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Assessing the Impact of Financial Barriers on Care and Outcomes for Patients with Cardiovascular-Related Chronic Diseases

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Assessing the Impact of Financial Barriers on Care and Outcomes for Patients with Cardiovascular-Related Chronic Diseases

by

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Abstract

Patients with cardiovascular-related chronic diseases, such as coronary artery disease and diabetes may face numerous barriers to accessing the complex care that they require. Even in Canada, which has a universal healthcare system, some patients may face financial barriers to accessing important goods and services. Our objective was to enhance the understanding of financial barriers and their impact on clinical outcomes.

This thesis is comprised of four reports of three independent studies that form an overarching sequential mixed methods program of research. The first study was a population-weighted survey of Western Canadians with cardiovascular-related chronic conditions in which we found that 1 in 10 respondents perceived having financial barriers to accessing goods and services required for their chronic disease. Those who reported having a financial barrier self-reported being 70% more likely to require hospital or emergency department care than those who did not perceive having financial barriers.

In the second study, we built on this by linking data for patients self-reporting financial barriers within a series of national health surveys to outcomes available within administrative data sources. Those who perceived having a financial barrier to any aspect of their care had a hospitalization rate and mortality rate that was 36% and 24% higher, respectively, than those who denied having financial barriers.

In the third study, we explored patients' experiences with financial barriers using grounded theory methodology. We developed a conceptual framework for understanding how financial barriers impact patients' lives. We outlined protective, predisposing, and modifying factors that ultimately determine how resilient an individual can be in the face of financial barriers. Finally, we undertook a qualitative descriptive analysis to describe the aspects of care to which patients most commonly experience financial barriers. These include: non-insured goods and services, items required to support self-management and incidental expenses associated with insured services.

Many Canadians with chronic diseases face financial barriers to care, which are associated with adverse health outcomes. Interventions to address the prevalence and impact of financial barriers are possible but have never been tested in rigorous trials. Such studies would inform important policy reform at all levels of government.

Preface

Based on work from this thesis, the following manuscripts have been published in peer-reviewed journals. For the papers below, David Campbell led the conceptualization and design of the studies. He was also responsible for drafting the manuscripts, conducting the analysis and interpreting the data with guidance from his thesis committee (Drs. Braden Manns, Kathryn King-Shier, Brenda Hemmelgarn and Claudia Sanmartin) and other co-authors. All authors contributed important intellectual content and provided critical reviews of the papers.

Campbell DJT, King-Shier K, Hemmelgarn BR, Sanmartin C, Ronksley PE, Weaver RG, Manns BJ. (2014*). Self-reported financial barriers to care among patients with cardiovascular-related chronic conditions.* Health Reports, 25(5). Adapted from Statistics Canada, Health Reports, May 2014. This does not constitute an endorsement by Statistics Canada of this product.

Campbell DJT, Manns B, Weaver R, Hemmelgarn B, King-Shier K, Sanmartin C. (2017). *The association between financial barriers and adverse clinical outcomes among patients with cardiovascular-related chronic diseases: A cohort study.* BMC Medicine, 15(33). DOI 10.1186/s12916-017-0788-6. Adapted from BMC Medicine, February 2017.

Campbell DJT, Manns BJ, Hemmelgarn BR, Sanmartin, C, King-Shier, K. (2016). The *Development of a Conceptual Framework for Understanding Financial Barriers to Care for Patients with Cardiovascular-Related Chronic Disease: A Protocol for a Grounded Theory (Qualitative) Study.* CMAJ Open, 4(2): E304-308. DOI: 10.9778/cmajo.20160030. Available: http://cmajopen.ca/content/4/2/E304

Campbell DJT, Manns BJ, Leblanc P, Hemmelgarn BR, Sanmartin C, King-Shier K. (2016). *Finding resiliency in the face of financial barriers: Development of a conceptual framework for people with cardiovascular-related chronic disease.* Medicine, 95(49): 1-8. DOI: 10.1097/MD.0000000000005561. Adapted from BMC Cardiovascular Disorders, February 2017.

Campbell DJT, Manns BJ, Hemmelgarn BR, Sanmartin C, Edwards A, King-Shier K. (2017). *Understanding Financial Barriers to Care for Patients with Diabetes: An Exploratory Qualitative Study*. The Diabetes Educator, 43(1). DOI: 10.1177/0145721716679276. The final, definitive version of this paper has been published in The Diabetes Educator, Vol 43/Issue 1, February 2017 published by SAGE Publishing, All rights reserved.

A few select excerpts from the following manuscripts are also part of this thesis. While David Campbell is not the first author on these papers, he is the final/senior/supervising author. He was responsible for designing the data collection and analysis of these works, conducting the data analysis, and providing close and direct supervision to Dr. Aravind Ganesh and Ms. Kirnvir Dhaliwal in writing up the final manuscripts. The Community Health Sciences thesis guidelines state that the candidate must be the primary author, defined as “the author who has made the most substantial contribution” and as supervisor of these junior trainees working within a dataset he designed for his thesis, David Campbell fits this criterion.

Ganesh A, King-Shier KM, Manns BJ, Hill MD, **Campbell DJT.** (2016). *Money is Brain: Financial Barriers and Consequences for Canadian Stroke Patients.* Canadian Journal of Neurological Sciences, 44(2). DOI:10.1017/cjn.2016.411. Reprinted with permission.

Dhaliwal KK., King-Shier KM, Manns BJ, Hemmelgarn BR, Stone J, **Campbell DJT.** (2017). *Exploring the Impact of Financial Barriers to Care for Patients with Coronary Artery Disease: A Qualitative Descriptive Study*. BMC Cardiovascular Disorders, 17(61). DOI: 10.1186/s12872-017-0495-4

Analyses from some of the papers were based on data collected by Statistics Canada. However, the results and interpretations presented in these manuscripts do not represent the opinions of Statistics Canada.

Where applicable, permission to reproduce these papers was obtained from the publishers, except in the case of open access publishers where the authors have retained the copyright for this material.

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I would like to thank my PhD co-supervisors, Dr. Braden Manns and Dr. Kathryn King-Shier, for all their support and instruction over the years. Thank you for your availability and for prioritizing my work amongst numerous other priorities in your busy schedules. You have provided me with innumerable opportunities for personal and professional development, for which I will always be grateful. Most of all, thank you for your flexibility in accommodating my various clinical and family commitments and for helping me to achieve success in my PhD.

I would also like to thank my career mentor, Dr. Brenda Hemmelgarn, who was also a member of my PhD supervisory committee. You have always been a tremendous inspiration to me – thank you for the ongoing guidance and direction. Dr. Claudia Sanmartin, also a supervisory committee member, was instrumental in bringing this work to life in helping provide access to novel Statistics Canada data.

I would also like to express my appreciation for various members of the nephrology research group and nursing research group who contributed to my PhD in very meaningful ways. For their tremendous contributions, I would like to recognize: Ms. Jo Anne Plested, Ms. Pam Leblanc, Ms.

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I am very grateful for Drs. Jeff Schaefer and Marcy Mintz, program directors of the Internal Medicine Residency Program, for their flexibility in allowing me to complete my postgraduate clinical training simultaneously with my PhD program of studies.

Thank you to my professors, preceptors and mentors from the Departments of Medicine and Community Health Sciences at the University of Calgary under whose direction I have been privileged to learn, thank you all for taking your time to teach and educate me.

I must acknowledge the inspiration that I have received from patients in whose care I have had the privilege of being involved. Truly, those patients who struggle to access basic healthcare services are the reason for this work. I believe that we can and must to better to meet the needs of society’s most vulnerable and that all should have access to high quality healthcare, unencumbered by personal expense.

Without a doubt, my wife, Rachel, has been the most important influence on all aspects of my life, this work being no exception. Thank you for inspiring me and for supporting my work, including the long days, nights and weekends that my work has taken me away from our family. Thank you for proofreading and contributing your thoughts and ideas to this work. You inspire me with your commitment to your work both in our home and in the community. Thank you.

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List of Symbols, Abbreviations and Nomenclature

Symbol	**Definition**
Avg	Average
ACE	Angiotensin Converting Enzyme
ASA	Acetylsalicylic Acid (Aspirin)
BCPCHC	Barriers to Care for Persons with Chronic Health Conditions
CAD	Coronary artery disease
CCHS	Canadian Community Health Survey
CI	Confidence interval (95%)
CIHI	Canadian Institute for Health Information
CMDB	Canadian Mortality Database
CMG	Case-Mix grouper
CR	Cardiac Rehabilitation
CRNA	Cost-related non-adherence
CV	Coefficient of Variation
DAD	Discharge Abstract Database
GLM	Generalized linear model
IRR	Incidence rate ratio
OLS	Ordinary least squares
PDERR	Prescription Drug Expenditure Rapid Response Module
PCE	Patient Cost Estimator
PRR	Prevalence rate ratio
SLCDC	Survey of Living with Chronic Diseases in Canada

Epigraph

Study after study, in city after city, has shown us that
it is very expensive to give mediocre medical care
to poor or near-poor people living in a rich country.
~ Dr. Paul Farmer

CHAPTER 1:

INTRODUCTION TO FINANCIAL BARRIERS AMONG PATIENTS WITH CARDIOVASCULAR-RELATED CHRONIC CONDITIONS IN CANADA

1.1 Cardiovascular chronic diseases are a substantial burden to Canadians

As the Canadian populace ages, the prevalence of chronic diseases is also on the rise, with three-quarters of Canadian seniors reporting having at least one chronic disease [1]. In part, the rise in healthcare utilization and expenditure has been due to the increase in the prevalence of chronic diseases [1]. Estimates suggest chronic conditions cost Canadians over $93 billion per year in direct and indirect health care costs [2].

Diseases and disorders of the cardiovascular system are particularly important due to their high prevalence and significant associated morbidity and mortality. The work in this thesis focuses on diseases which are related to the cardiovascular system, including coronary artery disease (CAD), cerebrovascular disease, hypertension and diabetes mellitus.

CAD encompasses a variety of clinical presentations, including angina and myocardial infarctions, caused primarily by atherosclerosis – the deposition of cholesterol plaques in the walls of the arteries that feed the heart. These conditions are a major cause of premature death and disability in the Canadian population: Acute myocardial infarctions were responsible for 15,929 deaths in 2008 [3]. Cardiovascular disease is also the leading cause of hospitalization in Canada [4].

Cerebrovascular disease is when the same atheromatous plaques deposit within the circulation of the brain, and is manifest as strokes or transient ischemic attacks (mini-strokes). While stroke has a slightly lower risk of mortality than myocardial infarction [5], it is associated with a significant burden of morbidity, primarily due to cognitive and physical disabilities that result from the ischemic insult to the brain [6].

Hypertension, or high systemic arterial blood pressure, is widely accepted to be one of the main risk factors for the development of atherosclerotic disease as well as acute events such as myocardial infarctions and strokes [7].

Diabetes mellitus (or diabetes) is a chronic disease characterised by dysregulation of the intrinsic handling of blood glucose due to either lack of pancreatic insulin production, or relative deficiency due to peripheral insulin resistance. It is strongly linked to cardiovascular disease as one of its primary risk factors [8], and therefore mortality rates for those with diabetes are much higher than for those without it [9]. In addition to its contribution to cardiovascular death, diabetes was primarily responsible for 7521 deaths in Canada in 2008 [3].

These four conditions share numerous similarities. The terminal outcomes of interest for these conditions are the same, as each of these cardiovascular-related chronic conditions are independent risk factors for future cardiac events and strokes. They also have similar treatment regimens. Patients with any of these conditions stand to benefit from both health behaviour modification (i.e. tobacco cessation, physical activity, consuming a healthy diet) [10, 11] as well as preventive pharmacotherapies. Many recommended medications are common to these conditions as well, such as HMG-CoA Reductase Inhibitors (i.e. Statins) which lower serum cholesterol levels and prevent vascular events [12]; Acetylsalicylic Acid (i.e. Aspirin) which prevents platelet aggregation and blood clot formation [13]; and Renin-Angiotensin-Aldosterone System Antagonists (i.e. ACE-inhibitors or angiotensin receptor blockers) which lower blood pressure, protect against kidney damage, and help optimize cardiac function [14]. Due to these similarities, throughout this thesis we refer to CAD, cerebrovascular disease, hypertension, and diabetes jointly as *cardiovascular-related chronic conditions*.

1.2 Patients may experience a variety of barriers to accessing care

Optimal care for patients with cardiovascular-related chronic disease can reduce the risk of hospitalizations for these conditions. Studies have outlined a variety of types of hospital admissions and emergency room visits for patients with these conditions that can be reduced by appropriate management in outpatient settings by family physicians and allied health professionals (deemed “ambulatory care sensitive”)[15-17]. However, when these diseases are neglected or poorly managed, patients may experience decompensation of their condition or acute complications, which often require hospital admission and specialist care for stabilization.

As stated above, effective outpatient treatments for these chronic diseases include both medical therapies as well as health behaviour modification. Since these treatments are effective and safe, we postulate that those who fail to regularly adhere to these therapies have likely experienced some form of barrier to accessing these treatments for optimal disease management.

There are a variety of different factors which contribute to how patients access and utilize healthcare services. Medical sociologist, Ronald Andersen’s frameworks for understanding access to care note that there are both factors intrinsic to individuals as well as general factors (extrinsic to patients) which contribute to healthcare access [18]. Intrinsic, or patient-related factors include characteristics such as age, gender, income, education, biological factors and culture. Each of these may influence how individual patients access healthcare services to a greater or lesser degree. Furthermore, patients' satisfaction with the healthcare system from prior interactions has a bearing on their future utilization of services [18].

Extrinsic factors are those related to healthcare providers and the broader healthcare system. Provider-level barriers include providers' communication skills and style, their own personal knowledge, diagnostic challenges and personal biases [19]. System-level barriers are those which relate to the healthcare system such as inadequate number of providers, costs of access, and poor continuity or integration of services [20].

Many Canadians do not access the care they require for optimal management of their chronic disease [21]. The potential barriers present in these cases include intrinsic factors such as lack of education, inadequate health literacy and poor language skills, as well as extrinsic factors like distance to care and cost/economic factors [22, 23]. Even in Canada, despite its publicly funded healthcare system, patients may experience financial barriers to accessing the care they require. This can be due to the direct costs of services such as medications, or to incidental costs associated with seeking care (i.e. transportation and childcare).

1.3 Drugs for the management of chronic diseases are not universally covered in Canada

Universality, or the provision of access to medical care for the entire Canadian populace is a core tenet of the Canada Health Act of 1982 [24]. However, the legislation that preceded the development of the Canada Health Act was largely developed during the decades from 1950 to 1970 [25]. This was a time when nearly all life-saving treatments were delivered by physicians in inpatient settings. Due to this delivery model, provincial healthcare insurance plans developed to cover “medically necessary services”, defined as care provided in hospitals or directly by a physician. Other goods and services, such as outpatient pharmaceuticals, were deemed to be less critical and were deliberately left out of the basket of goods insured by public health insurance plans [26]. Since that time, due to significant medical advances, we now have at our disposal, effective preventive medical therapies which are primarily administered on an outpatient basis. Unfortunately, there has been minimal increase in the comprehensiveness of Canadian provincial public healthcare plans – as they continue to cover primarily inpatient treatments and physician services. This policy gap is particularly problematic for patients who have cardiovascular-related chronic diseases, as optimal management of these conditions is achieved through complex and extensive medication regimens and self-monitoring in the outpatient setting.

Over time, some provinces have incorporated provincial pharmaceutical plans, however, these plans are not universal as they only insure medications for select groups (i.e. seniors or social assistance beneficiaries) [27, 28]. Over time, the structure of these plans has changed in several provinces from age-based plans (prioritizing seniors) to income-based plans (prioritizing those with lower income) [29]. Both models leave a substantial portion of patients with chronic diseases uninsured against the high costs that they routinely face. Those not included in a province’s public drug plan must either pay out of pocket for their medications or obtain private insurance coverage through some other means (employment or direct purchasing), which often involves sizeable insurance premiums.

1.4 Those who are insured may still face substantial charges for their medications

In Canada, medications are rarely obtained free of charge, even for those who do possess supplemental insurance coverage. The majority of insurance plans include user charges (such as copayments, coinsurance or deductibles), whereby patients are required to pay some portion of the cost of their medications at the point of dispensation.

User charges serve two functions: (a) to offset some of the costs of care borne by the insurer, and (b) to reduce inappropriate use of medications and other resources [28]. Through out-of-pocket payments, patients only finance approximately 15% of Canada's total health expenditures [30]. Therefore, the primary reason for user charges is to reduce consumer moral hazard, or the excessive and inappropriate use of healthcare resources that is driven by patients' low threshold to seek care because they are not required to provide payment for that care [31]. However, patients are often unaware of which aspects of their care are necessary and which are of lesser value – therefore, patients may abandon aspects of care that are critically important, due to the financial barriers that were put in place to limit excess utilization. This has been demonstrated in the RAND Health Insurance Experiment where participants in lower income groups who were exposed to higher user charges were noted to decrease healthcare utilization across the board, not only in less important areas [32]. In Canada, between insurance premiums and point-of-dispensation user charges, patients may be required to bear a substantial cost to obtain care necessary for the management of their chronic diseases [33].

1.5 Financial barriers impact health services and pharmaceutical utilization

Despite the fact that most Canadians take great pride in our universal healthcare system [34], and feel that access to healthcare services in Canada is improving [35], many Canadians face difficulties in accessing adequate health care to meet their needs due to cost [36], henceforth referred to as *financial barriers*.

Financial barriers are important as they span both intrinsic and extrinsic aspects of access described by Andersen. There are several types of financial barriers that might reduce accessibility of appropriate care and impact health outcomes. For instance, some people may be unable to afford the direct costs associated with receiving healthcare, including medications (i.e., insurance premiums or user charges), self-monitoring supplies and ancillary services such as rehabilitation and home care.

Some patients may even struggle to access care that is fully funded by the public system, such as physician appointments or laboratory testing, because of an inability to pay for the incidental costs associated with these appointments. These costs vary across individuals but may include lost income from taking time off work, paying for transportation and parking costs, and arranging and paying for childcare, among other potential expenses. The types of financial barriers we postulated prior to this work are summarized in Figure 1.1.

Financial barriers may be especially important for persons living with chronic diseases. Cardiovascular-related chronic diseases have been shown to be more common in those with low socioeconomic status (SES) [37-39]. Furthermore, persons with chronic diseases and low SES are known to have worse outcomes relative to those with higher SES [40, 41], though it is unknown if these increased risks are directly related to the potential of experiencing financial barriers to care, or if they are related to other factors associated with low SES (i.e., low education levels, low health literacy and competing priorities).

Patients with chronic disease are likely to accrue considerable incidental expenses related to regular follow-up visits with primary care and specialist physicians and other members of an interdisciplinary healthcare team [42]. These patients also require ongoing monitoring including laboratory testing, and self-monitoring [43], through which they may incur significant personal expense.

The process of receiving necessary care for chronic diseases is complex and patients may experience barriers (financial and otherwise) at one or more of the many steps that must be navigated. An example of how this might occur is presented in Figure 1.2.

1.6 Financial barriers may interfere with optimal care for people with chronic conditions which may lead to adverse outcomes

When management of chronic disease is suboptimal for extended periods, patients may require a visit to a local emergency department, or even admission to hospital. For example, untreated hypertension may go unnoticed, but over time may lead to stroke, myocardial infarction, or other cardiovascular complications. Similarly, as a result of poor glycemic control, patients with diabetes may experience potentially life-threatening diabetic ketoacidosis, hyperosmolar non-ketosis, or hypoglycemic complications.

As previously described, cardiovascular-related chronic conditions are primarily ambulatory care sensitive, and therefore hospitalization for these types of conditions can serve as a proxy for poor chronic disease control [44] and represent an important potentially modifiable economic burden for healthcare systems [45].

One factor which may predispose patents to greater need for hospitalization for ambulatory care sensitive conditions is a lack of adherence to preventive medications [46]. Poor adherence may be due to a number of factors, including lack of insurance [47] and costs, with 10-12% of the Canadian population estimated to experience non-adherence due to costs [48, 49]. A Canadian survey also found that 23% of patients with chronic conditions have either skipped a dose of medication or failed to fill a prescription due to cost [50]. Several US studies have shown that reducing the financial burden borne by patients may improve adherence [51-53].

Since adverse outcomes may be avoidable if financial barriers are addressed, it is important to understand the role of financial barriers, their causes, and their consequences. This knowledge can inform interventions to reduce financial barriers and prevent avoidable negative outcomes. Prior to this research, several US studies had been published on the topic of financial barriers and their relationship with adverse outcomes among patients with chronic diseases. These studies have demonstrated that patients with a history of MI and financial barriers were more likely than those without financial barriers to have recurrent cardiac events [54, 55], as well as among patients with diabetes, financial barriers were associated with a 20-40% reduction in likelihood of achieving process targets and with a 23% increase in risk of diabetic complications [56]. While these were high quality observational studies, it is difficult to know how transferable the findings are to the Canadian population given the very substantial differences in healthcare systems and the fact that one might postulate that financial barriers should be less of an issue in Canada than in the US. Therefore, the purpose of this thesis research was to provide new insights into financial barriers to chronic disease care and their association with adverse clinical outcomes, specifically within the context of the Canadian healthcare system.

1.7 Outline of Thesis Contents

With this thesis, we undertook to examine and describe the relationships between perceived financial barriers to care and health outcomes among patients with cardiovascular-related chronic health conditions. Given the complexity of this issue, we conducted this investigation using a sequential mixed methods (qualitative and quantitative) design to provide a comprehensive understanding of financial barriers in Canadian patients with cardiovascular-related chronic diseases (Figure 1.3). The initial study was a survey, which we subsequently followed up by both a quantitative analysis of a linked survey-administrative database to confirm and extend the findings of the survey, as well as an exploratory qualitative study to provide depth of understanding to the relationships observed in the initial survey.

In this document, each chapter includes a report on a unique thesis component formatted for independent publication as part of a manuscript-based thesis. These chapters are linked by the common objective of improving knowledge regarding how financial barriers affect the care and outcomes among patients with cardiovascular-related chronic diseases. Each chapter represents an independent study distinguished by a specific research question.

In Chapter 2, we describe a cross-sectional observational study that uses a large population-weighted survey to determine the prevalence of and risk factors for perceived financial barriers. Furthermore, we assess for associations between perceived financial barriers and pre-determined self-reported outcomes and processes of care. Within this study, we also assess whether these associations are modified by multimorbidity (the presence of multiple chronic conditions).

In Chapter 3, we confirm and extend the findings of the previous survey by using a novel dataset linking national survey data to identify those with perceived financial barriers with reliable administrative data to ascertain hard outcomes such as death and disease-related hospitalizations. This linked dataset was chosen to overcome the primary limitation of the previous study – that of bias introduced through self-reported outcome measures.

We then, in Chapter 4, describe a qualitative grounded theory study where we developed a conceptual framework with the objective of explaining how a perceived financial barrier might translate into adverse clinical outcomes. We examine two main questions: (a) how an individual with cardiovascular-related chronic disease comes to perceive financial barriers; and (b) what the various factors are that contribute to the level of impact a financial barrier has on a given patient's life and health outcomes.

We subsequently conducted a descriptive analysis of the qualitative data collected for the grounded theory study for three subcohorts of participants: those with diabetes, CAD, and stroke, presented in Chapter 5. We summarize the details regarding what goods and services those with these conditions find difficult to afford as well as some strategies used to make accessing these possible.

Finally, we summarize and synthesize the findings of the thesis in Chapter 6. In this conclusion, we highlight the strengths and limitations of this program of research; clinical and health policy implications of these findings; and directions for future research.

1.8 Figures

Figure 1.1: Types of Financial Barriers Encountered by Canadian Patients

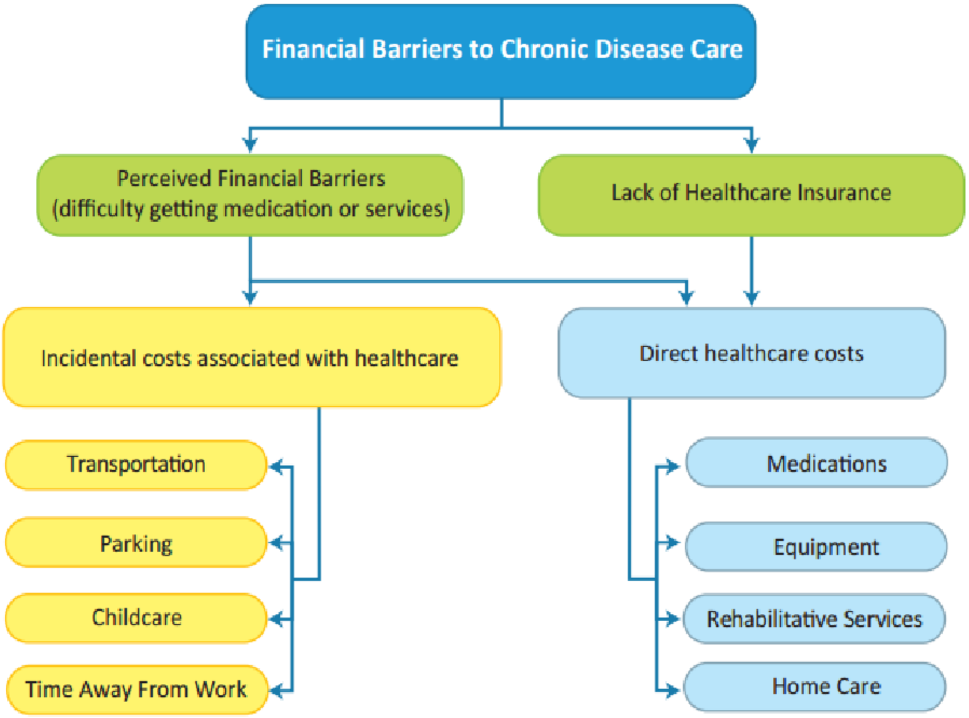
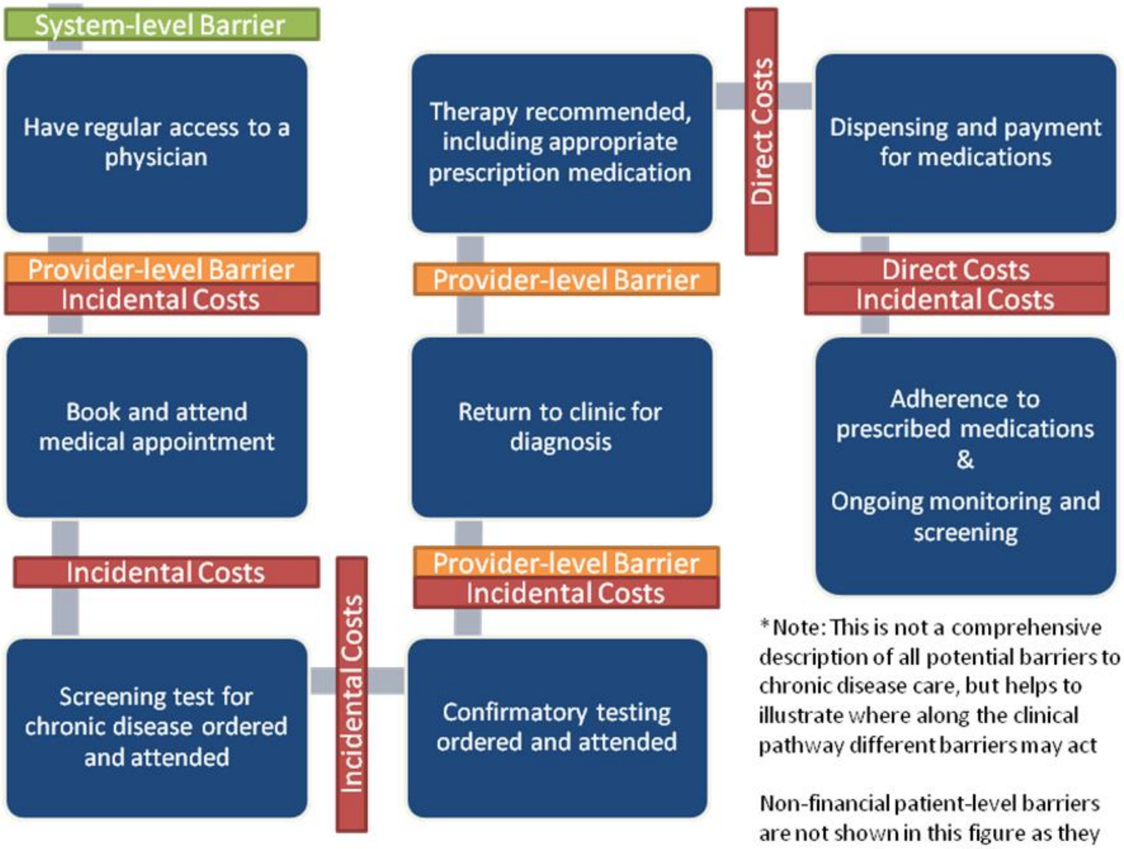


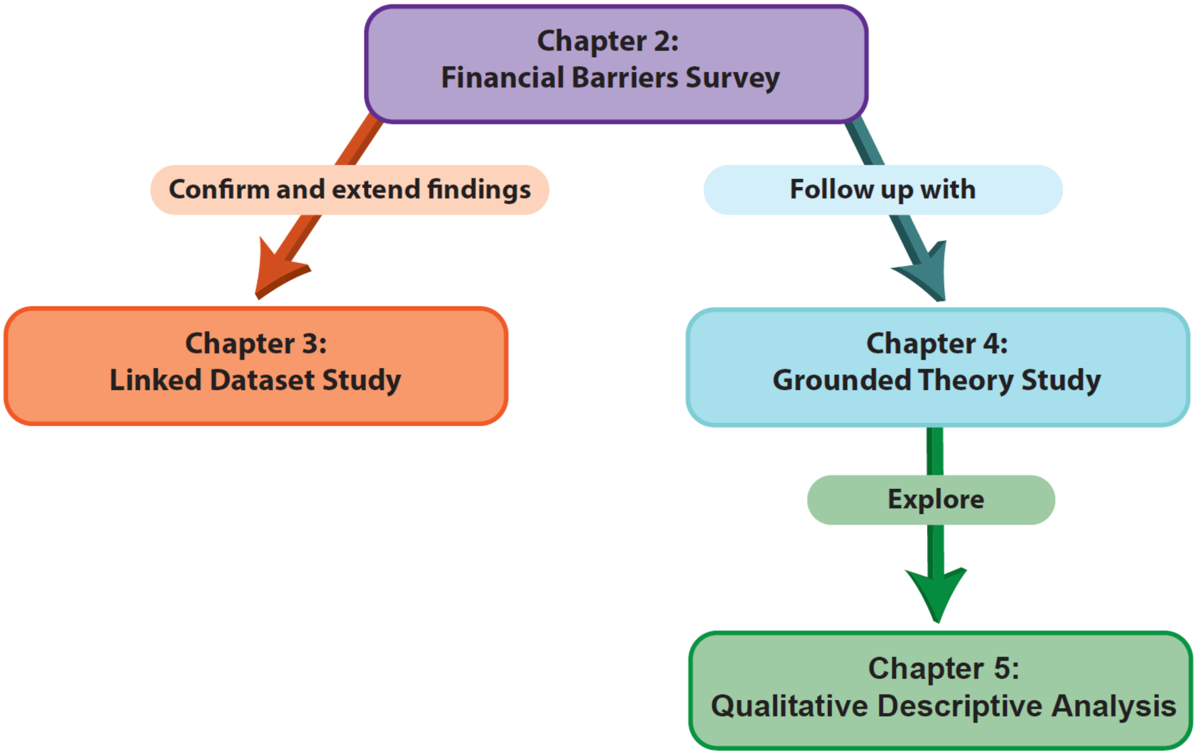
Figure 1.2: Process of Seeking Care for Chronic Disease in Canada and Common Barriers



*Note: This is not a comprehensive description of all potential barriers to chronic disease care, but helps to illustrate where along the clinical pathway different barriers may act

Non-financial patient-level barriers are not shown in this figure as they may occur at several different locations

Figure 1.3: Thesis Overview



CHAPTER 2:

ASSESSING THE PREVALENCE OF PERCEIVED FINANCIAL BARRIERS TO CARE AND ASSOCIATIONS WITH SELF-REPORTED OUTCOMES AND PROCESSES OF CARE AMONG PATIENTS WITH CARDIOVASCULAR-RELATED CHRONIC CONDITIONS

This Chapter is published as:

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2.1 Abstract

Background

People with chronic conditions who do not achieve therapeutic targets have a higher risk of adverse health outcomes. Failure to meet these targets may be due to a variety of barriers. This study examines financial barriers among people with cardiovascular-related chronic conditions.

Methods

A population-based survey was administered to Canadians with hypertension, diabetes, heart disease and/or stroke who lived in the four western provinces (n = 1,849). Financial barriers were categorized as general financial barriers; financial barriers to medications specifically; and lack of medication insurance. Using log binomial regression, associations between financial barriers and statin use, the likelihood of stopping use of prescribed medications, and emergency department visits or hospitalizations were assessed.

Results

More than 1 in 10 of respondents reported general financial barriers (12%) and lack of drug insurance (14%); 4% reported financial barriers to accessing medications. Emergency department visits or hospitalizations were 70% more likely among those reporting a general financial barrier (Prevalence Rate Ratio (PRR) 1.71; 95% CI: 1.01-2.87). Those reporting a financial barrier to medications were 50% less likely to take statins (PRR 0.47; 95% CI: 0.25-0.86) and three times more likely to stop using prescribed medications (PRR 3.52; 95% CI: 1.69-7.34). Individuals without drug insurance were nearly 30% less likely to take statins (PRR 0.73; 95% CI: 0.57-0.93).

Discussion

Among patients with cardiovascular-related chronic conditions, financial barriers were associated with lower use of guideline-recommended preventive medications, increased likelihood of non-adherence, and increased likelihood of emergency department visits or hospitalization.

2.2 Background

Financial barriers may reduce access to appropriate care and can impact health outcomes, even in a system which claims to have universal health care coverage. Some people may be unable to afford the direct costs of goods and services which fall outside public health coverage, while others may struggle with the indirect costs associated with accessing publicly covered health services. Since coverage for prescription medications is not provided for all citizens within many Canadian provincial healthcare insurance plans [33], patients without public coverage or private health insurance may not obtain indicated medications due to cost [48]. Those with drug coverage may still bear a financial burden related to cost-sharing, including copayments and deductibles [57].

These financial barriers may be especially important for people with cardiovascular-related chronic diseases (defined herein as diabetes, hypertension, heart disease and stroke) due to requirements for regular follow-up visits with primary care and specialist physicians and other members of an interdisciplinary healthcare team [42]. Patients with cardiovascular-related chronic diseases also require ongoing monitoring including laboratory testing and self-monitoring, as well as long-term use of prescription medications [43]. The costs of these medications, or costs associated with self-monitoring may be substantial for some patients [58]. In addition to a higher burden of chronic disease, people with low socioeconomic status (SES) [37, 38] also experience worse health outcomes relative to those with higher SES [40, 41]. Various factors associated with low SES have been shown to contribute to these outcomes, including education, social status, social support, geographic access, health literacy, as well as the actual financial barriers.

A few studies have examined the issue of cost and affordability of health care in Canada, including types of provincial drug coverage [27], out-of-pocket expenditures [33] and cost-related non-adherence [48] . However, the relationships between different types of financial barriers and quality care indicators or adverse outcomes in patients with chronic disease are uncertain.

A survey was utilized to examine financial barriers to care in Western Canadians with chronic diseases. The main goals were to determine the frequency of types of financial barriers, the factors associated with experiencing a financial barrier, and the implications of these barriers. Specifically, the authors sought to determine if financial barriers were associated with lower use of guideline-recommended medication, stopping one or more recommended medications, and greater out-of-pocket expenditures. Finally, the association between financial barriers and the need for chronic disease-related emergency department visits or hospitalization was assessed.

2.3 Methods

2.3.1 Survey design

From February 1 to March 31 2012, Statistics Canada administered a special survey designed by the Interdisciplinary Chronic Disease Collaboration (www.ICDC.ca)[59] entitled “Barriers to Care for People with Chronic Health Conditions” (BCPCHC), using computer assisted telephone interviews. The survey was designed to inquire about aspects of care and potential barriers, including financial barriers (reported herein), access barriers, geographical barriers, and healthcare system-related barriers to care for people with at least one of the chronic diseases of interest. With participant consent, the responses from BCPCHC were linked to their 2011 Canadian Community Health Survey (CCHS) responses to provide detailed information related to hospitalizations, demographic information and other characteristics. The study was approved by the Conjoint Health Research Ethics Board of the University of Calgary and the Health Research Ethics Board of the University of Alberta. In accordance with Statistics Canada procedures, the survey underwent pilot testing and multiple revisions to ensure the questionnaire content was relevant to the patient population [60].

2.3.2 Respondents

The initial sampling frame for the BCPCHC consisted of all 2011 CCHS respondents who: (1) resided in British Columbia, Alberta, Saskatchewan or Manitoba; (2) were aged 40 or older; and (3) self-reported having at least one of: heart disease, stroke, diabetes, and/or hypertension (n = 4,331).

Of an initial 4,331 CCHS respondents, 2,582 were considered “in scope” for the BCPCHC, that is: they had not participated in another Statistics Canada CCHS sub-survey in 2011; they confirmed that they had a cardiovascular-related chronic condition; and they agreed to have their BCPCHC results linked to their CCHS responses. From this sampling pool, 2,316 were randomly selected for the BCPCHC. The response rate was 80%, yielding a final study population of 1,849 individuals.

2.3.3 Variables

2.3.3.1 Exposure variables

Three types of self-reported *financial barriers* were examined: general financial barriers (difficulty paying for services, equipment or medications); financial barriers to accessing medications (not obtaining medications because of cost); and lack of insurance coverage for prescription medications (Appendix 2A)

2.3.3.2 Outcome variables

Use of guideline-recommended preventive medications: In separate questions, respondents were asked if they used statins and acetylsalicylic acid (Aspirin/ASA) regularly in the past month. These drugs were chosen since statins and ASA are recommended by clinical practice guidelines for most patients at high risk of cardiovascular events [61, 62]. Statins are relatively expensive medications, \$300-700 per year [63]; thus patients with financial barriers may be less likely to use statins on a daily basis, compared to ASA (roughly \$50 per year). Use of ASA was selected as a secondary outcome and negative control, meaning that it was hypothesized that having financial barriers would be less relevant for use of ASA than for statins. Therefore, those who were not using ASA might have reasons for non-use other than the cost of the drug. For the purposes of identifying who should ideally be taking these medications, a subset of our total population who were deemed to be at higher cardiovascular risk was defined using an algorithm modified from the 2008 Canadian Diabetes Association practice guidelines [64] and Canadian Hypertension Education Program recommendations [61], acknowledging that some clinical information required for this determination (e.g. blood pressure, family history, symptoms) was lacking. This high-risk group included: those who self-reported having heart disease or stroke; those who had both hypertension and diabetes; current smokers; those with hypertension only who were greater than 55 years old; and those with diabetes only who were greater than 45 years old for males or 50 years old for females.

Non-adherence to prescribed medication was identified if respondents reported that they had stopped taking one or more of their medications for at least one week in the past 12 months.

Out-of-pocket expenses for medications were identified by respondents' estimated self-report over the previous 12 months. The estimate was extrapolated from a 3-month recall if this was easier for the respondent than recalling the total amount over 12 months.

Hospitalization or Emergency Department visit for care of cardiovascular-related chronic diseases: Respondents were asked if, in the past 12 months, they had visited an emergency department or been hospitalized for care of their cardiovascular-related chronic condition. Their answers were used to derive a binary variable differentiating those who had an emergency department visit or who had spent at least one night in hospital from those who had neither.

2.3.3.3 Included covariates

Based on the literature, a list of potential covariates was generated to identify variables that were theoretical confounders (potentially independently associated with both the exposure and the outcome): age, sex, multimorbidity (having more than one of the four selected chronic conditions), having a regular family physician, and selected socio-demographic characteristics (for example, education, household income, ethnicity). Because the involvement of multidisciplinary teams has been shown to improve the quality of care for people with chronic conditions [65], the models also assessed whether involvement of a non-physician health care provider acted as a confounder.

2.3.4 Statistical analyses

All analyses were performed using STATA 11.0 (Statacorp, College Station, Tex.). Frequency weights were calculated by Statistics Canada to account for non-representative sampling and to reflect the adult population with chronic disease in the four Western provinces [66]. All proportions and models were done using these weights, and proportions were stratified by the presence of multimorbidity. Bootstrapping procedures with 500 replications were used to calculate standard errors and confidence intervals around the estimates.

Given that this was a population weighted survey, it was susceptible to sampling error. As recommended by Statistics Canada, the coefficient of variation (CV) was used to determine the reliability of reported proportions [67]. This measure is calculated by dividing the standard error of each estimate by the average value of the estimate itself. Estimates with CVs less than 16.5% are considered by Statistics Canada to have sufficient accuracy and reliability. When CVs fall between 16.5% and 33%, estimates are considered to have marginal accuracy and must be accompanied by a warning about potentially high levels of error. Estimates whose CV is in the unacceptable category (greater than 33%) are not allowed to be released by Statistics Canada.

Log-binomial regression models were used to calculate unadjusted and adjusted prevalence rate ratios (PRR), using a step-wise approach. Initially, bivariate models were generated to test the independent associations between the covariate and outcome of interest. Each covariate that proved significant in bivariate modelling was then tested in simplified models that included the covariate of interest, the exposure and the outcome. If the covariate was a potential confounder (change in point estimate by at least 10%), it was considered in the full model. The final model was obtained through a process of backwards elimination. Covariates with p-values >0.10 on the Wald test were removed sequentially; if there was no evidence of confounding (point estimate did not change by >10%), the variable was eliminated from the model. Each variable listed in Table 1 was considered a possible confounder and tested in this fashion. In addition, joint confounding and effect measure modification were assessed using modelling with specific interaction terms between lack of drug insurance and province, lack of drug insurance and age, and multimorbidity and age.

2.4 Results

2.4.1 Study population

Just over half (52%) of BCPCHC respondents were aged 65 or older; two-thirds (67%) were married; and a large majority (83%) lived in urban areas (Table 2.1). The respondents who had more than one of the selected cardiovascular-related conditions (multimorbidity) were more likely to be men, to live in lower-income households, and to have relatively low levels of education (Table 2.1).

2.4.2 Prevalence of barriers

The prevalence of having a general financial barrier to care, having a financial barrier to accessing medications specifically, and lacking prescription drug insurance was 12%, 3.9%, and

14.1%, respectively (Table 2.2). The presence of financial barriers varied by the number of chronic conditions. As compared to those with only one chronic condition, those with more than one chronic condition of interest were more likely to: experience general financial barriers (PRR: 2.69; 95% CI: 1.71-4.23), be unable to access medications due to cost (PRR: 7.64; 95% CI: 2.69-21.70), and have higher out-of-pocket expenses ($p<0.001$), though they had a similar likelihood of lacking drug insurance (PRR: 0.98; 95% CI: 0.67-1.44) (Table 2.2).

There were several patient factors associated with having general financial barriers and lacking drug insurance (Table 2.3). Low income, obesity, inadequate health literacy [68], and non-white ethnicity were each associated with experiencing general financial barriers. Living rurally or in a province other than Alberta were associated with not having drug insurance, even though Alberta is not a province with universal medication coverage.

2.4.3 Medication use

Almost half (48%) of respondents were using statins (Table 2.4). The prevalence of statin use was similar among people who did and did not report general financial barriers. However, those who reported difficulty accessing medications because of cost were 50% less likely to be taking statins (adjusted PRR 0.47; 95% CI: 0.25-0.86), compared with those who did not report this barrier. Those without drug insurance were nearly 30% less likely to take statins (adjusted PRR 0.73; 95% CI: 0.57-0.93) than were those with drug insurance (Table 2.5). By contrast, after adjustment, none of the three types of financial barriers was associated with ASA use (Table 2.5).

13% of respondents stopped taking one or more prescription medications for at least a week in the previous year (Table 2.4). A financial barrier to accessing medications was the only barrier associated with stopping the use of prescribed medications for more than a week in the past year (adjusted PRR: 3.52; 95% CI: 1.69-7.34) (Table 2.5).

2.4.4 Out-of-pocket drug expenditures

Mean annual out-of-pocket drug expenditures amounted to $539 (Table 2.6), but were significantly higher for people with more than one chronic condition ($714 versus $460). However, this difference reflected the situation among seniors; for people younger than age 65, out-of-pocket drug expenditures did not differ significantly by the number of cardiovascular-related conditions they reported.

Compared with people who reported no barriers, those who reported general financial barriers had significantly higher out-of-pocket expenditures on medications ($1,077 versus $466, p = 0.004) (Table 2.4). And compared with those who had drug insurance, those who did not also reported higher out-of-pocket spending on medications ($894 versus $480, p = 0.003) (Table 2.4).

Among people reporting financial barriers to medications specifically, the trend was toward higher out-of-pocket expenditures compared with people who did not report such barriers ($900 versus $524). The difference, however, was not statistically significant (p = 0.139), likely because of the small number of respondents identifying this barrier (Table 2.4).

2.4.5 Emergency department visits and hospitalization

Overall, 9% of respondents reported having had an emergency department visit or hospitalization related to their cardiovascular condition in the past year (Table 2.4). Emergency department visits/hospitalizations were 70% more likely among those who experienced a general financial barrier (adjusted PRR: 1.71; 95% CI: 1.01-2.87) than among those who did not (Table 2.5). However, financial barriers to medications or lacking drug insurance were not associated with an increased risk of an emergency department visit/hospitalization. Interaction terms between multimorbidity and age, province and age, and province and insurance status were not significant in any of the models.

2.5 Discussion

In the four western provinces, general financial barriers to health care and a lack of drug insurance were relatively common among people aged 40 or older who had cardiovascular-related chronic health conditions (12% to 14%).

In a previous survey conducted by the Commonwealth Fund / Health Council of Canada [50], a similar proportion of people with chronic diseases were noted to have financial barriers. This current study provides additional information regarding clinically relevant differences by the presence of financial barriers which was not previously known. The presence of these barriers seemed to be clinically important, manifest by higher likelihood of requiring hospitalization or emergency department visits for chronic diseases. This increased risk may be the result of a lack of access to preventive measures, such as ongoing monitoring, screening, educational programs and treatments, due to the direct costs of these services or to incidental costs associated with them. The findings of the present study are consistent with those of earlier Canadian and American research reporting that ambulatory care-sensitive hospital admissions are more common among people with limited financial resources [69, 70].

Those who did not have drug insurance were 30% less likely to be using statins, while those who reported a financial barrier to accessing medications were more than 50% less likely to be using statins. This makes sense given the cost associated with statin use – ranging from $300-700 per year [63]. Most of these patients should be taking both statins and ASA, yet use of ASA did not vary by presence of financial barriers, after adjustment for confounders. This lends further support to the hypothesis that non-use of statins may be related to lack of financial means rather than to other unmeasured factors (e.g., an aversion to taking medications). This finding is similar to what has been noted in other Canadian studies looking at initiation of statin therapy [71].

Living in a rural location was significantly associated with not having drug insurance. This association may reflect a greater tendency for people in these areas to be self-employed or to work for small businesses that do not provide extended health benefits.

Overall, people without drug insurance had mean annual out-of-pocket medication expenses of $894, compared with $480 for people who had drug insurance. However, individuals who did not have drug insurance were no more likely to report an emergency room visit or hospitalization for chronic condition care.

Several characteristics were significantly associated with reporting financial barriers—multimorbidity, non-White ethnicity (including Aboriginal), and an annual household income less than $30,000. Age was not a significant modifier or confounder in any model. This may be due to a dilution of effect, because Alberta is the only province with differential insurance coverage for people aged 65 or older; seniors in the other three western provinces receive no additional insurance benefits (see Appendix 2B).

This study had several limitations. First, despite adjustment there is potential for residual confounding – and it is possible that the observed differences outcomes between groups may be related to unmeasured patient differences. However, several important sociodemographic and clinical variables, such as obesity and multimorbidity, were adjusted for using the detailed CCHS survey results. Further, data on blood pressure, or information on severity of chronic disease was lacking which may have resulted in misclassification of the need for statins or ASA. However, Canadian guidelines were used to define those at highest risk based on key variables available including comorbidities, smoking status, sex and age. Despite the sample size of 1849 respondents, some subgroups of interest were small, limiting statistical power to detect certain differences. For most variables, covariates were only stratified into two groups, and some detail may have been lost in doing so. As in all surveys, data were by self-report, with its recognized limitations, though survey questions were tested prior to use and conducted by survey experts with rigorous standards. The survey may lack sensitivity to detect individuals who might choose to prioritize medications and spend less on other aspects of daily living, such as food [72]. Finally, this survey was only administered to respondents from the four western Canadian provinces, which could potentially limit the generalizability of the findings. However, these four provinces provide a broad cross-section of Canadians, including those who live in small communities as well as large cities; they also each have varying levels of socioeconomic prosperity and different public drug coverage schemes which are representative of the different models seen across Canada (provisions of the public drug programs in the western provinces is given in Appendix 2B). Furthermore, there is no reason to suspect that these findings would differ in other provinces, with the exception of the few provinces which offer more comprehensive drug insurance plans.

2.6 Conclusion

Several studies indicate that provision of drug insurance, particularly among those with cardiovascular-related chronic diseases, increases use of preventive medications [52, 53, 73, 74]. Others have shown that such insurance policies are associated with improved clinical outcomes, such as blood pressure [53] and cardiac events [57]. Some have also suggested that these policies may reduce costs in other areas of health care, such as emergency department visits and hospitalizations [74]. The findings of this study align with these prior studies, although we did not see increased use of emergency and inpatient services for those without insurance.

In summary, financial barriers or lack of drug insurance are common among patients with chronic disease, and are associated with lower use of guideline recommended medications, increased likelihood of non-adherence, and an increased likelihood of chronic disease-related hospitalization or emergency department visits. Because those who experience ‘financial barriers’ encompass a heterogeneous group of individuals, and the relationship between these barriers and increased risk of hospitalization is not clearly defined, further exploratory research is warranted.

2.7 Tables & Figures

Table 2.1

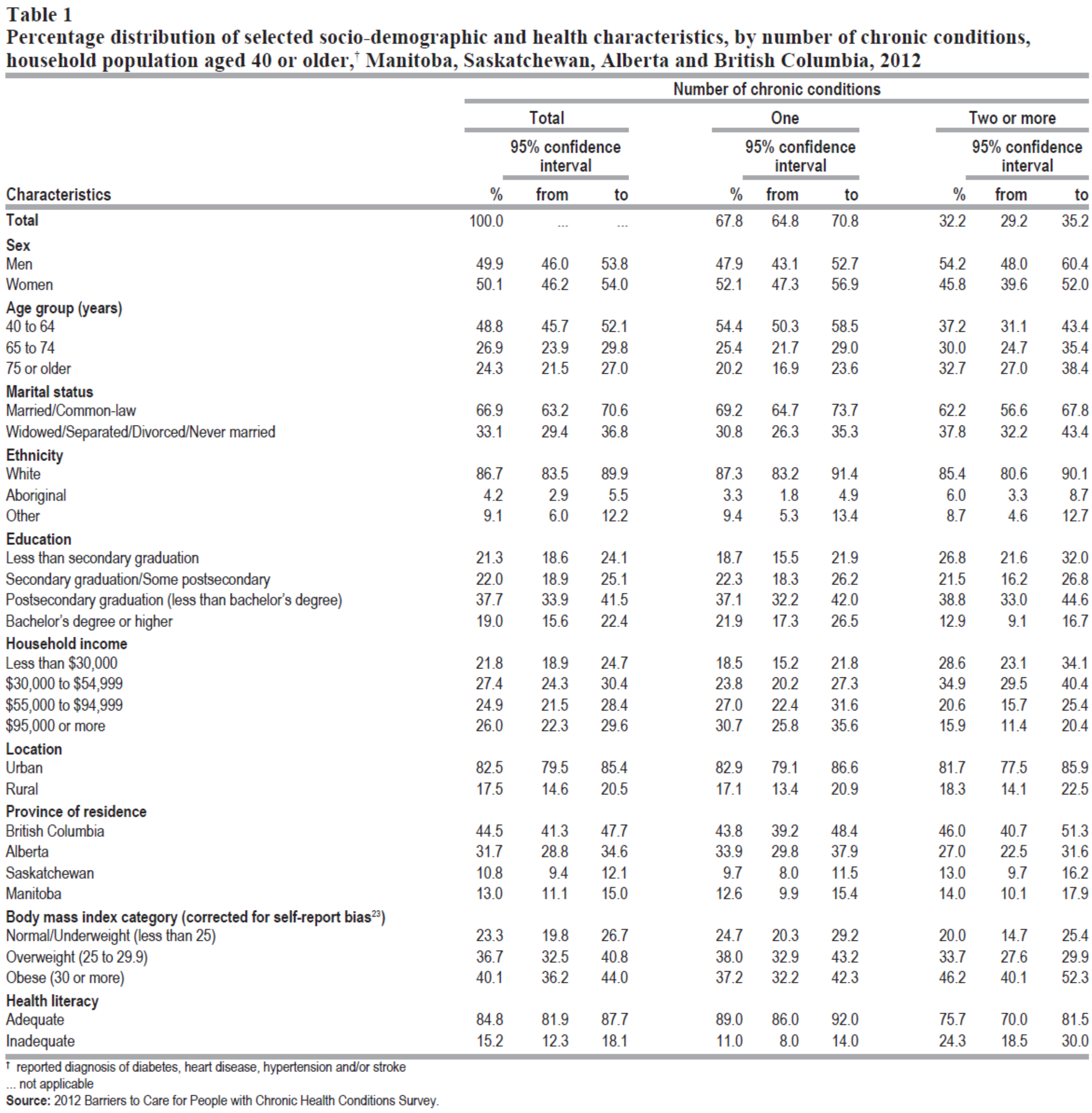

Table 1

Percentage distribution of selected socio-demographic and health characteristics, by number of chronic conditions, household population aged 40 or older,[†] Manitoba, Saskatchewan, Alberta and British Columbia, 2012

	Number of chronic conditions								
	Total			One			Two or more		
		95% confidence interval			95% confidence interval			95% confidence interval	
Characteristics	%	from	to	%	from	to	%	from	to
Total	100.0	...	...	67.8	64.8	70.8	32.2	29.2	35.2
Sex									
Men	49.9	46.0	53.8	47.9	43.1	52.7	54.2	48.0	60.4
Women	50.1	46.2	54.0	52.1	47.3	56.9	45.8	39.6	52.0
Age group (years)									
40 to 64	48.8	45.7	52.1	54.4	50.3	58.5	37.2	31.1	43.4
65 to 74	26.9	23.9	29.8	25.4	21.7	29.0	30.0	24.7	35.4
75 or older	24.3	21.5	27.0	20.2	16.9	23.6	32.7	27.0	38.4
Marital status									
Married/Common-law	66.9	63.2	70.6	69.2	64.7	73.7	62.2	56.6	67.8
Widowed/Separated/Divorced/Never married	33.1	29.4	36.8	30.8	26.3	35.3	37.8	32.2	43.4
Ethnicity									
White	86.7	83.5	89.9	87.3	83.2	91.4	85.4	80.6	90.1
Aboriginal	4.2	2.9	5.5	3.3	1.8	4.9	6.0	3.3	8.7
Other	9.1	6.0	12.2	9.4	5.3	13.4	8.7	4.6	12.7
Education									
Less than secondary graduation	21.3	18.6	24.1	18.7	15.5	21.9	26.8	21.6	32.0
Secondary graduation/Some postsecondary	22.0	18.9	25.1	22.3	18.3	26.2	21.5	16.2	26.8
Postsecondary graduation (less than bachelor's degree)	37.7	33.9	41.5	37.1	32.2	42.0	38.8	33.0	44.6
Bachelor's degree or higher	19.0	15.6	22.4	21.9	17.3	26.5	12.9	9.1	16.7
Household income									
Less than $30,000	21.8	18.9	24.7	18.5	15.2	21.8	28.6	23.1	34.1
$30,000 to $54,999	27.4	24.3	30.4	23.8	20.2	27.3	34.9	29.5	40.4
$55,000 to $94,999	24.9	21.5	28.4	27.0	22.4	31.6	20.6	15.7	25.4
$95,000 or more	26.0	22.3	29.6	30.7	25.8	35.6	15.9	11.4	20.4
Location									
Urban	82.5	79.5	85.4	82.9	79.1	86.6	81.7	77.5	85.9
Rural	17.5	14.6	20.5	17.1	13.4	20.9	18.3	14.1	22.5
Province of residence									
British Columbia	44.5	41.3	47.7	43.8	39.2	48.4	46.0	40.7	51.3
Alberta	31.7	28.8	34.6	33.9	29.8	37.9	27.0	22.5	31.6
Saskatchewan	10.8	9.4	12.1	9.7	8.0	11.5	13.0	9.7	16.2
Manitoba	13.0	11.1	15.0	12.6	9.9	15.4	14.0	10.1	17.9
Body mass index category (corrected for self-report bias[23])									
Normal/Underweight (less than 25)	23.3	19.8	26.7	24.7	20.3	29.2	20.0	14.7	25.4
Overweight (25 to 29.9)	36.7	32.5	40.8	38.0	32.9	43.2	33.7	27.6	29.9
Obese (30 or more)	40.1	36.2	44.0	37.2	32.2	42.3	46.2	40.1	52.3
Health literacy									
Adequate	84.8	81.9	87.7	89.0	86.0	92.0	75.7	70.0	81.5
Inadequate	15.2	12.3	18.1	11.0	8.0	14.0	24.3	18.5	30.0

[†] reported diagnosis of diabetes, heart disease, hypertension and/or stroke

... not applicable

Source: 2012 Barriers to Care for People with Chronic Health Conditions Survey.

Reproduced from: Campbell et al. (2014). *Health Reports*, 25(5):3-12.

Table 2.2

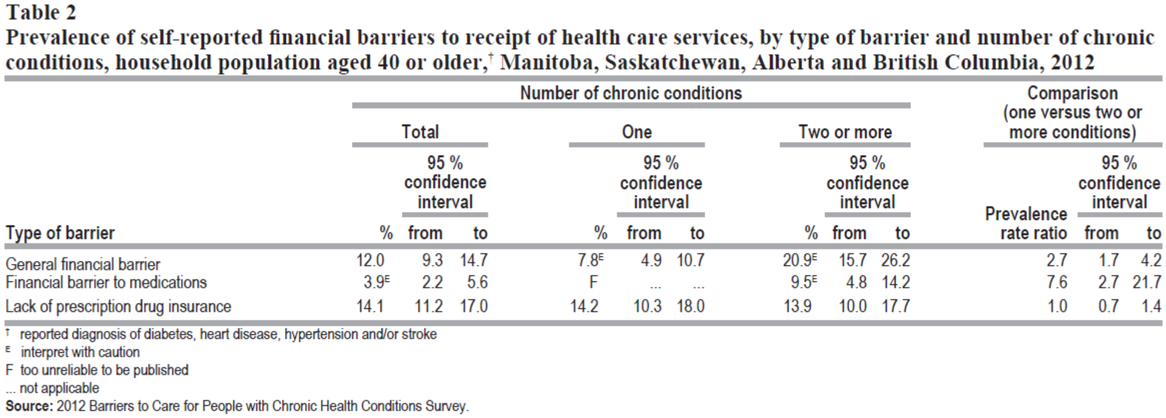

Table 2
Prevalence of self-reported financial barriers to receipt of health care services, by type of barrier and number of chronic conditions, household population aged 40 or older,[†] Manitoba, Saskatchewan, Alberta and British Columbia, 2012

	Number of chronic conditions									Comparison (one versus two or more conditions)		
	Total			One			Two or more					
		95 % confidence interval			95 % confidence interval			95 % confidence interval			95 % confidence interval	
Type of barrier	%	from	to	%	from	to	%	from	to	Prevalence rate ratio	from	to
General financial barrier	12.0	9.3	14.7	7.8[E]	4.9	10.7	20.9[E]	15.7	26.2	2.7	1.7	4.2
Financial barrier to medications	3.9[E]	2.2	5.6	F	...	...	9.5[E]	4.8	14.2	7.6	2.7	21.7
Lack of prescription drug insurance	14.1	11.2	17.0	14.2	10.3	18.0	13.9	10.0	17.7	1.0	0.7	1.4

[†] reported diagnosis of diabetes, heart disease, hypertension and/or stroke
[E] interpret with caution
F too unreliable to be published
... not applicable
Source: 2012 Barriers to Care for People with Chronic Health Conditions Survey.

Reproduced from: Campbell et al. (2014). *Health Reports*, 25(5):3-12.

Table 2.3

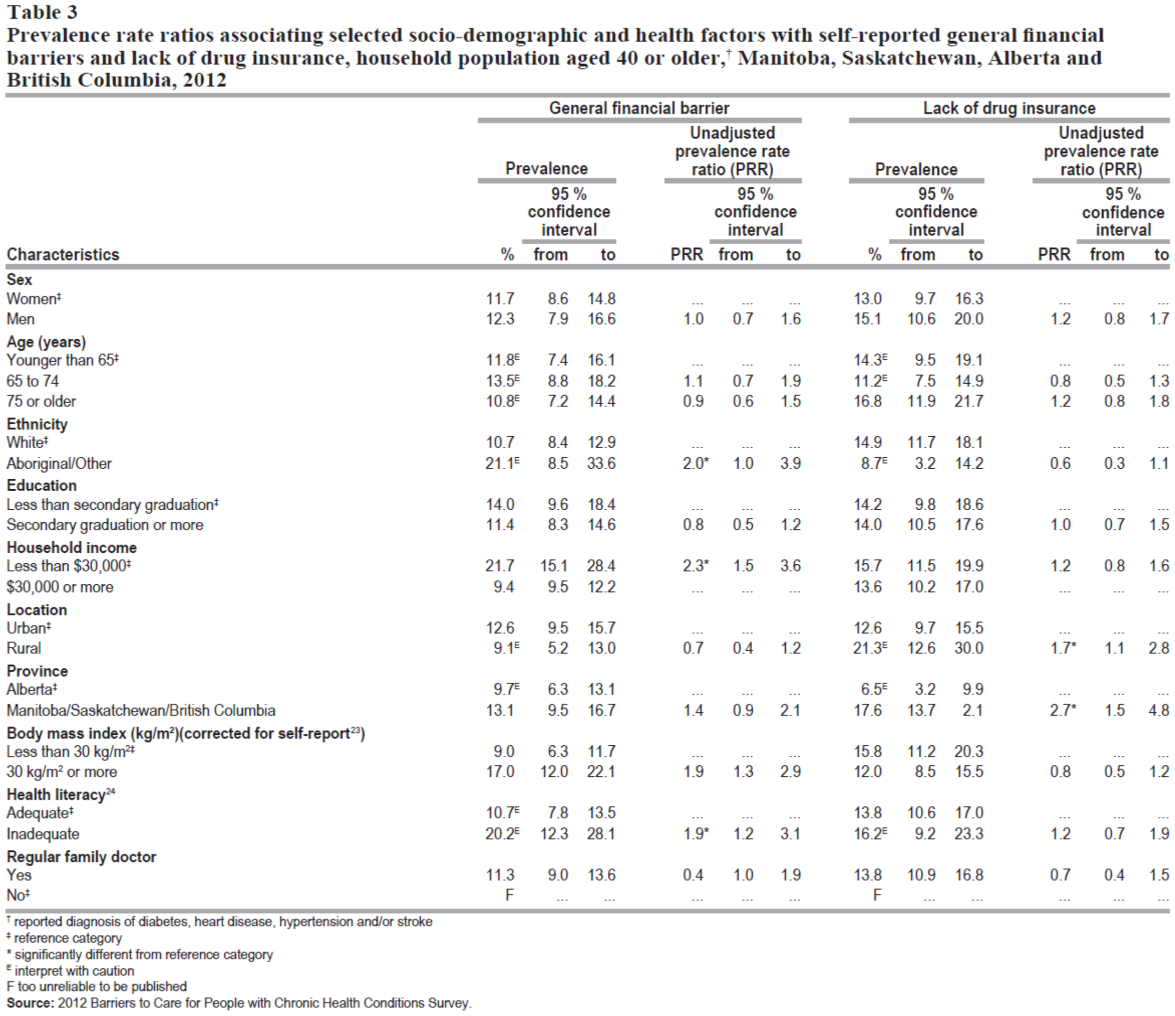

Table 3

Prevalence rate ratios associating selected socio-demographic and health factors with self-reported general financial barriers and lack of drug insurance, household population aged 40 or older,[†] Manitoba, Saskatchewan, Alberta and British Columbia, 2012

	General financial barrier						Lack of drug insurance					
	Prevalence			Unadjusted prevalence rate ratio (PRR)			Prevalence			Unadjusted prevalence rate ratio (PRR)		
		95 % confidence interval			95 % confidence interval			95 % confidence interval			95 % confidence interval	
Characteristics	%	from	to	PRR	from	to	%	from	to	PRR	from	to
Sex												
Women[‡]	11.7	8.6	14.8	...	...	...	13.0	9.7	16.3	...	...	...
Men	12.3	7.9	16.6	1.0	0.7	1.6	15.1	10.6	20.0	1.2	0.8	1.7
Age (years)												
Younger than 65[‡]	11.8[E]	7.4	16.1	...	...	...	14.3[E]	9.5	19.1	...	...	...
65 to 74	13.5[E]	8.8	18.2	1.1	0.7	1.9	11.2[E]	7.5	14.9	0.8	0.5	1.3
75 or older	10.8[E]	7.2	14.4	0.9	0.6	1.5	16.8	11.9	21.7	1.2	0.8	1.8
Ethnicity												
White[‡]	10.7	8.4	12.9	...	...	...	14.9	11.7	18.1	...	...	...
Aboriginal/Other	21.1[E]	8.5	33.6	2.0*	1.0	3.9	8.7[E]	3.2	14.2	0.6	0.3	1.1
Education												
Less than secondary graduation[‡]	14.0	9.6	18.4	...	...	...	14.2	9.8	18.6	...	...	...
Secondary graduation or more	11.4	8.3	14.6	0.8	0.5	1.2	14.0	10.5	17.6	1.0	0.7	1.5
Household income												
Less than $30,000[‡]	21.7	15.1	28.4	2.3*	1.5	3.6	15.7	11.5	19.9	1.2	0.8	1.6
$30,000 or more	9.4	9.5	12.2	...	...	...	13.6	10.2	17.0	...	...	...
Location												
Urban[‡]	12.6	9.5	15.7	...	...	...	12.6	9.7	15.5	...	...	...
Rural	9.1[E]	5.2	13.0	0.7	0.4	1.2	21.3[E]	12.6	30.0	1.7*	1.1	2.8
Province												
Alberta[‡]	9.7[E]	6.3	13.1	...	...	...	6.5[E]	3.2	9.9	...	...	...
Manitoba/Saskatchewan/British Columbia	13.1	9.5	16.7	1.4	0.9	2.1	17.6	13.7	2.1	2.7*	1.5	4.8
Body mass index (kg/m^2)(corrected for self-report[23])												
Less than 30 kg/m^2[‡]	9.0	6.3	11.7	...	...	...	15.8	11.2	20.3	...	...	...
30 kg/m^2 or more	17.0	12.0	22.1	1.9	1.3	2.9	12.0	8.5	15.5	0.8	0.5	1.2
Health literacy[24]												
Adequate[‡]	10.7[E]	7.8	13.5	...	...	...	13.8	10.6	17.0	...	...	...
Inadequate	20.2[E]	12.3	28.1	1.9*	1.2	3.1	16.2[E]	9.2	23.3	1.2	0.7	1.9
Regular family doctor												
Yes	11.3	9.0	13.6	0.4	1.0	1.9	13.8	10.9	16.8	0.7	0.4	1.5
No[‡]	F	...	...	...	...	...	F	...	...	...	...	...

[†] reported diagnosis of diabetes, heart disease, hypertension and/or stroke

[‡] reference category

* significantly different from reference category

[E] interpret with caution

F too unreliable to be published

Source: 2012 Barriers to Care for People with Chronic Health Conditions Survey.

Reproduced from: Campbell et al. (2014). *Health Reports*, 25(5):3-12.

Table 2.4

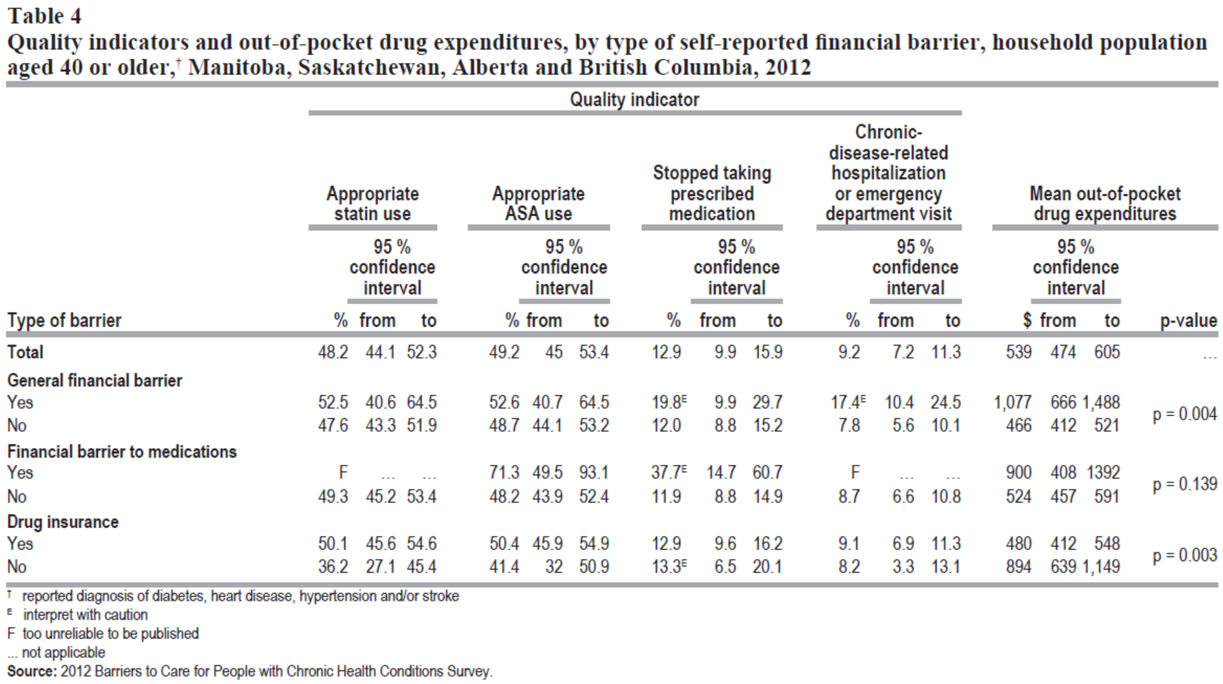

Table 4

Quality indicators and out-of-pocket drug expenditures, by type of self-reported financial barrier, household population aged 40 or older,[†] Manitoba, Saskatchewan, Alberta and British Columbia, 2012

	Quality indicator															
	Appropriate statin use			Appropriate ASA use			Stopped taking prescribed medication			Chronic-disease-related hospitalization or emergency department visit			Mean out-of-pocket drug expenditures			
		95 % confidence interval			95 % confidence interval			95 % confidence interval			95 % confidence interval			95 % confidence interval		
Type of barrier	%	from	to	%	from	to	%	from	to	%	from	to	$	from	to	p-value
Total	48.2	44.1	52.3	49.2	45	53.4	12.9	9.9	15.9	9.2	7.2	11.3	539	474	605	...
General financial barrier																
Yes	52.5	40.6	64.5	52.6	40.7	64.5	19.8^{E}	9.9	29.7	17.4^{E}	10.4	24.5	1,077	666	1,488	p = 0.004
No	47.6	43.3	51.9	48.7	44.1	53.2	12.0	8.8	15.2	7.8	5.6	10.1	466	412	521	
Financial barrier to medications																
Yes	F	...	...	71.3	49.5	93.1	37.7^{E}	14.7	60.7	F	...	...	900	408	1392	p = 0.139
No	49.3	45.2	53.4	48.2	43.9	52.4	11.9	8.8	14.9	8.7	6.6	10.8	524	457	591	
Drug insurance																
Yes	50.1	45.6	54.6	50.4	45.9	54.9	12.9	9.6	16.2	9.1	6.9	11.3	480	412	548	p = 0.003
No	36.2	27.1	45.4	41.4	32	50.9	13.3^{E}	6.5	20.1	8.2	3.3	13.1	894	639	1,149	

[†] reported diagnosis of diabetes, heart disease, hypertension and/or stroke

[E] interpret with caution

F too unreliable to be published

... not applicable

Source: 2012 Barriers to Care for People with Chronic Health Conditions Survey.

Reproduced from: Campbell et al. (2014). *Health Reports*, 25(5):3-12.

Table 2.5

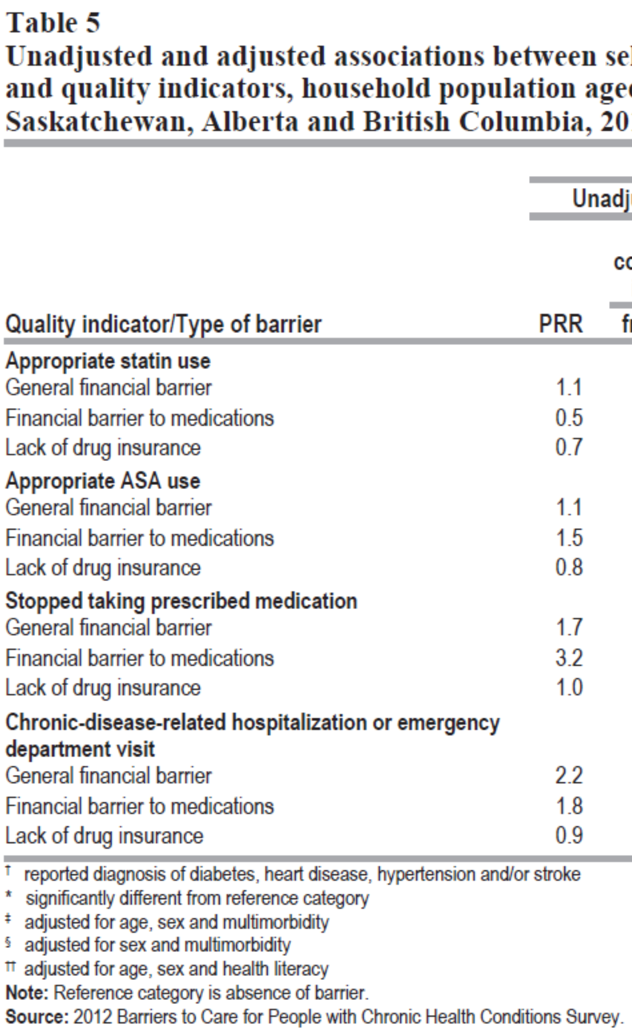

Table 5
Unadjusted and adjusted associations between self-reported financial barriers and quality indicators, household population aged 40 or older,[†] Manitoba, Saskatchewan, Alberta and British Columbia, 2012

	Prevalence rate ratio (PRR)					
	Unadjusted			Adjusted		
		95 % confidence interval			95 % confidence interval	
Quality indicator/Type of barrier	PRR	from	to	PRR	from	to
Appropriate statin use						
General financial barrier	1.1	0.9	1.4	1.0‡	0.8	1.2
Financial barrier to medications	0.5	0.3	1.0	0.5‡*	0.3	0.9
Lack of drug insurance	0.7	0.6	0.9	0.7‡*	0.6	0.9
Appropriate ASA use						
General financial barrier	1.1	0.8	1.4	1.0‡	0.8	1.2
Financial barrier to medications	1.5	1.0	2.1	1.3§	0.9	1.8
Lack of drug insurance	0.8	0.7	1.1	0.8‡	0.7	1.0
Stopped taking prescribed medication						
General financial barrier	1.7	0.9	3.1	1.7††	0.9	3.1
Financial barrier to medications	3.2	1.2	6.7	3.5††*	1.7	7.3
Lack of drug insurance	1.0	0.6	1.9	1.1††	0.6	2.0
Chronic-disease-related hospitalization or emergency department visit						
General financial barrier	2.2	1.3	3.8	1.7‡*	1.0	2.9
Financial barrier to medications	1.8	0.8	4.4	1.1‡	0.5	2.8
Lack of drug insurance	0.9	0.5	1.8	0.9‡	0.5	1.7

† reported diagnosis of diabetes, heart disease, hypertension and/or stroke
* significantly different from reference category
‡ adjusted for age, sex and multimorbidity
§ adjusted for sex and multimorbidity
†† adjusted for age, sex and health literacy
Note: Reference category is absence of barrier.
Source: 2012 Barriers to Care for People with Chronic Health Conditions Survey.

Reproduced from: Campbell et al. (2014). *Health Reports*, 25(5):3-12.

Table 2.6

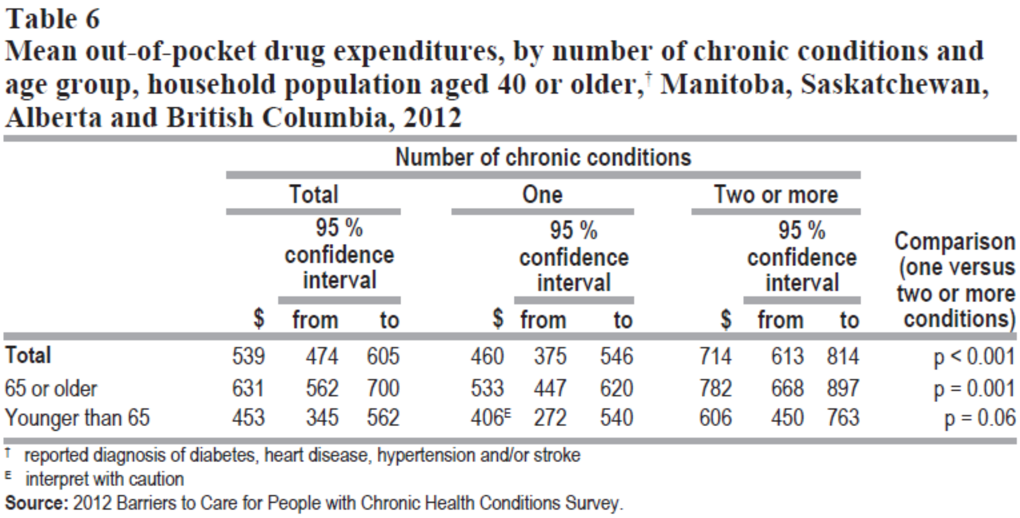

Table 6
Mean out-of-pocket drug expenditures, by number of chronic conditions and age group, household population aged 40 or older,[†] Manitoba, Saskatchewan, Alberta and British Columbia, 2012

	Number of chronic conditions									
	Total			One			Two or more			
		95 % confidence interval			95 % confidence interval			95 % confidence interval		Comparison (one versus two or more conditions)
	$	from	to	$	from	to	$	from	to	
Total	539	474	605	460	375	546	714	613	814	$p < 0.001$
65 or older	631	562	700	533	447	620	782	668	897	$p = 0.001$
Younger than 65	453	345	562	406[E]	272	540	606	450	763	$p = 0.06$

[†] reported diagnosis of diabetes, heart disease, hypertension and/or stroke

[E] interpret with caution

Source: 2012 Barriers to Care for People with Chronic Health Conditions Survey.

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Appendix 2A

Barriers to Care for People with Chronic Health Conditions survey questions

Exposures/Financial barriers

Perceived general financial barrier:

"In the past 12 months, how often did you have difficulty paying for services, equipment, medications for chronic conditions?"

Yes: always, often, sometimes No: rarely, never

Financial barrier to drugs:

"In the past 12 months, how often were you unable to access medications for your chronic condition due to cost?"

Yes: always, often, sometimes No: rarely, never

Lack of drug insurance

"Do you currently have insurance that covers all or part of the cost of prescription medications?"

Outcomes:

Use of statins:

"In the past month, did you take prescription medication such as Crestor, Lipitor or Zocor to control blood cholesterol?"

Use of acetylsalicylic acid (ASA):

"In the past month, did you take aspirin or other ASA (acetylsalicylic acid) medication every day or every second day?"

Adherence to prescribed medication:

"Over the past 12 months, have you ever stopped taking one or more of your drugs as prescribed for a week or more?"

Out-of-pocket expenditures:

"In the past 12 months, what were the out-of-pocket costs for your prescribed medicines, drugs and pharmaceutical products? Estimate the costs incurred by you. Include amounts not covered by insurance, such as exclusions, deductibles and expenses over limits. Exclude payments for which you have been or will be reimbursed. If it is easier for you, estimate your out-of-pocket costs in a 3-month period."

Chronic condition- related emergency room visit:

"How many times have you personally used a hospital emergency department for your condition in the past 12 months?"

Chronic condition- related hospital admission:

"In the past 12 months, have you been a patient overnight in a hospital for your condition?"

Covariates:

Regular medical doctor:

"Do you have a regular medical doctor?"

Self-perceived health:

"In general, would you say your health is . . . ?"

At least very good: excellent, very good Less than very good: good, fair, poor

Self-perceived mental health:

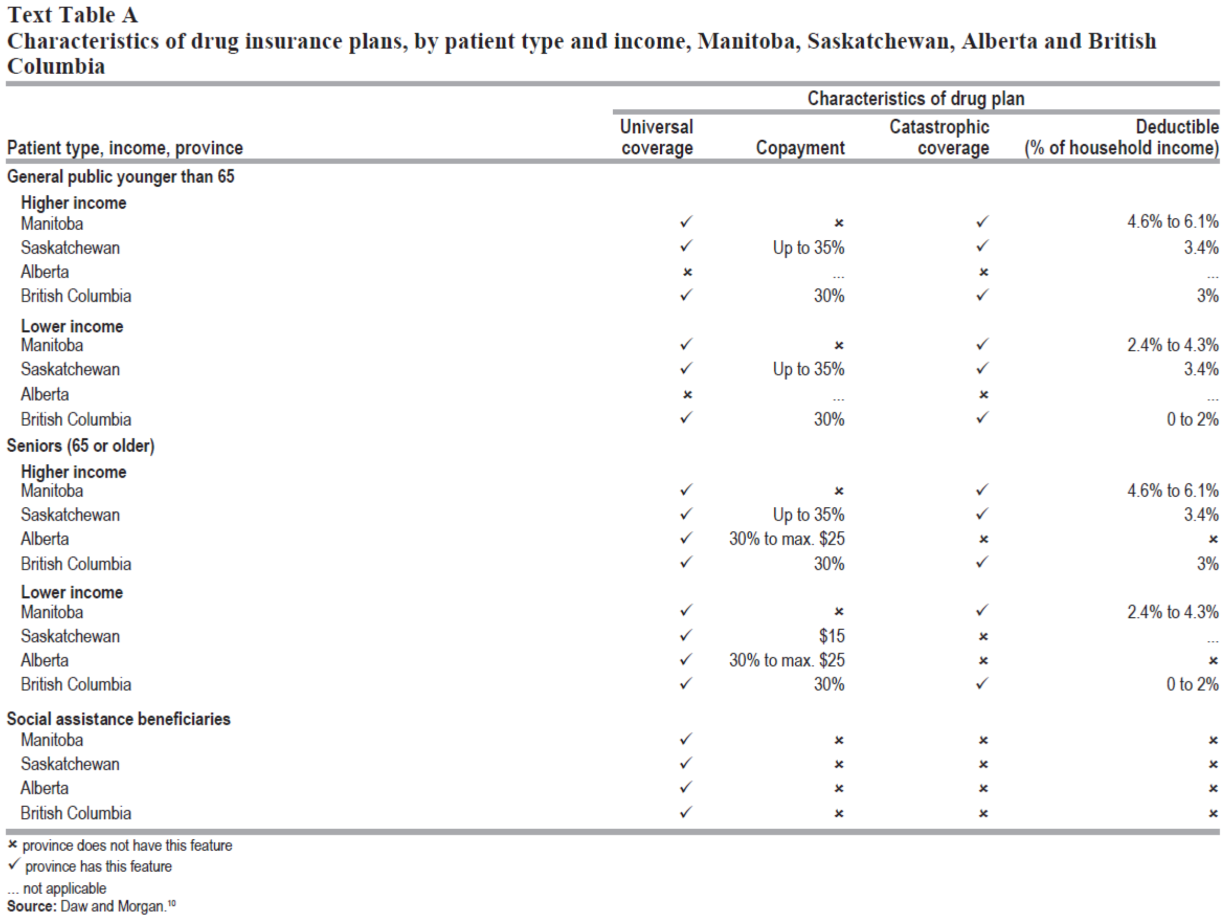
"In general, would you say your mental health is . . . ?"

At least very good: excellent, very good Less than very good: good, fair, poor

Inadequate health literacy

Imputed variable based on validated 3-item questionnaire

Appendix 2B



Text Table A
Characteristics of drug insurance plans, by patient type and income, Manitoba, Saskatchewan, Alberta and British Columbia

Patient type, income, province	Universal coverage	Copayment	Catastrophic coverage	Deductible (% of household income)
	Characteristics of drug plan			
General public younger than 65				
Higher income				
Manitoba	✓	×	✓	4.6% to 6.1%
Saskatchewan	✓	Up to 35%	✓	3.4%
Alberta	×	...	×	...
British Columbia	✓	30%	✓	3%
Lower income				
Manitoba	✓	×	✓	2.4% to 4.3%
Saskatchewan	✓	Up to 35%	✓	3.4%
Alberta	×	...	×	...
British Columbia	✓	30%	✓	0 to 2%
Seniors (65 or older)				
Higher income				
Manitoba	✓	×	✓	4.6% to 6.1%
Saskatchewan	✓	Up to 35%	✓	3.4%
Alberta	✓	30% to max. $25	×	×
British Columbia	✓	30%	✓	3%
Lower income				
Manitoba	✓	×	✓	2.4% to 4.3%
Saskatchewan	✓	$15	×	...
Alberta	✓	30% to max. $25	×	×
British Columbia	✓	30%	✓	0 to 2%
Social assistance beneficiaries				
Manitoba	✓	×	×	×
Saskatchewan	✓	×	×	×
Alberta	✓	×	×	×
British Columbia	✓	×	×	×

× province does not have this feature
✓ province has this feature
... not applicable
Source: Daw and Morgan.[10]

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CHAPTER 3:

THE ASSOCIATION BETWEEN PERCEIVED FINANCIAL BARRIERS AND OBJECTIVELY DOCUMENTED ADVERSE CLINICAL OUTCOMES USING A NOVEL LINKAGE OF NATIONAL SURVEY AND ADMINISTRATIVE DATA

The study we described in the previous chapter was useful for understanding the prevalence of perceived financial barriers in a Canadian population, and describing those who most commonly face financial barriers. We also showed some interesting associations between perceived financial barriers and outcomes of potential interest (i.e. increased use of emergency department and inpatient services for chronic diseases). However, this study was limited by the cross-sectional nature and reliance on self-report survey data for outcome ascertainment, which make the findings subject to numerous biases.

We undertook the study that we describe in chapter 3 to overcome some of the above limitations with the goal of confirming and extending the findings from the previous study using a linked dataset combining survey data (to identify those with various financial barriers) with administrative data (for longitudinal and objective outcome ascertainment).

This chapter is published as:

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3.1 Abstract

Background

Some patients with cardiovascular-related chronic diseases such as diabetes and heart disease report financial barriers to achieving optimal health. Previous surveys report that the perception of having a financial barrier is associated with self-reported adverse clinical outcomes. We sought to confirm these findings using linked survey and administrative data to determine, among patients with cardiovascular-related chronic diseases, if there is an association between perceived financial barriers and the outcomes of: (1) disease-related hospitalizations, (2) all-cause mortality, and (3) inpatient healthcare costs.

Methods

We used 10 cycles of the nationally representative Canadian Community Health Survey (administered between 2000 and 2012) to identify a cohort of adults age 45 and older with hypertension, diabetes, heart disease or stroke. Perceived financial barriers to various aspects of chronic disease care and self-management were identified (including medications, healthy food, home care) from the survey questions. The cohort was linked to administrative data sources for outcome ascertainment (Discharge Abstract Database, Canadian Mortality Database, Patient Cost Estimator). We utilized negative binomial regression techniques, adjusting for potential confounding variables (age, sex, education, multimorbidity, smoking status), to assess for associations between perceived financial barriers and rates of disease-related hospitalization and all-cause mortality. We used gross costing methodology and a variety of modelling approaches to assess the impact of financial barriers on hospital costs.

Results

We identified a cohort of 120,752 individuals over the age of 45 years with one or more of hypertension, diabetes, heart disease or stroke. One in ten experienced financial barriers to at least one aspect of their care, with the two most common being financial barriers to accessing medications and healthy food. Even after adjustment, those with at least one financial barrier had an increased rate of disease-related hospitalization and mortality compared to those without financial barriers with adjusted incidence rate ratios of 1.36 (95% CI: 1.29-1.44) and 1.24 (1.16-1.32), respectively. Furthermore, having a financial barrier to care was associated with 30% higher inpatient costs, compared to those without financial barriers.

Discussion

After adjusting for relevant covariates, perceiving a financial barrier was associated with increased rates of hospitalization and mortality, and higher hospital costs, compared to those without financial barriers.

3.2 Background

As the populace in western countries continues to age, the prevalence of chronic diseases is also on the rise, with three-quarters of seniors reporting at least one chronic disease [1]. Cardiovascular-related chronic diseases are the leading cause of hospitalization [4], and also the preeminent cause of premature death and disability [3].

Patients in countries around the world experience financial barriers to the care they require to manage their chronic conditions [75]. In Canada, 10-12% of patients with chronic diseases face financial barriers [48][Chapter 2]. This is in spite of Canada's single payer health care system – which provides universal full coverage for physician and hospital services, but coverage for outpatient services, including medications, is inconsistent and has been described as a "patchwork" across Canada's provinces [27]. Canadians with cardiovascular-related chronic diseases who perceive financial barriers self-reported being 70% more likely to require emergency department visits and/or hospitalizations for their chronic diseases [Chapter 2]. Similar results have been reported in the United States, where Americans with financial barriers were more likely to report having a cardiac-related readmission to hospital following an initial myocardial infarction [54].

These prior studies are based on self-reported outcomes and may be prone to bias, as patients may not be able to accurately identify if their hospitalization was in fact related to their chronic disease. Only one previous small study examined the relationship between perceived financial barriers and an objectively measured outcome – recurrent cardiac events [55].

We hypothesized that chronic disease patients who experience financial barriers would have more hospitalizations, a higher mortality rate and would accrue higher healthcare costs than those without financial barriers. To overcome the limitations of prior studies in this area, we linked national survey data with administrative health data to assess for associations between perceived financial barriers and objectively documented disease-related hospitalizations (primary outcome), as well as all-cause mortality and costs associated with disease-related hospitalizations (secondary outcomes).

3.3 Methods

3.3.1 Study Context

Canada is a federation with considerable autonomy vested in individual provinces and territories. The delivery of health and healthcare insurance falls under the purview of provincial and territorial governments. Despite significant inter-provincial differences, Canada has had universal publicly-funded insurance for hospital and physician services since 1966 and 1972, respectively. Under the Canada Health Act (1982) Canadian citizens and residents have full access to these services without being compelled to pay point-of-care charges [24, 25].

Public insurance plans for other services, such as medications and allied healthcare, are not provided universally and differ between provinces [27]. Those who do qualify for public supplemental health insurance are often still left to contribute significantly to healthcare expenditures through copayments and deductibles [33].

Within this context, Canadians may encounter a variety of financial barriers to accessing care for their chronic conditions. Patients may face direct costs for non-insured services including medications, allied healthcare provider fees and home care. Patients may also face indirect costs associated with accessing services which are fully insured. For example, the costs that patients are required to pay for transportation, parking, and childcare, as well as lost income from time away from work may all be disincentives to attending physician appointments or completing laboratory investigations.

3.3.2 Data Sources

The data source for this project is a novel dataset which linked the 2000 to 2011 cycles of the Canadian Community Health Survey (CCHS) with the Discharge Abstract Database (1996-2013) and Canadian Mortality Database (2000-2011). The linkage was conducted by Statistics Canada using probabilistic methods based on common variables including date of birth, postal codes, sex, health insurance number and name [76, 77]. The linkage was conducted among CCHS respondents who agreed to link and share their information.

The CCHS is a national cross-sectional survey that has been conducted annually since 2000. The survey is administered by Statistics Canada and collects information on the health, health behaviours and health care use of the non-institutionalized population aged 12 years and older. The survey excludes full-time members of the Canadian Forces and residents of reserves and some remote areas, together representing about 4% of the target population [78]. The CCHS was first conducted in 2000/2001 (cycle 1), and again in 2003 (cycle 2) and 2005 (cycle 3), each time with a sample of size of approximately 130,000. Starting in 2007, the survey was conducted annually (sample size of 65,000). Response rates have ranged from 69.8% to 78.9% [79].

We also used responses to other Statistics Canada health surveys that have been administered to sub-samples of CCHS respondents to obtain greater detail on a variety of topics. These included: the 2007 Rapid Response module about prescription drug expenditures (PDERR) (n=10,500); the Survey of Living with Chronic Diseases in Canada (SLCDC) from 2009-hypertension (n=6338) and 2011-diabetes (n=3747); and the 2012 Barriers to Care for Persons with Chronic Health Conditions (BCPCHC) administered to respondents with chronic conditions living in four western provinces (n=1849).

The Discharge Abstract Database (DAD) captures administrative and clinical data for all patients discharged from acute care hospitals in Canada (excluding Quebec) [80]. The data are coded by trained hospital coders and transmitted to provincial/territorial ministries of health who forward it to the Canadian Institute for Health Information (CIHI) [80]. One most responsible diagnosis along with up to 24 secondary diagnoses are coded according to the International Classification of Disease framework [81]. Hospital records were available from April 1, 1996 to March 31, 2013. For each individual, the pertinent hospital information extracted included: (1) number of hospitalizations in the follow-up period; (2) the most responsible diagnosis documented for each hospitalization; (3) coronary revascularization procedures (percutaneous coronary intervention and coronary artery bypass grafting); (4) length of stay of each acute care hospitalization; and (5) gross costing information assigned to each hospitalization to permit linkage to costing data.

The Canadian Mortality Database (CMDB) collects “information annually from all provincial and territorial vital statistics registries on all deaths in Canada” [82]. Mortality data were available from January 1, 2000 to December 31, 2011.

Within the DAD, each hospital encounter is assigned to a Major Clinical Category (similar to diagnosis related grouping) and a more granular case-mix grouper (CMG) – which is a code assigned to each hospitalization based on intensity of resources required during that stay [17]. Since 2009, the Patient Cost Estimator (PCE), generated by CIHI, provides annualized tables of estimated mean costs associated with each CMG code [83]. Linkage via CMG code allows an estimation of costs associated with each inpatient encounter.

3.3.3 Study Design and Cohort Creation

We used an observational cohort design. Our cohort was defined by all CCHS respondents eligible for linkage, who were at least 45 years old at the time of survey administration, who self-reported having at least one of the chronic conditions of interest (heart disease, diabetes, stroke, hypertension), and were residents of one of the provinces that reported hospitalization data consistently throughout the entire follow-up period (i.e. all provinces except Manitoba, Quebec and the territories) (see Figure 3.1).

3.3.4 Variables

3.3.4.1 Exposure Definition

The exposure of interest was perceiving a financial or cost-related barrier to care as defined by responses to the health surveys. In our qualitative study [See Chapter 5], we identified that beyond simply medications, patients may experience financial barriers to a variety of goods and services that are required for disease self-management. These include: (1) medications (given that cost sharing is often required even when insured); (2) indirect costs related to use of covered healthcare provider visits and laboratory investigations as well as direct costs related to healthcare provider visits that are not universally covered (eye exams and dental care); (3) access to healthy food; (4) ability to make health behaviour modifications (i.e., physical activity, weight loss and smoking cessation); and (5) home care (only those ≥75 years of age were included for this barrier). Finally, within several cycles of the CCHS, individuals were also asked whether they had an unmet need for healthcare due to cost.

The survey questions used to define these exposures are found in Appendix 3A. Given that not all CCHS respondents were asked about all types of barriers, these were each analyzed as individual cohorts. We conducted a final analysis by combining all eligible individuals who noted at least one of the above financial barriers.

3.3.4.2 Outcome Definition

The primary outcome was disease-related hospitalization, defined as a stay of greater than 1-day duration in a Canadian acute care facility for which the most responsible diagnosis was coded as either a cardiovascular or diabetes-related cause, or during which the patient underwent coronary revascularization, defined using administrative data codes (Appendix 3B). The diagnosis coded as most responsible in the discharge abstract database is that which was responsible for the greatest portion of the length of stay [80]. In previous validation studies this diagnosis is more reliably coded than the other diagnoses which often represent comorbid conditions [84]. Hospitalizations with a duration less than one day were excluded as these are generally hospital day surgeries and procedures which are: a) less reliably captured in the administrative data; b) less likely to have pertinence to cardiovascular disease or diabetes, and c) more likely to represent a planned procedure (such as an elective diagnostic angiogram) than one representing a true event of interest. Furthermore, emergency department visits are not represented within the DAD.

The secondary outcomes of interest were all-cause mortality – defined from the CMDB; and inpatient healthcare costs for disease-related hospitalizations. Since validated hospital costing data was only available for those admitted over a three-year period (2010 to 2012), we used this data to first establish a mean cost per hospital-day for disease-related hospitalizations by dividing the sum of the estimated costs of all disease-related hospitalizations during this period by the total number of hospital days. We combined average cost per day with length of stay data for the entire cohort to yield an estimate of the costs associated with each disease-related hospitalization in the entire dataset.

3.3.4.3 Covariates

Based on prior work we identified a number of covariates that have been shown to be independently associated with hospitalizations for chronic conditions and therefore important to consider as potential confounders [17]. These included: age, sex, smoking status, comorbidities, and socioeconomic status. Age, education, smoking status, and multimorbidity were included as categorical variables – as defined in Table 1. We also included mental health comorbidity, defined as anyone self-reporting a prior diagnosis of mood or anxiety disorders. Socioeconomic status was represented by level of educational attainment, as education has been shown to be among the most representative of overall socioeconomic status [85]. Furthermore, income was found to be very highly collinear with financial barriers, so education was chosen as the marker of socioeconomic status, though we did undertake sensitivity analyses that included income.

Finally, we assessed for effect modification by age using an interaction term (age category * financial barrier) and the corresponding Wald tests.

3.3.5 Statistical Analysis

As the follow-up time could vary for each participant (based on dates of cohort entry and death) we calculated rates of events to take into account differing observation times. We defined the index date as the first day of administration of the cycle of the survey to which the participant responded (for example Jan 1, 2010 for anyone completing the 2010 cycle). Since the perceived financial barrier and the chronic disease of interest were unlikely to be new at the time of the survey, we assessed the primary outcome over 5 years -- two years prior to the index date, as well as three years prospectively. For the mortality outcome, follow-up was from the time of survey administration to the date of death or end of follow-up for mortality data (Dec 31, 2011).

For the hospitalization outcome (count data), we initially fit Poisson regression models. We tested for overdispersion using the likelihood ratio test, and selected negative binomial models in such cases [86]. For the mortality outcome, we used modified Poisson regression models with robust standard errors to generate mortality rate ratios [87]. We present results for unadjusted, fully adjusted, and final reduced models after conducting backwards elimination procedures: covariates were sequentially removed from the model one at a time, those covariates whose removal changed the point estimate for the exposure by >10% were considered true confounders and were retained in final models (other than age and sex which, by default, were retained in all models). We calculated adjusted rates from the reduced models, by adjusting to the overall means/proportions of the covariates.

For the costing analysis, we fit various models, given the well documented difficulty analyzing skewed cost data [88]. We started with ordinary least squares (OLS) linear regression, but also considered other generalized linear models (GLM). We used several GLM models, and used the modified Park Test [89] to determine which GLM distribution provided the best fit for our data. According to the assessment of the fit of these various models, we found that the GLM with a Poisson distribution and log link was most appropriate.

Cases with missing data were left as missing in analyses – no imputation of data was undertaken. People with missing exposure statuses, who were not asked the pertinent questions were not considered exposed or unexposed but were excluded from the analysis altogether. All analyses were conducted with Stata v.14.0 (College Station, Texas). Ethics approval was received from the University of Calgary's Conjoint Health Research Ethics Board and all procedures were followed in accordance with the ethics board and Statistics Canada.

3.4 Results

From the initial 751,189 CCHS respondents, we identified 120,752 individuals who met all study inclusion criteria (Figure 3.1). The total follow-up time for the hospitalization outcome was 586,900 patient years (Avg: 4.86 years/participant) and for the mortality outcome was 573,200 patient years (Avg: 4.75 years/participant).

Overall, study participants were predominantly white, married, urban-dwelling and female (Table 3.1). Participants with a financial barrier were considerably different from those with no financial barrier across all clinical and sociodemographic characteristics, and were more likely to be younger, unmarried, female, with low income, lower education, multimorbidity and worse self-perceived health.

The barriers most commonly cited were financial barriers to accessing healthy food (8.9% of those asked these questions) and medications (7.5% of those asked this question) (Table 3.2). Overall, 10.2% of respondents perceived a financial barrier to at least one aspect of their chronic disease management, though this is likely an underestimate as not all respondents were asked about financial barriers to all relevant aspects of self-management.

We found that after adjustment and model reduction, there was a significant positive association between experiencing financial barriers and both clinical outcomes of interest (Table 3.2). Those with at least one financial barrier had a 36% higher rate of hospitalization for disease-related causes than those without financial barriers (IRR 1.36, 95%CI 1.29-1.44). Except for financial barriers to health behavior modification, the individual financial barriers were all significantly associated with disease related hospitalizations with incidence rate ratios ranging from 1.24 (financial barriers to seeing healthcare providers or having tests) to 1.68 (financial barrier to eating healthy food) (Figure 3.2). Despite concern regarding collinearity and overmodelling with the inclusion of income in the models, we conducted sensitivity analyses by adding income to the final reduced models (Table 3.3). In this analysis, we demonstrated that some barriers, including the aggregated exposure, was attenuated but remained significantly associated with the primary outcome, even after adjusting for income (IRR 1.16, 95%CI: 1.09-1.23).

Those with financial barriers had an adjusted mortality rate that was 24% higher than those without financial barriers (IRR 1.24, 95%CI: 1.16-1.32). The individual barriers that were significantly associated with mortality included financial barriers to homecare, healthcare providers/tests and healthy food (Table 3.2).

Using OLS linear regression, in the costing analysis, we demonstrated that on average those with financial barriers incurred inpatient disease-related healthcare costs of $1724 over a five-year period, compared to $1360 for those without financial barriers. Having a financial barrier was associated with excess costs of approximately $364/patient over the five-year observation period (95% CI: $204-524). We contrasted this finding with the theoretically ideal model (GLM with Poisson distribution and log link), which demonstrated that those with financial barriers had 37% higher inpatient costs – very similar to the estimate produced using OLS linear regression (Table 3.4).

3.5 Discussion

Using a novel national dataset comprised of linked administrative and survey data for adults with cardiovascular-related chronic diseases, we found that the perception of a financial barrier to care was associated with a 36% higher rate of cardiovascular- or diabetes-related hospitalization and a 24% higher mortality rate. This is the first time that data sources with objective outcomes have been used to demonstrate that chronic disease patients with perceived financial barriers have worse outcomes and higher resource utilization, as previous studies have relied solely upon self-reported outcomes.

The fact that our overall exposure (at least 1 financial barrier) retained a significant positive association with disease-related hospitalization despite adjustment for income suggests that financial barriers may be relevant, at least for some aspects of chronic disease care, regardless of income level. Consistent with qualitative research in this area [see Chapter 4], financial barriers appear to impact even some patients with higher income while they may not be experienced universally by those with lower income (due largely to greater availability of subsidies and public support). This suggests that a patient's perception of a financial barrier might be used in clinical and research settings as an additional measure to be used alongside standard measures of socioeconomic status (i.e. income, education, social status).

Previous studies using the CCHS have estimated that the prevalence of cardiovascular-related conditions in the Canadian adult population are: 1.2%-stroke, 5.0%-diabetes, 5.4%-heart disease and 15.5 %-hypertension [90]. Accounting for co-occurrence of these conditions, it is likely that approximately 1 in 5 Canadian adults is affected by at least one of these conditions (i.e. 5.6 million people)[91]. We have also shown that of those with these chronic conditions, 10% perceive financial barriers (i.e. 560,000 people) [see Chapter 2]. Since having a financial barrier was associated with an excess hospital cost of $364 per person, Canadian hospital costs may be higher by $200 million dollars over 5 years for those who experience financial barriers. Of note, this only includes the excess costs associated with disease-related hospitalizations, which account for only approximately 20% of all hospitalizations – therefore the total excess costs may be significantly higher than this estimate.

This study corroborates findings from the previously conducted self-report studies: that perceived financial barriers are associated with a higher likelihood of requiring hospital care for chronic conditions [54][Chapter 2]. The observed associations for those with financial barriers is potentially mediated by cost-related non-adherence to both medical therapies [48] and health behaviour modification [92], which result in poorer control of chronic diseases and ultimately culminate in hospitalizations and death. The demonstrable association with adverse outcomes and increased costs seen in this study may provide an impetus for policy makers to seek to invest in interventions which minimize the occurrence and/or impact of financial barriers, such as copayment elimination [57], patient navigation [93], and patient self-advocacy education [94] – though the true effectiveness of these interventions remains inconclusive.

There were some unexpected discrepant findings. Specifically, we found that some financial barriers had a (non-significant) trend towards being protective against mortality (i.e., perceived unmet needs and barriers to health behaviour modification). This may reflect that those more likely to acknowledge having an unmet need or a barrier to health behavior modification may be those who are more engaged in their care, or who have higher degrees of patient activation and/or health literacy – which may be the factor that confers the lower risk of mortality. This assertion is supported by a previous study that found no association between perceived unmet need and adverse outcomes [90], suggesting that there may be an offsetting of risk between those who truly have an unmet need and those who may simply be more sensitive to perceiving an unmet need because they are more active participants in their care.

There are several strengths of this study, including the use of a novel dataset linking national surveys containing detailed information on a variety of data not collected routinely, and high quality health administrative data containing objective information on hospital admissions and resource use. There are also limitations of this work. Firstly, as this is an observational study there is potential for residual confounding (e.g., we had no appropriate measure of disease severity), although we could adjust for many of the most important confounders in our regression models. Secondly, some types of financial barriers were only asked of a relatively small subset of the total sample (e.g. financial barriers to medications), making these analyses underpowered to detect significant associations with the less common outcome of mortality rate. Due to the high prevalence of financial barriers to obtaining healthy food and the large proportion of respondents who were asked these questions, the associations between having any financial barrier and the outcomes are likely being driven principally by this barrier. However, it is reassuring that when the other types of financial barriers are studied in isolation from each other, consistent associations are found (Figure 3.2) – though some are underpowered. While the outcomes data were longitudinal, the exposure was determined cross-sectionally in the survey – which does not allow for an assessment of how enduring financial barriers may be. Due to inconsistent reporting procedures, we were unable to include data from residents of several jurisdictions (5 provinces & territories). Finally, as this study only included Canadian patients, these findings apply specifically to Canadian patients with cardiovascular-related chronic diseases. A number of chronic disease patients in other Western nations report facing financial barriers to various aspects of chronic disease care [75]. Since the United States has an even less comprehensive medication insurance program than Canada, our findings are likely to apply in the US context as well.

In conclusion, using a novel dataset linking detailed national surveys with high quality health administrative data, we found that after adjustment, perceiving a financial barrier was associated with higher rates of both disease-related hospitalization and mortality for patients with chronic disease. These results may be used by health services researchers to inform the design of interventions to address financial barriers, with the goal of ultimately minimizing the prevalence or mitigating the impact of financial barriers on important outcomes for both patients and healthcare systems.

3.6 Tables & Figures

Figure 3.1: Cohort Formation

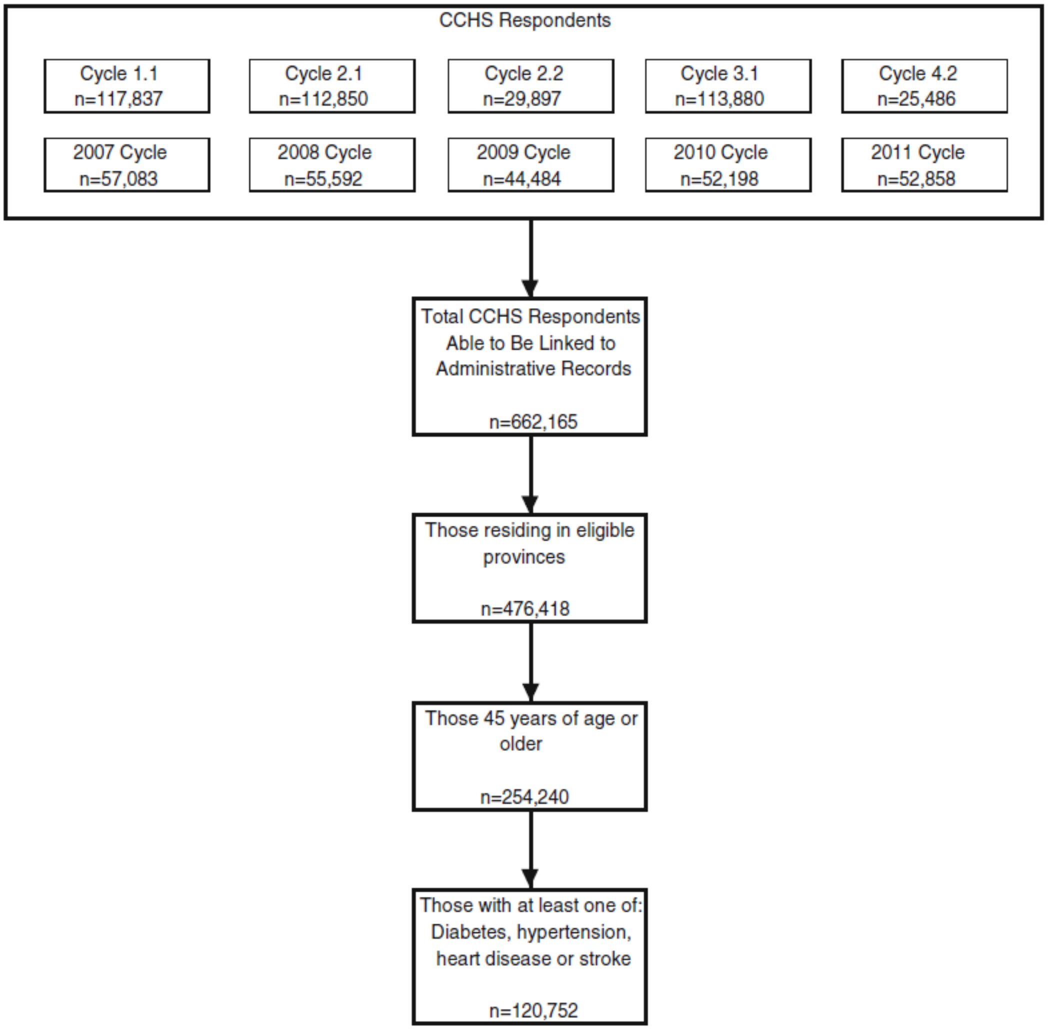

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Table 3.1

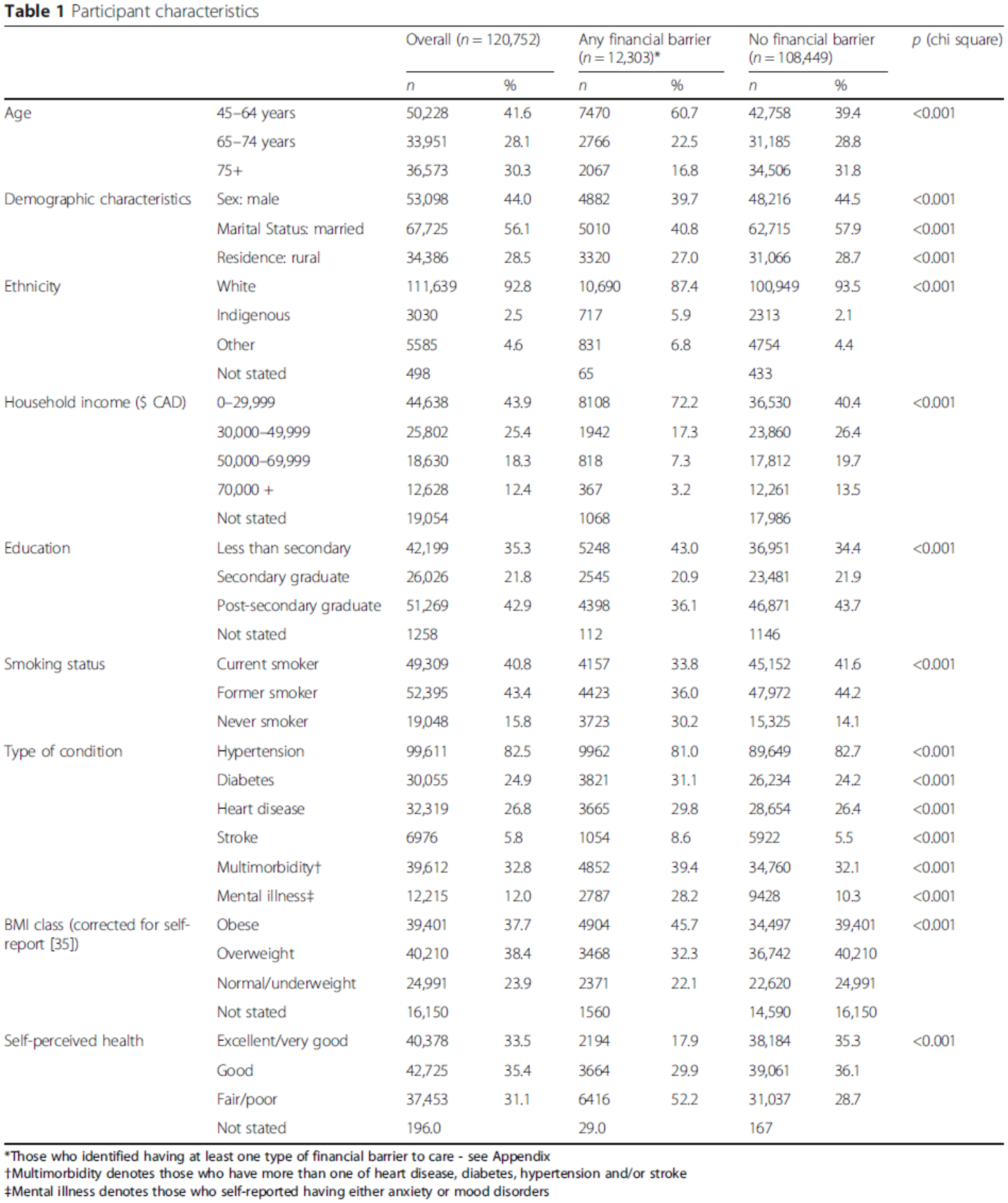

Table 1 Participant characteristics

		Overall ($n = 120{,}752$)		Any financial barrier ($n = 12{,}303$)*		No financial barrier ($n = 108{,}449$)		p (chi square)
		n	%	n	%	n	%	
Age	45–64 years	50,228	41.6	7470	60.7	42,758	39.4	<0.001
	65–74 years	33,951	28.1	2766	22.5	31,185	28.8	
	75+	36,573	30.3	2067	16.8	34,506	31.8	
Demographic characteristics	Sex: male	53,098	44.0	4882	39.7	48,216	44.5	<0.001
	Marital Status: married	67,725	56.1	5010	40.8	62,715	57.9	<0.001
	Residence: rural	34,386	28.5	3320	27.0	31,066	28.7	<0.001
Ethnicity	White	111,639	92.8	10,690	87.4	100,949	93.5	<0.001
	Indigenous	3030	2.5	717	5.9	2313	2.1	
	Other	5585	4.6	831	6.8	4754	4.4	
	Not stated	498		65		433		
Household income ($ CAD)	0–29,999	44,638	43.9	8108	72.2	36,530	40.4	<0.001
	30,000–49,999	25,802	25.4	1942	17.3	23,860	26.4	
	50,000–69,999	18,630	18.3	818	7.3	17,812	19.7	
	70,000 +	12,628	12.4	367	3.2	12,261	13.5	
	Not stated	19,054		1068		17,986		
Education	Less than secondary	42,199	35.3	5248	43.0	36,951	34.4	<0.001
	Secondary graduate	26,026	21.8	2545	20.9	23,481	21.9	
	Post-secondary graduate	51,269	42.9	4398	36.1	46,871	43.7	
	Not stated	1258		112		1146		
Smoking status	Current smoker	49,309	40.8	4157	33.8	45,152	41.6	<0.001
	Former smoker	52,395	43.4	4423	36.0	47,972	44.2	
	Never smoker	19,048	15.8	3723	30.2	15,325	14.1	
Type of condition	Hypertension	99,611	82.5	9962	81.0	89,649	82.7	<0.001
	Diabetes	30,055	24.9	3821	31.1	26,234	24.2	<0.001
	Heart disease	32,319	26.8	3665	29.8	28,654	26.4	<0.001
	Stroke	6976	5.8	1054	8.6	5922	5.5	<0.001
	Multimorbidity†	39,612	32.8	4852	39.4	34,760	32.1	<0.001
	Mental illness‡	12,215	12.0	2787	28.2	9428	10.3	<0.001
BMI class (corrected for self-report [35])	Obese	39,401	37.7	4904	45.7	34,497	39,401	<0.001
	Overweight	40,210	38.4	3468	32.3	36,742	40,210	
	Normal/underweight	24,991	23.9	2371	22.1	22,620	24,991	
	Not stated	16,150		1560		14,590	16,150	
Self-perceived health	Excellent/very good	40,378	33.5	2194	17.9	38,184	35.3	<0.001
	Good	42,725	35.4	3664	29.9	39,061	36.1	
	Fair/poor	37,453	31.1	6416	52.2	31,037	28.7	
	Not stated	196.0		29.0		167		

*Those who identified having at least one type of financial barrier to care - see Appendix
†Multimorbidity denotes those who have more than one of heart disease, diabetes, hypertension and/or stroke
‡Mental illness denotes those who self-reported having either anxiety or mood disorders

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Table 3.2

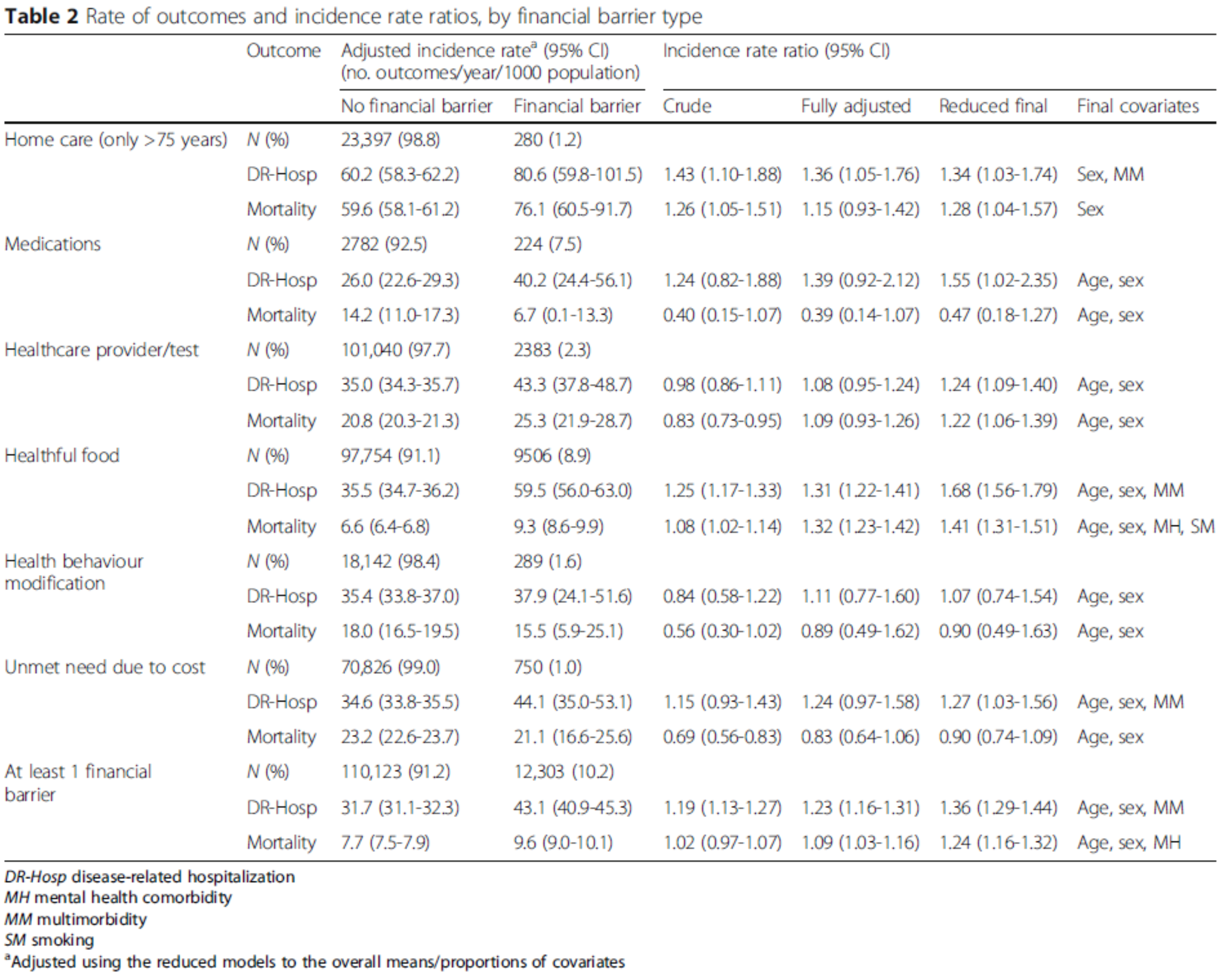

Table 2 Rate of outcomes and incidence rate ratios, by financial barrier type

	Outcome	Adjusted incidence rate[a] (95% CI) (no. outcomes/year/1000 population)		Incidence rate ratio (95% CI)			
		No financial barrier	Financial barrier	Crude	Fully adjusted	Reduced final	Final covariates
Home care (only >75 years)	*N* (%)	23,397 (98.8)	280 (1.2)				
	DR-Hosp	60.2 (58.3-62.2)	80.6 (59.8-101.5)	1.43 (1.10-1.88)	1.36 (1.05-1.76)	1.34 (1.03-1.74)	Sex, MM
	Mortality	59.6 (58.1-61.2)	76.1 (60.5-91.7)	1.26 (1.05-1.51)	1.15 (0.93-1.42)	1.28 (1.04-1.57)	Sex
Medications	*N* (%)	2782 (92.5)	224 (7.5)				
	DR-Hosp	26.0 (22.6-29.3)	40.2 (24.4-56.1)	1.24 (0.82-1.88)	1.39 (0.92-2.12)	1.55 (1.02-2.35)	Age, sex
	Mortality	14.2 (11.0-17.3)	6.7 (0.1-13.3)	0.40 (0.15-1.07)	0.39 (0.14-1.07)	0.47 (0.18-1.27)	Age, sex
Healthcare provider/test	*N* (%)	101,040 (97.7)	2383 (2.3)				
	DR-Hosp	35.0 (34.3-35.7)	43.3 (37.8-48.7)	0.98 (0.86-1.11)	1.08 (0.95-1.24)	1.24 (1.09-1.40)	Age, sex
	Mortality	20.8 (20.3-21.3)	25.3 (21.9-28.7)	0.83 (0.73-0.95)	1.09 (0.93-1.26)	1.22 (1.06-1.39)	Age, sex
Healthful food	*N* (%)	97,754 (91.1)	9506 (8.9)				
	DR-Hosp	35.5 (34.7-36.2)	59.5 (56.0-63.0)	1.25 (1.17-1.33)	1.31 (1.22-1.41)	1.68 (1.56-1.79)	Age, sex, MM
	Mortality	6.6 (6.4-6.8)	9.3 (8.6-9.9)	1.08 (1.02-1.14)	1.32 (1.23-1.42)	1.41 (1.31-1.51)	Age, sex, MH, SM
Health behaviour modification	*N* (%)	18,142 (98.4)	289 (1.6)				
	DR-Hosp	35.4 (33.8-37.0)	37.9 (24.1-51.6)	0.84 (0.58-1.22)	1.11 (0.77-1.60)	1.07 (0.74-1.54)	Age, sex
	Mortality	18.0 (16.5-19.5)	15.5 (5.9-25.1)	0.56 (0.30-1.02)	0.89 (0.49-1.62)	0.90 (0.49-1.63)	Age, sex
Unmet need due to cost	*N* (%)	70,826 (99.0)	750 (1.0)				
	DR-Hosp	34.6 (33.8-35.5)	44.1 (35.0-53.1)	1.15 (0.93-1.43)	1.24 (0.97-1.58)	1.27 (1.03-1.56)	Age, sex, MM
	Mortality	23.2 (22.6-23.7)	21.1 (16.6-25.6)	0.69 (0.56-0.83)	0.83 (0.64-1.06)	0.90 (0.74-1.09)	Age, sex
At least 1 financial barrier	*N* (%)	110,123 (91.2)	12,303 (10.2)				
	DR-Hosp	31.7 (31.1-32.3)	43.1 (40.9-45.3)	1.19 (1.13-1.27)	1.23 (1.16-1.31)	1.36 (1.29-1.44)	Age, sex, MM
	Mortality	7.7 (7.5-7.9)	9.6 (9.0-10.1)	1.02 (0.97-1.07)	1.09 (1.03-1.16)	1.24 (1.16-1.32)	Age, sex, MH

DR-Hosp disease-related hospitalization
MH mental health comorbidity
MM multimorbidity
SM smoking
[a] Adjusted using the reduced models to the overall means/proportions of covariates

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Figure 3.2: Forest plot of disease-related hospitalizations

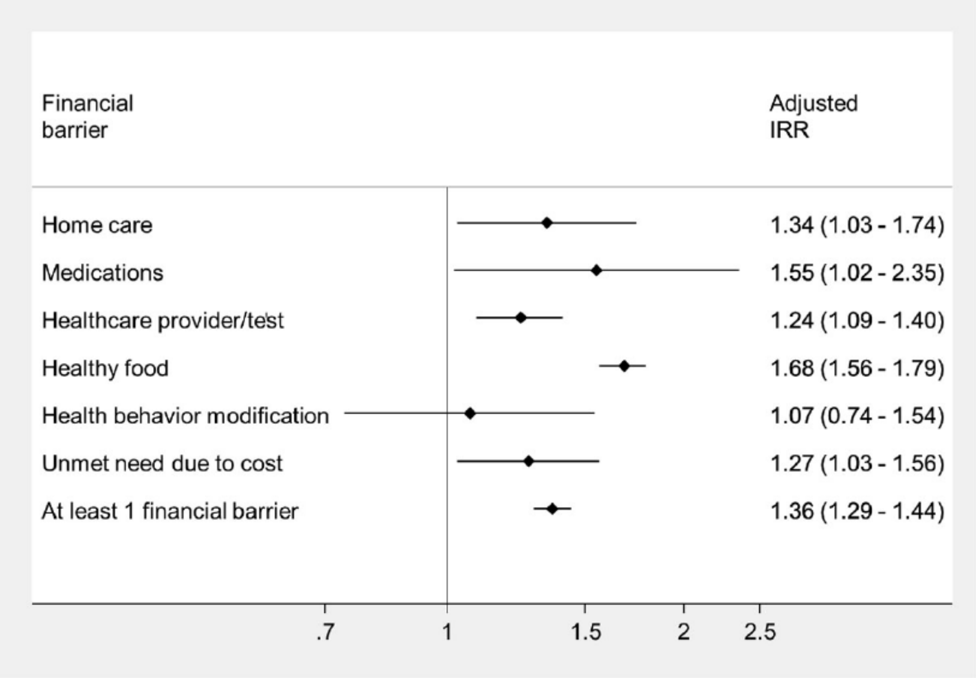

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Table 3.3

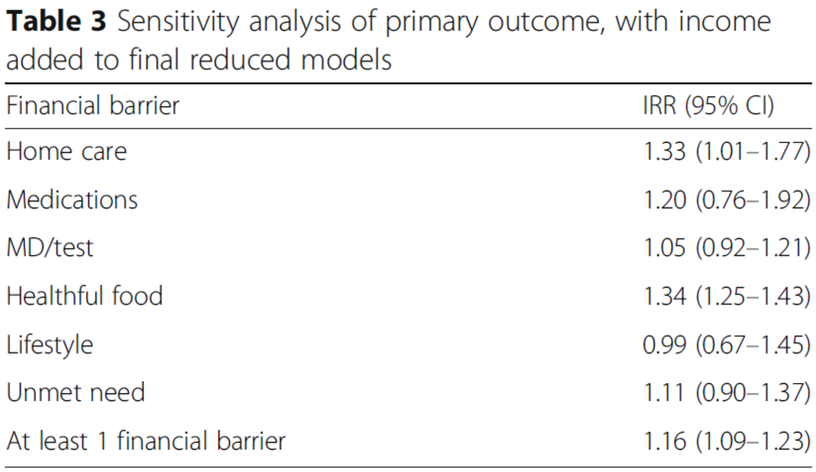

Table 3 Sensitivity analysis of primary outcome, with income added to final reduced models

Financial barrier	IRR (95% CI)
Home care	1.33 (1.01–1.77)
Medications	1.20 (0.76–1.92)
MD/test	1.05 (0.92–1.21)
Healthful food	1.34 (1.25–1.43)
Lifestyle	0.99 (0.67–1.45)
Unmet need	1.11 (0.90–1.37)
At least 1 financial barrier	1.16 (1.09–1.23)

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Table 3.4: Costing Analysis Models

Model	**Diagnostics**			**Coefficient**			**Average Costs ($ CAD)**		
	Park Test Chi2	**Mean Error**	**Pseudo R2**	**Crude** **$ (95% CI)**	**Fully Adjusted** **$ (95% CI)**	**Final Reduced** **$ (95% CI)**	**No Financial Barrier** **$ (95% CI)**	**Financial Barrier** **$ (95% CI)**	**Difference** **$ CAD**
OLS linear	N/A	2291.5	0.172	375 (233-518)	353 (193-513)	364 (204-524)	1360 (1315-1404)	1724 (1571-1876)	364
GLM - gamma	62.3	2318.8	0.209	1.25 (1.14-1.38)	1.35 (1.18-1.55)	1.42 (1.24-1.62)	905 (872-939)	1280 (1117-1443)	375
GLM - poisson	19.2	2263	0.303	1.25 (1.25-1.26)	1.37 (1.37-1.37)	1.39 (1.39-1.39)	967 (967-968)	1345 (1344-1346)	378
GLM - gaussian	277.3	2305.3	0.163	1.25 (1.16-1.39)	1.37 (1.28-1.48)	1.37 (1.28-1.47)	1077 (1028-1126)	1477 (1365-1589)	400

Appendix 3A

Definition of Exposure (financial barriers)			
Healthcare Provider or Test	ACC_12	In the past 12 months, did you ever experience any difficulties getting the specialist care you needed for a diagnosis or consultation? (Reason: Cost)	CCHS
	ACC_53	In the past 12 months, did you experience difficulties getting routine care that you or a family member that you required during « regular » office hours (that is, 9:00 am to 5:00 pm, Monday to Friday)? (Reason: Cost)	CCHS
	ACC_55	In the past 12 months, did you experience difficulties getting routine care that you or a family member that you required during evenings and weekends (that is, 5:00 to 9:00 pm Monday to Friday, or 9:00 am to 5:00 pm, Saturdays and Sundays)? (Reason: Cost)	CCHS
	ACC_63	In the past 12 months, did you ever experience any difficulties getting the immediate care needed for a minor health problem for yourself or a family member that you required during « regular » office hours (that is, 9:00 am to 5:00 pm, Monday to Friday)? (Reason: Cost)	CCHS
	ACC_65	In the past 12 months, did you ever experience any difficulties getting the immediate care needed for a minor health problem for yourself or a family member that you required evenings and weekends (that is, 5:00 to 9:00 pm Monday to Friday, or 9:00 am to 5:00 pm, Saturdays and Sundays)? (Reason: Cost)	CCHS
	ACC_67	In the past 12 months, did you ever experience any difficulties getting the immediate care needed for a minor health problem for yourself or a family member that you required during the middle of the night? (Reason: Cost}	CCHS
	PCU_56	What are the reasons that you have not had a check-up in the past 3 years? (Reason: Cost)	CCHS
	RAH_09	In the past 12 months, how often did you find it difficult to get healthcare services because you could not travel to the healthcare facility? What types of problems did you experience? (Reason: I can't afford the cost of travel / I can't afford to take time off work)	BCPCHC
	RAH_18	In the past 12 months, did you ever experience any travel related or other difficulties when trying to see a medical specialist? What types of problems did you experience? (Reason: I can't afford the cost of travel / I can't afford to take time off work)	BCPCHC
	RAH_09	In the past 12 months, how often did you find it difficult to get healthcare services because you could not travel to the healthcare facility? What type of problems did you experience? (Reason: I can't afford the cost of travel, I can't afford to take time off work, I can't afford the cost of parking)	BCPCHC

	GBC_03	In the past 12 months, what type of difficulties did you experience getting any healthcare services from your family doctor or general practitioner? (Reason: Cost)	BCPCHC
	GBC_05	In the past 12 months, what type of difficulties did you experience getting specific care for your chronic condition? (Reason: Cost)	BCPCHC
	WTM_06	In the past 12 months, did you require a visit to a medical specialist for a diagnosis or a consultation for a new illness or condition? Thinking about this visit, did you experience any difficulties seeing the specialist? What type of difficulty did you experience? (Reason: Cost)	CCHS
	BPC_16 RC_01C	What are the reasons you have not had your blood pressure taken in the past 2 years? (Reason: Cost)	CCHS BCPCHC
	RC_02B	What are the reasons you have not had your cholesterol measurement taken in the past year? (Reason: Cost)	BCPCHC
	RC_03B	What are the reasons you have not had your cholesterol sugar taken in the past year? (Reason: Cost)	BCPCHC
	ACC_32	In the past 12 months, did you ever experience any difficulties getting the tests you needed? (Reason: Cost)	CCHS
	WTM_37	In the past 12 months, did you require a diagnostic test? Did you experience any difficulties getting this test? What type of difficulty did you experience (Reason: Cost)	CCHS
	EYX_142	When did you last have an eye examination? What are the reasons that you have not had an eye examination in the past 2 years? (Reason: Cost)	CCHS
	DEN_132	When was the last time that you went to a dentist? What are the reasons that you have not been to a dentist in the past 3 years? (Reason: Cost)	CCHS
Medication	PDE_02	In the past 12 months, did you decide not to fill a new prescription for medication because of the cost? (Yes)	PDERR
	PDE_03	In the past 12 months, did you decide not to renew a prescription for medication because of the cost? (Yes)	PDERR
	PDE_04	In the past 12 months, because of the cost, did you do anything to make a prescription medication last longer? (Yes)	PDERR
	MEH_05	What are the reasons that you are not currently taking any prescription medications for your high blood pressure (Reason: Cost)	SLCDC

	MU_05	Over the past 12 months, have you ever stopped taking one or more of your drugs as prescribed for a week or more? What are the reasons that you did not take your medication as prescribed? (Reason: Cost)	BCPCHC
	INS_03	Do you currently have insurance that covers all or part of the cost of prescription medications? Why not? (Reason: I can't afford coverage)	BCPCHC
Home care	HMC_15 CR1_04	During the past 12 months, was there ever a time when you felt that you needed home care services but you didn't receive them? (Reason: Cost)	CCHS
Unmet Need	EBC_01	In the past 12 months, how often have you had difficulty paying for services, equipment or medications you need to help you manage your chronic condition? (Always, Often, Sometimes)	BCPCHC
	HCU_06 UCN_01	During the past 12 months, was there ever a time when you felt that you needed healthcare but you didn't receive it? (Reason: Cost)	CCHS
Healthy Food	FIN_01	In the past 12 months, how often did you or anyone else in your household worry that there would not be enough to eat because of a lack of money? (Often, Sometimes)	CCHS
	FIN_02	In the past 12 months, how often did you or anyone else in your household not have enough food to eat because of a lack of money? (Often, Sometimes)	CCHS
	FIN_03	In the past 12 months, how often did you or anyone else in your household not eat the quality or variety of foods that you wanted to eat because of a lack of money? (Often, Sometimes)	CCHS
	FSC_10	Which of the following statements best describes the food eaten in your household in the past 12 months? (Sometimes did not have enough, often did not have enough)	CCHS
	FSC_20	You and other household members worried that food would run out before you got money to buy more. Was that often true, sometimes true, or never true in the past 12 months? (Often true, sometimes true)	CCHS
	FSC_30	The food that you and other household members bought just didn't last, and there wasn't any money to get more. Was that often true, sometimes true, or never true in the past 12 months? (Often true, sometimes true)	CCHS
	FSC_50	You or other adults in your household relied on only a few kinds of low-cost food to feed the children because you were running out of money to buy food. Was that often true, sometimes true or never true in the past 12 months? (Often true, sometimes true)	CCHS
	FSC_80	In the past 12 months, did you or other adults in your household ever cut the size of your meals or skip meals because there wasn't enough money for food? (Yes)	CCHS

	FSC_90	In the past 12 months, did you (personally) ever eat less than you felt you should because there wasn’t enough money to buy food? (Yes)	CCHS
	FSC_100	In the past 12 months, were you (personally) ever hungry but didn’t eat because you couldn’t afford enough food? (Yes)	CCHS
	FSC_110	In the past 12 months, did you (personally) lose weight because you didn’t have enough money for food? (Yes)	CCHS
	FSC_120	In the past 12 months, did you or other adults in your household ever not eat for a whole day because there wasn’t enough money for food? (Yes)	CCHS
	SMH_04 SMH_02	What are the reasons you are not limiting your daily salt intake? (Reason: Cost)	BCPCHC SLCDC
	SMH_08 SMH_04	What are the reasons you are not choosing these types of foods (that is, fruits and vegetables, fish or lean meats, foods high in fibre or foods low in fat)? (Reason: Cost)	BCPCHC SLCDC1
	SMD_02	What are the reasons you do not change the type or amount of food you eat to help control your diabetes? (Reason: Cost)	SLCDC2
Health Behaviour Modification	SMH_08 SMD_04 SMH_10	What are the reasons that you are not exercising or participating in physical activities? (Reason: Cost)	SLCDC1 SLCDC2 BCPCHC
	PA2_13	What prevented you from doing more physical activities? (Reason: Cost)	CCHS
	SMH_10 SMD_06 SMH_21	What are the reasons that you are not trying to control your weight or lose weight? (Reason: Cost)	SLCDC1 SLCDC2 BCPCHC
	SMH_17	What are the reasons that you are not trying to quit smoking or cut down on smoking (Reason: Cost of smoking cessation products)	BCPCHC

CCHS: Canadian Community Health Survey
BCPCHC: Barriers to Care for Persons with Chronic Health Conditions (2012)
SLCDC1: Survey on Living with Chronic Diseases in Canada (hypertension component) (2009)
SLCDC2: Survey on Living with Chronic Diseases in Canada (diabetes component) (2011)
PDERR: Rapid Response Module on Prescription Drug Expenditures (2007)

Appendix 3B

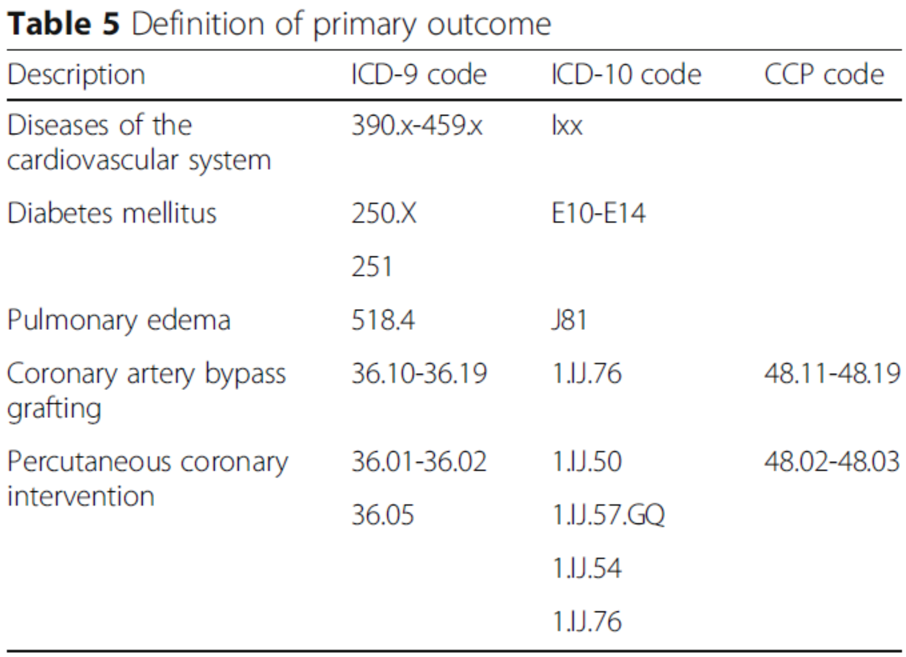

Table 5 Definition of primary outcome

Description	ICD-9 code	ICD-10 code	CCP code
Diseases of the cardiovascular system	390.x-459.x	Ixx	
Diabetes mellitus	250.X	E10-E14	
	251		
Pulmonary edema	518.4	J81	
Coronary artery bypass grafting	36.10-36.19	1.IJ.76	48.11-48.19
Percutaneous coronary intervention	36.01-36.02	1.IJ.50	48.02-48.03
	36.05	1.IJ.57.GQ	
		1.IJ.54	
		1.IJ.76	

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CHAPTER 4:

GROUNDED THEORY STUDY TO DEVELOP A CONCEPTUAL FRAMEWORK FOR UNDERSTANDING THE EXPERIENCE OF PATIENTS WHO PERCEIVE FINANCIAL BARRIERS TO CARE

In the studies described in the previous two chapters, we demonstrated significant statistical associations between perceived financial barriers and adverse clinical outcomes. However, with these types of quantitative studies we glean minimal understanding about how these associations arise or what individual patients may experience that leads to the observed findings.

To expand our understanding of the patient experience of financial barriers, we conducted a qualitative grounded theory study with a view to develop a novel framework that would be useful for researchers, clinicians and policy makers working in the area of cardiovascular-related chronic diseases.

This chapter is published as:

Campbell DJT, Manns BJ, Hemmelgarn BR, Sanmartin, C, King-Shier, K. (2016). The *Development of a Conceptual Framework for Understanding Financial Barriers to Care for Patients with Cardiovascular-Related Chronic Disease: A Protocol for a Grounded Theory (Qualitative) Study.* CMAJ Open, 4(2): E304-308.

Campbell DJT, Manns BJ, Leblanc P, Hemmelgarn BR, Sanmartin C, King-Shier K. (2016). *Finding resiliency in the face of financial barriers: Development of a conceptual framework for people with cardiovascular-related chronic disease.* Medicine, 95(49): 1-8.

Sections of this chapter have been reproduced from the following published works:

Campbell DJT, Manns BJ, Hemmelgarn BR, Sanmartin C, Edwards A, King-Shier K. (2017). *Understanding Financial Barriers to Care for Patients with Diabetes: An Exploratory Qualitative Study*. The Diabetes Educator, 43(1).

Dhaliwal KK., King-Shier KM, Manns BJ, Hemmelgarn BR, Stone J, **Campbell DJT.** (2017). *Exploring the Impact of Financial Barriers to Care for Patients with Coronary Artery Disease: A Qualitative Descriptive Study*. BMC Cardiovascular Disorders, 17(61).

4.1 Abstract

Background

Patients with cardiovascular-related chronic diseases often face financial barriers to optimizing their health; even in Canada where universal healthcare insurance is in place. As many as 12% of Canadians with chronic diseases experience a financial barrier to care. Unfortunately, no current theory or framework adequately describes the process of striving to achieve optimal health in the face of financial barriers. The overall objective of this study was to develop a framework to understand how financial barriers impact patients' lives and the mechanisms they use to cope with financial barriers.

Methods

We undertook an inductive qualitative grounded theory study to develop a framework to understand the role of financial barriers on patients with chronic disease. We used semi-structured interviews (telephone and face-to-face) with a purposive sample of participants with chronic disease (at least one of hypertension, diabetes, heart disease or stroke) from Alberta, Canada. Interview transcripts were analysed in triplicate using grounded theory coding techniques including open, focused and axial coding following the principle of constant comparison. Interviews and analysis were done iteratively to theoretical saturation. Member checking was used to enhance rigor.

Results

We interviewed 34 participants. We found that the confluence of two events contributed to the perception of having a financial barrier: onset of chronic disease and lack of income or health

benefits. The impact of having a perceived financial barrier varied considerably. Protective, predisposing or modifying of factors (filters) determined how impactful a financial barrier would be. An individual's particular set of filters is then shaped by their worldview (lens). This combination of filters and lens determines one's degree of resiliency which ultimately impacts how well they cope with their disease.

Discussion

The role of financial barriers is complex. How well an individual copes with their financial barriers is intimately tied to resiliency, which is related to the composite of a person's circumstances and their worldview. Our framework for understanding the experience of financial barriers can be used by both researchers and clinicians to better understand patient behaviour.

4.2 Background

Cardiovascular-related chronic diseases such as hypertension, diabetes, stroke and coronary artery disease are among the leading causes of morbidity and mortality in Canada [3, 4]. In Canada, hospital services and medically necessary physician services are covered by universal public health insurance [95]. Despite the increasingly important role of medication use and allied health care providers’ services in managing outpatients with chronic diseases [96], these are not universally included within provincial health care insurance plans. Public insurance plans for outpatient prescription medications vary by province, but no province offers universal public medication insurance [27]. Those fortunate enough to qualify for public medication insurance often still face considerable copayments and/or deductibles [33]. Thus, financial constraints can have a significant impact on the care required to optimize outcomes in people with cardiovascular-related chronic diseases [26]. In fact, many patients face barriers to obtaining adequate health care, such as necessary prescription medications, due to the costs associated with these services [36] (henceforth called financial barriers).

There are several types of financial barriers that might reduce accessibility to necessary care and impact health outcomes. Some people may not be able to afford the direct costs associated with medications (such as insurance premiums or user charges), self-monitoring supplies, rehabilitation or home care. While others may struggle to access care that is funded by the public system because of an inability to pay the indirect costs associated with these appointments (e.g. lost income from taking time off work; paying for transportation and parking costs; or childcare). Previous studies conducted by our group revealed that 10-12% of Canadians with cardiovascular-related chronic diseases experience financial barriers, and these people are 36% to 70% more likely to have hospitalizations or emergency department visits related to their chronic disease [Chapters 2 & 3]. These adverse outcomes may be potentially avoidable if the financial barrier which contributed to it could be addressed. It is therefore important to understand how an individual comes to perceive a financial barrier and the role and impact of financial barriers on patients' lives.

Researchers often use theories or frameworks to understand how a social phenomenon is operationalized. In preparing to design the initial survey focused on financial barriers, we were unable to identify a theory or framework which adequately described how financial barriers are experienced or how they impact care and outcomes. Rather, we found a number of frameworks which touch on relevant aspects of care seeking. There are three types of frameworks that relate to understanding financial barriers to care: (1) frameworks related to access to care in a general sense; (2) health economics frameworks for understanding health decision making and healthcare utilization behaviour; and (3) frameworks focusing on the impact of social determinants of health, or socioeconomic status (SES), on health resource utilization.

Several authors have attempted to create frameworks to comprehensively understand access to care for patients with chronic diseases. Finances are often considered as an aspect of access to care in these frameworks, but the focus of attention is not on how patients experience financial barriers. Some of these include: the Health Behavior Model [18] and the Health Care Access Barriers Model [97]. The breadth of these frameworks is often viewed as a strength as they are able to consider a variety of potential barriers at many different levels. However, taking such a broad perspective on the overarching topic of ‘access’ also limits the depth to which they can devote to fully comprehending a construct such as financial barriers.

Grossman’s health production model is an economic approach to understanding individuals’ health decision making [98]. There are limitations and criticisms of the Grossman theory, primarily based on the economic practice of simplifying the complexities of the human condition to a point where theories can be tested empirically [99]. Despite attempts to address these shortcomings [100], there remain ardent critics, who argue that numerous issues remain unaddressed “even after 40 years of effort” [101]. Also of note, the model is not as empirically sound as proponents suggest [102]. The main problematic empiric finding is that there appears to be a negative correlation between health status and demand for healthcare, while the model purports that healthier individuals will demand more health care. This discordant finding has been replicated in empirical studies [103]. Finally, a particularly concerning critique of the Grossman model arises from the combination of the fact that it exaggerates individuals’ ability to make rational choices. This model is guilty of overstating the ability of an individual to make choices freely. It does not consider how one’s agency is constrained by “supraindividual structures” [104], such as poverty, gender and low social class. To fully understand the role of financial constraints, “it is necessary to avoid economic reductionism” [104] as is openly employed by the Grossman model. The troublesome conclusion that can be drawn by reductionist approaches is to end up blaming the victim, which “serves to justify the retrenchment from rights and entitlements for access to medical services, and attempts to divert attention from the social causation of disease” [105].

A number of frameworks, including that proposed by Brown, focus on the impact and role of the social determinants of health or SES on health care access [106]. These frameworks are complicated by the significant interconnectedness of a multitude of individual and community factors, making them difficult to apply in practice. In particular, the Brown framework is troubled by endogeneity. While it is well known that SES can affect health outcomes, there is considerable cause to believe that poor health status can also lead to lower SES. Because of this reverse causality, it may be misleading to demonstrate a one-way relationship where low SES leads to poor health outcomes. Also, due to its complexity, with so many individual concepts and interrelationships, a framework like Brown's is difficult to interpret or test empirically. It is therefore less likely to be operationalized into practical solutions to address the SES gradient in health. The resultant danger is the likelihood of fatalism in response to this problem. Some may feel that with such a complex and vexing problem, it is fruitless to seek for solutions. Even in rare cases where social interventions are developed from such frameworks, when tested under randomized trial conditions these often yield equivocal or negative results [107]. This has resulted in many becoming "skeptical about the value of experimentation… they say that we are bound to fail with such designs" [107]. Finally, it is feasible that even those who may typically be considered to have higher SES may encounter financial barriers to care under certain circumstances (i.e. lacking health insurance), while those with lower SES may not experience financial barriers due to subsidies and benefit programs.

Given that none of the frameworks or models that we found are ideal for understanding the impact of financial barriers on people with cardiovascular-related chronic disease, nor how patients experience financial barriers (Table 4.1), a new model or framework was required.

Inductive qualitative research has as its goal the generation or development of a theory or framework. Our objective was to utilize an inductive qualitative methodology (grounded theory), to develop a novel framework for understanding the role of financial barriers in the health of patients with cardiovascular-related chronic health conditions. Specific objectives included:

1. To explore and describe the circumstances which contribute to an individual experiencing financial barriers.
2. To explore what factors affect how impactful a financial barrier may be on a given patient.
3. To explore the coping strategies used by patients with chronic diseases to overcome financial barriers, and at what cost.

4.3 Methods

4.3.1 Study Design

This study was informed by our previous research in the area of financial barriers. We previously conducted a survey of western Canadians with cardiovascular-related chronic diseases (n=1849) to understand the barriers that they face in self-managing their conditions (see Chapter 2). We found that financial barriers were common among this population (12%) and that there were significant associations between financial barriers and clinically meaningful outcomes (medication non-adherence, emergency department visits and hospitalizations).

The aim of pursuing qualitative research is to gain in-depth understanding of experiences and processes such as people’s behaviors, motivators, or perceptions. Qualitative methods are useful in studying topics which cannot be quantified, such as experiences and coping strategies [108].

We aimed to undertake a thorough exploration of the experience of persons with cardiovascular-related chronic conditions who have financial barriers, and therefore our research question necessitated the use of qualitative methods to probe deep into this very personal process.

Grounded theory allows researchers to move beyond simple description to a more abstract theory or framework of a given process. Grounded theory is used to describe processes of human behavior [109] through generation of frameworks and/or theories [110]. The principle of constant comparison is used to ensure that the theory generated is in fact grounded in the data, rather than from the preconceived notions of the researchers. We chose to use grounded theory methodology to reach past superficial description of the experiences of patients with financial barriers to care to a more theoretical and analytical description of the process of experiencing and coping with such a barrier.

4.3.2 Sampling

4.3.2.1 Inclusion Criteria

The study population consisted of English speaking Albertan adults with at least one of the following self-reported chronic medical conditions: hypertension, diabetes, coronary artery disease, or stroke. To be eligible, participants must have identified as having experiencing a financial barrier within the previous year by answering affirmatively to the following question:

> *"Some people have difficulty paying for services, equipment, and medications for chronic conditions. Other people may have difficulty paying for transportation or childcare to allow attendance at doctors' appointments… In the past 12 months, did you have difficulty paying for services, equipment, medications for your chronic conditions?"*

4.3.2.2 Exclusion Criteria

Individuals who were unable to converse in the English language (due to language barriers or physical impediments), those who did not have at least one of the pre-specified chronic conditions of interest and those with severe cognitive impairment were excluded from participation in the study.

4.3.2.3 Recruitment

We recruited study participants via signage in family physician offices and specialist clinics as well as via pre-existing research and clinical databases. We utilized a theoretical or purposeful sampling stategy [111], by identifying a number of strata that were important to have represented in our pool of participants, based on the prior survey – as these variables were notable contributors to the presence of financial barriers:

- Age: ≥65 years and <65 years (as government sponsored health benefits for seniors are provided to those over the age of 65 years)
- Gender
- Type of chronic disease
- Multimorbidity
- Aboriginal status
- Adequate and low health literacy [68]

4.3.3 Data Collection

We collected data using semi-structured face-to-face or telephone interviews. An interview guide (Table 4.2) was developed based on the findings of our preceding survey, and learnings from the related frameworks previously reviewed. Five domains were explored in the interview: (1) experience of living with chronic disease; (2) experience of financial barriers; (3) perceived reasons for financial barriers; (4) health consequences of financial barriers; and (5) mechanisms for coping with financial barriers. All interviews were completed by investigators who are trained and experienced in qualitative interviewing techniques. Interviews were digitally recorded and subsequently transcribed verbatim using standard linguistic conventions by a professional transcriptionist.

Data collection and analysis were conducted simultaneously which allowed us to continue sampling and data collection until theoretical saturation was achieved. Saturation was deemed to have been met once three consecutive interviews did not yield any new substantive codes during initial analysis. Based on prior reports of grounded theory studies of this nature [112], we anticipated needing to complete between 30 to 50 interviews to achieve saturation.

4.3.4 Data Analysis

We employed grounded theory coding using an inductive approach, as described by Charmaz [113] using techniques initially described by Strauss and Corbin [114]. Data collection and analysis were done iteratively which allowed us “to explore and fill out these codes” [113], as necessary. Data analysis began after each interview, when the interviewer reflected on the theoretical content in each interview and wrote memos to record analytic ideas. Finalized transcriptions were analyzed using NVivo 10 software (QSR International: Doncaster, Australia).

Initial or open coding proceeded in a line-by-line fashion. During this process the data was ‘fractured’ or broken down into granular codes [109]. Further analyses were based on the principle of constant comparison [110]. Firstly, data from interview transcripts was compared internally and subsequently, transcripts were compared to one another using incident-to-incident coding. The process of initial coding was done individually in triplicate, meaning that three experienced analysts individually coded the data. All coders met regularly to discuss their interpretations of the data to allow for consideration of various perspectives. Given that this research is informed by the interpretive paradigm, exact agreement was not the goal of these sessions, but rather to gather a multitude of viewpoints on the various incidents and themes derived from the data. However, consensus about how to code a given piece of data was achieved after thorough discussion of each point. In cases where consensus was not reached allowances were made such that a passage could retain multiple codes to enable future discussion.

Once all transcripts were initially coded, we proceeded with focused coding where we grouped initial fractured codes into coherent subsuming categories. The final analytic stage was axial coding. This process was done through a process where the research team met to discuss the relationships between the various codes and categories, while reviewing pertinent excerpts from the data.

4.3.5 Rigor and Trustworthiness

A number of procedures were planned to maximize the rigor and enhance the trustworthiness of this qualitative study. Member checking, the process of presenting research findings to participants to obtain their feedback, was accomplished by holding two focus groups of prior interview participants. The use of multiple analysts enriched our ability to interpret and understand incidents described by respondents. We used negative case sampling (the selection of individuals who stated that they had experienced financial difficulties associated with their chronic condition but that they would not describe these as "barriers") to help to illuminate why financial issues may be more pertinent for some than for others. Extreme case sampling involved including those who experienced a hospitalization or adverse event that was directly attributed to their financial barriers. Finally, throughout the process of data collection and analysis, we actively employed the principle of reflexivity – or thinking about how our own personal experiences and characteristics might have shaped participants' responses or our interpretation of the data [115].

4.3.6 Ethics approval

Ethics approval was obtained from our institution's Conjoint Health Research Ethics Board and study procedures were undertaken in accordance with Canada's Tri-Council Policy Statement guidelines. Informed consent was received verbally over the telephone for interviews and written consent obtained for focus group participation.

4.4 Results & Discussion

We completed 34 in-depth interviews- 10 in person (at the University) and 24 over the telephone – between only the interviewer and participant (participant's spouse was present in 2 interviews). 5 individuals declined participation or dropped out. Interviews average duration was 49 minutes (range: 33-92 minutes). Repeat interviews were not conducted. We interviewed 15 men and 19 women with a variety of chronic conditions (Table 4.3). Most participants had hypertension (28/34) and/or diabetes (24/34), with 28/34 having more than one condition. The participants' ages ranged from 31 to 76 years. The majority (30/34) had some form of supplemental health insurance to cover outpatient prescription medications.

Through our analytic process, we came to understand that there are two key elements for understanding the experience of financial barriers which must be included in the model. These include explanations of:

1) The factors that contribute to a given patient coming to experience financial barriers, and
2) The process that determines how impactful a financial barrier is on a patient's life, given considerable heterogeneity in terms of the importance of financial barriers on an individual's life.

The overall framework is depicted in Figure 4.1. Below we describe the components of the framework with supporting quotations embedded.

4.4.1 Contributors to the Perception of Financial Barriers

We heard overwhelmingly consistent stories of how participants came to experience financial barriers. This was attributed to the confluence of two factors: (1) diagnosis/onset of their cardiovascular-related chronic disease, and (2) lack of money or health benefits. Participants reported 'managing' financially despite lacking health benefits or having limited incomes, until the heart attack, stroke or diagnosis of diabetes – after which their lives were changed to a *'constant struggle'*. On the other hand, some participants could financially manage their chronic disease until they lost their jobs or retired, or a change of employment resulted in a loss of health benefits which precipitated a problematic financial barrier:

> *Up until October of last year, it [diabetes] really didn't have any financial bearing on me whatsoever. I've always had really good medical plans through my work, even if I had to pay a little bit it was not big deal…. I took a contract job and I don't have benefits and now I'm finding out exactly how much money in diabetes supplies and insulin that I'm using… It's huge and it's taking a real toll on me financially.*

These problems were often compounded. Numerous participants described how their chronic condition was linked to or resulted in their loss of employment and worsening of their subsequent financial barrier. These stories included: employers not tolerating participants with diabetes' requirements to eat regularly, or employers not continuing to provide jobs for contract workers after required time away (e.g. following a heart attack):

> *They don't wanna be flexible, they just don't. I told my employer about everything that's going on. I don't have to disclose anything and I did because we're like a family. They're*

> *always like: 'we're family… we love our employees'. Yeah, well, apparently not when it comes down to push or shove.*

This element of the process is portrayed to the left-hand side of our framework (Figure 4.1). We have chosen the image of a balance to represent that participants often stated that they were *'doing just fine'* until one of these changes (diagnosis of chronic condition or loss of financial resources) *'tipped them over'* to the situation where they then had to face a significant financial barrier.

4.4.2 Impact of Financial Barriers

As opposed to the uniformity of experiences about how financial barriers arose, we heard heterogeneous stories describing the impact that financial barriers had on participants. While some participants were profoundly affected by their financial barrier – with significant social, emotional and physical health repercussions – others stated that *"it's pinching but it's not exactly hurting yet"*. Upon discovering this wide variety in the impact of perceived financial barriers, we were left to consider and explore the reasons that one individual may be more affected than another. We heard that patients' experiences of having a financial barrier passes through a series of filters and a lens which contribute to the degree of resiliency displayed which determines the impact of the financial barrier, and may ultimately influence clinical outcomes.

4.4.2.1 Filters

Participants' experience dealing with financial barriers was shaped initially by a series of factors we have labelled filters. These were personal, inter-personal and experiential factors which could act in a protective fashion (to minimize the negative impact of financial barriers); a predisposing fashion (amplifying negative repercussions); or in a modifying fashion (having the potential to act in either protective or predisposing manners). Any given participant may have had any combination of these factors which is the starting point of how much potential for negative impact a financial barrier may have.

Protective Factors

Familiarity with Financial Difficulties

We heard from several participants that one's familiarity with living with limited resources and financial constraints played a significant role in how impactful a financial barrier could be in one's life. Participants who grew up in settings where finances were 'tight' spoke of having learned to budget, prioritize and live with minimal excess. These experiences, in turn, were helpful when they faced future financial constraints: "*Learning as a kid growing up that we need to budget because we don't have that money has been a Godsend. We were raised what to prioritize first.*"

Intrinsic Motivation

Several participants told us how their own self-motivation to maintain or improve their health protected them against the full impact of financial barriers:

> *I've talked to my doctor and I already told him that I'm gonna be very aggressive about this condition. I want it controlled completely by diet. I do not want to be taking medications for the rest of my life. If I have to I will but I'm gonna minimize them to the extent that I can.*

Intrinsic motivation was often manifested by a willingness to prioritize health care needs above nearly all else. Even in the face of very significant financial constraints, those who were self-motivated often described being able to meet their healthcare needs, largely through prioritization and budgeting: *"we cut other stuff out, whatever we have to cut out… I will never let my medications suffer. I need my medications"*.

Navigating Resources & Self-Advocacy

When one is faced with financial constraints it is important to be able to access resources that may be available. Participants identified numerous programs and subsidies which played important protective roles in their lives. These programs included: supplemental medication insurance; food banks; hospital and government programs for the provision of diabetes supplies; support for adaptive equipment; compassionate relief from pharmaceutical companies; and subsidies for fitness passes. To varying extents, each participant described resources upon which they relied to enable them to cope with their financial barrier.

Many participants acknowledged that one main problem was difficulty navigating the healthcare system and/or advocating for themselves to obtain the information or assistance they required. These participants seemed to struggle and only accessed resources when they were directly given to them: *"I don't know who else to access money from, I just… I haven't a clue."*. Another participant who recently moved from another province reported encountering difficulties identifying resources: *"It's been hard. I still don't know all the resources… everything is so split up here".*

Self-advocacy is operationalized as an individual's proactivity in speaking up for themselves when they feel they need something more than what was currently offered to them. Being able to effectively communicate with healthcare providers is a key navigation skill to overcome and mitigate an individual's financial barriers.

Participants demonstrated self-advocacy in a variety of ways: some approached their physicians and pharmacists to ask for generic medications, others found pharmacies with the lowest dispensing fees, and yet others found subsidy relief programs for various services by demanding them: *"I just had to do things on my own… you have to be willing to fight, you have to be willing to really push for what you want… you just learn to fight for yourself and just be strong. If you don't have the ability to do it nobody's gonna do it for you"*. Another participant felt unwell for some time following his hospital discharge, he stated: *"So after about a year I got a bit angry with the cardiologist and said look, there's a problem here, I want you to check what it is and fix it. And he kinda looked at me like who do you think you're talking to".* This participant's ability to advocate for himself led the cardiologist to order further testing and adjust his medications accordingly.

Several participants with higher levels of educational achievement stated that it was their education that enabled their self-advocacy ability. They expressed sentiments of compassion and empathy towards others with similar ailments and barriers but without their degree of education and competency.

Clearly, there was a 'skill set' that some participants demonstrated which enabled them to overcome financial barriers which was lacking for numerous others. Irrespective of participants' intrinsic navigation and self-advocacy skills, being connected with a program or social worker whose role was to seek and arrange appropriate resources was a universally protective factor. Participants praised healthcare providers that were able to help them navigate through the healthcare and community support systems: *"I mean these guys that I'm dealing with now with my heart problems… I've got nothing bad to say about these guys. They bent over backwards to get me back on [social programmes]. The nurses are real good to deal with"*.

Predisposing Factors

Perceived Injustice & Discrimination

Individuals who had been financially stable prior to their financial barrier arising were especially prone to faring poorly. They were not accustomed to experiencing tight financial circumstances: *"Emotionally I think it's very hard to go from a very independent single mom to all of a sudden have to worry about pennies"*. These people often described having undergone a very difficult identity transition or transformation. They were often particularly susceptible to feelings of shame and embarrassment.

Several participants voiced feeling sentiments of injustice or persecution. The injustice was either general (i.e. directed towards god, the universe, etc.…) or directed towards institutions (e.g. social service agencies, insurance companies, social assistance programs) or individuals (e.g. healthcare providers, the wealthy, family members). These sentiments were often based in significant negative experiences with these institutions or individuals.

Most participants described having had experienced some form of discrimination in their lives – from healthcare providers, service providers, police or the general public. They identified that this happened based on their illness/disability or because of their lack of financial means: *"…and then people look at you, some people that have money 'look at you, oh, you're just a welfare bum'"*. The dominant impression for many participants who felt persecuted or experienced discrimination was to develop feelings of inadequacy and inferiority which was not conducive to resiliency: *"You feel like almost like you're second class 'cause you don't have the money to do anything so if you don't have the money then you gotta be poor and so poor means you're second class"*.

Comorbidities

A variety of comorbid conditions acted to exacerbate and magnify the impact of financial barriers on participants' lives. These included: physical disabilities, chronic pain, and mental illness. Those who had physical disabilities and chronic pain described feeling stuck in their financial situation because their health limited their ability to work to improve their situation. This compounding effect of physical disability and financial barriers was particularly predominant among the cohort of participants who had suffered from strokes.

Participants who suffered from depression and/or anxiety disorders were especially susceptible to the impact of financial barriers. Some individuals identified that this experience exacerbated their mental health struggles through the inability to afford pursing their interests and social activities: *"Well, it's depressing, I have nothing to look forward to… I guess I'll be working the rest of the year just to make sure I can stay on top of these drugs"*. Others described having financial barriers to accessing mental health care services (e.g. counselling), which may be important for some participants to deal with the distress associated with chronic illnesses.

Another frequently identified comorbid situation was having had a personal history of traumatic experiences or difficult prior circumstances which hindered participants' mental and emotional ability to deal with additional challenges (such as financial barriers) in a resilient manner. These experiences included: physical and sexual abuse, unexpected deaths of loved ones, bankruptcy and financial mismanagement, criminal activity and prosecution, and addictions.

Modifying Factors

Situated between protective and predisposing factors in our framework are modifying factors. These are factors which by their very nature are dichotomous and have the potential to be either protective or predisposing.

Healthcare Provider Interaction

Healthcare providers had the potential to make a substantial impact in how participants perceived their financial barrier. Healthcare providers could either play a protective role (so as to minimize the effect of financial barriers) or through their interactions they may actually increase the impact of financial barriers by raising demands on patients with already limited financial resources.

Some participants outlined how various healthcare providers were very helpful and thereby minimized the effect of financial barriers. They recounted how their physicians offered to prescribe generic medications that were covered on their insurance plans. Others stated that their physicians found them samples to help them through particularly difficult times. Some spoke of providers who connected them with specific social programs, industry compassionate relief programs, or social workers who could address their financial burden and help them access necessary services.

By contrast, numerous participants described distinct negative experiences with a variety of healthcare providers. Some were described as exceptionally insensitive about their patients' financial circumstances: *"They don't understand the fact of 'well gee, mister, we need you to do this, we need you to do that'. Yeah, okay, but they don't take this all [the cost] into consideration".*

Other examples of negative experiences voiced by participants included feeling that their providers: do not care about their financial situation; have no ability to assist them; and/or discriminate against them on the basis of their financial situation. One participant recalled a negative interaction with a healthcare provider:

> *I needed new arch supports and she says "well you go and pay for 'em yourself"... she said "Oh, what do you think, you're a handout or what? Pay for it yourself." It's like, hello, how can I pay for my arch supports which are $450? I said I need them because I have fallen arches, I am a diabetic and I said feet are important, and she said "No, you don't deserve 'em". She humiliated me… Some people treat you like crap. They don't realize what you really go through in life and it's very degrading and as I said, it's been very hard.*

Many participants felt their providers simply could not understand the significance of their financial difficulties: *"Right now my doctor said 'no, you can't work, you can't work'. It's like,* *oh, I need to work, I need to get some money to survive. And I guess she really doesn't understand, I don't think she does."* Several participants voiced sentiments of frustration that their providers couldn't possibly understand the financial hardships that they face on a daily basis. Another example of this sentiment was a participant who stated:

> *They don't realize… I said you were a student at one time and I know you probably have big bills for your medical stuff… I know you were tight when you were going to school but come on, I probably live on less than what you did in school.*

Sometimes, patients recalled that their providers made recommendations without considering their financial ability to follow through: *"I tell 'em, I just say I can't afford it, just literally just cannot afford it. They want me to go and buy something and I said, 'Are you kidding, are you gonna pay for it?'"* Another participant recalled a specific instance of a provider not understanding how the patient's financial barriers would affect their ability to follow through with a prescription:

> *The doctor wanted to try me on [medication name], so she wrote me a prescription and I thought it was just gonna be, the pharmacist was gonna come out and grab something off the shelf. No, it wasn't and it was $160. I said I can't pay that. It wasn't covered.*

The most destructive experience patients described with their providers was when they felt that their providers had made unrealistic recommendations, being unaware or uncaring of their financial barriers, and then blaming the patient for their non-compliance with their instructions. A very potent example was one participant who recounted an interaction with her physician:

> *He said: "You're not interested in helping yourself". And I mean does that ever hurt your feelings, you go and sit in your car and cry. You think you made the effort to get down there to go to his appointments and make sure your blood work is done before your appointment and then he tells you that you're not interested in taking care of yourself.*

This participant recounted when this same physician was attempting to counsel her about choosing healthy foods:

> *He says to me "You can make yourself a great big sandwich for lunch with lettuce and tomatoes and cheese and a luncheon meat in there and crunch down on it". I thought, 'yeah, right, where do you come from? Maybe you can do that but I can't!' He made it sound like I'm just a lousy person. That's how I feel sometimes.*

Healthcare providers can be protective agents against the impact of financial barriers simply by asking patients about the presence of these as part of their routine clinical practice. We heard that often patients felt that some providers were more interested in their ability to afford treatments than others. One participant in particular implied that their specialist physicians simply didn't seem to have much interest in the reality of their financial barriers: *"My family doctor's very well aware of it, so is the pharmacy, they're great, in fact they're really, really great. And my specialists, they don't need to know, you only see them, you know…"*

Coping Mechanisms

Participants utilized a variety of coping strategies to deal with stressful circumstances related to the financial barriers they experienced. The psychology literature often refers to healthy strategies as 'adaptive' and negative coping as 'maladaptive'. One of the primary distinctions is that adaptive coping is ‘problem focused’, while maladaptive coping tends to be ‘emotion focused’ [116]. There were very clear examples of both types of strategies employed by our respondents. Adaptive, problem-focused coping strategies were plentiful among those who displayed determination/resiliency, such as: *“So the less money you make, you adjust… I mean sure it took a while to get used to but we’re getting by now”*. By contrast, emotion-focused coping strategies were predominant among the less resilient: *“Nowadays I can’t do nothing. It’s kind of frustrating… sometimes I’m still crying… Like I’m frustrated or devastated and I just flare out*”.

Individual Responsibilities

Many participants described having a variety of personal, family and professional obligations. Some described these as factors contributing to the stress of their financial barrier, while others felt that having external responsibilities helped them to cope with their barrier. For example, one participant described how he had several children to support both financially and emotionally; he needed to be strong. His strength was a source of comfort to his family through their very difficult times.

Conversely, a participant who was an immigrant to Canada had suffered a debilitating stroke, she could no longer afford to provide resources to her extended family in her home country. In this instance, she experienced guilt and stress about no longer being able to provide for them, and these responsibilities were deleterious: *“I supposed to help them but I am not… I said to my husband, ‘how can I help them when I can’t even help myself?’. They’re the ones to have to help me”.*

Social Support / Isolation

A variety of social influences on participants were modifying factors. Those who had strong social support networks were protected from negative impacts of their financial barriers. Social support could come from family, friends or even fellow patients and could come in the form of emotional support: *"What do I have to live for, really? I know I have my daughter which keeps me going"*, or financial assistance: *"We've always managed. We sacrifice, all my kids work and they throw in money for me too. We're a big loving family"*. Another important role of social support was that with more people helping out, healthcare system navigation abilities were enhanced. For example, one elderly participant's son purchased a used treadmill online which enabled her to remain physically active.

Social isolation plays an important role in the impact of having a financial barrier. Participants who felt some degree of isolation prior to experiencing their financial barrier were particularly negatively impacted. Many participants' primary social interactions involved some degree of spending (e.g. dining out, going for coffee) and they described having to substantially cut back on these activities because of their financial barrier, which often worsened feelings of isolation and despair: *"I don't go out to dinner… I don't go to shows, I don't go to concerts. I don't have much of a social life. I have some friends, but I don't do a lotta things in terms of going out places"*. For some this had significant consequences on their lives: *"I'm really becoming a shut in now I think… a lot of it is because I can't afford to do anything"*.

4.4.2.2 Lens

The aggregate of the various filters an individual possesses (protective, predisposing and modifying factors) often foreshadowed how impactful a financial barrier would be for any given participant. However, these filters were then viewed through the lens of an individual's attitude or worldview. For example, we heard stories of participants whose combination of filters were strongly predisposing – whom one might presume would experience significant negative impacts from their financial barrier – but who were able to rise above these challenges and keep the impact of their financial barrier to a minimum due largely to a positive worldview: *"I try to stay positive and… you know what, that's a great life. So I take my little treasures, my little trinkets and put it in my pocket and that carries me"*. Some of those with more positive worldviews described being shaped by religion or faith: *"I've never been without, the Lord has always provided and my faith is huge"*, while others leaned on a reliance in karma or fate: *"I've been pretty lucky. In the 11th hour things turn around and things happen and it gets better, so something will happen"*.

By contrast, there were other participants whose worldview was one of negativity and denial, which had the potential to overturn even the most positive set of protective factors. For example, a participant with post-secondary education, no comorbidities or traumatic life experiences, and a reasonable income stated categorically: *"Well I don't foresee this getting any better"*.

The 'lens' is an important element of the framework as it emphasizes that while a participants' underlying circumstances (i.e. filters) have a strong direct effect on the perceived impact of financial barriers, these are not necessarily deterministic – some participants with financial barriers and overall very difficult situations and backgrounds were able to achieve resiliency, at least partly due to positivity or faith.

4.4.2.3 Resiliency

Research team members and participants agreed that resiliency was the overarching theme that ran through virtually all experiences, even if participants did not name it as such. Some of the terms used to describe the notion of resilience included: *'perseverance'*, *'a constant battle'*, *'managing'*, *'getting by'*.

We conceptualized that the combination of filters and the lens projected each participant's experience somewhere on a spectrum of resiliency, ranging from determination to despair. Participants who demonstrated determination were exceptionally resilient and had the capacity to thrive in the face of significant financial barriers. These were individuals who continued to strive for positive mental and physical health despite the challenges in their path: *"Well, I think I'm just the type of person that doesn't let things, I mean I've had a tough life my whole life, but if I let everything bother me I'd be in a looney bin. [Laughter] So you can't, but I know there's a lot of people that get stressed out with everything"*.

Conversely, participants with a predominance of predisposing factors and a negative worldview often seemed to default to despair when the stress of their financial barrier and health concerns overwhelmed their ability to cope:

> *You know, you try and do all these things for your health and all that does is cost, cost, cost. So then you think 'ahh ok I'll just stay fat, keep smoking, maybe I should take up drinking too'. I'm frustrated because I'm trying so hard to get healthy, and it's just costing so much.*

There was a remarkable consistency in the idea of this experience being an ongoing struggle.

This was described using a number of phrases, some described: *'going in circles'*, *'chasing my tail'*, *'a chicken and egg thing', 'catch 22'*. However, the most commonly cited metaphor for this sentiment was that of a *'vicious cycle*' or *'downward spiral'* – represented graphically in the framework nested within the resiliency spectrum. The use of this graphic was validated through member checking, as participants strongly related to the idea that even if they were near the top of the resiliency spectrum, there is always a constant downward force that they had to battle daily. Several also voiced that once one starts down the spiral, it is a steep descent to despair and very difficult to climb back out.

4.4.2.4 Clinical Outcomes

While not the focus of this paper, several respondents described experiencing adverse clinical outcomes such as worsened disease control, emergency department visits, inpatient admissions or cardiovascular events. These adverse events were almost always described as being preceded by at least one of several deleterious behaviours including: inability to follow through with lifestyle/health behaviour modifications, discontinuation of regular self-monitoring, missing appointments with healthcare providers, and/or becoming non-adherent to preventive medications.

Anecdotally, adverse events seem to be associated with a participant's resiliency level. This is to say that a participant with a relatively minor barrier who had a predominance of predisposing factors and a negative worldview seemed to have less resiliency and be more prone to adverse events. However, even those with more significant barriers could overcome them through use of protective factors and a positive worldview thereby approaching their barrier with greater determination and resiliency, minimizing the likelihood of adverse events.

4.5 Conclusions

Using grounded theory methodology, we developed a novel framework to specifically understand the experience that patients with cardiovascular-related chronic disease may have in the face of financial barriers. We describe a variety of filters that influenced how impactful a financial barrier could be on any given patient, and when interpreted through an individual's worldview, their degree of resiliency was revealed. Although prior studies have suggested an association between experiencing financial barriers and adverse clinical outcomes [54][see Chapters 2 & 3], the nature or reasons for this association has been uncertain to date. Our study suggests that the link between these two phenomena is likely more complex than was previously envisioned. The potential of financial barriers to affect future adverse events may be closely linked to an individual patient's degree of resiliency, which results from their unique series of filters and their lens or worldview.

Coming from primarily clinical backgrounds, we anticipated hearing from patients how their financial barriers resulted directly in adverse medical outcomes. Given that a perception of financial barriers was requisite for study eligibility, we had assumed that financial barriers would have similar effects on all participants. This was not in fact the case, with the significant heterogeneity in the impact of financial barriers providing some of our richest findings.

This is a relatively small study (though adequate for qualitative work of this nature [117]), thus we cannot claim that this proposed framework will be representative of every individual who experiences a financial barrier. However, true to the principles of qualitative research, the objective of the study was to obtain a deep and thorough understanding of this phenomenon rather than striving for sampling adequacy from a quantitative perspective. The transferability of our study may be questioned given that we only included patients with cardiovascular-related chronic conditions. However, this framework could be applicable to other chronic conditions, such as respiratory or gastrointestinal chronic diseases (e.g. emphysema or inflammatory bowel disease), for example. There are, however, likely some chronic conditions, such as mental illness that may be experienced in substantially different ways than the more physical conditions we have described. It is also important to note that financial barriers are not exclusively reserved to those who have chronic diseases, as individuals who have limited financial resources may face financial barriers to accessing episodic care they may require – our framework is likely not transferable to this population.

Finally, the geographic transferability of the framework may be questioned on the basis that it was developed from a cohort of Canadian participants from the province of Alberta. Internationally, it is true that the nature of financial barriers may differ from one country to another (e.g. Western European nations with comprehensive health insurance versus the United States with a predominance of private insurance and large numbers of uninsured individuals). However, we feel that Canada is somewhat of a middle ground, with public coverage for physician and hospital services but primarily private coverage for medications. Furthermore, Medicare coverage for Americans over the age of 65 years is similar to the programs offered in Alberta. Under the Affordable Care Act, non-senior Americans are compelled to purchase or obtain private health insurance with significant premiums and copayments that may pose financial barriers [118]. While the exact services to which barriers are experienced may differ, the process experienced by individual patients is likely similar across countries, so the principles of our framework likely apply to settings beyond Canada.

Our framework can be used as the basis for future research on the topic of financial barriers. Investigators interested in the impact of financial barriers now have a dedicated conceptual framework, which is grounded in data, upon which to base their research questions and approaches. One particularly rich area for future research would be trying to quantify the associations between financial barriers, aspects of resiliency and clinical outcomes. Furthermore, we feel that our framework is instructive for clinicians who are likely to encounter patients who experience financial barriers. Clinicians should consider the various factors which contribute to their patients' likelihood of succeeding in self-management in the face of financial barriers and how they might contribute to bolstering protective factors while minimizing those that might predispose patients to the negative effects of their financial barriers.

This novel framework may also serve as a template for future health policy in the area of improving accessibility to healthcare services. Our framework demonstrates that in healthcare systems where the complete elimination of financial barriers is not possible or not feasible, other strategies may be employed to minimize the effects of these barriers, including enhanced provider education, improved patient navigation and adequate subsidy and support programs.

4.6 Tables & Figures

Table 4.1

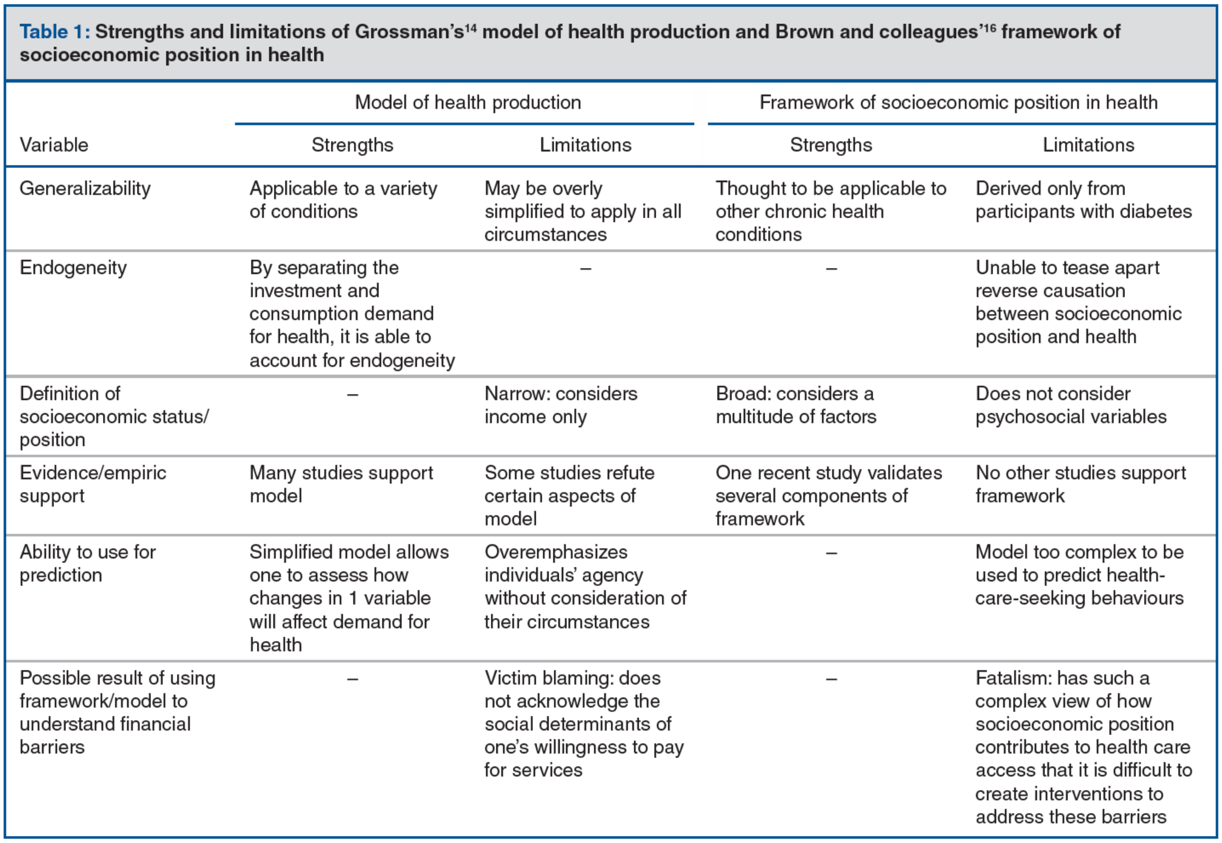
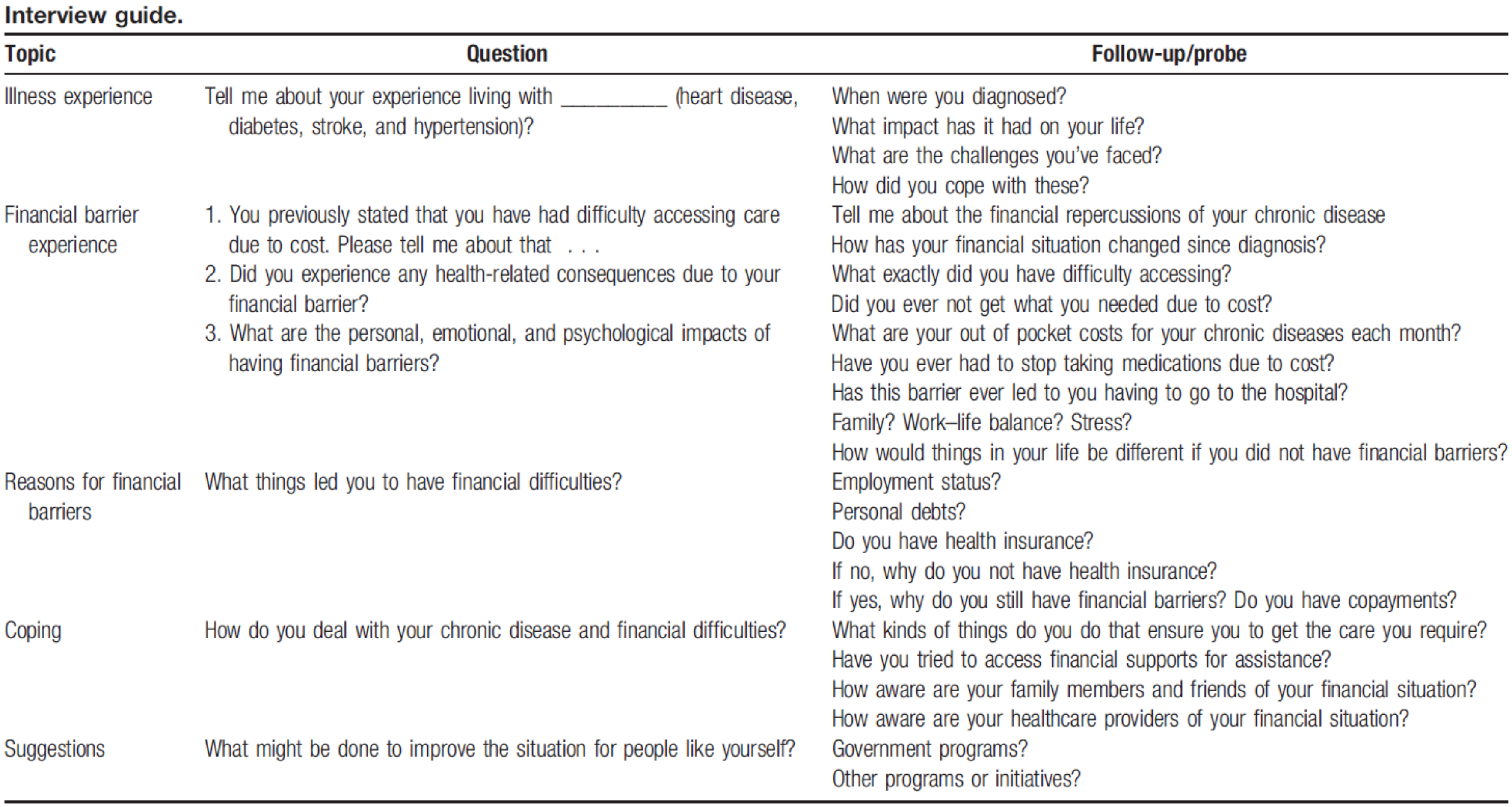


Table 1: Strengths and limitations of Grossman's[14] model of health production and Brown and colleagues'[16] framework of socioeconomic position in health

	Model of health production		Framework of socioeconomic position in health	
Variable	Strengths	Limitations	Strengths	Limitations
Generalizability	Applicable to a variety of conditions	May be overly simplified to apply in all circumstances	Thought to be applicable to other chronic health conditions	Derived only from participants with diabetes
Endogeneity	By separating the investment and consumption demand for health, it is able to account for endogeneity	–	–	Unable to tease apart reverse causation between socioeconomic position and health
Definition of socioeconomic status/ position	–	Narrow: considers income only	Broad: considers a multitude of factors	Does not consider psychosocial variables
Evidence/empiric support	Many studies support model	Some studies refute certain aspects of model	One recent study validates several components of framework	No other studies support framework
Ability to use for prediction	Simplified model allows one to assess how changes in 1 variable will affect demand for health	Overemphasizes individuals' agency without consideration of their circumstances	–	Model too complex to be used to predict health-care-seeking behaviours
Possible result of using framework/model to understand financial barriers	–	Victim blaming: does not acknowledge the social determinants of one's willingness to pay for services	–	Fatalism: has such a complex view of how socioeconomic position contributes to health care access that it is difficult to create interventions to address these barriers

Reproduced From: Campbell et al. (2016). *CMAJ Open*, 4(2): E304-308.

Table 4.2

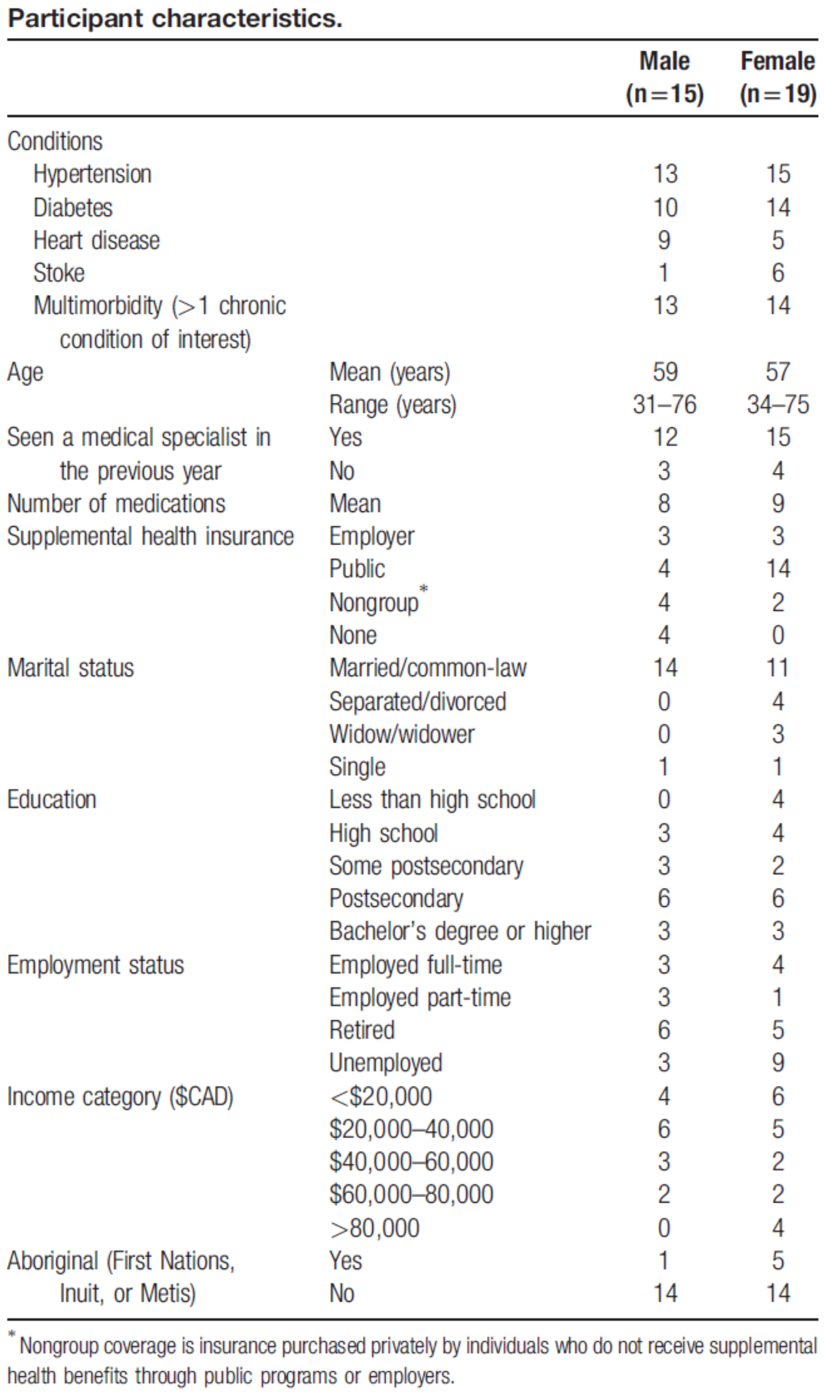


Interview guide.

Topic	Question	Follow-up/probe
Illness experience	Tell me about your experience living with __________ (heart disease, diabetes, stroke, and hypertension)?	When were you diagnosed? What impact has it had on your life? What are the challenges you've faced? How did you cope with these?
Financial barrier experience	1. You previously stated that you have had difficulty accessing care due to cost. Please tell me about that . . . 2. Did you experience any health-related consequences due to your financial barrier? 3. What are the personal, emotional, and psychological impacts of having financial barriers?	Tell me about the financial repercussions of your chronic disease How has your financial situation changed since diagnosis? What exactly did you have difficulty accessing? Did you ever not get what you needed due to cost? What are your out of pocket costs for your chronic diseases each month? Have you ever had to stop taking medications due to cost? Has this barrier ever led to you having to go to the hospital? Family? Work–life balance? Stress? How would things in your life be different if you did not have financial barriers?
Reasons for financial barriers	What things led you to have financial difficulties?	Employment status? Personal debts? Do you have health insurance? If no, why do you not have health insurance? If yes, why do you still have financial barriers? Do you have copayments?
Coping	How do you deal with your chronic disease and financial difficulties?	What kinds of things do you do that ensure you to get the care you require? Have you tried to access financial supports for assistance? How aware are your family members and friends of your financial situation? How aware are your healthcare providers of your financial situation?
Suggestions	What might be done to improve the situation for people like yourself?	Government programs? Other programs or initiatives?

Reproduced from: Campbell et al. (2016). *Medicine,* 95(49): 1-8.

Table 4.3



Participant characteristics.

		Male (n=15)	Female (n=19)
Conditions			
Hypertension		13	15
Diabetes		10	14
Heart disease		9	5
Stoke		1	6
Multimorbidity (>1 chronic condition of interest)		13	14
Age	Mean (years)	59	57
	Range (years)	31–76	34–75
Seen a medical specialist in the previous year	Yes	12	15
	No	3	4
Number of medications	Mean	8	9
Supplemental health insurance	Employer	3	3
	Public	4	14
	Nongroup*	4	2
	None	4	0
Marital status	Married/common-law	14	11
	Separated/divorced	0	4
	Widow/widower	0	3
	Single	1	1
Education	Less than high school	0	4
	High school	3	4
	Some postsecondary	3	2
	Postsecondary	6	6
	Bachelor's degree or higher	3	3
Employment status	Employed full-time	3	4
	Employed part-time	3	1
	Retired	6	5
	Unemployed	3	9
Income category ($CAD)	<$20,000	4	6
	$20,000–40,000	6	5
	$40,000–60,000	3	2
	$60,000–80,000	2	2
	>80,000	0	4
Aboriginal (First Nations, Inuit, or Metis)	Yes	1	5
	No	14	14

* Nongroup coverage is insurance purchased privately by individuals who do not receive supplemental health benefits through public programs or employers.

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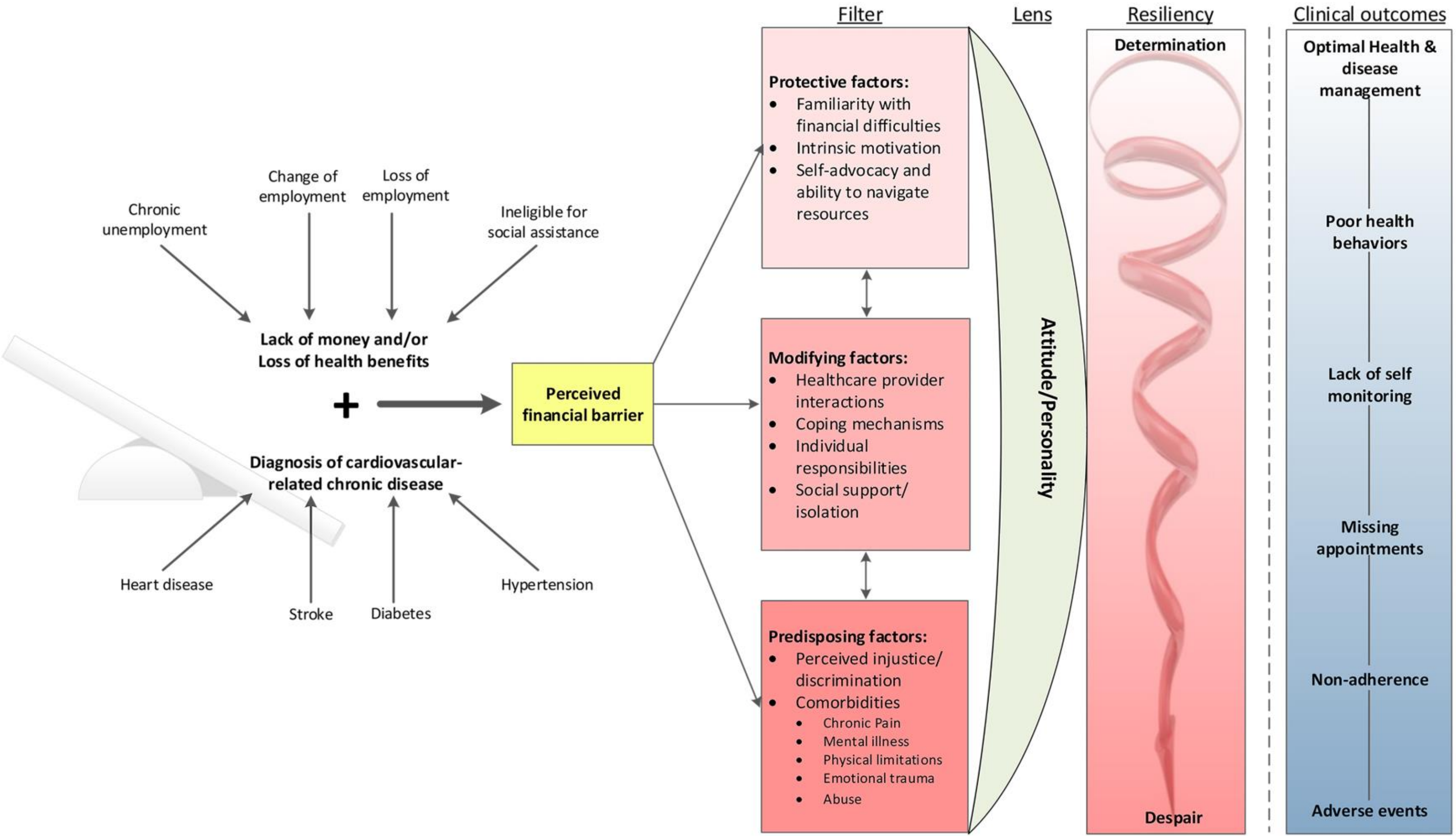
Figure 4.1: Finding Resiliency in the Face of Financial Barriers: A Conceptual Model



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CHAPTER 5:

QUALITATIVE DESCRIPTIVE ANALYSES OF FINANCIAL BARRIERS EXPERIENCED BY PARTICIPANTS WITH DIABETES MELLITUS, CORONARY ARTERY DISEASE AND STROKE

Our main objective in the grounded theory study described in Chapter 4 was to explore the process of how participants experience financial barriers. However, in the process of collecting this data we uncovered a wealth of patient data about the types of barriers they face and some strategies that are used to overcome such barriers. We undertook secondary qualitative descriptive analyses of these previously collected data and present a summary of these findings in Chapter 5.

Parts of this chapter are published as:

Campbell DJT, Manns BJ, Hemmelgarn BR, Sanmartin C, Edwards A, King-Shier K. (2017). *Understanding Financial Barriers to Care for Patients with Diabetes: An Exploratory Qualitative Study*. The Diabetes Educator, 43(1).

Ganesh A, King-Shier KM, Manns BJ, Hill MD, **Campbell DJT.** (2016). *Money is Brain: Financial Barriers and Consequences for Canadian Stroke Patients.* Canadian Journal of Neurological Sciences, 44(2). Reprinted with Permission.

Dhaliwal KK., King-Shier KM, Manns BJ, Hemmelgarn BR, Stone J, **Campbell DJT.** (2017). *Exploring the Impact of Financial Barriers to Care for Patients with Coronary Artery Disease: A Qualitative Descriptive Study.* BMC Cardiovascular Disorders, 17(61).

5.1 Abstract

Background

Patients with cardiovascular-related chronic diseases experience various barriers which impact their ability to optimally manage their condition. Financial barriers may result in cost related non-adherence to medical therapies and recommendations, impacting patient health outcomes. Patient experiences regarding financial barriers remain poorly understood. Therefore, we used qualitative methods to explore the experience of financial barriers to care among patients with cardiovascular-related chronic diseases.

Methods

We conducted secondary descriptive analyses of interviews with patients who fell into three cohorts based on chronic conditions (diabetes, CAD, stroke). These interviews were previously undertaken for a larger grounded theory study. Semi-structured interviews were undertaken either face-to-face or by telephone. Data analysis was performed independently for each cohort by two or three reviewers using inductive thematic analysis.

Results

Participants with diabetes commonly describe difficulties accessing diabetes supplies, prescription medications and healthy food to manage their condition. Those with CAD recounted financial barriers to medications, cardiac rehabilitation and psychological support services, as well as facing difficulties with transportation and parking. The stroke cohort described very similar concerns as the other cohorts but particularly focused on financial barriers in accessing rehabilitation services after their stroke.

Discussion

While there were some similarities in the types of goods and services that patients attempt to access, there were some differences. Barriers arose predominantly in three areas: 1) uninsured goods and services; 2) costs associated with self-management; and 3) incidental costs associated with insured services. We found that participants voiced difficulties accessing numerous goods and services despite the availability of numerous programs to facilitate appropriate use of these resources. We conclude that in several cases, patients' financial barriers may be best described as "perceived", and being primarily driven by lack of understanding or potentially unrealistic expectations.

5.2 Background

Patients with cardiovascular-related chronic conditions often face financial barriers – difficulties in receiving care or following through with recommendations due to fiscal constraints. More than 10% of Canadian patients with chronic conditions, including diabetes, report financial barriers [119]. In part, these barriers are related to the need for multiple medications, which can limit adherence [48, 120]. These conditions also disproportionately affect those with lower socioeconomic status [121, 122] – the same group who is most likely to have limited financial resources. In Canada, all citizens and residents have free access to hospital services and medically necessary physician services. However, outpatient medications are not universally covered. Even those with supplemental insurance are still subject to user charges (approximately 20-30% of medication cost plus arbitrary pharmacy dispensing fees) [28].

Although financial barriers and cost-related non-adherence have been associated with poor clinical outcomes [123-125], the preeminent barriers often in the minds of many physicians are those individual to patients, such as lack of motivation [126], while the experience of financial barriers remains poorly understood. Individuals' experiences with financial barriers have not been described in detail. This is particularly concerning as healthcare providers may be unaware of the struggles their patients encounter and may be ill-prepared to help them overcome the root causes of non-adherence to the therapies they prescribe. Being unaware of patients' individual circumstances and how financial barriers are operationalized in their lives may lead to victim blaming – or blaming non-adherence on personal choices without understanding the constraining context of those 'choices' [127].

Qualitative methods are well suited to gaining an in-depth understanding of phenomena. They are also useful in studying difficult to quantify topics such as how people's perceptions and social factors influence health and health behaviour [128, 129]. Qualitative research has been described as being particularly important in research on CAD [130, 131], stroke [132] and diabetes [133] as it "helps us understand the perspectives that providers and patients bring to their clinical encounters because it can shed light on the causes of undesirable care and therapeutic outcomes" [133]. The purpose of this study was to qualitatively explore the experiences of patients with cardiovascular-related chronic diseases who have financial barriers and the mechanisms they use to cope with such barriers.

5.3 Methods

5.3.1 Design

A secondary analysis of qualitative data was carried out with participants who participated in a broader grounded theory study. We undertook the grounded theory study to develop a new framework for understanding the experience of financial barriers in patients with cardiovascular-related chronic disease (See Chapter 4). In this chapter, we report a qualitative descriptive analysis [134] that describes and elaborates on the perspectives and views of patients regarding the specific aspects of their care to which they face financial barriers.

5.3.2 Participants

Participants were recruited via signage in physician offices and pharmacies in Calgary, Alberta and surrounding areas, as well as through pre-existing research and clinical databases. Purposive sampling [111] was used by pre-identifying strata important to have represented in the pool of participants (e.g., age, sex, aboriginal status, number of chronic conditions). To be eligible for participation in the original study, participants must have self-reported having at least one of: diabetes, hypertension, heart disease or stroke, and also answered affirmatively to the following question:

> *"Some people have difficulty paying for services, equipment, and medications for chronic conditions. Other people may have difficulty paying for transportation or childcare to allow attendance at doctors' appointments… In the past 12 months, did you have difficulty paying for services, equipment, medications for your chronic conditions?"*

Canada has a publicly funded universal healthcare system that provides a narrow range of services with no financial cost at the point of care, including physician services and hospital care. Public coverage for ancillary services, such as outpatient medications and allied healthcare providers, varies across provinces [27]. In many provinces, including Alberta, Canadians under the age of 65 years who are not receiving financial assistance often can only obtain insurance for these services through employment benefits or out-of-pocket purchasing.

5.3.3 Sampling and Data Collection

The detailed methods for the full grounded theory study are included in chapter 4. Sampling and data collection continued until saturation was achieved for the overall grounded theory study. Data were collected using semi-structured face-to-face and telephone interviews, conducted between January and April 2015.

5.3.4 Data Analysis

Interviews were digitally recorded and professionally transcribed. Transcripts were imported into NVivo 10 software (QSR International: Doncaster, Australia) for analysis. Thematic analysis

[113, 114] was used for this qualitative descriptive study. This process begins with line-by-line coding of each transcript to distil the underlying meaning of each passage. After initial coding of the first few transcripts, a coding template was created encompassing the major codes. This template was iterative and new codes were added as required by the data. Analyses were done independently by three reviewers. All reviewers met to discuss their interpretations of the data – codes were merged and collapsed to form broader categories or themes. Consensus among reviewers was sought. This process was refereed by a fourth experienced qualitative researcher, as needed.

5.4 Results

We included nearly all participants from the broader grounded theory study in this qualitative descriptive analysis (32 of 34; as 2 had only hypertension). This analysis includes 24 patients with diabetes, 13 with CAD, and 6 with stroke. Several participants were included in multiple cohorts for the analyses presented below: 8 participants had both diabetes and CAD, 2 participants had both diabetes and stroke, and one participant had all three conditions of interest (Figure 5.1).

5.4.1 Diabetes Cohort

Twenty-four participants with diabetes (including 10 who use insulin), comprised of 10 men (mean age 59 years) and 14 women (mean age 57 years) were interviewed (Table 5.1). They predominantly had lower incomes (16/24 ≤$40,000 CAD/year/household, gross). Consistent with expected levels in Alberta (see Chapter 2), 95% (23/24) had supplemental health insurance, to cover health expenses which are not included in universal public health insurance (i.e. medications and medical supplies).

Patients with diabetes reported financial barriers to a number of different goods and services that they require for the optimal management of their condition. The predominant aspects of care to which patients experience financial barriers were related to obtaining: diabetes supplies, medications, and healthy/nutritious food.

5.4.1.1 Diabetes supplies

Patients with diabetes, particularly those managed with insulin therapy and insulin secretagogues, are at risk of hypoglycemia and are directed to monitor their blood glucose levels multiple times per day. This monitoring requires a glucometer, glucose testing strips and lancets.

Nearly every participant reported having difficulty paying for their self-monitoring supplies. As expected, this theme was particularly prominent amongst those with type 1 diabetes and those with type 2 diabetes who are managed on insulin. These individuals unanimously commented that the level of public funding was insufficient to meet their needs, for example: *"They give me $600 to help to do them and oh, they cost $90 a box and I say I go through a box and a half a month. I said I'm gonna run out."*

Because patients use self-monitoring to titrate their insulin doses it is not surprising that participants described that their financial barriers to testing supplies impacted their glycemic control: *"It has gone up and I wonder what was my blood [glucose] up for? Oh yeah, you didn't do your testing earlier,"* and may predispose to dangerous lows: *"So I kinda had to go without, which was scary because I wasn't sure if I was low or high."*

The most commonly described strategy to deal with financial barriers to accessing testing supplies was to stretch the publicly funded allotment. This was usually accomplished by decreasing the frequency of testing: *"I am not checking the 4 times a day that the pharmacy required. I'm doing today after I woke up, tomorrow before lunch, after tomorrow before supper and the following day at bedtime."* However, some other individuals described not testing for prolonged periods after their supplies ran out: *"Whenever things got tight, I quit buying strips"*. Some indicated that they stopped testing routinely and alternatively test on an ad hoc basis, as they feel necessary: *"I measure a couple hours after a meal if I'm not feeling right. I've learned to identify my feelings."*

Participants also described similar barriers and strategies for other supplies, such as dextrose tablets and insulin pen needle tips: *"I would stretch 'em by using the same needle more than once. Yeah, I mean you can say oh, well that's horrible, it's unhygienic… that little, little thing helps a little bit."* Another participant stated: *"Realistically it's too expensive to use one [new] needle every time"*.

5.4.1.2 Medications

Patients with diabetes often require other cardio-protective medications, beyond their anti-diabetes agents, which include ASA, statins, and ACE-inhibitors or angiotensin receptor blockers. Patients with diabetes commonly have comorbid conditions that require medical management. The majority are therefore taking many medications (mean = 9). Unfortunately, most individuals described experiencing financial barriers to obtaining their prescription medications.

Despite the fact that nearly all participants had supplemental insurance, the user charges still represented a significant barrier for many people: *"…[for] just the medication I think my* *husband and I, because he has diabetes as well, I think we're paying almost four hundred dollars a month on medication. That's our portion of it. That's not even you know, what's covered."*

Furthermore, many participants described periods where they were completely without insurance – either due to job changes, loss of employment or retirement: *"I worked for a company that does have a health plan but because I'm [now] a contractor, they have an extended period of time before health coverage kicks in."*

These barriers can lead to cost-related non-adherence: *"If we had to buy another batch of pills or something… well, we would go without until such time as we did either have some cash left or find space on the credit card."* Another example was a participant with severe insulin resistance who decided she could not afford to continue the recommended up-titration of her insulin dose:

> *I've stopped taking more insulin because I was supposed to continue to go up but I've gotten to 300 units now, that's a whole disc for the pen and yeah, I just refuse to go over that. That's just… it's crazy that's the amount of insulin that I'm taking. And it's very expensive.*

One participant's specialist wanted to add a new anti-diabetes medication to his regimen. Since this particular agent was not covered on the provincial formulary, the patient and his spouse decided that they simply could not afford the costs of that medication and are trying to manage as best as they can with agents that are covered. He described that he still hasn't been able to achieve adequate glycemic control: *"It is not what I would like. We don't know… we're just surviving."*

Participants described employing a number of strategies to overcome their financial barriers and allow them to access medications. These included personal strategies, insurance strategies, and prescribing strategies.

Personal: These strategies related to individual choices and behaviours patients may utilize to offset the effect of their financial barriers. Most commonly, this was related to budgeting, limiting unnecessary expenditures and prioritizing one's health above other potential expenditures: *"At the end of the day I've been lucky that I can afford it. I mean I've gone without other things so that we can get it, you know, the medications are my priority."*

Insurance: Seniors and most of those who are employed have supplemental health benefits that cover the majority of their medication costs in Alberta. However, younger individuals who are unemployed or self-employed have no such benefits, and insurance must be purchased privately. Some choose to purchase additional health insurance to offset the costs of their medications. One participant identified that due to their pre-existing diabetes, when they calculated the out-of-pocket costs of insurance premiums and subsequent copayments, it was either equal to or more expensive than simply paying 100% of their medication costs out of pocket – so it was not clearly advantageous to purchase supplemental health insurance: *"It's costing me over $2,000 a year in premiums… so I mean it was just about a trade-off, is it worth spending $2,000 for $1,800 worth of coverage? Doesn't make much sense, right?"*

Prescribing: Participants described using a few strategies related to prescribing and dispensing. These included: (1) requesting that their physician prescribe each refill of their medications for 90 days, thereby minimizing payments required (as there are maximum copayments per medication): *"I ask for three months at a time that's what our coverage will cover, usually, three* *months, and I do that because I don't want to pay the dispensing fee every month;"* (2) requesting free samples of medications; (3) finding pharmacies with the lowest dispensing fees; and (4) asking physicians to prescribe generic medications.

5.4.1.3 Healthy Food

The optimal management of diabetes requires more than regular self-monitoring and adherence to prescribed medications. Health behaviour modifications are a cornerstone of diabetes management. Consumption of a healthy diet is particularly relevant for patients with diabetes – to improve glycemic control and minimize hypoglycemic episodes. Unfortunately, nearly every participant recounted experiencing significant financial barriers to eating a healthy diet as recommended by their healthcare team. One participant noted: *"It's a shame, if you're a diabetic, anything that's good for you, they charge more… it's true, anything that's good for you they charge more money."* Others described how the contrast to unhealthy food is particularly problematic:

> *And I really find that to be the challenge: buying the proper foods because as we all know, a bag of chips is a dollar and an apple is three dollars. You know, I would prefer the apple and not the chips but you don't get what you really need on a limited budget.*

Similar to medications, the most commonly described strategy for obtaining healthy food was budgeting and prioritization. However, it was far more common for participants to describe that adherence to dietary recommendations was a casualty to their budgeting which enabled them to get their medications: *"We make sure that we buy it [medication]. We prefer to cut in food, then our medicines."*

Other strategies that were commonly described included having individual or community gardens as well as fresh produce boxes: *"They have what they call the 'Good Food Box' which is all fruit and vegetables. Ours came in this week so I had gotten one of them this week and there's a lot of stuff. For $20 there's a lot of stuff in those boxes."* Some participants stated that they often had to access food from the Food Bank, which often was not particularly healthy or diabetes-friendly.

Patients also noted that the inability to access healthy food contributed to worsening glycemic control:

> *I need specialized food. And a very important part of a diabetic's food is fresh fruit and vegetables.... And when you don't have the money to buy food you don't have fresh fruits and vegetables so it has an impact on my blood sugars 'cause I can't be as aware of what I'm eating as I would be normally. So, it's tough on my diabetes, the months that I can't buy food.*

5.4.2 Coronary Artery Disease Cohort

We interviewed 13 participants with heart disease, 9 men and 4 women (Table 5.2). The age range was from 47 to 75 years. Most participants identified that they had a prior myocardial infarction (9/13). All participants had comorbid hypertension and/or diabetes. The median number of medications was high: 9 for men and 8 for women. The majority of participants had supplemental health insurance to cover the costs of medications (10/13). Most participants were married (9/13), retired or unemployed (10/13), with reported household incomes <$40,000 Canadian dollars (10/13).

Heart disease patients experience significant financial barriers to various aspects of care. These may hinder patients from accessing crucial healthcare services, and potentially contribute to worse health outcomes. The most prominently described aspects of care to which participants perceived financial barriers included access to: medications, cardiac rehabilitation and exercise, psychological support, and transportation/parking costs.

5.4.2.1 Medication Access

Medical therapies are critical to preventing future cardiovascular events. Nearly all participants raised concerns regarding the affordability of their medications. Unfortunately, many participants reported that paying for their required cardioprotective medications consumed much of their budgets: *“You kinda scrimp and save and pull all your resources together and then the cost of your medication just about gobbles that up.”* Similarly, another participant stated about her medications: *“well look at how much money I would save [if I stopped taking them]”.*

Several participants stated that their financial barriers resulted in cost-related medication non-adherence: *“The more you burden people with the medical costs the worse off they are. They can’t concentrate on getting better. Let’s face it, I’m sure it’s well known that people don’t take their pills. They can’t afford to.”* In the worst cases, some participants identified that their cost-related non-adherence led to adverse clinical outcomes: *“I was off them for 3 months and I really didn’t feel any difference. And then when you end up in hospital and realize that maybe I should’ve been taking them, kind of an eye opener but it’s an everyday struggle.”*

Participants discussed various strategies to overcome their financial barriers with respect to medications, including: prioritizing some medications over other needs; obtaining additional insurance; and the use of government programs. Some participants ‘separated’ their medications into essential and non-essential categories. For example, one participant said: *"Well my medication, my diabetes, the Metformin, I'll continue buying that but the rest of it will go by the wayside."* Unfortunately, some participants had to prioritize their medications over other critical preventive health needs, such as healthy food: *"And that's something that I have to do… if it's medication or food, well it's gonna have to be the medication in order to live and to get through this."*

Even though most respondents had supplemental health insurance, often sponsored by the government or employers, only a small number of participants reported being adequately insured. Many of those who had insurance reported substantial out-of-pocket costs in the form of copayments: *"Part of my prescriptions are paid by my company but still it's an expense... [For] a lotta people it'd be like $135, wow, that's not very much but for me it's still a lotta money."*

Some participants identified that government income support programs (which generally also include full coverage for medications) helped them overcome financial barriers: *"If it wasn't for me getting on [government program] and getting help with medication… it was costing me over $500 a month."*

5.4.2.2 Cardiac Rehabilitation and Exercise

Physical activity, especially in the context of a structured cardiac rehabilitation (CR) program is important to minimize the risk of subsequent cardiovascular events [135]. In this study, participants universally described being referred to a CR program following hospital discharge, and being encouraged by healthcare providers to engage in physical activity. Unfortunately, for many, participation in exercise activities was hindered by the cost: *"The downside of physical activity (is) I can't afford to even do that."*

In Alberta, there can be considerable direct fees for CR patients, however these can be waived if the patient states that they are unable to pay. Several participants were unaware of the fee waiver program and expressed concerns regarding the fees: *"I was shocked, like absolutely jaw dropping shock when I heard that it was gonna be like the huge amount, that it was gonna be"* and *"It was never said that there's financial assistance if you need it."* Another participant was advised of the program, but stated: *"The fee…they said it could be like a sliding scale. But I assumed that it couldn't slide that far down for me."* One participant recounted the shame experienced from the inability to pay: *"I've never needed that kind of help forever and then all of a sudden you're saying I have to go to this cardiac rehab, it's a good program but I can't afford to pay for it. So yeah, that kinda, it hits home…a little embarrassed I guess."*

Other than the direct cost of the program, several participants perceived financial barriers incurred due to the required time away from work:

> *"When you do the simple math it's like, 'oh well we want you here for 12 weeks, 2 times a week, 3 hours a day'… you lose an hour in the morning, you exercise an hour, an hour to get back to work. Three hours a day, 6 hours a week, 12 weeks, 72 hours. $25 an hour, plus the $500 that they don't cover in the exercise program. That's pretty close to $3,000 to me. I'm sorry but I'm not doing their exercise program."*

While the fee waiver program did not work for all respondents, many were able to enrol in this program: *"I told them I didn't have any money…I said there's absolutely no question that I can't afford any of this and they said 'okay then'. They said 'don't worry about it, we'll waive it'".*

Several participants expressed that they were very happy with the CR program they attended, but that they experienced financial barriers to ongoing physical activity after having completed their

CR program: *"I gotta buy a membership. Well I can't afford memberships."* Another respondent stated: *"We have got fees, you know, you have got charges to pay…about $60 a month or something"* and: *"[My doctor] wants me to do aquasizing. Well I can't afford that… it's not in the cards to even do the pool. I would love to but nope"*.

5.4.2.3 Psychological Support

It is well known that patients with heart disease are at risk of significant mental and emotional health difficulties [136, 137]. Many participants expressed that this was exacerbated by their inability to work due to their heart disease and that the subsequent need to rely on others was taxing on their self-esteem:

> *"When you work you're whole, but when you get to the point of having to depend on other people for your income… It's like you don't become a whole person anymore. You become pieces. And if you don't have that piece to help you through that life you can't be whole. It's like you're lost."*

Social isolation resulting from financial barriers also contributed to participants' feeling depressed. Most participants sacrificed social activities with the goal of saving money to spend on their healthcare requirements (e.g., medication costs). For example, several participants reported avoiding visiting the movie theatres, eating at restaurants, and other recreational activities. A participant stated: *"I can't remember the last time I went out. I'm in my apartment 7 days a week. So, you do miss out on interactions with other people…you have no social life because you can't afford it."*

Some participants identified that their financial barriers were not simply a cause of psychological distress, but that these also hindered them from being able to access necessary psychological supports. A participant stated: *"I really could've used more emotional support from the system in terms of you know, 'you've had a heart attack, how do you feel? How do you feel about life? To be able to discuss these issues of being confronted with one's own mortality."* One participant explicitly stated: *"So if I would've had some money to be able to afford (it) I probably would've went and got some professional help."*

5.4.2.4 Transportation and Parking

The incidental costs of seeking healthcare, such as transportation and parking were a barrier that hindered some participants' access to medical care. Transportation related issues included: not being able to drive independently, having to travel prohibitively long distances to healthcare facilities, costs of gasoline, and the cost of parking at hospitals and doctors' offices.

Numerous participants described incurring indirect costs due to driving long distances to healthcare facilities, such as one participant who lived far from the regional CR program*: "You gotta run all the way to [the city] and that's three-quarters of an hour at very best…one way, so I mean you lose your day."* Others described that the cost of gasoline was prohibitive to them following up as directed: *"I had to pay my gas to drive into town and everything. You gotta drive an hour, over an hour to the [rehab centre] to go to cardiac rehab twice a week? That is a huge financial burden on people."*

Finally, a commonly cited transportation-related financial barrier was related to the high cost of parking at healthcare facilities. Many participants stated that they had multiple specialist appointments to attend, and these each required them to spend significantly for transportation and parking:

> *It’s just a strain. This week we had Dr. [cardiologist] this morning at 8:15 and I had an 11:15 at the [hospital] and was there ‘till quarter after 2. Tomorrow I have the health nurse coming in and then I have to drive all the way up to the [other hospital] to see the vascular surgeon.*

Unfortunately, participants reported avoiding healthcare services (e.g., CR, appointments) because of transportation related issues: *“I started [CR] and it was going to be way too much travel for me.”*

5.4.3 Stroke Cohort

Six participants with a history of stroke were interviewed. This included one man and five women, ages 42 to 73 years. Three participants were from ethnic minorities including one First Nations person. All participants were working prior to their stroke, but only two continued to work, while four had become unemployed following their stroke. The modified Rankin Score of stroke disability [138] in our cohort ranged from 1 (No significant disability despite symptoms; able to carry out all usual duties and activities) to 4 (Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance). One of the participants used to run a small business before having to sell it because of his post-stroke disability, while another had worked as a healthcare professional prior to having a stroke.

Despite receiving inpatient care with no costs to the patient at the time of their acute event, each participant identified challenges in accessing several key services following their discharge owing to financial barriers. The services participants had a difficult time accessing included allied health professional services, medications and healthful food.

5.4.3.1 Rehabilitation Services

Participants expressed that accessing long-term physiotherapy – which is required by most patients who experience a moderately severe stroke – was a challenge:

> *"Well, they kinda just drop you like a hot potato. I do know that the physiotherapists here are really backed up and that it's very difficult to get into. The physiotherapy at the hospital, we don't have to pay for, but if you go to these private physio clinics … it was $30 a visit."*

Another participant specified that they had a difficult time accessing occupational therapy:

> *"In my situation, it's not just the therapy for 4 months. No, because my work too is different from the other ones, right. So I need my therapy, it should be a continuous therapy. You can go home but you have to go here until you, it's, you need more, more, more, more hours, more, more focussed therapy."*

5.4.3.2 Other Support Services

Psychological support services were another area where participants faced financial barriers. One participant stated:

> *"That's one of the things I quit doing because it was just getting so expensive. I went a couple times on my own dime 'cause I thought, you know, I'm worth that kind of money."*

Participants also described difficulties accessing adequate home care and assistive equipment to accommodate their post-stroke disability. Regarding assistive equipment, one participant stated:

> *"The doctor wanted me to get walking sticks for the support because when I've got the two braces, because I have no knees left, nothing left … And he wanted me to get those but they're $112, each. [Laughter] So it's forget that, that doesn't work."*

5.4.3.3 Medications

Medication expenses emerged as a consistent concern. Participants recognized this as an essential expense to prevent recurrent events and noted that they often had to keep other purchases in check to ensure that they could buy their medication:

> *"I can't complain that I'm paying because I have to take the medication. I am making sure for myself that I have the money before I go buy the medication."*

However, the added expense burden of being prescribed brand-name versus generic medications was also problematic. One person said:

> *"I'm on the generic of my high blood pressure pills. Before I was on [brand name antihypertensive] which is not covered and the doctor doesn't have any more cards so I can't get [it] ... I had to go back to the generic … sometimes I have side effects with generic drugs and then I have to pay the extra money to get the other one."*

5.4.3.4 Healthy Food

Competing health-related expenses included the cost of medication versus the cost of abiding by more expensive dietary regimens to manage stroke risk – like fresh fruit and vegetables, unprocessed foods to meet low-salt and low-fat requirements, and low-glycemic-index sources of carbohydrate for diabetic control. In order to retain access to their medications, participants often ended up sacrificing on nutrition:

> *"Yes, low sodium for my hypertension, low fat for cholesterol and that. I try to manage as is possible so sometimes there's some money to afford that, sometimes not. It's about the priorities. It's sometimes really hard to keep the budget."*

One participant had to use the local food bank to meet her nutritional needs. She struggled to find healthy dietary options and was forced to spend additional money on groceries:

> *"Because my income has gone down I've gone to the food bank and basically you're getting starch and it's junk, but it is food so I can't say no… Sometimes the food that they give you is wrong and they give me stuff that I can't even eat, so I give it right back to them. So it's a waste of time sometimes… So by the time I pay my bills I think I have $50 for groceries a month."*

5.4.3.5 Transportation

Some examples of difficult trade-offs included sacrificing several hours of wages and bearing major costs of transportation and parking to attend critical health appointments:

> *"Oh, appointments, I lose, I have to be up there at quarter to three tomorrow which means I have to leave at two o'clock. You only get paid for the hours you work. There's no sick time."*

Transportation issues were sometimes a direct consequence of the participant's inability to drive as a result of their stroke. One participant said:

> *"I can't drive so I gotta rely on sort of public transportation... they've cut back and changed the way people can get in for appointments."*

5.5 Discussion

As anticipated, there are clear areas of overlap across the different types of cardiovascular-related chronic conditions. In the results presented above there were three themes observed in the types of goods and services patients struggle to access due to finances: (1) Non-insured goods and services; (2) Self-management supports; and (3) Insured services, due to the associated incidental costs (Figure 5.2).

5.5.1 Access to non-insured goods and services

The goods and services to which chronic disease patients face financial barriers is largely consistent with the areas where Canadian public health insurance is not comprehensive. The predominant theme was that participants struggled to access necessary goods and services that fell outside of their Alberta Health Care Insurance Plan.

Notably, financial barriers to accessing prescription medications was a recurrent theme that appeared in all three cohorts of participants, which was not surprising since patients with all three chronic conditions require ongoing medical therapies with multiple agents to lower the risk of further complications. All three conditions require multi-faceted medical approaches that not only deal with the primary issue, but also with other common related metabolic comorbidities (i.e., elevated cholesterol, high blood pressure, chronic kidney disease). Specifically, clinical practice guidelines recommend that nearly all patients who have one of these three conditions be prescribed cholesterol-lowering therapies (i.e. statins) and renin-angiotensin-aldosterone system blocking agents (ie. ACE-inhibitors or Angiotensin receptor blockers), as well as ASA in many cases [139-141].

Those who suffer from heart attacks and strokes are known to have a high burden of psychiatric and psychological comorbidity, particularly major depression [142, 143]. Given that psychological services, such as counselling, are not covered by most provincial public health insurance plans, it could have been anticipated that in the cohorts of participants who had coronary disease or stroke, difficulty accessing these services was particularly problematic. This is important, as studies have shown that the presence of depression post-myocardial infarction is a negative prognostic factor [137, 144], and is associated with higher healthcare costs [145]. Given that depression is twice as prevalent among patients with diabetes than those who don’t have diabetes [146], it is notable that access to psychological services was not commonly referred to by the diabetes cohort. In a previous international study, many patients with diabetes were shown to require psychological services, but few actually received these services [147]. It is likely that among our cohort of participants with diabetes some would have benefitted from such services as well, but perhaps there were so many other pressing financial barriers to discuss that this never rose to the fore.

Rehabilitation services are another area where access is constrained by financial barriers. Again, as these traditionally fall outside of the basket of publicly funded services patients may be left to pay out of pocket or obtain private insurance for the physiotherapy, occupational therapy, speech/language pathology and cardiac rehabilitation that they may require. These were highlighted by those in the CAD and stroke cohorts but not in the diabetes cohort. This may be because patients with diabetes don’t typically think of themselves as requiring rehabilitation to the same extent that defined rehab programs exist for those post-stroke or post-MI. However, over the past decade some have advocated for the development of ‘diabetes rehabilitation’ programs that use a multidisciplinary approach to incorporating principles of cardiac rehabilitation, which have been demonstrated to improve outcomes for patients with diabetes [148]. Therefore, although participants with diabetes may not have stated that they faced financial barriers to rehabilitation services, this may be attributable to the fact that they weren’t offered such services and therefore they didn’t know they could have benefitted from a structured rehab program.

Those with diabetes nearly universally stated that they faced financial barriers to accessing diabetes supplies. While some support is available, diabetes supplies are, again, a good that is not fully funded through the public system.

5.5.2 Access to items to support self-management

Beyond goods and services which one might expect to have covered by public insurance, patients faced financial barriers to a number of other aspects of self-management. Most notably, many participants voiced frustration that they were expected by their healthcare providers to eat healthy food but that they could not realistically afford to eat well. The other aspect of self-management that some participants in the CAD cohort described was difficulty engaging in ongoing physical activity after the structured cardiac rehabilitation program was complete. Participants cited high costs of fitness centre memberships and difficulties with being physically active outside during harsh Alberta winters.

5.5.3 Incidental costs associated with accessing insured services

Finally, several participants, particularly those in the CAD and stroke cohorts, voiced that they had difficulty accessing services that may be covered by public insurance due to the incidental costs associated with these. Transportation difficulties were frequently cited in these groups, due largely to the fact that they were prohibited from driving by virtue of having recently had an MI or have resultant disability from their stroke. Finally, as others have pointed out [149], the costs of parking in publicly-run hospital facilities was stated as a deterrent for many to access the outpatient follow-up care they required.

5.5.4 Critical Reflections

The analysis in qualitative descriptive studies is generally limited to a simple synthesis of the qualitative data presented by participants without much of a critical lens brought by the investigator. However, in this case, we felt compelled to highlight that the experiences shared by several of our participants were discordant with existing policies. There were a number of areas where participants reported barriers to care that theoretically *shouldn't* have been problematic because policies or subsidies exist to circumvent these problems. These included the following goods and services: diabetes supplies, medication insurance, healthy food, cardiac rehabilitation and exercise, and post-stroke rehabilitation.

5.5.4.1 Diabetes Supplies

In our cohort of patients with diabetes, the vast majority of participants described that they faced troublesome financial barriers to accessing diabetes supplies, principally to enable self-monitoring of blood glucose. This difficulty was voiced by virtually every patient with diabetes, despite the fact that only 3/24 had type 1 diabetes and fewer than half (10/24) were using insulin at the time of their interview. It is important to note that, by and large, the decision to not fund diabetes supplies has been made consciously at government levels. The decision to not fully fund diabetes monitoring supplies is at least, in part, due to the fact that increased frequency of self glucose monitoring has not been conclusively linked to improved glycemic control [150] or reduced episodes of hypoglycemia [151], particularly for patients with type 2 diabetes who are not treated with insulin therapy. The $600 of coverage that was cited by some of our participants was from the Alberta Monitoring for Health program that was offered by the Canadian Diabetes Association and funded by the Alberta Government, which has since been abandoned [152]. This amount of support should be sufficient to allow testing at intervals that are recommended by Diabetes Canada (formerly the Canadian Diabetes Association), at least for those who have type 2 diabetes and who are not treated with multiple daily injections of insulin (i.e. once to twice daily testing) [153]. Therefore it is likely that many of our participants with diabetes who perceive financial barriers to self-monitoring supplies may be wishing to test more frequently than is required or recommended by modern clinical practice guidelines [153]. This may be more of an issue of patient education than one of a true funding problem. As described in Chapter 4, providers have the potential to exacerbate financial barriers for patients, and this may be an area where well-intentioned providers make recommendations (i.e. increased frequency of monitoring) that are not supported by high quality evidence, which in turn increase patient anxiety and exacerbate the impact of financial barriers. The strategies that some patients identified using (i.e., varying daily times of testing, episodic testing when symptomatic) may be, in fact, appropriate strategies that many clinicians recommend and are supported by clinical practice guidelines [153].

5.5.4.2 Medication Insurance

Some participants voiced that they could not afford to pay insurance premiums, or that their total out-of-pocket costs would be increased by purchasing insurance privately. However, all participants in this study were residents of Alberta, which offers a government-subsidized non-group medication insurance program through Alberta Blue Cross. Through this program, annual insurance premiums for a single individual range from $530 to $762, based on income (compared to the $2000 cited by our participant) [154]. The participant voiced that they felt that their premiums would be exorbitant given their ‘pre-existing’ diabetes, however, through this government-subsidized program, premiums are not actuarially-based, and are therefore a fixed price, regardless of health conditions (neither can Albertans be denied coverage). For those with low medication expenditures, there is indeed a threshold below which it is advantageous to remain uninsured and pay out of pocket. However, for individuals with low income, if one's annual out-of-pocket medication expenditure were to exceed approximately $600, it would be less costly to purchase this non-group coverage. As mentioned earlier in this thesis, most patients with diabetes have indications to take both statins and ACE-inhibitors or angiotensin receptor blockers in addition to their antihyperglycemic therapies; therefore, it is likely that all patients with diabetes would in fact benefit from non-group coverage if they did not have employer-sponsored insurance.

This discrepancy in participant perspective and policy reality again highlights the fact that perhaps the primary problem is not a lack of public programs to assist those with limited financial resources, but rather that knowledge of these programs is not widely disseminated to those who need the information – or that they lack the ability to navigate such programs (see Chapter 4). One policy alternative that might address this problem would be to institute a provincial mandatory health insurance policy. This might be similar to the Régie de l'Assurance Medicale de Québec program [155], where each resident in Quebec must have a supplemental health insurance policy. For most, this is provided through employers, however, those who do not receive such employment benefits must pay insurance premiums to Revenue Québec (which are determined on a sliding scale based on annual income). Such a policy takes away the option for uninformed individuals to remain uninsured and therefore shoulder excess out-of-pocket costs.

5.5.4.3 Healthy Food

Participants from both the diabetes and stroke cohorts voiced concerns that they faced financial barriers to accessing the healthy food recommended by their healthcare providers. Some studies have corroborated that healthy dietary patterns do objectively cost more than less nutrient-rich diets, however the difference in cost is relatively marginal [156]. It has also been shown that cost is but one factor in a complex set of determinants in the dietary patterns that Canadians follow [157]. The participant from the diabetes cohort stated that they must eat unhealthy foods because they are cheaper, the example provided was: *"a bag of chips is a dollar and an apple is three dollars".* At first glance, it is difficult to believe this example, as fresh fruit purchased at the grocery store is certainly not this expensive. However, on further reflection, the analytic team came to see that this participant worked a manual labor job and his usual source of food was likely from convenience stores, cafeterias, and mobile lunch dispensing vendors, where these prices are much more credible than what we may be accustomed to seeing at the grocery store. This supports the notion that perhaps the problem is not that healthier food in itself is more expensive than unhealthy food, but rather that readily available or prepared foods that are of higher nutritional value tend to be more expensive than other easy options (i.e. fast food). The fact that this barrier was so important may reflect not only a primarily financial problem, but also on of a lack of time and/or skills in grocery shopping and food preparation among participants. Another problem that may be playing a role in such situations is the accessibility of sources of healthy foods, forcing people to purchase food from unhealthier sources. In some contexts, these geographical locations have been described as 'food deserts' [158]. Among the Albertan participants we interviewed, this phenomenon is primarily experienced by those who live in rural areas, in particular those living in First Nations communities (i.e. reservations) – for whom accessing grocery stores is very problematic.

Since it is difficult to prescribe solutions to problems that are principally determined by market economics, the most viable immediate solution to the problem of chronic disease patients not being able to afford healthy foods might be through improved patient education on the vital self-management skills of navigating grocery stores and healthy food preparation. This does not address the issue of accessibility, and this is where consideration might be given to a solution where subsidies are provided for patients to subscribe to services such as the 'Good Food Box' that was described by our participants.

Finally, as many participants mentioned needing to access food from food banks, policy alternatives may be considered that encourage donation of more healthy foods. Many grocery store chains offer patrons the option of a 'quick pick' assortment of groceries that can be purchased and donated to food banks. Unfortunately, most of this food is of low nutritional value. It would likely be to the best interest of food bank patrons if the contents of these donations were altered to reflect the foods that are most needed and of higher nutritional value. Food banks might also consider the implementation of policies that give patients with cardiovascular-related chronic diseases priority to healthy foods, since they are those at highest risk of suffering from sequelae of poor nutrition.

5.5.4.4 Cardiac Rehabilitation and Exercise

As described above, participants in cardiac rehabilitation in Alberta are asked to contribute $500 to their otherwise publicly-subsidized program. Many stated that this was a financial barrier to their participation in the program. However, as noted, there is a program in place such that the fee is either reduced or fully waived for any individual who identifies that they cannot afford it. Numerous participants stated that they were not made aware of this program, which is why they didn’t start or didn’t register in the program. However, after attending several introductory information sessions, I have witnessed that at least for the Calgary CR program, it is their practice to make this clearly known to all potential participants. This would seem to suggest that those who stated *“it was never said that there’s financial assistance if you need it”*, may have been referring to information they received prior to the introductory session (either by word of mouth, or in the introductory materials given to them in hospital). This is clearly an area where more transparency about the fee waiver program may result in its more frequent use and may address concerns from patients with financial barriers – enabling them to enrol in and benefit from a well proven program for preventing recurrent events.

Some participants with CAD had expressed that they faced financial barriers to ongoing exercise after completion of their cardiac rehabilitation program. They referenced not being able to afford the purchase of memberships for fitness clubs and swimming pools. Many of these participants may have qualified for municipal programs that provide low income individuals access to city recreation facilities at very minimal cost [159, 160]. Furthermore, this degree of infrastructure is not absolutely required for the physical activity recommended for chronic disease patients. Free activities, such as walking or jogging, are equally valid and proven forms of exercise. Our CR programs may be designed to encourage over-dependence on facilities when they could instead be more focused on promoting independence and preparing patients to transition away from their structured programs back to individual physical activity in the community. Many have cited concerns, such as icy sidewalks and short daylight hours, as barriers to engaging in these free forms of physical activity, however, others referenced accessing programs such as free mall walking groups that enabled them to still engage in physical activity for free, even in the winter. Others purchased used personal/home fitness equipment, which may be more economical than paying ongoing membership fees at a fitness centre. This is another area where improved patient preparation and education (including enhanced navigation, as necessary) would improve patients' ability to overcome financial barriers and follow through on medical recommendations.

5.5.4.5 Post-Stroke Rehabilitation

Participants in the stroke cohort highlighted that they faced financial barriers to accessing post-discharge rehabilitation services as outpatients. This is certainly possible given that allied health services are generally not covered by the Alberta Healthcare Insurance Plan. However, after a cerebrovascular accident with neurological deficits, a number of Alberta Health-funded programs administered by Alberta Health Services are in place, such as the Early Supported Discharge Program, the Community Accessible Rehabilitation Services Program, and the Ambulatory Community Physiotherapy Program. These programs provide limited coverage for eligible individuals and discharge from the program is often decided collaboratively between patient and provider. While the optimal duration of rehabilitation has never been proven, contemporary guidelines recommend at least 8 weeks of regular therapy [161]. As per these recommendations, the public programs cited above routinely provide funding for patients to receive these services for this entire duration.

This is another situation where perhaps the biggest drivers of a patient's perceived financial barriers are an inability to navigate public programs or a lack of communication leading to untenable patient expectations. In many cases, the government attempts to make funding decisions on the basis of the best available medical evidence (similar to the diabetes supplies, above), yet patients are not told why the government only funds a limited duration within a program, and they are left to feel unjustly treated and conclude that their health is suffering as a consequence. Help navigating and enrolling in such public programs as well as improved clarity of communication regarding health policy/funding decisions may help alleviate some of these problems caused principally by discrepancy in patient expectations and medical best practice.

5.5.5 Limitations

There were some notable limitations to this descriptive analysis. Firstly, given the high degree of multimorbidity, there was certainly overlap between the three cohorts – which may be responsible for some of the homogeneity of themes between the cohorts. However, even with this overlap there are some interesting differences as noted above. Since this is not a quantitative comparison, it is less pertinent that the samples be strictly independent. Secondly, while we are confident that we achieved saturation in the overall parent study (see Chapter 4), these analyses represent a secondary analysis among these individual cohorts and sampling did not explicitly proceed through to saturation for each sub-cohort. It is therefore possible that some of these cohorts are not fully saturated and that the inclusion of additional participants might yield previously undescribed themes.

5.5.6 Conclusions

Albertan patients with cardiovascular-related chronic conditions face financial barriers to a variety of goods and services that they require to optimally manage their chronic conditions. These financial barriers are predominantly in three different areas: (1) goods and services that are not included in public insurance (medications and allied health provider services); (2) aspects of self-management which are expensive (healthy food and physical activity); and (3) incidental costs associated with seeking publicly funded care (transportation and parking). While there are some differences across conditions, there is considerable heterogeneity in the types of goods and services that chronic disease patients struggle to access due to financial barriers.

Some of the goods and services participants struggled to access are not well supported. However, in bringing a critical lens to some of the descriptive data, we found that participants also described encountering financial barriers to some aspects of care in spite of programs to facilitate access – or alternatively, in the face of government policy meant to curb excessive use. Many of these were due to patient expectations that went beyond the available supports, such as excess diabetes testing supplies, unnecessary physical activity supports and prolonged rehabilitation provider visits.

Beyond participants' difficult financial situations, major contributors to the impact of these barriers were that participants had an abundance of 'predisposing' and 'negatively modifying' filters (see Chapter 4). Some of these may be amenable to well-designed cognitive and behavioural interventions, such as: enhanced patient-provider communications, the use of patient navigators, as well as novel and holistic approaches to patient education. These types of micro-level policy options to address the factors that contribute to the impact of financial barriers on patients may be effective; yet unfortunately as they rely predominantly on patient education, many of these strategies also have the potential to lead to victim blaming – by putting the onus back on the patient themselves. This type of approach "ignores what is known about human behavior and minimizes the importance of evidence about the environmental assault on health" [162].

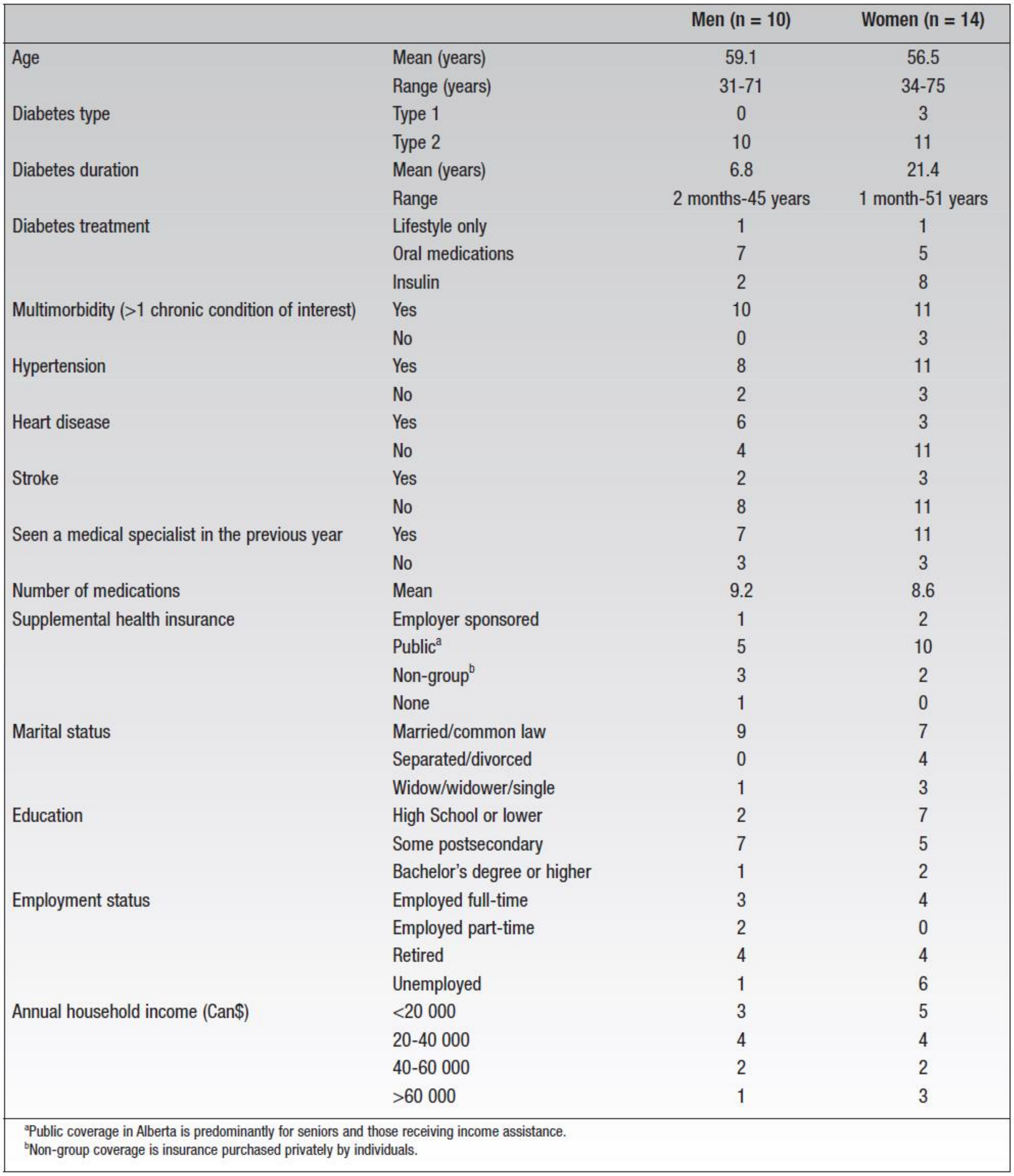
Alternatively, decision makers may consider a radically different policy approach in order to address the true root causes of both chronic disease and the predisposing filters: the social determinants of health [163]. In order to more fully address these issues, policy makers would need to eschew further investment in health services interventions in favor of more upstream social programs (i.e., education, housing, income support, food security, etc.). The theory behind this strategy is that reducing general social disparities may minimize the incidence of predisposing factors (i.e., abuse and emotional trauma), while bolstering protective factors (i.e., navigation/self-advocacy ability and motivation) – in effect, raising the level of resiliency of the entire society. Such an approach is supported by numerous studies, for example McGinnis et al estimate that only 10-15% of preventable deaths could be avoided by enhanced medical care [164]. Similarly the Canadian Medical Association estimates that Canadians' lack of access to health care services accounts for only 25% of the total burden of illness [165]. Furthermore, a recent US study demonstrated that states with higher social-to-health spending ratios actually demonstrated better health outcomes than states which prioritize spending on health-related programs [166].

In conclusion, through our qualitative descriptive analysis, we came to see that Alberta patients with chronic diseases perceive financial barriers to a variety of goods and services that they feel are required for the management of their conditions. Some of these barriers might be considered 'real' – or for which no public supports exist, while others may be 'perceived' – or for which public supports exist, but may not be easily accessible, or may not provide the degree of support desired by individual patients. In these cases, the problem may arise out of a discordance between patient expectations and public policy, which may be supported by medical evidence. A variety of policy alternatives exist to address the problems arising from financial barriers. Increasing public supports for the goods patients struggle to access (i.e. expanding the scope of pharmaceutical insurance) is one approach. Alternatively, micro-level policies to address individuals’ sets of filters to build resiliency to financial barriers (i.e. enhancing community supports for patient navigation of existing public programs) may be considered. Finally, by addressing the root causes of socioeconomic disparities such as poverty, education, and housing instability, we may build more resilient individuals and communities who are at much less risk of being negatively impacted by the financial barriers they may experience.

5.6 Tables & Figures

Table 5.1

Diabetes Cohort Participant Characteristics



		Men (n = 10)	Women (n = 14)
Age	Mean (years)	59.1	56.5
	Range (years)	31-71	34-75
Diabetes type	Type 1	0	3
	Type 2	10	11
Diabetes duration	Mean (years)	6.8	21.4
	Range	2 months-45 years	1 month-51 years
Diabetes treatment	Lifestyle only	1	1
	Oral medications	7	5
	Insulin	2	8
Multimorbidity (>1 chronic condition of interest)	Yes	10	11
	No	0	3
Hypertension	Yes	8	11
	No	2	3
Heart disease	Yes	6	3
	No	4	11
Stroke	Yes	2	3
	No	8	11
Seen a medical specialist in the previous year	Yes	7	11
	No	3	3
Number of medications	Mean	9.2	8.6
Supplemental health insurance	Employer sponsored	1	2
	Public[a]	5	10
	Non-group[b]	3	2
	None	1	0
Marital status	Married/common law	9	7
	Separated/divorced	0	4
	Widow/widower/single	1	3
Education	High School or lower	2	7
	Some postsecondary	7	5
	Bachelor's degree or higher	1	2
Employment status	Employed full-time	3	4
	Employed part-time	2	0
	Retired	4	4
	Unemployed	1	6
Annual household income (Can$)	<20 000	3	5
	20-40 000	4	4
	40-60 000	2	2
	>60 000	1	3

[a] Public coverage in Alberta is predominantly for seniors and those receiving income assistance.

[b] Non-group coverage is insurance purchased privately by individuals.

Reproduced from: Campbell et al. (2017). *The Diabetes Educator*, 43(1).

Table 5.2

Coronary Artery Disease Cohort Participant Characteristics

Table 1 Participant Characteristics

		Men ($n = 9$)	Women ($n = 4$)
Age	Mean (Years)	61.11	60.25
	Range (Years)	47–71	55–75
Heart Disease Type	Angina	3	1
	Myocardial Infarction	6	3
Heart Disease Duration	Mean (Years)	7	4
	Range (Years)	1–20	1–10
Heart Disease Treatment	PCI alone	5	1
	CABG	3	0
	Medical management only	1	3
Comorbid Conditions			
Hypertension	Yes	7	4
	No	2	0
Diabetes	Yes	6	3
	No	3	1
Stroke	Yes	0	2
	No	9	2
Seen a medical specialist in the previous year	Yes	8	3
	No	1	1
Number of medications	Median	9	8
	Range	6–13	5–12
Supplemental Health Insurance	Employer-Sponsored	2	1
	Publicly Funded	4	2
	Non-Group*	3	1
Marital Status	Married/Common-law	7	2
	Separated/Divorced/ Single	1	2
	Widow/Widower	1	0
Education	High School or less	3	3
	Some Post-Secondary	5	1
	Bachelor's Degree or Higher	1	0
Employment status	Employed	2	1
	Retired	5	1
	Unemployed	2	2
Income category	<$20,000	2	2
	$20 – 40,000	4	2
	>$40,000	3	0

*Non-Group coverage is that purchased privately by those not otherwise insured

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Figure 5.1: Qualitative Descriptive Participants, by Type of Condition

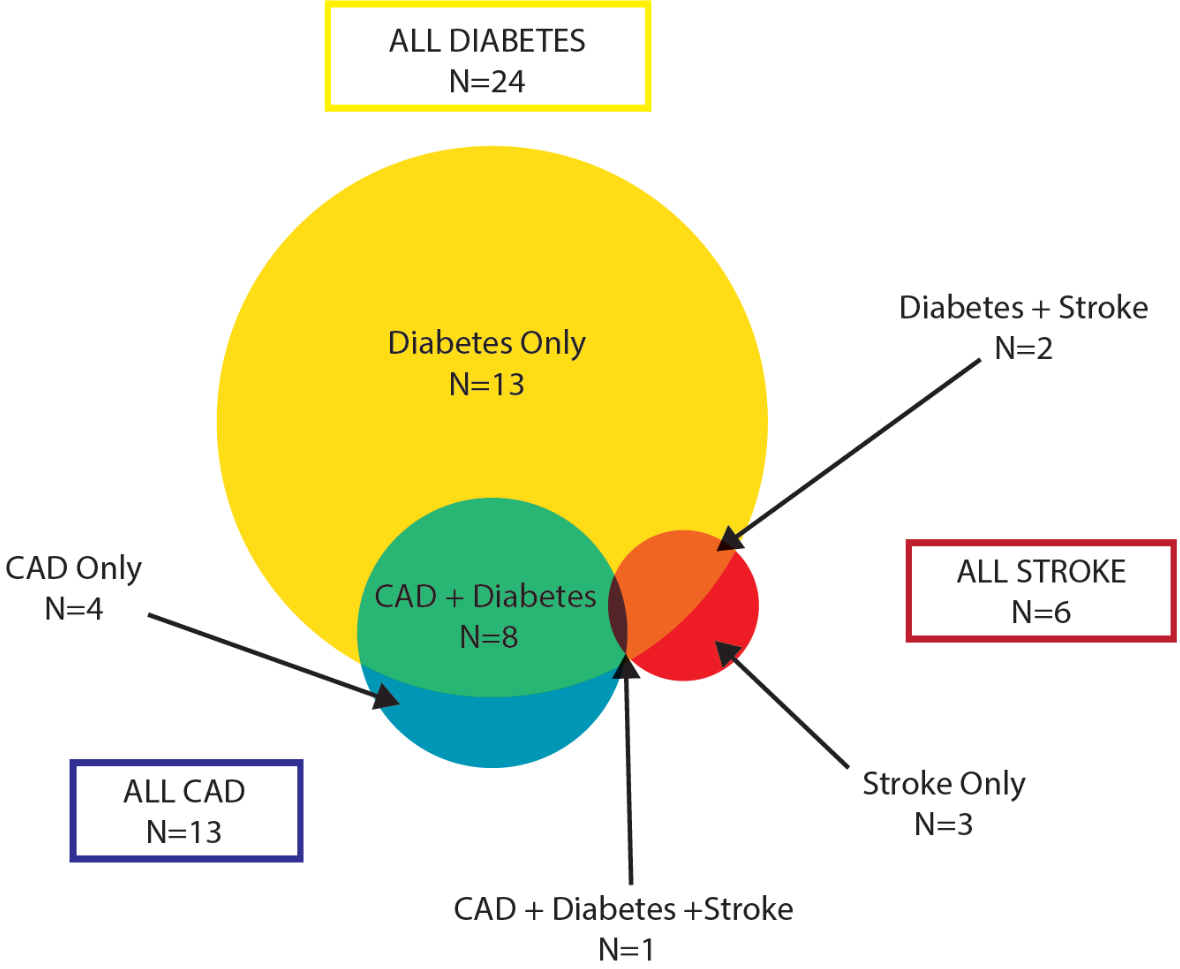

Figure 5.2: Themes of Financial Barriers, by Type of Condition

	Diabetes	**CAD**	**Stoke**
Non-Insured Goods & Services			
Medications	🟨	🟦	🟥
Testing supplies	🟨		
Rehab services		🟦	🟥
Psychological support		🟦	🟥
Home Care			🟥
Items to Support Self-Management			
Healthy food	🟨		🟥
Exercise		🟦	
Incidental costs of insured services			
Transportation		🟦	🟥
Parking		🟦	🟥

CHAPTER 6:

SUMMARY OF FINDINGS

6.1 What was known about financial barriers to care in Canada prior to this work?

Due to the fact that Canada's universal public health insurance system is such a source of pride [34], many Canadians fail to recognize that many in our society face financial barriers to accessing necessary medical care. One of the primary contributors to financial barriers in Canada is the limited basket of goods included within provincial public health insurance plans [25]. As per the Canada Health Act, "necessary medical care", defined as that provided by physicians or in hospitals is fully covered with no payment required from individual patients [24]. However, there is no universal rule that governs how provinces fund care that falls outside these narrow bounds.

Outside of physician services, there are a multitude of goods and services that patients with cardiovascular-related chronic diseases require which are often underinsured. Furthermore, even those that have supplementary insurance coverage are not immune from facing out-of-pocket costs that arise due to required copayments and deductibles [33, 118] and may present financial barriers.

While there have been several studies regarding financial barriers in the United States, prior to our group's research, the notion of having financial barriers was an understudied phenomenon in Canada. The studies conducted in the US have demonstrated that among post-MI patients, perceiving financial barriers was associated with a 30% increase in the likelihood of all-cause and cardiac-specific re-hospitalization [54]. Another study among women with CAD found that financial difficulties were associated with a three-fold increase in the likelihood of having recurrent events [55]. Finally, among patients with diabetes, those with financial barriers were

20-40% less likely to achieve recommended process markers and were 23% more likely to have micro- or macro-vascular complications [56]. Whether these same associations hold true in Canada was unknown prior to the research reported in this thesis.

In Canada, some studies have recently been published on the notion of cost-related non-adherence, a closely related construct to financial barriers. Law et al. have demonstrated that approximately 10% of Canadians have experienced cost-related non-adherence, or failing to take their medications as prescribed due to costs [48]. Cost-related non-adherence was more commonly described by those with poor self-perceived health, lower incomes and those without medication insurance [48]. Kennedy described considerable interprovincial variability, with respondents from Quebec being 50% less likely to report cost-related non-adherence than those from Ontario, perhaps because all citizens in Quebec have medication insurance (either private or public) [167]. In a recent review article, Tang described potential approaches to minimizing the prevalence of patient-borne medication cost barriers, including those at the system-level and at the individual physician-level [168]. While these studies on cost-related non-adherence are related to the notion of financial barriers and informed the work in this thesis, it is a much narrower construct – only identifying those who struggle to afford their medications due to cost. Given that patients with chronic diseases require far more than only medications for the management of their condition and that financial barriers may be pertinent to other aspects of self-management and even to insured services (via incidental costs), we felt it was important to consider more than just financial barriers to medications or cost-related non-adherence.

6.2 Who faces financial barriers to care in Canada?

We have shown that financial barriers to care are not exclusively a US phenomenon and that many Canadians with cardiovascular-related chronic diseases face financial barriers to accessing required care. In fact, in Chapter 2 we showed that 12% of those with at least one cardiovascular-related chronic condition surveyed in the Western Provinces identified experiencing financial barriers to care in the previous 12 months. The prevalence was as high as 21% among those who have more than one cardiovascular-related chronic condition, and also among those with income <$30,000/year. In this study, financial barriers were significantly more common among those with low income (PRR 2.3, 95%CI: 1.5-2.6); among those of Indigenous or other non-white ethnicity (PRR 2.0, 95%CI 1.0-3.9); and among those with poor health literacy (PRR 1.9, 95%CI 1.2-3.1).

In the subsequent study using CCHS data from across Canada (except Quebec, Manitoba and the territories), Chapter 3, we found a similar prevalence of financial barriers, with 10% experiencing a financial barrier to at least one aspect of their chronic disease care. The most commonly experienced financial barriers were to accessing healthy food (8.9%) and medications (7.5%). In this study, similar associations were found between financial barriers and: multimorbidity, low income and non-white ethnicity. Additional significant associations were noted for younger Canadians, lower levels of educational attainment and poorer self-perceived health. Interesting differences were noted across the different chronic conditions of interest. Among patients with cardiovascular-related chronic diseases who had financial barriers, 31% had diabetes and 9% had stroke, while only 24% and 6% of those without financial barriers had diabetes and stroke, respectively. Differences in hypertension and heart disease were considerably smaller, which may suggest that patients with diabetes and stroke are more susceptible to having financial barriers than those with heart disease and hypertension.

6.3 What are the clinical implications of financial barriers to Canadians?

In Chapter 2, we demonstrated significant associations between perceived financial barriers and self-reported measures, including process measures such as use of appropriate cardioprotective medications (statins) and discontinuing prescribed medications. Experiencing a financial barrier was associated with a 50% reduction in the likelihood of taking statins and three-fold increase in the likelihood of stopping prescribed medications. Furthermore, having a perceived financial barrier was associated with a 70% higher risk of self-reporting use of emergency department or hospital inpatient services for their chronic condition in the preceding year (95%CI 1.0-2.9).

Given the limitations of using these self-reported survey data for outcomes, we conducted the study in Chapter 3 to assess for these associations in a novel dataset of linked national survey and administrative data which allowed for ascertainment of objectively documented outcomes. In this study, we again found a statistically significant, though attenuated, association between any perceived financial barrier and hospitalization for chronic conditions (diabetes or cardiovascular condition) with a prevalence rate ratio of 1.36 (95%CI 1.29-1.44). This association held for nearly all types of financial barriers, with PRR ranging from 1.07 (0.74-1.54) for financial barriers to health behaviour modification to 1.68 (1.56-1.79) for financial barriers to healthy foods. In addition to looking for a relationship between financial barriers and hospitalization, we also found significant associations between financial barriers and death, with those who endorsed having at least one financial barrier having a mortality rate that was 24% higher than those without financial barriers.

6.4 How do patients experience financial barriers?

While the previously described quantitative studies describe interesting and potentially important associations between financial barriers and clinically relevant outcomes, the experience of a patient who perceives such barriers remained unknown and previously undescribed. In order to inform public policy, specifically about how to mitigate the impact of financial barriers, a greater understanding of these barriers was sought through qualitative study.

In our grounded theory study, we found that financial barriers were experienced very differently by each individual. Some were profoundly devastated by their financial barriers while others were seemingly able to deal with such financial challenges with minimal impact on their life. We developed a model to describe the factors that might determine how impactful a financial barrier might be. We identified protective, predisposing and modifying factors to this relationship. Protective factors included being familiar with financial difficulties as well as having the ability to be an advocate for one’s self in navigating the healthcare system. Important predisposing factors that amplified the impact of financial barriers included the presence of various comorbid conditions or the perception of injustice or discrimination. Modifying factors have the potential to play either a protective or predisposing role in a patient’s experience with financial barriers. Importantly, we found that patients’ interactions with their healthcare providers were quintessential modifying factors – that providers could either help shield their patients from the impact of financial barriers, or could contribute to it. Finally, an individual’s inherent attitude or worldview played an important intermediary role as a ‘lens’ in determining how troubling one’s financial barrier was in their life, essentially projecting an individual onto a spectrum of resiliency ranging from determination to despair.

The degree of resiliency displayed by a given individual in the face of financial barriers may be related to their likelihood of experiencing adverse clinical outcomes: those who are more resilient or determined may be less likely to have adverse outcomes as a consequence of their financial barriers while those who were in a state of despair may be more likely to become non-adherent and eventually have complications of their chronic conditions. The heterogeneity of resiliency displayed by individuals may account for the fact that the association between financial barriers and outcomes is not stronger (see Chapter 2 &3) – as only a select group of those with financial barriers (those with lower levels of resiliency) are actually adversely affected.

6.5 What goods and services do patients have a difficult time accessing due to financial barriers?

We found that there were three main types of goods and services that participants struggled to access due to financial barriers: (1) goods and services that are not included in public insurance plans; (2) items to support self-management including healthy food and physical activity; and (3) publicly funded services (such as doctor’s visits) that demand high incidental costs, such as parking in hospital facilities. We found that the financial barriers most commonly described by patients with cardiovascular-related chronic diseases were to medications and obtaining healthy food.

In our survey studies, we demonstrated that individuals with all forms of cardiovascular-related chronic conditions are susceptible to financial barriers, yet in our qualitative descriptive analyses we came to discover that there are notable between-condition differences in the exact goods and services that patients struggle to access.

Participants in all three cohorts (diabetes, CAD and stroke) stated that they faced financial barriers to accessing prescription medications. Rehabilitation and psychological support services were required by those with CAD or stroke and participants recounted difficulties accessing these due to the associated costs that fall outwith Alberta's public health insurance plan. Both those with stroke and diabetes described difficulties following through with medical and allied health recommendations to eat healthier diets as these were perceived to be costly and out of reach for many. Finally, nearly all participants with diabetes found the costs of their self-monitoring supplies to be problematic.

In summary, we have demonstrated that financial barriers are commonly experienced by Canadians with cardiovascular-related chronic diseases (~10%), and that these are even more common among those with multiple conditions and/or lower incomes. Financial barriers often arise as a result of the combination of limited financial resources along with the challenges of living with a chronic medical condition. Patients may experience financial difficulties associated with accessing a variety of goods and services that they require for the optimal management of their condition(s). These are predominantly in three areas including: non-insured goods and services, items to support self-management, and incidental costs associated with insured services. Those who experience financial barriers are more likely to have important adverse clinical outcomes, like hospitalizations and death. Yet, not all who experience financial barriers are deeply affected by them. Individuals who, due to their inherent characteristics and personal history, are able to demonstrate higher degrees of resiliency may be less likely to experience the full negative impact of having financial barriers.

The knowledge gained through these studies opens numerous avenues for possible interventions that address both the root causes of financial barriers as well as the factors that make such barriers more likely to have negative impacts on individual patients. Such interventions have the potential to improve patient outcomes and reduce system-level healthcare expenditures by reducing patients' need for high cost inpatient services.

6.6 Strengths and limitations of this work

The empirical work described in Chapters 2, 3, 4, and 5 contribute significantly to our current understanding of the complex relationship between perceived financial barriers and clinical outcomes in Canadian patients with cardiovascular-related chronic diseases. However, these studies should be interpreted in light of their limitations. The main limitation of the study in Chapter 2 was the cross-sectional nature of the survey data and the fact that outcomes were also self-reported, which is subject to differential misclassification bias in the form of reporting and recall biases. Fortunately, these biases were remedied by the addition of longitudinal administrative data in the study described in Chapter 3, which allowed for the objective ascertainment of prospectively observed outcomes of interest.

Secondly, there may be some problems with the exposure variable (financial barriers) used in these studies, particularly in Chapter 3. Unfortunately, since the succinct question asked in

Chapters 2, 4 & 5 was not asked of all CCHS respondents, we defined the presence of financial barriers as a composite of numerous questions that asked about financial barriers to a diverse array of goods and services, ranging from access to medications to ability to make health behaviour modifications and/or to access healthy food. These various financial barriers, which might be assumed to be linked by a common exposure (i.e. lack of financial resources), appeared to have similar effects on the outcomes of interest. Furthermore, the exposure variable in Chapter 3 was still obtained from cross-sectional sources. We remain unsure how durable financial barriers may be. If financial barriers are intimately tied to enduring components of socioeconomic status, such as income and level of educational attainment, these may persist throughout an individual's life. However, if they are more strongly related to situational factors, such as employment benefits or insurance status (as suggested by our grounded theory), they may be more fleeting and may not persist for years at a time, meaning that some misclassification may have occurred by assuming financial barriers persist for a five-year period as we did.

Third, in the statistical models used in both Chapter 2 and Chapter 3, we attempted to adjust for relevant covariates that were suspected confounders or effect modifiers. Despite our efforts, it is certainly possible that residual confounding is present and that the observed associations between perceived financial barriers and outcomes might be attributable to unmeasured differences between the groups. For instance, we did not have a satisfactory measure of disease severity (multimorbidity was used as proxy) or social status (education was used as proxy). As described in Chapter 4, it became clear that financial barriers did not affect all participants equally, but that factors intrinsic to each individual have significant effect on the impact of financial barriers. It is conceivable that this heterogeneity accounts for the small effect size noted in Chapter 3. Unfortunately, at present, the CCHS surveys do not include a valid summary measure of resiliency [169-171]. In future work this would be important to capture in order to assess for modifying effects of resiliency – it could be reasonably anticipated that those with lesser degrees of resiliency would be more susceptible to negative effects due to financial barriers.

Finally, there may be concerns regarding the generalizability or transferability of the findings presented in this work. Certainly, these findings are Canada-centric and were not intended for application outside of the Canadian context. However, even with this in mind, none of the studies were truly national. In the study presented in Chapter 2 we utilized only survey data from the four western provinces, while for the study in Chapter 3 we attempted to use national data, but had to exclude respondents of Quebec, Manitoba and the northern territories as they did not reliably report administrative data to CIHI during this period. For our qualitative work, presented in Chapters 4 and 5, only participants from Alberta were included. That said, we have little reason to believe that the findings of these studies would have been substantially different if national data were available. The only differences might be related to the fact that specific social programs and public insurance plans vary by province. However, we anticipate that there are those who fall through the cracks of social programs in each province, and even internationally.

Despite these limitations, there are several strengths in this work that should be highlighted. Firstly, we used a mixed methods approach to investigating financial barriers in this population. We feel that this was important as financial barriers represent a complex problem that cannot be satisfactorily explored using either quantitative or qualitative methods in isolation. Using quantitative methods, we were able to demonstrate that financial barriers are common among chronic disease patients in Canada (>10%) and that these have demonstrable associations with adverse clinical outcomes, even after adjusting for relevant confounding variables. We were then able to use qualitative methods to delve deeper into this topic to discover how individual Canadian patients experience financial barriers which led to several rich findings that could not have been garnered with the use of quantitative techniques alone. The result of using mixed methods is that we have demonstrated and quantified the significance of this problem, but also provided depth of understanding that may permit the development of policies and interventions to address financial barriers.

Another significant strength of this work is the use of a novel linked dataset of CCHS responses to the discharge abstract database. This linkage allowed us to determine the presence of a subjectively experienced exposure like perceived financial barriers (not available in administrative data) but simultaneously ascertain outcomes objectively, overcoming the biases inherent in surveys. Similar datasets have been used by researchers from the Institute of Clinical and Evaluative Sciences, but these studies include only the Ontario cohort of the DAD. Previous University of Calgary researchers [90] used similar data, but their dataset only included the initial two cycles of the CCHS as opposed to the current work that includes 10 cycles, plus other relevant national surveys.

Finally, the fact that the surveys were conducted by Statistics Canada is a considerable strength of this work. Statistics Canada is a respected and trusted Canadian institution – this trust in manifest in Canadians' willingness to participate in Statistics Canada surveys. In 2008/09

Statistics Canada reported that 95.5% of economic statistics and 99.1% of social statistics met predetermined levels of sampling accuracy [172].

6.7 Future Directions, Policy and Clinical Implications

Given that we have demonstrated that financial barriers are both relatively common and associated with adverse and costly clinical outcomes among Canadian patients with cardiovascular-related chronic diseases, addressing these should be of interest to provincial and federal policy makers. While this work is important, it is only preliminary and observational. It is possible that well-designed interventions may have the potential to mitigate the impact of financial barriers that we have observed. Applying the learnings from the qualitative study described in Chapters 4 and 5, interventions could either target one of two aspects of financial barriers:

1) **reduce patients' exposure to financial barriers,** attempting to reduce the prevalence of such barriers in the population. Some interventions that might achieve this objective would be programs that: provide publicly-funded pharmaceutical insurance to those who are uninsured; expand the basket of goods that are insured (i.e. providing rehabilitation services, food baskets or leisure centre passes); or reduce cost-sharing arrangements for those who do have insurance.

Alternatively, interventions could attempt to

2) **augment the resiliency of patients** who may face financial barriers in order to minimize the impact of the barriers on patients' lives and health outcomes. Such interventions might strive to: enhance financial literacy, help patients navigate

> healthcare and social services, and build self-efficacy and intrinsic motivation. Alternatively, a redistribution of public spending towards addressing upstream social determinants would very likely augment individuals' ability to demonstrate resiliency in the face of financial barriers.

While some trials of interventions such as these have been reported in the literature, none to date have been undertaken in the Canadian context. Fortunately, several are currently underway. This work has already been used to procure public funding and support for a large clinical trial testing the impact of two interventions (copayment elimination and self-management support) for low-income Alberta seniors [173]. Another trial is currently underway in Ontario, looking at the provision of first-dollar coverage for a limited set of essential prescription medications [174]. Another University of Calgary study is looking at the impact of a lay patient navigator/community health worker to help patients with chronic diseases access health and social services.

These ongoing trials as well as the foundational work described in this thesis will hopefully provide decision-makers at the federal, provincial and health region levels with the evidence required to move forward with bold public policy initiatives to address and minimize the impact of financial barriers to care for the betterment of Canadians with cardiovascular-related chronic conditions.

This work also has relevance for individual front-line clinicians. As shown in our conceptual framework, providers play crucial modifying roles in how impactful financial barriers are in patients' lives. Even if they can't prevent a barrier from existing, providers have the potential to protect patients from feeling the full impact of financial barriers. Participants recounted with great fondness the clinicians who display empathy towards them and help try to connect them with resources – even if that is a simple referral to psychosocial care (i.e. social work). On the other hand, numerous participants described how destructive their healthcare providers could be through ignorance and judgement. When counselling patients about self-management of cardiovascular-related chronic conditions, physicians should take care not to exaggerate patient agency and acknowledge the financial difficulties patients may face in their attempts to follow recommendations regarding diet and physical activity. This form of victim-blaming counselling may result in patient self-blame and ultimately despair in the face of financial barriers [127].

Unfortunately, we also found that patients are not always forthcoming about their financial barriers with their healthcare providers, especially with their specialists. Therefore, it is important that physicians and other healthcare providers incorporate inquiry about patients' access to care and whether they experience financial barriers into their routine clinical interviews. Some have advocated for routine screening for socioeconomic vulnerabilities and social determinants of health [175, 176]. When this is accompanied by a coordinated support system, objective improvements in cardiometabolic health have been demonstrated [177]. Given the association between perceived financial barriers and outcomes we have documented in this thesis, a reasonable screening item for routine clinical practice might be similar to the question we used to ascertain exposure to a financial barrier in our studies:

> *"Some people have difficulty paying for services, equipment, and medications for chronic conditions. Other people may have difficulty paying for transportation or childcare to*

> *attend doctors' appointments… In the past 12 months, did you have difficulty paying for services, equipment, medications for your chronic conditions?"*

A logical follow-up study to those described in this thesis would be to qualitatively interview physicians (both specialists and primary care) about their experience with patients who have financial barriers. Some physicians might not screen for financial barriers as they may feel unable to help patients address them. If this is the case, provider education about available public and non-profit supports may be helpful.

6.8 Conclusions

Despite universal public health insurance plans for physician and hospital services in all provinces, we found that approximately 1 in 10 Canadians with cardiovascular-related chronic conditions experience difficulty accessing required care due to costs. Accessing medications and healthy food seem to be the most commonly experienced financial barriers. Not only are financial barriers common in this population, but they are also associated with important adverse clinical outcomes such as non-adherence to recommended medications, the need for hospital and emergency department care and higher inpatient costs. We noted considerable heterogeneity in how financial barriers are experienced with barriers being much more impactful on some patients. There are numerous factors, protective, predisposing and modifying, that contribute to the degree of impact these barriers have on an individual patient. Patients with different chronic conditions experience financial barriers to disparate goods and services, but all patients are susceptible to facing difficulties accessing medications. These findings suggest that governments may have a financial incentive to consider investing in programs and interventions that address and minimize the impact of financial barriers since it may reduce expensive hospitalization. However, further experimental research is required to determine which interventions are effective and inform health policy in order to minimize the frequency and impact of financial barriers among Canadian patients with cardiovascular-related chronic diseases.

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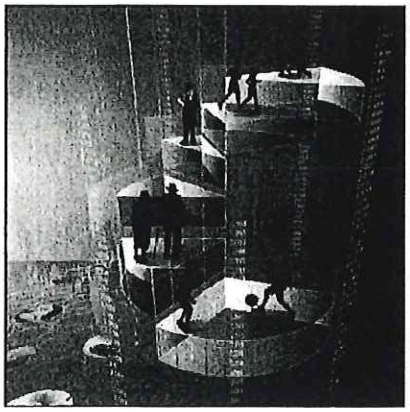

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BMC Medicine

RESEARCH ARTICLE

Open Access

Financial barriers and adverse clinical outcomes among patients with cardiovascular-related chronic diseases: a cohort study

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Abstract

Background: Some patients with cardiovascular-related chronic diseases such as diabetes and heart disease report financial barriers to achieving optimal health. Previous surveys report that the perception of having a financial barrier is associated with self-reported adverse clinical outcomes. We sought to confirm these findings using linked survey and administrative data to determine, among patients with cardiovascular-related chronic diseases, if there is an association between perceived financial barriers and the outcomes of: (1) disease-related hospitalizations, (2) all-cause mortality and (3) inpatient healthcare costs.

Methods: We used ten cycles of the nationally representative Canadian Community Health Survey (administered between 2000 and 2011) to identify a cohort of adults aged 45 and older with hypertension, diabetes, heart disease or stroke. Perceived financial barriers to various aspects of chronic disease care and self-management were identified (including medications, healthful food and home care) from the survey questions, using similar questions to those used in previous studies. The cohort was linked to administrative data sources for outcome ascertainment (Discharge Abstract Database, Canadian Mortality Database, Patient Cost Estimator). We utilized Poisson regression techniques, adjusting for potential confounding variables (age, sex, education, multimorbidity, smoking status), to assess for associations between perceived financial barriers and disease-related hospitalization and all-cause mortality. We used gross costing methodology and a variety of modelling approaches to assess the impact of financial barriers on hospital costs.

Results: We identified a cohort of 120,752 individuals over the age of 45 years with one or more of the following: hypertension, diabetes, heart disease or stroke. One in ten experienced financial barriers to at least one aspect of their care, with the two most common being financial barriers to accessing medications and healthful food. Even after adjustment, those with at least one financial barrier had an increased rate of disease-related hospitalization and mortality compared to those without financial barriers with adjusted incidence rate ratios of 1.36 (95% CI: 1.29–1.44) and 1.24 (1.16–1.32), respectively. Furthermore, having a financial barrier to care was associated with 30% higher inpatient costs compared to those without financial barriers.

(Continued on next page)

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Research

Development of a conceptual framework for understanding financial barriers to care among patients with cardiovascular-related chronic disease: a protocol for a qualitative (grounded theory) study

David J.T. Campbell MD MSc, Braden J. Manns MD MSc, Brenda R. Hemmelgarn MD PhD, Claudia Sanmartin PhD, Kathryn M. King-Shier RN PhD

Abstract

Background: Patients with cardiovascular-related chronic diseases may face financial barriers to accessing health care, even in Canada, where universal health care insurance is in place. No current theory or framework is adequate for understanding the impact of financial barriers to care on these patients or how they experience financial barriers. The overall objective of this study is to develop a framework for understanding the role of financial barriers to care in the lives of patients with cardiovascular-related chronic diseases and the impact of such barriers on their health.

Methods: We will perform an inductive qualitative grounded theory study to develop a framework to understand the effect of financial barriers to care on patients with cardiovascular-related chronic diseases. We will use semistructured interviews (face-to-face and telephone) with a purposive sample of adult patients from Alberta with at least 1 of hypertension, diabetes, heart disease or stroke. We will analyze interview transcripts in triplicate using grounded theory coding techniques, including open, focused and axial coding, following the principle of constant comparison. Interviews and analysis will be done iteratively to theoretical saturation. Member checking will be used to enhance rigour.

Interpretation: A comprehensive framework for understanding financial barriers to accessing health care is instrumental for both researchers and clinicians who care for patients with chronic diseases. Such a framework would enable a better understanding of patient behaviour and nonadherence to recommended medical therapies and lifestyle modifications.

Cardiovascular-related chronic diseases such as hypertension, diabetes, stroke and coronary artery disease are among the leading causes of morbidity and mortality in Canada.[1,2] Hospital services and medically necessary physician services are covered by Canada's universal public health insurance.[3] Despite the increasingly important role of medications and services of allied health care providers in managing outpatients with chronic diseases,[4] these are not universally included within Canadian health care insurance. For example, public insurance plans for outpatient prescription medications vary by province, but no province offers universal public medication insurance without some cost.[5] Those fortunate enough to qualify for public medication insurance are still faced with considerable copayments or deductibles or both.[6] Thus, financial constraints can have a significant impact on the care required to optimize outcomes in people with cardiovascular-related chronic diseases.[7] In fact, many patients face barriers to obtaining adequate health care, such as necessary prescription medications, owing to the costs associated with these services.[8]

There are several types of financial barriers that may reduce accessibility to necessary care and impact health outcomes. Some people may not be able to afford the direct costs associated with medications, self-monitoring supplies, rehabilitation or home care (such as insurance premiums and user charges). Others may struggle to access care that is fully funded by the public system because of an inability to afford the indirect costs associated with appointments (e.g., lost

Competing interests: None declared.

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Qualitative Study

Medicine

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Finding resiliency in the face of financial barriers

Development of a conceptual framework for people with cardiovascular-related chronic disease

David J.T. Campbell, MD, MSc[a], Braden J. Manns, MD, MSc[a], Pamela Leblanc, CCRP[b], Brenda R. Hemmelgarn, PhD, MD[a], Claudia Sanmartin, PhD[c], Kathryn King-Shier, PhD, RN[b,*]

Abstract

Patients with chronic diseases often face financial barriers to optimize their health. These financial barriers may be related to direct healthcare costs such as medications or self-monitoring supplies, or indirect costs such as transportation to medical appointments. No known framework exists to understand how financial barriers impact patients' lives or their health outcomes.

We undertook a grounded theory study to develop such a framework. We used semistructured interviews with a purposive sample of participants with cardiovascular-related chronic disease (hypertension, diabetes, heart disease, or stroke) from Alberta, Canada. Interview transcripts were analyzed in triplicate, and interviews continued until saturation was reached.

We interviewed 34 participants. We found that the confluence of 2 events contributed to the perception of having a financial barrier —onset of chronic disease and lack of income or health benefits. The impact of having a perceived financial barrier varied considerably. Protective, predisposing, or modifying of factors determined how impactful a financial barrier would be. An individual's particular set of factors is then shaped by their worldview. This combination of factors and lens determines one's degree of resiliency, which ultimately impacts how well they cope with their disease.

The role of financial barriers is complex. How well an individual copes with their financial barriers is intimately tied to resiliency, which is related to the composite of a personal circumstances and their worldview. Our framework for understanding the experience of financial barriers can be used by both researchers and clinicians to better understand patient behavior.

Abbreviations: None.

Keywords: barriers to care, finances, financial barriers, framework, grounded theory, health services accessibility, healthcare disparities, qualitative research

1. Introduction

Cardiovascular-related chronic diseases such as heart attacks, strokes, and diabetes remain among the most common causes of morbidity and mortality in North America.[1] This remains the case in spite of remarkably effective medical[2] and lifestyle therapies[3] to delay the onset and progression of cardiovascular disease.

Patients with these conditions may face a variety of barriers to receiving these effective therapies.[4] In particular, many studies have demonstrated significant associations between lower income levels and adverse health outcomes.[5,6] However, since some individuals have assets beyond their income and others have significant fixed expenses despite a reasonable income, other measures may be more useful determinants than income. The perception of a financial barrier among patients may be a helpful marker as this includes consideration of both an individual patient's assets and financial demands. Our previous research has demonstrated that despite public health insurance, 12% to 20% of Canadians with cardiovascular-related chronic diseases experience financial barriers to care.[7] This is largely driven by the limited scope of public health insurance and the fact that outpatient medications for many chronic conditions are not universally covered. Even when patients are insured, they may face substantial copayments when trying to access medications at their pharmacy.[8,9] We have also demonstrated that those who perceive having a financial barrier are more likely to self-report adverse outcomes such as requiring emergency department visits and hospitalization for their chronic disease.[7,10] Similarly, in the United States, Rahimi et al[11] demonstrated a significant association between perception of having a financial barrier and rehospitalization, as well as lower quality of life amongst myocardial infarction patients.

The presumptive mechanism for these findings is via cost-related nonadherence: those who experience financial barriers may be less likely to take prescription medications appropriately due to cost constraints,[7] resulting in poorer disease management and higher use of acute care services. However, the link between

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Understanding Financial Barriers to Care in Patients With Diabetes

An Exploratory Qualitative Study

Purpose

The purpose of this study was to better understand the impact that financial barriers have on patients with diabetes and the strategies that they use to cope with them.

Methods

A secondary analysis was conducted of 24 interviews with patients who had either type 1 or type 2 diabetes and perceived financial barriers, which were previously undertaken for a larger grounded theory study. Semistructured interviews were undertaken either face-to-face or by telephone. Data analysis was performed by 3 reviewers using inductive thematic analysis. Sampling for the original study continued until data saturation was achieved.

Results

The predominant aspects of care to which participants described financial barriers were medications, diabetes supplies, and healthy food. A variety of strategies are used by these patients. Participants described that their health care providers had the potential to either play an important supporting role; or alternatively, that they could also worsen the impacts of financial barriers.

Conclusions

Patients with diabetes experience financial barriers to various aspects of their care. While they use a variety of

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RESEARCH ARTICLE Open Access

Exploring the impact of financial barriers on secondary prevention of heart disease

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Abstract

Background: Patients with coronary artery disease experience various barriers which impact their ability to optimally manage their condition. Financial barriers may result in cost related non-adherence to medical therapies and recommendations, impacting patient health outcomes. Patient experiences regarding financial barriers remain poorly understood. Therefore, we used qualitative methods to explore the experience of financial barriers to care among patients with heart disease.

Methods: We conducted a qualitative descriptive study of participants in Alberta, Canada with heart disease ($n = 13$) who perceived financial barriers to care. We collected data using semi-structured face-to-face or telephone interviews inquiring about patients experience of financial barriers and the strategies used to cope with such barriers. Multiple analysts performed inductive thematic analysis and findings were bolstered by member checking.

Results: The aspects of care to which participants perceived financial barriers included access to: medications, cardiac rehabilitation and exercise, psychological support, transportation and parking. Some participants demonstrated the ability to successfully self-advocate in order to effectively navigate within the healthcare and social service systems.

Conclusion: Financial barriers impacted patients' ability to self-manage their cardiovascular disease. Financial barriers contributed to non-adherence to essential medical therapies and health recommendations, which may lead to adverse patient outcomes. Given that it is such a key skill, enhancing patients' self-advocacy and navigation skills may assist in improving patient health outcomes.

Keywords: Coronary artery disease, Secondary prevention, Cardiac rehabilitation, Qualitative research, Financial barriers

Background

Coronary artery disease (often referred to simply as heart disease) is a leading cause of morbidity and mortality globally [1]. While some people die following an initial cardiac event, advances in thrombolytic therapy [2] and percutaneous coronary intervention [3], have enabled the vast majority to survive. Given that more people are surviving their first cardiac event, the importance of outpatient management of chronic heart disease is ever growing. A mainstay of heart disease management is the use of proven cardio-protective medications [4, 5]. Another important facet in secondary prevention is engagement in a structured physical activity program, often called cardiac rehabilitation, which has been proven to reduce risk of subsequent events [6].

Many patients with heart disease who should have access to medical therapies do not receive the care that might benefit them. Patients' access to optimal therapies is hindered by a myriad of barriers, such as physical barriers (e.g., transportation, distance to services) [7], system-level barriers (e.g., wait times [8, 9], access to

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Money is Brain: Financial Barriers and Consequences for Canadian Stroke Patients

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ABSTRACT: ***Background:*** Stroke patients of lower socioeconomic status have worse outcomes. It remains poorly understood whether this is due to illness severity or personal or health system barriers. We explored the experiences of stroke patients with financial barriers in a qualitative descriptive pilot study, seeking to capture perceived challenges that interfere with their poststroke health and recovery. ***Methods:*** We interviewed six adults with a history of stroke and financial barriers in Alberta, Canada, inquiring about their: (1) experiences after stroke; (2) experience of financial barriers; (3) perceived reasons for financial barriers; (4) health consequences of financial barriers; and (5) mechanisms for coping with financial barriers. Two reviewers analyzed data using inductive thematic analysis. ***Results:*** The participants developed new or worsened financial circumstances as a consequence of stroke-related disability. Poststroke impairments and financial barriers took a toll on their mental health. They struggled to access several aspects of long-term poststroke care, including allied health professional services, medications, and proper nutrition. They described opportunity costs and tradeoffs when accessing health services. In several cases, they were unaware of health resources available to them and were hesitant to disclose their struggles to their physicians and even their families. ***Conclusion:*** Some patients with financial barriers perceive challenges to accessing various aspects of poststroke care. They may have inadequate knowledge of resources available to them and may not disclose their concerns to their health care team. This suggests that providers themselves might consider asking stroke patients about financial barriers to optimize their long-term poststroke care.

RÉSUMÉ: Votre argent, votre cerveau : les obstacles financiers et les conséquences auxquels font face les patients canadiens victimes d'un AVC. ***Contexte:*** Les patients de statut socioéconomique inférieur victimes d'un AVC se distinguent par de moins bons pronostics de réadaptation. On comprend encore mal si cela est attribuable à la gravité de leur affection ou bien à des obstacles financiers personnels ou liés aux systèmes de santé. Dans le cadre d'une étude pilote qualitative de nature descriptive, nous avons ainsi voulu nous pencher sur les cas de patients victimes d'un AVC faisant face à des obstacles financiers. À cet égard, nous avons cherché à comprendre les difficultés qu'ils perçoivent et qui sont susceptibles de nuire à leur santé et à leur récupération post-AVC. ***Méthodes:*** Nous avons interviewé six adultes albertains (Canada) ayant des antécédents d'AVC et faisant face à des obstacles financiers. Nous avons cherché à nous enquérir de : (1) leurs expériences à la suite de leur AVC ; (2) de leur vécu en lien avec leurs obstacles financiers ; (3) des raisons qui, selon eux, expliquaient ces obstacles ; (4) des conséquences de ces obstacles sur leur santé ; (5) et des moyens à leur portée pour y faire face. Deux évaluateurs se sont ensuite penchés sur ces données au moyen d'une analyse thématique par raisonnement inductif. ***Résultats:*** Au dire des participants, ils ont commencé à éprouver des difficultés financières ou ont vu ces dernières s'aggraver en raison de l'invalidité consécutive à leur AVC. Leurs troubles post-AVC et leurs obstacles financiers ont aussi eu de graves répercussions sur leur santé mentale. Ils ont dû se démener pour avoir accès à des soins de longue durée post-AVC, ce qui inclut des services de santé connexes, des médicaments et une alimentation adéquate. Ils ont aussi décrit le manque à gagner et les compromis financiers au moment d'avoir accès à des services de santé. Dans bien des cas, ils ignoraient l'existence de ressources à leur disposition et étaient réticents à révéler leurs difficultés à leurs médecins et même à leurs familles. ***Conclusions:*** Certains patients aux prises avec des obstacles financiers considèrent l'accès à des soins post-AVC comme un défi. Il est possible qu'ils possèdent une connaissance réduite des ressources à leur disposition et qu'ils ne fassent pas part de leurs préoccupations à leur équipe soignante. Cela nous porte à croire que les dispensateurs de soins devraient eux-mêmes envisager de questionner les patients victimes d'un AVC au sujet de ces obstacles financiers, et ce, afin d'optimiser les soins de longue durée post-AVC leur étant prodigués.

Keywords: Stroke, Cerebrovascular disease, Communication, Doctor-patient relationship, Education, Financial barriers, Health services research, Outcomes research, Qualitative research, Quality of care

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