

**EXPERIENCES OF ETHNIC MINORITIES WITH CHRONIC ILLNESS**  
**ACCESSING PRIMARY HEALTH CARE**

by

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# Abstract

Living with a chronic illness such as diabetes or heart disease and accessing health care over many years can be a challenge for anyone. This experience is further impacted by experiences associated with being an ethnic minority where challenges in communicating with health care providers or encountering different views on health care can make navigating the system more difficult. Within the current health care system in British Columbia, the Primary Health Care (PHC) Charter articulates a clear role for PHC as the setting in which chronic illness care is organized and delivered. Unfortunately, interactions in PHC can be both a source of support and of stress for individuals. In order to provide care which supports individuals to self manage their health, it is important that PHC providers understand common experiences and priorities for diverse populations when seeking care in the ongoing management of their condition.

Through secondary analysis, this study analyzes data from a recent research project exploring the experiences of ethnic minorities in PHC by Dr Wong. Data from twelve focus groups with a subset of participants with chronic illness was examined to further advance aspects of chronic illness management within the context of the current health care environment in British Columbia (BC). This data was viewed within a critical cultural perspective to inform both current and future practice in order to promote care which is culturally safe and at the same time supports individuals in adopting healthier lifestyles and maximizing their confidence in managing their health. Results from this study highlight the challenges encountered by anyone managing a chronic illness but also how ethnic minorities may face an increased burden of illness. This study also explores how approaches in the charter, specifically the expanded

chronic care model, need to be viewed critically in terms of the potential to promote a sense of individual responsibility for care or further racialization through subcategorizing individuals based on ethnicity. This study also highlights benefits in the approaches to CDM especially in the investments in resources in multiple languages and potential for building stronger linkages to community programs.

# Preface

This study is a secondary analysis of a qualitative research study completed by Dr. Sabrina Wong to understand ‘Chinese and South Asians’ Preferences and Expectations of Primary Health Care’. Part of this research involved a convenience sample of 78 Cantonese- and Mandarin-speaking Chinese and Punjabi-speaking South Asians individuals aged 19-75 years who had immigrated to Canada within the past 20 years. This was the initial phase of a larger proposal to develop and administer a PHC instrument and evaluate its psychometric equivalence across English-, Chinese-, and Punjabi-speaking groups.

Ethics approval for the original study including secondary analysis was obtained through the University of British Columbia’s Behavioral Ethics Review Board. Certification numbers are: H06-80200, B06-0200.

Some results from the original study have been published in 2010 by: Marshall, E., Wong, S.T., Haggerty, J.L, Levesque, J. as, ‘Perceptions of unmet healthcare needs: what do Punjabi and Chinese-speaking immigrants think?’ A qualitative study in *BMC Health Services Research*, 10:46.

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# Chapter I: Background to the problem

## *Problem statement*

Imagine having a chronic illness such as diabetes or heart disease and, consequently, requiring access to health care in the ongoing management of this condition over many years. Now imagine this as a member of an ethnic minority (EM) where you may experience challenges in communicating with health care providers or have different health beliefs and values from those in the dominant majority. How would this impact your ability to meet your health care needs? Coping with a chronic illness can be a burden for anyone in the current health care environment, but when there are additional challenges in being an EM and recent immigrant, these challenges can become overwhelming. Primary health care (PHC) is the setting in which much of the ongoing management of chronic illness is organized and delivered, yet these interactions can also be a source of stress for individuals. In order to optimize these interactions in health care for ethnic minorities (EMs), it is important that PHC providers understand common experiences and priorities for these populations when seeking care in the ongoing management of their condition.

## Chronic illness and prevalence in Canada

Chronic illnesses are diseases of long duration and generally slow progression which have a profound effect on the physical, emotional and mental well-being of individuals, affecting the ability to carry on with daily routines and relationships (British Columbia Ministry of Health (BCMoH), 2007; World Health Organization (WHO), 2009). These illnesses include heart disease, stroke, cancer, depression, respiratory diseases, dementia and diabetes, and are by far the leading cause of mortality, morbidity and disability. Chronic illnesses represent 43% of the

global burden of disease with a projected increase to 60% by 2020 (WHO, 2002). In 2005, the WHO estimated that 35 million people died of chronic illness, or over 80% of all deaths. While the prevalence varies from report to report depending on which illnesses are considered, the projected increases are between 30 – 60% over the next two decades (BCMoH, 2007; Public Health Agency of Canada, 2005; WHO, 2002).

Chronic illnesses have become the most common problems in health care (Grumbach, 2003). The WHO notes the four most prominent chronic diseases (cardiovascular disease, chronic obstructive pulmonary disease, cancer and type 2 diabetes) are associated with biological risk factors of hypertension, high cholesterol and obesity along with behavioral risk factors of unhealthy diet, physical inactivity and tobacco use (WHO, 2002). They further note these behavioral risk factors are influenced by a complex web of social, political and economic interactions.

Within the current health care system there is a growing awareness of the impact of chronic illnesses and how this influences health care costs. In an attempt to shift from a reactive model of care to a proactive model of care, the BCMoH has introduced the PHC charter. Components of this charter include improved access to primary care, increased chronic disease prevention and management and improved management of co morbidities (BCMoH, 2007). For individuals and their families, once diagnosed with a chronic illness they enter an arena of health care where everyday life is influenced by health care advice and success or failure is measured through how well they follow this advice (Thorne & Robinson, 1988). Individuals face many challenges when they attempt to follow health care advice, creating tensions in relationships with PHC providers. For EMs, these challenges can be even more pronounced.

## Immigration patterns in Canada and British Columbia

Patterns of immigration in Canada have evolved over time in response to world events, politics, immigration policies and economic factors. Prior to 1962, immigrants to Canada were accepted primarily from European countries. The immigrant population of 50 years ago consisted of a higher ratio of men to women, primarily Caucasian and younger, healthier population able to work in labor related fields (Boyd & Vickers, 2000). By 1967, the system adapted to include family reunification and humanitarian grounds, leading to a far more diverse population of immigrants. By 1996, the top 3 sources were Hong Kong, China and India (Boyd & Vickers) with most arriving under the family class, where family members sponsor a relative (Government of Canada (GC), 2009). At this time, only 10% were able to speak English, there was a higher proportion of women, lower levels of education and elderly immigrants comprised 18% of the immigrant population (Hansen, 2004). British Columbia attracts a high proportion of the immigrant population in Canada with most immigrants re-locating within urban areas. It is projected that by 2017 one quarter of Vancouver's population will be from a Chinese or South Asian background (Belanger & Malenfant, 2005).

## Ethnicity and chronic illness

Ageing increases the likelihood of developing a chronic illness, yet the age factor may well affect immigrants even more so than their Canadian-born counterparts (Beisner, 2005). Although immigrants are healthier upon entering Canada - primarily due to health screening - the stress of immigration is associated with a decline in health over time (Beisner, 2005). Immigration itself is linked to stress, and chronic stress is linked to illness and cardiovascular issues (Raphael, 2006). The process of emigrating creates many challenges in terms of adjusting to a new culture, language barriers, employment and the impact of sponsorship (Anderson, 1998;

Koehn, 2006). With the growing burden of chronic illness in the general population and with EMs, there is an increased acknowledgment of the role of PHC in preventing chronic illness, minimizing complications and supporting individuals in ongoing management of their health (BCMōH, 2007).

### Primary health care and its role in managing chronic illness

Primary care is the first line of clinical services or entry point to the health care system providing continuous, comprehensive and coordinated care - usually through a general practitioner or nurse practitioner. Primary Health Care goes beyond basic medical services to include a focus on promoting health and preventing illness through addressing social, political and economic environments as determinants of health (Canadian Nurses Association, 2003).

Within PHC, the responsibility for health is transferred from the physician as a healer to a PHC provider as a partner. Within this model, the PHC provider works within a coordinated system with a team from a variety of health care disciplines and services (BCMōH, 2007). In BC, the Ministry of Health acknowledges the role of the PHC provider in chronic illness in its approaches to Chronic Disease Management (CDM) through the PHC Charter.

### Services and research in chronic illness for ethnic minorities

In light of the increasingly diverse population in BC and the complexities inherent in chronic illness management, the specific needs of EMs need to be understood and articulated more comprehensively in the PHC charter as well as within its approaches to CDM (BCMōH, 2007). Services geared to prevention and ongoing management of health are not as effective for immigrants for a variety of reasons including language and cultural differences and also how services are organized (Beisner, 2005). The intersection of ethnicity and PHC through the lens of chronic illness and CDM warrants further exploration. In the current health care environment

in BC, CDM is being promoted as the panacea to cope with the unsustainable costs in the health care system yet there is little understanding of how EM populations describe their experiences and what is important to them when accessing PHC within the context of chronic illness. Further research is needed to explore specific issues in relation to language and how culture shapes experiences collectively and individually. Research must challenge cultural stereotypes as they limit health care providers' effectiveness in providing care and reinforce differences rather than commonalities in human experiences (Beisner).

### *Purpose of study*

My purpose in this research is to explore the intersection of: managing a chronic illness, being an ethnic minority (South Asian and Chinese immigrant) and accessing Primary Health Care (PHC) in British Columbia (BC), to inform the delivery of health services; specifically, approaches to chronic disease management (CDM).

### *Research question*

Within the context of having a chronic illness, how do ethnic minorities describe their experiences in the ongoing management of their health in the Primary Health Care setting?

### *Significance of study*

Little is known about how EMs manage chronic illness within the PHC setting. This study will add to the growing body of literature in chronic illness, PHC and ethnicity. Through managing a chronic illness, EMs experience many commonalities with their Canadian-born counterparts, yet these experiences are also impacted as a result of their ethnicity and the experience of immigrating to Canada. Through examining these intersections, within the context of CDM, this study offers a nuanced understanding about EMs self management and experiences

in PHC. These understandings can be used to inform current and future approaches to CDM to optimize in individual's abilities to participate in their care.

### *Summary*

Chronic illness requires a lifetime of treatment and is often characterized by acute episodes of illness along with periods of time where symptoms may be reduced or absent (Schueler et al, 2009). In recognition of the impact of chronic illnesses on health care costs the province of BC has adopted structured approaches to CDM through the PHC charter. As the population within the province becomes more diverse the specific needs of EMs and their interactions in PHC would benefit from thoughtful exploration. To provide effective care, PHC providers need to understand not only the complexities of managing a chronic illness but also how this experience is impacted by the stresses of immigration and other issues related to ethnicity. As the setting in which care is organized for the ongoing management of chronic illness, the PHC setting merits further exploration.

## Chapter II: Literature review

There is a well-established body of literature exploring the chronic illness experience (Thorne et al, 2002), including the impact that a chronic illness may have upon ethnic minorities (Anderson, 1991; Hwu, Coates & Boore, 2001; Hjelm et al, 2005). There is also a growing body of literature exploring PHC (Broemeling et al, 2009; Wong, Young & Regan, 2008) and interactions with EMs (Ahmed & Lemkau, 2000; Marshall et al, 2010; Wong, 2006). However, the intersection of EMs and PHC through the lens of chronic illness and CDM warrants further study. This section will describe key aspects identified by research and literature on the topics of chronic illness, PHC and CDM and EMs which will provide a platform for further exploration into this intersection.

### *Chronic illness*

#### Definition

Most studies in chronic illness explore a specific condition or group of conditions. In population based studies, respondents are generally asked about specific diseases or conditions which last longer than 3- 6 months (Ng et al, 2005; Public Health Agency of Canada, 2005). The WHO describes the term broadly as, ‘diseases of long duration and generally slow progression’ (Strong et al, 2005). The BC Ministry of Health describes chronic illnesses as prolonged conditions that often do not improve, are rarely cured and have a profound effect on the physical, emotional and mental well-being of individuals (BCMoH, 2007). There are common characteristics that many individuals with a chronic illness experience such as dietary and lifestyle adjustment over many years and also distinct characteristics associated with specific conditions such as shortness of breath with lung disease (Strong et al, 2005; Thorne, Paterson &



Russell, 2003). The terms chronic disease, illness and conditions are often used interchangeably although some of the literature does make clear distinctions. The term disease generally refers to impairments in the normal state of the body or one of its parts that interrupts or modifies the performance of the vital functions, a condition is simply a state of being and illness refers more broadly to an unhealthy condition of the body or mind (Merriam-Webster, 2011). Within this study, I am using the term chronic illness to refer loosely to both chronic diseases and the patient's experience of related chronic conditions.

### Prevalence in British Columbia

In BC, the Ministry of Health (MoH) indicates that over 1/3 of the population is currently coping with a chronic illness and this is expected to increase significantly in the future in response to a shift in demographics to an older population (BCMoH, 2007). According to the Public Health Agency of Canada between 1994 and 2005, the rates of hypertension increased by 60% (2005). One chronic illness which demonstrates a well documented increase is type 2 (adult onset) diabetes. The current global rates estimated at 171 million are expected to double by 2030 (Canadian Institute of Health Information, 2010). The Canadian Diabetes Association (CDA) estimates that 3 million Canadians have diabetes and predict this will increase to 3.7 million by 2020. Disturbingly, one in every three children born in North America in the year 2000 will likely develop diabetes in their lifetime (CDA, 2010). For all chronic illnesses noted in the National Population Health Survey (NPHS), the incidence was higher for those in the low and low-middle income category with a higher proportion in the female population (Beaudet et al, 1998). Along with ageing a sedentary lifestyle combined with the amount of processed foods ingested contribute to this epidemic (CDA). Globally, the WHO attributes the rise in chronic

illness to be related to either insufficiencies associated with poverty or excesses in diet and substances such as alcohol and tobacco (2002).

### Prevalence in ethnic minorities

While the incidence of chronic illness is increasing, there is a disproportionate growth of these conditions in EM populations. Although immigrants are healthier and report less chronic illness upon arriving in Canada, their health deteriorates progressively over time and they become comparable to their Canadian-born counterparts after 30 years (Perez, 2002). Studies on some illnesses including diabetes, obesity, cardiovascular disease and mental health also indicate that the health of immigrants can get even worse than the general population (Beisner, 2005). Immigrants report a lower income than Canadian-born (Lindsay, 2001a; Lindsay, 2001b) which is associated with a higher prevalence of chronic illness (Beaudet et al, 1998).

### Managing a chronic illness

As the WHO recognizes, the development and progression of chronic illness is influenced by a 'complex chain of environmental effects . . . shaped by broader socioeconomic determinants' (WHO, 2002, p 13). Societal and cultural factors shape both biological and behavioral risk factors (Coleman & Newton, 2005; WHO, 2002). Current approaches in chronic illness management include both behavioral intervention to decrease harmful behaviors and pharmaceutical treatment to limit biological impacts (Strong et al, 2005). Literature described in the following section highlights the limitations of the traditional health system in meeting the needs of those with chronic illnesses.

### Contrasting acute and chronic illness management.

In acute care, underpinned by the biomedical model, the focus is on consent to a single curative therapeutic event (Redman, 2005) in contrast to managing a chronic illness which

involves complex dietary and lifestyle adjustments along with ongoing medical treatments and recommendations over many years (Thorne & Robinson, 1988). Within the acute model, health is related to biological factors and its medical management.

The acute management of illness is based on Parsons conceptualization of the 'sick role', where patients are exempt from some social role responsibilities and the responsibility for being ill, they are obligated to want to 'get well', to seek competent help and comply with treatment regimens (Parsons, 1975). Patients are viewed as passive recipients of health care (Curtin & Mapes, 2001) with the underlying assumption that health care advice is based on scientific evidence and will benefit the patient therefore, the rational patient will be compliant and follow advice (Russell et al, 2003). Therefore, compliance results in cure and noncompliance results with morbidity and mortality (Hess, 1996; Redman, 2005).

## Compliance

Adhering to medical advice is reasonable when coping with a short term issue which will be resolved yet may not be realistic in the ongoing management of a chronic illness over time (Hess, 1996; Redman, 2005; Thorne, 1993). Sackett defined compliance as, 'the extent to which the patient's behavior in terms of taking medications, following diets or executing lifestyle changes coincides with medical advice' (1976).

Many studies point to the limitations and even harmful effects emerging from the ideology of compliance (Paterson, Russell & Thorne, 2001; Redman, 2005; Van Dam et al, 2003; Wellard, 1998). While the literature promotes the notion that adapting healthier lifestyle behaviors can positively influence chronic illness (Strong et al, 2005; Thorne, 1993; WHO, 2002; Yawn, et al, 2001), it is compliance and how it implicitly influences care which is of concern. Surveillance of compliance is implicitly embedded in clinical practice with success

measured through physiological and biochemical tests (Wellard 1998). While other terms have been used in place of compliance, such as adherence, mutuality, conformity, cooperation and therapeutic alliance these terms continue to describe how individuals' behaviors correlate with advice from the perspectives of health care professionals (Kyngas, Duffy & Kroll, 2000, Thorne, 2008). Health care providers (HCP) need to be aware of the paternalism and coercion inherent in these terms and understand how they reinforce the dominance of the professional and minimize the efforts of individuals (Playle & Keeley, 1998). They must understand that it is population-based evidence which informs professional practice which has many limitations when applied to individual life situations (Thorne, 2008).

The influence of the medical model on health has also led to the perception of many chronic illnesses as lifestyle diseases where the development and progression of disease are assumed to be the result of poor lifestyle choices instead of looking at the broader issues of environmental, economic and social pressures at both individual and population levels (Raphael, 2006; Wellard, 1998; WHO, 2002). This view promotes a sense of individual responsibility for health based within Western liberalist ideals and obscures the challenges that individuals face (Doane & Varcoe, 2005).

Despite acknowledging the limitations of the acute care system in managing chronic illness (Thorne, 2008) the need to shift from this default model of care toward patient participation, patient centered, and patient empowerment models remains (Coleman & Newton, 2005; Van, Dam et al, 2003). Scientific research continues to 'trump' research in the social sciences (Wellard, 1998). This is evident in current research. Research within the medical field in specific chronic illnesses focuses on minimizing the physical impact of disease through pharmaceutical management, symptom control and educational strategies to change lifestyle

behaviors (Brunner et al, 2009; Ebrahim, 2009; He et al, 2009; Hooper et al, 2009; Jurgens et al, 2009; Nield et al, 2009; Suckling et al, 2009). Research within the social science arenas focus on decision making and self management, health care relationships and the chronic illness experience (Redman, 2005; Steed et al, 2003; Thorne et al, 2002; Thorne et al, 2003; Thorne & Paterson, 2001; Van Dam et al, 2003).

### Health care relationships

The literature in chronic illness supports the need to approach care with an in-depth understanding of the complexities of both the development of chronic illness and its ongoing management. As mentioned above, the goal of care is to support others to adopt healthier lifestyles and approaches to minimize symptoms; to maximize their ability to function in daily life and achieve the highest level of well being (Hwu et al, 2001). It is integral that PHC providers understand how skills and expertise in illness management evolve from experimentation, not compliance with standard approaches (Thorne, 2008).

Evident in the research on the chronic illness experience, health care providers play a significant role in self care and chronic illness management and how successful management is defined (Redman, 2005; Steed et al, 2003; Thorne & Paterson, 2001). The role of PHC providers is to support individuals as they attempt to integrate these changes within their own life context over many years, through periods of success and struggle (Thorne & Paterson). The challenge is to ensure these relationships are supportive of individuals gaining confidence in managing their illness, not undermining their efforts.

### Self management/care

Effective self management of a chronic illness means an individual must understand his or her health and manage their care including taking medications, participating in treatments and

decision-making and manage the impact of the condition on their daily life (Gallagher et al, 2008). Underlying assumptions of self care include that: those active in decision making are healthier, that decision making is a rational, linear and consistent process and that the goal in decision making is to minimize symptoms and comply with recommended treatments (Paterson, Russell & Thorne, 2001). Approaches to chronic illness management acknowledge that much of decision making occurs outside the health care arena (Thorne, 2008). However, despite this understanding and believing in the concept of patients as self-managers, in practice clinicians find it difficult to relinquish control or responsibility for care (Curtin & Mapes, 2001).

Self care goes beyond learning and complying with therapeutic regimes, individuals rely on their personal experience and knowledge of the disease within their own lives (Paterson, Russell & Thorne, 2001). Living well entails an ‘increasingly sophisticated and integrated capacity to weigh alternatives, make choices, attend to evidence, listen to one’s unique body cues and develop an individualized system by which to know whether one is doing better or worse over time’ (Thorne, 2008 p 11).

Individuals evaluate and adopt treatments not based on health but on social criteria (financial, family expectations, relationships with practitioners) and beliefs in effectiveness of treatment (Wellard, 1998). When promoting self-care PHC providers must recognize the potential to reduce confidence or increase frustrations causing a greater burden and negative impact on overall well-being (Steed et al, 2003; Thorne & Paterson, 2001). Consciously not following medical advice should be viewed as an attempt to preserve their quality of life and protect themselves from inappropriate clinical decisions, not as resistance or lack of understanding (Hwu et al, 2001). While the health practitioner may be the expert on the general pattern of disease, it is the individual living with the illness who understands the intricacies and

challenges of maintaining their overall well-being (Paterson & Sloan, 1994). Interactions in health care must be acknowledged as social processes where the focus should be encompassing the illness experience not the disease process (Thorne & Robinson, 1988). While efforts to promote supporting patient participation and self care may improve health outcomes the complexity of this support needs to incorporate the knowledge that education itself is poorly related to behavior change and that significant others in an individuals social context have the greatest impact on behavior changes (Steed et al, 2003; Van Dam et al, 2003).

### Challenges

Common challenges associated with chronic illness include the time devoted to medical management and self-care, the financial burdens associated with managing their conditions, educational levels, literacy, and the tensions between the biomedical model focusing on disease specific care and the social context within which decisions are made (Coleman & Newton, 2005; Redman, 2005; Thorne & Paterson, 2001). In their research comparing diabetes and other chronic illnesses with acute care, Yale et al noted that those with diabetes and chronic illnesses had more visits and spent more time each visit with their primary care provider than those with acute illnesses (2001). This is consistent with the characteristics of chronic illness identified in the literature where there is a focus on ongoing assessment, prevention and management of symptoms and health promotion (Strong et al, 2005).

Along with more intensive contact in PHC involving the burden of transportation and time away from work, the ongoing management of a chronic illness requires adequate financial resources to cope with medical requirements and lifestyle changes. Even in the current health care environment in Canada, where basic services are covered, there remain many hidden costs to care. Many individuals are not reimbursed for medications and individuals may require

medical supplies and equipment to monitor their condition. Changing diet and lifestyle behaviors also requires adequate financial resources. Those with lower incomes, more apt to experience a chronic illness may also find the financial burden is greater (Redman, 2005).

Educational levels and literacy impact the burden of chronic illness. Those with lower education and rates of literacy have a greater burden of illness and more difficulty in managing these conditions related to a lack of skills and ability to access support and follow up (Redman, 2005). The biomedical model, promoting disease-specific care, also contributes to confusion as recommendations for one illness may aggravate another (Coleman & Newton, 2005). Most importantly, every day decision making in chronic illness (including what to eat, which activities to participate in, medical management and monitoring) is based on an individual's own responses and goals in maintaining their quality of daily life (Thorne & Robinson, 1988).

### Priorities

Many studies identify characteristics of successful management of chronic illness as the activities an individual must engage in to monitor and promote their health, access resources, limit the impact of disease and cope with the psychosocial problems associated with the condition (Coleman & Newton, 2005; McGowan, 2003; Redman, 2005). In studies exploring the chronic illness experience, individuals identify some of the subtleties within this description. Thorne, Paterson & Russell (2003) examined everyday decision making in chronic illness and note that: individuals seek to balance health care advice with all aspects of their life, that they veered to HCP who would acknowledge and assist them to develop their own expertise, that their engagement in decision making varied according to their beliefs about the role of HCP and that at times, self care decisions were overwhelming and 'unhealthy choices' were necessary to cope.



## Gaps

Managing and living with a chronic illness is complex. Further research is warranted to understand not only how individuals make decisions throughout the progression of illness but how PHC providers support endeavors to strengthen confidence in self-management. How do we shift further from the biomedical approach which measures success with adhering to treatment advice and biochemical parameters? How does population based evidence influence successful evaluation of an individual's illness management? How can exploring individuals' experiences inform future approaches to defining successful chronic illness management?

## *Primary health care*

### Role of primary health care in chronic illness

As the rates of chronic illness have increased, in the general population and with EMs, the role of PHC in preventing chronic illness, minimizing complications and supporting individuals in the ongoing management of their condition has become more recognized (BCMoH, 2007). PHC encompasses five principles of: accessibility, public participation, health promotion, appropriate technology and intersectoral cooperation (CNA). To be effective all five principles must be implemented simultaneously (Lemire Rodger, 2001). At its core, PHC advocates care by the right person at the right time in the right setting (Starfield, 1994). PHC includes providers from a variety of health care settings including: acute care, community health centres, outpatient clinics, public health units and outreach centres (Frankish, 2006).

There is a growing body of literature in PHC with studies on partnership, collaboration, experiences with Aboriginals, and health care utilization (Saba, 2006; Watson, 2005; Wong, 2006). In a research study on PHC in BC, Wong conducted focus groups with English-speaking adults to determine what features of PHC were important and how PHC could be improved.

Results identified dimensions of PHC important to the public such as: accessibility, continuity, responsiveness, interpersonal communication, technical effectiveness and whole-person care. Participants emphasized the importance of building long-term relationships based on mutual respect and trust (Wong, 2008).

These results are consistent with an international research study on the experiences of chronically ill patients and PHC providers where core foundations were identified as feelings of coherence, confidence in care, trusting relationship and accessibility (Bültzingslöwen et al, 2006). The broad focus and relationship context in PHC settings represent its greatest advantages and also unique challenges in improving care for those with chronic illnesses (Yawn et al, 2001).

#### Primary health care interactions with ethnic minorities

In chronic illness, where interactions in PHC are even more frequent and prolonged, relationships are especially important. Unfortunately, for EMs, these interactions may be less effective due to issues related to immigration and language (Campbell & Greene, 2001). Preventative measures including screening and preventing complications are less effective for immigrants, largely due to challenges with language (Beisner, 2005). Supporting individuals in the ongoing management of their health is even more challenging without an in-depth understanding of the complexities of being an EM. In a British study of asthma patients, Griffiths et al, found that South Asian patients experienced more barriers in effective partnerships in PHC for many reasons including communication difficulties, differences in health beliefs and issues related to socioeconomic status (2001). In another British study, Sheikh noted deficiencies in preventative care, responsiveness of services and again, issues related to language (2009). Research in BC notes that feeling discriminated against or a sense of being 'othered' are

common experiences for EMs in health care interactions, even when being cared for by PHC providers of the same ethnicity (Johnson et al, 2004). Along with language challenges, the failure to understand immigrants' medical complaints within the social context of their lives compromises the effectiveness of interactions in PHC (Wu et al, 2005), especially important in the ongoing management of a chronic illness.

### *Conceptual frameworks*

#### Chronic disease management in British Columbia

The recent discourse on health care reform has promoted the need to shift from an acute reactive approach of the health care system to more planned and proactive care to meet the needs of the growing, diverse population in British Columbia (BCMōH, 2007). As a strategy to cope with the evolving demands, the provincial government introduced the Primary Health Care Charter (PHCC) in March of 2007. This charter, as a policy directive, influences care at all levels within the health care system from policy development to front-line care. As mentioned previously, the components of this charter include improved access to primary care, increased chronic disease prevention and management and improved management of co morbidities (BCMōH, 2007). The BCMōH describes CDM as a systematic approach to improving health care for people with chronic illness and notes that health care can be delivered more effectively and efficiently if patients with chronic illnesses take an active role in their own care and providers are supported with the necessary resources and expertise to better assist their patients in managing their health (BCMōH).

Within this charter, approaches to chronic illness are based on the Expanded Chronic Care Model (Barr et al, 2003) which was extrapolated from Wagners' Chronic Care Model (Wagner, Austin & Von Korff, 1996). This version more clearly articulates the role of

population health promotion in the prevention and management of chronic illness (see Appendix B), acknowledging that most of the care for chronic illness occurs outside of the clinical arena (see Appendix A and B to view the model and distinctions between the two versions). In this population-based approach, CDM is based on the four components of: self-management support, decision support, delivery system support and clinical information support with the ‘expanded’ portion including strategies at the community and policy level to guide health promotion including educational campaigns. These educational campaigns are also available in multiple languages. One example is ActNowBC, a campaign to promote healthy lifestyle behaviors such as preventing obesity and promoting fruit and vegetable consumption, physical activity and tobacco and alcohol reduction (BCMōH, 2008). Within the four components of CDM: self management support involves supporting individuals to self manage their care, delivery system design involves re-orienting the health care system to focus on teamwork and expanded scopes of practice for clinicians, decision support involves the integration of evidence-based guidelines into daily practice and clinical information systems involve the development of information technology based on identifying patient populations and subgroups to provide relevant client data (BCMōH, 2007).

These components appear consistent to those identified in a systematic review of the evidence in chronic disease (Singh, 2001). The PHCC articulates a comprehensive approach geared to provide coordinated, efficient care based on principles of proactive follow up, supporting self-management and following clinical practice guidelines for common chronic illnesses with significant investments in PHC (BCMōH, 2007). This approach to CDM is a step in the direction of shifting from the acute model of care towards more effective chronic illness care yet more critical exploration is needed on how this impacts individuals and families. Within

this model, the disease remains the issue therefore expertise resides within the realm of the professional. In identifying approaches to care, PHC providers must be cognizant of the tensions between following standard guidelines and the need for individualization (Thorne, 2008).

The BCMoH statements related to the costs of chronic illness and reporting that large percentage of these diseases can be avoided through lifestyle behaviors are also concerning. Within this charter it is noted that 80% of some chronic illnesses can be prevented through moderate diet and exercise and 80% of health care expenses are consumed by 34% of the population with chronic illnesses (BCMoH, 2007). Not only do these statements heighten the anxiety of the public in terms of the financial sustainability of the health care system, they also become a way of ‘othering’ those with chronic illness (Canales, 2000) and place the responsibility for the illness and its management on the individual. For EMs with a chronic illness, there is now the potential to be ‘othered’ not only through race, but also health. Within this context, self-management takes on a new meaning.

### Chronic disease self management programs

Self-management programs are increasingly being advocated as an integral approach in the shift from a paternalistic model of care to a partnership model of care (Foster et al, 2007). These programs recognize the limitations of the acute care system to meet the needs of chronically ill individuals and that the majority of illness management occurs outside of the clinical visit (Thorne, 2008). Self-management has been defined as a patient’s ‘positive efforts to oversee and participate in the health care in order to optimize health, prevent complications, control symptoms, marshal medical resources and minimize the intrusion of disease in their preferred lifestyles’ (Curtin & Mapes, 2001, p 386). Components of self-management include: gaining confidence in medical management, role management and emotional management

whereas traditional patient education offers information and skills for a specific disease (MacGowan, 2005). In BC, self-management programs that are promoted have been adapted from the Chronic Disease Self Management Program developed by Kate Lorig at Stanford University (<http://patienteducation.stanford.edu/>). These programs are based on Bandura's theory of self-efficacy in which the central belief is that one can exercise control over one's health habits and can produce desired effects (Bandura, 2004). The University of Victoria, Centre for Aging organizes self-management programs throughout the province and also provides education sessions to clinicians based on this program.

I examined a systematic review by the Cochrane Library on self management education programs by lay leaders for people with chronic conditions which did include two studies with ethnic minorities (Foster et al, 2007) and a meta-analysis of chronic disease self-management programs for older adults (Chodosh et al, 2005). Both of these articles highlighted the need for a strong evidence base to support the growing enthusiasm for self-management programs for people with chronic illness. The authors conclude that for those attending, these programs may lead to small, short term improvements in participants' self-efficacy, perceptions of health, symptom management and exercise levels, but they could find no evidence that they improve psychological health, symptoms or health-related quality of life or that they alter health care use. Overall, they suggest a mismatch between the available evidence in support of self-management programs and the enthusiasm of health care providers and consumers in advocating these approaches. A key point to note is that these syntheses are limited by the need detect the impact of interventions through measurable data with a limited ability to capture the complexities of successful chronic illness management.

Approaches to self-management are strategies which appear to show benefits for individuals attending but also need to be viewed critically in terms of the impact they have on people when coping with conditions over many years. The growing acceptance of self-management as a health care strategy is influenced by the need to provide cost effective care to this growing population yet this is also based on ‘increasingly optimistic assumptions of the capacity of patients to take on responsibility for their health’ (Foster et al, 2007, p 2.). We need to balance the goal of supporting individuals to gain confidence and skills in managing their health with the potential of adding further burden (Thorne, Paterson & Russell, 2003), promoting individual responsibility for illness (Allen, 2006) and a sense of frustration (Steed et al, 2003). Further research is needed to understand the impact of these approaches for individuals and inform future approaches to research within this area.

#### *Chronic Disease Management and Self Management with Ethnic Minorities*

Despite the increasingly diverse population in BC, there is little attention to the specific needs of EMs in approaches to CDM and self management. While there have been improvements made in the availability of printed material in various languages and education programs, the impact of approaches targeting individual behaviors needs to be understood within a cultural context. In contrast to Western societies, many Asian societies have foundations in a collectivist approach. How are approaches to individual behavior change received? Are there other issues to consider in terms of accessibility of care and access to resources needed to manage care? Without an adequate understanding of the experiences of EMs as they interact in PHC, efforts to promote self-management will continue to risk instead promoting individual responsibility and blame for their health instead of promoting health and an environment which enables health (Anderson, 2003).

## *Ethnicity*

### Factors influencing chronic illness in ethnic minorities

There is a mounting awareness that ethnicity itself is not a biological marker for health and does not provide meaningful distinctions (Kreiger, 1999). Current discourse advocates for the need to move beyond simply understanding another's culture and ethnicity but to view culture as a dynamic and shifting process shaped by relations at both interpersonal and political levels (Allen, 1999; Doane & Varcoe, 2005). Cultural safety provides a framework for developing this understanding as it focuses on dimensions of power and social relationships and shifts the gaze from the other to the self (Browne et al, 2009). This awareness that culture does not apply only to those who receive services, but also to those who provide them is key in providing ethical health care (Coward & Ratanakul, 1999). Acknowledging that rather than ethnicity, issues affecting health are linked to the process of racialization where an individual's skin color or ethnic attributes limit their economic and social opportunities and therefore influence their health and illness management (Anderson, 1998; Kreiger). Kreiger notes five areas where discrimination may impact health including: economic and social deprivation, exposure to toxic elements, socially inflicted trauma, targeted marketing of psychoactive substances and inadequate health care. A study by Koehn, specifically working with ethnic seniors in BC, also identified issues related to sponsorship and dependency along with the tension between traditional values and the adoption of Western cultural norms between generations. These issues lead to greater health care needs and increased barriers in accessing care in terms of communication and family involvement in care (2006).

While the incidence of chronic illness is increasing throughout the country, there is a disproportionate growth of these conditions in EM populations. In a study following both Canadian-born and immigrants, non-European immigrants were twice as likely to report a



decline in their health (Ng et al, 2005). Upon immigration, 60% report a chronic illness compared to 65% of Canadian born yet when examined through length of residence, after 30 years, the rates are comparable (Perez). In the South Asian population, diabetes alone can be three to five times higher (Beisner; Fraser Health Authority, 2008). When analyzing data for the National Population Health Survey in Canada, Kaplan et al, found that the prevalence of hypertension in the Asian immigrant population increases concurrently with the length of residency in Canada with a rate under 3% at immigration to over 13% after 10 years (2002).

### Challenges in managing a chronic illness as an ethnic minority

Ethnic minorities with chronic illnesses face the same challenges as the general population in terms of the acute care orientation of the health care system underpinned by the ideology of compliance and how this impacts relationships with PHC providers in the ongoing management of their condition. These challenges are further complicated through issues associated with language and culture in terms of navigating the health care system, negotiating health beliefs and the impact of immigration.

### Language

Communication is essential in understanding a chronic illness and its management (Tang, 1999). The health care system in BC has been structured to meet the needs of those who are able to converse in English (Anderson, 1991). Although in recent decades there have been investments in resources for those in the larger minority groups including Punjabi and Chinese (BCMOH, 2008) and an increase in the availability of interpreter services, these resources remain underutilized partially due to clinicians lack of understanding of the complexities of language issues (Koehn, 2009; Tang). Most individuals continue to rely on family members frequently to interpret if they are unable to speak English.

Immigrants are less likely than their native born counterparts to access preventative care and treatment (Beisner, 2005). When access to culturally and linguistically appropriate care is inadequate, the decision to seek care can be delayed, often with individuals waiting until their symptoms are significant (Fung & Wong, 2007). When they do seek care communication barriers mean that basic information about their condition and its management may not be conveyed making it difficult for individuals to follow recommendations (Koehn, 2009; Tang, 1999). Along with this, individuals are unable to communicate their own concerns and how the illness is impacting their daily lives leading to information and advice which is not meaningful to them (Anderson, 1998; Wu et al, 2005).

Relying on family members to interpret has many ramifications. Information may not be conveyed accurately due to a lack of understanding of the medical terms, a reluctance to discuss personal information and trying to avoid causing worry (Grewal et al, 2005; Tang, 1999). Other issues include the need for family members to take time away from work and other responsibilities to interpret and the need for them to negotiate contacts with the health care system and provide transportation (Anderson, 1991). Along with increasing burden in the family, individuals may feel their competence is undermined as illness management is defaulted to family members (Anderson, 1998; Grewal et al; Tang).

Clearly, challenges with language influence direct care but also access to other sources of information and resources, how employment is structured, access to public transportation and roles within the family (Anderson, 1998). Along with these issues which impact the daily management of a chronic illness, language challenges also limit access to the societal discourses on self-care and how this influences health care interactions (Anderson, 1991).

## Impact of immigration

The experience of immigration affects daily life and opportunities and necessitates individuals to redefine themselves and roles of family members. Often, HCP don't take into account the stressful impact of migration and how it affects health and illness management (Lee et al, 2001). Immigration increases poverty and unemployment, social exclusion, discrimination and health inequities (Beisner, 2005). The transition from a familiar culture to a new country is emotionally and physically challenging in many ways (Ahmed & Lumkau, 2000). The stresses of lower income and language barriers are compounded by tensions between traditional and Western values contributing to intergenerational conflicts (Lee et al, 2001). While family relationships can be both a source of support and stress (Grewal et al, 2005), the struggle to succeed in a new country affects the entire family with age and gender impacting the experience in various ways (Beisner).

Older immigrants may find the transition more difficult when they leave employment or a more affluent lifestyle behind (Ahmed & Lemkau, 2000). Many come to Canada under the family class sponsored by their children which has lead to diminished self esteem and confidence for some when they are no longer self-reliant (Lee et al, 2001). The status of the older generation becomes reversed as parents become dependent on their children both financially and socially (Koehn, 2009). Often, parents who may have had servants in their home country, now become responsible for caring for the home and children (Grewal et al, 2005). Language barriers contribute to social isolation for many elderly and they must rely on their children to translate information, provide transportation and to act as cultural brokers (Chung, 2001). For men, their sense of masculinity may be measured by their qualifications, education, expertise, career, community standing and role within the family (Oliffe et al, 2007). These are impacted by immigration as skills and credentials may not be recognized, leading to underemployment and

unemployment. Many feel demoralized by this downward class mobility and link this to stresses within their family relationships and health (Lee et al, 2001). Marital relationships are impacted and roles within the family shift as men may not be able to solely support the family and their wives must now also work to meet their needs (Hjelm et al, 2005).

For women, adjusting to immigration may be associated with even more stress. Older women are more likely to be illiterate, unemployed, widowed and dependent on others (Fikree & Pasha, 2004). Younger women face the burden of working outside home along with maintaining the household, child care responsibilities and caring for elders (Ahmed and Lumkau, 2000; Anderson 1998; Bauer et al, 1992; Tang & Dion, 1999). For those with chronic illness, survival in the workforce and balancing family life with illness management are key priorities (Anderson). Many immigrant women face underemployment with little flexibility in their work life yet still need to make adjustments for family care (Anderson). In their study, Grewal et al (2005) found that family responsibilities often meant that women delayed seeking medical attention until their symptoms were significant and those with chronic illnesses worked beyond what was reasonable.

### Negotiating health beliefs

For those with a chronic illness it is important their viewpoints and beliefs are valued helping to foster self confidence in their ability to manage their health (Anderson, 1991). The management of chronic illness is influenced by many layers of cultural and spiritual meaning (Anderson, 1998). Health beliefs and culture must be explored with an understanding of the complex interaction of these aspects including gender and positioning within society, shared histories, material contexts and access to health care and health promotion (Browne et al, 2009; McAllister & Farkham, 1992). Individuals' experiences will vary depending on the unique

experiences of their own lives (Anderson, 1991). ‘Attendance to cultural nuances is not in opposition to an antiracist agenda; we all come to interactions with cultural and symbolic meanings that organize the ways we experience our worlds’ (Anderson, 1998, p 205).

Research with EMs highlights tensions between traditional views of health and the Western medical system (Anderson, 1998; Hilton et al, 2001; Hwu et al, 2001; Oliffe et al, 2007). These tensions arise when beliefs are poorly understood or incongruent with how HCP think illness should be managed, not because they are in conflict with treatment (Anderson, 1991). Effective care in chronic illness will need to encompass both traditional and Western approaches (Hwu et al), building on commonalities, not highlighting differences. Future research needs to focus on these commonalities (Beisner, 2005). Understanding cultural attributes and meanings of health and illness must be balanced against the risk of promoting a racialized view where health beliefs become a tool of marginalization (Browne et al, 2009). Instead, exploring cultural variations is an opportunity to reflect on the complexities in all interactions (Oliffe et al, 2007) and to understand how views of culture can both obscure and reveal connections in the various contexts of health care (Coward & Ratanakul, 1999).

In the following section, I explore traditional health beliefs of both Chinese and South Asian culture and shared histories of these populations in general including issues related to ‘culture’ and the experience of immigration. The goal in this exploration is to prompt critical reflection on the complexity of the intersection of the many factors involved in the chronic illness experience for EMs including the culture of health care.

### Traditional health beliefs of chinese

Many Chinese people try to integrate the physical, psychosocial and spiritual health behaviors to restore the balance of *Ying* and *Yang* and increase *qi*. ‘*Ying* and *Yang* are the forces

for living phenomena, *qi* is the vital energy and source of life: excess and deficiency will result in illness' (Hwu et al, 2001, p 631). In their research on dietary and health beliefs of Chinese people, Kwok, Wong & Blum (2009) note that traditional health beliefs (THB) include: eating 3 meals a day, dietary adjustments with illness (including food, herbs and nutrients), seasonal changes to maintain bodily harmony and the balance of 'yin' (cold) and 'yang' (hot) foods to maintain good health. They also note that beliefs include a high correlation between diet and disease and that many rely on diet to treat minor illness before seeking HCP or to compliment medical treatment. In their research on health care seeking behaviors of Chinese immigrants with chronic fatigue and weakness, Lee et al (2001), note that 84% of respondents sought help from practitioners of traditional Chinese medicine. Anderson also noted that many Chinese participants acknowledge using herbal remedies yet are receptive to Western medical advice if they understand the advice and think it will help (1991). Unfortunately, the role of the dietitian in the Western medical system is poorly understood and consequently, few individuals seek their advice (Kwok, Wong & Blum).

Within Chinese THB, there is less concern with pathologic changes and more preoccupation with the restoration of balance. Spiritual health behaviors involve engaging in religion or acting according to a high order to achieve inner peace and strength. Exercise, rest and avoiding known health risks is also very important for life balance and self management includes following dietary, medication and exercise regimens prescribed by HCP (Hwu et al, 2001). Factors with a negative influence on health include worries, depression and stress (McAllister & Farquar, 1992).

As with the general population, individuals engage advice based on their responses to treatment . . . dimensions of daily functioning are more important than physiologic abnormalities

(Hwu et al, 2001). As part of balance in life, social events with family, friends and food are important (Kwok, Wong & Blum, 2009; McAllister & Farquar, 1992). In Chinese culture people expect to make decisions for themselves to achieve overall balance therefore, non-compliance, as a Western phenomenon, is not meaningful (Hwu et al). Decisions concerning care are not made on an individual basis, but rather family based decision making is the cultural norm (Koehn, 2006).

### Traditional health beliefs of south asians

Within the South Asian population balance is also important with health viewed as the totality of well-being, physical and mental happiness (Hilton et al, 2001). Traditional health practices, or '*desi-ways*' include a wide range of home remedies, dietary practices, non-Western medicines and therapies provided by healers and supported through rituals and spiritual practices (Hilton et al; Ismail et al, 2005). Most of these therapies seek to restore balance and harmony in life through diet, herbal remedies and lifestyle modifications and may also include physical therapy, acupuncture, chiropractics, massage, purification practices, hydrotherapy, counseling and prayers. Most individuals access a combination of both traditional and Western medicine (Hilton et al; Ismail et al; Oliffe et al, 2007). Many access Western medicine for acute and complex problems and traditional sources as a form of prevention and health promotion (Hilton et al, 2001; Ismail et al, 2005). Not only are '*desi ways*' a means of promoting health but also an integral part of daily life and a way to maintain and preserve cultural heritage and identity (Hilton et al). The use of these practices vary greatly between individuals depending on their family and social networks (Grewal et al; Hilton et al; Ismail et al).

Within the South Asian population spirituality, health, food practices and community are firmly intertwined. Foods are viewed as fuel for the body but also an integral aspect of faith and

community involvement (Lawton et al, 2008; Oliffe et al, 2007). For some, Sikh temples provide a setting for worship in which food is consumed based on sacred rituals and practices (Oliffe et al). Some feel they risk alienating themselves from their culture and community if they do not participate in these rituals (Lawton et al). Spirituality and health guide participation within the community (Lawton et al, Oliffe et al). Through providing community service (*sewa*) individuals may be rewarded with good karma in their next life and also influence the amount of suffering in death (Oliffe et al). Destiny (*kismet*) is strongly linked to God therefore illness is outside of direct control (Ismail et al, 2005; Oliffe et al). Some literature highlights HCP belief that this sense of fatalism negatively impacts compliance (Davison, 1992; Sohal, 2008) and has underlying connotations of ignorance, irrationality, primitivism and passiveness (Ismail et al). In a study of South Asians with epilepsy, Ismail et al note that a belief in the power of a supreme being did not prevent people from taking steps to alleviate symptoms or seek a cure (2005).

### Issues associated with culture

Acknowledging the risk of promoting a 'Culturalist' view, I have explored issues commonly associated with culture. Although the experiences and how they are perceived will vary greatly between individuals, cultural values and the tensions between traditional Chinese and South Asian values and Western values shape the experiences of both men and women who have immigrated to Canada (Bauer et al, 1992; Grewal et al, 2005; Koehn, 2008). As with many countries in Asia, both Chinese and South Asian cultures share a basis in patriarchy where power resides within the men of the family (Meagher, 2011). Within patriarchal societies the emphasis is on gendered roles, hierarchical family relationships, collectivism and filial piety (Kandivoti, 1988; Koehn, 2008).



Historically, within both cultures, gendered roles have subordinated women (Ahmed & Lumkau, 2000; Bauer et al, 1992; Fikree & Pasha, 2004). Women carry the responsibility for maintaining the physical environment of the home including responsibility for meal preparation and child rearing, tending to sick, maintaining family harmony and preserving family traditions (Ahmed & Lumkau; Grewal et al; Tang & Dion). Men are more likely to be educated and carry the responsibility for maintaining economic stability (Ahmed & Lumkau; Kandivoti, 1988). In their research exploring women's health and family relationships, Grewal et al, note that for South Asian women, their identities, actions, conduct, emotional and physical well-being are strongly influenced by their family relationships (2005). For men, their sense of masculinity is impacted by their qualifications, education, career and community standing (Oliffe et al, 2007).

Families are also structured through hierarchical relationships where older members have more authority and status over younger family members (Kandivoti, 1988). Decisions are viewed collectively on what is best for the family unit (Koehn, 2006) although men are often the principal decision makers (Grewal et al, 2005). One impact of immigration is that some older men feel they have less status within the family due to subtle shifts in roles (Oliffe et al, 2009). Food preparation offers a glimpse into the complexities of gendered roles and hierarchical relationships and the impact on following health care advice. Astin (2008), in a study of cardiac patients in UK, explores issues of diet. Within the South Asian community, it is usually the role of the wife or daughter in law to prepare food for the entire family. To adjust to recommendations, if the patient was male, the amount of salt and fat would be reduced for the entire family if the male was willing to compromise on taste. If the patient was female, this was less likely and often resulted in women preparing a separate main course for themselves as they did not consider it appropriate for whole family to consume dishes perceived as less enjoyable.

‘Saving face’ in the Chinese community, or preserving family ‘*izzat*’ (honour and respect) in the South Asian community is also very important, shaping relationships between the family and community (Ahmed & Lumkau, 2000; Grewal et al; Koehn, 2008; Tang & Dion). As well, within both cultures respecting and caring for aging family members and the responsibility to extended families is a core value which has implications in illness management and also the impact of immigration (Chui, Tran & Flanders, 2005; Koehn, 2006).

### Culture of health care

As mentioned previously, the Western health care system is based on the biomedical model where the focus is on physiologic abnormalities and strategies are targeted at individual behavior changes. In other cultures, where health is the result of balance in life, the tendency to reduce health to biomedical labels has little meaning and concept of compliance makes little sense (Hwu et al, 2001; Oliffe et al, 2007). The concept of compliance, however, is embedded within the Western health care system where the emphasis is on self care and the expectation of practitioners is that patients will follow advice (Anderson 1991). When advice is not followed, individuals are potentially viewed as ‘non-compliant’ creating tension in health care relationships and preventing effective partnerships (Tang, 1999).

The hidden assumption of self care is that individuals have equal access to resources yet fails to consider the complex sociopolitical, cultural and economic context in which decisions are made (Anderson et al, 1991). Along with challenges in accessing resources, failing to follow advice is also challenged by recommendations which are not practical within an individual’s family context (Anderson, 1998). Not only are the impact of gender hierarchies poorly understood, but also tensions between the individualistic focus of the Western health care system and collectivist foundation of both the Chinese and South Asian cultures. Along with this, the

impact of migration and how this structures daily life and health is also poorly understood (Lee et al, 2001; Wu et al, 2005).

### *Summary*

As the incidence of chronic illness continues to rise, there is growing recognition of the need to shift from a health care system structured to meet the demands of acute illness to a system oriented to manage chronic illness more effectively. In BC, the Ministry of Health has acknowledged the role of PHC in chronic illness management and invested significant resources through the PHC Charter to help support this role. Along with screening and identifying individuals at risk of developing chronic illnesses, the role of PHC providers is to promote health through ongoing assessment, prevention and management of symptoms and to engage patients as partners in care.

PHC is the setting in which most of the care of chronic illness is organized. In order to provide effective care for EMs as they try to integrate a chronic illness into their daily lives, PHC providers need to gain a broader understanding of their experiences and priorities when seeking care. Along with this understanding, PHC providers need also reflect upon the culture of health care and how this shapes interactions including how the concept of compliance, or how closely individuals follow medical advice, continues to shape the medical system. The ability to follow advice is shaped by access to resources, profoundly shaped by language. When an individual does not converse in English, they often do not have access to the information they require. Limited skills in English also shape employment opportunities for many EM, impacting their income and again, access to resources to manage their care. While there have been investments in printed materials and interpreter services, family members continue to be used as interpreters.

Implications for this may include filtering of information, misunderstanding key information and subtle shifts in family dynamics.

The process of immigration itself creates challenges in managing a chronic illness, a key factor which is often not recognized by HCP. Stresses of unemployment or underemployment impact both men and women. Chronic illnesses generally demand both financial resources and commitments of time by both the patient and family. Older immigrants, sponsored by their families, are often dependent on their children, both financially and socially and often carry the burden of caring for the home and children. These challenges with immigration affect each family member in different ways, creating shifts in traditional roles and power relations leading to intergenerational tensions.

Many Asian cultures share a basis in patriarchy where gender roles are clearly defined. Generally, women carry responsibility for the family and home and men provide financial stability. Decisions are often made collectively, with regard to the impact on the family as a whole, not on an individual basis as with Western society (Tang & Dion, 1999). PHC providers need to understand the complexities in decision making when managing a chronic illness and how these may be shaped by culture. The study discussed earlier of cardiac rehabilitation programs noted that with South Asian patients, following dietary recommendations varied depending on gendered roles within the family. Critical reflection points to the limitations of approaching education and self management support from the Western medical standpoint of individual behavior changes without exploring the complexities of decision making.

Health beliefs also provide an opportunity for reflection. On the surface, when exploring beliefs such as ‘yin’ and ‘yang’, or ‘desi ways’, these beliefs seem very foreign to Western health beliefs which promote disease or organ specific care. However, when you explore both of these

belief systems within the context of chronic illness, where the focus is encompassing and adapting their condition into daily life over many years, these beliefs seem less exotic. Both these approaches advocate balance in life through being active physically, avoiding excesses in diet and being spiritually aware. Unfortunately, instead of exploring the potential benefits of these 'beliefs', most discussions involve how these beliefs are in contrast to Western health care.

The use of traditional health practices is often not revealed to HCP during health care interactions related to the inherent values attached to them (Hilton et al, 2001). Many EMs are reluctant to disclose the use of traditional health practices for fear of a lack of understanding and even ridicule from HCP (Hilton et al; Ismail et al, 2005). What follows are lost opportunities for important dialogue. 'Continuing to ignore or discourage the use of these practices cuts off the possibility of meaningful health care interactions' (Hilton et al, 2001, p 565). Individuals want to be offered choices to include traditional practices along with Western medicine (Hilton et al; Oliffe et al, 2007). Traditional medicine, as an adjunct to Western medicine, offers hope and may benefit psychological coping; embracing traditional medicine does not reduce adherence to medical advice (Ismail et al).

The goal in PHC interactions in chronic illness is to support individuals to adopt healthier lifestyles and approaches to minimize symptoms; to maximize their ability to function in daily life and achieve the highest level of well being (Hwu et al, 2001). The role of PHC providers is to support individuals as they attempt to integrate these changes within their own life context over many years, through periods of success and struggle (Thorne & Paterson, 2001). In providing effective care for anyone with a chronic illness, PHC providers need to explore an individual's previous experiences, beliefs and values and also need to understand how the culture

of health care influences their interactions, specifically the impact of CDM and approaches to self management.

Within this study I have focused on the aspect of self management support in chronic disease management paying attention to the influence of ethnicity in PHC interactions. In order to understand the complexities of this intersection, I employed a critical cultural perspective to explore the role that ethnicity plays in these interactions. Within this research I have focused on the experiences of EMs with chronic illness in PHC interactions as they access care. Through a critical cultural perspective I have explored how being an EM, including aspects of language and experiences of immigration, impacts access to care and self management. I have also explored how characteristics of a PHC provider also influence long term management of health.

# Chapter III: Method

## *Theoretical framework: critical cultural perspective*

In this research, through a critical cultural perspective, I have explored the intersection of chronic illness, ethnicity and PHC in BC to gain a deeper understanding of the priorities and experiences of EMs in their interactions in PHC in order to promote effective, culturally safe care. Within PHC interactions, where relationships throughout the trajectory of illness are paramount, how culture is viewed has a profound impact on care and how it is received. The underlying theoretical framework I have used in this research is a critical cultural perspective which challenges common approaches to culture in health care.

## Common approaches to culture

Over recent decades, most approaches to cultural care can be categorized under a cultural competence approach in which the goal is to improve the skill of care providers in communicating with and understanding those from different cultural backgrounds from the dominant majority. Gustafson identifies how culture is defined within these approaches as ‘a discrete set of learned attitudes, beliefs, biases, values and practices held by an individual or group and passed along from one generation to the next’ (2008, p. 48). While these approaches have many names including: transcultural care, culturally appropriate care, culturally responsive care, cultural effectiveness and cultural tolerance (Gustafson, 2008), a common term used in Canadian health care is cultural sensitivity. As the population has become more diverse, a lack of cultural sensitivity has been identified as a key factor in health inequities by PHC providers (Betancourt et al, 2005; Geiger, 2001; Selig et al, 2006)

At its most basic, within a cultural sensitivity theoretical perspective, culture is seen as a static entity in which health care providers seek to understand the beliefs and practices held by groups of people, the 'ethnic other' (Anderson et al, 2007). Overgeneralizations, using 'culture' and socially constructed views of race, are used to create distinctions between 'us' and 'them' (Koehn, 2009). Difficulties in accessing care or following health care advice is then believed to be due to cultural differences therefore, if HCP understand more about the cultures of different ethnic groups, they are better able to provide culturally sensitive health care (Anderson et al). Cultural sensitivity aims to improve cultural interactions so the health care provider is better able to help the patient with their daily health (Gustafson, 2005). This approach shares a basis in liberalism where individual rights and responsibility for health and well-being are valued and promoted without attending to the intersection of gender, class, race, age and social relations and how this influences access to resources and power imbalances (Gustafson).

Cultural sensitivity, with an overly simplistic view of culture, has the potential to promote care which diminishes, demeans and disempowers the cultural identity and well-being of an individual (Farmer, 2006). In order to promote effective interactions in PHC, we need to shift beyond simply viewing culture as a means of understanding the 'other' but also to include understanding how dominant organizational, institutional and structural contexts shape health, social relations and practice (Doane & Varcoe, 2005).

### Critical cultural perspective

A critical cultural perspective challenges the assumption that culture can be a fixed set of beliefs and practices separate from a social, historical or political context (Gustafson, 2005). Culture is viewed as a dynamic and shifting relational process (Allen, 1999; Doane & Varcoe,



2005). Cultural identity is shaped by relations within the micro level (interpersonal engagement) and macro level (policy and practices) (Gustafson).

Gustafson identifies two distinctive characteristics of a critical cultural perspective. The first is examining how diversity, social categories and human differences are conceptualized. This goes beyond the view of culture as a shared set of beliefs or traits to acknowledging the complex intersection of race, religion, gender and sexuality within a dynamic social and political context. This view explores how individual and group identities evolve over time in response to influences from within the group and influences outside the group. This exploration includes understanding how social relations are influenced by power imbalances and structural constraints (Gustafson, 2005). An example of how this may be viewed within chronic illness care would be shifting from a biological or dietary causation for disease based on racial categories to a broader understanding of the challenges inherent in immigration and how this may impact chronic stress and influence health.

The second characteristic is viewing 'change' as an overt political act. Within this view, the focus is not on supporting individual behavior change but rather on exploring connections between social practices, identities, representations and identifications. The focus of change becomes the organizational and political structures which shape everyday experiences instead of the individual behavior. An example in chronic illness management may be highlighting inadequacies in the use of interpreter services and how this may impact access to resources.

Cultural Safety is compatible with a critical cultural perspective as it: focuses on dimensions of power, inequitable social relationships in health care and problems of culturalism (Browne et al, 2009). Cultural safety is a way of bringing critical inquiry into the dimensions of power and considers that the patient and HCP interact in relation to each other as individuals,

each bring to the exchange their own unique history and experience (Anderson et al, 2003).

Culturally safe nursing practice involves actions which recognize, respect and nurture the unique cultural identity of an individual (Anderson et al). Providing care which is culturally safe does not mean you must ignore the cultural meanings of health and illness but must also attend to the structural, political, historical and gendered issues (Browne & Varcoe, 2006).

A critical cultural perspective shifts the gaze from the other and their culture to the self. It is a relational process, acknowledging the historical, social, economic and political relationships of all individuals involved (Browne & Varcoe, 2006). For HCPs, this critical self reflection should explore both the micro level in terms of the interaction and the macro level in terms of policy and practices and how cultural norms are being reinforced (Gustafson, 2008).

#### How this lens will add to the study and findings

Within this study, a critical cultural perspective provides a framework for understanding the complexities inherent in issues commonly associated with culture and how these influence chronic illness management within PHC. This perspective helps to understand how issues of language and health beliefs influence PHC interactions. Through this lens, I have also explored issues related to the organization of the health care system in terms of continuity of care and how this impacts illness management.

#### *Methodology*

In my research, through a critical cultural perspective, I have explored the intersection of chronic disease, ethnicity and PHC within the health care system in British Columbia to gain a deeper understanding of the priorities and experiences of the ethnic minorities in BC in their PHC interactions to promote effective, culturally safe care.

## Research design

I have conducted a secondary analysis on a qualitative research study completed by Dr. Sabrina Wong to understand ‘South Asian and Asian’s perspectives and preferences of primary health care’. In this research, PHC was identified as, ‘the first point of contact with the healthcare system and as the setting where short-term, acute health issues are resolved and the majority of chronic health conditions are managed’ (Wong, 2008, p 93). This was the initial phase of a larger proposal to develop and administer a PHC instrument and evaluate its psychometric equivalence across English, Chinese, and Punjabi languages (Wong, 2006). Through an interpretive description approach, I have explored this existing qualitative database to develop themes that emerged but weren’t fully analyzed in the original study (Thorne, 1998). Specifically, within the context of chronic disease management, I have delved into how South Asian and Chinese people describe their priorities in accessing PHC and their experiences in managing their chronic illnesses.

## Research question

Within the context of having a chronic illness, how do ethnic minorities describe their experiences in the ongoing management of their health and their expectations for care in the primary health care setting?

## Original study

Dr Wong’s research involved a convenience sample of 78 Cantonese- and Mandarin-speaking Chinese and Punjabi-speaking South Asians individuals between the ages of 19-75 who had immigrated to Canada within the past 20 years. Subjects were recruited through community-based organizations (immigrant services, religious groups) and primary care practices.

Recruitment materials were presented in Chinese, Punjabi and English. Subjects self-selected through agreeing to participate.

Twelve focus groups were conducted in participants' language of choice (Cantonese/Mandarin or Punjabi) by a bilingual and bicultural facilitator. Focus groups were organized in two age groups (<50 years, ≥50 years) and also according to gender. Open-ended questions were used to guide the focus group discussion. Each focus group detailed key aspects of PHC as identified in a previous research study of English-speaking participants (Wong, 2008). These aspects included: priorities, continuity, interpersonal communication and unmet health needs. Primary Health Care was defined as the first point of contact with the healthcare system and as the setting where short-term, acute health issues are resolved and the majority of chronic health conditions are managed. Data were transcribed and translated into English by one of the facilitators. Two of the twelve transcripts were checked against the taped focus group by another assistant for accuracy.

### *Ethics*

Ethics approval for the original study including secondary analysis was obtained through the University of British Columbia's Behavioral Ethics Review Board.

### *Sample and data collection*

The sample in this secondary analysis included the transcriptions and field notes of the 12 focus groups in the original data set with a total number of 78 participants. Six of the focus groups were with Punjabi-speaking adults and 6 with Chinese-speaking (Cantonese and Mandarin). The age of participants ranged between the ages of 19 and 75 years (Table 1). The average time since immigration to Canada was 11.5 years. The average education level for Punjabi-speaking individuals was grade 12 whereas for Chinese speaking, the average education

level was post secondary. Of the total participants, 44 individuals indicated that they had at least one chronic illness. The Punjabi-speaking participants in these groups appeared to have a larger burden of chronic illness with 73% reporting at least one chronic illness and 40% reporting multiple illnesses. Punjabi-speaking participants with a chronic illness rated their health between good and poor. The Chinese-speaking participants reported fewer chronic illnesses with 41% reporting one illness and 7% reporting more than one condition. Chinese-speaking participants with a chronic illness rated their health between very good and good. Across all focus groups, the most common illnesses reported were hypertension at 41%, arthritis at 30%, diabetes at 20% and depression at 18%.

First I reviewed the entire transcripts from all the focus groups. I then reviewed a subset of the data, specifically the responses of the participants who identified as having at least one chronic condition. Through a critical cultural perspective, I reviewed the responses in relation to managing a chronic illness. I have analyzed these responses through interpretive description, to identify themes that emerged in the existing database but that weren't fully analyzed in the original study (Thorne, 2004), specifically considering the context of managing a chronic illness within the current arena of health care in BC.

### Analysis of dataset

Prior to conducting secondary analysis on qualitative data there were many considerations to ensure the appropriateness of the use of this data to answer the secondary research question and ensure the rigor of the original data. The first concern was to ensure that the data fit the secondary research question yet also yielded new information and was credible (Thorne, 1998).

### Appropriateness of data

The first two main methodological issues to address were whether the data generated by the original study were amenable to the secondary analysis and whether the research purpose of the secondary analysis differed enough from the primary study yet doesn't invalidate the effort and findings (Thorne, 1998). First I examined the focus group interview questions and whether they were consistent with my research question. Although the primary research purpose was similar, it was within the context of managing a chronic illness in the current health care system that I wished to explore in greater depth. As the study question was closely related to the phenomena I found exploring this question was likely to yield data of appropriate depth and pertinent detail (Hinds, 1997). After ascertaining the fit of the data, I then conducted a feasibility assessment through reviewing three randomly selected focus groups to ensure the study purpose could be achieved.

### Credibility of data

In order to ensure credibility I examined the professional integrity, intellectual rigor and methodological competence (Polit & Beck, 2008) demonstrated in the original qualitative research. The investigator has firmly established credibility in the areas of EMs and PHC through her previous and ongoing research projects and publications at the local, national and international level. In terms of intellectual rigor, the investigator structured the research questions based on her findings in a previous study, 'What Do People Think Is Important about Primary Healthcare?' (Wong, 2008) and based on input from the research team. Moreover, expert researchers who had previously conducted focus groups regarding PHC in Canada were consulted throughout the process.

To guide the development of the coding scheme, the Results Based PHC Logic Model, developed by the Treasury Board of Canada was used. Goals of this model were to provide a

common language among stakeholders, define areas where information and evidence are important and evaluate outcomes of PHC in the areas of: the appropriate provider and place, healthcare system efficiency, acceptability or satisfaction and healthcare system equity. Questions guiding the focus group were consistent with this model. This was an appropriate framework demonstrating methodological competence in the primary study with a goal to develop a tool to evaluate PHC.

### Assessing the quality of the data set

Another priority was to assess the completeness and quality of the data set (Hinds, 1997). I ensured that the transcripts appeared accurate and understandable. The relationship between the participants' responses and researchers' prompts appeared to be congruent. I also determined that the specific questions I analyzed were uniformly addressed throughout the primary study (Hinds). Along with conducting a feasibility study to examine the fit of my research question, I also examined three randomly selected focus groups to determine the quality and completeness of the data set.

### Analysis

Once I extracted the data and determined its credibility and fit with my research question, I analyzed the data to sort and classify the data and identify themes (Thorne et al, 2004). The first step in understanding the data was to thoroughly immerse myself in the data prior to creating linkages followed by strategic periods in the field throughout the ongoing analysis (Thorne et al, 1997). Through reading through the transcripts, then spending time in the field, the emphasis was more on intellectual inquiry than simply sorting and classifying data. Questions to guide this inquiry to explore a broad range of possibilities prior to drawing

conclusions included: Why is this happening? What does this mean? (Hunt, 2009; Thorne et al, 2004).

### Credibility in qualitative research

To maintain credibility and validity, I adhered to the same standards of intellectual rigor, professional integrity and methodological competence as in the original study. Throughout the process of data analysis, I maintained documentation of the process of analysis through: identifying the category scheme and approach to data analysis, demonstrating accuracy of interpretations and clearly describing the findings (Polit & Beck, 2008). I've enhanced credibility through checking with experts in the field to ensure claims were plausible and confirmatory at the same time describing new relationships and understandings (Thorne et al, 2004).

### Reflexivity

Throughout this process I also reflected critically on myself and my practice to analyze and note personal values which could affect the data collection and the interpretation of this data (Polit & Beck, 2008). Within this context I explored my experiences working in chronic disease management with a significant proportion of patients from Chinese and South Asian backgrounds (20-25%). I've ensured throughout that I am not placing my own preconceived notions of what the issues may be, but was interpreting the data itself. I also reflected on my own position within society as part of the dominant majority and educated in a 'white-based' education system and how this impacts my interpretations (Allen, 2006). Being reflexive also required that I recognize my position as a nurse and the priority I may be inclined to place on issues which may be addressed by the field of nursing.



## Limitations

One limitation that I faced in this secondary analysis was that I couldn't obtain the kind of elaboration and clarification that I may have had access to in a primary study. While there were many responses which shed light on nuances of the experiences in relation to the research question, there were also other areas which would have been interesting to explore further. Social dynamics of the focus groups also has the potential to shape responses and, at times, when discussing traditional health beliefs, this did appear to be a factor in the character of some responses. As well, with focus groups, interactions with others may trigger other memories and expand the discussion yet the discussion may also lack the depth that individual interviews are able to explore (Marshall et al, 2010). As well, any biases in the primary research may be enhanced through secondary analysis of the same data set. While the use of 2 distinct ethnic groups may support the advancement of themes applicable to both groups (Marshall et al), how well these are generalized to other EMs may be open to debate.

## Strengths

One strength of this research design is in the efficiency of using this data set to explore deeper meanings of a similar phenomenon. The data are relatively current; the original study began in 2006 and is now complete. Another strength was using a structured approach to secondary analysis based on critiques from experts in the field.

## *Analytic framework: interpretive description*

### Interpretive description

Interpretive Description (ID) as a form of qualitative research is an inductive analytic approach developed to guide inquiries of the health and illness experience where the ultimate goal is the generation of knowledge meaningful within applied health disciplines (Hunt, 2009).

Interpretive description evolved in response to the limitations when applying traditional qualitative approaches to research in the applied health fields and need for more freedom to examine methodological questions within the context of this research (Thorne et al, 1997). Interpretive description shares foundations in naturalistic inquiry with philosophical underpinnings including that: wholly objective knowledge is unattainable through empirical analysis, that the researcher and object of interest influence each other and that prior theoretical knowledge cannot adequately account for the phenomenon being explored (Thorne et al, 2004; Hunt 2009).

While acknowledging the role of conventional science, ID advocates a systematic approach to ‘develop knowledge about human health and illness experience phenomena without sacrificing the theoretical or methodological integrity that traditional qualitative approaches provide’ (Thorne et al, 1997, p 169). Integral to ID is the understanding that trustworthy research reports display coherent logic within the analytic frame and a traceable audit trail for the inductive reasoning process (Thorne et al).

Interpretive description requires an informed understanding of the phenomena and encourages critical reflection on how this body of knowledge has evolved within methodological guidelines consistent with a purpose of informing clinical reasoning and extending the available insight for practice decisions. At its core it is an investigation of phenomena to capture themes and patterns within subjective perceptions and generating interpretive description capable of informing clinical understanding.

Interpretive description acknowledges the theoretical and practical knowledge that researchers bring to a project and how this provides a platform on which to design a study. This framework is then challenged and honed throughout the research illuminating how assumptions

and preconception may influence the process (Hunt, 2009). While individual biases can also influence a project, so too can the biases or perspectives of professional standpoint (Thorne, 1997). This approach accepts that it is not feasible for the researcher to truly 'bracket' themselves from the research but instead must seek to understand how their position influences the study and work to minimize this effect. The use of multiple sources of information is also encouraged to enhance credibility and provide a broader basis of understanding (Thorne).

### How interpretive description fits the research question

Interpretive description is ideally suited to exploring the chronic illness experience. This approach recognizes the inherent complexity in the interactions between biological and psychosocial phenomena, integral to exploring the experiences of chronic illness and how this is impacted by issues related to ethnicity. Within this approach, the expertise of the individual living the phenomena is recognized, yet at the same time provides a framework to distinguish 'eccentricities from commonalities' (Thorne et al, 2004). Effective care in managing chronic illness requires an effective collaborative effort by the patient and clinician over many years and occurs within context. This study aims to explore not only the individual experience, but also the impact of the primary health care provider in supporting chronic illness management.

There is a solid foundation of research within the chronic illness experience and ethnicity and growing body of literature in PHC. Through ID, this knowledge base is not ignored but instead is used as a starting point to understanding the intersection of chronic illness, ethnicity and PHC. As well, it acknowledges that my own clinical experience and professional orientation is not something which can be excised from my study, but its impact needs to be critically explored throughout. Ultimately, through this study, I highlight the issues that influence this

experience in ways which are accessible to PHC providers in the context of the current health care environment when organizing care for this population.

### Implications

Research findings from this study will describe what this population identifies as priorities in PHC and their experiences in the ongoing management of chronic conditions. A greater understanding of the inherent complexities within this phenomenon can then be used to enhance and direct care at the policy, institutional and individual level to ensure this population is not further marginalized when seeking care within the current health care environment.

## Chapter IV: Findings

As I explored the focus group data; specifically responses of participants with a chronic illness, three central areas emerged. First is the role of self in maintaining health and how participants felt they could influence their own health. Second, navigating the health care system with a chronic illness and speaking English as a second language presented many challenges in day to day management. Finally, how characteristics of their Primary Health Care Provider (PHCP) influenced chronic illness management. While the focus groups contained participants who did and did not have a chronic condition, all quotes presented here are from those who had one or more chronic conditions.

### *Role of self in maintaining health*

Consistent throughout all focus groups was the belief that seeking health care was for acute issues such as infections or injuries. For day-to-day issues or long term issues individuals first tried home remedies (both over the counter medications and traditional medicines or treatments). This appeared to emerge for two main reasons. Some indicated that maintaining health is the responsibility of the individual and others highlighted a necessity to cope with minor problems as PHCPs often were not accessible. Many described barriers in obtaining a family doctor, timely appointments and in ongoing communication with their regular provider.

### *Sense of self responsibility*

A sense of self responsibility came through clearly. Many indicated that it was their responsibility to keep themselves and their families healthy, especially for day-to-day recurrent issues such as coughing, stomach upset, headaches, blood pressure monitoring. Both the

**Table 1 Characteristics of focus group participants**

Table 1: Characteristics		Language		Age Group		Total
		Punjabi-speaking N=27	Chinese-speaking N=17	< 50 years N=13	≥ 50 years N=31	N=44
Gender	Male	8	12	5	15	20
Marital Status	Married/Living with a Partner	22	14	10	26	36
Education (%)	Less than grade 12	11	2	2	11	13
	Grade 12 or GED	2	5	0	7	7
	Some post secondary	4	2	4	2	6
	Diploma/Degree	10	8	7	11	18
Language	1=not at all; 2=not well; 3=well; 4=very well	2.55	2.38	3.25	2.17	2.5
Has a regular provider		26	17	13	30	33
PCHP speaks native language (%)		19	14	8	25	33
Uses Alternate care		11	7	7	11	18
Self-rated health (average) 1=excellent; 2=very good; 3=good; 4=fair; 5=poor		3.11	2.82	2.8	3.25	3.11
Total chronic illness		52	23	17	58	75
Hypertension		16	4	3	17	20
Arthritis		10	4	2	12	14
Diabetes		6	3	3	6	9
Depression		8	1	3	6	9
# Chronic illness/person (Average)		1.93	1.35	1.31	1.87	1.7

Chinese- and Punjabi-speaking participants came from societies without a publicly funded health care system where access to resources was dependent on their family resources. They indicated that seeing a PHCP for minor problems caused undue burden on the health care system. As one Cantonese-speaking woman in her 70's with diabetes noted, *'If there are tiny problems that you can solve yourself then of course you won't bother to see the doctor. Sometimes I feel dizzy, it maybe low blood sugar, I eat some candy and won't feel dizzy'* (Focus Group 1, participant 6).

Another gentleman with multiple chronic conditions noted, *'In my opinion, if we can solve the*

*problem ourselves, if the medication I've used worked for me before and now the same problem happens, then if I go to see the doctor because of this it will not only waste doctor's time it, also waste others time, and finally wastes your time. For myself, I will see 'myself'. I will check my blood pressure myself first...if high blood pressure, going to a family doctor once for check up is no use'* (Focus Group 3, participant 5).

#### Access to primary health care providers

Along with a sense of self responsibility difficulties in accessing an appropriate PHC provider also influenced the choice to first treat themselves before seeking health care.

Challenges were articulated first in securing a family doctor, then in obtaining timely appointments and finally in areas of communication. Several participants commented on the difficulties in obtaining a family doctor, that there were few doctors accepting new clients. This meant that instead of choosing a doctor based on their own preferences (e.g., language, gender) or health care needs the choice was made based on availability. A gentleman in his late 60's with hypertension described how their choices were limited, *'Even if they are good or bad, whatever their behaviors are, whether we like it or not, we are helpless to go there because we don't have any other alternative'* (Focus Group 6, participant 5).

Some felt it was more of a burden to seek care than to take care of themselves. Even if able to secure a suitable family doctor, many described waiting up to a week for an appointment and then further delays with a scheduled 10 minute appointment often taking up to 2 hours. One gentleman described his challenges, *'I will regularly check my blood pressure...for my family doctor you may need to wait 2 weeks to see him. Nowadays if you want to change to another not too busy family doctor, it is impossible'* (Focus Group 3, participant 5). Especially for older participants where they had many responsibilities within the family, taking care of themselves

was the sensible option. Another elderly man described how responsibilities at home made it difficult to spend time for waiting for an appointment, *'We seniors are very busy even though we don't work. We have to feed our grandchildren, pick them up from school... Chinese class, dancing class, swimming class...how can we sit at the clinic for a long time? I have many medicines at home that I brought from China so for minor problems I can treat myself. When I have big problems then I have to see my doctor'* (Focus Group 10, participant 6). The perceived waiting time to obtain an appointment and then time spent at the clinic before an appointment was a deterrent for some participants who opted instead to treat themselves first.

### Strategies to influence own health

Participants in the focus groups described how they used a variety of strategies to maintain their health and manage long term issues or when Western medicine was not effective. These strategies included paying attention to the impact of diet on health and using a variety of traditional approaches.

### Diet and health

Discussions in both Chinese- and Punjabi- speaking focus groups indicated a strong belief in the relationship between diet and health. Participants understood how their diet may impact their health including conditions like hypertension and diabetes and overall prevention of illness. A Mandarin-speaking woman with diabetes in her late 30's noted, *'We should learn to control our own health because health belongs to ourselves. Doctors can't always follow and take care of us for a long term. The most important is that we should understand more about nutrition and how to prevent sickness'* (Focus Group 7, participant 1). Another woman in her early 40's who was coping with multiple sclerosis advocated for better access to resources to manage her health, *'Half of the things can be fixed if we had some charts on good diet...I think*



*that the doctor should send your tests to the dieticians and once or twice a year they should definitely see all our tests and recommend a diet'* (Focus Group 4, participant 4). This woman also pointed out the need to have dietary advice within the context of her cultural background. Within this context, especially when attempting to integrate long term dietary adjustments, a dietitian who was aware of the foods available within a home and also of the potential complexities in following a specific dietary regime in terms of social and gender issues was more able to provide meaningful advice. *'Dieticians should be available in all different ethnic communities, like Chinese and Punjabi, so that they know what kind of food we eat at home and would not recommend foods which we have to go out especially to buy. We should be able to get essential nutrients from our own diet'*. This was especially important when making long term dietary adjustments necessary for chronic illness management as indicated by this woman in her late 50's, *'Nowadays there are many cases that require long term care, in Chinese culture, "food therapy" is very important'* (Focus Group 1, participant 4). Food therapy, could consist of eating hot or cold foods or a variety of teas or other herbal remedies, *'We are Chinese, if we have small problems, maybe we'll eat some hot foods'* (Focus Group 1, participant 3).

This woman also highlighted how issues of culture and gender influence dietary management, *'Being housewife as me, we have the responsibility because the one who shops for food is us, the one who cooks the meal is us...the responsibility of a housewife is very important to control the health issue of the whole family'* (Focus Group 1, participant 3). These quotes highlight the importance food plays within Chinese culture and that approaches to chronic illness management which involve dietary changes need to take into account other aspects which influence food choices and preparation.

## Traditional medicines

Many participants also discussed the role that traditional medicines such as acupuncture, herbal medicine, played in maintaining their health. This gentleman with hypertension and arthritis notes, *'Chinese medicine: herbal, acupuncture, I believe in them all...when Western medicine can't treat you, people tend to find alternative'* (Focus Group 3, participant 5). There was a common understanding throughout the focus groups that Western medicine is used for treating urgent situations or illness but that traditional approaches also have merit in secondary health promotion. One participant with arthritis described how he viewed approaches, *'Chinese medicine has its good side, it helps you to 'keep' your body healthy'* (Focus Group 3, participant 3). A younger gentleman in his late 20's suggested, *'I want something to 'improve health' like soup, so Chinese medicine has its own advantage, and Western medicine has its own advantage. Chinese medicine is more on 'improve health' instead of use something to kill the bacterial'* (Focus Group 5, participant 6). While tensions between traditional and Western approaches were evident in both language groups, the concerns seemed to have a different character for each group. Within the Chinese- speaking groups, the role of traditional approaches in conjunction with Western approaches appeared to be openly discussed, with tensions arising from not having access to PHCP who understood both approaches, *'Will some Chinese medicine have conflict with western medicines? We need to find a doctor to ask but don't know which doctor knows both Chinese medicine and Western medicine'* (Focus Group 1, participant 4). Comments from Punjabi- speaking individuals alluded to a general mistrust of traditional medicine by Western health care professionals, highlighted by this gentleman in his early 50's with hypertension, *'ayurvedic treatments are very good yet allopathic people do not agree with it'* (Focus Group 6, participant 3).

Within the Punjabi-speaking groups, a variety of teas or other kitchen-based remedies were often the first line of treatment for health issues ranging from a simple cough or headache to cholesterol and blood sugar management. These were openly discussed in most groups, however, when conversations about traditional approaches included seeing traditional doctors or other care providers the responses appeared more guarded. In one Punjabi-speaking group, all denied seeing any traditional doctors due to a ‘risk’ and indicated they would only do *‘those things about which we have knowledge, that don’t have any side effects...’* (Focus Group 11, participant 2) yet many described using home remedies and accessing health advice through the gudwara at the Sikh temple. A gentleman with hypertension in his early 50’s noted that, *‘In homeopathic and ayurvedic there is treatment for some diseases which are not available in allopathy’* (Focus Group 6, participant 3) another noted that, *‘they have recognized Chinese medicine somewhat, yet homeopathy which is so effective and cheap should be recognized by them...’* (Focus Group 6, participant 4).

Consistent with the literature, many of the Chinese-speaking participants discussed traditional health approaches and were also receptive to Western medicine. Along with accessing Western health care, many felt it important that traditional approaches were also accessible as one gentleman with hypertension asserts, *‘We hope that traditional Chinese medicine could be included in the primary health care because many health conditions could be nurtured by it’* (Focus Group 10, participant 6). Another gentleman noted, *‘Chinese medicine can compliment this...I accept Chinese medicine like Western doctor’* (Focus Group 5, participant 1).

### *Navigating the health care system with a chronic illness*

While many participants appreciated their role in maintaining their health, how they were able to do this was acutely impacted by gaps in their knowledge. Comments conveyed a lack of understanding of the Canadian health care system including the types of services available and how to access them. A Punjabi-speaking woman in her early 40's notes that, *'I don't know who can arrange help for us and till today my mother in law's family doctor has not even told us whether we are eligible for the home support or not'* (Focus Group 4, participant 4). Some expressed a desire to know more about both preventing and how to manage chronic illness. They understood the relationship between their diet, activity levels and their health and felt that if they had more information they could shape their own health but did not know where to access dietary counseling and other basic monitoring resources. This woman, who is also coping with hypertension also indicated, *'They should educate people, like there are groups of seniors, and 70% of them have diabetes, or arthritis or high blood pressure. The doctors should educate them about some simple precautions. If a senior has to just check his blood pressure where can he check it, what can they do about it?'* (Focus Group 4, participant 4).

### *Speaking English as a second language*

The complexities of managing a chronic illness are further intensified when English is the second language. For those with difficulties in speaking and understanding English, they either had to secure a PHC provider who could speak their language, rely on family members to interpret, or simply get by. For some having a PHC provider able to speak their native language meant sacrificing other aspects of care such as timeliness or length of appointments. For others, relying on family members added further burden to care. For those who coped independently there were other ramifications to the difficulties in communicating.

While some pointed to an increase in the amount of community programs available and translated information, others were not aware of these resources. One woman in her late 50's requested, *'I think if there are Chinese pamphlets/information, for example, some professional term like heart disease, or heart specialist or other specialists they want to let people know, they can translate and print them on paper, not only Chinese, but also other languages'* (Focus Group 1, participant 3).

### Securing a PHCP with their native language

Primary health care providers able to speak their native language were often in limited supply and high demand. This often meant that an individual may need to book the appointment far in advance, spend a longer time in the waiting room and that the appointment itself may be very short and rushed, leading to ineffective chronic illness care. This woman described her experiences in seeking care, *'our family doctor, she has a lot of patients who are Punjabi--a lot of patients to see in one day, so she just rushes a lot. Like if you tell her 2-3 things, she says that she will just listen to only one'* (Focus Group 4, participant 1).

### Relying on family members for interpretation

Those unable to secure a PHCP able to speak with them directly are forced to rely on their family members to interpret. This not only reinforces a sense of dependence but also increases the burden illness and care. One gentleman in his 70's who was trying to understand more about his heart disease indicated, *'I will ask my daughter to help, many medical terms I don't know but it is very inconvenient because my daughter needs to work, she needs to take leave and go to the hospital with me'* (Focus Group 3, participant 3). Communication is essential if an individual is to understand their condition and make adjustments to their lifestyle, yet many may not have access to this information. For this gentleman with both diabetes and heart disease

he felt it very important to understand *‘the complete history as to why you are having this, how to control it and how you should exercise and do other things... the doctor gives us a form, and we don’t know which tests are given on the form’* (Focus Group 6, participant 1).

### Ramifications with basic English skills

Even for those with basic language skills, challenges in coping with a chronic illness and negotiating care over time was ongoing challenge. This woman with in her late 50’s pointed to the difficulties with understanding terminology and describing her symptoms of arthritis, *‘...if English is not very good or even if English is good but some special terms we still can’t express’* (Focus Group 1, participant 3). Another woman further described, *‘it is hard when you are trying to say something but the doctor is not able to understand you. You don’t feel satisfied at all, if you go to a white doctor and say that my “heart is beating” how would he understand what we mean, or “something is happening to my heart”, some old ladies say like this only, and the white doctor can’t understand it at all’* (Focus Group 4, participant 1).

A gentleman with sleep apnea highlighted the complexities of managing his condition and challenges with follow up care. Even though he was able to communicate in basic English, his ability to follow through on the recommendations of his PHCP was compromised with challenges in understanding the written language. He described his experience, *‘they told me to buy a machine which can help improve my breath, but none of the Chinese participants purchased the machine. One reason is because it’s expensive, the other reason is because of the language barrier, you have to fill out many forms’*. Because of his difficulties his faith in the care he received was undermined even though he felt his family doctor was good. He indicated, *‘He recommended me to see the doctors in that clinic. But he never dare to ask how your visit was, never asked whether it was helpful or anything improved? They didn’t ask.’* (Focus Group

10, participant 6). Within this scenario, the PHCP arranged for a full assessment, but failed to understand and appreciate the impact of speaking (and writing) English as a second language and ensure this didn't affect care. The results are an individual who remained concerned and worried about his health, but didn't have the resources to manage it. Clearly, language barriers impact chronic illness management and need to be fully understood and assessed. Many described a desire that their PHC provider may be able to connect them with resources to manage their health and to navigate the health care system.

### *Characteristics of PHCP influencing chronic illness management*

For individuals and families coping with a chronic illness, the role of the PHC provider is pivotal in helping individuals make and sustain changes to their health. Through frequent repeated interactions, the goal is to support individuals and families as they gain confidence in managing their own health over time. Within this context of chronic illness, PHC providers include the family physician but may also include other health care practitioners as main contributors to care. Within the focus groups, although responses varied, clearly the characteristics of PHC providers and how they interacted had a strong impact on chronic illness management. Key areas were highlighted in these discussions including understanding cultural aspects, continuity of care and effective partnerships. In terms of culture, many discussed how understanding family roles, gender and issues associated with immigration influenced care. Continuity in care also benefited those with chronic illness as their PHC provider was able to understand an individual's family background and health history and were able to build communication and confidence in care over time. Care which acknowledged the role of the individual in daily management in partnership with the PHC provider led to more effective interactions.

## Respect for client's cultural environment

Within the context of chronic illness, many described how respecting and understanding cultural influences leads to more effective partnerships in care over time. Respecting culture was demonstrated through the recognition of challenges in chronic illness management and how these can be influenced by family roles and relationships. Understanding culture included the recognition that there were many challenges in daily management and potentially, these were influenced by the impact of immigration and also tensions between Western values and those of their native country. A Punjabi-speaking woman in her 40's with hypertension talks of the benefits of her doctor understanding her role within the family and how this impacts her health, *'if I go to my doctor and say that my mother in law is sick and I am very stressed out, my blood pressure is very high, he understands that our values are such that my mother in law has to live with me-- if it is someone else he might say that I should send my mother in law to an old age home and stay happy.'* (Focus Group 4, participant 4). Within this scenario, she felt that her doctor understood her living situation and gave her advice which she was able to apply within her own life context. Her PHC provider acknowledged the challenges that she faced and that decisions on how she was able to manage life on a daily basis may be more complex than a matter of individual choice.

Issues of culture and gender also influence chronic illness care in terms of family roles. Often, women bear the responsibility for health of the family through managing diet and activity levels. A woman in her late 50's highlighted this aspect, *'Being a housewife as me, we have responsibility because the one who shops for food is us, who cooks the meal is us...the responsibility of a housewife is very important to control the health of the whole family'* (Focus Group 1, participant 3). Although gendered roles impact chronic illness management, in discussions involving chronic illness care the gender of the PHCP was of little concern. One



woman in her early 50's noted, *'I don't care if the family doctor is male or female, because from his/her point of view, patient is patient, there is no female or male. From my point of view as long as you are good it doesn't matter [whether] you are male or female'* (Focus Group 1, participant 3).

### Relationship continuity

When describing encounters in chronic illness management, many described benefits in seeing the same PHC provider over time as they were more aware of their medical history and were better able to monitor their treatment over time. This continuity enabled individuals to develop a relationship in which they felt confident in the care provided and were able to communicate more effectively. Continuity went beyond simply knowing individuals' medical history but knowing the individuals themselves and how they had responded to different regimes of medication or treatment. One gentleman with diabetes described, *'It would be good if you see the same doctor, because this time he prescribes this medicine, next time he will treat you with the same treatment plan. If you change to a different doctor, he may have a different treatment plan . . . for patients who have chronic diseases, it is good if you have a regular family doctor because he will know you and provide you consistent treatment'* (Focus Group 10, participant 7).

### Effective partnerships: acknowledging the role of the individual

How PHC providers communicate with individuals with chronic illness was very important to how they perceived the effectiveness of interactions. Participants felt it important that the role they played in daily management of their condition was acknowledged and that this led to more effective partnerships. When their PHCP was willing to explain more of the disease and its treatment and give information beyond medical treatment but also to focus on issues of lifestyle and their life context, individuals felt more satisfied with their care. As one Cantonese-

speaking woman indicated, *‘being a doctor not only needs compassion, but also the patience to listen to the patient, don’t treat a patient’ is a “product” like send them away right after the consultation’* (Focus Group 1, participant 3). These discussions pointed to the need to provide care which considered the challenges that individuals face and promoted a sense of success through activities and behaviors they could do to influence their health. A Punjabi-speaking gentleman described the need to have complete information on his condition and treatment, *‘If some one has diabetes or high blood pressure, if they give a high dose in the very beginning but don’t say you should diet or exercise... the family doctor should tell the patient the complete history as to why you are having this and how to control this and how you should exercise and do other things’* (Focus Group 6, participant 1). A woman with diabetes expressed the need for individualization, *‘the system has its own pattern, it can’t be changed with people’s individual cases...even though you talk to them about your worries, they will still follow their own steps, they won’t be flexible and treat your case differently’*. Another gentleman in his late 60s with both hypertension and depression pointed to his frustrations, *‘I have high blood pressure and I take medicine, if ever I have any other problem my doctor always says one thing, always talks about my weight, decrease your weight...always embarrasses by saying that I am not reducing my weight. I say that I try to do everything that I should be doing, like in my situation what ever I can do.’* (Focus Group 6, participant 5). This pointed to an interaction which did not explore this person’s effort to manage his blood pressure and build on future success but instead of promoted a sense failure.

Other participants described positive experiences and an appreciation for monitoring and education programs that are in place in our current health care system. This gentleman described the benefits in approaches to diabetes management, *‘I think some health care services in Canada*

*are very good, they are very advanced. For example, patients who have diabetes are provided a meter and diabetic education materials so they know more about their disease and know how to prevent it from getting worse'* (Focus Group 10, participant 7).

### *Summary*

Discussions within these focus groups highlight how challenges that individuals with a chronic illness encounter are influenced by issues related to being an EM. This included coping with day to day concerns in their health partly due to a sense of responsibility but also because of barriers to accessing PHC providers effectively. When English was a second language, they found it more difficult to access information about their condition and to communicate effectively with their PHC provider. How PHC providers were able to support individuals with chronic illness influenced their health and how they were able to make and sustain changes to influence their health over time.

## Chapter V: Discussion of findings

The previous chapter described how participants with a chronic illness used a combination of dietary and traditional approaches to maintain their health on a daily basis. This was partly due to a sense of responsibility but was also influenced by challenges they encountered in navigating the health care system, particularly in matters of language and communication. Access to PHC providers and how they were able to engage with them impacted how they were able to manage their care over time. They described feeling supported when the role they played in managing their health was acknowledged and when explanations of their health went beyond the disease itself to include issues of lifestyle and life context.

While participants' comments demonstrate a preference and ability to self manage their health, findings from this study highlight how EMs faced an increased burden when navigating the health care system in chronic illness management. The ability to navigate the health care system was influenced by the fact that English was often a second language but also that the default model of care was not only in English but also based on Western values and social structures. Some found it difficult to communicate effectively about their condition and when they received advice about their health it did not make sense within their own life context.

In the following section, I will explore how participants' discussions of cultural aspects of chronic illness management can inform our approaches in PHC acknowledging that culture itself is far more complex than a fixed set of beliefs and practices of a specific group. Within this exploration a critical cultural perspective helps illuminate culture as a dynamic and shifting relational process in which the culture of the health care system, specifically approaches to chronic disease management, influence interactions.

### *Culture and managing a chronic illness*

The importance of food, family roles, relationships and social networks on chronic illness management is significant, yet this understanding must also be balanced against the risk of promoting a racialized view where this becomes a tool of marginalization. Along with pharmaceutical management and ongoing monitoring of biochemical parameters, behavioral interventions to promote dietary and lifestyle adjustments are a keystone of chronic illness care. Although there were challenges described in all these aspects, perhaps most frequently discussed were challenges in understanding and following dietary advice. As such, this provides a good framework for discussion of how managing a chronic illness is influenced by cultural aspects and how we can integrate this knowledge of chronic illness, EMs and PHC interactions within the context of the current health care system. As PHC providers, critical self reflection is an integral component of our interactions. Within this study, my goal is that the understanding gained from exploring this data is used to remind us of the various possibilities in how individuals and families manage their health, not to make assumptions about specific ethnic groups. Within PHC interactions we need to explore how decisions are made within a particular family and also reflect the values of the health care system in which decision making is viewed as an individual responsibility and behavior change is targeted at the individual level. Some participants pointed to the primary role of the wife in ensuring the health of the family; if this is so, then we need to ensure that dietary advice incorporates those organizing and preparing food for the family. It is also important that we not make assumptions that food choices are based on ‘culture’ but ensure there are not other barriers food choices.

One aspect that I found concerning was the comments of wanting access to more information on the impacts of traditional approaches including ‘food therapy’ and comments

alluding to the general mistrust of allopathic practitioners to traditional medicines. This has also been consistent with my own practice where clients are reluctant to disclose traditional approaches to Western PHC providers, even those as straightforward as special teas. We know, however that chronic illness management clients often experiment with non-Western approaches in managing symptoms (Thorne, 2008). The concern is that, especially in chronic illness management, where a cure is not necessarily the goal of treatment but management of symptoms is, if PHC providers are not aware of what practices individuals are accessing, they cannot discuss appropriate information (especially important with some conditions such as renal disease, hypertension and diabetes). Along with being able to assess alternate approaches, it is important that an individuals' viewpoints and beliefs are valued, helping to foster self confidence in an ability to manage health. Effective care in chronic illness needs to encompass both traditional and Western approaches to build on commonalities not highlight differences. We need to work towards building better partnerships between PHC providers and resources within the community to gain a better understanding of alternate approaches and explore ways in which they complement each other or identify areas of concern. At a minimum, it is essential that PHC providers are open to discussing alternate approaches that individuals may wish to explore.

### *Health care reform and chronic illness management*

It is important that approaches to supporting chronic illness management in PHC incorporate an understanding of the complexities of daily management and how this is influenced by being an EM. Recent approaches to health care reform in BC geared to reorient the system to encompass a broader range of care are based on the Expanded Chronic Care Model (Barr et al, 2003). Within this model, PHC providers play a key role within a system of care. This model, which straddles both the health system and community, provides a basic framework

to organize chronic illness care around the four components of: delivery system design, decision support, clinical information systems and self management support. This approach incorporates efforts to address some of the challenges that EMs encounter yet there are still many areas where the advances have not yet filtered down to the point of care and there remain many areas for improvement.

Discussions in the focus groups underscore the challenges that EMs with a chronic illness encounter in PHC interactions including difficulties in communication and access to care providers. In the following section, I'll discuss the expanded chronic care model and how results from this study exploring participants' experiences along with information in the literature can highlight potential areas of strength and limitations of the framework for chronic illness management. As indicated earlier, my main focus in this study is to examine the complexities in self management support; however the other 3 domains and how they influence chronic illness management also warrant exploration. Information from these focus groups helps to strengthen the case for building better linkages between PHC and resources within this model.

### Delivery system design

Delivery system design encourages PHC providers to move beyond clinical and curative services to support individuals and communities in a holistic way, acknowledging the connections between health and broader social, political, economic and physical environment conditions (Barr et al, 2003). Within the component of the expanded chronic care model the focus is on an expanded scope of practice for PHC providers and on teamwork including stronger connections with community programs. Participants' responses support this approach. They indicated that they felt better supported when care and advice they received included clinical advice yet also took into account the context in which they lived. They wanted to be

able to access other services within the community and other care providers. They also indicated that importance of understanding the challenges that they faced in issues related to family roles or how decisions were made within the family. In viewing this through a critical cultural perspective, culturally safe care does not mean understanding how families from specific ethnic backgrounds are structured or decisions are made in different cultures, but that the design of the system allows for explorations and flexibility at the point of care.

### Decision support

Decision support is access to evidenced base practice for disease and treatment such as clinical practice guidelines for specific disease or conditions. Within the expanded chronic care model, this also encompasses strategies for being well and staying healthy. While guidelines may provide a framework for producing baseline competence, we need to be cognizant of the difficulties in applying population based evidence on an individual basis. Discussions in the focus groups highlighted tensions when PHC providers followed standardized guidelines for care without taking into account the individual needs. Individuals also described frustrations when they did not fall within the guidelines as one man who struggled with his weight discussed. Instead of an effective interaction where successes he may have had managing his health could be explored, he felt that he was blamed for his inability to lose weight. In terms of the potentials of decision support in encompassing evidenced base practice, recent growths in technology may provide an opportunity to develop an evidence base for traditional health approaches. Within the focus groups, participants advocated for care which could encompass both traditional and Western approaches, wanting access to informed PHC providers.



### Clinical information systems

Clinical information systems within the expanded chronic care model refer to the development of information systems based on patient populations to provide relevant client data. These function as surveillance systems to provide alerts, recall and follow up information and the identification of relevant subgroups requiring proactive care. While these systems are immensely helpful in organizing care on a large scale, there are cautions which need to be considered. Identifying subgroups based on ethnicity may contribute to racialization. Another concern is the limitations of the data gathered in these systems. Clinical biomarkers are the easiest to capture and therefore become the gauge by which we measure successful management yet it is increasingly evident that these are a very small part of the complexity of living with a chronic illness (Thorne, 2008). While discussions of clinical information systems were not addressed in the focus groups, how these are used to define and measure successful management appears to influence interactions in PHC.

### Self management support

In terms of self management support the goal is not simply to learn information and skills for a specific disease but also to gain confidence in role management and emotional management so individuals may exercise control over their own health. Effective self management of chronic illness means understanding illness and its care including both the clinical and social aspects influencing the impact on daily life (Gallagher et al, 2008).

Speaking the same language and being literate, not only in English but also the language of health care, is needed for both the individual and PHC provider in chronic illness management. Consistently throughout all the focus groups were requests for more information in their native language and challenges in being able to communicate with their PHC provider.

Within this study, EMs who spoke English as a second language and did not have a regular provider able to speak their native language faced more vulnerability in chronic illness management. Some were not able to speak directly with their PHC provider and relied on family members to interpret which caused a greater burden on family members. Others were able to interact in basic terms and may have missed key aspects of communication so that information about their condition or treatment was not conveyed or understood. Some participants discussed the difficulty in being able to secure a PHC provider able to speak with them directly.

Communication is essential in chronic illness care yet interpretation and translation services remain underutilized (Tang, 1999). It is unrealistic that every PHC provider is able to speak the language of each individual they work with but they do need to recognize the limitations in these interactions and build supports within their own practice to minimize the impacts. These supports may include building linkages with the community such as gudhwaras or immigration agencies or accessing interpreter and translation services through other agencies associated with the Ministry of Health (HealthLink BC, ActNowBC). Supports may also include stronger links to programs within health authorities where more robust interpretation services are available and advocating for a standard of care in which interpreter services are essential in chronic illness management.

For those able to converse in English, discussions within this study mirror many of the challenges identified by the general population in terms of communication and understanding how to manage their health. When supporting self management, PHC providers need to recognize the potential to increase frustrations or undermine confidence in illness management. As discussed in Chapter II, decisions in everyday care occur within an individual's social context

and are based on how an individual not only responds to treatment but also takes action toward their own health goals.

Information or advice needs to be meaningful within an individual's social context, for example giving advice on a living situation without exploring the social structure of the home may not be applicable. We need to advocate for organizational structures which provide opportunities to learn about an integrate information about individuals' social context so information is meaningful. Participants indicated a desire to have dietary and other advice which is appropriate, and in order to sustain long term dietary changes, it needed to be something which they could adopt in their daily lives. This means that we need to have a variety of information sources and the ability to provide information in multiple languages. This could include organizational approaches which build on resources within community agencies whether this is gurdwara's for the Punjabi speaking communities or immigration support services.

Participants within this study articulated a sense of feeling responsible for their health, especially for day to day management. For issues that they had managed before such as blood sugar, hypertension, coughing or stomach upsets, they indicated it was a waste of the PHC provider and their own time to access health care. The role of PHC providers in these situations may be to offer opportunities for reflective dialogue with individuals about how they manage these issues on their own and foster the development of skills and expertise which comes from experimentation, not information. The PHC provider may be able to advance these discussions to include clinical aspects of the illness that the participant may not be aware of. Living well with a chronic illness means an individual needs to make choices while considering evidence and how their own body responds to various approaches. Effective self management support needs to focus on building this expertise.

Within BC, Chronic Disease Self Management Programs are promoted as one source of self management support. Studies indicate that these programs have shown benefits for those attending and they have been used in diverse populations. While these programs need to be evaluated critically on how they may impact individuals, they are also worth exploring as a potential support to PHC providers. Are there ways to promote more strategic partnerships within the PHC setting and these programs?

### *Implications primary health care providers*

Results from this study help to illuminate some of the challenges that EMs face in the ongoing management of a chronic illness in their interactions in PHC. To provide effective care, PHC providers need to understand these challenges and how these are impacted by approaches to chronic illness management. PHC providers need to understand how issues of language influence the ability to access appropriate care and also understand how aspects related to culture including the culture of health care impact not only chronic illness management but also how successful management is measured.

### *Limitations*

One main limitation that I encountered in this secondary analysis was not being able to explore in greater depth aspects of the participants' experiences in chronic illness management. While there were many responses which shed light on nuances of the experiences in relation to the research question, there were also other areas which would have been interesting to explore further including the roles of other health care providers or details on uses of traditional medications when managing a chronic illness. It also appeared that social dynamics of specific groups appeared to shape the group discussion, especially during the discussions of traditional health approaches. While accessing both Chinese-speaking and Punjabi-speaking groups to explore this topic may support the advancement of themes applicable to both these groups

whether these findings are generalized to other EMs is open to debate. As well, this exploration has focused on approaches to chronic illness management in the province of BC and may not be generalizable to other regions. In light of these limitations, the goal in this exploration was to expand the discussion on how EMs manage chronic illness in the PHC setting in the health care context of chronic disease management.

### *Summary*

Managing a chronic illness can be a challenge for anyone. Results from this study reveal how ethnic minorities with a chronic illness describe their experiences in PHC and demonstrate how this can be even more difficult when English is a second language. Participants articulated a desire and ability to self manage many aspects of their care including day to day management partly due to a sense of self responsibility but also because of challenges they encountered navigating the health care system especially in areas of language and communication. Some described a desire to have more information about both traditional and Western medicines and how they may work together but encountered either a lack of knowledge or resistance in PHC. Many described feeling supported when they felt the role that they played in their health was acknowledged and when advice they received went beyond the disease itself but also considered their life situation. Within this investigation, through a critical cultural perspective, I've looked at how insights from this study can be used to inform our approaches to chronic illness in PHC within the current context of health care in BC and approaches to chronic disease management.

The CDM approach provides a framework for organizing care for those with chronic illnesses and has both areas of strength but also areas of caution. Responses from participants support a system where PHC providers may also incorporate other health care professionals and community resources within their practice. While there have been investments in resources

available in other languages, responses reinforce the fact that these remain underutilized.

Decision support, through the use of evidence based guidelines, may help to guide care for those with chronic illness but they also have the potential to cause tensions when individuals may have difficulties following advice. Another component of CDM is clinical information systems.

Within this aspect there are two areas to consider. The first is that these systems involve organizing data in accordance to specific ethnic groups. As discussed earlier, this does not provide meaningful data and may promote racialization. The other aspect to consider is that as clinical data is the easiest to capture it therefore becomes a main tool for measuring success, yet these indicators are a very small part of the experience of managing a chronic illness. Most importantly, results from this study support the need to ensure that our efforts to support self management help promote a sense of confidence in emotional and role management along with managing the specifics of their illness.

### *Conclusion*

My goal in this study is to promote critical reflection on the part of all those involved in PHC as they interact with individuals with chronic illness recognizing that for ethnic minorities, the challenges may be further impacted by their experiences and challenges associated with immigrating, especially in terms of language and communication. It is not that the experiences described by participants are different from their Canadian born counterparts, but they do appear to be more vulnerable to common pitfalls that many experience as they attempt to adjust to a chronic illness. It is not necessary to understand '*desi ways*' or '*ying and yang*' or traditional health approaches of different cultures. It is necessary to recognize that individuals come from a variety of backgrounds and experiences which impact how decisions are made within their social context. The role of PHC providers is to support to individuals in decision making as they

attempt to integrate a chronic illness into their daily life. PHC providers need to reflect on the goals of self management; to move beyond providing disease specific information to supporting individuals to adopt healthier lifestyles and approaches to minimize symptoms and maximize their ability to function in their daily life and social context.

A key reminder is to be aware of how successful self management is currently defined. Population based evidence is what informs the development of clinical practice guidelines which in turn informs advice by PHC providers. The majority of this evidence is comprised of biochemical markers as these are the most convenient to acquire. Successful management is then measured by whether individuals fall within the expected biochemical ranges, which demonstrate how well they follow this advice. Results from this study reinforce the potential to contribute to frustration and a sense of failure when these markers are the measurement of success. Future research within this area needs to explore other measurements of successful management both at an individual and population level.

Health care reform and the approaches to CDM also provide an opportunity to improve care for ethnic minorities and other vulnerable individuals with a chronic illness. There have been investments in interpreter service and translation services. PHC providers need to ensure they are accessing these resources. The expanded chronic care model also provides the groundwork for creating stronger linkages and building partnerships with community programs. As the literature indicates and this study reinforce, the majority of decisions on the management of a chronic illness occur outside of the healthcare arena, therefore, it makes sense that community agencies are a potential source of support for individuals and families. Critical reflection on how health care is organized to support those with chronic illness should continually reach beyond the health care system to include community agencies and programs in

decision making. Most importantly for all those involved in chronic illness care, it is essential to ensure that approaches to chronic disease management and self management do not contribute to further burden but instead optimize and individuals ability to participate in their care and live a healthy, meaningful life.



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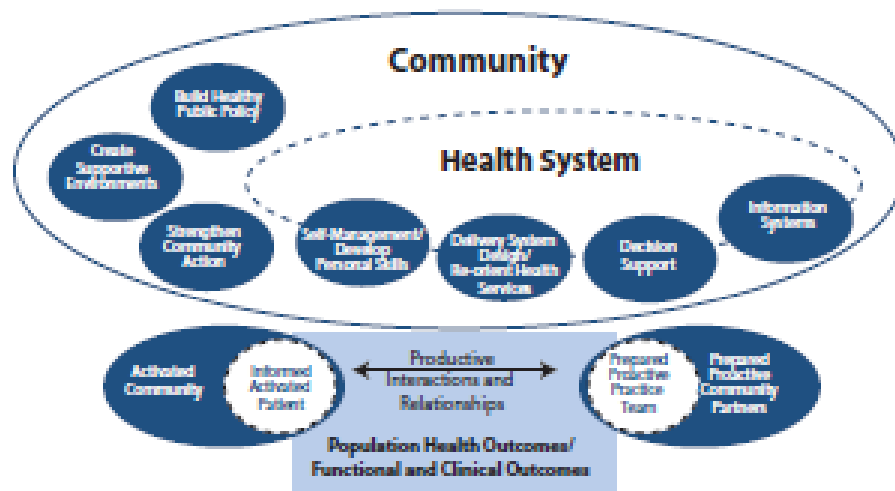
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# Appendices

## Appendix A: *expanded chronic care model*

**Figure 2.** The Expanded Chronic Care Model: Integrating Population Health Promotion



Created by: Victoria Barr, Sylvia Robinson, Brenda Martin-Link, Lisa Underhill, Anita Dotts & Darlene Ravensdale (2002)  
Adapted from Glasgow, R., Orleans, C., Wagner, E., Curry, S., Solberg, L. (2001). "Does the Chronic Care Model also serve as a template for Improving prevention?" *The Milbank Quarterly*, 79(4), and World Health Organization, Health and Welfare Canada and Canadian Public Health Association.(1986). Ottawa Charter of Health Promotion.

## Appendix B: Comparing expanded chronic care model with chronic care model

Table 2 Comparison of the Chronic Care Model with the Expanded Chronic Care Model				
COMPONENTS OF THE CHRONIC CARE MODEL		COMPONENTS OF THE EXPANDED CHRONIC CARE MODEL		EXAMPLES
Health System - Organization of Healthcare	Program planning that includes measurable goals for better care of chronic illness			
Self-Management Support	Emphasis on the importance of the central role that patients have in managing their own care	Self-Management / Develop Personal Skills	Enhancing skills and capacities for personal health and wellness	<ul style="list-style-type: none"> <li>• Smoking prevention and cessation programs</li> <li>• Seniors' walking programs</li> </ul>
Decision Support	Integration of evidence-based guidelines into daily clinical practice	Decision Support	Integration of strategies for facilitating the community's abilities to stay healthy	<ul style="list-style-type: none"> <li>• Development of health promotion and prevention "best practice" guidelines</li> </ul>
Delivery System Design	Focus on teamwork and an expanded scope of practice to support chronic care	Delivery System Design / Re-orient Health Services	Expansion of mandate to support individuals and communities in a more holistic way	<ul style="list-style-type: none"> <li>• Advocacy on behalf of (and with) vulnerable populations</li> <li>• Emphasis in quality improvement on health and quality of life outcomes, not just clinical outcomes</li> </ul>
Clinical Information Systems	Developing information systems based on patient populations to provide relevant client data	Information Systems	Creation of broadly based information systems to include community data beyond the healthcare system	<ul style="list-style-type: none"> <li>• Use of broad community needs assessments that take into account: <ul style="list-style-type: none"> <li>• poverty rates</li> <li>• availability of public transportation</li> <li>• violent crime rate</li> </ul> </li> </ul>
Community Resources and Policies	Developing partnerships with community organizations that support and meet patients' needs	Build Healthy Public Policy	Development and implementation of policies designed to improve population health	<ul style="list-style-type: none"> <li>• Advocating for / developing: <ul style="list-style-type: none"> <li>• smoking bylaws</li> <li>• walking trails</li> <li>• reductions in the price of whole wheat flour</li> </ul> </li> </ul>
		Create Supportive Environments	Generating living and employment conditions that are safe, stimulating, satisfying and enjoyable	<ul style="list-style-type: none"> <li>• Maintaining older people in their homes for as long as possible</li> <li>• Work towards the development of well-lit streets and bicycle paths</li> </ul>
		Strengthen Community Action	Working with community groups to set priorities and achieve goals that enhance the health of the community	<ul style="list-style-type: none"> <li>• Supporting the community in addressing the need for safe, affordable housing</li> </ul>



## *Appendix C: Focus group interview tool*

### Focus Group Interview Schedule

#### Subset of Focus Group Questions related to chronic illness

#### PRIORITIES

Imagine that, in your current state of health, you are due for a routine checkup (such as asthma, diabetes or a blood pressure check).

3. In this situation, what are the most important things to take into consideration in choosing this specific provider/place to go for health care or advice?

Can you tell me more about that? (20 min)

- Probes:
- a. Someone who speaks your language?
  - b. What about waiting time to schedule an appointment, waiting time in the place to see a provider? Convenience to travel to?
  - c. Availability during day? Night? Weekends?
  - d. transportation? Availability of telephone help?
  - e. Treatment by the office staff?

#### CONTINUITY

4. How important is it to see the same health care provider every time you need care?  
Can you tell me why this is important to you?

- Probes:
- a. Is it important the provider knows your personal circumstances?
  - b. Consistent, appropriate knowledge and skills?
  - c. Ongoing observation of condition?
  - d. Trusting relationships?

5. Is it enough just to see anyone as long as they have your health record?
6. How does knowing you as a person (e. g. your values, beliefs, expectations, medical history, family history, cultural background make a difference? In what ways?  
Know your family?
7. What happens when the provider does not know you as a person—your values, beliefs, expectations, family history or medical history?