Université de Montréal

Self-care experiences of Indonesian adults with chronic disease living in Montreal

Par

Nurul Akidah Lukman

Faculté des Sciences Infirmières

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Abstract

Background: Self-care is an essential aspect of chronic disease management. This experience is shaped by culture and values, health knowledge/literacy, support from others and access to care. We aimed to explore the chronic illness self-care experiences and various influencing factors among Indonesian immigrants living in Montreal. **Methods:** We used a qualitative descriptive approach. Eight men and women, living with various chronic illnesses, participated. We conducted a thematic analysis. **Results:** Three broad themes were identified: 1) "*What's Helpful for Indonesian' Self-care"* captures the different sources of support and/or ways of being and doing that helped the participants manage and monitor their illness and feel well and healthy, both physically and emotionally; 2) "*Self-care Challenges and Responses to Living with a Chronic Illness*" highlights the key challenges that participants faced while living with a chronic illness and provides a description of how participants responded to living with an illness; 3) "*Expectations regarding Self-care and Support"* reveals some of the participants' disappointments regarding their own self-care and/or support. **Conclusion:** Taken together the themes highlight several important points regarding the self-care experiences of Indonesian immigrants that should be considered during care. These include the importance of faith and religion for Indonesians in self-care; being helpful has an important place in self-care; self-care is a learning process; self-care; including family support, is experienced differently in Canada compared to being in Indonesia; social support may continue transnationally; and there is a need for health care professionals to provide more personalized care.

Keywords: self-management, self-maintenance, self-monitoring, chronic illness, diabetes, hypertension, arthritis, chronic kidney disease, immigrants

Résumé

Contexte : Les auto-soins sont essentiels dans la gestion des maladies chroniques. Ils sont influencés par la culture, les valeurs, la littératie, le soutien des proches et l'accès aux soins. Ce mémoire vise à explorer les expériences d'auto-soins en lien avec les maladies chroniques et divers facteurs aux Indonésiens qui vivent à Montréal**. Méthodes** : Une approche descriptive qualitative a été utilisée. Huit adultes (hommes et femmes) vivant avec des maladies ont participé. Une analyse thématique a été réalisée. **Résultats** : Trois thèmes ont émergé : 1) « *Qu'est-ce qui favorise les auto-soins chez les Indonésiens?* » permet de saisir les différentes sources de soutien et stratégies qui ont aidé les participants à gérer leur maladie; 2) « *Défis des auto-soins et de vivre avec une maladie chronique* » met en évidence les principaux défis et aux émotions vécues lié aux maladies chroniques; 3) « *Attentes par rapport aux auto-soins et au soutien* » révèle les déceptions à l'égard des auto-soins et du soutien. **Conclusion :** Ensemble les thèmes mettent en évidence plusieurs éléments à prendre en compte pendant les soins aux Indonésiens, incluant l'importance de la foi et de la religion, être serviable a une place importante dans les auto-soins, les auto-soins sont un processus d'apprentissage, les auto-soins sont vécus différemment dans le pays d'accueil, le soutien social peut se poursuivre au niveau transnational, les professionnels de la santé doivent fournir des soins plus personnalisés.

Mots-clés : auto-gestion, auto-entretient, autosurveillance, diabète, hypertension, arthrite, maladie rénale chronique, immigrants

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List of abbreviations

CINAHL : Cumulative Index to Nursing and Allied Health Literature

COVID : Coronavirus Disease

CVD : Cardiovascular Disease

ESRD : End Stage of Renal Disease

HCP : Health Care Professional

IOM : International Organization for Migration

PKK : *Pemberdayaan dan Kesejahteraan Keluarga* (Indonesian language)

Posbindu PTM : *Pos Bina Terpadu Penyakit Tidak Menular* (Indonesian language)

SES : Socio-economic Status

T2DM : Type 2 Diabetes Mellitus

TV : Television

WHO : World Health Organization

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Chapter 1: Introduction

In 2017, the number of immigrants in Canada reached about 8 million (International Organization for Migration, 2019), and this number is predicted to grow to 10 million by 2031 (Statistic Canada, 2018). Quebec receives the second most immigrants across the country and Montreal is the main city where immigrants resettle (Statistic Canada, 2018). During the resettlement process, immigrants may face many challenges including finding accommodation, and work, barriers in accessing public services and adapting to different lifestyles, and over time these circumstances can negatively impact health and lead to adverse outcomes including a chronic illness (Bhopal, 2014). The most recent data from the Government of Canada notes that 44% of adults aged 20 and over in Canada, are living with a chronic condition; the most common are hypertension, osteoarthritis, anxiety disorders, osteoporosis, diabetes, asthma, chronic obstructive pulmonary disease, ischemic heart disease, cancer and dementia (Government of Canada, 2019). Some research has shown that risk factors for chronic disease, and the prevalence of these illnesses, are higher among immigrants when compared to the Canadian-born population (Rana, de Souza, Kandasamy, Lear et Anand, 2014). Chronic disease among immigrants is therefore an important public health problem in Canada and Quebec.

Self-care is an essential aspect of chronic disease management (Grady et Gough, 2014). It involves the actions and behaviours implemented by an individual towards monitoring and managing his/her chronic illness and maintaining health (Riegel, Jaarsma et Stromberg, 2012). These experiences are complex as individuals may have different perspectives and priorities on their illness and on how they go about carrying-out their self-care, and their expectations for support, may also vary. These experiences are also shaped by several factors which may facilitate or hinder self-care, including cultural beliefs and values, health knowledge/literacy, confidence and skill, support from others and access to care (Riegel et al., 2012). For immigrants, these factors are influenced by the pre-migration and post-migration contexts (Gushulak et MacPherson, 2004). For example, self-care may be shaped by cultural practices and beliefs from the country of origin while post-migration, discrimination and language barriers, difficulties in adapting to a new health care approach and system, can impede immigrants from effectively managing their illness and maintaining health, while altered family roles and dynamics may result in limited support (Ehrlich, Kendall, Parekh et Walters, 2016).

To reduce disparities in chronic illness outcomes, and to adequately care for and promote self-care among immigrants, it is therefore imperative for health care providers, especially nurses who often play the support role to these patients and their families, to understand the self-care experiences of these populations. The chronic illness self-care experiences among immigrants has been studied quite extensively, however gaps in the literature remain. Given that the self-care experiences are complex and may vary across and within immigrant communities, we therefore chose to focus this study on Indonesians, a small, less established immigrant population in Quebec. As a small community with a strong cultural and religious identity, and known risks to developing a chronic illness, a focus on this group was deemed to offer an opportunity to examine the phenomenon of self-care more in depth in order to have a more nuanced portrait of what is already known and also to gain a deeper understanding of how the pre-migration and post-migration context shape experiences. This study therefore aimed to explore the chronic illness self-care experiences of Indonesian immigrant adults living in Montreal, Quebec.

Chapter 2: Research Problem

There are several different reasons to study chronic illness self-care among Indonesian immigrants in Montreal. Firstly, Indonesians may face many issues during the resettlement process that can make them more vulnerable to develop a chronic disease over time (Bhopal, 2014; Fatmawati, 2019). They may also have a predisposition and/or may have been exposed to other factors pre-migration that put them at risk of developing and living with chronic illnesses post migration (Gushulak et al., 2011; World Health Organization, 2016). Secondly, their cultural beliefs and values, as well as their lifestyle behaviours from back home (Bayhakki, Hatthakit et Thaniwatthananon, 2019; Indrayana, Guo, Lin et Fang, 2019; Ligita, Wicking, Francis, Harvey et Nurjannah, 2019; Mizutani et al., 2016; Rahmawati et Bajorek, 2018a), which are different from the Canadian context, may complicate their self-care experiences, including their access to health care in Canada. Thirdly, they are an allophone community and predominantly speak English as a second language, rather than French (Fatmawati, 2019), and this may diminish their capacity to effectively access and use health education and information. Fourthly, since Indonesians are a predominantly Muslim community (Fatmawati, 2019), they may face direct or indirect discrimination in the current social and political context in Quebec, which may also affect their health-seeking behaviours and experiences in the health care system. Finally, their social, family, and gender context which might support self-care (Amelia, Lelo, Lindarto et Mutiara, 2018; Dewi, Weinehall et Ohman, 2010; Kristianingrum, Wiarsih et Nursasi, 2018; Ligita et al., 2019; Rahmawati et Bajorek, 2018a), may be altered by the context of immigration.

2.1 Indonesians, Migration, and Their Risk of Chronic Illness

There are about 4 million Indonesian people living outside their country and 0,5 %, or about 15 thousand, have resettled in Canada (International Organization for Migration, 2019). In

Montreal specifically, there are 625 Indonesian migrants, including 260 males and 360 females (Statistics Canada, 2019). This number has slightly increased from year to year (Fatmawati, 2019). Indonesians therefore represent a very small immigrant community in Montreal.

While migration of the Indonesian community may be driven by different factors, including personal reasons, for instance marriage (many Indonesian women follow their husbands to Canada), economic opportunity and family reunification, Indonesian migrants generally come as economic immigrants or under the family sponsored program (Fatmawati, 2019). This means that most migrate as young adults and arrive in a generally healthy condition. However, over time after resettlement their health may deteriorate (De Maio et Kemp, 2010).

As economic migrants, Indonesian may face many challenges. Upon initial arrival, they certainly need to find long-term accommodation and need to learn how their new society and its institution work (Bhopal, 2014). For those with low skill levels, they often need to take additional courses to be adjusted in their work conditions or to have better work opportunities (Fatmawati, 2019). Consequently, these efforts may have them ignoring their health since it may not be their concern or priority at the time. Over time they may also acquire lifestyles and health-risk factors of the local population, such as less physical activity, high-fat, calorie-dense food, and acquire local health problems, including becoming overweight (also known as the "healthy-immigrant effect") (Bhopal, 2014; Gushulak et al., 2011). In this context, similar to other immigrants, Indonesians may be at risk of developing chronic diseases over time and their resettlement experience can contribute to this risk.

Chronic disease is also a product of environmental, economic, genetic, and socio-cultural factors that people were exposed to in their original home country (Gushulak et al., 2011). Indonesia has a high prevalence of death due to chronic disease, including cardiovascular diseases (35%), chronic respiratory diseases (6%), and diabetes (6%) (World Health Organization, 2016), which comparatively are much higher to the rates of death due to chronic disease in Canada (20%, 5% and 3% respectively) (Statistics Canada, 2013). These data suggest that those who migrated to Canada may also have a predisposition or may have been exposed to other factors that put them at risk of developing and living with these chronic illnesses after migration. In short, Indonesians are a community that is affected by chronic illness.

2.2 Indonesian Immigrants, Chronic Illness and Self-care

Performing self-care activities among Indonesian immigrants with chronic disease in Canada may remain challenging, as they may face several barriers in self-care practices related to religion, beliefs and health knowledge/literacy, social support and access to care. Indonesians are well-known for their religiosity, and many believe that religion and spirituality can be resources that help them cope with their illness (e.g., through prayer) and to partake in self-care, or alternatively, it may contribute to a fatalist approach and lower their motivation to actively maintain their health (Bayhakki et al., 2019; Indrayana et al., 2019; Mizutani et al., 2016). In addition, studies in Indonesia found that rather than using medical health care services, some people prefer to use complementary and alternative medicine (Bayhakki et al., 2019; Dewi et al., 2010; Ligita et al., 2019; Rahmawati et Bajorek, 2018a). In the Canadian context, health providers may be unfamiliar with these religious beliefs, values and treatment preferences and may therefore not acknowledge them or address them in care. Due to miscommunication, and a lack of understanding and support, Indonesian immigrants, consequently, may be affected in their ability to effectively monitor and manage their chronic illness and maintain health.

Indonesian patients with chronic condition often depend on their family, especially female family members to help them cope with managing their illness (Amelia et al., 2018; Dewi et al., 2010; Kristianingrum et al., 2018; Ligita et al., 2019; Rahmawati et Bajorek, 2018a). Indonesians are culturally collective and family-oriented, so the role of the family is often significant and there is an expectation that family help one another (Amelia et al., 2018; Cultural Atlas, 2019; Dewi et al., 2010; Kristianingrum et al., 2018; Ligita et al., 2019; Rahmawati et Bajorek, 2018a). However, the role of family in self-care may be altered in the immigration context. While for some Indonesians, they may have migrated and/or reunified with their family, and thus supports may be maintained, for others they may not have family, or the migration context may have altered the family dynamic and functioning. For example, some Indonesian women will go out into the workforce due to the need of additional income to support the family (Fatmawati, 2018), so they may be less available to help. Families may also not live as close to one another and so family support networks may be limited.

Gender roles within the family also need to be considered. In Indonesian culture, men tend to be protectors and are placed as the head of the family (Dewi et al., 2010). Within this role, Indonesian men may be more vulnerable to chronic disease and complications, because they tend to assume greater work obligations and therefore may experience significant stress that affects their well-being (Dewi et al., 2010). As breadwinners, especially in the context of migration, they may focus only on work and providing for the family and as a result, they may also neglect their health or be less likely to seek care. Women, on the other hand, in Indonesian culture are considered to have a more passive role (Dewi et al., 2010; Sarwono, 2012). Their role is determined by the feudalistic aristocratic system, in which they are given the role of "person watching from behind"[1] (Sarwono, 2012). This role tends to place Indonesian women as the ones who are responsible for household affairs and caregiving in their family. How this traditional

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[1] Refers to the role of women as morality keepers of the family and their responsibilities within the family, including "to give birth", "to cook", and "to dress up" (Sarwono, 2012, p. 49)

gender role influences the self-care experiences of Indonesian women with chronic disease living in Indonesia remains understudied. However, in the post-immigration context, where an Indonesian woman living with chronic illness may have the double-burden of taking care of the family and working, this role may have an important impact on her capacity to self-care. The maintenance of traditional gender roles, for both Indonesian men and women, therefore, may have deleterious effects on self-care experiences in Canada, especially without the support from extended family.

Community involvement in chronic disease self-care practices may also be altered in the context of migration. While in Indonesia, the community can offer specific disease-related advice and support when the family is not available (Bayhakki et al., 2019; Dewi et al., 2010; Mizutani et al., 2016), in Montreal, the Indonesian community is small and so may not be sufficiently linked and resourced to act as an extended source of support. In this sense, the role of the family especially for Indonesian people may become even more significant since they are the primary foundation of support.

Social support and networks also help buffer the stress of living with chronic illness, and promote positive self-care behaviours for patients, including following recommended care and treatments (DiMatteo, 2004). On the other hand, preferences for care are also influenced by a patient's health literacy, risk perception, beliefs, and attitude toward the illness and prescribed treatments (Bayhakki et al., 2019; Dewi et al., 2010; Ligita et al., 2019; Rahmawati et Bajorek, 2018a). Some studies in Indonesia have found that some patients with chronic disease were diagnosed late, under-screened, did not follow recommended treatments, and/or did not attend healthcare appointments (Bayhakki et al., 2019; Dewi et al., 2010; Ligita et al., 2019; Rahmawati et Bajorek, 2018a). These behaviours were influenced by beliefs that the chronic illness was their fate, and preferences for alternative medicine (Bayhakki et al., 2019; Dewi et al., 2010; Ligita et al., 2019; Rahmawati et Bajorek, 2018a). As Indonesians may maintain specific behaviours learned from their home country (Ho, Bos et Kunst, 2007; Stirbu, Kunst, Bos et Mackenbach, 2006), Indonesian people living in Montreal may show similar behaviours to what has been shown in the research with Indonesians living with chronic-illness in Indonesia.

Lifestyle behaviours, including eating habits and physical activity, which can improve or have a negative impact on health status, may also be carried over from the home country. A national survey in Indonesia found that 48% of Indonesia's population aged over 10 years lacked physical activity (Nurali, 2019). Low levels of physical activity may therefore continue once immigrated to Canada, especially in the early phases post-migration when time is largely devoted to resettlement. These behaviours once established are also likely to be maintained over the long term. People in Indonesia also tend to consume food that has a high content of carbohydrates, less protein, and low in vegetables and fruits (Schroders et al., 2017; Sugiharto, Stephenson, Yu-Yun et Nuniek Nizmah, 2017). Although several Indonesians may adopt Canadian diets (including both healthy and unhealthy habits, as described earlier), many may maintain their food behaviour from Indonesia, and this may not align with the recommended diets for healthy living, particularly for managing a chronic illness.

Furthermore, Indonesians are a predominantly English-speaking (as a second language, rather than French) immigrant community (Fatmawati, 2019) . In Quebec, where French is the primary language, Indonesians may not understand information provided about their chronic illness. Language barriers may also reduce their access to and use of prevention and health promotion information (Gushulak et al., 2011). Therefore, Indonesian people may not understand that their illness is a priority and/or they may not seek out information or integrate it into their self-care practices.

Lastly, many Indonesian immigrants are Muslim (Fatmawati, 2019) and the current social and political climate in Quebec is not very welcoming and open towards Muslims (Wilkins-Laflamme, 2018). This community therefore may face direct discrimination in which they are denied access to public services, including healthcare (Wilkins-Laflamme, 2018). Even if they can access services, they may also face indirect discrimination (Wilkins-Laflamme, 2018). These experiences can be detrimental to their mental health and well-being, result in negative coping responses (Dickson, Knafl, Wald et Riegel, 2015), or may lead them to search inappropriate treatments, or delay/avoid accessing care.

In Canada, nurses play an important role in supporting patients with chronic illness to self-care across the healthcare system continuum (front-line to tertiary care) (Health Council of Canada, 2012). They may provide coaching and education to help them acquire knowledge, skills and confidence in order to better manage and cope with symptoms which may have physical, social and psychological effects (Health Council of Canada, 2012). They may also be a source of moral support (Health Council of Canada, 2012). In order for nurses to provide appropriate support and care, they need to better understand the self-care experiences and the various factors affecting these experiences among different immigrant communities. This includes the challenges that immigrants may face in self-care due to their beliefs, health knowledge/literacy, and learned behaviours from their home country not being recognized by health care professionals (HCPs), the barriers and discrimination (direct and/or indirect) that they may experience in accessing care, and the loss of family and other supports associated with their migration to a new country. The "Middle-Range Theory of Self-Care of Chronic Illness" developed by Riegel et al. (2012) is a nursing framework providing guidance on key elements of self-care (i.e., monitoring and managing the illness and maintaining health) and a range of influencing factors to consider when examining this phenomenon. No studies have yet to focus directly on the self-care experiences of Indonesian immigrants with a chronic illness living in Canada. Using an immigration lens (Gushulak et MacPherson, 2004) and The "Middle-Range Theory of Self-Care of Chronic Illness" (Riegel et al., 2012), the current study aimed to address this gap.

2.3 Research Objectives

The purpose of this study was to explore and describe the chronic illness self-care experiences of Indonesian immigrants living in Montreal, Canada, and to gain a better understanding of how different factors, including cultural beliefs, values, health knowledge/ literacy, lifestyle behaviours, support from family and community and access to care, shape these experiences.

Chapter 3: Research Framework and Literature Review

3.1 Research Framework

This study used the “Middle-Range Theory of Self-Care of Chronic Illness” developed by Riegel et al. (2012) as a guide to explore and gain an in-depth understanding of the self-care experiences, and the factors affecting these experiences among Indonesians living in Montreal, Quebec. This middle range theory is inspired by the definition of self-care by Orem (2001) that emphasizes the practices of individuals to maintain life, health and well-being. However, this theory delineates self-care into three components including self-care maintenance, self-care monitoring and self-care management. Self-care maintenance refers to the behaviours performed by patients to sustain general well-being and preserve health (physically, emotionally, socially and spiritually) (Riegel et al., 2012). For those with chronic illness, this often includes lifestyle practices such as preparing healthy food, coping with stress, exercising and maintaining social activities (Riegel et al., 2012). Self-care monitoring refers to the routines and actions that chronic illness patients use to assess the illness (e.g., blood glucose level checks in patients with diabetes, weight checks in patients with heart failure) so that interventions may then be implemented towards controlling symptoms and/or improving outcomes. Self-care management is the active implementation of the treatments and taking medications to manage the disease and prevent health deterioration (Riegel et al., 2012). Although the specifics of monitoring, maintenance and management vary, all of these components are part of the self-care experience irrespective of the illness.

According to Riegel et al., (2012) a number of factors influence self-care experiences including one’s skill level and motivation, their functional and cognitive abilities, cultural beliefs and values, lifestyle and habits, support from others and access to care. In this study, certain factors were selected for examination as they were deemed to be particularly relevant to the immigrant context, including skill level, motivation, culture and values, lifestyle and habits, support from others and access to care (Chatrung, Sorajjakool et Amnatsatsue, 2015; Hjelm, Bard, Nyberg et Apelqvist, 2003; Joo et Lee, 2016; Kindarara, McEwen, Crist et Loescher, 2017; King, LeBlanc, Carr et Quan, 2007; Majeed-Ariss, Jackson, Knapp et Cheater, 2015; Mitchell-Brown, Nemeth, Cartmell, Newman et Goto, 2017; Sanon, Spigner et McCullagh, 2016; Sidhu et al., 2016; Walker, Weeks, McAvoy et Demetriou, 2005; Zhang et Verhoef, 2002). Functional and cognitive abilities, although important, were considered to not be unique to the immigration context so were not a primary focus in this study (note however that functional abilities are often discussed when one talks about support from others). Cognitive ability was also an inclusion criterion for participation, so it was not going to be possible to examine this factor. Moreover, based on the literature, health knowledge/literacy was deemed an important factor to consider (Amelia et al., 2018; Mizutani et al., 2016; Rahmawati et Bajorek, 2018a), so this was added to the list of factors. Since there is some overlap between the factors (e.g., health knowledge/literacy influences skill and motivation and culture influences lifestyle habits), and to simplify the synthesis of the literature, the factors were regrouped into four broader categories including: Culture and beliefs, Health knowledge/literacy, Support and Access to care.

Culture and beliefs, including religious beliefs and cultural beliefs and values, affect attitudes, motivation and perceptions about health and disease, including their causes, and how one should respond and treat the illness (Riegel et al., 2012). Culture also influences life-style choices and habits, which can be essential in maintaining health when living with a chronic disease (Riegel et al., 2012). Health knowledge, which for the purpose of this study, refers to ‘Western health knowledge’ (medical knowledge), and health literacy levels, are influenced by education (formal and informal), and will affect how an illness, symptoms and treatments are understood. More health knowledge/literacy (and education) is also often associated with more self-efficacy (i.e., confidence and belief in one's ability to achieve a goal) and skill level which can affect how actively engaged and effective one is in their self-care (Riegel et al., 2012). Support can come from a variety of sources, including family, friends, the community and healthcare professionals (Riegel et al., 2012). Support can be key in helping patients enact self-care, for example decision-making regarding treatment choices, and may provide emotional and practical support (Riegel et al., 2012). Finally, access (or lack of access) to health care service is a significant factor in self-care as it influences which treatments, including medicines and lifestyle recommendations are followed (Riegel et al., 2012).

Since many of these factors are shaped by the migration trajectory, this study also applied a migration lens and considered both the influences of the pre- and post-migration contexts on self-care experiences (Gushulak et MacPherson, 2004). Pre-migration, education and SES (Socio-Economic Status) level can influence health knowledge and literacy levels, while ethnicity and geographical area where one lives (i.e., community and political influences), can affect religious and cultural beliefs, as well as gender roles, which will in turn shape perceptions about health, practices and/or expectations for support; all of these factors can also affect lifestyle and access to healthcare (Gushulak et MacPherson, 2004). Post-migration, SES, cultural beliefs, lifestyle, health knowledge/ literacy and gender roles may be affected and shift due to exposure to the new environment and society (Gushulak et MacPherson, 2004). The schema below presents the overarching framework that guided this study.

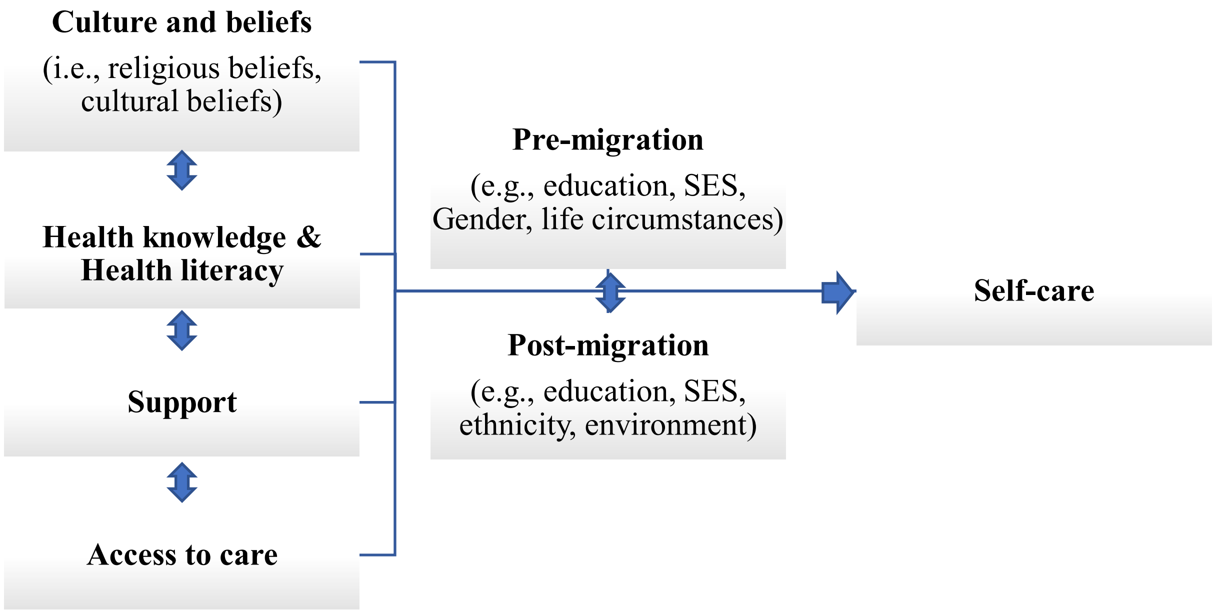

Figure 1: The Study Framework informed by Riegel et al. (2012) and Gushulak & MacPherson (2004)

3.2 Literature Review

To gain an understanding of Indonesian immigrants' chronic illness self-care experiences in a Western country like Canada, and to ensure an immigration lens, there are two bodies of literature to examine. The first is the literature about the chronic self-care experiences of Indonesians in Indonesia. This literature provides us some insight into how the pre-migration context may influence post-migration self-care experiences. The second body of writing is the research that has been conducted on the chronic self-care experiences of immigrants living in Western countries such as the United States of America (USA), Canada, Western European countries and Australia, particularly studies with immigrant communities who may have similar experiences to Indonesians. Both sections of the literature review are organized according to the framework, and include an examination of how culture and beliefs, health knowledge and literacy, support, and access to care may shape the chronic illness self-care experiences of Indonesians in Indonesia and of immigrants living in a Western country, respectively.

To identify relevant literature, searches were conducted in online databases, including CINAHL, Medline, PubMed and Google Scholar. Three central concepts were combined and used to guide the search, including “Self-care”, “Chronic disease”, and “Indonesia”/ “Immigrants” (“Indonesia” was used in the first search, while “immigrants” was used in the second search). *Self-care* terms included “self-care”, self-management”, “self-efficacy”, “long term care”; *Chronic disease* terms included “chronic disease”, “chronic illness”, “long term disease”, “diabetes OR diabetes mellitus”, “type 2 diabetes mellitus OR diabetes mellitus type 2”, “hypertension”, “chronic heart failure OR cardiovascular disease”, “arthritis OR osteoarthritis”, “chronic kidney disease”, “hemodialysis or dialysis”, “end stage renal disease”; *Indonesia* terms included “Indonesian OR Indonesians”, “Indonesian people”, “Indonesian patients” and lastly, the terms for *immigrants* included “immigrant OR immigrants”, “immigration”, “migrant OR migrants”, “ethnic community OR ethnic group”.

Papers were selected if they explored the self-care experiences of adults (men and/or women; immigrants) living with chronic illness in Indonesia (rural and urban areas) or in a Western country. Selection was restricted to peer-reviewed research, published in English, and that focused on the most prevalent chronic diseases in Indonesia (i.e., hypertension, cardiovascular diseases, chronic kidney diseases, type 2 diabetes mellitus, arthritis, chronic obstructive pulmonary disease). Studies that examined self-care from the perspective of healthcare professionals were excluded, since the focus of the current study was to explore experiences from the perspective of those living with an illness.

3.2.1 Self-Care Experiences in Indonesia

Nine articles focusing on the self-care experiences of Indonesians in Indonesia were identified. This literature includes Indonesians' experiences of living with a range of different illnesses such as cardiovascular disease/chronic heart failure/heart disease, hypertension, type 2 diabetes mellitus (T2DM) and end-stage renal disease (ESRD). Studies were conducted among varied adult populations in different treatment situations, including middle-aged and older men and women who were ill, living at home, hospitalized, or accessing community-based services, and in urban and rural settings. While different chronic diseases may require different types of self-care, the literature review covers the general common experiences associated chronic self-care including the management of risk factors, seeking medical service, medication taking, asking family for help, the use of traditional medicine, visiting traditional healers and praying. The review highlights commonalities as well as variations in these experiences. Qualitative and quantitative studies contribute to the literature (see appendix A for a summary of the literature).

3.2.1.1 Culture and Beliefs

Research on the self-care experiences of Indonesians living with chronic illness show that religion and faith can have a significant influence on experiences, both positively and negatively (Bayhakki et al., 2019; Indrayana et al., 2019; Mizutani et al., 2016). The positive effects of religion are evident across Indonesians with different illnesses and living in various regions and settings. For example, in the study with Muslim Indonesians living with end-stage renal disease (ESRD) undergoing hemodialysis in urban regions of Pekanbaru[2], a male participant in the study mentioned that prayer gave him spirit and serenity and helped him sleep. Going to the mosque or listening to the radio online, to hear Islamic preaching, also motivated some participants to seek

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[2] *Pekanbaru is* the capital of Riau Province and is the third largest city on the island of Sumatera, after Medan in the North, and Palembang in the South (Wonderful Indonesia, 2019a)

medical treatment and to “not to give up” on their illness (Bayhakki et al., 2019). Similarly, in the study by Indrayana et al. (2019) with Muslim patients with type 2 diabetes mellitus (T2DM), living in urban regions in Yogyakarta[3], examining the relation between prayer and foot care behaviour, results showed a significant association between praying and adopting good foot care behaviour; the more patients prayed, the more likely they were to adopt good foot care. This same study explained that praying was an occasion, up to five times a day, for patients to wash their feet, and therefore it helped them to maintain good hygiene and prevent foot ulcers. This study also explained that the participants were more likely to engage in good foot care behaviors because they perceived the illness as God's way of reminding them to take care of their health. It therefore encouraged them to take responsibility for their health and to follow recommended foot care in order to avoid foot ulcers and other complications.

In other instances, Indonesians believe that self-care is essential, but ultimately, that they have little control over their situation and that it is God who is the one to decide their fate. This fatalistic approach was shown in the study by Mizutani et al. (2016) where some middle-aged Muslim women participants, living in a rural area and who had hypertension, believed that if they fulfilled their obligations to God, for example by praying and fasting, their health would be delivered by God. Their faith was strong, and they believed that everything, including disease and health, was determined by God (Mizutani et al., 2016).

Many beliefs around chronic illness and responses are influenced by beliefs and culture (Dewi et al., 2010; Ligita et al., 2019). The eating behaviors of Indonesians, for example, are often determined by cultural and religious traditions and these can influence self-care in complex ways. For example, in the study by Indrayana et al. (2019), it was found that participants who

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[3] Yogyakarta is the capital city of Special Region of Yogyakarta in Indonesia and regarded as an important centre for classical Javanese fine arts and culture (Wonderful Indonesia, 2019b)

"always accepted food and drinks served by another person" was significantly associated with positive foot care behavior. The study explained that participants might have believed that they were not allowed socially or culturally to refuse food served by another person and therefore, they compensated by performing better foot care behaviors (Indrayana et al., 2019). Similarly, persons with chronic illness may also seek to compensate for the negative effects of smoking. Smoking is a common habit and widely socially accepted in Indonesia, especially among men (Dewi et al., 2010) and as such is very difficult to quit, even in the face of illness. Compensation is therefore a strategy that may be used to maintain health, rather than to quit the habit (Dewi et al., 2010). For example, high SES males in the study by Dewi et al. (2010), perceived smoking as unhealthy, but felt it was needed to help them cope in their job. Therefore, to compensate they believed that they needed to exercise.

Gender roles, which are culturally determined, can also affect how a chronic disease is perceived and self-care is practiced. For example, in the study of Dewi et al. (2010), male patients with cardiovascular disease (CVD), irrespective of their social status, believed that they were responsible for earning money to support the family and therefore they needed to prioritize their job, and felt that they did not have time to attend to their health. High SES male patients, however, reported that they believed that engaging in a healthy lifestyle could improve their outcomes, but didn't have time for these activities and therefore managed and monitored their CVD only by necessary medical examinations and care. Conversely, male patients of low SES believed that their heart disease was their destiny, and that they had no control in changing the outcome of their condition. They felt that any activities aimed at prevention would be useless.

Culture and beliefs about treatment also shape the choice on which treatments and care are used. For example, in the study of Ligita et al. (2019) in Pontianak[4], some patients with T2DM preferred to use unconventional therapies, as they believed that taking medications and drinking less water, as were recommended by health care professionals (HCPs), would exacerbate their illness. Instead of prescribed medications or treatments, these patients, therefore, used traditional medicines and other treatments, for example, a magnet device[5] around their waist to treat their diabetes (Ligita et al., 2019). Similarly, in the study of Dewi et al. (2010), with lay Javanese people living in Yogyakarta, an urban region in Indonesia, patients perceived that "too much exposure to wind" was what contributed to them developing cardiovascular disease (CVD); they also referred to CVD as "angin duduk" (sitting wind sickness). They also believed that their "angin duduk" could only be cured by rubbing the back with traditional oil and then scratching it with the coin (Dewi et al., 2010).

For some, herbal medicine is used as the core treatment for their illness, and medical treatment is considered the last resort (Ligita et al., 2019; Rahmawati et Bajorek, 2018a). In these cases, the use of alternative medicines lowers patients' intentions and motivation to seek medical treatment, and leads them to only visit doctors when their condition is severe (Ligita et al., 2019; Rahmawati et Bajorek, 2018a). For example, in the study by Rahmawati et Bajorek (2018a), some patients preferred to treat their hypertension by consuming certain foods including cucumbers, melons, watermelon juice, grated carrots, and said that they only visited medical services when they felt traditional approaches had no effect. Similarly, in a study of patients with T2DM, just following their diagnosis, some sought out traditional medicines and decided to use

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[4] Pontianak is the capital of West Kalimantan Province, Indonesia (Ligita et al., 2019)

[5] A device containing magnet, which is believed by some people to heal diabetic neuropathy, increase blood flow on lower extremities and reduce blood glucose levels (Vann, 2017)

these instead of medically recommended treatments to manage their glucose levels and treat their blurred vision (Ligita et al., 2019).

In some instances, traditional medicine and healers are believed to be complementary to medical treatment (Bayhakki et al., 2019; Ligita et al., 2019). For example, in the study of Bayhakki et al. (2019) with ESRD, while undergoing hemodialysis, some patients also used a traditional treatment called *bedah ayam* (chicken surgery)[6]. In the same study, other participants used massage[7] and consumed Tamarind[8] extract to relieve pain. Similarly, in the study of Ligita et al. (2019), some patients with T2DM, also used herbal medication as complementary to insulin injections.

Some Indonesians decide not to use traditional therapies at all and prefer to only follow medically prescribed treatments (Ligita et al., 2019; Rahmawati et Bajorek, 2018a). This decision appears to be influenced by a combination of factors, including fear of traditional medicines, support to use prescribed medicine, and beliefs that conventional therapies are more effective (Ligita et al., 2019). For example, in the study by Ligita et al. (2019), a female participant did not trust alternative therapies that were suggested by her friend because she feared overdosing since she did not know what amount of the medication would be appropriate for her. Moreover, it was important for her that there be medical evidence showing the effectiveness of a treatment in order for her to feel comfortable taking it.

Lastly, for some, traditional approaches may be used initially to manage and treat illness and to maintain health, but then due to adverse effects, are stopped (Bayhakki et al., 2019; Dewi

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[6] An alternative treatment that involves a healer slaughtering a chicken and performing rituals with the dead chicken in order to remove the illness from a patient's body (Bayhakki et al., 2019)

[7] Massage therapy is thought to improve blood circulation, relax soft tissue and to relieve pain (Burgan, 2016)

[8] Tamarind contains anti-oxidants and is anti-inflammatory and are therefore believed to help protect against heart disease, cancer and diabetes. They are also believed to lower blood sugar levels and help in body weight loss and to reduce swelling and pain (Jennings, 2016)

et al., 2010; Ligita et al., 2019; Rahmawati et Bajorek, 2018a). This was evident in the study by Dewi et al. (2010), where some patients who had used traditional methods including rubbing their back with oil and scratching it with a coin, reported it had had no effect for them or for other patients with CVD in the region who had used it. In the study of Bayhakki et al. (2019), some patients with ESRD, who had used the *bedah ayam*, massage and tamarin extract, reverted to only using hemodialysis due to feeling no effect from these alternative approaches. In the study by Rahmawati et Bajorek (2018a), some patients stopped consuming fruit (e.g., cucumber, watermelon, melon, and carrots) as a primary treatment because it had no effect on their blood pressure after consuming these fruits for a period of time. In another study, some participants with T2DM also stopped using herbal medicines because it caused them to be hypoglycemic (Ligita et al., 2019).

3.2.1.2 Health Knowledge and Health Literacy

For some Indonesians, having a better understanding of the disease results in more self-efficacy (i.e., confidence and belief in one's ability to achieve a goal), and ultimately more active and engaged self-care (Amelia et al., 2018; Mizutani et al., 2016; Rahmawati et Bajorek, 2018a). This was shown in the study of Amelia et al. (2018), which analyzed factors affecting the self-care behaviors of patients with T2DM in an urban region of Binjai, North Sumatera. Results showed that self-efficacy was significantly associated with self-care, including diet management, taking medications, seeking treatment, and engaging in other prescribed health and care-related activities. This was also evident in the study of Mizutani et al. (2016). For example, one participant knew that taking a rest would make him feel better, and therefore, he took action towards reducing how much he worked so that he could have time to relax and sleep. Similarly, another participant knew that he needed to reduce his stress and so he was active in addressing this by going for walks or accompanying his wife shopping. And still, in the same study, another patient knew that controlling his diet was important and he believed it would be positive for his health, and therefore he was motivated and integrated this change into his lifestyle. In each of these cases, the patients had the health knowledge/literacy, confidence and willingness to enact changes towards improving their health.

In contrast, a patients' lack of health literacy (i.e., capacity to access, understand, and use health information towards making appropriate health decisions) can also affect the self-care experience. For example, in the study of Rahmawati et Bajorek (2018a) conducted with adults living with hypertension in rural regions in Yogyakarta, some patients did not recognize that a systolic pressure of 150 mmHg wasn't healthy, and since they did not feel any symptoms, they did not seek any medical treatment. Similarly, in another study by Ligita et al. (2019), some patients believed that their diabetes was "not too bad" if they had boils on their leg. They thought this was only a small wound and not as severe as the foot ulcers of other patients they knew, and therefore, believed it was not necessary to seek care. Overall, a lack of understanding of the illness and its symptoms, prohibited the patients in taking action.

Knowledge about treatments and their effects are also varied and may be shaped by health literacy as well as beliefs (Ligita et al., 2019; Mizutani et al., 2016; Rahmawati et Bajorek, 2018a). For example, in one study, some Indonesians with T2DM believed that medications contained chemical materials and that they were dangerous for their body, and therefore, they decided to stop consuming the medication one week after they were prescribed (Ligita et al., 2019). However, in the study of Mizutani et al. (2016), patients who understood the medical basis of their health problems and the reason for the medical care, and who had had prior positive experiences in improving their health, reported buying medicines, taking prescribed treatments and seeking medical attention. Similarly, in the study by Rahmawati et Bajorek (2018a), some participants knew that hypertensive medication would bring a positive effect on their body if they took it regularly, and therefore, they made many efforts to maintain their treatment.

Understanding the advantages of self-care also seems to be a motivating factor for some Indonesian patients to act towards managing their illness and improving their health (Bayhakki et al., 2019). This was evident in the study of Bayhakki et al. (2019) where the participants saw their hemodialysis as an essential therapy to follow for them to feel well and to improve their quality of life. They also recognized that controlling fluid intake, reducing the 'toxins' in their body through diet, resting and using massage, helped them to manage and control their symptoms including weakness and pain. The positive outcomes, therefore, stimulated them to further engage in these behaviors. Similarly, in the study by Indrayana et al. (2019), when patients with T2DM believed foot care was a useful treatment, they would perform the foot care behavior. The study explained that patients who believed that their treatment was effective, were more motivated to perform better foot care.

In a similar vein, fear of negative outcomes or previous bad outcomes, can also stimulate patients to act and better monitor and manage their illness. This was seen in the study by Mizutani et al. (2016), which showed that some patients with hypertension practiced a more healthy lifestyle (e.g., checked their blood pressure regularly, controlled their diet, exercised) due to their previous experience of having a stroke (a complication of hypertension). Conversely, the potential adverse consequences and severity of the illness can demotivate patients from partaking in self-care. For example, in the study of Indrayana et al. (2019) examining the relationship between illness perception and foot care behavior, it was found that when patients perceived that the outcomes of their T2DM would be inadequate, they were less likely to have proper foot care behavior. The study explained that perceiving serious consequences of their illness causes stress and decreases patients' intention and drive to perform foot care behavior. In the study by Rahmawati et Bajorek (2018a), demotivation in the use of medicines was also noted, however this was due to feeling that they were not effective. The older patients in the study had tried many treatments and had made many efforts to treat their hypertension, but in the end felt there was little effect or progress. They, therefore, preferred to remain untreated as long as they could continue to work and not feel too dizzy. This decision was also motivated by the fact that these patients felt that given their older age, they just needed to simplify their life, and accept and live with their illness and its outcomes, whatever they may be.

Knowledge and where information are sought are influenced by various factors including gender, SES and personal characteristics. In the study by Dewi et al. (2010), in high SES households, both men and women tended to seek health information from various sources, including mass media, magazines, television, websites, while in low SES homes, women were mostly responsible for the task of finding information and their sources were not as broad (Dewi et al., 2010). Low SES women did not do research online or by reading, but rather they tended to seek information from peers or relatives who were living with a similar condition (Dewi et al., 2010). In the study by Ligita et al. (2019), participants reported that they examined and decided what information to use based on their prior knowledge, own experiences, and personal judgment. They also asked for the opinions of others in whom they had confidence (e.g., HCPs, peers, family) before finally choosing to trust or distrust information. In the same study, some participants also did research before deciding on whether or not to use a treatment (e.g., they searched for information online as they wanted to inform themselves about the function and the side effects of traditional treatments recommended by a friend before choosing to use it or not).

Finally, irrespective of having health knowledge and/or a desire to participate in certain self-care activities (e.g., an active lifestyle), life circumstances can be an important determining factor in actual behaviour. For example, men with CVD in the study by Dewi et al. (2010) felt that they did not have enough time to exercise. Similarly, in the study by Mizutani et al. (2016), some participants living with hypertension hesitated to do exercise because the location of the sports centre was far from their living area. In the same study, other participants wanted to improve their chronic condition by exercising, but they felt that exercising in hot weather would actually worsen their condition. In both studies, participants also believed that their job and farming activities (e.g., planting the fruit, digging, walking around) respectively, were sufficient as a form of exercise since it was physically demanding.

3.2.1.3 Support

3.2.1.3.1 Family Support

Family support includes giving motivation, financial help and daily life assistance, and may be provided by different family members (Amelia et al., 2018; Kristianingrum et al., 2018; Ligita et al., 2019; Rahmawati et Bajorek, 2018a). For example, in the study by Kristianingrum et al. (2018), some women participants with T2DM received support from their daughters to iron and wash their clothes, remind them to consume food and to take medicine. In the same study, women were accompanied to visit medical services, given money to buy the medications, and encouraged not to do housework and to rest, by their sons. Similarly, in the study by Rahmawati et Bajorek (2018a), some older patients also relied on their children to buy medications and prepare healthy meals for them. Studies also show siblings and spouses provide assistance to their ill family members (Kristianingrum et al., 2018; Ligita et al., 2019). For example, in the studies by Kristianingrum et al. (2018) and Ligita et al. (2019), siblings helped by giving reminders to monitor blood sugar levels, by accompanying their brothers/sisters to visit medical services, and by providing support to follow recommended diets. Lastly, in the study by Kristianingrum et al. (2018), some women were helped by their husbands to prepare meals and take a bath.

Family can play a particularly important role in terms of influencing motivation. For example, in the study by Amelia et al. (2018) positive feedback and encouragement from family members helped patients maintain a healthy diet and to control their blood glucose levels. Family is also a source of intrinsic motivation for self-care by providing a sense of purpose. In the study by Bayhakki et al. (2019), some participants in the study reported that they underwent hemodialysis because they wanted to be well and survive their illness so that they could be around to see their children's success. They also felt that their families needed them, and this therefore inspired them to stay healthy.

How family support is viewed and used may vary. For example, in the study by Rahmawati et Bajorek (2018a), some older participants did not want to bother their children and preferred to self-care independently. This was driven by not wanting to burden their children. They would, however, ask their children to help to accompany them to visit "village nurse practice" when they felt very ill.

Lastly, family support, in some instances, appears to be influenced by gender. For some Indonesian men, they consider that their family members, especially women, are responsible for assisting with their self-care (Bayhakki et al., 2019; Kristianingrum et al., 2018; Mizutani et al., 2016). For example, in the study of Bayhakki et al. (2019), some men with ESRD asked their wives to drive, prepare meals, and help them go to the restroom. Similarly, in the study by Kristianingrum et al. (2018) with Indonesians with T2DM in both urban and rural regions in East

Java, male participants also relied on women to help them for a bath, cook for them, and to remind them to control their stress and eat healthy food. Also, in the study by Mizutani et al. (2016), some men participants relied on their wives to remind them not to work so hard. Some women also feel it is their responsibility to care for their sick family members. This was shown, for example, in the study of Dewi et al. (2010), where women reported feeling that they needed to take care of their sick male family members living with CVD.

3.2.1.3.2 Peer Support

Fellow patient support also seems to be a key source of support for some Indonesians living with chronic illness in Indonesia (Ligita et al., 2019; Mizutani et al., 2016). For example, in the study by Ligita et al. (2019), some patients mentioned that sharing experiences with other patients living with similar conditions including information about symptoms and treatment, was helpful for them in dealing with the illness. Similarly, in the study by Mizutani et al. (2016), some male patients also stopped smoking on the advice from their friends, who also lived with the same disease, and who were advised by their doctor to stop smoking in order to lower their blood pressure.

3.2.1.3.3 Support from Health Care Professionals (HCPs)

Health care professionals (HCPs) mainly provide informational support. For example, in the study by Amelia et al. (2018) analyzing factors affecting self-care behavior of patients with T2DM, it was found that information about the development, prevention, and treatment of illness provided by physicians was significantly associated with positive self-care behavior, including controlling blood sugar levels and engaging in other activities to generally maintain their overall health. Similarly, in the study by Ligita et al. (2019), some participants reported HCPs provided them information regarding the treatment and the effects of taking medication regularly versus irregularly, and they used this biomedical knowledge to prevent complications of their diabetes. In the studies by Mizutani et al. (2016) and Rahmawati et Bajorek (2018a) in rural areas in Indonesia, several Indonesians with hypertension obtained information about reducing salty food and sweets as a way to help manage the disease. In the study by Rahmawati et Bajorek (2018a), some patients also received information about physical activity from the village midwife.

3.2.1.3.4 Community Support

Support from the community has also been shown to be essential in the self-care experiences of Indonesians (Bayhakki et al., 2019; Dewi et al., 2010; Mizutani et al., 2016). This includes support from neighbors, the religious community, and community organizations (Bayhakki et al., 2019; Dewi et al., 2010; Mizutani et al., 2016).

In the study of Bayhakki et al. (2019), some Muslims with ESRD mentioned that they were visited by members of their mosque, and this enhanced their spirit and motivated them to take better care of themselves. Neighbors and *Kader*[9] also can be helpful in patients' self-care (Mizutani et al., 2016). Some women patients reported being helped by their neighbors, such as escorting them to medical appointments and were reminded or accompanied by the *Kader* to visit community support services (Mizutani et al., 2016). In some cases, *Kader* also provide home care (e.g., blood pressure check, giving health information) (Mizutani et al., 2016).

In the study by Dewi et al. (2010), participants received support from the *Pemberdayaan Kesejahteraan Keluarga (PKK)*[10] and *Pos Bina Terpadu Penyakit Tidak Menular (Posbindu PTM)*[11], two well-known community organizations in Indonesia. These organizations

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[9] *Kader* is a health volunteer worker in the community who visits patients and provides care at home (e.g., blood pressure check, giving health information) (Mizutani et al., 2016).

[10] The *PKK* (Family welfare movement) is an influential women's group that encourages community participation towards improving family welfare (Dewi et al., 2010).

[11] The *Posbindu PTM* (Integrated health service for non-communicable diseases) aims to support the health of the people living with non-communicable diseases (NCD) (Dewi et al., 2010)

located in the community provide a range of health services, medical examinations (e.g., blood pressure and cholesterol level measurement/checks), and health information to patients (Dewi et al., 2010; Mizutani et al., 2016). These organizations are therefore key community supports for many Indonesians with chronic illness as they are helpful to patients by providing direct support to aid them in monitoring and managing their illnesses (Dewi et al., 2010).

Both gender and SES are essential factors in community support (Dewi et al., 2010). In the study of Dewi et al. (2010), it was women of low SES who were responsible for supporting health at the community level through community organizations, such as the *PKK* and *Posbindu PTM*. These organizations were mainly relied upon by men participants of low SES (Dewi et al., 2010). For high SES participants, they did not depend on the support of PKK and Posbindu PTM as much and preferred to visit professional medical services instead (Dewi et al., 2010).

3.2.1.4 Access to Care

Barriers to seeking and using care include cost, fear or discomfort associated with treatments, inconvenience and location of services (Ligita et al., 2019; Rahmawati et Bajorek, 2018a). Cost was an issue mentioned in the study by Ligita et al. (2019), where participants with T2DM hesitated to take medication because its cost was too expensive. Fear was also an issue in this study where some patients were afraid to do self-injections (of insulin), while some were also worried about the side effects of these injections, including fainting, which could prohibit them from performing their daily activities. Similarly, in the study by Rahmawati et Bajorek (2018a), some patients with hypertension also hesitated to seek care because they could not cover the expense. In the same study, some patients also stopped using medications because the smell of the medication made them nauseous or they were tired of taking the medications.

Time and convenience are issues that are usually associated with a patient's employment situation and their sense of responsibility to provide for the family. As already mentioned above, in the study by Mizutani et al. (2016) and Dewi et al. (2010) with Indonesians living with hypertension and CVD respectively, male participants positioned themselves as breadwinners who needed to earn money, and therefore, they felt that they did not have time to pursue their health. Their priority was to work and support the family.

Challenges associated with the location of health care services are mainly when patients live in rural areas. This was evident in both the studies by Rahmawati et Bajorek (2018a) and Mizutani et al. (2016), where several participants hesitated to seek care because the location of health care services was far from where they lived and the route to get there was rough terrain and they did not have appropriate vehicles to take these roads (Mizutani et al., 2016; Rahmawati et Bajorek, 2018a). For some, especially older people, walking was also difficult, and further added to the challenge of getting to health services. In these cases, it was therefore felt that seeking care in such conditions would actually exacerbate their illness. In addition to the distance and mobility issues, these services rely on HCPs coming from urban settings, who are sometimes late. This created more frustration and led to patients feeling disappointed and losing trust in the care-providers and services. This also resulted in patients not wanting to seek care (Rahmawati et Bajorek, 2018a).

Lastly, the expensive cost of medical visits, having a low-socio economic status, the location of health services, and fear to hear advanced diagnoses from HCPs, also contributes to patients self-medicating rather than using prescription drugs (Mizutani et al., 2016; Rahmawati et Bajorek, 2018a; Rahmawati et Bajorek, 2018b). This was evident in three studies among older Indonesians with hypertension living in rural areas where several participants tended to buy over the counter medications (without prescription) in *Warung*[12] or in some pharmacies in order to lower their blood pressure (Mizutani et al., 2016; Rahmawati et Bajorek, 2018a; Rahmawati et Bajorek, 2018b).

Summary

In summary, the literature reviewed provides several insights on self-care among Indonesians living with chronic illness in Indonesia and how culture and beliefs, health knowledge/ literacy, social support and access to care may influence these experiences. Overall, the participants of the studies were mostly female and older people; male and younger participants were less represented in this body of research. The studies, however, were conducted with different populations, including a mix of high and low SES individuals, a variety of ethnicities, and both in urban and rural areas of Indonesia. Although some studies considered gender, age, SES, and length of time living with the illness, as influencing variables, generally there was limited examination of these in studies. There are also some gaps in the research. The literature reveals little about what patients expect from healthcare professionals or their interactions with them regarding their self-care, including how religion, perceptions, cultural beliefs, life circumstances and the use of alternative therapies are discussed and navigated (or not) within the patient-healthcare professional dynamic.

3.2.2 Self-Care Experiences after Migration

No specific studies examining Indonesian immigrants' experiences were identified. The following includes a review of 12 studies which included immigrants with different origins (e.g., Chinese, Haitian), ethnicities (e.g., Arab, Hmong), characteristics (e.g., recently-arrived immigrants, immigrants with language barriers), and illnesses (e.g., heart disease, diabetes,

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[12] *Warung* is a small family-owned business (e.g., restaurant, café, minimarket) in Indonesia (Wowshack, 2017)

arthritis), and living in a variety of countries (e.g., USA, Canada, Australia). This section builds on the first section of the literature review by highlighting the commonalities and contrasts in self-care experiences between the body of research with immigrants in Western countries and the research done with Indonesians in Indonesia (see Appendix B for a summary of the literature).

3.2.2.1 Culture and Beliefs

Similar to research with Indonesians, studies with immigrants also suggest religion can play an important role in self-care, including God being a source of motivation to self-care (e.g., eat healthy food and exercise), meditation as a means to reduce stress, praying to increase emotional resilience and preserve well-being, and practicing religious traditions (e.g., fasting) as a way to maintain health and to access social support from family, friends and the community (Chatrung et al., 2015; Hjelm et al., 2003; Kindarara et al., 2017; Sidhu et al., 2016). A fatalistic approach is also seen among some immigrants, including those of different faiths (e.g., Buddhists, Christians), who believe that their illnesses are their fate, destiny or karma, and that God will decide the outcome (Chatrung et al., 2015; Walker et al., 2005).

One striking contrast between the literature with immigrants and the literature with Indonesians in Indonesia, is that immigrants seem to face greater conflict between practicing their religious beliefs and self-care. This was evident in the study by Hjelm et al. (2003), where Arabic females with type 2 diabetes mellitus felt that fasting not only prevented them from properly managing their illness and would exacerbate their condition, but it also made them sad and distressed that they were not practicing this tradition in Sweden with their family, as they had done before migrating.

The literature reveals that immigrants also have varying cultural beliefs about the causes of their illnesses, and this affects how the illness and symptoms are perceived and what treatments are used. For example, in a study by Kindarara et al., 2017, with African patients with T2DM, some believed that their sickness came from witchcraft and therefore believed medical services were not really necessary, only if they were really sick and had physical symptoms. In the study by Zhang et Verhoef (2002), some Chinese older women believed that their arthritis was caused by inadequate post-natal exercise, and therefore, they did low impact exercise to self-care. In the study by Zhang et Verhoef (2002) with Chinese immigrants, some believed that their arthritis was caused by "cold and wet" and so they treated it by warming their legs and/or arms. Similarly, Italian participants in the study by Walker et al. (2005) perceived their arthritis as "a normal sign of ageing which was bound to happen", and therefore, this led them to self-care in natural ways (e.g., avoid medication, use ice packs).

Adapting to a new culture also affects lifestyle behaviours such as diet (Hjelm et al., 2003; King et al., 2007). Immigrants may also have to adjust to new roles. For immigrant women, especially younger women, this may include entering in the workforce. This can create a situation where women struggle to balance their self-care with home and work responsibilities (Majeed-Ariss et al., 2015). This notion is supported by the study by Majeed-Ariss et al. (2015), where women reported difficulties to self-care because of the double burden associated with working and their role and responsibilities as women, including looking after their families' health. The multiple responsibilities and lack of time therefore resulted in these women neglecting their own health (e.g., ignoring their diet requirements). In the same study, however, the women also shared that they thought that men would actually have a more difficult time to self-care due to expectations of men to focus on their work and to fulfill their obligations to financially support the family.

Lastly, similar to Indonesians, herbal medicines and traditional treatments may be used by some immigrants as a core treatment for their illness or when they feel that Western medicine is not working (Zhang et Verhoef, 2002). Some immigrants believe that treatments or medications are not healthy, for example that medications contain many chemicals and additives which are dangerous for their body (King et al., 2007; Mitchell-Brown et al., 2017; Zhang et Verhoef, 2002). Some also believe that medical intervention will worsen the illness; this was found in the study by King et al. (2007), where some Chinese immigrants hesitated to undergo angioplasty since they believed that it could exacerbate their condition. In other instances, the inconvenience or side effects of the treatments, or feeling that they are not helping, or fear of something bad happening during the treatment (e.g., dialysis) leads to hesitance in following recommended care (Majeed-Ariss et al., 2015; Mitchell-Brown et al., 2017). A distinct feature of the literature with immigrants, is the influence that the migration context has on the use of traditional medicines. For example, in the studies by Walker et al. (2005) and Zhang et Verhoef (2002), Vietnamese and Chinese patients had used herbs and consulted traditional healers when in Vietnam and China respectively, but in Australia and Canada, these traditional treatments and services were deemed too expensive. Moreover, the immigrants also believed that the Chinese healers in Canada were inadequately trained and had a superficial knowledge of Chinese medicine (Zhang et Verhoef, 2002).

3.2.2.2 Health Knowledge and Health Literacy

Having health knowledge/literacy and understanding about the causes of a disease and its symptoms, and believing that they can alter the outcomes, are also important for immigrants in how they decide to manage their disease and maintain their health. For example, in the studies by Chatrung et al. (2015) and Kindarara et al. (2017), participants who had a medical understanding about their chronic kidney disease and T2DM respectively, were actively controlling their diet, exercising, and seeking the recommended treatments.

Knowledge of the disease is also sometimes shaped by experiences with family members who had the disease, and this too has been shown to prompt immigrant patients to seek care and address their symptoms, or alternatively to be less stringent in following recommended treatments and to focus more on quality of life instead (Chatrung et al., 2015; Majeed-Ariss et al., 2015). Along the same lines, motivation to self-care can be stimulated by being aware of, and fearing, the potentially bad outcomes. For example, in the study by Walker et al. (2005), participants with T2DM felt that they needed to "pace" themselves, monitor their blood glucose level, exercise, take medication, and consume healthy food in order to avoid the medical visits and their illness getting progressively worse. Similarly, in another study, patients with chronic kidney disease consumed certain foods and avoided long distance travel in order to avoid fatigue and having uncontrolled blood pressure (Chatrung et al., 2015)

Conversely, a lack of health knowledge or limited health literacy, can lead to not practicing self-care. In the study by Hjelm et al. (2003), Arabic participants did not know what their diabetes was, and so did nothing at all. In some instances, a lack of engagement in self-care seems to be exacerbated by stigma that is associated with having an illness. For example, in the study by Kindarara et al. (2017), some Sub-Saharan African immigrants considered their T2DM as a social stigma in their communities and therefore discussing their illness or accessing information and care were "taboo". In the same study, when information about the illness was given, it was not well understood because it was viewed as "too scientific" and this too led to poor illness monitoring (e.g., monitoring glucose levels) and management (e.g., diet).

Health literacy and positive experiences with treatments also shape which medications, interventions and recommendations immigrants will follow. For example, in the study by Chatrung et al. (2015), with patients living with chronic kidney disease, some mentioned how important they felt it was to receive dialysis in order to stay well. The positive outcomes associated with following treatments also further reinforced the continued use of treatments and healthy lifestyles (Chatrung et al., 2015).

Lastly*, s*imilar to Indonesians, many immigrants are selective in where they seek information and in which knowledge they use, and some prefer to seek information from culturally and linguistically-adapted sources. For example, in the study by Joo et Lee (2016), Korean participants preferred to seek information for dietary recommendations and learn about T2DM from Korean websites and television (TV) programs, since the information was delivered in Korean language.

3.2.2.3 Support

3.2.2.3.1 Family Support

Another strong similarity between the literature with immigrants and the studies with Indonesians in Indonesia, was the significant role of family support in self-care. Immigrants may receive support in various forms, including emotional support (e.g., providing encouragement), and daily life assistance (e.g., calling to make appointments, preparing meals, cleaning the house, and reminding them to take medications) (Chatrung et al., 2015; King et al., 2007; Majeed-Ariss et al., 2015). One important difference, however, is that immigrants often need and depend on their family for translation/interpretation help (King et al., 2007). This sort of support is essential for understanding medical advice and instructions for treatment and therefore can improve access to, and use of care and treatments, including medications (King et al., 2007).

Similar to Indonesians in Indonesia, support may be provided by different family members particularly children and spouses; extended family appear to have less of a role (Chatrung et al., 2015; Davidson et al., 2011; Joo et Lee, 2016; Kindarara et al., 2017; King et al., 2007; Majeed-Ariss et al., 2015; Sidhu et al., 2016). In the context of migration however, the degree of support provided by children, is sometimes less than what it would have been if they were in their home country (King et al., 2007). For some, they hesitate to ask for help, because they feel that their children are busy with their jobs and study commitments (Hjelm et al., 2003; Majeed-Ariss et al., 2015; Zhang et Verhoef, 2002). For others, they feel that their children are not really available or interested to help care for them, and that they would be better off if they were back in their home country (King et al., 2007; Majeed-Ariss et al., 2015; Zhang et Verhoef, 2002).

The role of gender in family support was also apparent in the literature with immigrants. Similar to what was seen in the studies in Indonesia, for many immigrants, there is an expectation that women will assist with self-care, especially when it's a man that is ill (e.g., asking their daughters or wives to accompany them for medical appointments or to prepare meals for them) (Chatrung et al., 2015; Kindarara et al., 2017; King et al., 2007; Majeed-Ariss et al., 2015). In addition, many immigrant women feel that it is their responsibility to care for their sick family members, even sometimes at the expense of their own health and self-care (King et al., 2007; Majeed-Ariss et al., 2015).

Lastly, a unique aspect of family support for immigrants, is that sometimes it's transnational. Family back home may provide support from a distance including emotional support (e.g., giving motivation) or practical support, for example by sending alternative medicine (Sanon et al., 2016). Family back home can also provide a sense of purpose and drive to stay healthy (Sanon et al., 2016). In the study by Sanon et al., (2016), some participants reported that they were motivated to control their blood pressure, and to take medication in order to be healthy, so that they could keep working and helping their family financially. Conversely, this cross-border relationship can also have negative effects on self-care. Some patients in the same study, reported that they needed to split their income in order to support their family back home, and consequently, they did not have enough money to buy medication, visit medical services, or cover urgent situations. This resulted in them using traditional home remedies instead to manage their blood pressure (Sanon et al., 2016). Moreover, since they felt responsible for their family back home, they also felt that they needed to work additional hours, which consequently exacerbated their condition (Sanon et al., 2016).

3.2.2.3.2 Peer Support

Fellow patients also seem to be a key source of support for some immigrants, particularly informational support (e.g., how to deal with symptoms, information on medical treatments or traditional treatments, recommendations on health care services, health education) (Joo et Lee, 2016; Kindarara et al., 2017; Majeed-Ariss et al., 2015; Walker et al., 2005). For some, however, meeting and hearing the stories of people with the same illness is avoided, because it makes them feel worse, and actually reduces their motivation to self-care (Hjelm et al., 2003)

3.2.2.3.3 Support from Health Care Professionals (HCPs)

Similar to what was found in studies done with Indonesians, HCPs mainly provide informational support to immigrant patients (e.g., information on healthy food, instructions on how to monitor blood glucose and take medications, how to engage in physical activity) (Chatrung et al., 2015; Kindarara et al., 2017; Sidhu et al., 2016). Some immigrants however, ignore recommendations or stop care because they lack trust in their HCPs and feel that the recommendations given are not in their best interest. This was evident in the study by King et al. (2007), where immigrants with CVD felt that the HCPs' recommendations for angioplasty were largely motivated by the financial gain that they would receive in performing the procedure. Similarly, in another study by Mitchell-Brown et al. (2017), the patients felt that their medical care was more of a business transaction than healthcare because the HCPs quickly resorted to prescribing medications for their diabetes and spent no time on health education. In the same study, certain participants also believed that the doctors would take advantage of them, especially those who were not covered by health insurance, and use them as test subjects for their research.

Confidence in HCPs' knowledge and skills is also an issue. In the study by Zhang et Verhoef (2002), patients with arthritis doubted their physician's clinical competence because they felt that the physicians overly relied on laboratory tests for diagnoses. In the same study, patients felt that their "blood coughing" was caused by inappropriate prescribed medication. Similarly, in the study by Mitchell-Brown et al. (2017), a patient perceived that the doctor did not prescribe him appropriate medication since it only made him feel comfortable temporarily. Lack of confidence in care is further exacerbated by ineffective communication and poor bedside manner (Sheridan et al., 2015; Zhang et Verhoef, 2002). In the study by Zhang et Verhoef (2002), some patients reported feeling that the physicians treated them like objects, and that the information delivered was unclear and overly technical, which led them to distrust their physicians. This was also seen in the studies by Sheridan et al. (2015) and Hjelm et al. (2003), with Cook Island, Samoan, Maori, Niuean, Tongan and Yugoslavian patients with comorbidities and type 2 diabetes mellitus in Auckland, New Zealand and in Sweden, respectively, who stated that Western HCPs did not provide them specific and consistent medical explanations, advice, and instructions, which led them to feel confused and distressed, and consequently, to have mistrust in their HCPs. These studies suggest that when immigrants lack trust or feel they are being manipulated by HCPs, they feel uncared for and this may lead them to discontinuing medications and treatments, and in some cases stopping to use medical services altogether (Sheridan et al., 2015; Zhang et Verhoef, 2002). Some may also turn to traditional healers and alternative treatments as a result of their misgivings about the medical care (Mitchell-Brown et al., 2017; Sheridan et al., 2015; Zhang et Verhoef, 2002).

Studies with immigrants also highlight that the capacity of HCPs to listen to their patients and communicate are essential, and when they are lacking these capacities, they negatively affect self-care. This was evident in the studies by Sheridan et al. (2015) and Zhang et Verhoef (2002), where immigrant patients in New Zealand and Canada, felt that the Western HCPs (e.g., physicians, nurses) ignored their feelings and past illness experiences, did not verify their understanding, and did not give them an opportunity to share their experiences. They also reported feeling like they were treated like “furniture”, and generally felt that the care was too medically focused and lacked compassion (Sheridan et al., 2015; Zhang et Verhoef, 2002). Language and a lack of consideration for culture were also identified in these studies, which left patients feeling confused and not respected (Mitchell-Brown et al., 2017; Sheridan et al., 2015; Zhang et Verhoef, 2002). These negative experiences can result in feelings of isolation, distress, and sometimes anger, which can in turn result in patients refusing medical treatments and care (Sheridan et al., 2015; Zhang et Verhoef, 2002). Conversely, when HCPs are attentive, make efforts to establish a relationship, to communicate and to understand their patients’ culture and needs, and actively provide support (e.g., accompany them during treatments, give compliments), patients feel supported and cared for (Kindarara et al., 2017; Mitchell-Brown et al., 2017). These positive experiences can be motivating for patients to more actively engage in self-care (e.g., follow HCPs' instructions and recommendations, undergo treatments) (Kindarara et al., 2017; Mitchell-Brown et al., 2017).

In contrast to the literature with Indonesians, in highlighting the negative experiences with HCPs, the literature on immigrants' experiences also reveals some of immigrants' expectations of HCPs and desires regarding support and care. For example, Chinese immigrants in the studies by King et al. (2007) and Zhang et Verhoef (2002) wanted HCPs to provide care in their language, while immigrant patients in the study by Sheridan et al. (2015) expressed wanting clinicians to provide more psychosocial support (e.g., listen to their experiences, show more compassion, and provide clear information in a way that they can understand), and Hmong immigrants in the study by Mitchell-Brown et al. (2017) shared that they wanted HCPs to spend more time to educate them about their diabetes and for it to be delivered in their language and in a manner that would help them understand it better (e.g., using pictograms). In the study by Hjelm et al. (2003), conducted in Sweden, Yugoslavian patients wanted HCPs to test their blood glucose as they considered it was the care-providers' responsibility to do so. They also desired that their care-providers be more open to and provide natural remedies, and that they spend more time on health education.

Lastly, the literature suggests that negative experiences and interactions with HCPs can lead to immigrants purposely seeking out care-providers that either have the same origin as them or who are more culturally sensitive and willing to adapt their approach and care. This was shown in a number of studies where patients expressly sought out physicians who had the same ethnic background (e.g., Chinese, Hmong, Samoan) and who spoke their language (Davidson et al., 2011; King et al., 2007; Mitchell-Brown et al., 2017; Sheridan et al., 2015). Similarly, in the study by Sanon et al. (2016), Haitian immigrants with hypertension, in addition to receiving treatment from their western HCPs, also relied on Haitian physicians in Haiti to prescribe medication for them.

3.2.2.3.4 Community Support

The community also has a role in supporting self-care among immigrants, including support from friends and religious organizations (e.g., church). Support is informational (e.g., how to treat hypoglycemia) and also social in nature (i.e., sharing stories and getting advice/feedback) (Joo et Lee, 2016; Majeed-Ariss et al., 2015). Some well-established immigrant communities also have health care centres that provide services and support that are linguistically and culturally adapted to the immigrant group (King et al., 2007). In contrast to the literature on Indonesians, however, it appears that immigrants are sometimes reluctant to seek community support. This was evident in the studies by Joo et Lee (2016), King et al. (2007), and Sidhu et al. (2016), where the immigrant patients hesitated to ask help from the community or to tell people outside their family about their condition for fear people would exaggerate the disease problem, and this would cause them distress rather than be helpful. In some cases, language barriers are the issue; this was seen in the study by King et al. (2007), where Chinese immigrants hesitated to ask for help from neighbors since they could not speak English well. In other instances, it is not that immigrants are not wanting support from their community, the problem is that their cultural/ethnic community is small. This was seen in the study by Joo et Lee (2016), where Korean immigrants living in the suburbs of a city in the Midwest of the United States, did not have an established community, and so organizations and culturally adapted services were very limited, and the few that existed were somewhat costly.

3.2.2.4 Access to Care

Similar to Indonesians, immigrants also face a number of barriers in seeking and using care including cost, language, care not being culturally-adapted, negative experiences or a lack of confidence or mistrust in HCPs, insufficient time to access care due to work or school, not understanding their illness and its symptoms, fear of being stigmatized by their community, and/or concerns regarding negative effects associated with treatments (Hjelm et al., 2003; Joo et Lee, 2016; Kindarara et al., 2017; King et al., 2007; Mitchell-Brown et al., 2017; Zhang et Verhoef, 2002). Cost was an issue in a number of studies, including those conducted by Hjelm et al. (2003), Joo et Lee (2016), Kindarara et al. (2017), Mitchell-Brown et al. (2017), Walker et al. (2005), and Zhang et Verhoef (2002), where participants hesitated to visit medical services and/or to take medications, including traditional medicines, because they were too expensive. The cost to pay health insurance was also identified as an issue in certain studies (Joo et Lee, 2016; Kindarara et al., 2017; Mitchell-Brown et al., 2017).

Language is a significant barrier to healthcare for immigrants and results in patients not being able to express their needs or concerns related to their illness, or to ask questions to HCPs, or to understand healthcare information provided (Joo et Lee, 2016; Mitchell-Brown et al., 2017; Zhang et Verhoef, 2002). These communication issues then affect a patient's ability to apply education given or to follow treatments properly (Joo et Lee, 2016; Mitchell-Brown et al., 2017; Zhang et Verhoef, 2002). Language barriers can also result in challenges finding relevant services including community supports (King et al., 2007).

As described earlier, a lack of confidence, mistrust and/or HCPs not being culturally sensitive or having poor bedside manner, are also barriers to care and affect how immigrants respond to treatment recommendations and care, including choosing a different care-provider and/or opting for traditional medicines and treatments instead. In the same vein, patients may also experience difficulties finding or having trust in services when the immigrant community is not well-established and there is a lack of knowledge about the available services and care, especially services that may be more culturally sensitive (Hjelm et al., 2003; Joo et Lee, 2016; Sidhu et al., 2016). Conversely, the availability of culturally-adapted health centres that are located within the immigrant community can motivate patients to access and use healthcare (King et al., 2007; Sidhu et al., 2016).

Time is also an issue for immigrants. Certain African participants in the study by Kindarara et al. (2017) with type 2 diabetes mellitus stated that they did not have a lot of time to take care of themselves (e.g., monitor their blood glucose, follow a healthy eating plan) due to work or their studies. In the study by Majeed-Ariss et al. (2015), this barrier was also commonly faced by men, since they prioritized their work because they felt it was their responsibility to financially support their family.

Lastly, the literature suggests that some immigrant patients may not seek health services or follow recommended care because they do not recognize that they need treatment, or they fear being judged and ostracised by their community or they are afraid of the treatments and worry that they will exacerbate their illness (Hjelm et al., 2003; Kindarara et al., 2017; King et al., 2007; Zhang et Verhoef, 2002). The severity of symptoms or the progression of the illness are also sometimes determining factors on when immigrants will seek medical care. This was seen in the study by Kindarara et al. (2017) with some immigrants with T2DM, who only sought medical treatment once they felt quite ill.

Summary

The body of research on immigrants' self-care experiences highlights a number of similarities and contrasts with the literature on Indonesians' self-care experiences in Indonesia. Similar to Indonesians living with chronic illness in Indonesia, immigrants' experiences are shaped by their religion/spirituality, beliefs, culture and health knowledge/ literacy and these can result in a variety of different self-care behaviours and reactions. Support for self-care from community organizations, HCPs and especially family, particularly by female family members, was also an important similarity across the two bodies of literature. Lastly, immigrants also reported some of the same barriers in accessing care, mainly the issue of cost.

For immigrants, the migration context, including living in a society with a different culture, language, and approach to health and care (i.e., Western medicine), seems to have an important influence on self-care experiences, including which healthy lifestyle behaviours they choose (e.g., diet), what type of treatments are sought and used, and who they decide to consult (HCPs and/or traditional healers) for care. The migration context can also create feelings of conflict regarding practicing religious traditions. For women, maintaining traditional gender roles (i.e., family caregiver), while also taking on work responsibilities, can make it challenging to practice self-care. Language, cultural differences, and a lack of confidence or mistrust or negative experiences with Western HCPs are important barriers for immigrants to accessing healthcare in a new country. Fear of being stigmatized by their community can also be a barrier. Support structures are also altered by the migration context, including a loss of support due to less family being available and/or being too busy (i.e., children) to provide support. Similarly, community support is less available for immigrant communities that are less established. Language barriers can also prevent accessing support from the broader non-immigrant community. And lastly, a unique feature to immigrants' support, is that it's sometimes transnational in nature.

The current study built on the existing literature and tried to nuance the general picture stemming from this literature by studying one community in particular. It focused on an immigrant group, Indonesians, that has not been the focus of previous studies. Immigrant Indonesians living in Montreal, are a small immigrant community, and thus this study also adds to the literature on the experiences of smaller, less-established immigrant groups. The study examined the influence of a range of factors affecting self-care, including religion, health knowledge /literacy, beliefs, culture, support (family, community, HCPs) and access to care and used a migration lens in order to better understand how both the pre-migration and post-migration context influences self-care experiences.

Chapter 4: Research Methodology

In this chapter, the method, procedures, including recruitment, data collection, analysis and how rigour were maintained, are presented. Ethical issues and measures that were put in place to address them, are also described.

4.1 Method

The method selected for this study was qualitative description. Qualitative description is useful for when a researcher wishes to obtain information directly from those who are experiencing a specific phenomenon, particularly for the purpose of informing clinical practice (Sullivan-Bolyai, Bova et Harper, 2005). It's also particularly effective when planning to explore the phenomenon using a guiding framework and when time and resources for gathering data are limited (Bradshaw, Atkinson et Doody, 2017; Kim, Sefcik et Bradway, 2017). The goal in qualitative description is to generate a rich description of experiences that remains close to the language used by the informants to express and describe their experiences (Bradshaw et al., 2017; Kim et al., 2017; Sullivan-Bolyai et al., 2005). Qualitative description was therefore deemed suitable for this student-led Masters' study since the objective was to learn more about the self-care experiences of Indonesian immigrants living with chronic-illness, from their perspective, and using the "Middle-Range Theory of Self-Care of Chronic Illness" developed by Riegel et al. (2012) and a migration lens to guide the data collection and analysis. This method was also considered appropriate since the ultimate purpose was to produce results that will help inform the practice of nurses providing support and care to Indonesians as well as other immigrant groups living with chronic illness in a Western country. Qualitative description involves the use of interviews and observations to gather data (Sullivan-Bolyai et al., 2005), and these methods were used in the current study.

4.2 Recruitment and Sample

Participants were recruited from two Indonesian community organizations. Both organizations supported the study and the recruitment process (see appendix C for the partnership agreement form). The student researcher completed recruitment and data collection over a three-month period (January 2020-March 2020). During this time, the student researcher visited each organization regularly and spent time and participated in some of the organizations' activities in order to meet people and to introduce the study with a poster. It was also an opportunity to make general observations about the community and the organizations. The coordinator/head person facilitated recruitment by identifying potential participants (the coordinators had been informed of the inclusion/exclusion criteria). They also posted and circulated the poster in their organizations and social media groups (see appendix D for the poster). The student researcher also identified some participants through referral from other participants. The student-researcher then contacted all potential participants to explain the study in more detail, confirm eligibility and to complete recruitment including setting up a time and place for an interview. The student was fully responsible for the recruitment process including explaining the study to potential participants, answering their questions and obtaining their consent (see Appendix E for the consent form) to ensure no conflict of interest. To maintain confidentiality, the organization coordinators/head person was not informed of who participated in the study.

Participants were recruited through purposive and snowball sampling. In purposive sampling, the researcher consciously selects the participants to be included in the study based on specific criteria (Grove, 2013), while snowball sampling allows a researcher to identify participants who have the criteria through referrals from participants (Sadler, Lee, Lim et

Fullerton, 2010). Purposive and snowball sampling were deemed appropriate strategies as this study sought to target a specific group (Grove, 2013; Sadler et al., 2010) (i.e., adult Indonesian immigrants living with chronic illness). Participants were included if they were: a) 18 years old or older; b) Indonesian immigrants living in Montreal; c) living with chronic disease(s) (i.e., hypertension, type 2 diabetes mellitus, chronic kidney disease, cardiovascular disease and osteoarthritis); and d) they were able to communicate in either Indonesian or English well enough for an interview (French was a third language in this population). Efforts were also made to recruit a diverse sample with regards to sex (men and women), age (younger and older), and length of time in Canada (recent and less recent immigrants). Participants were excluded from the study if they were unable to provide informed consent due to fragility, severe cognitive abilities and/or mental illness. The student researcher asked the coordinators/heads of the organizations to not refer participants that they believed may be unable to give informed consent. Individuals with cancer were excluded since cancer presents unique challenges given it is also an acute illness that involves intensive treatments and hospitalization. Participants were recruited until a data saturation was attained, meaning there was an abundant amount of data and there appeared to be no new information coming from the participants (Polit, 2012). Based on similar studies with the same theme (self-care experiences) (Chatrung et al., 2015; Davidson et al., 2011; Kristianingrum et al., 2018), the student researcher aimed to recruit 5-10 participants. This is also within the standard range of the required number of participants for qualitative studies (Neergaard, Olesen, Andersen et Sondergaard, 2009).

4.3 Data collection

Data collection was done via semi-structured interviews. An interview guide was developed based on the framework and included a range of questions to capture the chronic illness self-care experiences. Observational data (interactions and behaviours) were also gathered during the interviews. At the end of the interview, socio-demographic information (e.g., age, migration information, illness information) was collected using an interview-administered questionnaire. Throughout the recruitment and data collection process the student also kept general field notes.

4.3.1 Interviews

The participants were offered to be interviewed in a location of their preference (e.g., community organization, home, café, or University office); all but one was interviewed in their home. The interviews were conducted in the language of the participant's choice, either English or Indonesian. Participants were asked to participate in one interview, however, for two participants, follow-up interviews were done to ask for some clarifications from the first interviews. Most of the interviews lasted between 30 to 60 minutes. Six participants were interviewed longer because they wanted to have a longer discussion. One participant asked to have his interview done over two meetings. Participants were asked to sign and give separate consent for audio-recordings (see the consent form for details). One participant did not agree to have his interview audio-recorded, so the researcher took extensive notes which consisted of paraphrased answers to the questions. All interviews other interviews were audio-recorded and then transcribed verbatim and translated to English by the student-researcher.

Semi-structured interviews are commonly used in qualitative descriptive studies (Neergaard et al., 2009). They are useful when researchers want to be sure that specific topics are covered, especially when being guided by a framework, but also want to allow participants the opportunity to raise new or different topics that they deem important and relevant (Polit, 2012). An interview guide was therefore developed (see Appendix F) and used by the student researcher to stimulate discussion and to ensure all pertinent topics were covered. However, the student researcher also encouraged the participants to talk freely, to tell stories in their own words and to provide as many illustrations and explanations as they wished. In order to situate the interviews, the student-researcher paid particular attention to contextual data that highlighted the post-immigration situation of each interviewee.

The interview started by asking the participants to briefly describe their migration to Canada. The following question asked details about their illness (e.g., which disease(s) they have and when they were diagnosed); the subsequent questions asked participants to discuss what it was like living with their illness, what self-care meant to them and how they had practiced self-care including the ways that they monitored and managed their illness and maintained health (broadly defined). A number of questions sought to explore with participants what affected their self-care, including religion, beliefs, health knowledge/literacy, support and access to care, and also to understand how their experiences had changed over time and since migration (for those who were diagnosed prior to coming to Canada). For those diagnosed in Canada, the student researcher asked participants whether they thought their self-care experiences were different than what they would have been if they were still in Indonesia; if they answered yes, they were then asked to describe how they thought their experiences would have been different.

4.3.2 Observations

Observation is used to better understand and contextualize the information shared by participants (Grove, 2013). An observation guide was developed to assist with this process (based on a guide that was used in previous research by one of the supervisors). The student researcher aimed to document observations during the interviews; some general observations were also recorded during her time spent at the community organizations (see Appendix G for the observation guide).

During the interviews, the researcher observed and took notes on the context, dialogue and tone of the interaction, and also on the participants, including their appearance and demeanor. Attention was also made to record activities, interactions and/or items in the environment that might have been indications of self-care practices or factors that might have been influencing these. For example, the researcher noted family members who were present and how the participant reacted to them.

Finally, throughout the research process, the researcher reflected on what transpired and how the participants and the researcher interacted with each other, as well as her feelings and impressions. These data were also recorded through field notes.

4.3.3 Sociodemographic Information

A questionnaire was used to collect socio-demographic data (e.g., age, sex, marital status, migration status) (see Appendix H). The questionnaire was verbally administered by the researcher at the end of the interview. After its completion, the researcher reviewed the information to ensure it was complete.

4.4 Data Analysis

The interviews were transcribed by the student-researcher right after the interview had taken place (into English). For participants who did not provide audiotaping consent, the extensive observations were reviewed immediately after the interview to ensure that they were as complete as possible and that everything was captured in the field notes. The data collection and analysis process were done concurrently. In qualitative description, the researcher analyzes the informants' experiences in a close way but with low levels of interpretation (Neergaard et al., 2009). In this study, the data were thematically analysed using the approach described by Vaismoradi, Turunen et Bondas (2013). The process was done both inductively and deductively; the latter by using the framework by Riegel et al. (2012) as a guide. Thematic analysis involves examining narrative materials and breaking them down in order to identify patterns (themes) within the data (Vaismoradi et al., 2013). The student researcher first read and re-read the transcriptions and notes in order to become immersed in the data and to note initial impressions. Secondly, the student researcher examined the transcripts line-by-line and did open-coding (i.e., applied words to sections of the text that described and captured key ideas that the researcher identified as relevant and important to the phenomenon under study (self-care experiences)). Thirdly, the text was re-examined and coded deductively using the framework by Riegel et al. (2012) in order to identify the various factors shaping the self-care experiences, but equally staying open to new codes. Through these processes a codebook was developed. All of the coding was done in an excel file and each participant had their own 'sheet'. Fourthly, the codes were grouped into categories. The process involved looking for patterns across the codes and grouping them together into meaningful units. Initial impressions and the research questions were kept in mind during this process. Observational data were also used during this step to provide contextual information to help define categories. To specifically examine changes in self-care experiences associated with migration and/or whether participants felt that their self-care experiences were different than they would have been if they were still in Indonesia- a specific category was created for this (participants were directly asked a question about this). Fifthly, the text, codes and categories were examined for patterns (similarities and differences) by various characteristics of the participants (e.g., age, sex, time since arriving in Canada, migration status). This involved looking at the coding across the participants (across their excel sheets) and taking notes on the patterns identified. Finally, the student researcher aggregated the categories into broad themes that best described and summarized the data. This process involved selecting various categories and moving them around and seeing how they fit best together in order to respond to the research questions. This was done individually by the student-researcher (in excel, one master sheet was created that summarized the categories, codes and themes) and also through discussions with her supervisors. The themes were written-up in descriptive text and supported by quotes from the participants and/or extracts from the observation notes. The themes were also refined through the writing process. The socio-demographic data were summarized and are reported into a table to provide context to the results.

4.5 Trustworthiness

For research using a qualitative descriptive approach, rigour is determined by the degree of data trustworthiness (Milne et Oberle, 2005). Data trustworthiness has four components including authenticity, credibility, criticality and integrity (Milne et Oberle, 2005).

4.5.1 Authenticity and Credibility

Authenticity of the data is achieved by ensuring that the participants have the freedom to express themselves and that “their voices are heard”, while credibility refers to how well the results represent the “voices” of the participants (Milne et Oberle, 2005). To ensure that participants had the opportunity to express themselves, the student-researcher was flexible during the interview and allowed participants to focus on what they deemed important. The student-researcher was also careful to give time and remain silent so that participants could follow their train of thought without interruption. Participants were offered to have their interviews in *Bahasa*

Indonesia to minimize language barriers and foster easy communication. Probing was used to enhance richness and for seeking clarifications in order to promote understanding of participants' experiences. The researcher also verified understanding by summarizing the major points throughout the interview process. Audio-recordings and extensive note-taking allowed for more accurate remembering of what participants shared. Transcriptions were done in a timely manner and the coding and interpreting of data were ongoing to further optimize the quality of the analysis. During analysis, the context was kept in mind (using the observation notes and socio-demographic information) as well as the tone of participants' voices (the researcher returned and listened to the audio when needed). The analysis was done in a systematic way using line-by-line coding, with both an inductive and deductive approach. Triangulation was also used, including sources, methods, and analyst triangulation. This was done by verifying consistency in the data across different participants and between the observation and interview data. The student's supervisors also analyzed a selection of the data, as a means to corroborate the analysis and interpretation of the data. The themes and description remained close to the informants' words and supporting quotes were extracted to further enhance credibility of the findings. Lastly, to further validate the results were presented to obtain feedback from the community (presentation was done November 7th, 2020).

4.5.2 Authenticity and Credibility

Criticality in a qualitative descriptive study refers to the steps taken by the researcher to minimize their influence on the data and the findings (Milne et Oberle, 2005). The overall integrity of the study depends on how well the researcher is able to provide transparency with regard to each step of the study (Milne et Oberle, 2005). In addition to the strategies named earlier, the student researcher also used reflexivity and kept a detailed audit trail to attain criticality and integrity. A reflexive stance was maintained by the student researcher by continuously reflecting on how her biases influenced the overall process. This was done by keeping notes on her thoughts, feelings and impressions throughout the interview and analysis process and also via debriefing sessions with her supervisors. These reflections not only included her positioning as an “insider” of the community (i.e., as an Indonesian), but also as an outsider (i.e., as an international nursing student from Indonesia) and how this affected her interactions with participants. The audit trail included a detailed record of each aspect of the study (recruitment, data collection and analysis) and of all decisions made, including the rationale underlying each decision.

4.6 Ethical Considerations

The student-researcher obtained approval for the study from the CERSES (*Comité d’éthique de la recherche en sciences et en santé*) at the Université de Montréal (see Appendix I for the ethics’ certificate). A number of measures were put in place to respect the autonomy of participants, safeguard their welfare and to minimize harms. Special attention was given to prevent ethical issues due to vulnerabilities associated with the participants’ immigrant status, such as not being familiar with research principles and their rights as participants and not understanding information due to language barriers. Recruitment and data collection were therefore done in *Bahasa* (Indonesian Language) (when preferred). Simple language was also used throughout the study. The student researcher also translated the consent form to *Bahasa Indonesia* and allotted a good amount of time to explain the study objectives to participants and to respond to their questions. A copy of the consent form was left with them to read and to review before making their final decision (they had up to 10 days to notify the student researcher on whether or not they wanted to participate). Audio-recordings were only done for those participants who gave consent for it.

The Indonesian community in Montreal is quite small (Statistics Canada, 2019) and so confidentiality was a potential concern, especially since the student-researcher is part of the Indonesian community. To reassure participants, the student-researcher informed participants that she had a legal obligation to keep all information confidential. She also explained that all information shared, including their identity and other personal data (e.g., income), would not be communicated to anyone outside the research team. For participants who had their family members present, the student-researcher explained that confidentiality depended on everyone present agreeing to not share any information on what was discussed during the interview (this was also indicated in the consent form). No names were used on forms or audio-recordings and no personal identifiers, including the name of the organizations where participants were recruited are/will be reported anywhere. All quotes and experiences described remain general in nature to further ensure confidentiality. Lastly, all paper documents were kept under lock and key during the study (due to COVID they were temporarily kept by the student researcher). All documents have now been given to the supervisor and will be kept in a locked office at the University of Montreal (the supervisor's office) until they are destroyed (7 years). All electronic data is stored on the University's secure shared network drive.

There were no foreseen harms in participating in this study. However, to ensure participants always felt comfortable, throughout data collection the student researcher reminded them that they were not required to discuss anything that they didn't want to. In case any participants ever felt sad or distressed by the discussions, the student researcher had also planned additional time to be available and to stay longer with participants as needed- although this was never required. To minimize the time inconvenience, the student researcher was flexible and offered to do the interviews at a time and location that suited the participants. The interviews were also kept to a minimum amount of time or split into two meetings when requested by participants.

Lastly, for participants who were interested, the student researcher offered to call them to give them a brief summary of the study results (in English or Indonesian) and/or to send them a written summary (in English) by email (6 participants were interested and received a summary).

Chapter 5: Results

5.1 Description of the study participants

The overall description of the study participants is summarized in Table 1. The study included 8 participants, 5 males and 3 females. Three of the male participants were interviewed with their wives, and all but one participant, were interviewed in their home; participant 7 was interviewed by phone due to the COVID pandemic. All interviews were conducted in *Bahasa Indonesia* (Indonesian language) and audio-recorded, except for one participant who did not consent to recording.

Almost all of the participants were married and living with their spouses and children; a couple of participants were married to each other (i.e., there was one couple). Participants were mostly well-educated with a postsecondary education or higher. Most were working full time, and more than half were relying on employment as their main source of income. All participants spoke *Bahasa Indonesia* as their first language and were more comfortable in English as a second language, compared to French. In general, the participants had a relatively good socio-economic status; two of the eight seemed to struggle financially.

Table 1: Participant socio-demographic, migration and clinical characteristics

	N=8		**N=8**
Gender		**Age**	
Male	5	Middle-aged adults (36-65 years)	6
Female	3	Older adults (> 65 years)	2
Marital status		**Lives with:**	
Married	7	Husband/wife	1
Divorced	1	Husband/wife and children	6
		Lives alone	1

Highest level of education		**Current employment status**	
Secondary diploma	1	Working full time	6
Postsecondary diploma	4	Studying and not looking for work	1
Graduate diploma	3	Not working and not looking for work	1
Source of income		**First language**	
Employment	4	*Bahasa Indonesia*	8
Employment and help from relatives	1	**French (speak, write, read, understand)**	
		Well	2
Partner's employment	1	With difficulty	2
Other (e.g., social assistance, scholarship)	2	Well and with difficulty	2
		Not at all	2
		English (Speak, write, read, understand)	
		Fluent	4
		Well	3
		With difficulty	1
Combined family income ($)		**Migration (initial purpose)**	
$10,999-19,999	1	Work	3
$20,000-49,999	2	Study	1
$50,000-99,999	1	Followed family	1
≥ $100,000	3	Visitor (but seeking work)	2
Chose not to answer	1	Came for humanitarian reason	1

Length of stay in Canada		**Chronic illness**	
0-4 years	1	Hypertension	3
5-10 years	1	Diabetes	2
>10 years	6	Kidney failure	1
		Comorbidities	2
Timeframe of diagnosis		**Duration living with the illness(es)**	
Pre-migration	4	0-4 years	1
Post-migration	4	5-10 years	2
		>10 years	5
Healthcare insurance		**Perceptions regarding causes of illness***	
Provincial government insurance	3	Age	2
Private insurance	1	Heavy workload and/or other work stresses	4
Provincial and private insurance	4	Unhealthy lifestyle (e.g., consuming sweet and/or fried foods)	4
		Genetic risk	3

* A participant could have perceived more than one cause

Six of the eight participants had been in Canada for more than 10 years; all but one currently had permanent resident status or citizenship. The participant who did not have residency, was an international student. Three participants migrated as economic immigrants and they came to Canada with family and had lived in a few different countries before arriving here. One woman came to Canada because her husband had found employment while two others came as visitors, although with the intention of finding work and staying permanently. One of the latter eventually made a refugee claim and obtained permanent status through this process. Another participant came, and was accepted, based on humanitarian/refugee grounds.

The participants were living with different chronic illnesses, including hypertension, diabetes, kidney disease; two participants had comorbidities (one participant had hypercholesterolemia and arthritis, and another had hypertension, diabetes, and arthritis). Seven of the eight participants had been living with their illness for at least five years. The participants described different experiences in how they discovered they had an illness. The majority reported that they had had symptoms, and this is what prompted them to seek medical attention and subsequently be diagnosed. Two participants were diagnosed after being hospitalized when they fainted (which was a sequelae of their illness). One participant was never officially diagnosed, she suspects that she has hypertension and diabetes because there is a family history, and arthritis because she feels 'stiffness' in her feet and her sister in-law (in Indonesia) believes that this is what she has. The participants attributed various causes to their illnesses, including work stress, unhealthy lifestyle and genetics.

5.2 Themes

We identified three broad themes related to self-care experiences: "What's Helpful for Indonesians' Self-care"?, "Self-care Challenges and Responses to Living with a Chronic Illness", and "Expectations regarding Self-care and Support". Across and within participants there was a diversity of reflections and perspectives on self-care experiences. The multiple views and nuances of their experiences as well as the various influencing factors (as per Riegel, et al. 2012 and using a pre- and post-migration lens) are interwoven within the description of each theme. Supporting quotes are presented throughout the results section.

5.2.1 What's Helpful for Indonesians' Self-care?

This theme captures the different sources of support and/or ways of being and doing that helped the participants manage and monitor their illness and feel well and healthy, both physically and emotionally. What was helpful included "eating healthy", their religion, being helpful to others, and having support from family, peers and healthcare professionals.

With respect to eating healthy, all but one participant spoke about the importance of eating "healthy" or "properly" as a key part of their self-care. The emphasis on food seemed to be partly driven by the fact that their HCPs told them that managing their weight and reducing their intake of sugar, fat, etc., was important for staying well and ensuring that the disease did not worsen.

> *The dietician told me to do a strict diet. I then need to manage my food behaviour, for example, in the morning, I need to manage the amount of carbohydrate, fat, vitamins and minerals that I could consume, or what I should consume between breakfast and lunch.* (Participant 5, Female)

Four participants also mentioned unhealthy eating as one of the causes of their disease, and so this too appeared to be a motivating factor to eat in a healthy way. The participants described "eating well" as something that they learned over time, but that remained challenging for them; for some participants "eating well" also seemed to be an ideal that they were continuously striving for.

There was some variation across the participants regarding what "eating well" entailed and what strategies were implemented to achieve this. 'Good eating' was influenced by their illness (e.g., diabetes, hypertension) and their beliefs, which in turn were shaped by changes in their eating habits that had occurred with their migration to Canada, and also by what they had been told by their HCPs and learned on their own over time. 'Good eating' involved limiting or eliminating certain foods from the diet, reducing the amount of food that they ate, eating more fruits and vegetables and changing their way of cooking.

Faith and religion were also important to self-care. Some of the participants expressed that they believed that their illness was part of God's plan, which was reassuring and helped them process their emotions and come to terms and accept their illness. One participant reflected:

> *I see what I experience now, is one of God's (Allah's) plan for me, how then we react to it…and, how we accept it, how we do it, how we live with it, and return all these situations to Allah. I notice that this is Allah's plan for me, and I accept it sincerely, I do what I can do, and I live with it.....we call it, "resignation", so I resign, I return all to Allah, and I think that all is planned for me, and then…. this lead me feeling calm, light…* (Participant 3, Male)

One participant shared that he felt that God gave him the illness as a consequence to his unhealthy behaviour in the past: *"Allah will give us things as what we did. I notice that I lack exercise, I don't eat regularly, and consequently, I get this illness, something like that. So, we get bad due to our bad behaviour too".* He explained that the illness was God giving him an opportunity to learn and grow, which motivated him to move forward and "find the way out"*: "I believe there must be a takeaway of something given by God, including from the illness. However, we, human, we just always confuse on how to deal with it, but if we believe, we will find the way out".*

Some participants also mentioned that their faith guided their healing, helped them to behave healthier and encouraged them to treat their family better, which in turn contributed to their wellness. One participant shared: *"Maybe with the illness, I could be more caring with others, with my family, with my wife".* The participant also viewed faith as a source of strength which helped them to cope with the illness: "*I ask God to make me able to face or to deal with the illness. I ask God to make me strong so I can face the illness well*".

In contrast, one participant, when asked about religion and her illness, felt that there was no connection between the two. However, she still spoke about praying as a way to help others heal and get healthy when they are sick, and when she was asked about how she felt about living with her illness, she stated that it was God who gave her the illness - this therefore helped her process and accept the illness, which in turn motivated her "to deal with it".

> *I try to separate them. I don't want to relate my faith to my illness. If we're sick, then we are sick. I believe my illness is caused by my own fault in the past. I could not have avoided to take sweet and delicious foods. That's why I get the illness… Even if we know there are somebodies who are sick in our community, or live with chronic illness, we don't relate the illness to our faith, or worship. We just pray for them so they can get healed...*
> ***[later in the conversation]** : I was stress at first after being diagnosed. Diabetes is a chronic illness, and could not be healed, but why it must me who get the illness, and (I did not know) how to figure it out. This (lack of knowledge) made me more stressed. However, overtime, I think……………. that I need to deal with the illness. I think……. I need to accept it. That's what God give to me, and ok I accept that. I feel that living with the illness is my fate, that makes me accept it, and deal with it, so I'm not stressed.* (Participant 5, Female).

Similar to religion and faith, "being helpful" was also identified as an important aspect of the participants' lives. Across a number of interviews, participants spoke about "being helpful" to others as and caring for family and the community and this seemed to be an important source of their well-being. Although not directly a part of "self-care", it was a source towards achieving better health as it provided a sense of purpose and made participants feel good. Being helpful to others was shown in different forms, for example, sending money to family members back home and being concerned about their ill family member (Participant 7 who was worried about her sister) and helping them get the care that they needed. It was also shown by sharing their personal experiences with friends and the community, some participants hoped that others could benefit from it and prevent becoming ill or recover from their own illnesses. Despite being ill there was a sense of gratefulness, and therefore participants felt that they should give to others.

Despite the positive effects of being helpful, it also had some negative effects. Although one of the participants had a strong motivation to help her sister who was sick, sending money back home caused her major financial strain and affected her ability to take care of her own needs. The quote below expresses her feeling:

> *I had sent them money regularly, and I only have a little left for me. I did this so my sister's (medical) test would not be stopped. I was in deficit, and I asked help (to a community organization) to lend me some money for living. I did not have even money to pay bus pass, but at the same time, I needed to prioritize my sister's treatment*. (Participant 7, Female)

Receiving support from others, including family members, peers, the community and healthcare professionals was also helpful for self-care. All participants confirmed receiving support from relatives, mainly from their spouses (i.e., husband, wife). However, the degree of support received from family members and how it was experienced, varied. For one male participant, who struggled with his illness, he seemed to have an expectation that his wife provide assistance (for example, he expected his wife to bring him food or drink at his beck and call), which was in stark contrast to some of the other participants, who demonstrated great appreciation for the help and concern that their spouses showed. A couple of examples of the gratitude expressed in the following quotes: "*My wife is very good. Very helpful. She always reminds me to not sleep late at night",*

> *My wife is the most important partner. Don't forget!... Wife, her role, is very important, especially for me, who is sick, isn't it? She is the one who always remind me, and then…. not only for food, but also on how to face problem….* (Participant 3, Male)

One participant lived alone and had no spouse or children to help her with her self-care. She had some contact with a niece who lived in another city, and some communication with family members back in Indonesia (her sister, nieces and nephews), but she wished that she had more communication and support from them. She therefore planned to eventually return to

Indonesia in order to be closer to her family. Her feelings about her niece and the support received are shown in the following quote:

> *She tries to make me feel happy, for example, if I visit her, she usually invites me to have a walk around, going to the shopping centre, everything that could make me relax and happy. This proves that she tries to make me feel happy, at least when I'm with her. But it does not always happen.* (Participant 7, Female)

For the participants who received support from their spouses, they described receiving it in various ways, including assistance with daily life activities (e.g., washing clothes, cleaning the house, cooking), encouragement to engage in healthy life behaviours, help to deal with stress, and giving information. Support was also provided by being caring and very attentive and 'tuned-in' to their wives/husbands' needs. For example, one participant shared how her husband knew when she was hypoglycemic just by the way she spoke, while another participant, who was the husband of one of the other participants, described how he wanted to learn more about his wife's illness so he would accompany her to medical appointments or would even ask the doctor about diabetes at his own doctor appointments (they both had the same doctor). The same participant also spoke about how he knew his wife didn't like to be reminded about her illness, or to be treated like she was sick, so he was careful to not speak about her illness. This couple also described a relationship that was mutually supportive. The following quotes show how they helped each other:

> *I was working under pressure (so I needed to eat healthy food to have enough energy). My wife therefore shown me how to do a recipe and how to cook (so I could eat healthy food), and now, every weekend, I take over the kitchen and cook for me and my family.* (Husband, Participant 6).
>
> *On Saturdays, my husband usually takes over the cooking* (Wife, Participant 5).

With respect to support from children, this varied as well. One participant said his kids provided help by doing house chores, whereas two other participants received some direct assistance with monitoring their illness from their daughters who were nurses; one also said her other daughter helped with some of the day-to-day life tasks. The remaining participants did not really receive (or seem to expect) any direct support from their children. For the latter, for one participant, his children were young, while for another she did not want to be treated as sick, and for the others the exact reason was not really clear.

Support from family was mostly evident in just the everyday activities and daily living. It was about their presence and spending time together, being kind and generally helpful and just 'going with the flow' and adapting to some of the family-life changes that came with having a family member who was living with a chronic illness (e.g., eating the same food). This 'everyday support' is shown in the following quotes: "*I think when they invite to play with them, or joke, I think, it is like……well, it is somehow good for health*", "*We eat brown rice now, including my daughters, so with the bread. As I take the whole grain only, they also take it*.

Some of the participants also discussed receiving help from friends, work colleagues, and from the Indonesian community (via organizations). A few mentioned that this was in the form of informational support about diet and treatments, including alternative medicines while most described receiving social or emotional support. Regarding the information given, it was sometimes welcomed and viewed as helpful, and sometimes not, while for the social support, it seemed to be more about just connecting with others, having a social network and generally being kind and helpful rather than providing direct help for the illness. An example of kindness is shown in the following quote:

> *In our community, all my friends know already that I have diabetes, so they understand if I only take little food in the gathering. As they understand me, they sometimes prepare me less sweet food. While for me the food still very sweet, their work to prepare it for me should be appreciated, and helpful.* (Participant 5, Female)

In addition to the general informational and social support, one participant also mentioned receiving financial support from an organization, which helped her to meet basic needs, for example buying food, while another described receiving emotional support from a colleague, who also had diabetes, which made her feel she wasn't alone living with her disease. These two significant experiences are shared in the following quotes: "*I asked help to (an organization) to lend me some money. And they lend me some. They also understood my situation and allowed me to pay them back when I'm available. It helped me to buy rice" ,*

> *I have one Quebecer colleague. She said she took medication, but now she is with insulin. She said her doctor changes her treatment because it does not work with medication anymore. This sharing was somehow helpful for me. I do feel that I'm not alone with the illness. There are so many people out there who live with similar illness, and it is somehow motivating to get my life better from day to day.* (Participant 8, Female)

Lastly, there were also some varying views among the participants on whether the community should be a source of support. One participant suggested that the community could do more while a couple of participants said that they did not really have any expectations or did not want to be a burden on others. Their sentiments are expressed in the next two quotes:

> *I don't put expectation on them. Not only Indonesians, but also other people. I already accept my condition. I get this as a lesson from God. So, what I need to do instead is, give contribution to other people, so I can prevent them experiencing similar condition with me. I prefer to serve people than being served.* (Participant 6, Male)

Lastly, transnational ties to Indonesia was discussed as a source of support. All of the participants had ties to family and friends back in Indonesia, although the intensity of the relationships varied. Some reported visiting family or receiving visits, but mostly connections were maintained via phone, messaging and social media. For some of the participants, these connections served as a source of support for dealing with their illness. For example, one participant had traditional medication sent by her father, while other participants described receiving advice or suggestions regarding treatments, physical activity, diet or simply being asked about their condition. Some of the advice provided was more ‘professional’ (i.e., a family member who was a doctor), but mostly it was lay advice; a few of the participants specifically received guidance and support from family members who also had the same disease.

A couple of the participants, despite feeling grateful for the family’s efforts to be helpful and supportive, were less open to their family members’ suggestions. This mostly pertained to alternative medicine, and the participants preferred to follow the care given by their HCPs in Canada. Two participants shared this perspective:

> *My father-in-law was a doctor, and he had suggested me once to look for traditional treatment in Canada. While he was a doctor, he is not my doctor, and I follow only my doctor’s instruction, and it is taking medication.* (Participant 6, Male)

> *They (my family) say that olive oil is good for breakfast. They also said bitter food, such as bitter melon is good. They say if I take these regularly, I may be free from Insulin (not have to take it) later. But I do say to them that I can’t do it. I need insulin injection for the rest of my life. I can’t leave the insulin. I do need insulin to live. Some others suggest me to take this and that leaf, this and that traditional medicine, but I don’t do. I always remember nurse’s suggestion for me, that I can’t take alternative medicine anymore. All that can help me for living is insulin*. (Participant 8, Female)

In contrast, one participant purposely chose to not talk about their illness with family in Indonesia because he did not want to burden them. He explains in the quote below: *“We (myself and my family) prefer to not share with them (family in Indonesia). We do not want to give those in Indonesia any difficulty. We make it up ourselves as long as we can*”.

5.2.2 Self-care Challenges and Responses to Living with a Chronic Illness

This theme highlights the key challenges that participants faced while living with a chronic illness and also provides a description of how participants adapted (or not) and responded to living with an illness.

Two key challenges highlighted by the participants related to the support received from HCPs, mainly physicians. The HCPs were considered didactic, too focused on prescriptions or medical treatment, and had a different style compared to HCPs back home (which was preferred) and did not behave and adapt to the patients' approach to self-care and life circumstances. The participants described the communication as limited and unidirectional, and this resulted in disappointment with their care, feelings of not being supported, and hesitation to share their challenges with their HCPs. The frustration felt is expressed in the following quote:

> *How do you feel if you come to a health care service, and they (the doctor) only ask you like, "what may I help you?" and when you answered, for example, " I get flu", and they only give you medication like, "Ok. Please take this and that". What kind of service is it? Is it how they should behave with patients? They measure my blood pressure, they facilitate me to get the medication…However, Indonesia is still better. When I come, they will take my blood pressure, and in case it is higher, they would say like, "What did you consume before coming? Did you have a cup coffee this morning?". They assess such things, and (this manner) is very good. Compared to the clinic here, no. They don't ask such thing. All they talk about is medication, medication and medication…* (Participant 3, Male)

A few of the participants also spoke of negative interactions when they attempted to communicate their needs and to ask questions. The HCPs didn't seem to be open or welcoming to this communication and reactions were unsupportive. One participant even preferred to not seek medical treatment because she felt that it would be more stressful to do so. She explained:

> *I don't even want this illness to bring me to a doctor. Why? Because if I visit a doctor, I may be more stressful due to the doctor's recommendation. The doctor may tell me not to do this and that, instead of doing this and that.* (Participant 7, Female)

Waiting time was also mentioned to be an issue and contributed to the negative experiences with physicians. One participant described that the waiting was so long that she preferred to avoid seeing the doctor if she could: "*The waiting line is very long. About 2 hours…*

because of the waiting line, I meet him if I really needed, if I really feel ill. As long as I can hold it, I don't see him".

The participants wanted the HCPs' approaches to be more holistic and not only focused on medication or medical treatment. They wished that HCPs would inquire about how they were doing and to consider their preferences and living situation, and some wanted more direct support on how to live a healthy lifestyle. For some participants, they felt that the care was better in Indonesia. These feelings were expressed in the following:

> *……which one is better, the doctor here, or the doctor in Indonesia, the one in Indonesia is better. (My doctor in Indonesia) thinks that the (chemical) medication is not the only solution for this case (hypertension), but we need also to change our lifestyle.* (Participant 3, Male).
>
> *The doctor always gives us good recommendations, however, for us, things like consuming healthy food, exercising regularly are always challenging* (Participant 4, Male).

Despite the lack of holistic care and some challenging interactions with HCPs, participants still generally had a positive opinion and viewed HCPs as competent and helpful. For example, a couple of participants described how their physicians were attentive to their symptoms and which medications they were taking and adjusted their prescriptions to ensure they were receiving the most appropriate combination of medications:

> *After half a year here, I was feeling uncomfortable with the treatment effect (the one from Brazil). I got constipation. I then visited a physician here, and he gave me Colistin. I was finally taking Allopurinol and Colistin 1-2 times/day as recommended.* (Participant 1, Male)
>
> *He paid attention to the three medications I had taken. He even asked me why I should have the third one, while it is not appropriate for my condition (in his opinion). He also suggested me to stop taking the third one and to see how I will feel with that* (Participant 3, Male).

Another participant (participant 8) said she was shown how to administer insulin herself: "*She (the nurse) shown me how to check my own blood glucose and how to inject the insulin myself. I found it difficult at the first. But she kept make me sure that I could do it"*.

Another significant challenge to self-care was that participants felt that the treatments were overly medical, which did not align with how they wanted to treat their illness. Most of the participants expressed not wanting to take medications for various reasons. For some there was concern over negative side effects. A couple of participants felt that medications contain chemical substances and that these could negatively affect their health: "*[...] the medication contains chemical substance, I think. If I can choose medication or fruits, I prefer fruits. ... So, I prefer something natural. I don't like taking tablet or pills, even vitamins, I don't like taking them",*

> *I'm ……I'm not happy really, especially in terms that I need to take medication continually, honestly. How is it? What I want instead is ……because I read, the medications contain chemical substance. I have concerns in terms of consuming chemical medication for long term.* (Participant 3, Male)

Participants also had negative perceptions of medications due to past experiences. For example, one participant developed negative views because of her upbringing; her father was a physician and she was constantly exposed to medications growing up. For another participant, he associated the death of a family member to be related to overtaking medication: "*My father had taken medication for the rest of his life, causing damage to his liver, and passed away. So, (I conclude) he passed away due to medication taking.*

Despite some negative views and not wanting to depend on medications, two participants also conveyed acceptance and a need for them: "*Even now, for my condition, actually, I don't like taking diabetes medication. However, I need to….*", "*I am comfortable with my medication,* *and it works for my hypertension. My blood pressure gets normal with it, so I don't want to search another treatment, including the traditional one …*"

For certain participants, however, hope remained that medications could be stopped or reduced. One participant shared: *I want to reduce the medication taking, and if I do that, it means, I need to compensate it, I need to invest a healthier lifestyle, more strike, in more right way, don't I?*". Similarly, another participant explained how he had stopped a medication because he was feeling better:

> *I tried to stop the medication, and I saw….it worked, my blood pressure was normal, especially after exercise. And…. I…. feel better that way, I feel fresher. I thus stop it. However, I keep monitoring my blood pressure, 1 day, 2 days after, it was still good, and it continues to 1 week, 2 weeks, still good also, until some day, I felt ……sick again. I was wondering why suddenly I felt…. like (touching his neck) …. tension. And I soon checked my blood pressure, and it raised again, really. So, I think if I stop the medication, my blood pressure would raise. Finally, I take the medication again, and my pressure decreased as well.* (Participant 4, Male)

Accepting and taking medications therefore seemed to be a process. It required adapting not only psychologically, but also physically. It required some 'trial and error' to figure out which medication worked the best and to get used to taking the medications. This process is also shown in the next quote:

> *I was taking metformin at the beginning, but the doctor said that metformin is not good, since it could damage kidneys. Therefore, the doctor changes my medication. The new one still contains metformin, with additional substances. However, I don't feel really good with the new one. It seemed not perfect for me. It does not really work for my blood glucose. For me, metformin is still better. I did (tell to my physician) about this, but metformin is not available anymore. The production just stopped, since it is considered not good for diabetes.* (Participant 5, Female)

Generally speaking, self-care was a learning process and required adaptations over time. Six of the eight participants spoke more or less about making life adjustments and learning over time to live with their illness including how to manage and monitor their condition and maintain health. This was described as a process that was difficult and that involved acceptance of their illness. It was also motivated by not wanting their illness to get worse and a concern of developing other health issues (e.g., depression). This process is illustrated in the following quote:

> *I was stressed the first time after being diagnosed. Why it must me who get the illness? and (I did not know) how to figure it out. This (lack of knowledge) made me more stressed. However, overtime, I thought……………. that I needed to deal with the illness. I thought……. I needed to accept it …. if I don't, I could be more and more stressful, and may fall to depression. What can I do? All I can do is maintain and monitor my health, so the illness would not be exacerbated* (Participant 5, Female)

The participants described a number of adaptations including making changes in their eating and exercise habits, adjusting to taking medications, learning how to monitor their glucose levels (for those with diabetes), and learning to navigate (and accept the limitations of) the healthcare system. A couple of participants commented that their families also made adaptations with regards to food habits. This helped the ill family member maintain their healthy eating but was also viewed as a way to keep the whole family healthy and to prevent future disease. One participant talked about her daughters:

> *They (my daughters) say it was hard to eat the same food with me. They did not like brown rice. However, the nurse in hospital told me that my family need to learn and need to be careful due to genetic risk. Now, they like my food already.* (Participant 8, Female)

In addition to adjusting to the illness, some participants also spoke about having to simultaneously adjust to "getting older". Ageing exacerbated symptoms and made daily life tasks more difficult. For example, one participant described the impact of her diminishing eyesight:

> *Maybe my age contributes also [to her diminishing eyesight]. Moreover, the letter in mobile phone is quite small. Even for sending a message is challenging for me. If I can send the message, it must take me time, as I need to type it one by one on my phone and correct the overall words first before sending.* (Participant 7, Female)

Getting older and the associated physical changes, for example having less energy and less capacity, also affect what healthy lifestyle behaviours can be maintained and what support may be needed in order to self-care. These points are illustrated in the following quotes: "*when I was younger, I played football, but as I'm getting older, I don't play it anymore. I prefer low impact exercises, as they would not force my heart work", "I need to think my capacity, that will get reduced over time as I'm older. Therefore, the best solution is going back home. I can get closer to my family, to my sister"*, "*As we get older, our physical capacity would reduce. Now, we still can exercise, but overtime, the exercise may be not maximal anymore".*

Certain adaptations proved to be particularly challenging including maintaining 'healthy eating' and regular exercise. Most of the participants struggled; for food habits it was especially difficult when they saw their family members eating 'bad food'. Participants therefore talked about 'cheating' and consuming 'bad foods': "*I sometimes also really want it or fully consume the food I want. That's why I often "cheat*".

Although learning to live with the illness was a process and presented challenges for all, a few of the participants were particularly motivated and had a positive attitude and proactive approach in dealing with their illness. Some also used strategies to help themselves adapt to their new realities, for example using memory aids to ensure that they took their medications regularly and taking their blood pressure daily so that they can monitor and detect changes. These participants gave off a sense of mastery and control over their illness and seemed to have found a balance, for example not pushing themselves when they felt tired and still eating the foods that they craved and liked.

For a participant, she actually viewed herself as not sick; her illness was a part of her everyday life, but she did not attach specific significance to it. Living with an illness was the 'new normal' and she did not want to be reminded of her illness or be given special attention for it, especially since she was well and had everything under control. She shared:

> *I don't want them [my family] to understand me and help me because I'm sick. ……I still can do everything. I still can walk, I still can be physically active, I still can fix everything, so I hope they would not make it like a big deal…. if they remind me regarding my treatment, it just makes me notice that I'm sick. I don't want to notice that I'm sick.* (Participant 5, Female)

In contrast, some other participants seemed to not fully accept or take their illness seriously, and sometimes 'resisted' adapting, even in the face of potentially dangerous outcomes. This was particularly evident for one participant who was living with diabetes who shared that she would sometimes delay taking something to increase her blood sugar levels when she knew she was hypoglycemic: "*I sometimes, ……don't take it seriously. I don't take my juice immediately. I always delay the juice taking [when she is hypoglycemic] …".* Another participant also seemed somewhat in denial about her illness: "*I don't feel that I'm in a condition that I need to take medication, and I don't want. I may feel this because I don't see a physician yet*"(Participant 7, Female).

For another participant, when asked about his life with chronic illness, he seemed completely unable to accept his illness and visibly was strongly affected and struggling. He appeared angry at being ill and expressed sadness, as expressed in the following quote: *"Wohoooo…what is been like living with that...? what it is it? (asked his self ironically). …. wonderful, yeahhhhh…. wonderful. wonderful (with teary eyes and face lowered)".*

Lastly, when participants were asked to reflect on and discuss contrasts regarding self-care in Indonesia versus Canada, they highlighted differences concerning the use and availability of alternative medicines and other health products, the physical and social environments, which affect lifestyle and behaviours and levels of support and stress, and interactions with HCPs (as described earlier). Living in Canada therefore had an influence on how they were responding and living with their illness. Generally, there were both positive and negative impacts. In some instances, there was dismay and preference for the way it is in Indonesia (e.g., interactions with HCPs). For some participants, they described ways that they tried to make their self-care more like it would be if they were living in Indonesia (e.g., getting herbs [traditional medicines] when they are in Indonesia and bringing them to Canada) while for one participant, she shared that she hoped to eventually return to Indonesia because she felt it would be better to be close to her family and to have their support (and for her to also be able to give support to her family). In other cases, particularly for those living in Canada for longer, the differences that came with living in Canada were viewed positively or were just accepted/seen as the new norm, and participants simply adapted accordingly. Some examples of the contrasts are presented below:

> *In Indonesia, if I visit a pharmacy, there must be many promotions about (traditional) medication, for example, “”X” leaf is good for this illness”, “Red ginseng is good for this and that problem”...Compared to here, none of these things exist... You know, here, even looking for ginger is difficult. That’s why when I was in Indonesia, I get a lot ginger powder.* (Participant 4, Male)
>
> I*n terms of exercise, in Indonesia, I could exercise as I wanted, I could do it outside home for example, couldn’t I? But here, of course we could not do that, because of the weather (pointed at the snow fall outside). There are some changes, of course.* (Participant 3, Male)
>
> *In Indonesia, people are more social. We could always make gatherings, meet the families, and it was very helpful for me.* (Participant 4, Male)
>
> *The elderly here mostly lives alone. They do things for their self…Compared to those in Indonesia, no they don’t. The elderly here doesn’t live with their children…That’s crazy, but somehow motivating. If they can do that, why I can’t?.* (Participant 7, Female)

5.2.3 Expectations Regarding Self-care and Support

This theme highlights some of the participants' disappointments regarding their own self-care and/or support from family, the community and healthcare professionals, and describes what participants wished was different about their situation.

The first set of expectations were from themselves. Some of the participants put pressure on themselves and felt that they needed to strive for 'perfection' in their self-care, particularly with regards to food, exercise and medication. For example, one participant had an ideal about the amount of medication he should be taking and felt that if he could do better at staying healthy through lifestyle behaviours, he could then reduce his medication:

> *I want to reduce medication taking, and if I do that, it means, I need to compensate it, I need to invest in a healthier lifestyle, stricter, in more right way, don't I?.* (Participant 3, Male)

Similarly another participant also described how he felt responsible for his health and that it was up to him to ensure that he 'self-cared properly' in order to stay well:

> *I should behave healthier, control my activity. The one who know how to best manage myself, how well my capacity is, is myself. If I force myself, it is me also who will feel the consequence. That's why I said, it is me who need to be active for my health.* (Participant 1, Male)

Some of the participants also had expectations from their family and these expectations seemed to be fueled by the severity of the illness and the difficult social and migration contexts of the participants. Three participants in particular seemed to expect or want more support from their family members. For example, a participant had migrated to Canada by herself and lived alone and had less of a social network and she shared that she wished that her family in Indonesia (and those who lived elsewhere in Canada) would contact her more. This expectation also seemed to be shaped by cultural values, which from her perspective, seemed to not be held by the younger generations, especially if migrated outside of Indonesia. In addition, this participant also had been accepted to stay in Canada based on humanitarian reasons, and her economic situation was very challenging (she described not having enough money to live), thus making her hardships, and likely her need for support, greater. Similarly, Participant 2, also had a similar migration and economic situation, as well as an illness (kidney failure) that was gravely affecting him, so he too (as described earlier), seemed to expect his wife to take care of him. As for the Participant 8, based on her tone and how she spoke about her daughters, she generally seemed to just expect her children to provide help.

In contrast, the other participants had economic and social situations that made their situations less challenging and therefore likely led them to feel more satisfied with the support they were receiving. These participants also reported receiving a lot of support from family and some also felt they ‘had control’ over their illness. With respect to support from back home, one participant said that he felt that his family’s situation in Indonesia was difficult enough and he did not want to burden them.

As for expectations of the community, participants generally did not have any. This seemed to be because they already had strong support from family and/or because of their beliefs. For example, Participant 7 believed that everyone has their own struggles in life so she didn’t want to bother other people with her illness and Participant 8 felt that the community could not really be helpful and that it was her doctor that should help her. In contrast, one participant thought that the Indonesian community could do more regarding health education, especially those who are health care professionals. This is shown in the following quote:

> *We know that there are a couple of Indonesian physicians here (in Indonesian community), and you also, a nurse, and you study nursing here, so I expect that when we are in the community gathering, or in pengajian (practicing their Muslim faith), you all also can make something like health ....education. It could be very good and very helpful, and we can thus get new knowledge from it, which may be useful for our care*. (Participant 4, Male)

Lastly, the participants also had expectation of HCPs. As described earlier, some participants expressed that they would like more personalized care. They wanted HCPs to provide more holistic support and not be so focused on medications. They also said that they would like healthcare to be more organized, streamlined, and flexible and with shorter waiting times. One participant shared: "*I hope I can get better service. As what I see, the weakness in my clinic is the lack of interpersonal relationship with patients. They did not personalize (our need) for care*".

In summary, the themes provide a description of the challenges that Indonesians faced during self-care and also capture how self-care experiences were not static, but rather involved a process of adaptation and learning to live with the illness over time. The themes also provide insight into what was deemed helpful to Indonesians as they conducted self-care. These experiences were shaped by their expectations and also the migration context. Overall experiences varied, and for some accepting their illness was difficult and this negatively impacted how they lived and coped with their illness while for others, they were accepting and adapted well to living with an illness.

Chapter 6: Discussion

Taken together the themes highlight several important points regarding the self-care experiences of Indonesian immigrants with chronic illness in Montreal that should be considered in the context of care provision. These include: 1) The importance of faith and religion for Indonesians in self-care; 2) Being helpful has an important place in self-care; 3) Self-care is a learning process; 4) Self-care, including family support, is experienced differently in Canada compared to being in Indonesia ; 5) Social support may continue transnationally; and 6) There is a need for health care professionals (HCPs) to provide more personalized care.

Results show that religion and faith were sources of motivation to self-care and for a number of participants, helped them with their process of healing. It was a way for participants to better understand their illness, which in turn helped them to accept, cope and live with it. Similar findings have been shown in studies conducted in Indonesia, which explained the importance of religion and faith for self-care, including inspiring patients to seek care and helping them adjust to living with a chronic illness (Bayhakki et al., 2019; Permana, Ormandy et Ahmed, 2019). A research conducted with Arab, Muslim immigrants with chronic illness living in Canada also explained that praying, learning about religion, and participating in religious events were helpful to cope with life stressors, and were a source of motivation and guided their healing (Salma, Hunter, Ogilvie et Keating, 2018). Furthermore, in the review by Roger et Hatala (2017), many positive effects of religion and faith for patients with chronic illness were shown, including helping for coping, improving self-esteem, quality of life and sense of purpose, stabilizing patients emotionally, decreasing distress, being source of motivation, and guiding healing. However, the review also explained that some negative effects are possible (e.g., distress due to unanswered prayers for healing), which could reduce patients' well-being and hinder patients from seeking care and ultimately affect their long-term adaptation to living with the illness.

One of the important points that emerged in the current study with respect to religion and faith, was the covert role that it can play in self-care- i.e., it can be very present in one's experience yet not acknowledged by the person. This was highlighted by the participant who, when asked about religion, said it had no bearing on her experiences, however still talked about prayer and God when discussing ways to stay healthy and cope with living with an illness. Given the growing evidence showing that religion, faith and spirituality are important factors that impacts and shapes self-care for many people living with chronic illness, it is essential to consider these factors in chronic illness support and care, however the results here suggest that different approaches may be required depending on how one experiences their faith in relation to their illness (i.e., overtly or covertly).

'Being helpful', which can include supporting family or the community, both in Canada and in Indonesia, also has an important place in self-care for Indonesians and should be considered in care. Sihombing et Pongtuluran (2011) explain that *gotong royong* (mutual assistance) or helping each other is part of the collectivism culture in Indonesian society and is often used as a means for Indonesians to maintain balance and harmony in their lives. This notion has been supported in research in Indonesia where helping others through volunteering has been shown to have positive effects on well-being, including both physical and mental health, particularly for older people (Rahmawati et Bajorek, 2015). Studies with other immigrant groups in Canada have also shown that kindness and being helpful to others can have a positive effect for those living with chronic illness (Nielsen et al., 2012; Salma, Keating, Ogilvie et Hunter, 2018; Salma et Salami, 2020). Arney et al. (2020) described that when patients with long term illness shared information with their peers (people living with the same illness), this improved their confidence to achieve their own self-care goals (i.e., healthy lifestyle and behaviours). Through the sharing of potential solutions, patients felt reinforced and further motivated to apply self-care strategies (Arney et al., 2020). Furthermore, a review by Inagaki et Orehek (2017), which aimed to highlight the benefits of giving support, showed that helping others could be a way to maintain social relationships and form strong social bonds. Providing support to others can reduce social withdrawal and stress by being a source of distraction and diverting attention away from their own illness and associated complications (Inagaki et Orehek, 2017). Caring for others can also be a source of purpose, feeling one is needed and an important person for others can be motivating and promote healthy living too. For example, in Sanon et al. (2016) with Haitian immigrants, some participants were motivated to control their blood pressure and to take medication so that they could keep working and financially support their families back in the home country who depended on them. In contrast, however, helping others could potentially have adverse effects. One participant in our current study suffered and was unable to meet her own needs since she provided financially to her family in Indonesia. Another study has also shown that providing economically for family members abroad can have negative effects on well-being (Salma, Keating, et al., 2018). Care-providers therefore need to be aware that “being helpful to others” particularly in collectivist cultures like Indonesian can have an important role in self-care, however they also need to consider that the effects on a person’s self-care and health can be both positive and negative.

The study also highlights how self-care is a learning process that involves making life adjustments (e.g., changing their diet, taking medication), and coming to terms with living with an illness, while simultaneously adjusting to getting older. This process is not linear, it consists of ups and downs and it is not the same for everyone. Our results showed that some participants had positive attitudes and a proactive approach, and their outcomes were positive, while for others they resisted making adaptations or it was a terrible struggle and they never fully accepted their illness (e.g., participant 2 who seemed very depressed and angry at having to live with his illness). Some participants also seemed to be striving for perfection which also influenced this process. These experiences are not unique to Indonesians, or other immigrants, as other studies with non-immigrant populations have shown similar findings. For example, in three Swedish studies with non-immigrant adults living with diabetes, some of the participants described struggling to eat healthy and to learn how to make their eating work with their medication, and finding it challenging to follow their healthcare provider's recommendations for eating properly (Kneck, Eriksson, Lundman et Fagerberg, 2016; Kneck, Klang et Fagerberg, 2011, 2012). The same studies also revealed that some participants had to learn how to take their medication and adjust the dosage with their blood glucose level. Similarly, in two other studies, one conducted in Sweden and the other in Thailand, some of the patients, who were older adults living with chronic illness, also showed how they adapted and accepted their illness and learned to live with it over time (Chiaranai, Chularee et Srithongluang, 2018; Johansson, Österberg, Leksell et Berglund, 2016). Across these studies, patients used a range of strategies for self-care, including, for example, making an Excel sheet to help with food planning and to control their blood glucose levels, and creating a medication schedule that aligned with their work schedule as a way to ensure that they take their medication on-time. Telford, Kralik et Koch (2006) explained that some patients are very optimistic about their situation and figure out strategies that are helpful and make their life easier. On the other hand, the studies also showed that some patients found it challenging to make changes and to adapt to the new realities of living with a chronic illness. Telford et al. (2006) also found that due to their illness some patients developed negative perceptions about themselves, which made them worried about being stigmatized by others, including health care professionals, and this contributed to reluctance to seek medical help. Together, our results and the existing literature highlight that illness and self-care experiences are individual, and that support needs are likely to vary over time. Our study results also provide a reminder that there are similarities in experiences of living with an illness, irrespective of whether one is an immigrant or not.

Although learning to live with an illness is a universal phenomenon, for immigrants, they are often also adapting to different concepts and approaches to health and well-being, as well as a new environment, and also navigating an unfamiliar healthcare system. Our study focused on Indonesians, a group yet to be studied, and specifically highlighted a number of differences between living in Indonesia vs. Canada with regards to self-care. The most significant differences included the use and the availability of traditional medicines, some particular beliefs about medicines, and interactions with healthcare providers. For the participants, the implications of differences between the two countries were sometimes positive, for example eating behaviours changed for the better for some, while in other instances, they were negative, for example, living in Canada for some, was viewed as a more stressful, and isolating experience. Responses to differences and the degree to which participants carried-over beliefs and practices from Indonesia, overall were mixed. Some seemed to prefer how life was in Indonesia and attempted to maintain certain Indonesian practices while others adapted, or even preferred, the different approaches and ways of living in Canada.

A number of Canadian studies with other immigrant groups have also observed that self-care behaviors are influenced by the pre-migration context. These studies showed, for example, that immigrants may continue to use traditional therapies (e.g., Chinese medicine, remedies, acupuncture, herbs), and to maintain eating and cooking habits from the home country, as well as lifestyle behaviours (Nielsen et al., 2012; Salma, Hunter, et al., 2018; Salma, Keating, et al., 2018; Salma et Salami, 2020; Wang et Kwak, 2015; Zhang et Verhoef, 2002). They may also seek and consult with physicians from their own ethnic communities (e.g., Korean and Chinese family physicians) (Wang et Kwak, 2015; Zhang et Verhoef, 2002), or who speak their language (e.g., Arabic speaking physician) as a way to get care that mimics what they would have received in their home countries (Salma, Hunter, et al., 2018; Salma, Keating, et al., 2018; Salma et Salami, 2020). Some may also maintain beliefs about the causes of their illness, and use the same approaches to care based on what they learned in their homelands (Salma, Hunter, et al., 2018; Salma, Keating, et al., 2018; Salma et Salami, 2020; Zhang et Verhoef, 2002). In contrast, however, other research has shown that some immigrants adapt and take on more of the practices and ways of life of their new country, for example, eating different foods, doing certain physical activities , and taking medication from Western medicine (Huang, 2013). In presenting the Indonesian experience, our study adds to this body of literature, and also further highlights the importance that healthcare providers should not make assumptions based on someone's origin and should conduct individual assessments of one's personal beliefs and preferences for self-care.

Support from family for self-care was another aspect that looked different when compared to how it was experienced in Indonesia. One notable observation was the shifts in gender roles- in the current study, men seemed to have a more active support role than they would have had if they were in Indonesia. The review by Lukman, Leibing et Merry (2020), which aimed to document self-care experiences of Indonesian adults with chronic illness in Indonesia, showed that women tend to generally be the main source of support for ill family members in Indonesia. Results similar to our study, however, have been shown in other

Canadian studies, where gender roles and support were changed post-migration. For example, in the study by Salma, Hunter, et al. (2018) with older, Muslim, Arab immigrant women, from Syria, Lebanon and Palestine, some of the findings showed husbands who were very attentive and providing assistance to their wives who had chronic illnesses. Our study results provide yet another example in how culture is not static and how migration can influence not only behaviours (e.g., diet, exercise), but also gender norms and roles. It is therefore important that care-providers not make presumptions about gender roles and supports.

In a similar vein, the results showed that expectations for support from family (e.g., adult children and extended family) may also change post-migration. This seemed to reflect in part, generational changes, but also seemed to be due to individuals not wanting to be a burden to their family members, who were busy with work and their own family commitments, especially in the context of resettlement. Similar findings were observed in the studies by Zou (2019), Zhang et Verhoef (2002) and Salma, Hunter, et al. (2018), where a number of immigrants did not expect support from their family members. Zhang et Verhoef (2002) explained that post-migration, some immigrants may not rely on their families for support or even talk about their illness because they knew their family members already had significant pressure and were occupied with work and study commitments. These changes can therefore leave some individuals without much support (like participant 7 in our study). Studies in Indonesia highlight that family plays an important role in supporting self-care of family members with chronic illness (Kristianingrum et al., 2018; Permana et al., 2019). In addition, caring for the parents or the older generations in Indonesian culture is perceived as an obligation and an adherence to religion (Lukman et al., 2020), so a loss of family support can be significant for Indonesian immigrants. Moreover, when the value of family cohesion/support is maintained after migration, it can be very beneficial. For example, in one study with an immigrant community in Canada, the participants had an expectation that younger family members would provide care and help them with daily life activities, and the family members responded with support (Nielsen et al., 2012). This in turn resulted in better self-care and helped the ill family member to seek care and get healed because the hardships and the challenges were shared (Nielsen et al., 2012). Healthcare professionals working with Indonesians therefore, should be aware that although their Indonesian immigrant patients may not expect family support, it may still be a considerable loss for them, and have an impact on their well-being.

In addition to changes in family roles and expectations, support is also sometimes lost due directly to migration, especially for those who migrated under difficult circumstances (e.g., participant 7). Loss of support networks during migration is common and has been shown in multiple studies. For example, in the studies by Nielsen et al. (2012), Salma, Keating, et al. (2018) and Salma et Salami (2020), the loss of networks resulted in a loss of practical help and contributed to loneliness and mental health issues, which exacerbated and made coping with the chronic illness more difficult, especially for older participants. Given the reduced support, certain individuals may therefore need additional resources and assistance to help support their self-care. Moreover, the few family caregivers, when available, may also need extra attention and support, since they may be at risk for burnout in this context. Participants in our study seemed to mostly depend on their spouses, and in one case, the spouse also had a chronic illness. Families in this sort of situation may therefore be especially vulnerable to adverse health outcomes given that they only have a small number of people on whom they can depend for help with self-care.

The study results also bring to light an additional vulnerability that should be considered by care-providers who are providing support to Indonesians, or other immigrant communities that are small in number and who are more collectivist oriented. The Indonesian population in Canada is extremely small and so the impacts due to a loss of family support following migration may be even more detrimental (when compared to more established immigrant communities). The review by Lukman et al. (2020) showed that community organizations in Indonesia are often a main resource for Indonesians living with illness, but our results showed that the community in Montreal/Canada was not really a source of support. Therefore the loss of community support should also be considered in care.

Another element of support to consider is transnational support. Research on transnational support between immigrants and their home country tends to focus on the support that immigrants provide to their family back home, very few studies focus on support in the opposite direction. Our findings showed that some of the immigrants were receiving cross-border support from their family in Indonesia. Other research seems to align with our results; one study in Alberta and the other in Toronto, also showed that Arab and Korean immigrants, respectively, were supported informationally by their family and friends back home in regard to the illness and treatments (Salma, Keating, et al., 2018; Wang et Kwak, 2015). The support also included having traditional medicine from Saudi Arabia and Korea sent to Canada (Salma, Keating, et al., 2018; Wang et Kwak, 2015). Our results, however, illustrate nuance to how transnational support may be experienced by showing that not all Indonesian immigrants were open to informational support from family or friends back home, particularly when it pertained to traditional treatment (i.e., some preferred medical treatment over the alternative therapies and did not want to follow their family members' advice). In addition, some preferred to not ask for support for fear of burdening their family in Indonesia. Therefore, to have a more complete and full understanding of an immigrants' milieu and factors influencing their self-care, transnational links should be acknowledged and considered, including how these connections are perceived and experienced.

Finally, our study highlights a significant disappointment and some strong negative feelings pertaining to interactions with HCPs in Montreal and thus a strong need for improvements. In regard to the health care system generally, some complained about long waiting times which discouraged the patients to communicate their feelings to HCPs or even to have visits. Some also felt that health care providers in Indonesia provided better services. In terms of expectations, participants generally wanted HCPs to provide more personal care. A growing body of research with immigrants in Canada has documented similar experiences. For example, in the studies by Nielsen et al. (2012), Salma, Hunter, et al. (2018) and Zhang et Verhoef (2002) with Greek, Arab and Chinese immigrants respectively, the patients felt physicians were overly dependent on diagnostic tools instead of listening to patients' experiences and explanations. In addition, it was felt that the information given by HCPs was too technical and unclearly presented (Nielsen et al., 2012; Zhang et Verhoef, 2002). They also always seemed in a rush and did not give full attention to patients (Salma, Hunter, et al., 2018). The lack of rapport led to patients stopping their medications and or not taking them as prescribed (Nielsen et al., 2012; Zhang et Verhoef, 2002). The patients in these studies wanted the HCPs to reassure them, to provide clearer explanations, and allow them enough time and space to discuss their experiences. In the study by Hyman, Shakya, Jembere, Gucciardi et Vissandjée (2017), which examined patient-provider communication in an immigration context in Canada, they found that positive patient-provider interpersonal communication contributes to better decision making in self-care and improved patients' satisfaction towards health care access. It also contributed to increased adherence to treatments, and more regular reporting of their health status, symptoms experienced and emotional feelings (Hyman et al., 2017). To summarize, there is a need for healthcare professionals in Montreal to be more caring and responsive to Indonesians' needs to better support their self-care, especially considering they are a small immigrant community, and some may have very limited support networks.

6.1 Implications

The results shed some light on how care may be more responsive and adapted to Indonesians' needs. Firstly, participants expressed directly that they want HCPs to inquire more about how they are doing, take more time with them, and not be so focused on medical treatments. Results also suggest that to be more responsive to patients' needs, HCPs should adapt the support based on where the person and their family is in their learning and acceptance process. There should also be space for communicating about spirituality and religion, and practices and beliefs from Indonesia, including preferences for traditional medicines. Support networks, including transnational connections, should also be carefully assessed and additional resources provided accordingly.

Person-centred care has long been promoted in Canada, including in Quebec, for those living with chronic illness (Vedel, Monette, Beland, Monette et Bergman, 2011; Winsor et al., 2013). This approach aims to involve patients in decision-making and to support them so that they can effectively manage and monitor their illness and maintain their health in a way that aligns with their values and beliefs (Winsor et al., 2013). This includes considering the cultural religious, socio-economic, and educational diversity, as well as family context, of individuals, which can shape preferences and behaviours in self-care and the availability and depth of support for care (Winsor et al., 2013). Based on our results, to better achieve person-centred care for

Indonesian (and other immigrant) populations, there are a few specific things that HCPs may do, including assessing for and discussing religion/spirituality as a potential resource (and adapting their approach depending on whether their faith has a more covert or overt role), acknowledging 'being helpful' as a way to help patients who have a different perspective and approach to coping with their illness, and inquiring about practices and beliefs, including those from Indonesia that could be incorporated into care and support. For the latter, this should include asking about the use of traditional medicines and preferences for non-medical approaches (Deng, Zhang et Chan, 2019; Pistulka, Winch, Park, Han et Kim, 2012). HCPs should also provide practical strategies that can help support patients to adapt and learn to live with their illness (Inagaki et Orehek, 2017; Telford et al., 2006), and let patients know that they don't need to be 'perfect' and help them set realistic expectations- it may be more effective if HCPs put less emphasis on 'proper eating' and 'exercising' and focused more on the strengths and 'achievements' in self-care (i.e., strengths-based care) (Kauric-Klein, 2012; Wu, Forbes et While, 2010).

HCPs should also provide more involved support for those who need it- including those who lost their support networks and for those who are having a more difficult time adapting to Canada. For those having trouble adapting, simply listening and offering if there is something that can be done to help with this process, could be helpful. HCPs may also provide referrals to community-based activities with peers (people living with a similar/same illness) that share a language, culture and/or religious heritage (Pistulka et al., 2012). This would not only break isolation, but also provide an occasion for sharing or giving support to others (i.e., 'being helpful'), which could further help with coping with the illness (Arney et al., 2020; Inagaki et Orehek, 2017). Referrals to community agencies could be particularly helpful to those who have lost their support networks, or who have reduced networks (Pistulka et al., 2012; Salma, Keating, et al., 2018; Salma et Salami, 2020); it may even be helpful for the family caregivers, who may also require support because they have fewer friends and family around them in Canada (Martinez-Marcos et De la Cuesta-Benjumea, 2014). Consideration, however, needs to be given to the fact that the Indonesian community is small, so referrals to Indonesian organizations will be limited. Additional follow-up and/or home care services may therefore be needed for these more vulnerable families, especially as they age and require more hands-on assistance.

Incorporating a transnational lens into person-centred care may also be relevant. The literature on transnationalism and healthcare is limited and little is known about how best to address transnational ties in care (Rosemberg et al., 2016). It is clear however, that HCPs should at minimum, explore and ask about ties to family members and other forms of ties to their home countries. For example, HCPs could inquire about advice, health information and medicines that are received from family, community and HCPs back home (Rosemberg et al., 2016; Wang et Kwak, 2015). They should also ask about potential sources of stress associated with transnational ties, for example, sending money back home, or concern for family members living abroad. Listening to patients' transnational concerns and stresses can help with building rapport while learning more about the advice, other health information, and maybe even other medical care, being received from abroad, can help ensure continuity of care, and help with reconciling any differences that there may be between the various sources of information and healthcare. Some research conducted with other immigrant groups with chronic illness in Canada suggest that transnational support can also contribute to maintaining and promoting physical and psychological health and encourage the immigrants to self-care (Rosemberg et al., 2016; Salma, Hunter, et al., 2018; Salma et Salami, 2020; Wang et Kwak, 2015). Therefore, health care providers may also consider encouraging patients to maintain the long-distance communication with family back home, particularly for those who are living alone and/or struggling with their illness (Salma, Hunter, et al., 2018; Salma et Salami, 2020).

Person-centred care is interdisciplinary and usually involves a range of health care providers working collaboratively to provide comprehensive healthcare and to ensure continuity of care (Vedel et al., 2011). Person-centred care, however, is central to nursing practice, including "...empowerment and respecting the person's autonomy, voice, self-determination and participation in decision-making" (Nelligan et al., 2002). In Quebec, part of the nursing role is to support those living with self-care, including basic monitoring (e.g., blood glucose levels), identifying risky lifestyle behaviours (e.g., smoking habits) and patients' knowledge about their chronic illness, and providing education and promoting healthy lifestyles (Gagné, Gilbert et Roberge, 2015; Pomey, Martin et Forest, 2009). Nurses also usually play an important role in providing psycho-social support and are the main advocators for patients and their families. Nurses are often a key person in the healthcare team who can offer referrals for support and services according to a person/family's needs, including community support and ensure an appropriate follow-up and continuity of care across disciplines (e.g., social work, medicine, nutritionists). In the current study, most participants were receiving care from a family physician working in a private practice or family medicine group and they rarely mentioned interactions with nurses. It is unclear why exactly the participants in this study had limited interactions with nurses- it may be that the participants represented a select group, or it may be that the presence and involvement of nurses in chronic illness support care is limited in some family-medicine contexts. It may also be that nurses tend to provide more support to those who are very ill or who require more direct, hands-on support and care. Nevertheless, the results suggest that access to nurses needs to be improved and the role of nursing needs to be strengthened in self-care support for those (immigrants) living with chronic illness. Nurse practitioners may be one approach to improving access and to addressing the person-centred care gap as they are well-positioned to provide comprehensive supportive care to a broad array of patients living with chronic illness either through direct care or by working collaboratively with family physicians (Guillaumie et al., 2019). Future work could explore from the nurses', and family-physicians' perspectives on how nurses' role in self-care support in the context of private medical practice and family medicine groups, may be optimally achieved.

Lastly, although the participants did not raise issues related to discrimination or language barriers, our study still suggests a need for more cultural competency and cultural safety training for health care providers, including nurses. "Cultural competence" involves being aware of one's own beliefs and values, gaining knowledge on others' world views and practices, and being able to appreciate and respect differences. It also involves avoiding stereotypes and being able to communicate and provide effective care across cultures (Henderson, Kendall et See, 2011). Creating a "culturally safe" environment refers to addressing power differentials in interactions between patients and HCPs and also within the broader healthcare system (Curtis et al., 2019). Our results show that HCPs need to be more attentive to cultural influences (e.g., the use of alternative medicines) and how the migration context affects self-care experiences (e.g., loss of support networks) and create more safe spaces where patients feel they can express their needs and preferences (e.g., preference for non-medical approaches). Our study also suggests that this training should include familiarizing HCPs on the potential benefits of religion and spirituality on health and well-being, and also information on how to incorporate discussions about religion and spirituality into care (Roger et Hatala, 2017). Training should also involve raising awareness about the transnational contexts of immigrants and how cross-border relationships and connections may impact health.

6.2 Limitations and strengths

The study has a few limitations. Firstly, participants were only interviewed once (two participants had brief follow-up interviews, but this was just to clarify some of the information collected during the interview). Additional interviews may have yielded more information and the results could have had more depth since participants tend to open-up and become more comfortable over time. In addition, following participants and observing their self-care behaviour over time, and in different environments also could have provided more data. Nonetheless, our interviews generated a significant amount of data, and with the data we had we were able to sufficiently identify patterns and themes related to self-care experiences. Secondly, since the student researcher is part of the community (i.e., insider), the participants' responses may have been filtered. Results therefore might have been interpreted unconsciously with an "insider bias". Thirdly, there is always a risk of information loss during the process of translating the transcripts and notes from *Bahasa Indonesia* to English. The results therefore may not fully capture all of the nuances of the data. On the other hand, collecting data in Indonesian allowed participants to express themselves more easily, since it was their first language. Lastly, as mentioned above, the participants may have represented a select group and consequently we were not able to gather much data on the interactions and care provided by nurses specifically.

The study also has strengths. We recruited participants with different chronic illnesses, and with varied backgrounds (low and high SES, living with family and living alone, different levels of education, and varied migration trajectories), which provides more credibility to the results. The study also included middle-aged participants; much of the previous research has focused on older adults. The study also explored a range of factors that can have an influence on self-care experiences, and this allowed for a more holistic and broader exploration of participants' self-care experiences. Finally, the data analysis approach was rigorous, and the student researcher worked closely with her research supervisors to further enhance credibility of the findings.

6.3 Future research

Future research could explore the perspectives of family members of Indonesian immigrants (and/or other immigrant groups who have small communities in Quebec/Canada) who are providing support to their ill family members, especially those who have limited social networks. This would provide a more complete picture of these families' experiences, and their support needs. It may also be worthwhile to explore how religion and spirituality may be incorporated into care in the Quebec context, especially from the perspective of HCPS, since religion has a contentious place in Quebec society. Moreover, it is known that there are tensions within the political and public spheres specifically related to the Muslim faith. This research should therefore assess HCPs' perceptions on religion and spirituality in care, as well as how they feel about caring for patients of different faiths, particularly Muslim patients (if they are not Muslim themselves), and explore what approaches, if any, they already use in their interactions with patients to address religion and spirituality in self-care. Lastly, as mentioned above, it may be warranted to do further research to assess more closely the role of nursing in supporting patients living with chronic illness for those receiving care from family-medicine groups or private medical practices in Montreal/ Quebec and to contrast these experiences with other milieus of care (local community centres and hospitals). This would provide better insight on access gaps in nursing care and also on how the role of nurses may be improved to better support self-care across the healthcare system.

Conclusion

For Indonesians living with chronic disease in Montreal, faith, religion and being helpful to others, have an important place in self-care. Self-care is a learning process, and how one deals and lives with their illness shifts and evolves over time. Some, have high, and perhaps unrealistic expectations of themselves. Some really struggle with their illness, while others have adapted and live very well with it. Self-care and expectations regarding self-care and support are influenced by both the pre- and post-migration contexts, and the degree of influence of each of these varies across individuals. Loss of support networks due to migration is an important influencing factor on well-being for some. In contrast, transnational relationships offer an additional source of support for several Indonesians. Lastly, Indonesians are somewhat disappointed with healthcare and support provided in the Montreal/Quebec healthcare system and would like care to be more personal and adapted to their needs.

The results therefore provide insight on how HCPs can enhance care and help Indonesians, and other immigrant populations, with their self-care. These include providing support for the learning process, inquiring about preferences for care, promoting religion and spirituality as a resource, fostering connections with peers, supporting transnational relationships, and overall being more focused on strengths. Given that person-centred care is central to nursing practice, nurses could play an important role in improving person-centred care for Indonesians and other immigrant populations living with chronic illness in Montreal, Quebec. In order to identify how the role of nurses may be improved to better support self-care, future research is needed to better understand how nurses currently support self-care in different milieus across the Quebec healthcare system and to identify access issues and gaps in nursing care.

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Appendix A: Summary of Included Literature in The Review of Chronic Disease Self-Care Experiences in Indonesia

Study	Study objective	Location and Setting	Sample	Research Design	Methods	Key findings/ Themes	Limitations and Strengths
Amelia, R. et al. (2018). Analysis of factors affecting the self-care behaviours of Diabetes Mellitus type 2 patients in Binjai, North Sumatera-Indonesia	To determine the most dominant factor affecting the self-care behavior of patients with type 2 diabetes mellitus	Binjai, North Sumatera-Indonesia. Urban	115 respondents – males and females, middle-aged adults and elderly, educated and less educated, high and low socio-economic status (SES)	Descriptive quantitative and explanatory research	Questionnaires	Self-care behaviours of type 2 Diabetes Mellitus in Binjai were significantly influenced by motivation, self-efficacy, communication, knowledge, and attitude. Motivation was the most dominant factor.	**Limitations:** -Inclusion and exclusion criteria of the study are not mentioned -The process of data analysis is not explained **Strengths:** -The questionnaires using for the interview were tested for the validity and reliability -The study included participants with a range of characteristics (e.g., gender, age, education, SES)

							-The participants are representative of the population of interest since they were recruited from several public health centre in the city (Binjai) -The sample size is large enough for the study's purpose.
Bayhakki, H. et al. (2019). Self-caring in Islamic culture of Muslim persons with end-stage renal disease and hemodialysis: An ethnographic study	To explore self-caring among Islamic persons living with End stage renal disease undergoing hemodialysis	Pekanbaru, Indonesia. Urban	12 participants – males and females, middle aged adults and elderly, educated and less educated, high and low SES	Ethnography	Interview, observation, medical records	Identified themes: 1. Meaning of self-caring 2. Actions in self-caring 3. Islamic influences to self-care living 4. Cultural influences to self-care living	**Limitation:** -Very little information is provided on the methods and analysis **Strengths:** -The results are well described -The sample included a mix of male and female participants, and with varying lengths of time

							living with the disease -The methodology selected is coherent with the data collection (observation, interview)
Dewi, F.S.T. et al. (2010). Maintaining balance and harmony': Javanese perceptions of health and cardiovascular disease	To understand patients' perceptions of health and cardiovascular disease	Yogyakarta, Indonesia. Urban	78 Informants –males and females, high and low SES, educational status is not mentioned	Qualitative description	Focus group discussion, individual interview	Identified themes: 1. The cause of heart disease 2. Men have no time for health 3. Women are caretakers for health 4. Different information seeking pattern (high vs. low SES) 5. The role of community	**Limitations:** - Some of the focus groups were larger than planned so the views and experiences of the participants may not have been optimally explored. - The study only included Javanese participants from one city and the results therefore may not be transferable to Javanese living in

							elsewhere in Indonesia. **Strength:** **-**The study included a large number of participants with a range of socio-economic backgrounds and the results therefore are broadly applicable .
Indrayana et al. (2019). Illness Perception as a Predictor of Foot Care Behavior Among People with Type 2 Diabetes Mellitus in Indonesia	To characterize the relationships among demographic factors, foot care knowledge, illness perception, including local beliefs and foot care practices	Yogyakarta, Indonesia. Urban	200 patients – males and females, middle-aged adults and elderly, educated and less educated, high and low SES	Quantitative, Cross-sectional study	Foot care knowledge questionnaire, the brief Illness Perception questionnaire, the diabetes Foot Self-care behavior questionnaire, and local beliefs	1. Knowledge regarding foot care was strongly correlated with foot care behaviors 2. Perception about illness, including the consequences, the timeline, the treatment control, the identity, the concern and the	**Limitations:** **-**The study used convenience sampling that may limit the generalisability of the study -Since the participants were only recruited from outpatient department, the results may not be transferable in

	among people with type 2 diabetes mellitus				about diabetes mellitus were measured using a validated questionnaire.	coherence were correlated with foot care behaviors. 3. The “food-related and spiritual beliefs” factor was related to foot care behaviors 4. The participants who agreed more that “diabetes is only related to food problems; diabetes is a temptation from God; refusing foods and drinks served by another person is impolite” were more likely to have better foot care behaviors.	other units or contexts of care **Strengths:** -The sample size is large enough to answer the research questions -The questionnaires were validated and translated into Indonesian language (i.e., The Foot Care Knowledge questionnaire, the Brief Illness Perception Questionnaire) -The analysis controlled for potential confounding.
Kristianingrum et al. (2017). Perceived family	To explore perceived family support by older persons	East Java, Indonesia.	9 older people - males and females, educated	Descriptive phenomenology	Semi-structured interview, field notes	Family support included daily activity assistance, help with accessing	**Limitations:** -The recruitment setting (e.g., place, unit, rural

support among older persons in diabetes mellitus self-management	in diabetes mellitus self-management	(either urban or rural, location is not clear)	and less educated, SES is not mentioned			health services, food preparation, financial support, psychological support, advice and solutions regarding self-management.	or urban area) is not mentioned which makes it difficult to know for whom the results are applicable - The results are quite thin and brief for a phenomenological study **Strengths:** **-**The methodology selected (i.e., descriptive phenomenology) is appropriate since the purpose of the study was to explore family support with older people living with T2DM - Before data collection, the researchers were trained to

							interview and to respond participants so they can collect data properly
Ligita et al. (2019). How people living with diabetes in Indonesia learn about their disease: A grounded theory study	To generate a theory explaining the process by which people with diabetes learn about their disease in Indonesia	Pontianak, the capital city of West Kalimantan Province, Indonesia. Urban	28 participants – from inpatient and outpatient settings	Grounded theory	Face to face and telephone interviews	The core category and social process of the theory was: *Learning*, *choosing*, *and acting*: *self-management of diabetes in Indonesia*. This process includes five major distinctive categories: Seeking and receiving diabetes-related information, Processing received information, Responding to recommendations, Appraising the results, and Sharing with	**Limitations:** -Participants' characteristics are not mentioned (e.g., age, gender, education, origins, SES) so the generalisability of the results is hard to determine. **Strengths:** -This study produced a theory entitled Learning, choosing, and acting self-management of diabetes in Indonesia, which helps explain how people with diabetes learn about their

						others. People with diabetes acted after they had received recommendations that they considered to be trustworthy. Resource issues (affordability and accessibility of therapies) and physiological and psychological reasons influenced peoples' choice of recommendations.	disease and engage in health education in the Indonesian context -The methodology selected is appropriate since the study aimed to generate a theory of a learning process, and is well described
Mizutani, et al. (2016). Model development of healthy-lifestyle behaviours for rural Muslim Indonesians with hypertension:	To explore the perceptions of middle-aged husbands and wives, whose lives were affected directly or indirectly by hypertension,	West Java District, Indonesia. Rural	12 married couples, educated and less educated, middle and low SES	Qualitative case study design	Semi-structured interview	1. Behaving healthy by eating well, doing physical activity, resting, not smoking, managing stress, seeking health information, seeking health care, providing	**Limitations:** -The study does not appear to be a case study, the results include a model, which would suggest the study was more of a grounded theory -The subcategories of

A qualitative study	on their healthy-lifestyle behaviours and related reasons for practicing the behaviours					care for family and community, and fulfilling their obligations to God. 2. Reasons for practicing healthy-lifestyle behaviours were beliefs, competence, religious support, prior experience, social support, and health system support. 3. Reasons for not practicing healthy-lifestyle behaviours were personal, social, and environmental barriers.	the themes are mentioned but not described and not well supported by the quotes **Strength:** -The study included the perceptions of both husbands and wives which provided a more comprehensive description of the experiences of living with hypertension -The results include a number of themes regarding lifestyle behaviours which provided comprehensive insight about self-care behaviours of couples living with hypertension

Rahmawati et al. (2018). Understanding untreated hypertension from patients' point of view: A qualitative study in rural Yogyakarta province, Indonesia	To explore perspectives about hypertension from patients who do not take anti-hypertensive medications	Yogyakarta, Indonesia. Rural	30 participants – females, older people, educated and less educated.	Qualitative description	Face to face semi-structured interviews	Identified themes: 1. Alternative medicines for managing high blood pressure 2. Accessing health care services 3. The need for anti-hypertensive medications 4. Existing support and patients' expectations. Reluctance to take anti-hypertensive medications was influenced by patients' beliefs in personal health threats and the effectiveness of anti-hypertensive medications, high self-efficacy for taking alternative medicines, the	**Limitations:** -All participants were older people and women, although the intention was to recruit both sexes, 45 years and older - The study was not guided by a framework and the objective was quite broad **Strengths:** -The data were collected in the participants' language -The results are well described and supported with quotes - The sample included 30 participants and saturation was

						lack of recommendations regarding hypertension treatment, and barriers to accessing supplies of medicines.	reached after the 23rd participant
Rahmawati et al. (2018). Access to medicines for hypertension: a survey in rural Yogyakarta province, Indonesia	To explore how and where people in rural villages in Indonesia obtain their supplies of anti-hypertensive medications	Yogyakarta, Indonesia. Rural	384 participants – males and females, middle-aged and older adults, high and low SES	Descriptive quantitative study	Researcher-administered questionnaire	Among 384 participants, 203 people reported had taken medication the latest 30 days before the data collection. 97 of 203 participants (50%) obtained hypertensive medications from public health services, while 61 participants (30%) get the medications from private healthcare providers (e.g., private hospital, community pharmacy, private	**Limitations:** -The potential bias (e.g., forgetfulness) associated with the reliance on self-reported data -The study was undertaken in only district only; the results of this study may not be representative of the whole Indonesian population -More females than males joined this study, which may limit the

						nurse, private doctor and private nurse), and 45 participants (22%) reported obtaining the medications from varied sources (e.g., pharmacy, community health centre)	generalisability of the findings **Strengths:** - The findings are noteworthy because the participants were derived from a community setting rather than healthcare centres, which provides an opportunity to obtain data from untreated patients who rarely visit healthcare providers -The findings do reflect the practice in Yogyakarta province as well as other settings with a similar social context

Appendix B: Summary of Included Literature in The Review of Chronic Disease Self-Care Experiences after Migration

Study	Study objective	Location and Setting	Sample	Research Design	Methods	Key findings/ Themes	Limitations and Strengths
Chatrung et al. (2014). Wellness and Religious Coping Among Thai Individuals Living with Chronic Kidney Disease (CKD) in Southern California	To find the common meaning of wellness and religious coping and to understand ways Thai people in southern California cope with CKD	Southern California, United States Urban	8 Thai participants – males and females, middle-aged and older adults, educated and less educated, high and low socio-economic status (SES), length of living with the illness between 7 months-years, various religious affiliations, length of migration at	Ethnography	Face to face in-depth interviews that were audio-recorded, field notes.	Four themes were identified: 1. Wellness 2. Self-care 3. Impact of illness on life 4. Religious coping	**Limitations:** -The snowball method was used for recruitment, so the participants may reflect a select group **Strengths:** -The methodology selected (ethnography with the final outcome of a narrative description) is appropriate for the study's purpose -The methodology is coherent with data collection and data analysis

			least 5 years, migration status is not mentioned				-The study included participants with various religious affiliations, so the results may reflect the diversity of Thai population living in Southern California
Davidson et al. (2011). Health-seeking beliefs of cardiovascular patients: a qualitative study	1. To describe the experiences of Chinese Australians with heart disease following discharge from hospital for an acute cardiac event 2. To identify patterns and cultural differences	South Eastern Sydney, New South Wales, Australia, within an area highly populated by Chinese-Australian residents Urban	8 Chinese patients with chronic heart disease – males and females, older adults, length of migration between 2-32 years, migration status is not mentioned, length of living with	Qualitative methods (the design is not mentioned)	Focus group and individual interviews	Three themes were generated: 1. Linking traditional values and beliefs with Western medicine. 2. Reference for health professionals and family. 3. Juxtaposing traditional beliefs and self-management.	**Limitations:** -The convenience sampling and the small number of participants means results may not reflect the diversity of the Chinese population living in Australia - Since the design is not mentioned, it is difficult to determine whether the methodology selected was

	of Chinese Australians following discharge from hospital 3. To illustrate the illness/health seeking behaviors and health beliefs of Chinese Australians		the illness is not mentioned.				appropriate with the data collection and the data analysis **Strengths:** -The results are comprehensive, with detailed descriptions -The data was gathered in Mandarin, Cantonese or English (depending on the individual) with the use of interpreter, which might have enabled participants to fully express their experiences and views.
Hjelm et al (2003). Religious and cultural distance in	To explore beliefs about health and illness in	Sweden (the exact location	26 females (Ex-Yugoslavian and Arab	Qualitative method (The exact methodolog	Focus group interviews	• Ex-Yugoslavian Muslims emphasised enjoyment of life	**Limitations:** -Since the study setting is not mentioned (urban

beliefs about health and illness in women with diabetes mellitus of different origin living in Sweden	females with T2DM from different religious backgrounds living in Sweden.	isn't clear).	Muslims from Iraq, Palestine, Lebanon, Egypt) with T2DM – middle-aged and older adults, educated and less educated (some participants are illiterate), high and low SES, length of migration between 5-10 years, migration status of the participants is refugee, refugee with family ties or	y was not mentioned)		and a passive self-care attitude and were not inclined to self-monitor their blood glucose or to conduct preventive foot care. • Arabs emphasised adaptation to DM and a lot of 'musts' concerning diet and had a lower threshold for seeking care. They also believed that the cause of DM was 'the will of Allah or God'. • Cultural and religion are essential for understanding self-care practice	or rural), it is difficult to determine the generalisability of the results - The study design is not mentioned **Strengths:** -The study included participants from a range of countries, the diversity of the immigrant groups enhances the credibility of the results -The focus group interviews allowed for participants to build on each other's' responses

			labour migrants, length of living with T2DM is between 5-7 years.			and care seeking behaviour and need to be considered in the planning of diabetes care (both groups)	
Joo et al. (2016). Barriers to and facilitators of diabetes self-management with elderly Korean American immigrants	To explore barriers and facilitators of diabetes self-management among first-generation Korean American elderly immigrants with type 2 diabetes in the United States Midwest.	The suburbs of a city in the Midwestern United States of America (USA) Urban	23 Korean American participants – males and females, middle-aged and older adults, educated and less educated, low SES, average length of migration to USA was 25 years, migration status is not mentioned, most	Qualitative description	Focus group interview and individual interview (open-ended questions)	Five perceived barriers were identified: 1. The high cost of type 2 diabetes care 2. Language issues 3. Loss of self-control 4. Memory loss 5. Limited access to healthcare resources. Three perceived facilitators were: 1. Time 2. Seeking information	**Limitations:** - The convenience sampling and recruitment from suburbs means the participants may not reflect the diversity of the Korean living in the Midwest, United States **Study's strengths:** **-**The study employed both focus groups and individual interview, to optimize data collection

			participants lived with T2DM for 15 years.			3. Family and peer support	-The sample size is large and included both men and women
Kindarara, et al. (2017). Health-Illness Transition Experiences with Type 2 Diabetes Self-management of Sub-Saharan African Immigrants in the United States	To describe Sub-Saharan African immigrants' health-illness transition experiences associated with type 2 diabetes mellitus (T2DM) self-management.	Sacrament County, California United States Urban	10 Sub-Saharan African adults – males and females, educated and less educated, high and low SES, migrated to USA more than 10 years, migration status is not mentioned, lived with chronic illness more than 5 years.	Qualitative description	Demographic and transition experience questionnaire, semi-structured interview.	Four overarching domains described the health-illness transition experiences the participants had with T2DM self-management: 1. Knowledge of T2DM self-management behaviors 2. Current T2DM self-management behaviours 3. Inhibitors of T2DM self-management 4. Facilitators of T2DM self-management	**Limitations:** -Excluding Sub-Saharan African immigrants with T2DM who could not communicate in English means relevant data may have been missed **Strengths:** -The study results are described in-depth- details are provided on the domain, categories and sub-categories -The methodology selected for the study is appropriate for the research questions and the

							methodology is well described
King et al. (2007). Chinese immigrants' management of their cardiovascular disease risk	To describe and explain how ethnocultural affiliation and gender influence the process that cardiac patients undergo when faced with making behavior changes associated with reducing cardiovascular disease risk.	Calgary, Canada Urban.	15 Chinese immigrants – males and females, older adults, educated and less educated, high and middle SES, lived in Alberta more than 20 years, migration status and the length of living with chronic illness are not mentioned	Grounded theory	Audio-recorded semi-structured interviews, interpreter.	Theme: Meeting the challenge.	**Limitations:** -The generalizability of the results may be limited because many potential informants were more interested in receiving immediate feedback in the form of a report about their own health status than in participating in the interview process. **Strengths:** -There is coherence between the methodology and the results (e.g., a core category/social process was identified; the

							analysis was consistent with a grounded theory approach) -The methodology and results are described in depth

Majeed-Ariss et al. (2015). British-Pakistani women's perspectives of diabetes self-management: the role of identity	To explore the effects of type 2 diabetes on British-Pakistani women's identity and its relationship with self-management.	Teesside, England urban	15 British-Pakistani women – middle-aged and older people, educated and less-educated, high and low SES, length of migration and migration status are not mentioned, length of living with chronic illness is between 5-29 years. Participants were generally had comorbiditi	Exploratory qualitative	Semi-structured interviews	Four themes emerged: 1. Perceived change in self emphasized how British Pakistani women underwent a conscious adaptation of identity following diagnosis; 2. Familiarity with ill health reflected women's adjustment to their changed identity over time; 3. Diagnosis improves social support enabled women to accept changes	**Limitations:** -Migrant generation status was confounded with age and the length of living with the illness, which made it difficult to determine how these characteristics influenced the findings. **Strengths:** -The study used purposive sampling, which enabled to explore data patterns based on different characteristics -The data saturation was reached, which improved the

			es (HBP, Arthritis, thyroid, hernia, etc.).			within themselves 4. Supporting family is a barrier to self-management demonstrated how family roles were an aspect of women's identities that was resilient to change. The over-arching theme "Role re-alignment enables successful self-management" encapsulated how self-management was a continuous process where achievements needed to be sustained.	credibility of findings

						Inter-generational differences were also noted: 1. First generation women talked about challenges associated with ageing and co-morbidities; 2. Second generation women talked about familial and work roles competing with self-management.	
Mitchell-Brown et al. (2017). A Study of Hmong Immigrants' Experience with Diabetes Education: A Community-	To identify barriers and facilitators related to the diabetes education experience of Hmong	Central California, United States Urban	16 Hmong participants (an ethnic group of China, Vietnam, Laos, Thailand) –	Qualitative study using a hybrid analytic approach (i.e., deductive and	Focus group interviews, notes, interpreters.	The three barriers identified were language, self-management, and stress; the three facilitators are focused culturally specific	**Limitations:** - Some data might have been missed in the translation process, since some of the medical terms do not exist in the

Engaged Qualitative Study	Americans with type 2 diabetes, living in central California.		males and females, middle-aged adults older adults, less educated, low SES, length of migration to USA was between 20-35 years, migration status is refugee, the length of living with chronic illness is 3-16 years	inductive analysis)		education, use of media, and peer support group	Hmong language. Some concepts therefore may have been understood differently in the Hmong language **Strengths:** -The study was guided by a framework (i.e., Study of Access to Medical Care) which helped guide the analysis -The study was conducted in collaboration with a community partner
Sanon et al. (2016). Transnationalism and Hypertension Self-Management Among	To explore the influence of cross-border relationship on Haitian's immigrants with	Miami-Dade County, Florida, United States Urban.	31 Haitian immigrants – males and females, low and middle SES, the length of migration	Critical ethnography	Interview guide (open-ended question), face to face semi structured interviews.	Two major themes emerged: 1. Social support 2. Financial obligation Both themes are framed within the obligation to send	**Limitations:** -Since only four men participated in this study, the study did not fully represent the Haitian immigrant men's

Haitian Immigrants	Hypertension on their well-being or their ability to manage their disease and maintain their health.		to USA was 7,5 years, migration status and the length of living with chronic illness are not mentioned			money back home. In addition, while transnational support facilitated immigrants' self-management, it also represented a financial burden for them, since they felt obligated to support their relatives.	perspectives and experiences. **Strengths:** -The study used a transnationalism framework to guide the study -The methodology is well described, the authors described reflexivity which is important in a critical ethnography -Saturation and redundancy were reached, enhancing the credibility of the findings
Sidhu et al. (2016). Long-term conditions, self-management and systems	To explore the types of support accessed by Punjabi Sikhs living in	Birmingham and Black Country UK.	15 participants from Sikh Community – males and females,	Community-based qualitative interview approach	Narrative Interviews, audio taped.	Participants interpreted chronic disease self-management in relation to four	**Limitations:** -The sample was reached with the help of family members therefore the

of support: an exploration of health beliefs and practices within the Sikh community, Birmingham, UK	Birmingham and the Black Country, UK, who were living with non-communicable diseases	Urban	middle-aged and older people, educated and less educated, high and low SES, the length of migration and migration status and the length of living with chronic illness are not mentioned			primary systems of support: 1. Health services for disease management; 2. Multiple sources of care, including traditional Indian medicines and the Internet, for symptom management; 3. Community groups for lifestyle management; 4. Family for emotional and physical care. Within these systems of support, participants identified barriers	sample may reflect a select group - The study's focus on the four systems of support may have been to the neglect of other areas of interest e.g., some issues emerged, such as spousal support, which could have been addressed with more direct questioning **Strengths:** - The 'sharing stories' approach provided more spaces for participants to express their experiences. - The study reveals the importance of exploring

						and facilitators to the maintenance of a healthy lifestyle.	ethnicity, faith, generation and caste, and access to care (the analysis explored the diversity of views by gender, caste, generation and age)
Walker et al. (2005). Exploring the role of self-management programmes in caring for people from culturally and linguistically diverse backgrounds in Melbourne, Australia	To examine the extent to which the Chronic Disease Self-Management Program (CDSMP) required modification so the concepts associated with the program have relevance to the health behaviors of	Melbourne's north-eastern suburbs, Australia Urban	24 participants from various immigrant groups (Chinese, Italian, Vietnamese, Greek) – males and females, older people, educational background and SES are not	Qualitative (exact methodology was not named)	Focus group, using interpreters	Across and within the various ethno-cultural groups there were varying understandings and opinions about self-management programs. Literacy problems were the major barrier to participating in the programs.	**Limitations:** -The methodology was not named. -The approach used by the interpreters varied across focus groups and influenced the quality of the data collected -Due to cost and time constraints data were recorded in English rather

	immigrant groups with chronic illness (i.e., Chinese, Italian, Vietnamese and Greek groups)		mentioned, the length of migration and migration status and the length of living with chronic illness are not mentioned.				than the original language of the focus groups **Strengths:** -Since the participants were recruited from various immigrant groups, the results may provide a more comprehensive data and present diversity of responses towards the self-care management programs. -The study included participants with various chronic illness which also may make the results more broadly applicable.

Zhang et al. (2002). Illness management strategies among Chinese immigrants living with arthritis	To generate a substantive theory or model regarding illness management among Chinese immigrants living with arthritis in Calgary, Canada and to assess factors affecting the strategies.	Calgary, Canada Urban	19 Chinese immigrants – males and females, middle-aged and older adults, educated and less-educated, SES is not mentioned, the length of migration and migration status and the length of living with chronic illness are not mentioned	Grounded theory	Health assessment questionnaires (HAQ) for disease status, in-depth open-ended interview	The results of this study describe factors that impacted on illness management strategies. These include arthritic symptoms, beliefs about arthritis, beliefs about Western medicine based on treatment experience, beliefs about Chinese medicine, perceived barriers to using Chinese or Western medicine and social support. The emerging process of illness management shows that immigrants usually started	**Limitations:** -The study included only three males; men's illness management may therefore be less presented in the results **Strengths:** -The methods described including the analysis approach are coherent with a grounded theory methodology -The sample size is large and included participants with different ages and different origins (Taiwan, Hong Kong, Vietnam, and Mainland China), thus increasing the

						using self-care remedies, followed by consulting Western physicians, consulting Chinese healers, and then returning to Western medicine. The results illustrate that disease management strategies among Chinese immigrants are impacted by disease, personal and cultural factors.	transferability of the findings -The interviews were conducted in Chinese, thus enhancing the interview process

Appendix C: Partnership Agreement

Purpose: This document serves to detail the expectations and responsibilities of the researchers and the community organizations respectively, regarding the recruitment, data collection, analysis and dissemination of findings for the study "*Self-care experience of Indonesian adults with chronic disease living in Montreal"*. This study is a masters' project, and will be conducted by **Nurul Akidah Lukman**, who is a student in the Faculty of Nursing, at the University of Montreal.

This agreement is between:

- **Nurul Akidah Lukman** (student researcher), Master Student; **Lisa Merry** (supervisor), Assistant Professor; and **Annette Leibing (**co-supervisor**)**, Professor, Faculty of Nursing, University of Montreal

And

-

Agreement:

1. The student agrees to:
    a. Provide and all information regarding the purpose and methods of the study; relevant documents, including the protocol, consent form, interview and observation guides, and the socio-demographic form will be provided for reference.
    b. Be available to respond to any questions or concerns that the organizations may have.
    c. Be fully responsible for the recruitment process including explaining the study to potential participants, answering their questions and obtaining their consent.
    d. Be fully responsible for the data collection, management and analysis.
    e. Inform the organization(s) of any adverse events related to the study.
    f. Keep all information confidential including who participated in the study (i.e., the organizations will not be informed of who participates).
    g. Inform the organizations if the results are published in an academic journal, or other forum and/or presented at conferences and professional meetings.
    h. Provide a summary of the results (in English) for distribution to members of the organizations.
    i. Present the results in a brief presentation to the organizations and their members.

2. The and agree to:
   a. Allow the student researcher to spend time and participate in the organizations' activities in order to meet potential participants.
   b. Facilitate and support the recruitment of participants: by identifying individuals who meet the eligibility criteria [i.e., 18 years old or older; Indonesian immigrant; living with chronic disease(s) (i.e., Hypertension, Type 2 Diabetes Mellitus, Chronic Kidney Disease, Cardiovascular Disease and Osteoarthritis); able to communicate in either Indonesian or English well enough for an interview; and cognitively able to give consent] and introducing the student to them (if the individuals agree).
   c. Support the data collection process by providing a quiet, private space where the student may conduct interviews.
   d. Allow the researcher to present the study findings in a brief presentation to the organization and its members.
   e. Distribute a summary of the study results (English summary) if it is requested by a member.

This agreement was signed in Montreal:

Community Organizations

Name	:	Name	:
Function	: Head of	Function	: Head of
Signature	:	Signature	:
Date	: 9 November 2019	Date	: 11 November 2019

Research team

Name : Nurul Akidah Lukman	Name : Lisa Merry	Name : Annette Leibing
Function: Master Student	Function: Research Supervisor	Function: Research Co-supervisor
Signature:	Signature:	Signature:
Date : 9 November 2019	Date : 11 November 2019	Date : 15 November 2019

Appendix D: Poster for recruitment

(Bahasa Indonesia version)

Kami mencari responden penelitian

Penelitian ini mengenai "**pengalaman imigran Indonesia dewasa dengan penyakit kronik dalam perawatan diri (*self-care*) di Montreal".**

Apabila anda ataupun ada orang Indonesia lain yang anda ketahui:

✓ **Berusia 18 tahun atau lebih**

✓ **Tinggal di Montreal (Sementara ataupun menetap)**

✓ **Menderita penyakit kronik (diabetes, hipertensi, penyakit jantung, penyakit ginjal, asam urat, radang sendi)**

✓ **Senang membagikan pengalaman perawatan dirinya dengan penyakit kronik.**

✓ **Bisa berkomunikasi dalam Bahasa Indonesia, Inggris atau Perancis**

✓ **Tertarik menjadi responden penelitian (Wawancara)**

Untuk informasi detail, dapat menghubungi: ***<u>Nurul Akidah</u>*** **(call, text, WhatsApp) atau email**

(English Version)

We are looking for Participants!!

For a study on "**The self-care experiences of Indonesian adults with chronic disease living in Montreal**"

If you or other Indonesian(s) you know:

- ✓ **Are 18 years and older**
- ✓ **Live in Montreal (recently or less recently immigrated to Canada, temporarily or permanently)**
- ✓ **Lives with a chronic illness (diabetes, hypertension, Cardiovascular disease, chronic kidney disease, arthritis)**
- ✓ **Are able to communicate in Bahasa, English or French**
- ✓ **Are interested in sharing experiences in living with a chronic illness and in participating in research (interviews)**

For more details please contact: Nurul Akidah
(call, text, WhatsApp) or by email :

Appendix E: Information and Consent Form

Title: Self-care experiences of Indonesian adults living with chronic disease in Montreal

Research Team:

- Nurul Akidah Lukman (student researcher), Master Student, Faculty of Nursing, University of Montreal
- Lisa Merry (supervisor), Assistant Professor, Faculty of Nursing, University of Montreal
- Annette Leibing **(**co-supervisor**)**, Professor, Faculty of Nursing, University of Montreal

Funding:

Lembaga Pengelola Dana Pendidikan (LPDP) (Indonesia Endowment Fund for Education)

You are being invited to participate in this study. Before accepting to participate, please take the time to carefully read this document. It provides information about the study purpose and what participation would involve. Do not hesitate to ask the person who presents you this document any questions that you feel are important to be answered before accepting to participate.

A) Information for Participants

---

1. Research objectives

This project aims to explore and describe the self-care experiences of Indonesian adults (i.e., people who immigrated from Indonesia) living with a chronic illness in Montreal. We want to learn about how Indonesians who have a chronic illness, for example diabetes or heart disease, take care of themselves in order to get better and feel well and healthy. The project also aims to identify the factors that affect these experiences, for example support from family and friends. To achieve this objective, we would like to conduct interviews with approximately 5 to 10 Indonesian men and women who have a chronic illness, and who are living in Montreal.

2. Participation

Your participation would involve participating in one interview with the student researcher. The interview would take place at a time and in a location that is convenient for you (e.g., your home, coffee shop, university office, community centre). The interview would last between 30 and 60 minutes; it could be longer if you wish to continue sharing and talking. You may also do the interview in two parts if you prefer. We will begin the interview by asking you to briefly discuss your migration to Canada. We will then ask you some questions about your chronic illness (or illnesses if you have more than one), for example “when were you diagnosed?”. The rest of the interview will then focus on your experience of living with a chronic illness and how you take care of yourself and stay well despite your illness. We will also ask you some questions about what affects your ability to take care of yourself, for example, help from family or friends. Following the interview, we will then ask you some general background questions, for example your age, education level, marital status, and how long you have lived in Canada.

3. Audio-Recording

In order to help the student researcher remember what you share, would you be willing to have the interview audio-recorded? Please note that you may still participate even if you choose to not have the interview audio-recorded.

☐ I accept audio-recording
☐ I refuse audio-recording

4. Risks and inconveniences

There are no known risks to participating in this project. It is possible however, that some questions might make you feel sad or uncomfortable. The time required to participate in the interview may also be an inconvenience. At any time, you may refuse to answer any questions that you do not want to answer. You may also decide to postpone the interview or to completely withdraw your participation. If at any time you feel sad or distressed during the interviews, and if you feel it may be helpful, the student-researcher will be available to listen and talk with you about what you are feeling.

5. Benefits

There are no direct benefits to participating in this project. Your participation however, will contribute to us gaining a better understanding on the self-care experiences of Indonesians living with a chronic illness in Montreal. This information will be helpful for healthcare-providers (e.g., nurses, social workers, doctors) who provide care and services to immigrants living with chronic illness in Montreal.

6. Compensation

You will not receive any financial compensation for participating in this project.

7. Confidentiality

All information that you provide will be kept confidential. No identifying information will be made public. Each participant will be assigned an identification code and only the members of the research team will have access to the list of participant names and their identification codes. Please note that if other family members or friends are present during the interview, confidentiality will depend on everyone present agreeing to not share any information on what was discussed.

Only members of the research team will have access to the information collected in this project. All data will be kept in a locked office at the University of Montreal. Electronic data will be stored on the University's secure shared network drive.

The audio recordings will be transcribed. All recordings and personal information will be destroyed and disposed of 7 years after the project is completed. Only data, with no identifying information will be kept beyond that date.

8. Voluntary participation and withdrawal

You are free to accept or refuse to participate in this research project. You can take up to 10 days to make a decision on whether or not you want to participate.

You may also withdraw your participation at any time without giving a reason and without any consequence to you or your family. If you decide that you no longer wish to participate you just need to notify the student researcher (see below for contact information).

If you withdraw your participation, you can also ask that your data be destroyed and not be used. However, it will be impossible to remove your data from the project once the final results have been published or made public.

9. Dissemination of results

If you are interested, the student researcher will call you at the end of the project to give you a brief summary of the project results (in English or Indonesian). A written summary of the results (in English) will also be available and can be sent to you by email. The summary will also be available through the community organization where we made contact with you.

○ I want to receive a summary of the project results, by email: ……………………………….
○ I do not wish to receive a summary of the project results

The results may be published in academic journals (in one or more articles) and/or presented at conferences and professional meetings. No names or identifying information will be shared in any of the summaries, reports, publications or presentations that are a result of this project.

10. Responsibility of the research team

In no way does accepting to participate in this study waive you of your legal rights, nor does it relieve the researchers, funding agency or involved institutions from their legal and professional responsibilities.

11. Resource persons

If you have any questions regarding the scientific aspects of the project or if you wish to withdraw your participation, you may contact: Nurul Akidah Lukman, Master Student, Faculty of Nursing, University of Montreal, at the following number: or email address:

If you have any questions regarding your rights as a participant or the responsibilities of the researchers, you may contact the ethics committee for health research:

Email: cerses@umontreal.ca

Phone : (514) 343-6111 poste 2604

Website:https://recherche.umontreal.ca/responsabilite-en-recherche/ethique-humaine/comites/cerses/#c70895

If you have any complaints about this research project you may contact the ombudsman of the University of Montreal by phone at +1 (514) 343-2100 or by email at ombudsman@umontreal.ca. The ombudsman will accept collect calls and can speak in English and French. Calls may be made anytime during 9 am and 5 pm.

B) Consent

I understand that I can take the time necessary to think about my decision before accepting or refusing to participate in this project.

I can ask questions to the research team until I feel that I am satisfied with the responses given.

I understand that in accepting to participate in this study I am not waiving any of my rights, nor are the researchers relieved from their legal and professional responsibilities.

I have reviewed the information and consent form and I agree to participate in this study.

______________________________	______________________________
Participant's name	**Participant's signature**
(Print)	**Date:** ______________________________

The signature of the person who obtained consent, if different from the researcher who is responsible for the project: I explained the project and reviewed the information and consent form with the participant and answered all questions that the participant asked.

Nurul Akidah Lukman

	Student researcher’s signature
(Print)	
	Date:

Researcher’s commitment (researcher who is responsible for the project)

Myself, and the research team, pledge to respect what has been agreed upon in this information and consent form.

Lisa Merry

Supervisor’s name	**Supervisor’s signature**
	Date :________________ _____________
(Print)	

Appendix F: Interview Guide

I would like to begin the interview by asking you to briefly discuss your migration to Canada. I will then ask you some questions about your chronic illness (or illnesses if you have more than one), for example, *"when were you diagnosed"*. The rest of the interview will then focus on your experience of living with a chronic illness, for e xample, *"what do you do to take care of yourself and stay well despite your illness"*. The interview should last between 30 and 60 minutes. Please feel free to stop the interview at any time to ask questions or if you want to stop participating in the study. Also, please remember that you're not required to answer any questions you do not wish to answer.

Do you have any questions before we begin?

I will turn on the recorder now...

1. Can you tell me about your migration to Canada?
2. What chronic illness (es) do you have? Can you tell me a bit about your experience of being diagnosed?
3. Can you tell me generally what it is been like living with this illness (or illnesses)?
   Probes: How does it affect your life? How has living with this illness changed over time?
4. Can you tell me what self-care means to you? Can you tell me about the different ways that you practice self-care?
5. Can you tell me about how your self-care has changed over time (since coming to Canada if they had their illness(es) before coming to Canada)?
6. What would your self-care be like if you were still in Indonesia?
7. What helps you with your self-care here in Canada? What do you find the most challenging with your self-care?

In the next set of questions, I would like to ask you more specific details about your experiences of self-care. Some of these questions may not be relevant to you, and others might be. Please just answer whichever questions you feel are relevant to you and your situation.

8. Is there anyone that helps you with your self-care? If yes, who, and how do they help you?
   Probes: What is most helpful? What is less helpful and why? If no one provides help, is there any specific reason why?
9. Do you ever get help or support from friends or family back home (by phone, internet or through visits)? If yes, from who and how? Similarly, do you ever use health services or go on

10. What has your experience with healthcare professionals here in Montreal been like in terms of helping you in dealing with your illness(es)?
11. What sort of medicines or treatments, including non-traditional treatments, do you prefer, if any, for your illness(es)?
12. Does spirituality, faith or religion have any role in how you self-care? If yes, can you explain and give some examples?
13. Do you have any other thoughts or comments that you would like to share?

Thank you so much for answering my questions. I would now like to ask you some background questions.

Appendix G: Observation Guide

Participant ID:

During each interview, notes will be recorded on the environment, participant and exchanges, including the following:

1. **The physical environment:**
    - The date, time, length and location of the interview
    - Description of the location
    - Where is the participant seated during the interview?
    - Is there anyone else present during the interview? If yes, who?
2. **The participant:**
    - Describe the participant (sex, age range, general appearance and affect)
    - If anyone else is present, describe them too
3. **The exchanges:**
    - What language(s) is/are spoken?
    - What is the tone of the conversation?
    - What is the non-verbal communication (facial expressions, hand gestures, emotions expressed, eye contact)?
    - Which topics seem sensitive? Which topics are of most interest? Are any topics avoided?
    - If others are present, do they interact with the participant and/or with you (the interviewer)? If yes, how? What is the nature and tone of these interactions?
4. **Observation of « self-care»:**
    a. Note any actions that may reflect self-care (e.g., testing their glucose, eating a certain food, positioning, making an appointment, taking a medication)
    b. If anyone else is present, note any interactions that may reflect support from family, friends, or someone from the community (e.g., asking them how they're doing, assisting them to move or position themselves, bringing them food)
    c. Ask about and note any phone calls or exchanges by messaging that may reflect support with self-care (e.g., phone call to book an appointment, a note from a family member asking how they're doing)
    d. Ask about and note any visible self-care aids [e.g., information pamphlets, dossette box, calendar/agenda with appointments or other "health related activities", cane or walker or other medical devices (e.g., braces, bands, tensors), websites/online information, medication, traditional medicine/treatments, anything that may indicate participation in physical activity or physiotherapy or occupational therapy.
5. Record any other information that may be pertinent.

Appendix H: Socio-demographic form

This information will be collected from each study participant at the end of the interview. Questions will be interview-administered.

Answers to these questions will help us understand how Indonesians with different backgrounds, for example those of different ages, or those who arrived in Canada with different immigration statuses, experience self-care in different ways. All information you give will remain confidential, however please remember that you're not required to answer any questions you do not wish to answer.

Participant Identification #: ________________

1. **Are you**
   - ☐ Male
   - ☐ Female
   - ☐ Non-binary
2. **How old are you? ___________ (yrs)**
3. **What is your marital status?**
   - ☐ Married
   - ☐ Consensual union (unmarried partners)
   - ☐ Widowed
   - ☐ Separated
   - ☐ Divorced
   - ☐ Single
4. **Who do you live with? Check all that apply.**
   - ☐ Husband/Wife
   - ☐ A female or male partner (for unmarried partners)
   - ☐ Your children
   - ☐ Your Mother/Father
   - ☐ Your Brothers/Sisters
   - ☐ Your Partner's Mother/Father
   - ☐ Friend(s)
   - ☐ Other, specify ___________________

   OR ☐ I live alone

5. What is your highest level of education completed?

☐ Primary school

☐ Secondary diploma

☐ Postsecondary diploma (e.g trade school, college, university)

☐ Graduate diploma (Master's, Doctoral)

☐ None

6. What is your current employment status?

☐ Working full-time

☐ Working part-time

☐ Not working and not looking for work

☐ Studying and not looking for work

☐ Unemployed and looking for work

☐ Disabled or retired and not looking for work

☐ Other (please specify): ________________

7. If you are working, what is your current job?

____

8. How long have you lived in Canada?

__________ (months) ____________ (years)

How long have you lived in Montreal?

__________ (months) ____________ (years)

9. How do you pay for healthcare (check all that apply)?

☐ Provincial government insurance (Medicare/RAMQ)

☐ Refugee insurance [Interim Federal Health Program (IFHP)]

☐ Private insurance

☐ Pay out of pocket

10. What are your sources of income (Check all that apply)?

☐ Employment

☐ Partner's employment

☐ Help from relatives

☐ Social assistance (unemployment, child benefits, disability)

11. What is your combined family income for the past 12 months, before taxes from all sources (job, social assistance, help from relatives). If you do not know exactly, please estimate.

☐ Less than $ 10,999
☐ $ 10, 999 - $ 19,999
☐ $20,000 - $49,999
☐ $50,000 - $99,999
☐ More than $ 100,000
☐ Don’t know
☐ Chose not to answer

12. What is your mother tongue/first language? ____________________

13. How well do you know French?

	Fluent	Well	With Difficulty	Not at all
Speak				
Read				
Write				
Understand				

14. How well do you know English?

	Fluent	Well	With Difficulty	Not at all
Speak				
Read				
Write				
Understand				

15. What chronic illnesses do you have (it’s not necessary to ask this question if it’s clear from the interview which illnesses they have)?

_________________, _____________________, ______________________.

16. How long have you lived with each of your illnesses?

Illness __________: ____________ months or years;
Illness __________: ____________months or years;

Illness __________: ____________months or years;

17. Which health care services have you accessed (in Montreal) for your chronic illness(es) (check all that apply)?

Hospital (Emergency)	☐
Hospital (Specialized care)	☐
Residential and long-term care centres (CHSLDs)	☐
Family physician	☐
Local Community Services Centres (CLSCs)	☐
Walk-in clinics	☐
Other, specify …………………………………………………………	☐

This concludes the interview. Thank you for your time and for contributing to this research

Appendix I: Ethic Certificate

Université de Montréal

CERSES-19-131-D

Comité d'éthique de la recherche en sciences et en santé (CERSES)

CERTIFICAT D'APPROBATION ÉTHIQUE

Le Comité d'éthique de la recherche en sciences et en santé (CERSES), selon les procédures en vigueur, en vertu des documents qui lui ont été fournis, a examiné le projet de recherche suivant et conclu qu'il respecte les règles d'éthique énoncées dans la Politique sur la recherche avec des êtres humains *de l'Université de Montréal.*

Projet	
Titre du projet	**Expériences des auto-soins des Indonésiens adultes vivant avec des maladies chroniques à Montréal**
Étudiante requérante	**Nurul Akidah Lukman**, candidate à la maîtrise, Faculté des sciences infirmières
Sous la direction de:	Lisa Merry, professeure adjointe, Faculté des sciences infirmières, Université de Montréal & Annette Leibing, professeure titulaire, Faculté des sciences infirmières, Université de Montréal.

Financement	
Organisme	Non financé

MODALITÉS D'APPLICATION

Tout changement anticipé au protocole de recherche doit être communiqué au Comité qui en évaluera l'impact au chapitre de l'éthique.

Toute interruption prématurée du projet ou tout incident grave doit être immédiatement signalé au Comité.

Selon les règles universitaires en vigueur, un suivi annuel est minimalement exigé pour maintenir la validité de la présente approbation éthique, et ce, jusqu'à la fin du projet. Le questionnaire de suivi est disponible sur la page web du Comité.

Marie-Josée Bernardi, vice-présidente Comité d'éthique de la recherche en sciences et en santé (CERSES) Université de Montréal	**9 janvier 2020** Date de délivrance	**1er février 2021** Date de fin de validité
	1er février 2021 Date du prochain suivi	