Integrative Literature Review: Chronic Disease Self-Management for Indo-
Canadians Living with Chronic Kidney Disease

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Abstract

My goal in this project was to explore literature on chronic kidney disease management particularly as it relates to providing care for people within the Indo-Canadian population in British Columbia. I have conducted an integrative literature review of chronic kidney disease self-management sources to examine the effective provision of health care to Indo-Canadians living with chronic kidney disease. Using Whittemore and Knafl’s integrative review methodology, nursing literature and literature from other allied health disciplines were selected. Findings from the integrative literature review include two major themes. The first is the impact of language, culture and gender roles for the Indo-Canadian population; the second relates to chronic disease self-management programs for people living with chronic kidney disease. There remain significant gaps in the literature regarding how to engage effectively with Indo-Canadians in relation to chronic disease management in chronic kidney disease. Further, based on the research and chronic disease self-management model, I have developed recommendations and guidelines for practical solutions for those who will work with Indo-Canadians living with chronic kidney disease.
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“Vaheguru nah kita jo hona see, hun marai karain kush nahi hona, marai karn wala hore bhut kush hai.”

This Punjabi expression is a very common saying that I heard repeatedly when visiting my Indo-Canadian clients at home. It means: “God took my kidney function away! I must have done something bad. It is the punishment God gave me in return for my bad karma. Now, there is nothing I can do to prevent it, so why should I worry about self-management? I should do other chores in the house to help my family.”

Imagine trying to teach self-management to a patient with this type of thinking. This kind of belief system is held by many Indo-Canadian patients, who have one or more conditions such as diabetes, heart disease and/or chronic kidney disease (CKD). They have special challenges in communicating with health care workers. They hold different health beliefs and values from those in the dominant majority. It is important for health care practitioners to think about how these beliefs impact their ability to meet the health care needs of their clients. In this project, I explore chronic disease self-management as it relates to CKD within the Indo-Canadian population. Through an integrative literature review, important factors in providing care for this population will be considered.

The World Health Organization (WHO, 2002) estimates that chronic diseases will be the leading cause of disability by 2020. In addition to the human suffering, chronic disease is and will continue to be a problematic expense within the health care industry. (Barlow, Wright, Turner & Bancraft, 2005). Chronic health conditions are complex and are the main cause of morbidity and mortality within aging populations. Recognizing the importance and impact of chronic disease, Dr. Kate Lorig and Holman (2000), at
Stanford University, directed the development of Chronic Disease Self-Management (CDSM) for people living with arthritis. These CDSM programs focused on enhancing care for people living with complex conditions. In the ensuing years, CDSM has become an essential strategy in addressing chronic disease for many health care organizations. As shown in Appendix I, Wagner’s Chronic Care Model (CCM) (2002) was put forth to focus on providing strategies to address clinical issues. Prevention and health promotion programs to address chronic disease issues were also considered essential. In British Columbia (BC), the Expanded Chronic Care Model (ECCM) is a model that included the elements of prevention and recognized the social determinants of health, health promotion and the integration of multiple contexts into self-management programs (Barr et al., 2003; BC Ministry of Health, 2007). British Columbia is considered a leader in CDSM and there has been increased emphasis on research about the application and effectiveness of self-management (McGowan, 2005). In CDSM, self-management strategies are promoted to reduce the burden of health system costs, but there is little understanding of how the Indo-Canadian community describes their lived experience with CKD and the impact of their beliefs on their willingness and capacity to engage in CDSM strategies. Further research is required to explore specific issues in relation to health and health beliefs and how the culture shapes experiences collectively and individually for this community.

**Project Goal**

My objective in this project was to explore literature on CKD management particularly as it relates to providing care for people within the Indo-Canadian population in British Columbia. Specifically, I have conducted an integrative literature review of
CKD self-management sources to examine the effective provision of health care to Indo-
Canadians living with CKD. Furthermore, based on the research and CDSM model, I have developed recommendations and guidelines for practical solutions for those who will work with Indo-Canadians living with CKD.

Background

Chronic Kidney Disease and its Impact

In order to learn more about how to support patients living with kidney disease, it is important for us to understand what CKD is and the psychological and social impact of living with CKD. CKD usually progresses slowly, often destroying most kidney function before a person experiences any symptoms. CKD impacts people differently depending on their life stage and may have profound impacts on different aspects of a person's life. For example, a young individual diagnosed with CKD would experience a huge sense of grief, as their life expectancy would be seemingly cut short. They most likely have not yet reached their full potential. They may be still following educational pursuits or establishing their place within their family structure. This individual often feels a loss of control over their life decisions.

By comparison, a middle-aged adult with CKD may feel a sudden sense of disconnection from the people in their lives that were also affected by this disease. If we take a middle income adult with a family as an example, the diagnosis would definitely put a strain on the family's financial status. The impact would be greater if that person was the primary provider. There would also be considerable stress on the spouse with added financial pressure, caregiver’s fatigue, and the possible loss of physical intimacy. If the relationship were to break down, there would be a sense of division, loss and
isolation. Additional stressors would be placed on the patient in terms of compounded negative effects. The adaptations necessary to continue work with the disease may cause feelings of insecurity on the job, job loss or the breakdown of primary work-related relationships. It does not end here; the majority of CKD patients live with multiple comorbid conditions such as diabetes and hypertension. In fact, the greatest risk factors for developing CKD include a pre-existing diagnosis of diabetes or hypertension. Diabetes is the leading cause of CKD in western world (Thomas, Bryar & Makanjuola, 2008).

The Kidney Foundation of Canada (2009) estimates that approximately two million Canadians are affected with CKD. There are many different factors involved in the increased incidence of renal failure that relate to diabetes and hypertension (Ravenscroft, 2005; Thomas et al., 2008). Renal programs throughout the world are seeing an increase in the proportion of the number of patients who have co-morbidities of diabetes and cardiac disease. McCarley and Burrows-Hudson (2006) indicate that people with “chronic kidney disease be considered at highest risk for development of cardiovascular disease” (p.666). People at risk for CKD and those with comorbid conditions such as diabetes and cardiovascular disease should be evaluated regularly. Further, Rait and Burns (1997) indicate there is a “higher than normal incidence of maturity onset diabetes and coronary disease in people from the Indian subcontinent” (p.975). As researchers often explore the primary diagnoses of both diabetes and kidney disease separately, there is limited information on the patients who are living with both of these chronic conditions (Ravenscroft, 2005).
Patients are usually diagnosed with CKD when kidney function is between 30 to 60%. The aim of CKD treatment is to slow the progression of renal disease through managing comorbid conditions such as diabetes, hypertension and lipid levels. Diabetic clinics are important in promoting awareness and self-management of kidney disease that could reduce the progression of CKD (Thomas et al., 2008). Due to the silent onset, it is important to detect the disease in its early stages and to provide follow-up support for individuals with these ailments. CKD causes major lifestyle interruptions. Effectively managing the disease is time-consuming and frustrating. For many of those diagnosed with CKD, their lived experiences include feelings of uncertainty, hope, and loss of control, depression and guilt. Making adjustments to live with CKD involves managing, accepting, adopting, and finding a balance, coupled with uncertainty and finding hope (Ravenscroft, 2005).

A CKD patient’s age, employment, lifestyle, family and social support systems play a direct role in determining the recovery or deterioration of a CKD client because the client is faced with a disease that is complex and has multiple impacts on daily life. The CKD client has to have a complete lifestyle change, take a number of medications, and undergo many laboratory tests. In addition, they face major life decisions such as to have dialysis treatment or to opt for waiting for a kidney transplant. Given this complex situation, CKD clients need to consider their capacity to comply with the management with regard to their financial situation. They have to take a serious look at whether or not they have the financial means, social support networks and health services to help them cope with and manage their illness.
Tsay and Hung (2004) say, “Patients with end-stage renal disease (ESRD) undergo a complex treatment regimen involving dialysis and a wide range of dietary restrictions and lifestyle changes which affect their social and psychological functioning” (p. 59). CKD requires these complex fluid, dietary and medication regimens in conjunction with life-long behavioral and social re-adjustment (Costantini, 2006). The patient’s self-management is often considered as having a positive outcome contingent upon a high degree of patient compliance. Understanding the core concepts of compliance, adherence, and self-management of dietary, fluid and medication regimes is the highest priority for renal patients, and it could alter the trajectory of the disease (Costantini, 2006; Vlaminck, Maes, Jacobs, Reyntjens & Evers, 2001). While nephrology nurses commence the treatment regime, the patients are often left alone to make day-to-day decisions; that is when these strategies can fall apart.

CDSM is the most frequently used strategy to assist CKD patients with managing their own illness. CDSM is based on social-cognitive theory. Bandura’s conceptualization of social cognitive theory articulates the concept of self-efficacy as a focus for patients to gain confidence to achieve social re-adjustment (Costantini, 2006). “Bandura’s self-efficacy theory offers an easy framework for nurses to assist and support ESRD patients in the lifestyle adjustments they need to make” (Bandura, 2004) and is the theoretical foundation of CDSM models. Bandura describes social cognitive theory (of which self-efficacy is a central component) as a “multifaceted causal structure in which self-efficacy beliefs operate together with goals, outcome expectations, and perceived environmental impediments and facilitators in the regulation of human motivation, behavior and well-being.” (p. 143). Further he contends that “belief in one’s efficacy to exercise control is a
common pathway through which psychosocial influences affect health functioning.” (p. 143).

Dietary habits and fluid control are essential to the kidney management of self-care. The monitoring of these basic lifestyle changes do not, however, take into account the physiological and psychological impact on the patient. Bandura’s theory directly correlates patient well-being and confidence with the ability to manage self-care. Furthermore, self-efficacy also contributes towards nephrology nurses' knowledge to understand the patient’s capacity for health promotion practice. Self-management with CKD patients enables them to grasp problem-solving, decision-making, seek resources, establish partnerships with health care workers and take actions (Lorig & Holman, 2000).

I think we all, as nurses, have felt frustrated by the non-compliance of a patient. This would also seem to hold true for the CKD client because of all the uncertainties of the disease. A patient may not comply with treatment because they lack self-esteem due to an underlying depression, or feelings of isolation over having no social support system or financial pressures. There may also be particular needs within specific populations such as the Indo Canadian community.

**Indo Canadian People Living in British Columbia with Chronic Disease**

The world is getting smaller and smaller with people emigrating from one country to another. Indo-Canadians first immigrated to the United Kingdom in the early 20th century. At the beginning of the century, skilled and educated people were permitted to intersect with the work force in Canada (Boyd & Vickers, 2000) and by the 1970s, Canada became a leading destination for immigration of Indo-Canadian people (Anderson, 1998). Today it is estimated that there are approximately one million Indo
Canadians living in Canada. Economic and political reasons forced people to migrate from India. In 1962, new immigration laws were implemented. Under this law, people with education, skilled workers of any race and color were allowed to immigrate and sponsor other family members (Government of Canada, 2006). Health screening processes were vigorous and only healthy people were given the permission to immigrate. The criteria for migration included being a working class individual in good health (Anderson, 1998). Between 1980 and 1996, the immigration family law provision permitted all the family members to reunite; a family member was able to sponsor their families with a sponsorship period of 10 years (Boyd & Vickers, 2000). These policies allowed many Indo-Canadian families to sponsor elders, spouses and children, often resulting in three generations living under one roof. These family immigrants ranged in age from newborns to ninety year old parents. Some of them were young, healthy, skilled workers and others were illiterate, old, and living with multiple chronic diseases. As Rait and Burns (1997) suggest,

early theories regarding migration stated that eventually the new arrivals would assimilate by taking on the culture around them, absorbing effortlessly into the host community. However, it is now accepted that although there is a shift in cultural behavior, there is a great deal retained from the place of migration and also an incorporation of ideas and traditions from the host society (p. 974).

Aging generations of immigrants also face immense barriers like language, access to health care, and transportation issues (Ahmad et al., 2004; Anderson, 1998). These same immigrants encounter many challenges such as language, culture, social, and economic burdens to live day to day (Anderson, 1998) and are often required to engage in
work that earns minimum wages, scarcely enabling them to meet their living needs (Statistic Canada, 2005).

Poverty is linked to illness. Financial burdens often lead individuals to make decisions which are not in the best interests of their health. For example, sometimes individuals are given prescriptions that they are reluctant to fill because they are not covered under their existing medical plan. Oliffe, Bottorff, and Toor (2007) described a patient who came to the clinic complaining of a headache and dizziness. On examination, his blood pressure was 180/100 mm Hg, and although he had established hypertension, he was reticent to take prescribed antihypertensive medications. He explained that his doctor gave him free samples of tablets; however he would not take them as prescribed because he could not afford to buy more tablets from the drug store when his current supply ran out.

While the relationship between poverty and ill health has been well established, this relationship is even more complex for immigrant women. As Anderson (1991) discussed,

for the immigrant woman, the difficulties in living with a chronic illness are exacerbated by the experience of uprooting from her homeland, and resettling in a new country where she must deal with her marginality, social isolation and alienation in a foreign culture (p.710).

These humbling feelings play an important role in decision-making about health, chronic illness and its management. Further, some immigrant populations may be more likely to suffer from specific diseases. Osman and Cruzio (2012) indicate, “people of South Asian origin are four times more likely to develop diabetes than any other ethnic
group. The patients with Type 2 diabetes also have a greater risk of developing cardiovascular disease and renal problems” (p. 28). South Asians have a three to five times higher incidence of diabetes than Caucasians with genetic susceptibility, abdominal obesity, insulin resistance and metabolic syndrome being named as contributing factors (Sohal, 2008). Many studies illustrate that as the Asian immigrant population has increased in Canada, the prevalence of hypertension and diabetes has increased (Jain, Farooqi, & Feehally, 2008; Kaplan, Chang, Newsom, & McFarland, 2002; Osman et al., 2012). In The United Kingdom, the incidence of renal failure is three times greater in South Asians than native Caucasian populations (Jain et al., 2008).

The World Health Organization (2002) reports that the negative impacts of the social determinants of health further exacerbate health issues for immigrant populations. Low social status usually equates to poor educational attainment (if any at all), poor physiologic coping mechanisms (biological, social and mental adaptability), unsecured employment status, and poor social standing (feeling of isolation or being looked down upon thus the self-exclusion from society); these are leading factors contributing to chronic disease. Although the social determinants substantially impact one's health status, in my opinion, a culture of indifference rooted in the context of consumerism seems to drive the majority of people's lack of engagement, commitment or compliance in relation to their own health. Access to conditions that permit health is shaped by the circumstances in which people are born, grow up, live, work and age and an array of political, economic, social, cultural and environmental conditions and forces. Ulrich (2009) states, “as the world becomes smaller through global migration, the need for nurses to better understand its many cultures is becoming increasingly important to
delivering effective nursing care” (p.367). Registered Nurses Association of Ontario (2012) reports that “health inequities are a direct reflection of social inequalities, which means that chance for better health and a longer life increase along the socio-economic gradient” (p.1).

Lack of access to education, poor social networks and social isolation have significant effects on the lives of people, particularly immigrants living with chronic disease (Anderson, 1996). Being diagnosed with a chronic illness would be a huge shock to any individual but when you have other stressors around, they can change the outcome of the illness for better or worse. Socio-economic status can add a lot of stress for the client and also reduce the quality of life drastically (Graham, Bashir, Chantler, Burman, & Batsleer, 2002). Social exclusion can prevent clients from participating in activities normally expected from members of society. On the other hand, some people with chronic disease have little or no support system and this that tends to affect every attempt made at accepting the disease or trying to live as normal a life as possible. Clients who are educated, have good socio-economic status, and family support systems in place are better able to access good quality health care. In general, they have a better understanding of their condition and potentially would also be better able to manage their disease.

As the Indo-Canadian renal patient population continues to grow, healthcare workers are finding it difficult to effectively address the diverse needs of this population (Jain et al., 2008). To gain a better understanding of the challenges Indo-Canadians face in the Canadian health care system, I will provide an example of how the particular needs of Indo-Canadians are not being met. A situation that I have come across many times in my practice is that the many Indo-Canadian patients that come to the clinic have a
HgbA1C (indicator of glucose control) above normal of 7.0. When a nurse or dietitian sees that this number is higher than the recommended guideline, they suggest that the patient sees an endocrinologist, goes to a diabetic clinic for education and asks them to change their diet. It is my observation that the nurse or dietician will often reprimand the patient for not attending previous appointments with these specialists. The health care workers are forgetting to ask patients basic questions concerning their appointments, for example how access, transportation, language or other barriers may impact a patient’s ability to attend.

I have been asked many times why the Indo-Canadian families have a hard time participating effectively in self-management programs. There are a number of patients who have refused to come to the clinic due to the chidings they have received. Anderson (1991) states

people, especially those with chronic illness with no cure in sight, are increasingly being called upon to assume responsibility for their ‘self-care’ for example… The expectation that people should be able to assume responsibility for self-care is strongly voiced not only by policy makers but also by health care providers (p.714).

My practice includes home visits, hospital visits, and doctor visits. I try to coordinate care between patients and the kidney clinic. I get to know these people very well and understand their day-to-day life issues and how they are struggling or managing with multiple comorbid conditions. Health care providers are often not adequately prepared nor do we support the patients to handle the new and bewildering responsibility of chronic diseases. The assessment of psychological, emotional, and mental stability is
as important as assessing the signs and symptoms of the disease itself. The bulk of my patients are elderly women who are illiterate and do not speak any English. They cannot explain their personal issues to the nurse in their own words nor voice their concerns. Their ability to ask questions of the health care workers is very limited. They lack knowledge about the disease and the processes happening to their bodies. They are unsure and confused about the treatment and management of the disease. Complex gender roles and responsibilities may further create barriers. For example, as Ramakrishna and Weiss (1992) highlighted,

when a modern, urban, postgraduate woman from India agrees to marry a groom from the States not realizing he lives in a rural area and works on a farm. Matters are worse for her because she becomes cut off from her accustomed family support network (p. 266).

It is important for health care workers to understand the traditional gender roles in Indo-Canadian households. Women tend to stay at home and perform domestic duties for each member of the family. Men, on the other hand, typically go to work outside of the home. As (Oliffe et al., 2007) state,

men’s denial of illness or injury and pain are informed by persistent myths of masculinity – such as the perception that it is tough to hold on to symptoms of ill health in the hope that they will disappear, and that only weak men respond to stress (p.225).

It is very hard for health care workers to engage in conversations with people who are not open to learning and are unable to make decisions for themselves. Oliffe et al. (2005) say “health becomes a priority for many men only when they are under threat of
illness or injury” (p. 225). Men perceive their health through physical strength and expertise in their profession. Oliffe et al. (2007) state, “Dominant forms of masculinity also signify a position of cultural authority and leadership, centrally related to social control, and their rationale is to maintain authority over women and over subordinated masculinities” (p. 225).

Health and belief systems greatly influence a person’s way of interacting with others in the world, as well as their decision-making skills. “Sewa”, “kismet”, saying prayers and going to temples are common beliefs within the Indo-Canadian population that impact their decision-making skills. “Sewa” means helping others by sharing time and financial contributions to show good deeds so that God will help you, if needed. “Kismet” means fate or fortune. A study by Oliffe et al. (2007) highlights that “good deeds” were important because they believed that God was watching and, therefore, individuals might be rewarded with good karma” (p. 229). This system of health beliefs ultimately impacts people’s perceptions of chronic disease as well as how a person and their family may engage (or not) is self-management and treatment.

**Chronic Disease Self-Management**

To review, Chronic Disease Self-Management (CDSM) has been identified as an essential tool in addressing the needs of people living with chronic disease, to improve self-management of disease with the ultimate goal of enhancing quality of life and years of living well with chronic illness. Curtin and Mapes (2005) define self-management as “the patient’s positive effort to oversee and participate in their health care in order to optimize health, prevent complications, control symptoms, marshal medical resources, and minimize the intrusion of the disease into their preferred lifestyles” (p. 390). As the
population ages, the population with chronic diseases will continue to grow significantly, and will be responsible for an estimated 70% of the health care spending (Curtin & Mapes, 2005). With these growing demands, Foster, Taylor, Eldridge, Ramsay and Griffiths (2007) identified the importance of “shifting from paternalistic to partnership models of care” (p. 2). In recognition of the rising prevalence of chronic disease, the BC Ministry of Health has funded the development and implementation of many chronic self-management programs across the province. As Curtin and Mapes (2005) describe, the ultimate goal of a self-management program is: “patients with chronic illness manage the effects of illness on functioning, emotions, and interpersonal relationships and minimize the intrusion of the disease into their preferred lifestyles (p. 392). Furthermore, Curtin and Mapes suggest that “building patients’ confidence in their ability to affect the outcomes they have targeted seems to be another positive way to encourage successful self-management among people with chronic illness” (p. 392). It is an overwhelming situation when a patient is diagnosed with a chronic disease. Anderson (1996) refers to this as a biological disorder of embodying an element of uncertainty, involving “both uncertain knowledge about the impact and course of the condition and of appropriate behavior in the face of its effects” (p. 700). CDSM embodies medical, role and emotional management. Clark et al. (2008) describe self-management support “as the provision of education and support to increase patient’s skills and confidence in managing their health and illness” (p. S312). The intent is for health care workers to initiate interactions with patients about goal setting, problem solving and ongoing follow up of disease management (Coleman & Newton 2005). Furthermore, health care workers need to know the community/ self-management resources, patient’s self-management knowledge,
expectations, and priorities available for the particular population. Chodosh et al. (2005) say, “enthusiasm is growing for the role of self-management programs in controlling and preventing chronic disease complications” (p. 427). Chronic diseases are incurable and life-long diseases, with impacts on family, relationship, job, finances and quality of life.

Stone, Pound, Pancholi, Farooqi, and Khunti (2005) say that “involving patients as partners in their care may lead to more effective chronic disease management and there has been a call to empower patients with chronic conditions such as diabetes through education to encourage self-management” (p. 2005). Empowerment in patients’ lives may encourage them to participate actively in their treatment plan and achieve optimal care (Curtin & Mapes, 2005). Self-management and gaining knowledge about their disease will positively impact their health, the likelihood of taking medications as prescribed and improve communication with health care workers. According to Lorig et al. (2001), “A low cost program for promoting health self-management can improve elements of health status while reducing health care costs in populations with diverse chronic diseases” (p. 1217). Coleman & Newton (2005) define “self-management as support that goes beyond traditional knowledge-based patient education to include processes that develop patient problem-solving skills, improve self-efficacy, and support application of knowledge in real-life situations that matter to patients” (p. 1503).

Managing CKD is not an easy mission. As described previously, patients need to follow a renal diet, which will slow and prevent the progression of the disease. They need to make allowances for coping measures and accept a new lifestyle. They need to recognize the signs and symptoms of comorbid complications. Furthermore, within the context of CKD, it is purported that “patient(s) with kidney disease have better outcomes
if they take an active role in the management of their own condition” (Costantini, Beanlands, McCay, Cattran, Hladunewich & Francis, 2008). If this statement is true, health care professionals must recognize the importance of patient expertise about their chronic diseases, and connect with newly diagnosed patient to foster their involvement and development of expertise (Thorne, 2006). Involvement is essential to the development of self-management skills; as Curtin and Mapes (2005) suggest, “Self-management involves the patients’ engagement in activities that protect and promote health; their observation of symptoms and signs of illness; their adherence to treatment regimens; and their management of the effects of illness on functioning, emotions, and interpersonal relationships” (p. 390).

The significance of this project is to more fully explore chronic disease self-management within the context of CKD within the Indo-Canadian population. Through an integrative literature review, important factors in providing care for this population will be considered.

**Methodology**

The intent of this project was to conduct an integrative literature review from the nursing literature focusing on CKD self-management programs in the Indo-Canadian population. In order to accomplish the goal of my major project, I conducted a review of published research on CKD, CDSM and the Indo-Canadian population. This integrative literature review has the potential to facilitate and generate new insights and understanding from examining studies using diverse methodologies and secondly, to provide evidence based foundations for nursing practice (Whittemore & Knafl, 2005).
I undertook the literature review using several on-line data bases. I searched CINAHL and Medline for research articles using the word ‘self-management’. CINAHL and Medline offer a comprehensive variety of articles from a wide selection of professional peer review journals. Furthermore, I also checked reference lists of articles to ensure that the searches were complete. I chose the CINAHL database as my primary data source as it is an extensive database with a strong nursing and allied health care professional focus. The initial search of CINAHL using the terms chronic disease self-management resulted in the identification of thousands of articles. Based upon this information, I added additional keywords including chronic kidney disease, ethnic minority, South Asians, immigrants, and Indo-Canadian population to refine the category of self-management within professional practice and research overtime (Whittmore & Knafl, 2005). I further narrowed my search by identifying full text articles and secondly, by specifically looking for articles that included both genders. Results from this search elicited sixty-five articles. Again, I further refined the search to focus specifically on adult populations (excluding children and youth) and ended up with fifty-four articles that met the selection criteria for analysis. Articles published in English language were selected, the exception being some articles that include significant Punjabi words like ‘desi’ and ‘kismet’. These words describe traditions and beliefs that are important to more fully understand the focus of the search.

Through the search process, it became clear that there are more specific studies conducted with people of Indian heritage in United Kingdom (UK) than in Canada. This reflects the fact that immigration to the UK began in the early 20th century (earlier than Canadian immigration patterns). I chose to include UK authors' work in my project as
these articles have the potential to demonstrate issues and needs that are relevant to the Canadian context. I primarily focused on articles published within the last 10 years that included the references to the Indo-Canadian population and self-management (Barlow et al., 2005; Costantini et al., 2008; Curtin et al., 2008; Foster et al., 2007; Fung et al., 2009; Grewal et al., 2005; Hilton et al., 2001; Jain et al., 2008; Lorig et al. 2001; McGowan, 2005; Oliffe et al., 2007; Osman et al., 2012). I have also selected several classic articles that are frequently referenced and focus specifically on immigration and self-management (e.g., Anderson, 1991; Choudhry et al., 1998; McGowan, 2003).

In reviewing the search process, self-management and CKD are broad topics that elicited over a thousand articles published in last 10 years period from CINAHL. Similarly, when I initially conducted a search using the Medline database it resulted in close to 2000 articles. I used search terms to refine the search and was able to narrow the search to fifty-four articles. The beauty of the integrative literature review approach is that it also permits a variety of methodologies and therefore allows for the inclusion of articles that may play an important role in evidence-based practice (Whittemore & Knafl, 2005). Keeping this in mind, the search was further refined by focusing on primarily nursing research articles. I focused on the quality of the article with an emphasis on research-based findings. These research article findings are supported by information about data, sample, methodology, and peer review publishing, and provide further insight about need for further research.

Through the use of these increasingly specific criteria, I finally refined my collection of articles to 20 research articles. While initially there seemed to be a large volume of articles, in reality, there is paucity of research available specifically on self-
management of CKD within the Indo-Canadian population. After selecting the articles, they were read and the significant findings were highlighted with transparent marker, coded and transcribed onto the data collection sheet. I used concept mapping to draw themes and patterns and to identify the focal point of the article. Then I began arranging the data by drawing lines to group the data together. It occurred to me this process was useful to cluster the themes together. Initially, I identified themes found across the articles. These themes were condensed to two overall themes namely: 1) the impacts of language, gender roles, culture for the Indo-Canadian population; and 2) approaches to self-management in CKD for Indo-Canadians. Subsequently, a data collection table was created to assist in the analyzing articles for methodology, strengths and limitations of research, and significant findings. All of the key research articles are described in Appendix II. These themes and patterns will be used to describe findings and recommendations for health care providers.

Findings

Through the integrative literature review, the following themes were identified: first, the impact of language, culture and gender roles for the Indo-Canadian population; and second, approaches self-management in CKD for Indo-Canadians.

**Impact of Language, Culture and Gender Roles**

Without basic English language skills, it is difficult for patients to function in their adoptive country, to access health care and to obtain the information necessary to understand and manage their illness. Most of the time, language barriers are a substantial problem and this is further complicated by the difficulties in accessing a skilled interpreter. Throughout the literature, language barriers are identified as having profound
impacts on access to care (Donaldson, 1986; Graham et al., 2002; Oliffe et al., 2007; Osman et al., 2012). In practical terms, language barriers make client teaching and follow up care difficult. However, language is situated within broad cultural understandings and as Fikree and Pasha (2004) state, “education and improved economic circumstances alone are likely to be insufficient to change practices that have become culturally, socially, and in some cases legally, enshrined” (p. 825). Therefore, language barriers and interpretation practices are complex as they include not only translation but cultural beliefs and social processes as well. Health care practitioners often rely on family members and yet, as Anderson (1996) states, “family members may be expected to act as interpreter between patient and health care provider, even though the shortcomings of such arrangements are usually obvious. This means that clinical misunderstandings persist, and the possibilities for treatment negotiation are minimal” (p. 701). Similarly, Rait and Burns (1997) suggest that interpretation “by family members should be avoided, as information may be inaccurate or unobtainable” (p.975). These language barriers apply to those individuals who don’t speak English as well as for individuals who speak the language but whose first language is not English (e.g., Punjabi). While patients may know limited English, their language skills may not necessarily extend to understanding their disease process and or to having an open conversation with health care workers. As Osman et al. (2012) observe, “information and advice was often recalled from healthcare providers about healthy lifestyles, although it is not clear whether this information had been understood or acted on” (p. 31).

There are many implications for care suggested in the literature that identify important factors in developing appropriate care for diverse populations. Some of these
factors are disease specific, for example in the case of CKD, where it is especially important to educate patients at early stages of their illness before cognitive skills are impaired by the disease (Costantini et al., 2008). Others are more general and involve language and the capacity of patients to engage in learning about their illness. For example, in Ahmad et al.’s (2004) qualitative study findings involving 24 East Indian immigrant women demonstrate that when education is delivered in their own language, it makes education easy and the women were better able to pay attention.

Issues of language and culture become even more multi-faceted when examined in the context of gender roles. Choudhry et al. (2002) state:

Many South Asian women lack knowledge of health risks, have differing ideas as to self-care, experience language barriers, and are economically dependent.

Women are particularly subject to the stress of isolation, are preoccupied with their family needs, and have a little time to attend to their own health (p. 75).

When women are sponsored to come to Canada by their children, they are often obligated to take care of their grandchildren and to do household chores. In turn, women depend on their family for basic needs such as: food, housing, transportation and clothes. These women are not focusing on themselves, expanding their connection with Canadian culture, or trying to learn the English language due to their workloads at home. In India, grandparents are supposed to supervise the work of other younger family members rather than working themselves.

Gender roles in relation to language barriers and interpretive processes that are embedded within broad cultural understandings influence how illness is viewed and understood. It is typical for Indo-Canadian families to live within extended families and
for women to care for grandchildren and do household chores. In the Indo-Canadian culture, being a good woman or mother means a woman will take care of the whole family first; she will put everyone else first. After caring for the whole family, cooking, cleaning and laundry, there is often no time left for women to take care of themselves. Further as Rait and Burns (1997) state, “it is important to remember that families that live together do not necessarily provide company or care for older members” (p. 974).

Cultural barriers may have a profound impact on access to care and in patient’s abilities to engage in self-care or self-management activities. Osman et al. (2012), examining a series of randomized controlled trials, reviewed eight studies involving Indian, Pakistani, Bangladeshi people and state, “cultural barriers to exercise were a theme, particularly the social roles of women that prevented them from engaging in activities outside the home and many thought physical activity would exacerbate illness” (p.31). These issues were also identified in a qualitative study by Graham et al., (2002) who reported that respondents describe a range of systemic issues that negatively impact access to care including “social, political and economic pressures; domestic violence; poverty; language problems; family and children’s issues; and health” (p. 339). Graham et al. (2002) recommend rapid response when services are requested because South Asian women typically do not seek help prior to a crisis point.

Cultural values such as izzat and the power of gossip may lead to oppression, distress and self-harm. Izzat, as used in the Indo-Canadian community, refers to the honor or good reputation of a person, family, or group of people. Graham et al. (2002), in their qualitative study exploring the needs of South Asian women, report that
Izzat was given precedence and preference over the care and happiness of children in some families. The groups also theorized that izzat could be misused to reinforce women’s roles in family life, often to coerce women into remaining silent about their problems (p. 341).

Furthermore, this oppression does not allow women to express their feelings because they may fear the family or community will find out and cause further distress in their life. If a woman is a victim of domestic violence, she may be trying to seek social services. In some situations, this could lead into further violence in the house and ultimately lead to divorce. Indo-Canadian men who place high value on traditional values believe that their masculinity will not tolerate divorce. The inability to express feelings, a sense of isolation, lack of knowledge, and a lack of awareness of rights are even more profound for women living in abusive situations (Graham et al., 2002). These factors may lead to a sense of desperation and distress. As Graham et al. (2002) describe, “deliberate self-harm is a particularly distressing symptom prevalent in the South Asian community” (p. 345). Even in non-abusive contexts, Indo-Canadian women give importance to the cultural beliefs and traditional values, not complaining about their own health issues, but caring for every member of the house (Choudhry et al., 2002). Lack of female practitioners further contributes to the problem because immigrant women may feel uncomfortable communicating with male practitioners.

South Asian women are dependent on men for basic needs. Fikree and Pasha (2004) claimed that “women in South Asia find themselves in subordinate positions to men and are socially, culturally, and economically dependent on them” (p. 823). Grewal, Bottorff, and Hilton, 2005, in a critical ethnographic study with 47 South Asian women,
report that South Asian women are not usually part of the decision-making process and have limited access to resources. In fact, if women try to succeed in their career, they may be condemned and belittled to make them feel insecure and ashamed.

While cultural roles may have a particular impact on Indo-Canadian women, Indo-Canadian men are also affected by those cultural values in different ways. Oliffe et al. (2007) in an interpretive ethnographic qualitative study with 14 Sikh men indicate that South Asian men often stay silent with regard to symptoms because they think weak men respond to stress. Further, they do not want anything to interfere with their work status, social class, and culture, which are priorities for them. They tend to ignore symptoms related to disease. The findings from Oliffe et al.’s (2007) study also demonstrate that for South Asian men, poor health is related to denial, underutilization of health care services and participation in activities that risk health. Punjabi men come across as self-sufficient in managing and regulating their body; they disguise the impact of socio-economic factors involved and put high priority on preserving their self-image. Oliffe et al. (2007) suggest, “South Asian Canadian men have been stereotyped as patriarchs with a propensity for violence” (p. 226). These stereotypes may further impact the capacity of South Asian men to reveal symptoms and access care.

Cultural beliefs perhaps most significantly impact the elderly who may hold especially strong traditional values. Donaldson (1986) stated:

Immigrant elderly may depend on others for their contact with the world outside their own community, particularly in health settings… Living within extended family also reduces the opportunity for privacy, as the data relating to sharing of
bedrooms indicate. There is no way of knowing how harmonious life is in these large multigenerational households (p.1081).

In summary, language barriers contextualized within cultural beliefs and values create unique issues for Indo-Canadians living with CKD. While there is some written information about these issues, there continues to be a significant gap in the literature in how to address these cultural, gender and language issues in ways that are effective. There is evidence that it is not easy or even possible for nurses to learn each culture, its beliefs, and health practices (Ulrich, 2009), but it is essential that health care providers attend to the confluence of language, culture and gender within their care (Osman et al., 2012). This is particularly true when considering how Indo-Canadians manage CKD with all its complexities and specifically in relation to CDSM.

**Approaches to self-management in CKD for Indo-Canadians**

Chodosh et al. (2005), in a meta-analysis of 780 studies focused on CDSM in older adults, found that self-management programs have a significant meaning for patients with chronic conditions, in particular diabetes and hypertension. Specifically Chodosh et al., in a sub-analysis involving 53 studies found that patients in CDSM programs have better controlled blood glucose and lower blood pressure. These findings are significant and relevant to CKD as both diabetes and hypertension are preexisting conditions that often lead to kidney disease. As Osman et al. (2012) point out, South Asians are in high risk group for developing diabetes. Oliffe et al. (2007) concur stating that both cardiovascular disease and diabetes are prominent in immigrants from South Asia. There is a need for health education programs to educate Indo-Canadians about the risk of developing kidney disease. Unfortunately, as Thomas et al. (2008) found in their
study examining the literature and conducting interviews with patients at high-risk, many patients who are diagnosed with diabetes may not be aware of the consequences of developing kidney disease. Furthermore, Thomas et al. (2008) also report that patients complain about inconsistent messages from health care workers and lack of clarity about the complications of diabetes. Thomas et al.’s findings suggest that incorporating self-management into health education care for diabetes is highly important. In fact, when patients were asked if they knew that kidney failure is one of the complications of diabetes, no one reported knowing. Foster et al. (2008), conducting a systematic review of lay-led CDSM programs (included 17 randomized controlled trials), found some improvement in self-efficacy (short term), perceptions of health, cognitive symptom management and participation in aerobic activity with the self-management programs.

Curtin et al. (2008), in a research study focused on assessing the relationship between self-efficacy and self-management, used a patient-physician interaction questionnaire to assess the needs of 174 CKD patients. To measure perceived self-efficacy, the Patient-Physician Interaction Questionnaire (PEPPI) was used; these findings show that self-efficacy and self-management behavior increase adherence to the treatment regime. Self-management behaviors were found to be associated with improved quality of health, as measured by Curtin et al. (2008). Curtin et al. further reported that CKD patients found self-management programs to be empowering, providing an opportunity for patients to take the initiative to talk to healthcare workers about their health issues and self-care activities. True partnerships only develop when patient and health care worker can communicate effectively. The participants in the study by Curtin et al., through participation in a self-efficacy index survey, reported that they are
confident to participate in making decisions and negotiating care with health care workers. Further, study participants with strong self-efficacy also demonstrate self-advocacy by seeking other health care opinions, and adding other interventions/treatments to their prescribed plan. In the context of this study, self-management behavior adherence was defined as being related to taking medication as prescribed and improved health outcomes as indicated by glycemic control and A1C levels.

Similarly, Tsay (2003), in a randomized controlled trial involving 62 patients in a Taiwan dialysis unit, found that patients who participated in a self-efficacy program have significantly lower intra-dialytic weight gains than the control group. As Tsay (2003) puts forth, “a person with an increased perception of self-efficacy is more likely to participate in self-care activities and thus increase their adherence to the treatment regime” (p.371). Further, in another randomized controlled trial, Tsay and Hung (2004) studied 25 dialysis patients in an empowerment group and 25 in a control group. Tsay (2003) defined empowerment as including the “identification of problem areas for self-management; exploration of emotions associated with these problems; development of a set of goals and strategies to overcome these problems to achieve these goals; creation and implementation of behavioral change plans; and stress management” (p. 59). Tsay and Hung’s findings indicate that patients in the empowerment program were better able to deal with stress, practice self-management skills and were better able to overcome their depression than the control group. Kennedy et al.’s (2007) randomized control trial involving 629 patients living with chronic conditions illustrates lay led self-care programs were able to increase self-efficacy and energy. Overall, findings in the
literature consistently indicate that self-management programs enhance the empowerment of patients, participation in self-care, and communication about health issues and health care plans (Chodosh et al., 2005; Costantini et al., 2008; Curtin et al., 2008; Foster et al., 2007; Kennedy et al., 2007; Tsay & Hung, 2004; Tsay, 2003).

Choudhry et al. (2002), in a participatory action qualitative research study involving two groups of South Asian women, report that knowledge and empowerment was associated with self-efficacy and that those women who felt empowered engaged in team projects, directing presentations and other health education activities. This study provides evidence that it is important to shift our thinking from being primarily focused on biomedical indicators to an approach that encompasses patient involvement, sharing information and decisions to accomplish the goals of self-management. As has been pointed out earlier, this is especially important in CKD where if patients are diagnosed at an early stage they may not feel symptoms related to the disease.

In another study, Costantini et al. (2008), using a qualitative exploratory methodology, studied 14 individuals with a diagnosis of kidney disease. They showed that people need disease-specific education in order to understand the link between no symptoms and diagnosis of CKD, and secondly, they described the importance of developing a collaborative care model to support self-management. Costantini et al.’s (2008) study involved people with mild to moderate CKD (six males and eight females). In this study, patients claimed that after their diagnosis of kidney disease, they were not prepared to manage the disease due to lack of knowledge. These findings suggest that when patient is newly diagnosed with kidney disease they do not know what to ask, and it
is then the healthcare worker’s responsibility to make them aware about the disease process.

Much research evidence specifies that self-efficacy training programs support patients to make wise decisions for their health. Empowerment is seen as integral to this process. As Anderson (1996) states, empowerment is a social process of recognizing, promoting, and enhancing peoples’ abilities to meet their own needs, solve their own problems, and mobilize necessary resources to take control of their own lives. More simply [it is] a process of helping people assert control over what affects their health (p.698).

One example is Nygarth and Malm’s (2012) study of 46 dialysis patients who participated in an empowerment intervention. The intervention group using a Swedish version of a diabetes empowerment scale reported improved quality of care with a personal sense of empowerment. The empowerment group was more able to identify the problem, cope and find solutions for the problem than comparison group. Empowerment then appears to be related to improved self-management where individuals use their own resources, meet their needs, feel in control and solve their own problems.

Findings from the literature also demonstrate that self-management of kidney disease is a complex task. It should be pointed out that Indo-Canadians with CKD face the same challenges as the general population in terms of complexity of the disease, multiple comorbid conditions and on-going self-management of the disease as well a experiencing the confluence of impacts of language, culture and gender roles. While there are few studies specifically focusing on CDSM in CKD in the Indo-Canadian or South
Asian population, many of the important issues are described in the literature related to co-morbid conditions (e.g., diabetes). Sohal (2008) found that

Suboptimal treatment of diabetes in South Asians may be due to several barriers, including a lack of knowledge about diabetes, negative beliefs and attitudes relating to diabetes, and noncompliance with lifestyle changes such as diet, weight control and physical activity, all of which are compounded by lack of culturally sensitive and ethnic-language-specific diabetes education centers in Canada (p. 206).

Jain et al. (2008), in an action research qualitative study involving six South Asian focus groups, found that lack of knowledge and available resources to explain causes and risk factors of kidney disease among those most at risk were of particular importance. The focus of this action research was on the development of educational material appropriate for South Asians and included creating a DVD entitled: ‘Preventing Kidney Disease – The Silent Killer Affecting You’. Peer educator work in this project demonstrates that positive life style modifications and increased access to a risk factor assessment may be effective in the prevention of renal disease. Ahmad et al., (2004), in a qualitative research study involving 22 women from China and 24 women from India, stated that the women’s main resources for information were family, social networks, television programs, posters, newspapers, magazines, other printed materials, gyms, yoga centers and doctors.

The needs of the Indo-Canadian population in relation to CDSM in CKD also may be illuminated by examining studies involving immigrant populations. One example is a study by Wu, Penning and Schimmele (2005) involving 16,046 immigrants and
102,173 non-immigrants aged 18 and older across Canada. This study used logistic regression models to analyze data from Statistics Canada to examine help-seeking behaviors and found three consistent themes evident in immigrant families: 1) a higher occurrence of unmet needs because of perceptions that the care would be inadequate, 2) not knowing where to access health care including transportation barriers, and 3) language problems. It may be important to examine these findings within the context of CDSM in CKD as there continues to be a significant gap in the literature specific to the Indo-Canadian populations. Research is necessary to understand how Indo-Canadian renal patients make decisions during the progression of disease, their emotional adjustments, and how nephrology nurses can assess their values and health beliefs to best incorporate self-efficacy in managing renal disease.

In summary, the findings from the integrative literature review include two major themes. The first is the impact of the impact of language, culture and gender roles for the Indo-Canadian population; the second relates to CDSM programs for people living with CKD. There remain significant gaps in the literature in relation to how to engage effectively with Indo-Canadians in relation to CDSM in CKD.

Implications and Recommendations for Care

CKD is a complex condition where patients need to understand the physiological, psychological, and social impacts on day-to-day life. This becomes even more complicated when issues of language, cultural, gender and basic knowledge about disease are present such as in the Indo-Canadian population. Findings from the integrative literature review suggest that organizing an interpreter or simply translating materials to solve language barriers is not adequate: nurses’ need to understand the
complexity of these issues. Doane and Varcoe (2006) describe that “as nurses we work with the diversity of human life. At times we find ourselves in situations where we are working with families who come from backgrounds, religious faiths, or life situations different from our own” (p.7). In these situations, it becomes important for nurses to create the bridges necessary to effectively care for patients whose values and beliefs may be substantially different than their own. Assuming a set of values and beliefs based on ethnicity (e.g., Indo-Canadians) is ineffective. Browne et al. (2009) refer to this narrow approach as culturalism suggesting that it is “the process of viewing people through the lens of culture, defined narrowly as shared values, beliefs and practices, and often conflated with ethnicity” (p. 168). The findings from the integrative literature review for this project suggest that nurses then require a broad understanding of how language, cultural beliefs and gender roles are interwoven in order to effectively care for patients and implement supportive programs such as CDSM. This approach is congruent with Browne et al. (2009) who describe culture is not something fixed or static, and as primarily comprising the beliefs, values, behaviors, and customs inherent to those identified as other. As we have gained a deeper understanding of the complex contexts of people’s lives and as we have taken up critical discourses, we have reframed our way of thinking about culture (p.170).

The implications of the findings from this project are therefore complex. Nurses both need to understand the potential meaning of traditional cultural practices such as “desi ways” and at the same time keep a broad focus or complex view of culture
understanding that traditional beliefs may be held closely or not by particular individuals/families.

Findings from this integrative literature review make evident the importance of having an awareness of the impact of gender roles within the broader understanding of culture. As Hilton et al. (2001) describe, “Desi ways provided a way to maintain and preserve their cultural heritage and identity as South Asian women…women who did not follow desi ways were believed to lack knowledge about these practices because their families of origin did not embrace these traditions” (p.559). From this perspective, it is important for nurses to understand the meaning of Indo-Canadian traditional practices; ignorance of these practices could limit interaction and the development of trust between patient and health care workers. As Grewal et al. (2005) suggest women made decisions about their health in consultation with family members.

Overall, family members were perceived to be supportive and provided direct and indirect assistance to women in ways that influenced their health. Expected roles and responsibilities often had detrimental influences on women’s health (p. 242). Similarly, Osman et al. (2012) notes nurses should consider beliefs that may prevent South Asian people from developing a healthier lifestyle, and give advice according to cultural needs…promoting physical activity while understanding cultural barriers and perceptions can allow nurses to tailor advice to individual needs and allow patients to access services (p.31).

Furthermore, it is important to construct a bridge between the health care system and the community in order to understand the patients’ lived culture and create
individualized well-thought-out plans. As Hilton et al. (2001) suggest, in describing what is necessary to meet the needs of women, “health care providers must be culturally sensitive and respect women’s choices to use traditional health practices” (p. 554). Again, it is important to point out that there may be great variability between women in the Indo-Canadian community and therefore, it is important for nurses to have an awareness of these gender related beliefs; it is also important for nurses to understand how a particular woman/patient may incorporate/not incorporate these beliefs in her everyday life.

Evidence in the literature consistently indicates that CDSM programs are useful to address the epidemic of chronic disease specifically for CKD patients. However there continues to be gaps in the literature related to effectiveness of self-management programs in particular populations. Findings demonstrate that self-management behaviors improve patient outcome, and quality of life (Chodosh et al., 2005; Foster et al., 2007; Tsay et al., 2003; Curtin et al., 2008). **Self-management program outcomes improve with embracing patient’s beliefs, values and addressing their concerns regarding renal disease management** (Costantini, 2006). As suggested by Thomas (2008), self-management programs are effective when patients can express their concerns, tell a story, ask what can be done to control the condition, and educate about the consequences of kidney disease. This is consistent with Costantini (2006) who states “self-management gives clients greater onus over their renal failure regime and allows individuals to actively utilize their chronic illness expertise. These findings are in keeping with the origins of self-management practices. Lorig, Ritter, Villa and Armas (2009) found self-management programs that include problem-solving and decision making improved
diabetic self-care and health outcomes. Theoretically, self-management could be an important link between nursing practices and client expertise in CKD.

Self-efficacy, the conceptual foundation of self-management programs, is essential in demonstrating positive changes in health behavior whereby patients have confidence and the ability to participate in their health care decisions. Self-efficacy creates a context where patients set goals and inspires their desire and capacity to achieve those goals. Understanding the concept of self-efficacy would advance nurses ability to incorporate self-management into the care of renal patients and also foster the capacity of renal patient’s to follow self-management (Mabe Newman, 2006). Nephrology nurses need to assess client self-efficacy which encompasses the ability to understand disease process, management of symptoms, emotional balance as well as to encourage dealing with its impact on behavior (Costantini, 2006). Self-efficacy and self-management strategies need to be incorporated within an overall understanding of the impacts of language, culture and gender. Ulrich (2009) positions that “nurses shall use effective, culturally competent communication with clients that takes into consideration the client’s verbal and nonverbal language, cultural values and context, and unique healthcare needs and perceptions” (p. 367).

Findings from this integrative literature review also indicate that Indo-Canadian CKD patients should be empowered to understand the disease process, management, dietary restrictions, symptoms control and emotional management through their relationships with health care workers. Indications are that Indo-Canadians may learn better in group sessions where they do not feel alone. Jain et al. (2008) suggests that “peer education is an established technique for promoting health awareness in ‘hard-to-
teach’ groups” (p. 174). Thus, findings indicate that self-management programs in the Indo-Canadian community should focus on early detection of CKD, deliver education in patient’s language within group settings, and involve community services and counseling services.

In summary, CDSM programs have been demonstrated to be effective in CKD for improving health and quality of care. These programs may require some refinement within specific populations. These refinements need to be more than “translation or interpretation” but need to include understanding how cultural beliefs and gender roles may influence understandings of living with CKD. Nurses then must also shift their care from a medical model of care where the lab indicators take precedence over a model of care where patients' values and beliefs are integral to care planning. In today’s care plan incorporating self-management and understanding cultural health beliefs along with medical management is essential.

Discussion

Since we know that CKD is a complex disease itself, and there is no cure for this disease, education to slow the progression of the disease, self-management of symptoms and participation in the care is critical to the management of disease and to the effective use of resources within our health care system. For Indo-Canadians living with CKD, understanding cultural beliefs will improve care and ultimately help to provide quality of life. Findings indicate that self-efficacy is integral to CDSM behaviors and that these strategies may empower patients to get involved in decision making process for their health. In spite of the success of self-management programs, there is gap in how these self-management programs address gender, language and cultural issues and these factors
may ultimately impact their effectiveness. Findings from this integrative literature review indicate that it is important to tailor programs to learning needs. We cannot make assumptions about cultural beliefs based on group identity (e.g., Indo-Canadian), and because we all learn differently, it is therefore important that we ask our patients which method would be best for them to learn about their disease. At the same time, there are some research findings that indicate that Indo-Canadians may prefer to receive information through group settings and peer to peer communication where they do not feel alone. Ultimately, communication is the key that will allow us to plan appropriate programs, actively listening for feedback and ultimately to set appropriate goals with patients. Contextualized within language, cultural beliefs and gender roles, Indo-Canadians may appear to play a relatively passive role when it comes to making health related decision. We need to learn how to better deliver health related knowledge so they are empowered to participate in their care. This includes the involvement of family members from the time of diagnosis because findings from the literature suggest women usually do not make decision without their family and men may not access health care unless they are acutely ill. This is further amplified in CKD where patients may be unaware of any major symptoms until later stages of the illness. The high prevalence rates in the South Asian populations of diabetes and hypertension, two co-morbid conditions leading to CKD make it particularly important to understand how to develop self-management programs that will allow nurses to engage effectively with Indo-Canadians.
References


BC Ministry of Health, (2007). Primary health care charter: A collaborative approach:


Statistic Canada (2005). Perspectives on labour and income. Fact sheet on minimum


Appendix I – Expanded Chronic Care Model

![Diagram of the Chronic Care Model](image)

Table 1: The Chronic Care Model (Wagner et al. 1999)

<table>
<thead>
<tr>
<th>MODEL COMPONENTS</th>
<th>EXAMPLES</th>
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<tbody>
<tr>
<td>Health System - Organization of Healthcare</td>
<td>Program planning that includes measurable goals for better care of chronic illness</td>
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<tr>
<td>Self-Management Support</td>
<td>Emphasis on the importance of the central role that patients have in managing their own care</td>
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<tr>
<td>Decision Support</td>
<td>Integration of evidence based guidelines into daily clinical practice</td>
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<td>Delivery System Design</td>
<td>Focus on teamwork and an expanded scope of practice for team members to support chronic care</td>
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<tr>
<td>Clinical Information Systems</td>
<td>Developing information systems based on patient populations to provide relevant client data</td>
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<tr>
<td>Community Resources and Policies</td>
<td>Developing partnerships with community organizations that support and meet patients’ needs</td>
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Appendix II: Summary of Research Article Findings
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<thead>
<tr>
<th>Year</th>
<th>Author</th>
<th>Title, Journal</th>
<th>Purpose</th>
<th>Sample characteristic</th>
<th>Methodology</th>
<th>Strengths and weaknesses</th>
<th>Key Findings</th>
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<tbody>
<tr>
<td>2004</td>
<td>Ahmad, F., Shik, A., Vanza, R., Cheung, A., George, U., Stewart, D.</td>
<td>Popular health promotion strategies among Chinese and East Indian immigrant women</td>
<td>To understand health promotion strategies and what factors influence to deliver health messages</td>
<td>Eight focus groups involved 46 immigrant women – 22 from China and 24 from India</td>
<td>Qualitative research method using focus group data to collect the information</td>
<td>This study was involved with women who speak Mandarin and Hindi, and moderators and facilitators were bilingual as well</td>
<td>Both of these Indian and Chinese group of women’s main resources for information were family, social networks, television programs, posters, newspapers, magazines, other printed materials, gyms, yoga centers and doctors</td>
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<td>2001</td>
<td>Campbell, J., Ramsay, J., Green, J.,</td>
<td>Age, gender, socioeconomic, and ethnic differences in patients’ assessments of primary health care</td>
<td>To examine variations in assessments of primary care according to age, gender, socioeconomic, and ethnicity variables</td>
<td>4819 adult respondents. Respondents were allocated to one of four categories: 16-30 years, 31-45 years, 46-60 years, and 61 years or older. Half of the respondents reported white, most of other half said black or South Asians</td>
<td>A cross sectional survey of consecutive patients attending 55 inner London practices was performed over 2 weeks period using General Practice Assessment Survey (GPAS) assessment of 13 important dimensions of primary care</td>
<td>Major limitation of using a cross sectional survey to examine differences in assessments of care between subgroups in the population because there are three differences variables; 1. Difference in reported assessment reflects quality of care, 2. Cultural differences reflected by willingness to report, 3. Reflected by needs of health care. Further research needs to be done to analysis reflected variables.</td>
<td>This study shows significant lower score for black and South Asian respondent than White respondent for patient assessment of primary care. Primary care providers need to ensure that services provided are appropriate for all patient groups within their communities</td>
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<tr>
<td>2005</td>
<td>Chodosh J., Morton S., Mujica, W., Maglione M., Suttorp M., Hilton L., Rhodes S., Shekelle P.</td>
<td>Meta-Analysis: Chronic Disease self-management programs for older adults,</td>
<td>To assess the effectiveness and vital components of self-management programs for hypertension,</td>
<td>780 studies screened, 53 studies (randomized trials) of self-management with control group and usual care for diabetes and hypertension and search strategies were not comprehensive, reviewers disagreement resolved by consensus or third party</td>
<td>Strategies to identify studies clear. Uneven quality and quantity of the studies. Evidence of possible</td>
<td>Self-management programs for diabetes, hypertension may produce clinically important</td>
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<td>Year</td>
<td>Author(s)</td>
<td>Title</td>
<td>Journal</td>
<td>Participants</td>
<td>Methods</td>
<td>Findings</td>
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<td>2002</td>
<td>Choudhary U., Jandhu, S., Mahal, J., Singh, R., Sohi, P., Mutta, B.</td>
<td>Health Promotion and Participatory Action Research with South Asian Women</td>
<td>Journal of Nursing Scholarship</td>
<td>Two groups of South Asian women from India and of Indian origin. 7 Punjabi and Hindi language speaking women from South Asian Senior Women’s Association of Peel (SASWAP) and 6 women Gujarati language speaking from Inter-Cultural Neighbourhood Social Services (ICNSS)</td>
<td>3 years of qualitative data collection through focus groups using participatory action research. Data interpreted through iterative process and dominant themes identified</td>
<td>Small size of sample to generalize the information. Only women were considered for this study. This empowered participants group who gained knowledge and planned, promoted and conducted health educational workshops</td>
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<tr>
<td>2008</td>
<td>Costantini, L., Beanlands, H., McCay, E., Catran, D., Hadunewich, M., Francis, D.</td>
<td>The self-management experience of people with mild to moderate chronic kidney disease</td>
<td>Nephrology Nursing Journal</td>
<td>6 male and 8 female educated diagnosed with kidney disease from 1 to 18 years</td>
<td>Qualitative exploratory study was part of descriptive, cross sectional, quantitative investigation exploring using face-to face interviews, psychosocial and health behaviors in people living with CKD</td>
<td>Very small number of participants from which to generalize the results. This study does not describe the ethnicity of the population as well. The findings show that people need disease specific education in order to link between no symptoms and diagnosis of CKD, and develop collaborative care model to support self-management</td>
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<td>2008</td>
<td>Curtin, R.B., Walters, B.A.J., Schatell, D., Pennell, P, Wise, M., Klicko, K.</td>
<td>Self-efficacy and self-management behaviors, in patients with chronic kidney disease</td>
<td>Advances in Chronic Kidney Disease</td>
<td>174 patients with chronic kidney disease. Sample of this study included a white and black CKD population</td>
<td>Patient-Physician Interaction Questionnaire (PEPPI) was used</td>
<td>Sample of this study was white and black CKD population, however the South Asians population was not included. Five self-management behaviors were reported: communication with health care workers, participation in care, self-care, speaking for them- selves, and taking medications as prescribed. In the study, self-management seemed to improve quality of health. Patients are taking initiative to talk to healthcare workers about their health issues, self-</td>
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<td>Year</td>
<td>Authors</td>
<td>Article Title</td>
<td>Methods</td>
<td>Participants</td>
<td>Main Findings</td>
<td>Implications</td>
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<td>2007</td>
<td>Foster G., Taylor SJC, Eldridge, SE, Ramsay J, Griffiths CJ</td>
<td>Self-management education programmes by lay leaders for people with chronic conditions</td>
<td>Cochrane Database of Systematic Reviews</td>
<td>Randomized controlled trials, comparing self-management programmes against no interventions or clinical health care programs, 17 trials, 7442 total participants</td>
<td>70% population was white, others were Hispanic, Chinese, Bangladeshi, Vietnamese, Greek, Italian. This study did not include South Asians living with chronic renal disease</td>
<td>These self-management programs were effective for the short term in participants to address cognitive symptom management. There is no evidence of improvement in health related quality of life</td>
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<td>2009</td>
<td>Fung, K., Wong, Y.</td>
<td>Factors influencing attitudes towards seeking professional help among east and southeast Asian immigrant and refugee women</td>
<td>International Journal of Social Psychiatry</td>
<td>To examine the relationship of culture beliefs, perceived service accessibility and attitudes towards seeking mental health care</td>
<td>Mental Distress/illness Explanatory Model Questionnaire (MDMEQ) used for survey. Attitude Towards Seeking Professional Psychological Help</td>
<td>However this study included five different minority group of women three Chinese, Korean, Vietnamese Canadian communities, South Asian community was not involved</td>
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<td>2002</td>
<td>Graham, C., Bashir, C., Chantler, K., Burman, E., Batsleer, J.</td>
<td>South Asian women, psychological distress and self-harm: lessons for primary care trusts</td>
<td>Health and Social Care in the Community</td>
<td>To investigate self-reported needs of South Asian women suffering distress and mental health issues leading to self-harm and suicide</td>
<td>Qualitative study using focus group, interview guide used, principles of framework analysis used to analyze the data. The discussion occurred in Urdu, English and Punjabi</td>
<td>Study focused on women only, Time constraint due to short time funding, Interpreter was used for Bangladeshi women group (inability to speak English leads to social isolation and linked with lack of knowledge</td>
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<td>2005</td>
<td>Grewal, S., Bottorff, J., Hilton, B.</td>
<td>The influence of family on immigrant South Asian women’s health</td>
<td>Journal of Family Nursing</td>
<td>To examine the influence of family members on immigrant South Asian women’s health and health seeking behaviors</td>
<td>Critical Ethnographic Study</td>
<td>This study indicated the need for services to be able to respond rapidly when Asian women did ask for help, because they do not seek help prior to the crisis point. Izzat and power of gossip leading to oppression and self-harm</td>
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<tr>
<th>Year</th>
<th>Authors</th>
<th>Title</th>
<th>Focus</th>
<th>Methodology</th>
<th>Findings</th>
<th>Notes</th>
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<tr>
<td>2001</td>
<td>Hilton, A., Grewal, S., Popatia, N., Bottorff, J., Johnson, J., Clarke, H., Vенables, L., Bilkhu, S., Sumel, P.</td>
<td>The Desi ways: Traditional health practices of South Asian women in Canada</td>
<td>To describe the use of traditional health practices and importance of these practices in women’s daily life</td>
<td>Total of 50 participants between ages of 20 to 80 living in Canada from 10 months to 31 years. Sikh (21), Hindu (11), Muslim (14), Christian (3) and one not specified</td>
<td>Critical Ethnographic Method, face to face interviews conducted, Involvement of women who might not have a voice, Literacy level was not identified, women based study only, lot of Punjabi vocabulary used in this article, which could limit to understand the deepest meaning for many readers. It is older study but it focuses on South Asian population</td>
<td>Health care workers need to be culturally sensitive and respect women’s choices of traditional health practices. The ignorance of exploration of Desi ways could leads to minimize the important interaction between patient and health care workers.</td>
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<td>2008</td>
<td>Jain N, Farooqi A, Feehally, J</td>
<td>Raising awareness of chronic kidney disease among south Asians and primary care: The ABLE Project,</td>
<td>To develop methods to increase community awareness and to support practices to improve detection and management of CKD</td>
<td>South Asian from renal outpatient clinics, primary care hypertension, diabetes clinics and community centres. Each group had 8-10 participants</td>
<td>Action research qualitative study conducted to create baseline knowledge of kidney disease and risk factors among South Asian community of Leicester. Six focus group sessions lasted 60 minutes, were audio-taped, transcribed and translated by one of the multilingual researchers</td>
<td>This study is specifically focused on South Asian population, but there is no specific indication of gender, age group and language proficiency of participants in this study. Educational material appropriate for South Asians was developed. Peer educator reports positive life style modifications, and increased access to a risk factor assessment to prevent renal disease.</td>
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<td>2007</td>
<td>Kennedy, A., Reeves, D., Bower, P., Lee, V., Middleton, E., Richardson, G., Gardner, C., Gately, C., Rogers, A.</td>
<td>The effectiveness and cost effectiveness of a national lay-led self-care support programme for patients with long-term conditions: a pragmatic randomized controlled trial</td>
<td>To assess supporting patients with self-care helps to manage chronic conditions</td>
<td>629 patients living with chronic conditions were involved</td>
<td>Two-arm pragmatic randomized controlled trial design comparing the clinical and cost-effectiveness of the programs. 6 weekly sessions on self-care skills given to assess patient’s self-efficacy, reported energy, and health care utilization</td>
<td>28 health authorities in England were involved in this study, Only white population with different chronic conditions involved in this study. The CKD patients were not involved. These programs were able to increase self-efficacy and energy but did not affect utilization of health care services</td>
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<td>Year</td>
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<td>2012</td>
<td>Nygarth, A., Malm, D.</td>
<td>Empowerment intervention in outpatient care of persons with chronic kidney disease predialysis</td>
<td>46 patients attending predialysis clinic in southern county of Sweden applied for both intervention and comparison group</td>
<td>Demographic questionnaire, Comparison of pre and post-evaluation of an intervention increasing empowerment of patients with CKD</td>
<td>This study does not indicate the specifics of ethnicity of the participants and CDSM programs are not component of the study</td>
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<td>2007</td>
<td>Oliffe, J., Bottorff, J., Toor, H.</td>
<td>Elderly South Asian Canadian immigrant men</td>
<td>To investigate complex health issues, contribute to an emergent body of knowledge, and build contextual understanding about the way South Asian men approach health and illness</td>
<td>Fourteen Sikh men age between 63 to 88 years old living in Canada from 9-41 years</td>
<td>Study is only focused on men. Too small sample and a single site limit the ability to generalize</td>
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<td>2012</td>
<td>Osman Amina, Cruzio Joan</td>
<td>South Asian Cultural concepts in diabetes</td>
<td>Eight studies focused on South Asian origin with type 2 diabetes</td>
<td>Randomized controlled trails</td>
<td>South Asian are four times more likely to develop diabetes, furthermore, they are on high risk population to develop renal diseases. It is important for nurses to understand cultural health beliefs</td>
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<td>2004</td>
<td>Shiow-Luan</td>
<td>Empowerment of</td>
<td>To investigate 25 patients in</td>
<td>Experimental</td>
<td>The specific</td>
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<td>Year</td>
<td>Author(s)</td>
<td>Title</td>
<td>Study Design</td>
<td>Participants</td>
<td>Intervention</td>
<td>Outcome Measures</td>
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<td>2003</td>
<td>Shiow-Luan Tsay</td>
<td>Self-efficacy training for patients with end-stage renal disease</td>
<td>Randomized control study</td>
<td>62 patients Taiwan dialysis unit, n=31 in experimental group and n=31 control group received routine care</td>
<td>This article examined self-efficacy in 20-65 years old ESRD in a non-Caucasian population however did not include South Asian or immigrant populations</td>
<td>This study found patients in self-efficacy program have significantly lower intra-dialytic weight gains than the control group</td>
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<td>2008</td>
<td>Thomas, N.,</td>
<td>Development of a self-management package for people with diabetes at risk of chronic kidney disease</td>
<td>Multi-method study</td>
<td>11 men and 4 women between the ages of 45-78 years. 11 were white, 2 were Asian and 1 was mixed race</td>
<td>Small sample and the sample did not represent all patients with diabetes and early kidney damage</td>
<td>This study showed inconsistent message from health care workers, lack of clarity about complications of diabetes are indicated. The study findings suggesting incorporating self-management in the health education caring for diabetes. When patients were asked if they know that kidney failure is one of the complications of diabetes, no one knew it</td>
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<td>2005</td>
<td>Wu, Z., Penning, M., Schimmele, C.</td>
<td>Immigrant Status and unmet health care needs</td>
<td>Study sample 16,046 immigrants and 102,173 non-immigrants age 18 and older across Canada</td>
<td>Data collected from Canadian Community Health Survey 1.1 from Stats Canada in 2000-2001</td>
<td>Difference in immigrant and non-immigrant data is not significant p&gt;0.05</td>
<td>The study shows new immigrants' unmet health care needs; also this study indicates there is no difference among the immigrants</td>
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<td>who residing 15 years or longer and non-immigrants</td>
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