- perceived knowledge of diabetes
- awareness of diabetic complications
- awareness of the nutritional content of their diet
- importance with keeping their clinical appointments
- anxiety if treatment was not adhered, and
- importance of control of diabetes.

Hawthorne and Tomlinson (1999) found that among South Asians of Pakistani origin living in the U.K, level of self-care (for example, glucose monitoring) was low.<sup>122</sup> Rates between males and females were similar even though females had much lower fluency in English (12%) compared with males (55%). The authors further concluded that while females had similar levels of self-care, they were less likely to know how to handle persistently raised glucose levels. Thus, they lacked the capacity to problem-solve.

Additional studies have explored the influence of cultural, religious, social and personal attributes associated with self-care. In a recent metasynthesis of literature, Flemming and Gillibrand proposed the following cultural influences impacting self-care in South Asians.<sup>118</sup>

- Causation of diabetes - the two most commonly cited beliefs were heredity and stress, and these were based on study participants' personal experiences. Those with a strong family history of diabetes often discussed inevitability of developing this disease, reflecting the perceived lack of control. As a result, these patients are less likely to engage in self-care. Meetoo (2004) also showed that patients with greater sense of control over their disease were more likely to adhere to their diet plan<sup>123</sup>. Another study investigating illness perceptions and self-efficacy and diabetes self-care among Europeans, South Asians and Pacific Islanders in New Zealand, showed that among South Asians, treatment control perceptions were associated with self-care, specifically glucose testing, indicating that those who perceived diabetes to be more controllable were more likely to test their glucose levels regularly.<sup>117</sup>
- The principle of balancing treatment and management of type 2 diabetes - South Asians often balance the management of diabetes by balancing the intake of substances such as complementary medicines and food. For example, the perceived side-effects of pharmaceuticals are balanced by eating strong foods such as chapattis and curries. Patients will also adjust their medicines if consuming restricted or unhealthy foods.<sup>123</sup> In the case of Muslims, they may substitute certain dietician-recommended foods with others they perceive to be similar given their religious restrictions with foods containing animal fat. Incorporating these balancing practices within their everyday diet and alongside dietary changes prescribed by primary care practitioners can greatly impact self-management care and food choices.<sup>123</sup>

- Reliance on lay knowledge networks - South Asians are much more likely to use lay knowledge as a source of information and support about chronic disease, its risk factors and management. This can be drastically different from a practitioner-prescribed care plan. Strong family ties play a key role in shaping attitudes and experiences of patients, especially in self-management.<sup>10</sup>
- Service inequity - cultural and ethnic differences may be responsible for delayed diagnosis, misdiagnosis and missed appointments, which place South Asians at a considerable disadvantage in accessing and using self-care.

Other cultural factors of note impacting South Asians' risk profile for chronic disease and their self-management practices include:

- Low knowledge of disease - studies have shown that South Asian diabetics know less about the disease and its management than white patients. And although improvement in knowledge does not necessarily translate to health enhancement, knowledge is fundamentally important in diabetes self-management. A recent Canadian study found that low educational attainment was associated with increased risk of diabetes in immigrant women.<sup>2</sup> This is especially an issue with South Asian women, as those migrating from rural areas have lower levels of education and are likely to be less knowledgeable about their chronic disease.<sup>101</sup> Since women tend to be the main carers and food preparers in South Asian families, their lack of knowledge about chronic conditions could likely impact diabetes management for any member of the household.
- Acknowledged importance of self-care not matched by action - a study comparing South Asian and Caucasian patients with diabetes found that even though South Asian patients were highly receptive to learning about their disease and acknowledged the importance of self-management, most appeared unwilling to attend group or individual sessions themselves.<sup>10</sup> Issues with recruitment of South Asian patients to educational programs has been previously reported.<sup>124,125</sup>

This passive approach may partially be based on the traditionally held belief that the health care professional is the expert and thus the provider of care and advice. As opposed to a collaborative relationship, the patient is seen as the recipient of this care and is responsible for following the instructions or care plans.<sup>114</sup>

- Ethnic congruence with current self-management models - the most widely used self-management model, the Stanford Chronic Disease Self-management Model, is based on Bandura's theoretical model of self-efficacy.<sup>126</sup> This model's theoretical underpinning of effective self-management relies on high self-efficacy, self-directedness and motivation and confidence, all attributes generally shown to be lacking among South Asians.
- Structural barriers such as transportation, distance to clinics or educational sessions, and date and time of appointments restrict people's ability to access services.
- The two most important modifiable factors in the prevention and management of chronic disease - physical activity and diet - are deep-rooted, often driven by culture, religion, social acceptance and customs. To a large extent, cultural

norms are significant drivers of South Asians' willingness to engage in these practices.

Although type 2 diabetes self-management has been associated with positive patient outcomes, on the whole, self-management programs are not currently well suited to overcome certain cultural aspects, especially for people with low proficiency in English and those who lack the level of literacy required for reading program literature or manuals.<sup>3</sup> For example, the main domains of self-care for people with type 2 diabetes - managing dietary intake, engaging in physical activity, monitoring blood glucose levels, practicing proper foot care, managing medications, and seeking regular medical care – are highly demanding on the individual.

Even though considerable responsibility still remains with care practitioners, self-management is moving away from a system dominated by the healthcare practitioners, where they are seen as the experts and the patient as passive recipient of care to a more collaborative approach where both work as equal partners to achieve best possible management of disease.<sup>114</sup> Wagner et al., based on their large literature review proposed four essential elements or underlying characteristics of successful self-management models that would allow a primary care practitioner to maximize the opportunities that patients will self-manage<sup>127</sup>:

- Collaborative problem definition - programs that facilitate patients' defining their own problems with the support of other primary care practitioners
- Targeting, goal-setting and planning - programs that target issues of greatest concern to the patient and health care provider, that have realistic, personalized goals, targets and care plans and that weigh patients' readiness and self-efficacy
- Self-management training and support - comprehensive programs that include education, behavioural change support, physical activity and diet support and those that address emotional demands and stress with having chronic illness
- Active and sustained follow-up - reliable and scheduled follow-up and support as well as patient-initiated support on an as-needed basis

**Table 9. Summary of Barriers to Self-Management**

<b>SOCIO- DEMOGRAPHIC</b>	<ul style="list-style-type: none"> <li>• Low levels of English fluency and literacy, especially among women, the elderly and migrants originating from rural areas</li> <li>• Limited knowledge of chronic disease and risk factors</li> <li>• Lower awareness of health care services and health-enhancing programs</li> <li>• Highly heterogeneous population in terms of knowledge, skills and attitudes, place of origin, religion and language</li> <li>• Social isolation among women with low education, elderly and new migrants</li> </ul>
<b>CULTURAL &amp; RELIGIOUS</b>	<ul style="list-style-type: none"> <li>• Onset of disease seen as inevitable, due to fate</li> <li>• Illness attributed mostly to external factors such as fate, stress or cold weather</li> <li>• Passive approach to prevention and disease management</li> <li>• Little preventive or promotional outlook about chronic disease prior to diagnosis</li> <li>• Multi-generational interdependence and support (dependence of elderly on other family members)</li> <li>• Reluctance to share personal and illness-related information: “saving face” is common practice</li> <li>• Reluctance to change dietary habits due to customary and religious values attached to food, and thus, healthy dietary practices are often ignored for the social norms of hospitality</li> <li>• Reliance on lay persons (family, relatives, friends) about diagnosis, disease and its risk factors, and health-promoting practices</li> <li>• Family members withholding information from patient about serious diagnoses: concept of avoidance</li> <li>• Non-adherence and self-regulation/adjustment of prescriptions and care plans: concept if “balancing”</li> <li>• Lower levels of physical activity and participation in organized sports among females</li> <li>• Lack of opportunities for physical activity and organized sports in countries of origin, especially among females and the elderly</li> <li>• Lower utilization of (overall) care services</li> <li>• Religious obligations restricting food choices</li> </ul>
<b>ECON- OMIC</b>	<ul style="list-style-type: none"> <li>• Financial challenges for new immigrants, women and elderly</li> <li>• Prescription costs for the elderly and new immigrants</li> </ul>
<b>STRUCTURAL</b>	<ul style="list-style-type: none"> <li>• Lack of interpreters, especially in community settings</li> <li>• Limited evidence-based interventions that are long-term</li> <li>• No ethnic-based data to measure outcomes</li> <li>• Fit of current research evidence to Fraser Health South Asian population: demographics of UK South Asians are significantly different from those residing in Fraser Health</li> <li>• Lack of transportation options, distance to clinics, appointment times for certain South Asian groups: new immigrants, women, the elderly</li> <li>• Time constraints, especially for females and others working long hours</li> <li>• Lack of control over food served at social and religious gatherings</li> </ul>

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**Table 10. Summary of Enablers to Self-Management**

<b>CLIENTS</b>	<ul style="list-style-type: none"> <li>• Use family in educational and self-management care plans</li> <li>• Involve food preparers and food shoppers in dietary interventions</li> <li>• Use cultural and religious beliefs as assets to develop and deliver interventions</li> <li>• Implement interventions that concord with people’s lay understanding of disease</li> <li>• Incorporate physical activity into everyday life events</li> </ul>
<b>HEALTH CARE PRACTITIONERS</b>	<ul style="list-style-type: none"> <li>• Practitioner’s ability to speak group-specific language</li> <li>• Engage clients in developing lifestyle changes and care plans</li> <li>• Build meaningful relationships and engagement</li> <li>• Referral to peer supports</li> <li>• Use bilingual link workers in practices to bridge cultural and linguistic gaps</li> </ul>
<b>SYSTEM LEVEL</b>	<ul style="list-style-type: none"> <li>• Base new interventions on existing initiatives showing self-management successes in South Asians</li> <li>• Build targeted interventions with community based on thorough knowledge of the target group</li> <li>• Consider the heterogeneity of South Asian community when planning, implementing and evaluating self-management initiatives</li> <li>• Work with organizers of community events to plan healthy meals</li> <li>• Use religious places and leaders in the community for increasing buy-in</li> <li>• Increase support for peer and family networks</li> <li>• Use ethnic media to provide culturally appropriate material and messages</li> </ul>

## **Self-Management and Culturally-Appropriate Educational Interventions**

Self-management support entails two streams of action: the provision of education and the provision of supportive interventions by health care practitioners. Self-management education focuses on teaching disease-specific skills (such as screening, managing medications, understanding and following care plans, problem solving, accessing community resources) that clients can utilize to self-manage their disease.

This section reviews the published literature on educational interventions and assesses how they can be commonly designed for South Asians to ensure that they are culturally applicable and the type of factors that need to be considered in this process.

Overall, the results of educational interventions among South Asians aimed at reducing the impact of type 2 diabetes and heart disease are mixed and inconclusive given the lack of research evidence available to date. Three recently published systematic reviews are used here as a link to the research literature, highlighting key issues and findings on this topic.

The Khunti et al. review focused exclusively on educational interventions for migrant South Asians with Type 2 diabetes.<sup>128</sup> Only nine studies met the inclusion criteria; five were randomized controlled trials (RCT) and four non-RCTs. The Hawthorne, Robles, Cannings-John and Edwards (2008) review included multiple ethnic groups, with four of the total eleven studies being South Asian.<sup>129</sup> This review of RCTs only compared culturally tailored educational interventions with those providing “usual” care. The interventions tested were educational, tailored clinical sessions with education, and enhanced care using link workers or nurses and education. Outcome measures were change in knowledge, awareness and self-management, and biochemical outcomes such as glycaemic level, blood pressure, lipid levels and weight. Main findings of these reviews included the following:

- Improvements were seen in glycaemic control, total cholesterol and knowledge about diabetes for culturally appropriate interventions compared with those providing “usual” care.
- Improvements were generally short-term and authors noted the need for more randomized control trials of longer duration to assess the long-term clinical, health status and knowledge retention measures in culturally appropriate interventions.
- There was difficulty associated with determining concisely the type of effective interventions among South Asians given the lack of studies completed on this topic, especially those showing conclusive improvements in educational interventions.

While these reviews failed to pinpoint the exact aspects of culturally appropriate education that are thought to make the difference compared with a “standard” intervention, Hawthorne et al. (2008) concluded that the key to this success was to use a combination of one-on-one and group educational interventions instead of using one or the other, and to ensure that adequate intensity of exposure to the health education intervention was applied.<sup>128</sup>

Another RCT not part of these systematic reviews investigated the effectiveness of a culturally adapted lay-led self-management program in UK Bangladeshi adults with chronic disease.<sup>130</sup> Using trained and accredited lay tutors from the South Asian community, the intervention group received six weekly three-hour sessions of the culturally adapted Chronic Disease Self-Management Program. Pre-post intervention outcomes were measured using a questionnaire and included self-efficacy, self-care behaviour, communication with physician, health status (depression, anxiety, pain, fatigue and shortness breath) and health care use. The authors concluded that the program improved participants' self-efficacy to control their disease and improved their self-management skills. Other outcomes were not significantly different between groups. Attendance to sessions was an issue and the barriers often mentioned for low attendance were social roles, poor health and views of predetermination and destiny.

Two additional studies have explored the concept of meeting the needs of South Asians through the use of modified versions of educational programmes. The X-PERT Programme, originally developed for the Aboriginal population, was culturally modified by Choudhury et al (2009) for UK residents of Bangladeshi origin.<sup>102</sup> The second study by Stone et al. (2008) adapted the DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed) module for use in South Asian patients.<sup>131</sup> Both of these educational programs used interpreters, peer educators and a variety of visual resources and drawings. While the intent of these studies was not to measure biomedical or long-term effects, the interventions were feasible and well received.

In a 2010 systematic review, Netto et al. investigated interventions for preventing coronary heart disease in Pakistani, Chinese and Indian communities.<sup>132</sup> Interventions included promoting physical activity, smoking cessation and healthier diets. The authors identified the following five principles for adapting culturally appropriate behavioural interventions for these three ethnic groups.

- *Use community resources to increase intervention accessibility*  
This includes drawing on community resources such as ethnic media, networks, community leaders and community events to market and increase accessibility.
- *Identify and address barriers to access and participation in interventions*  
Increase access and participation through minimizing structural barriers (transport, admission costs, location and time of service provision, etc.) and other social, cultural and demographic factors addressing age-, gender- and religion-specific needs and barriers.
- *Develop communication strategies addressing language use and differential information requirements*  
Address language and literacy requirements of the audience including the sensitivity and strength of the message and the differing efficacy levels of individuals, using bilingual and culturally knowledgeable facilitators and print material. Ensure that the message is audience-specific and sensitive.
- *Identify and work with cultural or religious values that either provoke or inhibit behavioural change*

Design interventions that incorporate religious or cultural beliefs and norms, given that these factors are critical for behavioural shift. This means that health prevention and health promotional interventions that are incompatible with religious and cultural values need to be revised. For example, a mixed-gender swim or jog club will likely not be acceptable to Muslims, traditional households or the elderly.

- *Accommodate degrees of cultural affiliation in the planning and evaluation of targeted interventions*

This principle is to take account of the diversity of cultural identification, acculturation, integration and permeability of external influences on individuals that make up the larger ethnic group that is addressed. Among South Asians, acculturation varies considerably depending on one's religion, language, country of origin, age, gender, education level and length of residency.

An important component of a culturally competent approach is ensuring that the health care systems are designed to meet the needs of multi-ethnic populations. While the importance of cultural balance between patients and health care providers has been noted earlier, Anderson et al. proposed that in order to have culturally competent health care, the following must be available:<sup>133</sup>

- culturally diverse staff that reflect the needs of communities being served
- providers or translators who speak client's language
- training for providers about the culture, language and religion of the people they serve
- signage and instructional literature in the client's language that is consistent with their cultural and/or religious norms and at the proper literacy level
- culturally specific health care settings.

## **Primary Care Interventions**

Management of chronic diseases such as type 2 diabetes and heart disease is multifactorial. Health education interventions can target biomedical improvements (blood pressure, haemoglobin levels, lipid levels, BMI, etc.), behavioural improvements (changes in smoking, diet, physical activity, etc.) or service access and utilization improvements (clinic attendance, taking prescribed medication, following care plans, etc.).

As an illustration of best practices, a sample of key primary care interventions incorporating these components implemented in South Asian populations are presented next.

## **United Kingdom-based Initiatives**

### **The United Kingdom Asian Diabetes Study (UKADS)**

This study investigated the effectiveness of an enhanced, culturally sensitive care in UK general practices for improvement of cardiovascular risk factors in South Asian patients with type 2 diabetes over a two-year period. The impetus for this study was the promising evidence from the UK Prospective Diabetes Study Group, a large multicentre longitudinal investigation which demonstrated in a mostly Caucasian population (82%) that control of glycaemia and blood pressure significantly reduced the risk of microvascular and macrovascular complications.<sup>134</sup> In the UKADS, a randomized controlled trial, 21 practices were assigned to either the enhanced care group or the control (standard care). Enhanced care included the use of additional diabetes-trained practice nurses, link workers and community diabetes nurses, and patients were followed up with every two months in clinics held by the practice nurses. Practice nurses worked with primary care physicians on care plans, provided face-to-face patient education and implemented patient-specific targets for blood pressure, lipid and glycaemic control. Link workers contacted patients before and after appointments and provided interpretation services in local languages. Diabetes nurses provided additional education and clinical support, such as insulin initiation.

After two years, small but statistically significant improvements were seen in blood pressure but not in lipid or glycaemic control between the control and intervention groups. The authors also concluded that the financial investment incurred by this enhanced intervention did not produce sufficient health-related gain in the quality of life outcomes.

### **Project Dil (Heart), 1991<sup>136</sup>**

This was a coordinated primary care and community health promotion programme for improving the effectiveness of primary and secondary prevention of coronary heart disease (CHD) in volunteer general practices with a high volume of South Asian patients and to increase awareness of behavioural risk factors through a peer-education programme. Recruitment of patients was from local general practices through volunteer invitation following a series of open meetings and visits. Initially, 23 practices of 63 general practitioners agreed to participate. A key component of the programme was the highly trained peer educators responsible for increasing the profile and knowledge of CHD through peer education. Each volunteering practice also attended an accredited training programme on CHD and

its care, especially as it applies to South Asians. Through peer educators and a CHD nurse, practices were supported in the development of secondary prevention plans through

- CHD registers development,
- clinical audit of practice records against local CHD guidelines,
- care plans to improve standards of care, and
- re-evaluation of above items.

An important outcome of this process was the written action plans for each practice which they were responsible for implementing. Project Dil's partnership with secondary care was to train peer educators for the provision of cardiac rehabilitation services to South Asians. Peer educators have been employed by hospitals to assist with this critical service. The importance of using a culturally appropriate liaison referral method has been highlighted recently by Grewal et al. (2010).<sup>135</sup>

This programme has been recognized for engaging, recruiting and supporting primary care health teams through a culturally appropriate intervention. Patient uptake and attendance, as well participation in clinical audits, has been high. The success of this project has been attributed to dedicated funding, leadership of key health organizations in increasing the profile of CHD through broader public health policy initiatives, and the acceptance and recognition of this program becoming a mainstream service within UK.

#### **Apnee Sehat (Our Health) Program, 2005<sup>137</sup>**

Based on the social enterprise model, Apnee Sehat's goal is to raise awareness and screen for vascular diseases in order to reduce the risk of cardiovascular disease and diabetes in South Asians. This is being accomplished through facilitating preventive lifestyle changes using education, self-care and risk-reduction interventions.

The program began in 2005 with collaborations among local communities, universities, health care providers, academics and the pharmaceutical industry to serve the South Asian communities' chronic disease needs using culturally tailored interventions. The success of the program is based on its local focus, community engagement and collaboration, patient empowerment, evidence-based approach, cost-effective care provision and the use of an educational model to reach some of the most hard-to-reach South Asian sub-populations. One strategy to accessing these groups is through the religious organizations and places of worship.

Apnee Sehat envisions innovatively redesigning patient care pathways and developing integrated models that overcome traditional barriers to both primary and specialist care services. Apnee Sehat has been nominated for six national awards.

#### **The Khush Dil (Happy Heart) Project<sup>138</sup>**

Khush Dil started in 2002 on a grant to explore and test ways of implementing local, culturally appropriate coronary heart disease prevention and control services for South Asians. This primary-care led project arose in response to local needs and as a focused response to national and local health policy initiatives targeting chronic disease management and health status inequalities and establishing

broader partnerships. Specific aims of the project were to identify people with CHD risk requiring primary and secondary prevention and to provide them with culturally relevant information and practical support. This included one-on-one nutritional support, knowledge-based education on CHD and diabetes, cooking workshops, physical activity training, walking and jogging groups, stress management, smoking and alcohol management, and other health promotion seminars.

The initial one-to-one health assessments are done by the nurse/health visitor to establish patient risks and care goals. Family physicians are provided copies of blood tests, care plans and interventions. The impact of these services is assessed from 6 to 12 months after initial assessment using self-reports, physical measures, and laboratory tests conducted or facilitated by trained South Asian community health workers, dietitians, health visitors and interpreters in various community settings, including religious places.

Pre- and post-measures indicated increased motivational status, increased physical activity and improvement in biomedical markers including reduction in cholesterol, blood pressure and weight. Cost effectiveness and randomized controlled trials are needed to validate these findings on a longer-term basis.

Again in 2006, the Khush Dil Project started providing culturally appropriate diabetes information to black and minority ethnic (BME) residents. Coordinated by a community diabetes specialist nurse (CDSN), the two services included a clinic at an inner-city surgery centre and weekly physical activity sessions for women. The clinic, held every two weeks by a diabetes physician, provided intensive, culturally appropriate diabetes care to BME people with type 2 diabetes with an HbA1c of greater than 8%.

Evaluation of these interventions showed overall satisfaction with the clinics and physical activity sessions and reduction in HbA1c. The South Asian clinic assistant was a key individual, given that she was responsible for all language-related needs, appointment reminders and all other non-clinical correspondence.

Some of the issues identified by patients were the inapplicability of health information to some clients, early morning sessions which interfere with Muslim prayers, inability to attend due to work, as most were not entitled to paid leaves, shift work interfering with eating and exercise schedules, working long hours and lack of transportation options.

## **Canada and BC-based Initiatives**

### **Primary Health Care Charter, BC**

The BC Primary Health Care Charter is a collaborative initiative between the BC Ministry of Health, the BC Medical Association, the health authorities and health consumers that establishes the direction, targets and outcomes to support primary care system redesign that is integrated, patient-centred and addresses priority areas and high-risk populations. The charter places strong emphasis on chronic disease and will re-orient services for specific at-risk patient groups, improve access and provide team-based and culturally safe care. With patients as partners, the goal is to design and implement integrated health network teams that support

patients through coordinated care in the areas of evidence-based chronic disease self-management, education, life coaching and group clinical visits.

### **The Practice Support Program (PSP) and Family Practice Incentive Program<sup>141</sup>**

Through a joint committee of the BC Ministry of Health Services and the BC Medical Association, the Practice Support Program (PSP) and the Family Practice Incentive Program were set up to support primary care physicians to improve patient care using training modules for physicians and their staff, as well as provide fee incentives for physicians providing complex care to patients. The goals of these training modules is to enable physicians and their staff to assist clients take a more active and informed role in managing their disease.

The programs also enable physicians to bill additional fees for care and conferencing for each of their patients having diabetes mellitus, hypertension, congestive heart failure or COPD (chronic obstructive pulmonary disease), and for those requiring complex care (patients with two or more of the following: diabetes mellitus, kidney disease, vascular disease and respiratory disease).

Further, practices engaging in chronic disease management (CDM) through the PSP learn how to

- develop and use patient registries,
- use the CDM toolkit, and
- implement planned recall.

The toolkit allows medical practices to complete patient information on a secure web-based platform that guides care plans based on clinical guidelines and generates recall lists of patients that are due for an office visit or those who require scheduled tests or procedures.

An external evaluation of the Family Practice Incentive Program showed that for diabetes, congestive heart failure and hypertension patients, standardized annual costs were lower for patients who had received incentive-based care than those with physicians not in the incentive payments program. Further, these initiatives have encouraged physicians to be more proactive in their clients' care—from ensuring that patients are seen on a regular basis to reviewing lab results on time to taking on patients with complex conditions and care needs. A 2009 survey of both the patients and general practitioners revealed that both groups were satisfied with the service and were supportive of these initiatives.

### **Centre for Aging Chronic Disease Self-Management, University of Victoria**

For the past number of years, the Chronic Disease Self-Management Program (CDSMP), delivered by the University of Victoria Centre on Aging, has become a permanent program in BC. In 2009, a Punjabi version of this model developed by Stanford Patient Education Research Centre using peer-based project leaders was implemented and evaluated. Over a one-year span, 75 Punjabi program leaders were trained and 108 Punjabi participants attended the 6-week CDSM modules. Pre- and post-program questionnaire scores for the leaders showed statistically significant changes, whereas the participants showed no significant change, although participants were generally very satisfied with the content and delivery of the program.

To date, both the Chronic Disease and the Diabetes Self-Management programs continue to be offered in Punjabi throughout the province.

**South Asian Diabetes Prevention Program (SADPP), Ontario**

Developed by the Flemingdon Health Centre, the SADPP is intended to provide culturally appropriate educational resources and to enhance equitable access to diabetes services for Tamil (southern India and Sri Lanka) and Muslim South Asians speaking Tamil or Urdu. The program provides outreach early detection clinics, educational workshops and referrals. It has recently produced a culturally and linguistically appropriate diabetes prevention resources care kit in three languages (English, Tamil and Urdu). This kit includes a handbook and DVD outlining prediabetes and lifestyle changes required for preventing or delaying the onset of diabetes, using a health promotion perspective.

## KEY POINTS

- **Scarcity of health promotion initiatives in South Asian population**

The extent of research evidence on this topic is limited among the South Asian population. Only a limited number of health promotion interventions and initiatives have been implemented and evaluated, mostly randomized control trials and interventions measuring long-term effects and outcomes. Netto et al. suggested that without a good foundation of research evidence and theoretical frameworks, it becomes difficult to pinpoint the exact aspects of culture likely impacting health-related behaviours or to establish potential causal pathways.<sup>132</sup>
- **Address deep-rooted factors**

Behavioural shift is more likely to occur if interventions target deep-rooted factors related to cultural, religious, social, psychological and environmental characteristics.<sup>132</sup> Interventions that target only surface influences, such as language, while increasing receptivity are unlikely to result in behavioural change.
- **Community involvement in planning, implementation and evaluation**

Involving the relevant ethnic and non-ethnic communities is important in publicity, marketing, recruitment of participants and increasing buy-in. Further, community involvement is also important to ensure that cultural and religious elements are incorporated and that cultural, gender and age compatibility of interventions with the intended target group is addressed. During implementation, cultural and functional acceptance and use can be facilitated using community members, interpreters, bilingual health care workers and other resources that minimize language barriers. Using the concept of ethnic pride, ethnic role models and ethnic media to promote interventions are some other potential strategies.
- **Tailored approach based on in-depth knowledge of target community or ethnic group (and adequate resources)**

That the research evidence does not provide a focused and tested approach to health promotion and prevention for South Asians suggests that tailored or flexible strategies to targeted subgroups are likely to be most effective and, where successful, to replicate these interventions in other South Asian groups. Knowledge of target community is vital given the high heterogeneity of South Asians. Cultural and social factors fundamental to promotional interventions such as literacy and educational experiences vary considerably across South Asians.<sup>139</sup> Consequently, a sound understanding of their distribution as well as the role of religion, gender and social norms is important in designing any culturally appropriate intervention.

- **Incorporate ethnic-based targeted interventions into mainstream approach**

While the literature clearly indicates the value in developing targeted interventions for South Asians, it is important that while these are being developed, interventions that target the general mainstream population are also inclusive of South Asian populations. This may mean that these broader programs are adapted to ensure uptake and acceptance by South Asians.

- **Integrated approach to Type 2 diabetes care**

Both the increasing cost of hospital-based care and the increase in patients needing care for chronic diseases such as type 2 diabetes and cardiovascular disease are dictating the shift of care to primary care settings, consisting of an integrated team approach involving both primary and secondary care practitioners.

The role of primary care within diabetes was a critical component of the 2003 National Service Framework (NSF) for Diabetes launched by the UK National Health Service. This framework set out twelve new standards and key interventions necessary to raise the standard of diabetes care across the U.K. The intent of this national initiative was to make best practice the norm, including supporting patients with their care and lifestyle adjustments, reducing complications and setting up community-based diabetes clinics. This framework was also intended to standardize the quality of diabetes care across all jurisdictions, populations and in high-risk groups through local diabetes networks housing primary and secondary care practitioners. In order to facilitate this partnership, responsibility and accountability for the management of diabetes and the provision of continuous and consistent care, a pay-for-performance was introduced in the UK in April 2004. This new contract for general practitioners required a certain level of achievement in type 2 diabetes outcomes in order for them to earn approximately one quarter of their salary. For example, practices earn points for achieving established glycaemic control targets.

These innovative primary care initiatives based on integrated and co-operative approaches are seen as necessary steps in reducing the impact of chronic disease in high-risk populations.<sup>140</sup>

## 7. CONCLUSIONS

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This concluding section summarizes the findings from earlier sections and highlights the main cross-cutting themes and issues.

This literature review further reinforces the point that there is an urgent need for the development and implementation of culturally targeted interventions to prevent and manage chronic disease in South Asians. The existing burden from established chronic diseases such as diabetes and cardiovascular disease in South Asians requires a coordinated primary and secondary care approach that facilitates client-based self-management practices.

The findings of this review have particular relevance for Fraser Health, given that South Asians are the largest ethnic group in Fraser Health and, according to the 2006 Census, is home to 69% of BC's total South Asian population.

This review also suggests that cultural beliefs and values play an important role in how South Asians view health and how they engage in health-improving initiatives. How these ethnic differences play out—in terms of health and disease outcomes—vary considerably among South Asians because of their considerable heterogeneity resulting from their place of origin, religion, language, literacy, socioeconomic status, social rank, class and gender. Thus, the challenge for those involved in planning and providing self-management services to South Asians is to ensure a culturally sensitive, targeted approach with in-depth knowledge of their clients and the community and to bear in mind that not all problems or difficulties are due to one's ethnicity. For example, there is increasing evidence that socio-economic status, age and gender are as important as ethnicity in determining a person's health and health care needs.

Regardless, the literature clearly suggests health and self-management inequity in South Asians. How can this be addressed? Through the provision of culturally and linguistically competent care strategies that support self-management. These strategies must be built on the enablers and address the barriers to self-management highlighted in this review. The primary care interventions highlighted in the previous section as well as Netto et al.'s five principles for adapting culturally appropriate behavioural practices (also listed in the previous section) provide viable starting points for initiating targeted self-management solutions.

Further, approaches to tackling self-management capacity in Fraser Health needs to address a wide range of issues and not just language fluency. There needs to be a focus on successful partnerships between health care providers, patients, carers and the community. Health care professionals remain the critical component of this partnership, and evidence suggests that they often struggle to offer culturally appropriate care to South Asians. As a result, they require additional training and skills to increase their level of knowledge and cultural awareness. This includes increasing practitioners' cultural capacity, understanding clients' cultural beliefs, norms and gender roles, and minimizing stereotypes about an ethnic group's race, religion and other cultural domains.

Key findings of this literature can be summarized as follows:

- **Limited linguistic and literacy capacity among South Asians**  
Literacy and language fluency are integral to self-management, and the literature suggests low levels of both in South Asians. Building linguistic and literacy competence of high-risk subgroups will likely entail developing culturally acceptable, evidence-based health education techniques to reach high-risk South Asians.
- **Limited knowledge of chronic disease and self-care among South Asians**  
Knowledge of disease and self-care varies considerably among South Asians. Improvements in knowledge, understanding and management of chronic disease will require a multi-pronged approach, including multi-media resources, and use of bilingual care providers to enable more direct communication with patients and their concerns.
- **Ingrained health beliefs and attitudes related to disease**  
This review has highlighted the role of culture, religion and gender on beliefs about health and health-inducing behaviours. Interventions can use these beliefs as a resource to bring about positive attitudinal and behavioural changes.
- **Significant heterogeneity and diversity among South Asians**  
There is considerable diversity among this ethnic group along the lines of religion, place of origin, language, gender roles, levels of acculturation, educational levels and length of residency. Understanding this intra-ethnic diversity is important for motivating individuals to consider, initiate and maintain self-management practices.
- **Structural barriers impact the most vulnerable South Asians**  
For South Asians women with little or no education, the elderly and recent immigrants, structural and material barriers (such as limited mobility, limited financial support, gender inequalities, transportation and distance to services) are just as important as cultural/religious/linguistic-based barriers for engaging in self-management and other health-seeking behaviours.
- **Need for cultural adaptation of interventions**  
The literature reveals the application of a wide array of strategies for adapting interventions to take into account the cultural context of target groups—from the use of link workers, diabetes nurses, interpreters, ethnic case workers, peer-educators, to the use of community venues and places of worship and overcoming structural barriers by providing taxis to participants, etc. The key is to ensure that the community is fully involved from planning to evaluation.
- **Cultural competency of care providers**  
Increasing the cultural competency of health care practitioners is considered an important strategy in reducing disparities in health status and health care use among South Asians. This entails increasing their

knowledge, attitudes and skills about multicultural care in order to facilitate more meaningful interactions with their clients.

- **Mainstreaming of new and existing initiatives**

Given that targeted intervention can take considerable time, resources and effort, it is imperative that in parallel to this process, mainstream initiatives are developed and implemented with South Asian ethnic groups' input and expertise. This ensures that South Asians with lengthy residence in Canada and those that are well acculturated receive appropriate care.

- **Implement best practice checklists for planning and service provision**

Given the both inconsistent and limited level of promotion, prevention and self-management services for South Asians, the literature suggests improved coordination and delivery of community-based services and increasing primary health care capacity for prevention, early detection, early intervention and chronic disease self-management.

- **Scarcity of research evidence and diversity of studies**

- Limited studies on self-management and studies that evaluate generalizable interventions. Most of the evidence is from the UK.
- Lack of theoretical frameworks on this topic, and as a result, almost all studies lacked the planning and assessment of interventions underpinned by theories. This is important given the dynamic and fluid nature of both culture and ethnicity over time.
- Most of the interventions reviewed were short-term, suggesting RCTs of long-term duration are required to evaluate the effectiveness of initiatives beyond the typical 6 to 12 month duration.
- The studies reviewed in this literature search were diverse and multi-faceted in terms of the target audience, age groups, setting, nature of interventions, scale and duration.

- **Lack of ethnic-based data**

Currently, very little demographic, utilization and health-related data exist for South Asians. Quality data are needed for planning, implementing and evaluating interventions and health outcomes. Targeted approaches are difficult to implement without adequate levels of ethnic-based data.

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