

HEALTH INSURANCE COVERAGE FOR BREAST CANCER CARE:  
A FEMINIST POLITICAL ECONOMY PERSPECTIVE ON WOMEN'S  
EXPERIENCES IN ONTARIO AND NEW YORK

ALISON JENKINS JAYMAN

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## **Abstract**

This thesis examines how the health insurance systems of Ontario and New York impact women's health insurance experiences in relation to breast cancer care.

The analysis provided draws on insights from feminist political economy scholarship to consider the roles of states and markets as well as households and voluntary sectors in health insurance coverage. Women's experiences in Ontario—where public health insurance plays a primary role—and in New York—where private health insurance plays a primary role—are addressed against the background of welfare state transformation and neoliberal reform reaching beyond jurisdictional boundaries. Review of secondary literature, legislation and policy documents establishes the context for analysis of 42 semi-structured interviews conducted with women diagnosed with breast cancer in the neighboring jurisdictions of Lanark and Leeds Grenville in Ontario and St. Lawrence County in New York.

Thematic analysis of the interviews conducted identifies three overarching themes: 'commodified coverage', 'responsibilized individuals' and 'gradation in consequences'. With the primacy of private health insurance in New York's health insurance system, participants' narratives are found to reflect more commodified coverage, more responsibilized individuals, and greater gradation in the consequences of financing breast cancer care than in Ontario, where public health insurance plays a primary role. This thesis underlines the importance of health insurance coverage as a

women's issue and highlights the importance of public policy in shaping the conditions under which women use health insurance to finance breast cancer care.

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## **Introduction**

### **Background**

The concerns that underlie this thesis began to take shape several years ago when I was commissioned by Women and Health Care Reform, formerly the National Coordinating Group on Women and Health Care Reform, to conduct a literature review about women and private health insurance. Established as part of the Women's Health Contribution Program, this group's mandate was to coordinate research on women and health care reform in Canada, identify gaps in knowledge, and share findings with women from diverse backgrounds (Armstrong, 2012: 3-4). While reviewing literature about women and private health insurance in 2007, I found much scholarship on private health insurance did not approach this form of health care financing as a women's issue. Moreover, much of the scholarship that did focused squarely on circumstances in the United States, and most of this work was quantitative in nature (Jenkins, 2007). When commissioned to complete an updated review on the subject in 2010, I found that the broad parameters of research on women and private health insurance had not expanded considerably.<sup>1</sup> The limited attention to private health insurance in Canada, much less its implications for women as a group and different groups of women, was striking. So too was the scarcity of comparative research addressing women's health insurance experiences in different jurisdictions. Findings, often from the United States, identified disparities in health insurance coverage between women and men and among different

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<sup>1</sup> This later review of literature on women and private health insurance was utilized in a book chapter entitled "Women and Private Health Insurance" (Jayman & Willson, 2012).

groups of women. Yet I searched in vain for richly textured comparative accounts of women's experiences using different forms of coverage under different health insurance systems.

### **Purpose and Goals**

Although health care is well established as a women's issue and health insurance is a well established method of health care financing, little attention has been devoted to how different mixes of private and public health insurance shape women's access to and experiences with care. With the complexity and variation in health insurance systems among and within countries discouraging finely grained comparisons across jurisdictions, little comparative health insurance scholarship has embraced a qualitative approach in studying women's use of coverage in accessing care. This thesis aims to address this gap by comparing the health insurance experiences of women in two jurisdictions, one in Canada and one in the United States. It addresses health insurance in Ontario and New York, focusing on its use in relation to one condition of particular concern for women: breast cancer. The most frequently diagnosed cancer in women aside from skin cancer, breast cancer is the second leading cause of cancer mortality among women in Canada and the United States (Canadian Cancer Society, 2013: 26, 36; American Cancer Society, 2013: 9). By using a political economy lens to locate health insurance arrangements in Ontario and New York in relation to breast cancer care and within larger developments, this thesis seeks to facilitate comparison of the health insurance systems in these jurisdictions and assess their implications for women as a group and particular groups of women.

## **Health Insurance Considerations in Canada and the United States**

The matter of who should pay for health care—and how—has become central in popular and scholarly debates about health care in Canada and the United States.

Decisions about payment have profound implications because how health care is financed shapes not only its availability, but who has access to care and the degree of protection offered from costs of illness (Ostlin, 2005: 8). Yet while debates about how forms of health insurance should be organized and regulated are routine and often heated in both of these “liberal” welfare states (O’Conner, Orloff & Sharver, 1999), they begin from different points.

Most Canadians who seek care for breast cancer and other conditions do so within a system in which public health insurance covers most physician and hospital care, and private health insurance is largely restricted to a supplementary role. Those in the United States, in contrast, seek health care within a system centered on private health insurance, in which public health insurance is confined to a residual role. Caricatures of ‘socialized medicine’ feature prominently in popular discussions of Canada’s health insurance system in the United States.<sup>2</sup> where “Canadian Medicare” has been “painted as both savior and foe for American patients” (Flood, 2009: 585). In Canada, the privatized health insurance system that has for many become synonymous with American health

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<sup>2</sup> As Deber (2003: 20) among many others has emphasized, Canada does not in fact have ‘socialized medicine’: health services are delivered by private providers.

care has been both praised and condemned. However, it is often treated as a distant extreme rather than a source of practical lessons about privatization in health insurance.<sup>3</sup>

Sensational pronouncements and broad generalizations not only misrepresent health insurance systems in Canada and the United States, but also obscure a host of factors that complicate comparative scholarship. Within both countries, the financing of health care is shaped by federal as well as provincial/state-level involvement. As Peterson (2009: 501) has observed, in both cases the “national government cannot dictate policies to the governments below. Instead, each one relies on motivating sub-national action by offering substantial matching funds, or transfers, in exchange for compliance with specified policy provisions.” Indeed, it has been suggested that there is no “Canadian system” per se, but rather a “set of publicly financed, provincially run insurance plans covering all legal residents for specified service categories” (Deber, 2003: 20). Provincial and territorial health insurance systems are all supposed to abide by the criteria of public administration, comprehensiveness, universality, portability and accessibility set out in the 1984 *Canada Health Act*. At the same time, there are some variations in public coverage and even more in regulations surrounding the role of private health insurance among provinces and territories (Flood & Haugan, 2010). In the United States, public health insurance varies even more widely among states, as does the regulation of the private health insurance industry. As the U.S. Department of Health and Human Services (2008) succinctly explains, “aspects of regulating the business of insurance vary by state

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<sup>3</sup> Armstrong et al. (2003) represent an important exception. These authors argue circumstances in United States offer useful lessons about what happens when public and private for-profit services are mixed on the basis of market principles and business practices.



and by type of coverage.” Moreover, while Medicare is a federal program, public health insurance offered through Medicaid differs from state to state (U.S. Department of Health and Human Services, 2012).

Although it is important to recognize differences in health insurance systems *within* Canada and the United States, it is also important to understand how health insurance arrangements are shaped by developments that extend beyond borders in a globalizing world. As Whiteside (2009: 79) has argued health insurance does not operate in a vacuum, but rather “is intimately bound up with the prevailing social relations of power and thus with developments occurring within capitalism itself.” Health insurance policy within particular jurisdictions in both Canada and the United States can be seen as occurring not only within national settings but also within the context of neoliberalism as a political economic project reaching beyond jurisdictional boundaries. Against this background, the restructuring of health insurance can be understood as a “national phenomenon only in a limited sense” (Whiteside, 2009: 79). It is thus important to consider commonalities in context and policy direction as well as differences.

It is no less important to recognize that health insurance systems have varying consequences for those who use health care. Research in the United States in particular suggests disparities in public and private health insurance coverage, with rates and types of coverage varying with income, sex, race, age and ability among other factors (Center for Disease Control and Prevention, 2012). While provincial health insurance systems provide doctor and hospital coverage for those who qualify as legal residents (Deber, 2003: 20), only 66 percent of the Canadian population is estimated to hold supplementary

private health insurance (Flood & Haugan, 2010: 321). Such findings make it clear that not all of those who use health insurance systems are equally situated in relation to the different types of coverage offered. Health insurance systems can thus be understood to have different implications for individuals in different social, political and geographical locations.

The consequences of particular health insurance systems for women as a group and for different groups of women are seldom highlighted in health care financing debates. Scholarship on forms of public and private health insurance, much of which addresses circumstances in the United States, does however point to inequalities in coverage between women and men as well as among women (for a review, see Brittle & Bird, 2007). Yet while such scholarship is helpful in identifying differences in coverage, it is less suited to addressing the significance of different forms of health insurance under different health insurance systems for the daily lives of women in different social, political and geographical locations. A scarcity of comparative qualitative research focusing directly on women's experiences using health insurance in relation to specific conditions in jurisdictions within Canada and the United States makes it difficult to compare the implications of the health insurance systems in place for women's everyday circumstances in the face of illness.

### **Scope of the Project**

In the context of insufficient comparative qualitative scholarship examining women's health insurance experiences in different jurisdictions, this thesis focuses on women's health insurance experiences in relation to breast cancer care in Ontario and

New York. Breast cancer care is the focus of this study of women's health insurance experiences due to its prominence as a women's health issue as well as the emphasis on treatment involving costly medical care. Simply being female has been identified as the main risk factor for developing breast cancer (American Cancer Society, 2013; Canadian Cancer Society, 2013), making access to treatment for this condition a particularly pressing women's health issue. The focus of treatment on costly medical interventions (Hassett et al., 2006; Campbell & Ramsey, 2009; Vera-Llonch et al. 2011) makes this a particularly vital area in which to compare women's experiences with health insurance coverage as a method of health care financing.

Examining health insurance in New York and Ontario allows for attention to the complexities of provincial/state regulation as well as national regulation in two jurisdictions that are relatively restrictive in maintaining different roles for public and private health insurance. Attention to women's health insurance experiences in adjacent areas within these jurisdictions further focuses the present project. Separated by the St. Lawrence River, Lanark and Leeds Grenville in Ontario and St. Lawrence County in New York provide the immediate setting for study. Attention to women's health insurance experiences in these adjacent counties allows for consideration of women's health insurance experiences in relation to breast cancer care in two areas in Ontario and New York that encompass similar rural and small town communities that have predominantly English speaking, non-immigrant, white populations (Statistics Canada, 2013a, Statistics Canada, 2013b, U.S. Census Bureau, 2013). Thus beyond geographical

proximity, these areas have the advantage of offering environments and populations that are similar in these respects.

Exploration of how the health insurance systems of Ontario and New York impact women's health insurance experiences in relation to breast cancer care in Lanark and Leeds Grenville and across the river in St. Lawrence County is guided by theoretical insights from feminist political economy scholarship. In broad terms this tradition points to the importance of considering historical context, material conditions, and change over time in analysis that values critical attention to women's perspectives and experiences. More specifically, feminist political economy insights offer guidance about understanding the roles of states, markets, households and the voluntary sector in shaping women's health insurance experiences as well as direction for contemplating the significance of health insurance for social reproduction more generally.

This thesis begins by exploring literature about women and forms of health insurance in Canada and the United States in order to locate and justify the research undertaken. Findings about health insurance systems, women and health insurance, and health insurance coverage for breast cancer care are examined in order to identify contributions and limitations of scholarship in these areas. Attention then turns to the theoretical contributions of feminist political economy in allowing for analysis of health insurance that encompasses political economic contexts as well as women's experiences within them. Insights into the roles of states, markets, households and the voluntary sector in relation to social reproduction are taken up as offering a way to understand the significance of health insurance as well as the implications of particular state-market-

household-voluntary sector arrangements for women's experiences using different forms of coverage for breast cancer care in different jurisdictions.

Discussion of methodological considerations involved in the comparative qualitative study of women's health insurance experiences in relation to breast cancer care in Lanark and Leeds Grenville in Ontario and St. Lawrence County in New York allows for attention to the particular choices that underpin the current project. In addition to addressing more abstract methodological issues this discussion is important in providing a rationale for comparative qualitative research in Lanark and Leeds Grenville in Ontario and St. Lawrence County in New York. It addresses how women in these jurisdictions came to be interviewed about their health insurance experiences in relation to breast cancer care, the characteristics of the women who participated in the study, and the analysis undertaken. Attention subsequently turns to how the health insurance systems in Canada and the United States developed in order to set the stage for an exploration of health insurance policy pertinent to women's use of health insurance in Ontario and New York specifically. With health insurance arrangements in these jurisdictions shaping the more immediate context for women's health insurance experiences, contemporary forms of public and private coverage are examined.

Attention to existing literature, theoretical concerns, methodological choices as well as the development of health insurance systems in Canada and the United States and contemporary forms of public and private health insurance in Ontario and New York establishes the context for subsequent analysis of 42 semi-structured interviews conducted with women in Lanark and Leeds Grenville in Ontario and St. Lawrence

County in New York. Thematic analysis underpins a comparative account of central themes in participants' health insurance experiences in relation to breast cancer care. Based on this analysis, the final chapter draws out implications of different forms of public and private health insurance, leading to more general conclusions about the impact of different health insurance systems.

In addition to adding to empirical knowledge about women's health insurance experiences under the health insurance systems of Ontario and New York, and in Lanark and Leeds Grenville as well as St. Lawrence County in particular, this thesis aims to contribute to how health insurance is understood and studied. One goal is to underline the importance of social relations of gender, class, race and age in shaping women's relationships with forms of health insurance coverage. Another is to encourage attention to state-market-household-voluntary sector arrangements in shaping health insurance, the terms on which women access and use it and the consequences for them. A broader goal is to indicate the importance of health insurance for social reproduction, the process through which "the daily and generational production and maintenance of people is completed" (Bezanson & Luxton, 2006: 3).

In addressing matters relevant to health insurance policy, this thesis aims to offer insight into the significance of different types of public and private health insurance for women's experiences as well as the implications of health insurance systems that involve different roles for public and private health insurance. In considering its contribution, it is important to understand that the central concern of this thesis is women's health insurance experiences as they relate to breast cancer care in the jurisdictions examined.

Breast cancer care is thus approached as a useful area in which to explore women's experiences with coverage. It is, however, specifically the *financing* of care—not the nature of breast cancer or the provision of care itself—that is of primary concern.

### ***Organization of Subsequent Chapters***

The analysis that follows is organized into five chapters followed by a conclusion. Chapter One, "Locating the Study of Women, Health Insurance and Breast Cancer Care", situates the research pursued in relation to scholarship about health insurance in Canada and the United States, women and health insurance, and health insurance for breast cancer care. Chapter Two, "Feminist Political Economy, Health Care Reform and Social Reproduction" addresses the theoretical concerns that underpin the project as a whole. This chapter discusses feminist political economy scholarship and explains how theoretical insights from this tradition are taken up to understand women's health insurance experiences in relation to breast cancer care in Ontario and New York.

Chapter Three, "Studying Health Insurance Coverage for Breast Cancer Care in Ontario and New York", addresses the methodology and methods used to address the question of how the health insurance systems of Ontario and New York affect women's health insurance experiences in relation to breast cancer care. This chapter discusses qualitative research and the influence of feminist concerns in the present effort as well as the research strategy utilized. A rationale is provided for studying the health insurance systems of Ontario and New York and for interviewing research participants living in Lanark and Leeds Grenville in Ontario and St. Lawrence County in New York. Demographic information is then provided about the 42 women interviewed, all of whom

had been diagnosed with breast cancer in the last eight years. Thus, beyond considering methodological matters this chapter introduces characteristics of study participants.

Chapter Four, “Health Insurance Reform in Canada and the United States”, is devoted to addressing broad contextual considerations. This chapter examines the historical development of health insurance systems in Canada and the United States as well as more recent trends in health insurance reform against the background of the rise and entrenchment of neoliberalism as a political economic project. Attention is devoted to developments in health insurance policy setting the stage for the health insurance systems operating in Ontario and New York. Contemporary forms of health insurance in these jurisdictions are discussed in some detail as providing the more immediate context of participants’ health insurance experiences in relation to breast cancer care.

Chapter Five, “Commodified Coverage, Responsibilized Individuals and Gradation in Consequences of Financing Breast Cancer Care”, presents the results of a thematic analysis of the interviews conducted. Guided by feminist political economy insights, this chapter is organized around three main themes: commodified coverage, responsabilized individuals and gradation in consequences. These themes are used as the basis for comparing participants’ accounts of their health insurance experiences in relation to breast cancer care. While these overarching themes are evident in participants’ accounts of health insurance experiences in both Ontario and New York, they are apparent to very different extents in these contexts. The concluding chapter moves from examining specific findings to considering more general implications of these findings. Beyond reviewing the research conducted, this chapter identifies limitations of the study



before considering empirical, theoretical and policy contributions and directions for future research.

## **Chapter 1: Locating the Study of Women, Health Insurance and Breast Cancer Care**

### **Introduction**

The Oxford English Dictionary (1989 [2012]) defines health insurance as insurance against financial loss through illness. As a method of financing health care, this form of insurance aims to offer protection from the unpredictable—and potentially ruinous—costs associated with ill health by pooling financial risk among people over time (Thomson & Mossialos, 2004: 7). The purpose of the present chapter is to situate this thesis and its central concerns in relation to contemporary literature about health insurance, women and breast cancer care. It aims to contextualize attention to women's experiences of breast cancer care within the health insurance systems of Ontario and New York with respect to key perspectives, findings and limitations in related bodies of scholarship. In order to locate experiences in this state and province within broader national contexts, the chapter orients readers to the study of health insurance and scholarship comparing health insurance systems in Canada and the United States more generally. This is important because, while the research conducted focuses on the health insurance systems in a state and a province due to variations between provincial and state health insurance systems in Canada and the United States respectively, provincial and state systems are nevertheless shaped by broader developments in these national contexts. The chapter next considers literature addressing women and health insurance, and health insurance and breast cancer care in particular.

Offering a critical perspective on existing scholarship, this chapter argues that the feminist political economy approach guiding analysis in this thesis, together with use of

qualitative research methods and attention to women's health insurance experiences, makes a useful contribution to the study of women and health insurance, and health insurance and breast cancer care more specifically, building on existing scholarship to understand women's health insurance experiences in relation to breast cancer care and the contexts within which they take place. The study of breast cancer care in particular allows for attention to health insurance in relation to a condition that is both a prominent women's health issue and, as will be discussed, one involving extensive and often expensive medical treatment that makes the matter of health insurance especially pressing.

Considered in detail below, comparisons of health insurance systems in Canada and the United States have drawn attention to historical and institutional differences. This scholarship is very helpful in underlining the importance of understanding the specific historical and institutional contexts within which health insurance arrangements develop and change. The gendered, classed and racialized implications of these systems for women have not, however, been particularly prominent in much comparative scholarship. Much of the literature that specifically addresses women and health insurance is quantitative in nature, and much of this literature focuses on health insurance in the United States in particular. This scholarship is useful in identifying broad trends in health insurance coverage as well as issues of concern for women as a group and different groups of women. Health insurance is, however, typically approached as an isolated variable in this literature. As such, it is not ideal for furthering critical understanding of

women's health insurance experiences and the political economic context within which they occur.

In contrast, qualitative literature addresses women's perspectives and experiences on a range of issues related to breast cancer care in rich detail. Yet health insurance, and the material constraints and possibilities this form of health care financing offers women, is seldom a central concern in this literature. In focusing on women's perspectives and experiences, moreover, much of this literature does not adequately address the particular health insurance systems within which women's experiences occur. In this context, this thesis seeks to build on insights offered in existing scholarship. It does so in order to further critical understanding of women's health insurance experiences in relation to breast cancer care under two different health insurance systems, and to advance understanding of how different policy choices surrounding public and private health insurance affect women's lives on a daily basis. In exploring the question of how the health insurance systems of Ontario and New York impact women's health insurance experiences in relation to breast cancer care, this thesis contributes to better understanding the significance of health insurance policy for women diagnosed with breast cancer and the political economic context within which they use forms of health insurance in accessing care.

### **Understanding Health Insurance**

It is useful to begin by considering the nature of health insurance and efforts to categorize it. Health insurance may be publicly and/or privately funded and organized. The OECD Adhoc Group on Private Insurance considers the difference in how health

insurance is funded to be the key criterion in distinguishing between private and public insurance (Savodoff & Sekhri, 2004: 4). As Savodoff & Sekhri (2004: 4) explain, “Ultimately, all money comes from household income, but in public insurance programs this money is channeled through the State, via a general or social insurance tax collector, whereas in private insurance the money is paid directly to the risk pooling entity”. Private health insurance can also be distinguished from public health insurance by its funding through non-income related premiums, typically on the basis of a contract between a private party (including employers) and an insurance entity (Colombo & Tapay, 2004a: 11). Unlike public health insurance premiums, private health insurance premiums are generally risk-rated (on the basis of an individual’s or group’s risk of ill health) or community-rated (the same for all members of a particular ‘community’ such as a company or a geographically defined area) (Thomson, Foubister & Mossialos, 2009: 28).

Public health insurance can be understood to encompass a range of schemes variously referred to as ‘social’ or ‘national’ health insurance (Savodoff & Sekhri, 2004: 4). Long considered a “central pillar of the modern welfare state” (Maioni, 1998: 3), public health insurance can be understood as a social right of citizenship (Bhatia, 2010). Indeed, Maioni (2010: 226) has argued,

Health care represents perhaps the most important example of the way in which government social programs can enhance citizenship and state legitimacy. Through its involvement in health care, the modern state takes on a crucial role in social protection in the sense of literally “protecting” its citizens from the effects of ill health. In helping to finance the provision of health care services, governments offset the potentially catastrophic costs associated with illness. In regulating the health care sector,

governments shape the rules of the fundamental relationship between providers and patients. In essence, involvement in health care represents a way in which the state can help establish the boundaries of social consensus and mutual rights and responsibilities between citizens.

As in the case of other citizenship entitlements, eligibility for public health insurance differs in different contexts. Public health insurance may be based on respect for the principle of universality, as in the *Canada Health Act* (1984). It may be limited to select groups on the basis of characteristics such as age, disability, and means, as in the United States (U.S. Department of Health and Human Resources, 2007). Thus while abstract discussion of public health insurance emphasizes access to this form of insurance as a right, public health insurance systems differ significantly in practice.

In contrast to public health insurance offered as a right of citizenship, private health insurance is a commodity available for purchase. Although sometimes described as “voluntary” health insurance coverage (Mossiolos & Thomson, 2004), this euphemism ignores both the conditions under which private health insurance is made available and those under which individuals “volunteer” to purchase it. The OECD identifies four main types of private health insurance coverage: (i) primary, (ii) duplicate, (iii) complementary and (iv) supplementary (Colombo & Tapay, 2004a: 31). Where private health insurance is *primary*, it offers the only available access to health insurance coverage because individuals do not have access to public health insurance. Private health insurance plays a primary role in providing health insurance coverage in the United States, where it is the main method of funding health care for the employed population. This shapes the

conditions under which the one in eight women estimated to face a breast cancer diagnosis (National Cancer Institute, 2012) seek treatment in the United States.

In contrast, *duplicate* private health insurance provides those already covered under public health systems with private coverage for the same set of services, as in Australia and Ireland. *Complementary* private health insurance complements publicly insured services or those offered by other forms of private coverage, covering either all or part of the costs not otherwise reimbursed, such as co-payments, as in France.

*Supplementary* private health insurance provides coverage for health services not covered under public schemes, as in Canada, where most provinces prohibit other types of private health insurance for areas encompassed by public health insurance (Colombo & Tapay, 2004a: 31). This shapes the conditions under which the one in nine women estimated to face a breast cancer diagnosis seek treatment in Canada (Canadian Cancer Society, 2013: 15). Overall, this kind of health insurance typology is helpful in understanding that different types of private health insurance play different roles in different countries. Private health insurance is, however, regulated differently in different jurisdictions, leading to differences in insurers' behavior in terms of the structure of benefits, premiums and their method of calculation, cost-sharing arrangements, and insurers' relationships with health care providers (Colombo & Tapay, 2004a: 15).

In practice, it is useful to recognize a spectrum of health insurance arrangements that runs from purely private, for-profit commercial insurance to purely publicly funded and publicly managed insurance, with combinations in between (Savodoff & Sekhri 2004: 4). Within the OECD, countries use a mix of public and private sources to pay for

health care to varying degrees. OECD (2011: 157) data indicate that in 2009 in Canada 71% of health care financing was from government, 15% from out of pocket, 13% from private health insurance and 1% from other forms of financing. The comparable data for the United States was 48%, 12%, 33% and 7%. The government contribution to total expenditure on health was thus significantly higher in Canada than in the United States, while private health insurance made a significantly higher contribution to total health expenditure in the United States than in Canada. Nevertheless, state spending per capita is similar in Canada and the United States: this amounted to \$ 3964.10 (USD) in Canada and \$3954.20 (USD) in the United States in 2011 (World Health Organization, 2013). Differences in the public and private contributions in relation to total health expenditure can be seen to reflect differences in the health insurance systems operating in these countries, a topic which is discussed in the following section.

### **Health Insurance Systems in Canada and the United States**

Health insurance offers an important point of contrast between Canada and the United States (Armstrong & Armstrong, 2008: 24).<sup>4</sup> The health insurance systems in place do differ significantly, with public and private coverage playing different roles. Under the *Canada Health Act* (1984), public provincial and territorial health insurance plans are required to cover medically necessary hospital and physician services in accordance with the criteria of universality, comprehensiveness, accessibility, portability and public administration. All legal residents of Canadian provinces and territories are eligible for public health insurance coverage. Yet while public health insurance covers

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<sup>4</sup> Armstrong and Armstrong (2008: 24), for instance, title a section comparing health insurance in Canada and the United States as “Canada and the United States: Public vs. Private”.



physician services and hospital care, it does not cover all health care related expenditures. Other services are funded privately, although there is some limited coverage through government programs such as those targeting seniors, the disabled and low-income groups.

Private health insurance has traditionally played a supplementary role in Canada, offering coverage for goods and services *not* covered under the public health care system (Colombo & Tapay, 2004a: 39-40). Private health insurance for publicly financed services (i.e., duplicate private health insurance) has been prohibited in British Columbia, Alberta, Manitoba, Ontario and Prince Edward Island (Flood & Archibald, 2001) and, until recently, in Quebec (Flood & Xavier, 2008). No single source of information summarizes the number and characteristics of all Canadians who have private health insurance (Hurley & Guindon, 2008). In supplementing public health insurance, private health insurance plans in Canada offer benefits such as out-of-hospital prescription drug coverage, dental care, semi-private or private hospital accommodation, private duty nursing, vision care and some medical equipment, and can extend to other services such as counseling (Canadian Life and Health Insurance Association, 2001).

In the United States, in contrast, private health insurance is the primary method of funding health care for the employed population and public health insurance is available only to restricted groups. The U.S. Census Bureau (2010) recognizes three categories of private coverage: employment-based health insurance offered through one's own employment or a relative's, own employment based health insurance through one's own employment where only the policyholder is covered, and direct-purchase health insurance

in which coverage is purchased directly by an individual from a private company.

Employer-based health insurance plans take a variety of forms. The U.S. Department of Health and Human Services, Office of Women's Health (2007) identifies two main kinds: *fee-for-service* and *managed care*.

Historically, private coverage in the United States was set up in a fee-for-service manner, taking the form of a conventional indemnity health insurance plan. In this type of plan, a provider submits a claim to the insurance company for payment and is paid for each covered service. Over the past decades, however, insurers have become involved in directing and overseeing health care through *managed care*. Managed care sees insurers assume "some degree of legal responsibility for both the financing and management of care delivery" (Weiner et al., 2008: 1109). Managed care plans have contracts with certain providers, and individuals who have this kind of plan typically receive health coverage for a restricted network of providers for a fixed fee. Managed care has become the dominant form of employer-sponsored insurance in the United States (Wenzel & Steeves, 2008: 1477). The 2012 Employer Health Benefits Survey lists the most common plan type as the preferred provider organization (PPO), enrolling 56 percent of covered workers (Claxton et al., 2012: 2). Another 19 percent of covered workers are enrolled in a high deductible health plan with a savings option (HDHP/SO), 16 percent are enrolled in a health maintenance organization (HMO), 9 percent in point-of-service (POS) plans, and 1 percent in a conventional plan (Claxton et al., 2012: 2). Differences between kinds of managed care largely relate to rules about the circumstances under which beneficiaries

may or may not seek treatment from providers outside of managed care provider networks.

The major categories of public coverage in the United States, which the U.S. Census Bureau (2010) conceptualizes as “government health insurance”, are Medicare, Medicaid, the Children's Health Insurance Program (CHIP), military health care, the Indian Health Service and various plans specific to particular states. Medicare is a federal program that “helps pay health care costs for people 65 and older and for certain people under 65 with long-term disabilities” (U.S. Census Bureau, 2010). It consists of four “parts”. As explained by The Henry J. Kaiser Family Foundation (2012a), Medicare Part A addresses inpatient hospital, skilled nursing facility, home health, and hospice care, with benefits subject to a deductible and co-insurance. Medicare Part B pays for physician, outpatient, and home health visits, and preventive services, and benefits are subject to a deductible and cost-sharing generally applies. Medicare Part C refers to the Medicare Advantage (MA) program, which enables one to receive integrated coverage for hospital, physician, and, in most cases, prescription drug benefits by enrolling in a private managed care plan. Medicare Part D is an optional subsidized prescription drug benefit program that is delivered through private plans that contract with Medicare.

Medicaid is a jointly financed state-federal program administered by states that targets certain low income individuals (U.S. Census Bureau, 2010). Eligibility for Medicaid varies between states and involves both categorical and income-related requirements. Categorical groups eligible for Medicaid coverage include pregnant women, those with children under 18 years of age, seniors and the disabled, with each

group facing different income-eligibility requirements (Salganicoff, Ranji & Beamsderfer, 2012). The Children's Health Insurance Program (CHIP) is administered at the state level and targets low income children with parents who do not qualify for Medicaid (U.S. Census Bureau, 2010). Military Health Care, which includes TRICARE, CHAMPVA and care provided by the Department of Veterans Affairs, targets members of the military and their dependants and survivors. The Indian Health Service, offered through the Department of Health and Human Services, provides assistance to eligible "American Indians" (U.S. Census Bureau, 2010).

Approximately 54 percent of people in the United States have some form of private health insurance coverage, 30 percent have some form of public coverage and 16 percent are uninsured (The Henry J Kaiser Family Foundation, 2013a). As with Canadian provinces, there are differences in the regulation of private health insurance between states. New York, the third largest state by population, requires private insurers to adopt a pure community rating system that prohibits variation in private health insurance premiums on the basis of demographic characteristics including gender (National Women's Law Center, 2009).

While health insurance typologies employ static categories, health insurance systems are dynamic. In Canada, efforts to restrict the scope of public coverage are expanding the scope of the coverage private health insurance can provide (Canadian Life and Health Insurance Association, 2001). One strategy that contributes to this process is "delisting", defined as a decrease in coverage for, and even the complete removal of, procedures, devices, and drugs from the list of "medically necessary" services that are

publicly funded through provincial health insurance plans (Stabile & Ward, 2006). Meanwhile, legislation restricting private health insurance to a supplementary role is being challenged in the courts. In 2005, the Supreme Court of Canada ruled that Quebec's legislation banning private health insurance for publicly insured health care was in violation of the *Quebec Charter of Human Rights and Freedoms (Chaoulli v. Quebec)* (see Flood, Roach & Sossin, 2005). The success of this challenge has emboldened others to launch similar challenges in other provinces, including Ontario (Flood & Xavier, 2008).

In the United States, the 2010 *Patient Protection and Affordable Care Act (ACA)* is leading to changes in public and private health insurance coverage, having survived legal challenges. As Grogan (2011) explains private health insurance is the bedrock of the ACA. Rather than rollback privatization, the ACA, or 'Obamacare' as it is often known colloquially by supporters and detractors alike, can be seen to further entrench and expand the role of private health insurance through regulation and public subsidies for private coverage. While the Act does call for an expansion of Medicaid, private policies are set to become compulsory for uninsured people with higher incomes (Himmelstein & Woolhandler, 2010). While some commentators in the United States have attempted to characterize the ACA as a 'government takeover' of health care (see Grogan, 2011), critics have pointed out that it will essentially direct additional funds into the country's existing market-driven health insurance system (Himmelstein & Woolhandler, 2010). Efforts to expand the scope of private coverage are thus apparent in both the United States and Canada. Given that there is now far greater reliance on private health

insurance in the United States than in Canada, these efforts clearly begin from very different points in furthering private coverage. Yet while literature underlines the differences between health insurance in Canada and the United States, it is also important to recognize common pressures towards market oriented reform.

Collectively, efforts to classify health insurance and to delineate the basic categories of public and private health insurance in Canada and the United States are important in providing a foundation for comparative study as well as for consideration of women, health insurance and breast cancer care in particular. In outlining key differences between public and private health insurance, identifying differences between forms of insurance in each category, and providing an overview of health insurance in Canada and the United States, this section has aimed to provide readers with contextual information helpful when considering scholarship in areas vital to this thesis. It is to review of this scholarship that this chapter turns.

### **Analyzing Health Insurance Systems in Canada and the United States**

There is an expanding body of scholarship that compares health insurance systems in Canada and the United States. One branch of this scholarship is particularly relevant to this thesis insofar as it is concerned with differences in the historical development of these systems. Historical intuitionist perspectives are prominent in this literature, with accounts highlighting cultural similarities between Canada and the United States and yet the divergence in health insurance systems (see Hacker, 1998; Maoini, 1998; Tuohy 1999). In explaining this divergence, analysis in this tradition tends to concentrate on the roles of political institutions and parties in shaping particular historical

trajectories in each jurisdiction. While this scholarship has limitations, which will be discussed below, it is useful in seeking to develop a contextualized understanding of health insurance that problematizes these different systems rather than simply describing them.

Maioni (1998: 13) has considered the emergence of health insurance in Canada and the United States in terms of “a journey that leads two countries with many similar characteristics to embark on different paths on the road to health reform.” This idea of diverging paths is prominent in historical institutional scholarship on this subject. Summarizing key concerns in this tradition, Hacker (1998: 59) has argued “for a historically grounded approach that emphasizes the political institutions within which policy decisions are made and the diverse feed-back effects that those decisions have on subsequent political struggles.” Tuohy (1999) has drawn on a mixture of historical institutionalism and rational choice theory to explore the “accidental logics” of health care systems in the United States, Canada and Britain. She has characterized features of these health care systems as “accidental” in the sense that they have been put forward during times of opportunity, become entrenched, and have come to shape the context within which subsequent developments occur. Such works are useful in suggesting the importance of historical analysis of differences in the development of health insurance systems in Canada and the United States.

Yet historical intuitionist analysis of health insurance has important shortcomings. As Sokolovsky (1998: 248) has pointed out, focus on formal political structures within this tradition can lead to broader relations of class, gender and race

becoming “merely part of the background against which institutional incrementalism is played out.” Attention to institutions at the expense of the social relations within which they are embedded can risk depoliticizing health insurance policy and conflicts surrounding it. Offering a different account of the roots of difference in Canadian and U.S. health insurance systems, Boychuk (2008) emphasizes the importance of the politics of race in the United States and the politics of territorial integration in Canada in explaining differences in the health insurance systems that developed. This style of analysis suggests the importance of broader social relations and concerns. It is important to understand, however, that comparative literature on health insurance systems that attends to historical context tends to focus largely on the causes of health insurance systems, rather than on their consequences for the people who use them. Women as a social group do not figure prominently in these accounts, much less particular groups of women. In Canada, the work of Women and Health Care Reform is a notable exception to this trend (see, for instance, Armstrong et al., 2012; Grant et al., 2004; Armstrong et al, 2002)

This thesis aims to consider the historical context within which health insurance systems in Canada and the United States have developed; however it pursues this goal within a framework that situates health insurance within the broader political economy and the social relations that shape it. The critical political economy perspective utilized prioritizes understanding political and economic factors as integrally related, a historical and materialist orientation, attention to interrelated social relations of power, and sensitivity to change over time (Armstrong, Armstrong & Coburn, 2001). From this



perspective, health insurance is approached not as a technical or neutral topic but as a sphere of conflict shaped by power and inequality within province/state, national and international contexts, with implications for women as a group and different groups of women. The particulars of this perspective, and the specific uses of feminist political economy insights in this thesis, are discussed in more detail in the following chapter. Attention is devoted not only to differences and similarities at the national level, but also to those below at the state/province level and to those above at the international level in the context of neoliberal globalization. As utilized here, this approach prioritizes a nuanced understanding of the context(s) within which health insurance systems operate in Canada and the United States, and more specifically in Ontario and New York. The analytical focus of the current study encompasses not only differences and similarities in the health insurance systems in Ontario and New York but also their consequences for women, specifically women diagnosed with breast cancer.

### **Women and Health Insurance**

Women as a group and different groups of women have complex—and sometimes contentious—relationships with health insurance as a form of health care financing. Lower incomes combined with higher demand for care over much of their lives place women at greater risk than men for accruing large medical expenses (Rustgi, Doty & Collins, 2009). The basis on which health insurance is made available, and the coverage it offers, are thus arguably matters of particular concern for women. Yet, it would be a mistake to homogenize women's concerns in this respect. In their roles as health care users, providers and decision-makers, women can relate to health insurance in a variety

of ways. In the context of attention to women's use of health insurance in relation to breast cancer care in this thesis, literature about women as users of health insurance is of primary concern in this section. Scholarship in this area addresses issues surrounding women's access to sources of health insurance, disparities in coverage between women and men as well as among women, and the nature of the health insurance coverage women have. Largely quantitative in nature, this literature is useful in suggesting issues that public and private forms of health insurance raise for women as a group and particular groups of women. The focus on health insurance as an isolated variable in much of this literature does, however, risk obscuring its significance in the broader context of women's lives as well as within the health insurance systems within which they live.

### ***Women's Access to Health Insurance***

Literature concerning women and health insurance highlights the issue of access to coverage. Research on this topic underscores the importance of access to health insurance for women, the role of public health insurance in promoting equity in health insurance access, disparities in access to sources of private health insurance coverage between women and men as well as among women, and the existence of practices in the private health insurance industry that can make private coverage an exclusive and costly option for women as a group and particular groups of women.

In a review of scholarship about the gendered effects of health care reform for the World Health Organization, Ostlin (2005: 4) observes:

There is substantial evidence from both high-income and low-income countries that taxes and social insurance schemes provide the most equitable

basis for health care financing. Other schemes, such as private insurance or direct out-of-pocket payment, are likely to increase inequities, particularly in access to care and health-seeking behavior and this may affect women more, as they generally have fewer financial resources.

One key issue is access to health insurance coverage itself. Public coverage can address this issue in different ways. As discussed earlier in this chapter, one of the central criteria set out in the *Canada Health Act* (1984) is universality: all legal residents are entitled to have access to public health insurance and insured services on uniform terms and conditions. As Forget and colleagues (2005:125) have observed, Canada's public health care system is premised on a judgment that health care is a "social good", one that "ought to be equally accessible to every Canadian regardless of ability to pay". Coverage does not, however, extend to the undocumented (Magalhaes, Carrasco & Gastaldo, 2010). Recent reforms have also excluded refugees (Citizenship and Immigration Canada, 2012). Some Canadian provinces, including Ontario, impose a three month waiting period for public health insurance coverage on immigrants. Nevertheless, the accessibility of public health insurance in Canada is quite broad in comparison to the United States.

The exception rather than the rule, public coverage in the United States is residual rather than universal. Traditionally, women have been more likely than men to qualify for Medicaid because, on average, women have lower incomes and they are also more likely to fall into one of the program's eligibility categories: pregnancy, parent of a dependent child, over 65 or disability (Salganicoff, Ranji & Beanesderfer, 2012: 1). Welfare reforms have, however, narrowed Medicaid eligibility, making public health insurance increasingly difficult to obtain for economically vulnerable women and children (Cawley,

Schroeder & Simon, 2006). Some 59 percent of Medicaid beneficiaries in the United States are women (The Henry J. Kaiser Family Foundation, 2013b).

Women, who on average live longer and experience higher rates of many chronic illnesses than men, depend disproportionately on Medicare, accounting for 55 percent of the beneficiaries of this program (The Henry J. Kaiser Family Foundation, 2013c). For most working age women in the United States, however, private health insurance coverage is the only coverage option available.

Literature about private health insurance suggests this form of coverage involves a number of access issues for women. The main sources of private coverage are employment, a spouse's employment, and individual purchase (Glied, Jack, & Rachlin, 2008). Different women and men face different relationships with each of these sources of coverage, with important implications for access to this form of health insurance. Employment status and income are recognized as the main predictors of private health coverage (Brittle & Bird, 2007: 67; Wyn et al., 2001: 49). Education is also recognized as a strong predictor of private insurance coverage in promoting access to occupations with benefits and higher incomes (Montez, Angel & Angel 2009: 134). Many women have, however, historically been excluded from employment-based private health insurance schemes (Murray, 2007, Fuller, 1998) and continue to encounter challenges accessing this source of coverage.

In the United States, men are more likely than women to obtain private health insurance through their own employment (Salganicoff, Ranji & Wyn, 2005: 14). As authors such as Jeckner (2003: 663-4) and Miles and Parker (1997: 218) argue, employer-

based health insurance amplifies structural inequalities women face in existing labour markets. Eligibility continues to be tied to male patterns of full-time, full year employment, while women predominate in lower paying, lower status, non-union and part-time jobs that are less likely to offer private coverage. Due to unpaid care giving roles women workers are more likely to enter and leave the workforce, making them vulnerable to clauses in employer insurance plans that exclude or limit coverage for preexisting conditions (Jeckner, 1993; Miles & Parker, 1997). Employer-based health insurance also means women who work at home without pay cannot access this coverage unless this occurs through a family member who can provide it (Jeckner, 1993: 664).

Women in different social locations face particular challenges accessing private health insurance through employment, with research suggesting the importance of gender, class, age and race. Dewar (2000) has found that gender-related employment segregation is a strong indicator for private coverage, with those in male-dominated industries more likely to have coverage. Low-income women working in service industries, in part-time and temporary positions, and in small firms, have been identified as having especially limited access to employment-based coverage (Wyn et al., 2001). Merzel (2000) found work was *not* associated with health care coverage among men and only weakly associated among women in one low-income community, suggesting the difficulty of obtaining private coverage in low-paid employment for both men and women. In Canada, female industry and service sector workers have faced the lowest rates of private coverage in the country (Cyrus & Curtis, 2004: 27). Older workers also confront significant challenges accessing coverage through their employment. In the US,

workers age 60-64 have been less likely than prime-age workers to obtain offers of employment-based coverage, with women in this age group facing lower rates of employer coverage relative to their male counterparts (Monheit, Vistnes & Eisenberg, 2001). Observers have also pointed out that women of colour are particularly likely to be in lower level-jobs that offer poor health coverage or none at all (Zimmerman & Hill, 2006: 494). Studies suggest that when women do hold employment-based health insurance this can affect their employment decisions. In the U.S., health insurance has been found to inhibit job mobility (Cooper & Monheit, 1993), particularly for women (Buchmueller & Valleta, 1996). Work arrangements have also been found to be related to the health and health insurance coverage of spouses (Bradley et al., 2007; Wenger & Reynolds, 2009).

Although employment is the main avenue for private coverage for women in the United States, employer-based health insurance has been in decline (Glied, Jack & Rachlin, 2008: 14; State Health Access Data Assistance Center, 2013: 3). Structural changes have resulted in more jobs in sectors of the economy that have low pay and offer rates for private health insurance coverage (Wyn et. al. 2001; Cubbins & Parmer, 2001). Meanwhile, increasing health care costs have led employers to embrace strategies such as not offering health insurance, offering coverage to employees but not to their families, and increasing employees' share of health insurance premiums. Offers of employer-based health insurance have declined among white and African American men and women in the United States, however such offers have declined even further among Hispanic women and men (Keene & Prokos, 2007). Gibson and Fuller (2006:32) have identified a

decline in Canada overall, finding supplementary health coverage fell by almost 25 percent between 1995 and 2000.

Findings from the United States suggest employment-based health insurance is becoming increasingly expensive. The most recent Employer Health Benefits Survey conducted by the Kaiser Family Foundation and Health Research and Educational Trust, found that the average annual premium for employer sponsored health insurance in 2012 was \$5,615 for single coverage and \$15,745 for family coverage (Claxton et al., 2012: 1). This represented a rise in cost of 3 percent and 4 percent respectively since 2011 (Claxton et al., 2012: 1). Since 2002, average premiums for family coverage have increased 97 percent, while worker contributions to premiums have increased 102 percent (Claxton et al., 2012: 1). The rising cost of coverage stands to make coverage less and less affordable for workers and to involve difficult choices for those struggling to make ends meet.

Findings suggest women are especially hard hit by cost-cutting strategies applied to employer-based private health insurance. As Salganicoff, Ranji and Wyn (2005: 47) explain, “higher premium costs, larger co-payments and increased cost-sharing combined with rapid growth in the cost of prescription drugs fall increasingly hard on women because of their higher use of health care services and their disproportionately lower incomes”. Even when employment-based health insurance is offered, women can have difficulty taking advantage of it. Participants in one study reported the employee contribution demanded was too large a part of their income and they could not afford it, with co-payments and deductibles presenting major barriers to coverage (Angel, Lein &

Henrici, 2006: 125). Newly retired women and men have also had to contend with declines in employment-based coverage (Stuart et al. 2003: 1). Collectively, such findings underline that despite its traditional importance, employment is becoming an increasingly costly and inaccessible route to private health insurance coverage.

Employment based coverage is sometimes available to those who qualify as a dependant of the primary policy-holder. Coverage as a dependant is more prevalent among women than among men (Robertson & Collins, 2011). In the US, 23 percent of non-elderly women receive health insurance coverage as a dependant, via a family members' job-based health insurance plan (Kaiser Family Foundation, 2012b). Keene and Porkos (2010) suggest that gendered family contexts and employment structures influence individuals' choices about health benefits. Significantly, this form of coverage is often available only to those in particular kinds of relationships. In the U.S., Claxton et al. (2012: 45) found only 37% of firms surveyed reported offering health benefits to unmarried opposite-sex domestic partners, and only 31% reported offering health benefits to unmarried same-sex domestic partners.

As with coverage based on one's own employment, indirect coverage as a dependant has a variety of drawbacks. Dependents are susceptible to losing coverage when premium costs rise to unaffordable levels, or when employers reduce or end their contributions for family coverage (Salganicoff, Ranji & Wyn, 2005: 14; Henry J. Kaiser Family Foundation, 2012b:1; Robertson & Collins, 2011: 3). Since this source of coverage hinges on an individual's relationship status, it can be lost in the event of divorce (Zimmer, 2007) or the death of the primary policy holder (Salganicoff, Ranji &



Wyn, 2005: 14). Disruption of women's coverage as a dependant can also occur when the primary policy-holder becomes eligible for Medicare, with consequences for health care utilization and health (Shumacher et al., 2009). Women between ages 55 and 64 are at particular risk of lacking health insurance when married to men age 65 or older who are covered under Medicare (Angel, Montez & Angel, 2011). Coverage as a dependant can also end when a teenager reaches the maximum age limit for coverage under a parent's policy (Adams et al., 2007; Collins et al., 2007). Private health coverage for dependants can thus be exclusive as well as precarious.

In addition to being offered as an employment benefit, private health insurance is available for purchase by individuals. Individually purchased health insurance plans tend to be less popular than employment-based plans. Indeed, Lambrew (2001: 8) suggests that those who purchase this form of insurance generally do so because they have few alternatives. In the United States, only 7 percent of women purchase coverage through the individual market (Henry J. Kaiser Family Foundation, 2012b: 1). Significantly, findings from the Commonwealth Fund 2010 Biennial Health Insurance Survey suggest half of the women who tried to buy a plan in the individual insurance market in the United States in the preceding three years never in fact did so (Robertson & Collins, 2011: 2). Nearly half (46 percent) of the women surveyed who had tried to buy health insurance on the individual market reported that they found it "difficult or impossible to find a plan that offered the coverage they needed", while three in five (60 percent) found it "difficult or impossible to find coverage they could afford" (Robertson & Collins, 2011: 4). Compared with men, women who purchase individual insurance in the United

States are more likely to be single and less likely to have children. They also tend to be healthier than women in the United States more generally (Lambrew, 2001: 8).

Women's difficulties purchasing appropriate and affordable private health insurance in the United States can be explained in part by risk selection and rating practices that are particularly prominent in markets for individually purchased health insurance. Commercial insurers have strong incentives to lower costs—and thus increase profits—through risk selection. Essentially, this practice involves “encouraging custom from individuals with below average risk and discouraging or refusing custom from individuals with above average risk” (Mossialos & Thomson, 2004:18). The use of sex and/or gender in determining eligibility for private coverage and premiums through risk selection, adjustment<sup>5</sup> and rating<sup>6</sup> is well established (Dranove, 2008). These strategies disadvantage women in particular, who have been calculated to be “distinctly more expensive than males of the same age” (Ellis, 2008: 205). Insurers have also been found to charge higher premiums to older people and those with illnesses (Davis et al., 2009: 15), placing women in these groups at higher risk of costly premiums or denial of coverage.

Use of sex and gender in setting private health insurance premiums has been prohibited in some jurisdictions, including some U.S. states (National Women's Law Center, 2009: 5) and Quebec (Hurley & Guindon, 2008: 12). Where permitted, as it has traditionally been in 42 U.S. states (National Women's Law Center, 2009: 5), this has

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<sup>5</sup> Risk adjusters are “characteristics used to estimate likely health expenditures”, and can include age, gender, disability, income, employment status, region (Carrin & James, 2004: 30).

<sup>6</sup> Risk rating refers to the practice of charging “premiums based on an individual's health risk profile estimated from personal characteristics such as age, gender and behaviors, or actual use of services” (Sekhri, Savedoff & Thirpathi, 2005: 16).

resulted in dramatic gender gaps in premiums. The National Women's Law Center (2009: 4) reports women in United States may pay up to 84 percent more than men for similar coverage. Findings also reveal discriminatory practices related to exclusions for coverage that only women need, such as maternity care, and rejection of applicants for reasons of particular concern for women, such as having had a caesarean section or having experienced domestic violence (National Women's Law Center 2008, 2009). While these sorts of practices are especially prevalent in the individual health insurance market in the United States, they also shape the market for group health insurance, where insurers are permitted to determine premiums based on the number of women a business employs (National Women's Law Center, 2009: 4). Although recent health care reform efforts are set to eventually end gender rating in the individual and small group health insurance markets, the National Women's Law Center (2010a) has warned that loopholes threaten to allow the practice to continue with large group plans.

Advances in genetic testing have the potential to further private insurer's risk-related strategies, particularly in relation to breast cancer. The identification of BRCA1 and BRCA2 allows for the possibility of genetic discrimination by health insurance companies. Some authors contend fears about the potential impact of this testing are overstated (Hoy et al., 2003), while others suggest its use by insurers has the potential to "create a genetic underclass, unable to afford life or health insurance, unable to gain employment and facing serious health problems" (Edwards, 2001: 3). In one U.S. study, women eligible for BRCA testing reported the potential for discrimination by insurers as a reason for declining to be tested (Peterson et al., 2002). Pollitz et al. (2007: 365) have

observed that while industry experts have insisted genetic discrimination seldom happens, the findings of their study suggest some individual market insurers in the United States would act on genetic information if they discovered it. This suggests it is important to consider how insurers' risk-related strategies are evolving in the context of technological developments.

As Blomquist (2008:25) has argued, differences in health insurance premiums based on risk are "inconsistent with many people's idea of equity, especially when risk differences to which the premium differentials correspond are due to factors over which the individual has no control". While routinely presented as a technical matter, insurers' risk-related practices are in fact intensely political. Use of sex and gender-based calculations effectively penalizes women for biological differences from men—and their interaction with structural inequalities in society. Although conducive to profit-making in the insurance industry, sex- and gender-based assessments of risk operate to the disadvantage of women as a group and are particularly detrimental for older women and those facing health issues as well as others deemed especially likely to require health care. As the National Women's Law Center (2009: 3) has noted, insurance companies have treated women "like a preexisting condition". Central to the business of private health insurance, risk-related strategies used by insurers can be seen to reinforce existing lines of inequality.

While much attention has been devoted to gaining private health insurance, it is just as important to consider its loss and absence. This issue has been the subject of attention in the United States given the primary role played by private coverage in

financing care. With employment, income, and personal status all liable to change, the stability of private health insurance coverage has been identified as an important concern (Salganicoff, Ranji & Wyn, 2005: 15). Although individuals may report having private coverage at a particular point in time, changes in employment and/or personal relationships or even age can lead to loss of coverage. Nearly one of three women ages 19 to 64—an estimated 27 million women—were uninsured in the United States during 2010 (Robertson & Collins, 2011: 1). In one study, Salganicoff, Ranji and Wyn (2005: 15) reported that among women who experienced a spell of uninsurance, the majority (60%) lacked coverage for one year or less, but one in five uninsured women lacked coverage for four years or more. These authors have underlined that gaps in coverage place women at risk for some of the same problems faced by the chronically uninsured, including delays in obtaining treatment. Health conditions that develop during these gaps can later become classified as ineligible for coverage (Salganicoff, Ranji & Wyn, 2005: 15). Those who have experienced a gap in coverage must thus not only confront the consequences of this gap in the present, but may be further penalized when attempting to obtain health insurance coverage in the future. Although this is set to change with health insurance reform in the United States, it has been the reality faced by those within the existing system.

In the United States, uninsurance has emerged as a fundamental shortcoming of the primary role of private health insurance in health care financing and a key impetus for reform. Uninsured women account for 20 percent of the non-elderly population of women (ages 18 to 64) (Henry J. Kaiser Family Foundation, 2012b: 1). A lack of health

insurance has been found to negatively affect use of health services. Uninsured women have also been found to be less likely to use ambulatory care services (60 percent) than their publicly (86 percent) or privately (82 percent) insured counterparts (Taylor, Larson & Correa-de-Arauj, 2006). Indeed, women under age 65 uninsured all year in the United States have been found to be significantly less likely to use any health services (71 percent) compared to women with either public (94 percent) or private (92 percent) coverage. In the face of unaffordable medical care, research suggests some women attempt risky forms of self-care (Vuckovic, 2000). The Institute of Medicine (2002) has found that uninsured adults in the United States not only have less access to recommended care, but receive poorer quality of care, and experience worse health outcomes than insured adults do. Concluding a literature review of the effects of insurance in the United States, McWilliams (2009:443-444) finds that the health consequences of uninsurance are real, vary in a clinically consistent manner, and strengthen the argument for universal health insurance coverage. Ultimately, a lack of coverage can be fatal; one study has associated almost 45,000 deaths per year among Americans ages 18 to 64 with a lack of health insurance (Wilper et al., 2009).

### ***Disparities in Health Insurance Coverage***

With differences in access to sources of health insurance coverage, it is not surprising that there are disparities in coverage itself. While public health insurance coverage in Canada is based on the principle of universality, private coverage is not. As noted earlier, no single source of information captures the number and characteristics of all Canadians who have private health insurance; however as previously mentioned

approximately 66 percent of the Canadian population is estimated to hold supplementary private health insurance (Flood & Haugan, 2010). Data from the United States, however, points to striking disparities in health insurance coverage among women. These disparities, which can be seen to reinforce existing lines of power and inequality, are discussed below.

Summarizing significant inequalities in U.S. health insurance coverage, Ranji and Salganicoff (2011: 2) explain, “lower-income women and women of colour are at greater risk for being uninsured, as women who are single, young, or in fair or poor health. These groups of women tend to have lower rates of employer sponsored coverage and are more reliant on Medicaid than their counterparts.” The importance of income, which can be understood to relate to social relations of class, is especially striking. Ranji & Salganicoff (2011: 13) have found that 85 percent of higher income women in the United States have employer-sponsored coverage, compared to 73 percent of modest income women, 41 percent of near-poor women and 13 percent of poor women. While only 1 percent of higher income women are listed as having Medicaid coverage, 3 percent of modest income women, 16 percent of near poor women, and 38 percent of poor women have this form of coverage. While only 4 percent of higher income women are uninsured, 8 percent of modest income women, 29 percent of near-poor women, and 35 percent of poor women are uninsured (Ranji & Salganicoff, 2011: 13). Married women are more likely to have private coverage than unmarried women, while unmarried women are more likely to be uninsured or to rely on public insurance (Anderson & Eamon, 2004). Gendered family

arrangements, as well as income, can thus be understood to shape inequalities in women's health insurance coverage.

Differences in health insurance coverage are also racialized. As Montez, Angel and Angel (2009: 133) observe, "minority group status constitutes a significant structural barrier to health insurance in the United States." Women of colour are more likely to work in low wage jobs, have disproportionately lower incomes, and are less likely to work in jobs offering health insurance coverage or to be able to afford coverage when it is offered (Ranji & Salganicoff, 2011: 14). Moreover, marriage increases the odds of private health insurance coverage more for white women than it does for African American or Hispanic women (Montez, Angel & Angel, 2009: 141). Uninsurance is also a racialized condition. As Ranji and Salganicoff (2011: 14) explain,

Lack of insurance is a problem for women of all races and ethnicities but a staggering 42% of non-elderly Latina women are uninsured, a rate 2.5 times higher than African American women and 3.5 times white women—and the highest rate of uninsurance of all groups of women examined in this survey. Just 40% of Latina women have employer-sponsored health insurance, as compared to 67% of white women. Like Latinas, African American women have lower rates of employer-sponsored health insurance (49%) but have higher rates of Medicaid coverage (23%) than white women.

There is also a substantially higher rate of uninsurance among non-citizen immigrants (Buchmueller et al., 2007), with welfare reform having increased the uninsurance of low-educated unmarried immigrant women and their children in particular (Kaushal & Kaestner, 2005). In addition, it is important to note that private health insurance is less common in rural areas than in urban areas (Ziller & Coburn, 2009: 1). Disparities in private health insurance coverage in the United States are particularly striking when



compared to universal public health insurance coverage in Canada. While universal public health insurance coverage can be understood as a measure ameliorating structural inequalities grounded in gender, race, class, age and other social relations, statistics concerning private health insurance coverage in the United States point to the role of this coverage in reflecting and reinforcing structural inequalities. Overall, the available findings about disparities in coverage not only between women and men but among women reveal this is not only as a gendered form of health care financing, but one also shaped by class, race, age, marital status, health status and location among other considerations.

### ***Shortcomings in Health Insurance Coverage***

While much of the literature about women and health insurance focuses on which women have—or do not have—coverage and how it is obtained, the nature of the health insurance coverage that women have is also an important concern. Scholarship in this area suggests that when women do have health insurance, the insurance they have does not necessarily cover the care they require or offer adequate protection from associated costs. Studies point to shortcomings in public and private health insurance plans, which may exclude coverage of care particularly important for women or limit the coverage provided in ways that leave women vulnerable to out-of-pocket expenses even when care is officially insured.

In Canada, Forget et al. (2005) have found that the country's current system of public coverage, free from user fees, co-payments and deductibles, best addresses the risks women face in terms of higher lifetime health care utilization, arguing that change

emphasizing market principles will disadvantage women as a group. Current public health insurance arrangements in Canada do, however, privilege a model of health care centered on physicians and hospitals. This leaves other services to be funded privately or through some limited public programs targeting particular groups. Key limits in public health insurance in Canada include those relating to pharmaceuticals, long term care, dentists and optometrists and complementary and alternative medicine (Armstrong & Armstrong, 2008). Indeed, as Armstrong and Armstrong (2008: 51) note, “Outside of hospitals, drug coverage in Canada looks very much like health care in general does in the United States”. The same could be argued of other health-related goods and services beyond the purview of the *Canada Health Act* (1984). With a variety of developments, including technological change, increasingly drawing care out of hospitals this is a matter of particular concern. In this context, the most significant limitations of public health insurance in Canada relate to the scope of the coverage offered.

In the United States, the role of public health insurance in making health care accessible and protecting women from associated costs is undermined by limitations not only on eligibility, which have been discussed above, but also on the scope and extent of the coverage offered. As Rowland, Salganicoff and Keenan (1999: 403) point out, Medicaid “has resulted in better coverage, access, and health care for millions of poor children and their parents”. Women on Medicaid are less likely to face cost barriers to care than uninsured women (Ranji & Salganicoff, 2011: 4). Indeed, Long, Coughlin and King (2005) suggest that low income mothers on Medicaid have access and use of health care that is better than that obtained by the uninsured and comparable to low income

privately insured mothers. Nevertheless, affordability of care remains an issue for women insured through Medicaid. Some states impose limits on the number of visits or prescriptions covered under the program and many states charge “cost-sharing” fees to varying extents (Salganicoff, Ranji & Beamesderfer, 2012: 6). Further challenges have traditionally been posed by the limited participation by private physicians, particularly specialists, due to the lower rates of payment offered by Medicaid in comparison with private insurers (Salganicoff, Ranji & Beamesderfer, 2012: 6).

Medicare coverage, while relied upon by eligible women in the United States, can also present grave challenges. As Salganicoff et al. (2009: 242) explain,

Medicare provides considerable protection to women aged 65 and older, and is a key element of financial security for older women in their retirement years. Without Medicare, women would be hard-pressed to find comparable health insurance coverage in the private marketplace. Yet, Medicare falls short in protecting older people from potentially high out-of-pocket costs associated with their medical and long-term care needs.

The cost-sharing requirements of Medicare can be particularly difficult for older women, who tend to have fewer financial resources than their male counterparts (The Henry J. Kaiser Family Foundation, 2013d). While supplemental private health insurance can address gaps in Medicare coverage, women with supplemental insurance remain “at risk for large out-of-pocket expenses in the face of rising health care costs”, while facing the expense of private health insurance premiums (Salganicoff et al., 2009: 243).

Nor does holding private health insurance coverage necessarily guarantee access to health care or protection from associated expenses. In the United States, the cost of health care has been found to pose significant challenges even for women who have

private coverage (Kinney et al., 1997; Almeida, Dubay & Ko, 2001; Salganicoff, Ranji & Wyn, 2005; Rustgi, Doty & Collins, 2009; Robertson & Collins, 2011). Broadly, “underinsurance” involves holding health insurance coverage that does not offer adequate protection from health care expenses. One way to define ‘underinsurance’ more precisely is having health insurance all year but nevertheless facing “medical expenses, excluding premiums, that represent 10 percent or more of income (5 percent or more of income if household income is below 200 percent of the federal poverty level) or a deductible that represents 5 percent or more of income” (Schoen et al., 2008 as cited in Rustgi, Doty & Collins, 2009: 7). This definition does not, however, address the burden of premium costs and may not necessarily encompass the full range of expenses (medical *and* non-medical) associated with obtaining health care.

Although women who are underinsured are counted as having coverage, the plans they have are not adequate to meet their health care needs. In 2007, more than one third (35 percent) of working-age women in the United States spent 10 percent or more of their income on out-of-pocket costs and health insurance premiums (Rustgi, Doty & Collins, 2009: 3). Ranji and Salganicoff (2011: 4) report that “Between 2004 and 2008, the share of women reporting they “had to spend less on other basic needs to pay for health care” doubled from 8 percent to 16 percent. The 2010 Commonwealth Fund Biennial Health Insurance Survey found an estimated 42 million women in the United States, both with and without health insurance, reported medical bill problems (Robertson & Collins, 2011). Medical bill problems forced women to cut back on essential health care expenses (32 percent), spend savings (41 percent), take on credit card debt (25 percent), take out a

mortgage or loan (12 percent), and declare bankruptcy due to medical bills (6 percent) (Robertson & Collins, 2011). Such findings underline that even when women in the United States do have private health insurance, the plans they have do not necessarily offer adequate protection from health care expenses.

It is important to understand that private health insurance plans vary tremendously. Due to exclusions and other kinds of limitations, some private policies may not cover the conditions women have or the treatments they seek. Pre-existing conditions may be ineligible for coverage, as discussed earlier in this chapter.

Salganicoff, Ranji and Wyn (2005: 24) found 16 percent of insured women in the United States had been denied approval or payment by their health plan for a health care service, with 18 percent of those denied approval or payment delaying care and 23 percent never receiving the care. Ranji and Salganicoff (2011: 2) found 12 percent of women with private health insurance reported they were not able to see a specialist when needed, as did 30 percent of women on Medicaid and 43 percent of women without health insurance. These authors also report that 14 percent of women with private coverage and 31 percent of women with Medicaid went without or delayed care because they could not afford the cost (Ranji & Salganicoff, 2011: 4). Kinney et al. (1997: 186) have found women being denied services considered experimental. Collectively, such findings suggest the limits of health insurance coverage are significant even for women with private health insurance plans.

There are some indications that managed care plans in the United States may pose particular difficulties for women. Critical appraisals of managed care in Medicaid

challenge the notion of consumer ‘choice’ in this area in the context of the poverty (Hill, Zimmerman & Fox, 2002). It has been suggested that Medicaid managed care functions as a means of social control over the poor and uninsured (Hackey & Whithouse, 1996). In a study of Medicare managed care, women were found to rate their managed care slightly more positively than men, yet they were also found to encounter slightly more problems getting referrals, equipment and assistance, and were less likely to indicate that their plan provides help, equipment and services (Cleary, Zaslavsky & Cioffi, 2000). At the same time, a study of managed care in private health insurance plans by Mitchell and Schlesinger (2005: 1505) found health plan managed care practices were associated with “significantly greater problem reporting among women than men”. These authors explain that “Although managed care has the potential to improve care by reducing fragmentation of care and focusing on preventive care and disease management, it also has the potential to undermine appropriate care by altering treatment patterns and imposing barriers to care” (Mitchell & Schlesinger, 2005: 1490). Clearly, it is not sufficient to simply study how many women have—or do not have—which forms of health insurance. It is vital to examine the nature of the health insurance in question, and its significance for women who use it to obtain health care.

### **Health Insurance and Breast Cancer Care**

As a condition, breast cancer is far more common in women than in men (Cancer Society, 2013; American Cancer Society, 2011). While women of different ages are at risk, breast cancer has been found to occur primarily in women 50 or older (Canadian Cancer Society, 2013: 27), with ninety-five percent of new cases occurring in women age

40 or older (American Cancer Society, 2011: 2). Findings from the United States suggest white women have a higher rate of developing breast cancer than women of other racial and ethnic groups yet also have better survival rates (American Cancer Society, 2011). Research in both Canada and the United States suggests that unlike some other types of cancer, risk of breast cancer may increase with socio-economic status (Borugian et al., 2011; Reynolds et al., 2004).

Research on health insurance and breast cancer care suggests a number of issues of concern for women. Much of this research appears in medical, rather than in sociological journals. Moreover, much of it is quantitative in nature and addresses circumstances in the United States. This literature tends to treat health insurance as a variable to be isolated rather than a form of health care financing to be problematized. Although a comprehensive review of this scholarship is beyond the scope of this section, attention is given to recent contributions suggesting points relevant to this thesis. Broadly speaking, studies suggest that having health insurance is important for breast cancer screening, diagnosis and treatment. Findings also suggest inequalities among women with different forms of health insurance in relation to aspects of breast cancer care. Qualitative study of health insurance in relation to breast cancer care, while not prominent in this literature overall, suggests additional issues of concern for women using health insurance to obtain treatment.

In the United States, having health insurance coverage has been found to be associated with having had mammography screening both for women as group and for particular groups of women (National Center for Chronic Disease Prevention, 2004;

Wells & Roetzheim, 2007; Leong-Wu & Fernandez, 2006; Yu, Hong & Seetoo, 2003). Private coverage has been associated with higher rates of breast self-examination and clinical breast examination (Chen, 2009), mammography (David et al., 2005; Colbert et al., 2004; Legg, 2003), repeat mammography (Rakoski et al., 2004), and timely follow up after abnormal breast cancer screening (Battaglia et al., 2007; Ferrante et al., 2007). One study found that the “gatekeeper” requirements<sup>7</sup> common in managed care plans were associated with higher utilization of mammography (Phillips et al, 2007). Private health insurance “reinforcement”, via requiring mammography to remain insured, has also been found to provide motivation for women to obtain this test (Wu & Bancroft, 2006: E74). Among the lowest prevalence of mammography reported in the United States has been by women without health insurance (Centers for Disease Control, 2010). A literature review on barriers to mammography has identified not only lack of health insurance, but also *lack of knowledge about health insurance* as a concern (Alexandraki & Moradian, 2010). Differences in mammography screening are important given that mammography has been found to be the most consistent of breast cancer screenings methods and is considered important for early detection of breast cancer (Kearney & Murray, 2009) and reducing breast cancer mortality (Magnus et al., 2011).

In the United States, women without health insurance and those with Medicaid have been found to be more likely to present with advanced stage breast cancer (Halpren et al., 2007; Bradley et al., 2008, Henry et al., 2011). Women lacking health insurance have also been found to have less favorable prognostic indicators compared to women

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<sup>7</sup> “Gatekeepers” are “primary care providers that coordinate care and control access to specialists” (Phillips et al., 2007: 154).



with private health insurance (DeSantis, Jemal & Ward, 2010). Insurance status has been found to affect women's odds of receiving forms of breast cancer treatment, including radiation and chemotherapy (Richardson, 2004; Richardson et al., 2006). Women with private coverage have been found to have higher rates of breast cancer survival than those with other or no coverage (McDavid et al., 2003). In reviewing the literature on social determinants of disparities in cancer mortality in the United States, Gerned and Pai (2008: 2916) observe, "In general, women who are privately insured have a more favorable disease stage at diagnosis than do women who are publicly insured. Publicly insured women, in turn, tend to fare better than women not covered by any health insurance plan." Overall, the studies considered do suggest disparities in breast cancer care endured by women who are privately insured, publicly insured, and uninsured in the United States.

Some research suggests that private health insurance may not adequately protect women from expenses associated with breast cancer care. These expenses can be substantial. Published estimates on the costs of treating breast cancer vary, with one review in the United States finding estimates of lifetime per-patient costs of breast cancer ranged from \$20,000 to \$100,000 (Campbell & Ramsey, 2009). A study of healthcare costs in women with metastatic breast cancer found cumulative healthcare costs averaged \$128,556 (Vera-Llonch et al. 2011: 1 of 7). Adverse events related to breast cancer treatment can also be costly: a study of privately insured women found chemotherapy recipients "incurred large incremental expenditures for chemotherapy-related serious adverse effects (\$1,271 per person per year) and ambulatory encounters (\$17,617 per

person per year)” (Hassett et al., 2006: 1108). In the context of high costs of breast cancer treatment, the role of health insurance in protecting women from financial distress can be seen as particularly important.

Yet, in a U.S. study, Arozullah et al. (2004) found that even among women with comprehensive health insurance policies, the financial burden of breast cancer treatment was onerous, with the majority of out-of-pocket expenses arising from co-payments for hospitalizations and physician visits. These authors report “the financial burden of breast cancer accounted for a mean of 98%, 41%, and 26% of monthly income among female breast cancer patients with annual household income levels of  $\leq$  \$30,000, \$30,001–\$60,000, and  $>$  \$60,000, respectively” (Arozullah et al., 2004: 271). In another study, Kinney et al. (1997) found some women diagnosed with breast cancer struggled to obtain benefits even when insured. In the face of the expense of breast cancer care, such studies suggest private health insurance does not necessarily translate into financial security.

Even maintaining insurance during breast cancer can itself be problematic, forcing women to make difficult decisions. This condition can make employment challenging, with one study finding U.S. breast cancer survivors less likely to be employed than women not diagnosed with breast cancer (Bradley et al., 2002). Yet the financial demands of breast cancer care may also lead women or their spouses to maintain employment offering health insurance. In one study of women with breast cancer, 31.6 percent of respondents indicated “that they or their spouse stayed in a job to keep health insurance and implied that they wanted the freedom to leave” (Kinney et al., 1997: 186). When women have coverage tied to marital relationships this can also lead to

hard choices. As Kinney et al. (1997: 187) learned, some women have stayed in “unsatisfactory” marriages in order to retain private health insurance to finance breast cancer treatment.

Research on breast cancer that compares the United States with Canada has yielded significant if controversial insights. These countries have been ranked first and second respectively in breast cancer survival, with a recent study reporting only a small difference in relative survival (Coleman et al. 2008). Comparative studies of breast cancer care and survival have, however, found stronger inverse income-survival and income-care associations among cohorts in the United States than in Canada (Gorey et al. 2010a; Gorey et al 2010b; Gorey 2009; Gorey et al. 2009a; Gorey et al. 2009b; Gorey 2006). In attempting to understand why American women in low income areas fair worse than their counterparts in Canada and worse than women in high income areas in both countries, Gorey and his colleagues have theorized that differences in health insurance systems provide the best explanation (see Gorey et al. 2010a, 2010b). This idea has, however, has been disputed (see Zhang-Salomons et al. 2006). Among women with public health insurance in Canada, disparities have been found in wait-times for radiation therapy, which Benk et al. (2006) suggest may be related to assessments of risk and urgency. Canadian breast cancer patients with private health insurance have been found to be more likely to use supportive care (Grey et al., 2000) and complementary and alternative medicine (Grey et al., 2003), which are not typically covered under public health insurance programs. Recent research in Canada found out-of-pocket expenses related to breast cancer care, calculated to be a median of \$1,002 in the year after

diagnosis, played a secondary role compared to wage loss in affecting women's financial circumstances (Lauzier et al., 2013).

Relatively little of the qualitative literature on breast cancer addresses health insurance coverage. Recent issues of interest have included perspectives on breast cancer screening (Griffiths et al., 2010), ownership in decision-making (Mendick et al., 2010), suffering (Arman & Rehnsfeldt, 2003), emotional journeys (Blow et al., 2008), spirituality (Vigen, 2004; Cutts 2006), online support groups (Seale, Ziebland & Charteris-Black, 2006), volunteering as research subjects (Armstrong & Morris, 2010) becoming a medical consumer (Sulik & Eich-Krohm 2008), survivor identity (Kaiser, 2008) and challenges faced by women of colour (Nelson & Agyapong, 2004). Vigen (2004) considers a variety of social dynamics affecting the quality of care provided to black and Latina women with breast cancer in the United States; however women's experiences with health insurance are not considered in detail. Jones (2006) devotes some attention to women's fears surrounding the inadequacy of health insurance coverage in her study of how young African American women and their mothers conceptualize breast cancer. In general, however, women's health insurance experiences are not as prominent in this literature as one might expect given attention to health insurance as a variable in quantitative scholarship.

In Canada, Gould (2004) has identified a range of challenges facing low income women with breast cancer, devoting some attention to gaps in public health insurance coverage for a range of breast cancer related expenses but offering little attention to private health insurance. In exploring older, low income, and Aboriginal women's

experiences of cancer system exclusion in Canada, Gould and colleagues (2009) have noted the role of private health insurance in funding supportive-care drugs, such as anti-nausea pills, however these authors do not explore this at length. Sinding (2010) and Gould (2004) have highlighted the plight of women unable to afford the expense of breast cancer drugs even with private coverage. Such findings suggest private health insurance may not be sufficient to make breast cancer care affordable. In considering treatment decision-making and older women in Canada, Sinding and Wiernikowski (2009) have noted the roles of public and private health insurance in making particular drugs accessible. These qualitative studies about the challenges faced by particular groups of women all suggest the importance of women's material circumstances in shaping breast cancer care, yet health insurance is not examined at length in these efforts.

The relatively few studies employing qualitative methods that focus squarely on women, breast cancer and health insurance coverage suggest the importance of considering this form of health care financing within the broader context of women's lives. Women's health insurance related work does not appear to end with obtaining and maintaining health insurance coverage. Studies highlight the knowledge and work involved in managing managed care for breast cancer in the United States. Bourjolly et al. (2004) suggest women lack knowledge about how to use their health insurance to access treatment. Wenzel and Steeves (2008) expose women's difficulty completing the tasks required by insurers, anxieties about coverage, and the work involved in mediating between health care insurers and health care providers. These studies underscore the importance of considering the knowledge and work involved in the use of health

insurance from the perspective of those who use it. However, they do not compare women's health insurance experiences in different jurisdictions. Collectively, findings suggest health insurance affects not only how breast cancer care is financed, but women's access to care, quality of life, and even employment and marital relationships.

## **Conclusion**

In reviewing literature on women and health care reform, Ostlin (2005: 4) has suggested, "Privatization, accompanied by emphasis on reducing costs and maximizing efficiency, may have an important impact on gender equity in health care access and financial protection". The review of scholarship offered in this chapter provides support for this idea in highlighting crucial differences in public and private coverage for women in Canada and the United States. Issues surrounding women's access to coverage and the quality of coverage provided have emerged as central concerns.

When juxtaposed against the universal public health insurance coverage offered in Canada for medically necessary hospital and physician services, disparities in access to sources of private health insurance coverage, among holders of private coverage, and in the nature of coverage offered by private health insurance plans are especially striking. Yet the literature reviewed in this chapter also points to limits inherent in public health insurance in Canada as well as in the United States that merit scrutiny. Public coverage of hospital and physician care in Canada, while free from user fees, co-payments, and deductibles and available to all legal residents, nevertheless leaves important goods and services within the domain of private health insurance coverage or out-of-pocket payment. Prescription drugs are an important example. Meanwhile, public health

insurance coverage in the United States, available to only select groups, often involves fees and limits reminiscent of those used in the private health insurance industry.

Within the health insurance systems of Canada and the United States, public and private health insurance can be understood to present opportunities and constraints for women as a group and different groups of women. It is within this context that this thesis seeks to examine how the health insurance systems in Ontario and New York in particular shape women's health insurance experiences in relation to breast cancer care. The analysis developed in this effort departs from comparative scholarship on health insurance in Canada and the United States that focuses on the roots of contemporary differences through a historical institutionalist lens. While the historical context of contemporary health insurance policy is an important concern, it is within the context of a critical feminist political economy analysis that focuses on the contemporary implications of health insurance policy for women diagnosed with breast cancer. Attention is thus devoted not only to institutions and their histories, but to the broader social forces and relations within which they are embedded. Similarities, as well as differences in health insurance systems in Canada and the United States, and Ontario and New York specifically, are of interest, and they are considered within the context of neoliberal reform in both jurisdictions.

Much of the existing English language scholarship on women and health insurance, particularly private health insurance, considers circumstances in the United States. Much of this scholarship is concerned with quantifying health insurance coverage. Such scholarship is invaluable in revealing disparities in access to health insurance and in

health insurance coverage itself along lines including those of sex, income and race. It is also useful in revealing some shortcomings in the quality of the health insurance women hold. Yet, in addressing health insurance coverage as an attribute of individuals, and treating it as an isolated variable, this scholarship is not well suited to considering health insurance systems shaped by social relations of gender, class and racialization. Nor is it well suited to offering insight into women's experiences using various forms of health insurance, or understanding these experiences in the context of women's lives and the conditions within which they live.

Quantitative scholarship on health insurance and breast cancer care suggests disparities among women with public, private and no health insurance coverage. Unfortunately, this scholarship does little to illuminate women's perspectives and experiences with health insurance coverage in relation to breast cancer care. This approach to studying health insurance risks stripping it of context. Recent qualitative scholarship on women's breast cancer experiences, in contrast, offers insight into a range of breast cancer-related topics yet devotes little attention to the significance of health insurance coverage. Qualitative literature about health insurance and breast cancer care is still developing, yet recent studies suggest issues of knowledge, anxiety and time are concerns that merit further enquiry. As much of this work has focused on women's experiences in the United States, the comparative perspective offered in this thesis is well suited to expanding this scholarship to consider circumstances in Canada as well.

Situated at the intersection of comparative health insurance scholarship, literature about women and health insurance, and studies on health insurance and breast cancer



care, this thesis employs qualitative methodology within a feminist political economy framework in order to advance scholarly knowledge about women's health insurance experiences in relation to breast cancer care. This allows analysis to address the complexity of women's experiences of health insurance in relation to breast cancer care while locating these experiences within larger contexts in ways that expose issues that public and private health insurance raise for women. The approach employed primarily draws on analysis of policy and its historical context and semi-structured interviews with women diagnosed with breast cancer in Ontario and New York. By building on existing literature, this project aims to further understanding of the health insurance systems in Ontario and New York and, in particular, their implications for women. The feminist political economy framework guiding this undertaking is addressed in the following chapter.

## **Chapter 2: Feminist Political Economy, Health Care Reform and Social Reproduction**

### **Introduction**

This chapter examines theoretical concerns central to this thesis, locating them within the realm of feminist political economy scholarship in Canada. In order to orient readers the discussion begins by considering the theoretical orientation of political economy in broad terms, addressing how the study of health and health care is approached within this tradition. The chapter then examines key contributions of feminist political economy scholarship and considers how these are taken up in exploring women's health insurance experiences in relation to breast cancer care in Ontario and New York. The analysis provided draws on theoretical insights from feminist political economy in terms of both its general orientation and its specific concerns. As utilized in this effort, theoretical concerns from feminist political economy allow for critical analysis of the consequences of health insurance systems in women's lives as well as the broader political economic context. Feminist political economy insights are used to approach women's activities and experiences as important concerns, consider social relations of power, examine the roles of households and the voluntary sector as well as states and markets in health insurance, and explore how health insurance systems are implicated in social reproduction, understood within a broader political economy.

### **Political Economy Analysis**

Broadly considered, political economy offers “a holistic approach to understanding society from a materialist perspective” (Clement, 1997: 3). As a school of analysis, it has been influenced by both liberalism and Marxism (Armstrong, Armstrong & Coburn 2001: vii). The tradition known as ‘new Canadian political economy’ offers critical space for political economy analysis. A progressive strand of political economy analysis, new Canadian political economy is grounded in engagement with Marxist traditions of radical social criticism (Clement & Vosko, 2003: xii). This tradition of political economy thought understands the political and economic as integrally related, involves a historical and materialist orientation, and emphasizes the importance of attention to social relations of power and conflict (Armstrong, Armstrong & Coburn, 2001). As Clement (1997: 3) explains, production and reproduction are starting points for a materialist analysis that ultimately seeks to connect the economic, political, and cultural/ ideological moments of social life. Moreover, in seeking to understand the world new political economy analysis strives for reflexivity and transparency about its underlying assumptions (Clement & Vosko, 2003: xii).

Historically, critical political economy analysis has centered on the sphere of production, the roles of states and markets, and social relations of class in examining the workings and consequences of capitalism. While this style of analysis does not ignore culture, ideology or discourse, it does seek to consider developments in these areas in the context of historical and material conditions. It is understood that “people collectively and individually make their own history, although not under conditions of their own choosing or simply as a result of ideas that spring independently to their minds”

(Armstrong, Armstrong & Coburn, 2001: iiv). Tensions, contradictions and changes over time are central concerns (Clement, 1997: 4). As Clement and Vosko (2003: xiii) explain, “objects and subjects of study taken to be fixed or static and unproblematic in empiricist and positivist traditions of political science and neoclassical economics are conceived dialectically.” Scholarship in this tradition is thus sensitive to how tensions and contradictions in particular social arrangements provide impetus for change.

Critical political economy analysis has been described as aiming to “trouble and challenge conventional ways of framing issues” (Clement & Vosko. 2003: xiii). From this vantage point, developments in health and health care are understood to occur within the context of capitalism as a mode of production, in which the search for profit plays a central role. Health and health care are thus understood to be shaped not only by circumstances and interests in the field of medicine, but by broader political and economic conditions and conflicts. Health and health care-related concerns within this tradition include matters such as the historical role of capitalism as a social system in shaping health, illness and health care (Doyal & Pennell, 1979; Leys, 2009), the health implications of shifts in the global political economy (Bond, 2008), and the management of health and health care under global capitalism (Petchesky, 2003). Substantial attention is devoted to understanding determinants of health, which are considered to be shaped not only by health care delivered and received, but by the social circumstances within which people live (Armstrong, Armstrong & Coburn, 2001).

From a political economy perspective, health and health care are not technical considerations best left to members of the medical establishment. Rather, these concerns

emerge as spheres of conflict shaped by social relations of power operating at a variety of levels. Within this tradition, questions of who gains—and who loses—from particular understandings and configurations of health and health care assume particular importance and urgency.

Such questions lie at the heart of the present effort, with its focus on understanding women's health insurance experiences in relation to breast cancer care under the different health insurance systems in Canada and the United States and in Ontario and New York in particular. Health insurance systems are approached as contentious, and understood to have uneven consequences. These systems, and their consequences for women diagnosed with breast cancer, are problematized. In focusing on critically understanding women's health insurance experiences and the contexts within which they take place, this effort can be understood to lie within the realm of "applied political economy", approached not as a formula but rather as "the application of ways of seeing, thinking and enquiring" characteristic of political economy to "practical situations and political actions" (Clement & Vosko, 2003: xv).

### **Feminist Political Economy Analysis**

While the analytical terrain of conventional political economy analysis is potentially vast, feminists have revealed the dominant concerns of this tradition to be exclusive and limiting. As Creese and Stasiulus (1996: 5) put it, the promise of political economy has been "marred by theoretical limitations that render central facets of our existence marginal, and indeed, often completely invisible in much contemporary research." Feminist interventions have played a vital role not only in exposing and

problematizing sex- and gender-blindness in mainstream political economy scholarship, but in developing theoretical insights allowing for more thorough analysis. In the context of the present study, contributions of feminist political economy scholarship are particularly important in four areas: attention to women's activities and experiences, consideration of intersecting social relations, examination of households and the voluntary sector together with states and markets, and interest in social reproduction under capitalism. Collectively, these theoretical concerns inform this analysis.

#### ***Attention to women's activities and experiences***

Feminist political economy scholarship has identified and troubled the absence of women's activities and experiences in mainstream political economy analysis. As Ferguson (2008: 42) observes, this tradition of feminist scholarship has involved both a "comprehensive focus on the full spectrum of practical activity" and an "expansive definition of labor". Feminist interventions have both exposed the exclusion of women from political economy analyses and argued that their meaningful inclusion requires political economy not only to recognize the existence of women, but to embrace new concepts, categories and concerns.

In early efforts to engage with and expand Marxist thought in useful directions, feminists in Canada and elsewhere debated "domestic labour". Broadly speaking, literature engaging with this debate focused on understanding women's unpaid housework and conceptualizing this as labour vital to capitalism as a mode of production. In the 1970s and 1980s a range of Canadian feminist interventions appeared to address the use and usefulness of Marxist categories for understanding women's domestic

activities (see, for instance, Benston, [1969] 1970, Armstrong & Armstrong, [1983] 2003, Luxton, 1980, 1983; MacDonald & Connelly, [1989] 1992). The terms of this debate have been contested and critiqued: Armstrong and Armstrong ([1983] 2003: 25), for instance, suggest confusion about the Marxist meaning of productive work under capitalism in this literature. They also suggest the debate focused on women's domestic labour to the exclusion of their wage labour. For these authors, the importance of the domestic labour debate was to be found precisely in its success in establishing the inadequacy of the wage labour categories used for addressing work within the household (Armstrong & Armstrong, ([1983] 2003: 31).

Despite shortcomings, the emergence of debate about how best to understand women's domestic labour can be seen to play an important role in establishing women's unwaged labour as an important concern for feminist political economy analysis. These debates can also be seen as vital in prompting discussion of the need to consider not only women's unwaged work or waged work, but the relationship between the two (see Armstrong and Armstrong [1983] 2003; Maroney & Luxton, 1987; Clement, 2003). In the context of the present effort, these concerns point to the need to consider not only women's waged labour when understanding health insurance coverage under capitalism within Canada and the United States and Ontario and New York specifically, but women's unwaged labour as well.

Understanding waged and unwaged labour and their significance for women's health insurance coverage arguably allows for a richer and more comprehensive understanding of access to, and use of, health insurance coverage than does attention to

women's involvement in either of these forms of labour in isolation. Understanding the implications of paid work—or lack thereof—for women's access to private health insurance coverage as a commodity obtained through employment or relationships with the employed is particularly important here. However, unpaid work performed in the course of utilizing health insurance coverage to finance breast cancer care also deserves attention.

While early feminist political economy theorizing was sometimes considered to focus on structure at the expense of experience (Ferguson, 2008), contributions to this tradition have come to consider women's experiences as well as the structural contexts within which they occur. Bannerji's (1995) insights are especially useful in drawing attention to the importance of experience and subjectivity for feminist political economy analysis.<sup>8</sup> Bannerji (1995: 78) has suggested that a positivist reading of Marx leads to incorrectly dismissing "experience, the self, the social and the cultural, that is, anything subjective.... as an ideologically contaminated form of unreality" (Bannerji, 1995: 78). Readings in this vein, Bannerji (1995: 78) suggests, privilege structure and do not facilitate understanding consciousness and agency. Experience, in Bannerji's (1995: 87-88) view, can be usefully approached as an interpretive relation rather than a repository of "truth". As such, she argues, it can offer a "point of departure or a set of references for a comprehensive social analysis." She has asserted that "the social analysis we

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<sup>8</sup> Bannerji (1995) is understood by some to challenge Canadian feminist political economy from outside this tradition (see Ferguson, 2008). In my view, however, Bannerji's (1995) vision of historical materialism, attention to the workings of capitalism, and interest in social relations of class as well as race and gender suggest her work can be understood within the tradition of feminist political economy scholarship in Canada, considered inclusively. In her review of feminist political economy scholarship in Canada, Vosko ([2002] 2003) also situates Bannerji within this tradition.



need...must begin from *subjectivity*, which asserts dynamic, contradictory and unresolved dimensions of experience” (Bannerji, 1995: 88).

Subjectivity has since emerged as a complex matter in feminist political economy scholarship. Bakker and Gill (2003: 21), for instance, discuss human subjectivity as "constituted and constrained by different moments of class formation, racialization, sexuality and gender". Thus far from occurring in a vacuum, subjectivity can be understood within this analytical tradition as implicated in social relations of power. Empirically, attention to women's subjectivities and experiences can be seen in a turn towards theoretically grounded case study research within feminist political economy scholarship in Canada (Vosko, ([2002] 2003). Women figure prominently in such studies, with the experiences and perspectives of particular women in specific contexts approached as offering insight into broader structures, institutions and relations. Ongoing interest in case studies is reflected in contributions to edited volumes such as *Feminism in Action: Studies in Political Economy* (Connelly & Armstrong, 1992) *Studies in Political Economy: Developments in Feminism* (Andrew et al., 2003), *Social Reproduction: Feminist Political Economy Challenges Neoliberalism* (Bezanson & Luxton, 2006) and *Neoliberalism and Everyday Life* (Braedley & Luxton, 2010). This scholarship is useful in suggesting the importance of political economy analysis that attends to women's experiences and perspectives as well as to the contexts within which they take place.

In the present study, women's experiences using health insurance in relation to breast cancer care are a central concern together with the contexts within which they occur. Women's subjective understandings of their experiences are approached as a

valuable source of insight into the health insurance systems within which they occur. Rather than accepting women's perspectives and experiences as self-explanatory, however, the goal in this study is to consider them critically. As Bannerji (1995: 66-67) has written, it is important to show how "experience is distinctively, particularly, locally itself and yet/also constituted by and exemplary of social forces that lie in, around and beyond it." It is in keeping with this concern that this thesis places emphasis on examining and interpreting the experiences of women in concrete contexts in order to gain insight into broader structures, institutions and relations within which they are located.

### ***Consideration of interacting social relations***

With attention to social class long central to critical political economy analysis (Armstrong, Armstrong & Coburn, 2001: vii), feminist interventions have been vital in expanding attention to other social relations as well. Feminist political economy scholars have argued that it is crucial to consider sex and gender as they interact with each other as well as with other social relations in particular times and places (Doyal, 1995). In this scholarship, emphasis is thus placed not only on understanding how the biological and social are interwoven, but on approaching a variety of social relations as relevant to political economy analyses.

Feminists have long emphasized the importance of sex and gender for political economy scholarship. As Armstrong and Armstrong ([1983] 2003:11) explain, "The issue is not 'women's questions' or 'the question of women' but the efficacy of an analytical framework that fails to recognize or explain how and why sex differences pervade every

aspect of human activity.” These authors emphasize bodies do not exist outside of power structures, and cannot be considered independent of their economic and social settings, arguing for the use of ‘sex’ to encompass both notions of ‘sex’ and ‘gender’ (Armstrong & Armstrong, [1983] 2003: 39-40). Fudge & Vosko (2003:185) suggest gender can be understood as “the social processes through which cultural meanings come to be associated with sexual difference and the ways in which sexual difference forms the basis for social exclusions and inclusions and constitutes inequalities in power, authority, rights and privileges”. The concepts of sex and gender—and relations between them—remain controversial in feminist scholarship, however, as Luxton (2006a: 22-23) explains.

While it is important to recognize that the terms ‘sex’ and ‘gender’ are contested, in this thesis ‘sex’ is understood to reference biological factors and ‘gender’ is understood to reference social relations without dismissing the complexity of interactions between the two. Women’s experiences with health insurance coverage are approached as shaped by both biological factors relevant to sex and social relations of gender that attach meaning to sexual difference in ways that affect women’s access to and use of health insurance coverage, as well as the consequences, within different health insurance systems. While this thesis uses the specific example of breast cancer to explore women’s experiences of health insurance coverage as a means of financing health care, sex and gender shape women’s interactions with health care systems more generally. Indeed, this gendered context is the subject of Chapter Four.

Along with sex and gender, class remains important in feminist political economy analysis. While liberal understandings of class are, in Luxton’s (2006a: 19-20) words,

“sociological descriptions of socio-economic status”, Marxist approaches maintain class is a social relation “created when the owners of the means of production are not also the direct producers.” In this situation, “one class, by virtue of its control over means of production, can compel the labour of another class and appropriate the wealth produced by the laboring class for its own consumption” (Luxton, 2006a: 20). Historically, Marxist conceptualizations of class focused on an individual’s direct relationship to the means of production, with a woman’s class position generally supposed to correspond to that of the head of the household, assumed to be a man (Goldthorpe, 1983 as cited in MacDonald & Connelly, [1989] 1992: 23). In engaging with Marxist approaches, feminist inventions have argued that investigation of women’s class position needs to take into account not only their own productive *and* reproductive labour but that of their family members as well (MacDonald & Connelly, [1989] 1992: 27). It is no less important to recognize diversity in family and household arrangements (Stasiulus, 1999:284-85). Traditionally, Canadian feminist political economy scholarship has placed particular importance on understanding the circumstances of working class women and their labour (Luxton, 2006a: 20). This thesis continues in this tradition in considering the significance of class in women’s health insurance experiences in relation to breast cancer care. The women whose health insurance experiences are considered in subsequent chapters all work for pay (or have in the past) and/or are (or have been) in domestic relationships with men who work for pay (or have in the past). Yet, their financial circumstances vary significantly, as will be discussed in the next chapter.

In addition to sex, gender and class, feminist scholarship has come to recognize the importance of attention to racialization in political economy analysis. This recognition can be seen to both draw on and reflect interventions critical of feminist analyses inattentive to race and racism (see, for instance, Bannerji, 1995; Jhappan, 1996; Stasiulus, 1999). Such interventions underline that inadequate attention to race results in skewed and incomplete understandings of power and inequality. Creese and Stasiulus (1996: 7) underline that race and racism should not merely be considered descriptively, but must be approached as “a constituent part of all relations”. Integration of attention to race and racism into feminist political economy analysis remains a work in progress. While race is often acknowledged to be important, it is less often fully integrated into analysis, with some arguing it is effectively sidelined (Ferguson, 2008). Where accounts do address race, this is often in relation to women of colour (see, for instance, Dua & Robertson (eds.), 1999; Razack, Smith & Thobani (eds.), 2010), leaving the matter of whiteness less well examined (an exception is Arat-Koc, 2010). The present effort contributes to addressing this concern by considering the significance of racialization for the health insurance experiences of participants who largely identify as white.

Attention to the articulation of multiple social relations has been widely discussed under the banner of ‘intersectionality’.<sup>9</sup> Intersectionality has been praised for shifting concern “away from isolating and ranking particular forms of oppression, and toward interrogating the manner in which they reinforce and/or contradict one another in and through people's lived experiences” (Ferguson, 2008: 43). Some intersectional theorizing

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<sup>9</sup> For an examination of the history and varied uses of this term, see Davis (2008).

has, however, been critiqued by feminist political economists for confining attention to the level of experience at the expense of understanding how the dynamics of capitalism shape the context within which multiple oppressions are experienced and movements develop (see Porter, 2003: 17). As Ferguson (2008: 43) explains, “scholars who have adopted an intersectional perspective tend to limit their field of inquiry. They usually set out to describe and explain how specified social locations shape experience and identity, rather than to understand how such locations interact as part of a dynamic set of social relations.” This focus can make it difficult to keep broader structural considerations in focus.

As taken up within feminist political economy scholarship, intersectionality has been described as involving “probing intersecting systems of domination” (Vosko, [2002] 2003: 314). In seeking to construct analyses that are attentive to the articulation of multiple social relations, feminist political economy scholarship has emphasized the importance of attention to context. As Williams (1995: 128) observes, “the significance of particular social relations changes over time and place”. Similarly, Connelly and Armstrong (1992: ix) suggest that although “gender, race, ethnic and national identities are never absent, they interact with class in various ways with one being more salient than another at different points in time.” Other authors have highlighted the importance of additional relations, divisions and identities in political economy analysis, including those grounded in ethnicity, (dis)ability, sexuality, religion and region (see Williams, 1998: 183; Creese & Stasiulus, 1996: 9). Within feminist political economy analysis, attention to the articulation of multiple social relations thus demands careful

consideration of particular circumstances and conditions rather than a formulaic approach to intersectional analysis.

Examination of intersecting relations and systems within feminist political economy scholarship invites attention to how the articulation of multiple social relations impinges on women's health and health care. In taking up this challenge, the present study understands gender, race, class and age relations as interwoven in examining how the different health insurance systems in Ontario and New York impact women's experiences of breast cancer care. The importance of these relations is suggested in literature about women and health insurance coverage. Findings about variations in health insurance access, coverage and utilization associated with income, employment, sex, gender, race and age-based categories, reviewed in the previous chapter, suggest relations of class, gender, race and age should be considered in understanding health insurance systems and their implications for women's experiences using health insurance in relation to breast cancer care. The analysis undertaken places emphasis on these relations without foreclosing on the possibility that other social relations may be relevant.

### ***States, markets, households and the voluntary sector***

States and markets have been central in much conventional political economy analysis. Feminist interventions have emphasized the importance of rethinking these areas of inquiry with women in mind as well as the need to introduce the household and voluntary sector into political economy investigations. Feminist analysis of the state, market, household and voluntary sector offers insight into the gendered, classed and

racialized nature of arrangements in these areas and their implications for women as a group and different groups of women.

The emergence of the Keynesian welfare state in the post-war period and its transformation over time has been of particular concern for feminist political economy. As Brodie (2007: 97) has explained, “Postwar welfare states operationalized the idea that the state was responsible for the just distribution of social resources...”. In this context, “ideals of social justice and citizen equality prescribed that certain goods – for example, education and health care – should not be entrusted to the capitalist market because it was incapable of ensuring fair distribution” (Brodie, 2007: 98). Maioni (1998: 3) has observed health insurance represents “a central pillar of the modern welfare state, both because it can be seen as a ‘social right’ of citizenship and because it is the largest social policy expenditure for most countries.” Such insights suggest the importance of some welfare state policies in transforming health insurance from a commodity obtained on the basis of one’s relationship to the market to a right of citizenship obtained on the basis of one’s relationship to the state. In practice, welfare state arrangements have varied considerably. Esping Anderson (1990) famously identified three distinct types—liberal, corporatist-statist and social democratic—with Canada and the United States falling into the first category despite variation in the treatment of health insurance in particular.

Feminist authors have come to understand welfare states and regimes in ways more attentive to the significance of gender and the place of women. Work in this tradition has engaged with mainstream comparative efforts, proposing and responding to critiques that highlight the limitations of assuming gender-neutral citizens and implicitly



accepting the activities and entitlements of male workers as standard (see, for example, Lewis, 1992; Daly & Rake, 2003; O'Connor, Orloff & Shaver, 1999). Feminist contributions underline that particular welfare state arrangements can be seen to rest on specific models of the workplace, household and gendered division of labour with implications for women as a group and different groups of women. The post-war Keynesian welfare state model has been understood by some to presume “a stable working/middle-class nuclear family support by a male breadwinner...” (Brodie, 1996: 129). It is useful to keep in mind, however, that the male-breadwinner model highlighted in feminist analysis was never monolithic in practice, as Porter (2003: 10) has observed. Indeed, this model could be seen as most representative of a particular group of white heterosexual families with sufficient incomes.

While controversy about the classed, gendered and racialized nature of welfare states and their benefits remains, the rise and entrenchment of neoliberalism as a political economic project has become a key concern in Canadian feminist political economy scholarship. This scholarship has played a crucial role in revealing the gendered, classed and racialized nature of neoliberal reforms and their negative impact on women as a group and on different groups of women.<sup>10</sup> The rise of neoliberalism can be dated to the global recession of the 1970s, when developments including rising oil prices, stagflation, fiscal crises in various states, and the collapse of the Bretton Woods system of fixed

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<sup>10</sup> Although a comprehensive review of Canadian feminist political economy scholarship on neoliberalism is beyond the scope of this section, edited volumes such as *Rethinking Restructuring: Gender and Change in Canada* (Bakker, 1996), *Women and the Canadian Welfare State: Challenges and Change* (Evans & Wekerle, 1997), *Social Reproduction: Feminist Political Economy Challenges Neoliberalism* (Bezanson & Luxton, 2006), and *Neoliberalism and Everyday Life* (Braedley & Luxton, 2010) can be seen to reflect this interest.

exchange rates backed by gold reserves began to pose severe challenges for welfare states of the global North (Harvey, 2005: 12) as well as to spur disastrous consequences for the global South. Considered broadly, neoliberal ideals can be understood to demand a significant departure from “postwar ideals of universal, publicly provided services and social citizenship”, however imperfectly realized (Brodie, 1996: 131). As a theory of political economic practice, neoliberalism “proposes that human well being can best be advanced by liberating individual entrepreneurial freedoms and skills within an institutional framework characterized by strong private property rights, free markets and free trade. The role of the state is to create and preserve an institutional framework appropriate to such practices” (Harvey, 2005: 2). From a neoliberal perspective, health insurance is best treated a commodity and the role of the state is to support rather than interfere with the primacy of the market in relation to health insurance coverage. Feminist political economy scholarship, with its attention to the roles of markets in perpetuating and deepening inequalities grounded in social relations including those of gender, class and race is useful in problematizing the commodification of health insurance coverage through neoliberal reform and in examining unequal implications of commodified coverage for women as a group and different groups of women.

Neoliberalism is seen by some to reassert “liberal principals of freedom, market individualism and small government” (O’Connor, Orloff & Shaver, 1999: 52). Yet neoliberalism can be understood to move beyond traditional liberalism. In taking up this idea, Brodie (2007: 99-100) argues neoliberalism “is in many ways far more radical and invidious than its predecessor”, breaking down earlier distinctions between public and

private spheres and extending “market logics into the everyday calculations of who we are and how we should live our lives.” Thus, as a project, neoliberalism can be seen to extend not only to the economy but to social life more broadly. The rise and consolidation of neoliberal reforms are sometimes presented and understood as inevitable in this context. Harvey (2005: 13) reminds us, however, the “capitalist world stumbled towards neoliberalization as the answer through a series of gyrations and chaotic experiments”, with this process occurring differently in different places. It thus remains important to attend to differences as well as similarities in examining the realization of neoliberal priorities in different contexts, including in Canada and the United States.

Feminist political economy interventions have emphasized that consideration of neoliberal reforms cannot be limited to study of the shifting roles of states and markets, however important. Attention, it has been argued, must also extend to households—and the people within them—as well as to the voluntary organizations that make up what is sometimes referred to as the ‘third sector’ or civil society (see, for instance, Bezanson & Luxton, 2006; Braedley & Luxton, 2010; Katz, 2001; 2008; Roberts, 2008). This insight is useful in allowing for a more nuanced understanding of neoliberal transformations, one more conducive to recognizing implications for women’s waged and unwaged labour in a variety of areas. When applied to the study of health insurance systems, this position suggests the importance of understanding the shifting roles of states, markets *and* households and the voluntary sector in relation to this form of health care financing with the ascendancy of neoliberal priorities. The uneven effects of these shifting roles—and the shifting burdens of responsibility that they involve—can be understood to have

implications for creating and entrenching inequalities between women and men and among women from a feminist political economy perspective. Insights from this tradition are thus not only useful for directing attention to how neoliberal emphasis on the role of the market involves shifts in responsibilities for markets, states, the voluntary sector and households, but for seeing how these changing responsibilities have unequal implications for individuals in different social and geographical locations. This invites attention to what can be understood as ‘gradation’ in the consequences of neoliberal reform.

Privatization has been identified as a core element of neoliberal reform (Brodie, 1997: 235-36). As Fudge and Cossman (2002a 3-4) observe, this term was once used to denote the sale of government assets to the private for-profit sector but has, more recently, come to reference a broader reconfiguration of public policy that casts responsibility for people’s welfare and well being as a private rather than a public responsibility. Fudge and Cossman (2002a: 4) suggest privatization “has come to represent a fundamental shift not only in government policy but in the balance of public and private power, both globally and nationally.” This reference to the global as well as the national is significant, suggesting the need to consider how developments at the national level can be understood to reflect and contribute to neoliberal trends that extend beyond national borders.

Health care has not escaped the reach of neoliberal reform prioritizing privatization. Connell (2010: 24) observes that “Under neoliberalism the private, and specifically the corporate, part of the health sector is allowed to grow, fuelled by demand from the affluent, subsidies from government, and the profit logic of insurance firms—

which themselves have been transformed from mutuals (a kind of cooperative) into profit seeking corporations.” Yet while broad recognition of privatization in health services under neoliberalism is vital, closer examination suggests a range of forms of privatization can occur. Armstrong and colleagues (2002: 9) argue that forms of privatization in health care may include:

- privatizing the costs of health care by shifting the burden of payment to individuals;
- privatizing the delivery of health services by expanding opportunities for private, for-profit health services providers;
- privatizing the delivery of health care services by shifting care from public institutions to community-based organizations and private households;
- privatizing care work from public sector health care workers to unpaid caregivers; and
- privatizing management practices within the health care system by adopting the management strategies of private sector businesses, by applying market rules to health service delivery and by treating health care as a market commodity.

While this typology was initially developed to understand forms of privatization in the context of health care reform in Canada, its focus on health care costs, delivery, work, and management practices is arguably useful in understanding developments elsewhere as well.

Privatization of the costs of care is the main form of privatization addressed in this thesis. More particularly, it is concerned with how states and markets as well as households and voluntary sectors are involved in the health insurance systems in Canada and the United States, and more specifically in Ontario and New York. It focuses on understanding women’s access to and use of public health insurance that is obtained—or not—on the basis of one’s relationship with the state. It also focuses on private health insurance that is obtained—or not—as a commodity through the market under the

different health insurance systems in place in these jurisdictions. The consequences of these differences are explored.

While the focus of this thesis on health insurance coverage relates most closely to the matter of privatization in the costs of care, it is useful to recognize that different forms of privatization may in practice be interrelated within a broader neoliberal agenda. This is to say, the basis on which health insurance is financed may impact where it is delivered and by whom as well as how it is managed. Thus, while it is important to distinguish between forms of privatization in health care conceptually, it is also vital to remain attentive to how they intertwine in practice. The analysis seeks to understand the consequences of this form of privatization in the context of broader patterns of privatization in health care, at a time in which neoliberal priorities have become normalized in Canada and the United States.

### ***Social reproduction under neoliberalism***

The concept of social reproduction has come to figure in scholarship examining how life is created and sustained under contemporary capitalism. As Bezanson and Luxton (2006: 3) explain, within a feminist political economy framework “social reproduction offers a basis for understanding how various institutions (such as the state, the market, the family/household, and the third sector) interact and balance power so that the work involved in the daily and generational production and maintenance of people is completed.” Health and health care are arguably fundamental in this regard, as authors writing from both Canada (see Ferguson, 2008) and the United States (see Katz, 2001; 2008) have recognized. Attention to social reproduction provides guidance in

understanding the significance of health insurance, direction as to the importance of investigating the interrelated roles of states, markets, households and the voluntary sector in health insurance systems, and a way of understanding the experiences of women under different health insurance systems as embodying broader social conflict.

Social reproduction has been somewhat ambiguously described as “the fleshy, messy, indeterminate stuff of everyday life” (Katz, 2001: 709). In one article, Laslett and Brenner (1989: 382) use this term to refer to “activities and attitudes, behaviors and emotions, responsibilities and relationships directly involved in the maintenance of life on a daily basis and intergenerationally.” In their view, this encompasses “various kinds of work—mental, manual, and emotional—aimed at providing the historically and socially, as well as biologically, defined care necessary to maintain existing life and to reproduce the next generation” (Laslett & Brenner, 1989: 383). Within a feminist political economy framework, attention to social reproduction can be used to problematize arrangements for meeting human needs and their consequences. This concept is useful in problematizing the roles of health insurance systems in meeting women’s health insurance needs in relation to breast cancer care. In this effort attention to social reproduction involves understanding the roles of the state, market, household and voluntary sector in the health insurance systems under investigation and implications for women’s health insurance experiences. Social reproduction is approached as offering a conceptual tool to comprehend how these experiences are implicated in far reaching tensions within health insurance systems and the contemporary capitalist system within which they exist.

As observers have noted, the concept of social reproduction has been used in a variety of ways in feminist political economy analysis (Bezanson, 2006b; Luxton, 2006a). Bakker and Gill (2003: 32) suggest most definitions relate to three key aspects: biological reproduction of the species, reproduction of the labour force, and reproduction of provisioning and caring needs. Health insurance can be seen as relevant in each of these areas. As a form of health care financing, health insurance can be seen to shape access to health care. At this level, it can be understood to affect health, and ultimately survival itself. Health insurance can also be seen as vital to the reproduction of the labour force to the extent that it finances access to health care that contributes to maintaining a labour force healthy enough to be able to work. The basis on which health insurance is provided can be seen as central to the reproduction of provisioning and caring needs in the area of health services, which Bakker and Gill (2003: 32) conceptualize as being privatized, socialized, or a combination of the two. The basis on which needs for health insurance, as a means of health care financing, are met are a key concern in the present effort, with analysis considering particular combinations of public and private coverage that characterize the health insurance systems of Ontario and New York. Thus, in this effort health insurance is approached as important for social reproduction on a number of levels.

As Bezanson (2006b) observes, social reproduction may be used to refer to a process or specific tasks, with different implications. When applied to a set of tasks, it can be understood to refer “to the components of transforming wages and other inputs into reproduction, in a physical, social, and psychological sense” (Bezanson, 2006b: 25).



As a process, social reproduction addresses “the balance of power between capital’s pursuit of profit and people’s access to income” (Bezanson, 2006b:25). In the present project health insurance is understood as impinging upon particular tasks associated with social reproduction as well as the broader process of social reproduction under capitalism. This concept is used both to situate this study of health insurance systems within larger questions of survival on a daily and generational basis and to identify this form of health care financing as a terrain upon which conflicts between the roles of states, markets, households and the voluntary sector take place with consequences for women shaped by social relations of gender, class, race and age in particular.

Instead of simply assuming social reproduction occurs, feminist scholars have worked to identify and problematize its dynamics. Laslett and Brenner (1989) point to the historical separation of production and social reproduction under capitalism, considering the gendered nature of the changing organization of social reproduction within the institutions of the family, market and state. Picchio (1992) develops the idea that under capitalism the processes of production and social reproduction are not only separate but fundamentally contradictory. While production prioritizes the requirements of capital, social reproduction prioritizes the needs of the laboring population. For Picchio (1992: 123), this population encompasses all people “who directly or indirectly depend on a wage for subsistence and who have no access to property as a main source of income”.

Picchio (1992) identifies two main mechanisms that mediate conflict between production and social reproduction: the state and unwaged housework. She maintains that although the state “may intervene by supporting the process of social reproduction

when it is undermined”, it has “no interest in changing the social organization based on a division of labour between waged work and wageless housework and between men and women” (Picchio 1992: 85). The family, in her account, functions as a kind of “alternator”, reversing the flow of energy from goods and services to people (Picchio 1992: 98). Picchio (1992) recognizes that within the labouring population it is largely women who face responsibility for unwaged housework. This insight leads to the recognition of social reproduction as profoundly gendered as well as class specific.

Picchio’s (1992) insights about the conflict laden nature of social reproduction under capitalism are taken up in the work of authors such as Luxton (2006a; 2006b) and Bezanson (2006a; 2006b) in examining contemporary developments. For these authors, conflict between production and social reproduction is conceptualized as taking place within an expanded mode of production rather than separate spheres with distinct dynamics (for an alternate view, see Ursel, 1992). Analysis of social reproduction involves attention to conflicts inherent in and between the roles of the state, market, household and voluntary sector. When applied to the study of women and health insurance, this work suggests the importance of examining tensions in and between the roles of the state, market, household and voluntary sector in relation to the health insurance systems that finance women’s breast cancer care in Ontario and New York. Attention to the conflict-laden nature of social reproduction under capitalism is helpful in considering how women’s health insurance experiences in relation to breast cancer care can be seen to reflect broader structural tensions.

Analyses of social reproduction under neoliberalism suggest pressing challenges in both Canada and the United States. Writing from the United States, Katz (2008: 18) argues neoliberal imperatives

have been associated with concerted attempts by the state and capitalists to *offload responsibility* for social reproduction onto individuals and households as well as civil society organizations such as community groups, religious institutions, and other non-governmental organizations. These largely successful efforts have had deeply problematic and sometimes disastrous consequences, particularly for poor and disenfranchised people, especially women of color [emphasis added].

Similar dynamics have been identified in Canada. In Ontario, Bezanson (2006b) writes of finding low income households especially hard hit by neoliberal policies imposing increasing responsibility for social reproduction on households, with consequences including household dissolution, breakdown of intra-household support, and even attempted suicide. Such studies suggest women's capacities to cope with the increasing demand for both their paid and unpaid work under neo-neoliberalism, although flexible, are not infinitely so. Indeed, a number of authors go so far as to warn of crises in social reproduction under neoliberalism (Fudge & Cossman, 2002a, 2002b; Brodie, 2003; Peterson, 2003; Luxton, 2006a; Bezanson, 2006a, 2006b; Vosko, 2006; Katz, 2008). This work is especially important in suggesting the need to problematize the ways in which households—and women in particular within them—have been responsibilized in relation to social reproduction with neoliberal reforms. This concern is taken up in this thesis in examining women's use of health insurance coverage, and more specifically the unpaid work women assume responsibility for performing in utilizing forms of health insurance coverage in relation to breast cancer care in Ontario and New York.

Arat-Koc (2006) proposes the concept of “stratified reproduction” for making sense of a range of inequalities in social reproduction. Coined by Colen (1995: 78), this concept is intended to suggest that “physical and social reproductive tasks are accomplished differently according to inequalities that are based on hierarchies of class, race, ethnicity, gender, place in the global economy, and migration status and that are structured by social, economic and political forces”. As Colen (1995:78) observes, these tasks are “differently experienced, valued, and rewarded according to inequalities of access to material and social resources in particular historical and cultural contexts.” As taken up by Arat-Koc (2006: 87), the concept of stratified reproduction is used to explore “the power relations by which some categories of people are empowered to nurture and reproduce, while others are disempowered”. As such it offers an avenue for exploring not only relations of gender and class, but also those of race in social reproduction. Understanding social reproduction as stratified allows for attention to how different women are differently implicated in this process and face inequalities in relation to it.

As Arat-Koc (2006: 87) observes, attention to stratified social reproduction can encompass not only economic concerns narrowly defined, but also social, political and policy systems. As I understand it, this concept invites examination of how systems and policies—including health insurance systems and relevant policies—enable and/or imperil social reproduction for those in different social and geographical locations. This allows for recognition that the changing roles of the state, market, household and voluntary sector in social reproduction can impact different women differently in shaping the constraints within which they act. As applied in the present study, attention to

stratification in social reproduction invites consideration of the ways that state, market, household and voluntary sector involvement in the health insurance systems of Ontario and New York affect women in different social and geographical locations in different ways. This focus promotes attention to gradation in the consequences of health insurance coverage for women using different forms of health insurance within two different health insurance systems. It allows for consideration of inequalities not only in access to forms of coverage and in their use, but in the outcomes for women who use different types of health insurance to finance breast cancer care.

Ferguson (2008) underlines the importance of considering the socio-spatial aspects of social reproduction. In her words, “it’s not just what we do to reproduce society, but where we do it that counts in an imperial capitalist world” (Ferguson, 2008: 51). In other words, as Katz (2001: 715) bluntly reminds us, social reproduction “always takes place somewhere.” In making the case for greater attention to space in feminist political economy scholarship on social reproduction, Ferguson (2008: 51) argues that location, which is always socially determined,

can be teased apart analytically into two basic types of spaces: the territorially based geo-political (defined, for example, by state and regional boundaries, military liaisons, multinational capital investment patterns and trade agreements); and the systemic social relations between people (defined by class, gender and racial divisions). While analytically distinct, these two aspects of space are never experienced in isolation from each other. The geo-political is always lived in and through relations of class, gender and race in a complex unity.

This argument underlines the need to consider the importance of geo-political location as well as social relations in analysis of social reproduction. In the context of the present

effort, this insight is useful in suggesting the importance of attending to the particularities of geo-political boundaries as well as social relations in understanding the different health insurance systems in Ontario and New York and their implications for women's health insurance experiences in relation to breast cancer care. Provincial/state boundaries are approached as vital in understanding the health insurance systems under investigation, as are the larger national boundaries within which they are situated. Within the particular areas under study, Lanark and Leeds Grenville in Ontario and St. Lawrence County in New York, relations of gender, class, race and age are understood to shape the social locations within which women experience health insurance coverage and its consequences for social reproduction.

## **Conclusion**

As Armstrong, Armstrong and Coburn (2001:vii) explain, political economy as a field of enquiry is "constantly shifting boundaries and core concerns in response to theoretical debates, research and changes both within and across societies". This chapter has aimed to situate the theoretical concerns of this thesis within this changing terrain, and, more specifically, within feminist efforts to expand its scope and sharpen the analysis offered. The account provided is guided by concerns central to Canadian feminist political economy scholarship in particular in considering women's health insurance experiences in relation to breast cancer care within the health insurance systems of Ontario and New York and the broader political economy within which they are embedded.

The analysis undertaken in the chapters that follow is directed by feminist political economy insights about the importance of accepting women's activities and experiences as vital concerns for political economy analysis, the need to consider sex and gender as well as class, race and age, the advantages of understanding the roles of states and markets as well as households and the voluntary sector, and the importance of investigating how health insurance systems are implicated in social reproduction in places in which neoliberalism has become normalized. In drawing on these insights, this thesis compares women's experiences and the contexts within which they occur in two neighboring jurisdictions. In so doing, it draws on feminist political economy insights to understand the consequences of these systems in women's everyday lives in concrete contexts as well as the implications for social reproduction more broadly.

While the nature and significance of social reproduction remains contentious within feminist political economy scholarship, the analysis offered here aims to draw on critical insights from the study of social reproduction to:

- (a) understand health insurance as contributing to social reproduction through financing access to life sustaining health care;
- (b) examine the roles of the state, market, household and voluntary sector in relation to health insurance in Ontario and New York;
- (c) consider stratification in examining women's health insurance experiences;
- (d) examine health insurance systems and women's experience within them in relation to breast cancer care as embodying broader tensions under contemporary capitalism.

The present effort can thus be understood to apply feminist political economy scholarship on social reproduction in order to better understand the health insurance systems in Ontario and New York and women's experiences within them during breast cancer care. Feminist political economy commitments also inform methodological choices made, which will be discussed in the following chapter.



## **Chapter 3: Studying Health Insurance Coverage for Breast Cancer Care in Ontario and New York**

### **Introduction**

This chapter addresses the methodology and methods used in this thesis to explore how the different health insurance systems in Ontario and New York affect women's health insurance experiences in relation to breast cancer care. It begins by situating this project within the terrain of qualitative research and the realm of feminist engagement with this terrain. Subsequently, the chapter discusses the study conducted and explains why Ontario and New York have been selected for consideration. Attention then turns to elements of the research strategy employed. The second part of the chapter addresses sampling and goes on to discuss recruitment of interview participants, the interview process, analysis of the interviews completed, and characteristics of interview participants. The chapter concludes by assessing the strengths and weaknesses of the methods used in this study before discussing the assessment of quality in qualitative research.

### **Qualitative Research**

As a form of social inquiry, qualitative research involves “an interpretive, naturalistic approach to the world” (Denzin & Lincoln, 2011: 3). As Denzin and Lincoln (2005: 10) explain, research in this tradition emphasizes “the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape enquiry”. The terrain of contemporary qualitative

research is, nevertheless, extraordinarily varied: different paradigms are grounded in different assumptions about the nature of the social world and what can be known about it.

The approach that underpins this thesis fits best within a critical theory paradigm of qualitative research, which is characterized by a historical-realist ontology and a transactional, subjectivist epistemology (Lincoln, Lynham & Guba, 2011: 100). This is to say, the conception and design of research reflect the conviction that an historical, material reality can be apprehended and interpreted, that the investigator and the investigated are linked through their interaction, and that research findings are mediated by the values of those involved in the research undertaken. Within the broad paradigm of critical theory, the present study is influenced by concerns prominent in feminist traditions of research.

### **Feminist Concerns**

Feminist research can be understood to problematize “women’s diverse situations as well as the gendered institutions and material and historical structures that frame those” situations (Olesen, 2005: 236). In seeking to generalize about this tradition, Gustafson (2000: 718) argues feminist research is political in standpoint, gendered in focus, reflexive in process and transformative in outcome. Yet, as Oleson (2005: 235) underlines, feminist qualitative research is diversified, dynamic, and challenging. This complicates discussion of feminist research methodology, understood as “a theory and analysis of how research should proceed” (Harding, 1987: 2). Ramazanoglu and Holland (2003: 171) suggest this methodology is distinctive “to the extent that it is shaped by

feminist theory, politics and ethics and grounded in women's experience" yet different feminist traditions embrace different theories, politics, ethics and approaches to experience as well as an array of research methods.

Although feminist epistemology is not homogeneous, this tradition as a whole has done much to promote the recognition of women as agents of knowledge, attention to knowledge as socially situated, and an understanding that women's experiences can provide important, if not unproblematic, empirical and theoretical resources (Harding, 1987). Following feminist researchers such as Harrison (2007: 24), the present project draws on feminist methodology that "underscores the value of women's voices, experiences and agency and the socio-cultural and political-economic contexts in which they are situated." This fits well with feminist political economy's theoretical emphasis on understanding not only women's activities and experiences but the broader structural contexts within which they take place.<sup>11</sup>

The feminist commitments that orient the present study underpin the idea that the implications of different health insurance systems for women constitute a worthwhile topic for sociological inquiry. The emphasis in this project is, unapologetically, on studying women's health insurance experiences in relation to a gendered form of cancer that disproportionately affects women. It is guided by the assumption that to understand health insurance systems it is vital to learn about the experiences of women who use

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<sup>11</sup> Following feminist theorists such as Harding (1987) and health researchers such as Wuest (1995), I approach feminist commitments not as necessarily dictating any particular research method, but rather as applicable to a variety of research methods.

them. In seeking to contribute to feminist political economy scholarship, this project aims to consider not only the experiences of women, however, but the institutional, historical and material contexts in which these experiences occur.

### **Comparing Ontario and New York**

It would no doubt be instructive to compare women's experiences in a range of liberal welfare states that organize health insurance differently. Yet frequent references to Canadian and U.S. health insurance systems in health care debates in both countries, with claims of myths, caricatures and lessons from each (Deber, 2003; Angell, 2008; Peterson, 2009), makes this comparison a particularly timely one. In focusing on the contemporary implications of different health care systems within these jurisdictions for women's health insurance experiences in relation to breast cancer care, this study seeks to contrast the different insurance systems and their implications while remaining attentive to commonalities that reach across jurisdictions.

In light of provincial and state variation in health insurance regulation within Canada and the United States, comparison of health insurance systems at this jurisdictional level is most appropriate. While national level comparisons can be useful for making broad generalizations about differences and similarities between countries, these risk homogenizing health insurance systems within national settings. State-province comparison is better suited to capturing the details of health insurance systems that women use in relation to breast cancer care due to the importance of province and state involvement in public health insurance programs and regulation of the private health insurance industry. As the particularities of state and provincial health insurance systems

form the more immediate context for women's health insurance experiences they are approached as crucial for this study.

It is sometimes contended that regulation is the key to improving the workings of private health insurance as a method of health care financing alongside public health insurance systems (Thomson & Mossialos, 2004; Greb, 2005; Colombo & Tapay, 2004b). The focus of the present effort on Ontario and New York in particular is useful due to both similarities and differences between these jurisdictions in this regard. Adjacent and closely linked through trade (Ontario, 2013), Ontario and New York are nevertheless active in maintaining different roles for public and private health insurance within their respective health care systems. New York is not a case offering an extreme *laissez-faire* approach to health insurance within the United States, but rather is a state that is relatively restrictive in regulating the private health insurance industry (National Women's Law Center, 2009). Nor is Ontario an outlier within Canada when it comes to limiting private health insurance to a supplementary role (Boychuk, 2006; Hurley & Guindon, 2008). Under the circumstances, this particular state and province can be seen to offer opportunity for comparing some of the best of what actively regulated private health insurance has to offer women in Canada and the United States when it comes to financing breast cancer care. Problems facing women in even these jurisdictions could be more grave in jurisdictions in which private health insurance is less regulated.

### **Research Strategy Overview**

In keeping with the theoretical commitments of feminist political economy scholarship, the research strategy used here aims to address not only women's

experiences using health insurance in relation to breast cancer care but also the contexts within which these experiences take place. The goal is not to consider women's perspectives in isolation. Rather, it is to interpret women's accounts of their experiences in light of broader social systems and the political economy structures within which they are embedded. This necessitates a research strategy attentive to multiple sources of information.

To study the contexts within which women diagnosed with breast cancer in Ontario and New York experience health insurance coverage this study draws on critical review of relevant secondary literature as well as legislation and policy documents. Primary sources (legislation and policy documents) and secondary sources (accounts of historical and contemporary health insurance policy) are reviewed in order to understand the historical development of health insurance in Canada and the United States and the contemporary state of health insurance in Ontario and New York in particular. The analysis of primary and secondary sources focused on identifying key policy changes shaping the health insurance systems in place in Canada and the United States, with the overall aim of understanding the policy environments confronting women using health insurance in Ontario and New York from a feminist political economy perspective. Particular attention is devoted to policy developments relevant to women's use of health insurance coverage for breast cancer care.

In-depth semi-structured interviews with women diagnosed with breast cancer have been used to gain insight into women's health insurance experiences in relation to breast cancer care in two areas within the jurisdictions considered: Lanark and Leeds

Grenville in Ontario and St. Lawrence County in New York. This type of interviewing is well suited to pursuing feminist political economy interest in addressing women's experiences and activities in so far as it provides an opportunity for women to discuss these matters themselves and to reflect on their significance. In-depth semi-structured interviewing in combination with attention to primary and secondary literature relevant to health insurance policy contexts in Canada and the United States, and Ontario and New York specifically, allows for a richer and more contextualized account of women's health insurance experiences in relation to breast cancer care in these jurisdictions than would in-depth semi-structured interviews alone. Due to the centrality of interviewing in this thesis, the particular approach taken is discussed in greater detail below.

### **Interviewing Approach**

As Reinharz (1992:19) observes, use of interviewing as a qualitative research method has the advantage of offering "access to people's ideas, thoughts and memories in their own words rather than the words of the researcher". In-depth interviews can be used to learn about the "lived experiences" of individuals and they are often "issue-oriented" (Hesse-Biber, 2007: 118). Moreover, this approach to interviewing commonly features in research aiming to analyze respondents' experiences in order to bring thematic dimensions into view (Crouch & McKenzie, 2006: 488). For these reasons in-depth interviewing was used in the present study to gain insight into women's health insurance experiences in relation to breast cancer care.

Semi-structured interviewing involves use of an interview guide containing a set of questions to be covered in each interview; however it also allows space for spontaneity

in asking questions and probing participants' responses (Hesse-Biber, 2007: 115). This form of interviewing was used in the present project as theoretical insights from feminist political economy and critical review of literature about women and health insurance suggested the importance of particular questions about respondents' health insurance experiences. The semi-structured format allowed opportunity to ask all participants basic questions and facilitated comparison within and between the accounts provided in Ontario and New York while also allowing for the pursuit of issues raised by participants themselves. Interest in participants' experiences and perspectives necessitated an approach flexible enough to allow for the discussion of additional issues that emerged during interviews.

Following cross-national qualitative researchers such as Gómez and Kuronen (2011: 690), my use of interviewing as a research method has been based on the conviction that it is possible to learn about the social world beyond the interviews through analysis of the interviews while still recognizing the interactional nature of interviewing itself. Thus while it is important to acknowledge that interviews are interactions leading to negotiated, context-sensitive results (Fontana & Frey, 2000: 646), this research is underpinned by the assumption that participants can reflect on and communicate information about their health insurance experiences in relation to breast cancer care and their accounts represent a useful source of information about their experiences and the health insurance systems within which they have taken place.

While interviews have been used as a means to understand women's experiences in this thesis, the significance of experience itself is not approached as unproblematic. As



Scott (1991: 797) has observed, “experience is at once always already an interpretation *and* something in need of interpretation”. Following Oleson (2000: 249), attention to women’s reported experiences alone cannot be expected to fully elucidate the historical, material and social circumstances in which experiences occur. Use of in-depth semi-structured interviewing as a research method in this study is thus complemented by attention to secondary sources and policy and legislative documents considered within a feminist political economy framework.

### **Sampling Strategy**

Sampling remains a controversial matter in qualitative research. Coyne (1997: 629) contends all sampling in this type of research can be considered “purposeful”. The logic and power of this type of sampling, according to Patton (2002: 230), derive from the selection of “information rich cases for study in depth”. In the context of qualitative research, information rich cases can be understood as those from which “one can learn a great deal about issues of central importance to the purpose of the enquiry” (Patton, 2002: 230).

Purposeful sampling has occurred on different levels in the present project. As discussed above, sampling of national and provincial/state jurisdictions has been based on the purpose of contrasting health insurance systems in two neighboring jurisdictions where public and private health insurance play different roles. Rather than contrast a state that takes a *laissez-faire* approach to private health insurance with a province that actively regulates this form of health care financing, the present effort focuses on one

state and one province within which private health insurance is relatively actively regulated.

Within this context, selection of interview areas was shaped by concerns of theoretical saturation as well as project feasibility. The counties of Lanark and Leeds Grenville in Ontario and St. Lawrence County in New York both encompass rural and small town populations that are predominantly English speaking, non-immigrant and white<sup>12</sup> (Statistics Canada, 2013a; Statistics Canada, 2013b; U.S. Census Bureau, 2013). Although the median income is higher on the Ontario side of the border than on the New York side, median incomes in Lanark and Leeds Grenville as well as St. Lawrence County are below those in their respective state and province more generally (Statistics Canada, 2007; U.S. Census Bureau, 2013). The study initially began by focusing recruitment efforts on Leeds Grenville in Ontario; however due to recruitment challenges the recruitment area was eventually expanded in November 2012 to include parts of Lanark County in order to obtain more interview participants. Women living in Perth and Smiths Falls, parts of Lanark County that fall within the South East Local Health Integration Network (LHIN) together with much of Leeds Grenville (Ontario, 2005) were invited to be interviewed for the study as well.

The proximity of these areas and the relative homogeneity of their populations make them useful locations for the present study due to considerations of theoretical saturation. The concept of theoretical saturation figures prominently in discussions of sample size in qualitative literature, where, as Morse (1995: 147) succinctly explains, it

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<sup>12</sup> This is the terminology used by the U.S. Census Bureau (2013); Statistics Canada (2007) uses the term “not a visible minority”.

refers to “data adequacy” and is operationalized as “collecting data until no new information is obtained.” Patton (2002: 244) suggests optimal size depends on what one wants to find out, why, how the findings will be used, and the resources available.

Sandelowski (1995: 182) proposes that sampling for homogeneity and selected phenomenal variation is one “way that that a researcher working alone with limited resources can reduce the minimum number of sampling units required within the confines of a single research project but still produce credible and analytically and/or clinically significant findings”. In the context of the present project, the selection of two similar research locations with relatively homogenous populations was undertaken with a view to enhancing the feasibility of the study. The use of purposeful sampling of women diagnosed with breast cancer in each location was undertaken to facilitate access to information-rich respondents in the context of the study’s examination of women’s health insurance experiences in relation to breast cancer care. Participation in interviews was, accordingly, open to women residing in the jurisdictions in question who had been diagnosed with breast cancer and were willing to discuss their experiences with health insurance. Initially I sought women who had been diagnosed within the last five years; however I subsequently elected to lengthen the timeframe for diagnosis to eight years in order to facilitate recruitment, which is discussed in more detail below.

### **Recruitment**

Prior to beginning recruitment of interview participants, the present project was reviewed by the Human Participants Review Sub-Committee of York University’s Ethics Review Board and was approved as conforming to the standards of the Canadian Tri-

Council Research Ethics Guidelines (see Appendix A). These standards, as outlined in the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada and Social Sciences and Humanities Research Council of Canada, 2010: 8), are based on the basic principles of respect for persons, concern for welfare and justice. As discussed in this document, respect for persons emphasizes human dignity and autonomy, concern for welfare focuses on protecting the well being of research subjects, and justice requires fair and equitable treatment of subjects as well as the distribution of the risks and benefits of research.

Free, informed and ongoing consent from study participants is central to contemporary ethical standards. In accordance with these standards an informed consent document was distributed to interview participants prior to each interview and written consent for participation and audio-recording was obtained (see Appendix B). This form provided information about the identity of the researcher, the purpose of the study, the nature of involvement requested, potential risks, discomforts and benefits, the voluntary nature of participation, potential for withdrawal from the study, and efforts to ensure confidentiality.

As Fisher (2009: 162) has observed, individuals make decisions about research participation “in light of their individual experiences of broader political, economic and social contexts”. In recruiting interview participants a particular concern was material constraints and the effort to ensure that they should not present barriers for women interested in being interviewed. In order to make participation as financially accessible as

possible, participants were provided with an honorarium of \$30.00 CDN/US. Care was taken in arranging interviews at times and in locations preferred by participants.

Recruitment for this study followed the same recruitment strategy in both Ontario and New York; however efforts produced different results in each location. The different levels of interest and support encountered in each jurisdiction became significant, making it useful to address the recruitment efforts in some detail.

Initially, the recruitment strategy focused on contacting organizations involved with women and/or cancer in St. Lawrence County and the United Counties of Leeds and Grenville in order to seek assistance in recruiting women to interview. Recruitment was pursued in both places simultaneously between April 2012 and January 2013. In New York, these efforts were met with interest and cooperation. Contact with two local hospitals led to a meeting with the Director of Oncology Services at one. This director was enthusiastic about this study, and she agreed to raise awareness about it among members of the breast cancer support group she co-facilitated. This led to an invitation to speak at a breast cancer support group meeting as well as at a dinner for breast cancer survivors. This in turn led to meetings with other helpful contacts and potential participants. At the second hospital, an oncology social worker agreed to print and distribute notices about the study to eligible women.

The coordinator for the St. Lawrence County Cancer Services Program was also enthusiastic about the study. This coordinator agreed to ask the women she worked with, Medicaid Cancer Treatment Program recipients, if they would participate in this study. She was extremely helpful in sharing her knowledge about the St. Lawrence County

Cancer Services Program and about the Medicaid Cancer Treatment Program. Over the course of recruiting, meetings occurred with a number of other individuals, including a representative of the American Cancer Society and a member of a local charitable organization offering support for women with breast cancer. However, recruiting efforts in St. Lawrence County largely came to revolve around the support received from two local hospitals and the county Cancer Services Program. Potential participants learned about the study through an email or hardcopy version of the Call for Participants (see Appendix C), because they were asked directly by the Cancer Services Program Coordinator, or because they were asked by someone known to them who had already participated in the study.

In Ontario, recruitment efforts began with contacting the local hospital in Brockville. By chance, one of the individuals contacted qualified for the study herself. This woman not only agreed to participate, but to raise awareness about the study among eligible women of her acquaintance. So began the more successful “track” of recruitment efforts in Leeds Grenville, with participants finding out about the study through someone known to them and agreeing to participate. The other, more formal track, which involved finding contacts within organizations dealing with women and/or cancer to assist with recruitment, proceeded much more slowly. A second contact referred the project to the hospital’s ethics review board. Eventual completion of the hospital’s ethics review process led to a study notice being posted at the hospital; however this did not result in any participants.

The local health unit, along with several other organizations in Leeds and Grenville, suggested it would be useful to approach the nearest branch of the Canadian Cancer Society. From there, the project was passed on for ethics review at the organization's head office. After successfully completing this process, study notices were left at the local Canadian Cancer Society office and flyers were handed out at a local event. This event was noteworthy not because it resulted in participants, but because it crystallized what seemed to underlie recruitment efforts in Leeds and Grenville more generally: lack of interest in the topic of health insurance and in this study in particular. At the event in question, it emerged that speaking about the study would not be permitted and that it would only be possible to distribute study flyers. Efforts to hand out flyers were most often greeted with polite suspicion.

Efforts to contact other women and/cancer related organizations also proceeded slowly in Ontario. A nearby breast cancer action organization emailed the study notice to its members, resulting in a couple of participants. One woman who found out about the study this way explained that she had come forward because she suspected not many people would. Months of emails and telephone calls eventually resulted in the opportunity to speak briefly at a local breast cancer support group meeting, after which a few more women agreed to be interviewed. One of few locals to return emails or telephone calls, the president of a local women's group helped to raise awareness about the study in a newsletter and on Facebook. An advertisement was placed in the local paper about the study and a local journalist was persuaded to run an on-line news story about it, all without result. With recruitment in Ontario lagging behind New York, the

decision was made to expand the recruitment area in Ontario to include parts of neighboring Lanark County within the same Local Health Integration Network (LHIN) as much of Leeds Grenville in a bid to find more interview participants. The leader of a local breast cancer support group there agreed to advertise the study. The study's Call for Participants subsequently appeared in a local newspaper—one that had initially been contacted without success. This resulted in several more potential participants coming forward.

It appears this is not the only recruitment effort to involve difficulty recruiting women diagnosed with breast cancer for interviews (see, for instance, Rager, 2000; Vigen, 2004; Cutts, 2006). Yet, the differences in recruiting in Lanark and Leeds Grenville in Ontario and in St. Lawrence County in the New York were striking. A lack of experience with marketing research could account for difficulties encountered. Yet in the New York context, this project seemed, for lack of a better phrase, to “sell itself”. Health insurance appeared to be widely understood not only as an important way of paying for health care, but as a *problem*. Indeed, during interviews even women who praised their own coverage saw health insurance as a problem for others. As such, it was understandable that someone would want to do research about women's health insurance experiences. Recruiting efforts were met with enthusiasm: women volunteered for the study even when they didn't meet all of the criteria. One man who had had breast cancer showed up to be interviewed alongside his wife, who had also had breast cancer. Men who had had other kinds of cancer volunteered. Overall, it is difficult to envision an environment more supportive of research about health insurance experiences.



In contrast, in Ontario, health insurance seldom seemed to be seen as a *problem*. Instead, as become apparent during interviews, many people simply took public health insurance coverage for hospital and physician care for granted. Many of the women who agreed to be interviewed appeared to be motivated less by the nature of the research than by a desire to help complete a school project. Several talked about having children or grandchildren in graduate school and knowing how difficult this career path could be. It seemed that for many Ontario participants, the idea of helping a graduate student to further her education was more compelling than the particulars of the project. Women did not tend to come forward unless they fit the requirements of the study precisely, and few expressed curiosity about the study findings. Memorably, one woman jokingly expressed delight that she *didn't* qualify to participate. Overall, it was far more difficult to generate interest in research on health insurance experiences in this context.

Different levels of enthusiasm for this project in New York and Ontario may be less indicative of research 'salesmanship' than of the understanding of health insurance as a problem in need of research. In New York, the study of women's health insurance experiences seemed not only to make sense to people, but to be an important focus for attention and analysis. In Ontario, in contrast, where health insurance coverage often seemed to be taken for granted, the project more often appeared to be approached as an academic exercise. This contributed to an extended recruiting period in Ontario as well as an expanded recruitment area within the same South East LHIN in a bid to attract sufficient numbers of participants.

### **The interview process**

Contact with participants began when they telephoned or emailed, or when a person known to them passed on their telephone number with their prior approval. Depending on how contact was initiated, potential participants were contacted either by telephone or email to confirm eligibility, reiterate information about the study provided in the Call for Participants notice (see Appendix C), and arrange a time and place for an interview. Of the potential participants I was in contact with about the study, none directly declined to participate but three could not find time to be interviewed. In order to make interview participation as accessible as possible, participants were offered multiple options for interview times and locations. In Ontario women had the option of being interviewed in their home or office or at a café or other setting of their choosing. In New York, in addition to these options the option of meeting in borrowed office space at a local university was available. While a university office initially seemed to be a good location for interviewing due to the privacy and quiet environment offered, participants often preferred to be interviewed at their home, a café or in their workplace and seemed particularly comfortable in these settings.

All interviews in Lanark and Leeds Grenville in Ontario and St. Lawrence County in New York were conducted using the same interview guide (see Appendix D). Interviews were audio-recorded after the approved informed consent form had been signed (see Appendix B). While all interviews followed the same general trajectory provided by the pre-determined questions, the semi-structured format allowed for probes and additional questions that varied in response to participants' comments. Interviews were initially projected to last between 45 and 60 minutes; however in practice they

varied in length. In New York, interviews ranged from 38 minutes to 103 minutes, lasting on average 64 minutes. In Ontario, interviews ranged from 26 minutes to 121 minutes, lasting on average 61 minutes. With participants' permission written notes were taken during interviews. As soon as possible after each interview additional notes were written summarizing what had taken place. These notes, which involved review of the interview conducted and the environment, considered issues that seemed striking. Such notes provided an initial way to begin to think through each interview.

During early interviews audio recording was halted upon finishing the last of the interview questions. It emerged, however, that participants would sometimes become especially talkative at this point and when signing the receipt provided for their honorarium. When this happened, permission was sought to resume audio-recording. This was always granted; however the decision was later made to continue audio-recording until after all paperwork had been completed in order to record participants' comments without interruption. Throughout interviewing, offers were made to pause or totally stop the interview and recording if participants appeared at all upset. Only one New York participant accepted such an offer, having become tearful in the midst of recounting an upsetting health insurance experience. Recording stopped immediately and this participant was asked if she wanted to end the interview at this point, or even withdraw from the study entirely. She did, however, opt to continue the interview after a few minutes break. It later emerged that this woman had called a mutual contact after her interview to report that although she had found the questions more difficult than expected, she was nevertheless happy to have been interviewed.

Generally, when participants had health insurance coverage they considered to be good, interviews did not seem particularly emotionally taxing. When women had faced health insurance problems, however, interviews were far more emotionally fraught. While interested in learning about the nature of women's health insurance problems, emphasis was placed on the researcher's responsibility not to cause distress. Some interviews did include discussion of upsetting experiences—such as having to postpone breast cancer treatment due to not having enough money to pay for it. In these circumstances, an empathetic response was chosen over a disinterested one. This course of action seemed to be the only honest one, and it may have helped participants feel more comfortable discussing their experiences.

### ***Reflexivity***

In discussing qualitative inquiry, Creswell (2007: 38) underlines the importance of the researcher as “a key instrument” in research. In taking this insight seriously, reflexivity, “the process through which a researcher recognizes, examines and understands how his or her own social background and assumptions can intervene in the research process”, is arguably crucial (Hesse-Biber, 2007: 129). In the present study, my position as a white, university-educated Canadian woman studying women meant I shared at least one important characteristic with all interview participants. Sometimes I shared more: nearly all of the women interviewed identified as white, and two explained that they too were “ABD”, having completed all requirements for a doctoral degree but for a dissertation. Yet while certain commonalities may have facilitated recruitment and interviewing, my social position and experiences also differed from those of the women

interviewed in various ways. All participants were older than I was at the time of the interviews, often by several decades. Dividing my time between Ontario and New York over the course of this project enabled me to gain experience using both public health insurance in Ontario and private health insurance in New York. Unlike the women interviewed, I have never been diagnosed with breast cancer.

In considering the analysis offered in subsequent chapters it is important to recognize the significance of my authorial role. While qualitative research does, as discussed earlier, offer access to participants' interpretations of their experiences expressed in their own words (Reinharz, 1992), in my role as author I am in turn interpreting and presenting participants' accounts of their health insurance experiences in relation to breast cancer care for an academic audience. I have identified and labeled themes in participants' responses, and in developing an account of these themes I have selected and presented excerpts from interview transcripts. I have frequently quoted participants at some length in an effort to provide readers with a sense of 'voices' of the women interviewed. Yet the views I express in this thesis are my own. I do not seek to speak for participants or to simply report their perspectives. Rather, I aim to contextualize participants' views and to consider them critically, guided by theoretical insights from feminist political economy scholarship discussed in the previous chapter.

### **Analysis of interviews**

The approach to analyzing the transcripts of the 42 interviews conducted has been directed by the research question at the heart of this thesis, namely how the health insurance systems of Ontario and New York affect women's health insurance experiences

in relation to breast cancer care. It has also been guided by issues emerging in the literature on women and health insurance, theoretical insights from feminist political economy scholarship, and practical advice about coding in qualitative research. Neither purely deductive nor purely inductive, the approach taken can best be described as iterative.

Initially, the plan was to use Nvivo to code the interview transcripts as this program appeared to offer a useful system for storing and classifying coded material. After a considerable amount of time and resources had been devoted to learning how to use Nvivo, however, it became clear that this program did not assist but rather hindered analysis of the interview transcripts. The distracting interface and the many functions of the program took attention away from the accounts to be analyzed. Using this program was tantamount to trying to make sense of a picture by using a kaleidoscope. It was more useful to analyze interviews using Word, the same program used in transcribing them.

The details of the approach to analysis were inspired by the recommendations of Bloomberg and Volpe (2012). While slowly transcribing the interviews each was listened to and read a minimum of three times to ensure accuracy. This was when the contents of each interview began to be considered in a detailed way and attention devoted to the major and minor ‘storylines’ in participants’ accounts. After Nvivo had been set aside, consideration was given to what had been learned about participants’ accounts through transcribing and reading them repeatedly. The goal became to develop tentative conceptual categories related to the research question. These categories subsequently

evolved and were joined by others emerging directly from later readings of the interviews, however they provided some initial direction for coding.

The comment feature in Word was used to record tentative codes next to blocks of interview text. This allowed consideration of codes in the context of each interview as a whole rather than as isolated fragments. Both lower level, more concrete codes, what Morse & Richards (2003: 118-120) describe as “topic” codes, as well as more abstract conceptual codes, which these authors refer to as “analytic” codes, were developed. Work was done on an ongoing basis to understand how these fit together. Although coding began with some tentative categories, initial codes were joined by others emerging directly from the interviews. All were developed and refined over time as the contents of each interview and the collection of interviews as a whole became increasingly familiar.

In moving from codes to themes, prose and diagrams were used to develop ideas about how codes related to each other in groups and how these groups of codes could be encompassed under the umbrellas provided by more abstract themes. These ideas were reworked on an ongoing basis. After ideas about potential themes and codes were developed, excerpts from the coded interviews became the basis for summary charts to organize coded material (Bloomberg & Volpe, 2012). As these charts were developed attention was given to rethinking and reworking the codes and their relationships in themes. The next stage was to write a first draft of the analysis. During this stage the coded interviews and the summary charts were repeatedly consulted. This manual approach had the advantage of allowing familiarity with the interviews as a whole as well as with their constituent parts.

### **Interview participant characteristics**

In order to protect the confidentiality of women interviewed in rural and small communities and to facilitate comparison of those in Lanark and Leeds Grenville in Ontario and St. Lawrence County in New York, this section provides an overview of select participant characteristics instead of individual profiles. All participants in this study were women who had lived in the United Counties of Leeds and Grenville or parts of Lanark County falling within the South East LHIN in Ontario, or St. Lawrence County in New York, during breast cancer treatment.<sup>13</sup> All had been diagnosed with breast cancer within the last eight years. In Ontario, three participants had been diagnosed with breast cancer more than once. In New York, only one participant had been diagnosed with breast cancer more than once. The dates of participants' latest breast cancer diagnosis varied, but all but one had been diagnosed within seven years of their interview. The remainder, a woman in St. Lawrence County, had been diagnosed eight years ago.

Beyond the date(s) of diagnosis, the specifics of participants' breast cancer diagnoses were not addressed in interview questions. I elected not to address these specifics due to the sensitive nature of the topic and the importance of ensuring that interviews would present minimal risk of emotional distress for participants. The focus of interview questions was women's *health insurance experiences*, not their experiences of breast cancer or breast cancer treatment. Based on information that many participants provided without being asked, however, type and stage of breast cancer, treatment, and stage of treatment did vary among study participants. It also appears that women differed

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<sup>13</sup> In Ontario, one participant had lived in Leeds and Grenville during treatment but subsequently moved out of the county but still within the South East LHIN.



in terms of their health status beyond breast cancer. Although not asked directly about their health, some participants discussed having conditions in addition to breast cancer, including vision impairment, hearing impairment, fibromyalgia, heart problems, arthritis, and high blood pressure.

The chart below provides an overview of select characteristics of the women interviewed in each jurisdiction:

Participant Summary Chart

Participant Characteristics	Ontario n = 20	New York n = 22
<b>Age</b>		
31-40	1 (5%)	0 (0%)
41-50	3 (15%)	6 (27%)
51-60	4 (20%)	8 (36%)
61-70	5 (25%)	7 (32%)
71-80	6 (30%)	1 (5%)
81-90	1 (5%)	0 (0%)
<b>Birthplace</b>		
Born in current country of residence	17 (85%)	19 (86%)
Born in another country	3 (15%)	3 (14%)
<b>Education</b>		
Primary	1 (5%)	1 (5%)
Secondary	2 (10%)	5 (23%)
Post secondary	17 (85%)	16 (73%)
<b>Marital Status</b>		
Married	14 (70%)	14 (63%)
Separated	2 (10%)	0 (0%)
Divorced	0 (0%)	7 (32%)
Widowed	4 (20%)	1 (5%)
<b>“Race”</b>		
“White” or “Caucasian”	16 (80%)	21 (95%)
“Canadian”/ “American”	4 (20%)	0 (0%)
“With colour”	0 (0%)	1 (5%)
<b>Approximate yearly personal income</b>		
Not clear/refused to answer	1 (5%)	2 (9%)
\$20, 000 or less	5 (25%)	11 (50%)
\$21,000-\$40, 000	8 (40%)	6 (27%)
\$41,000- \$60, 000	2 (10%)	1 (5%)
\$61,000- \$80, 000	3 (15%)	0 (0%)
\$81, 000- \$100, 000	1 (5%)	2 (10%)

<b>Approximate yearly household income</b>		
Not clear/refused to answer	1 (5%)	1 (5%)
\$20, 000 or less	1 (5%)	5 (23%)
\$21,000-\$40, 000	3 (15%)	6 (27%)
\$41,000- \$60, 000	1 (5%)	3 (14%)
\$61,000- \$80, 000	5 (25%)	3 (14%)
\$81, 000- \$100, 000	3 (15%)	1 (5%)
\$101,000- \$120, 000	0 (0%)	2 (10%)
\$121, 000- \$140, 000	2 (10%)	1 (5%)
\$141, 000- \$160, 000	3 (15%)	0%
\$161,000- \$180, 000	0 (0%)	0%
>\$180, 000	1 (5%)	0%
<b>Household</b>		
Lives alone	5 (25%)	3 (14%)
Lives with spouse	11 (50%)	10 (45%)
Lives with spouse and children	3 (15%)	4 (18%)
Lives with children	0 (0%)	4 (18%)
Lives with children and grandchildren	1 (5%)	0 (0%)
Lives with a parent	0 (0%)	1 (5%)

As described in the above chart, Ontario participants as a group were somewhat older than New York participants. While 64 percent of New York participants were between 41 and 60 years of age, 35 percent of Ontario participants fell within this age range.<sup>14</sup> In Ontario, 60 percent of participants were 61 years of age or older when interviewed, while in the New York 36 percent of participants were 61 years of age or older. More specifically, 45 percent of participants in Ontario were 65 years of age or older, while 27 percent of participants in New York were in this age group. Age has some health insurance implications. In Ontario, individuals age 65 or older are entitled to public coverage under the Ontario Drug Benefit, which supplements public coverage under the Ontario Health Insurance Plan (OHIP) by covering the cost of many prescription drugs and some other products (Ontario Ministry of Health and Long Term Care, 2013). In New York being age 65 or older is one way to qualify for public health

<sup>14</sup> Percentage totals are not exact due to rounding off.

insurance coverage under Medicare, parts of which provide hospital coverage, medical coverage and prescription drug coverage (U.S. Centers for Medicaid and Medicare Services, 2013: 13). Although the samples in Ontario and New York do not precisely mirror each other in terms of age, both nevertheless contain women of a range of ages, reflecting the experiences of women below age 65 as well as above.

In Lanark and Leeds Grenville as well as St. Lawrence County, the majority of women interviewed had been born in the country in which they currently resided (85 percent in Ontario compared to 86 percent of women interviewed in New York). This can be seen to reflect the populations of Lanark and Leeds Grenville as well as St. Lawrence County more generally, which, as previously explained, largely consist of people who are not immigrants. The “foreign born” make up only 4.1 percent of the population of St. Lawrence County (U.S. Census Bureau, 2013) and immigrants make up only 6 percent of the population in Lanark (Statistics Canada, 2013a) and 7 percent of the population in Leeds Grenville (Statistics Canada, 2013b). Women interviewed in Ontario had higher levels of education than those interviewed in New York, with 85 percent having some type of post-secondary education compared to 73 percent in New York. Yet of the women interviewed in St. Lawrence County, 96 percent had a high school education or higher, which made them a relatively well educated group compared to the population of their country more generally. In St. Lawrence County, only approximately 86 percent of the population has been found to have this level of education (U.S. Census Bureau, 2013). In both locations the majority of the women interviewed were married (70 percent in Ontario and 63 percent in New York), however more women in New York were

divorced (32 percent compared to none in Ontario) while more women in Ontario were widowed (20 percent compared to 5 percent in New York).

In Lanark and Leeds Grenville as well as St. Lawrence County, participants were overwhelmingly white. In Ontario, 80 percent of participants explicitly identified themselves as “white” or “Caucasian”. The remaining 20 percent described themselves as “Canadian”, which could be seen to reflect an assumption that being Canadian is synonymous with being white. In New York, all participants except one readily identified as “white” or “Caucasian”, while one woman identified herself as “with colour”. The predominance of white women in the interview samples can be seen to reflect the populations of the counties in which women were interviewed. In St. Lawrence County, approximately 93 percent of the population has been categorized as white (U.S. Census Bureau, 2013). In Lanark and Leeds Grenville, approximately 98 percent of the population has been categorized as “not a visible minority” (Statistics Canada 2013a; Statistics Canada, 2013b).

As a group, the Ontario participants in this study had higher incomes than those in New York. While half of New York participants described their approximate yearly personal income as \$20,000 or less, only 25 percent of Ontario participants did so. While 25 percent of Ontario participants had incomes between \$41,000 and \$80,000, only 5 percent of New York participants did. Approximate yearly household incomes were also reported as being higher in Ontario, where 40 percent of participants described approximate yearly household incomes between \$61,000 and \$100,000. In New York, half of the participants described approximate household incomes at or below \$40, 000 a

year. These differences in income level are in keeping with differences in household incomes between Lanark and Leeds Grenville and St. Lawrence County more generally. The median household income in St. Lawrence County has been calculated to be \$43,390 compared to \$56,951 in New York State (U.S. Census Bureau, 2013). In Leeds Grenville the median household income has been calculated to be \$64,600 (Statistics Canada, 2007a) and in Lanark this has been calculated to be \$66,328 compared to \$69,156 in Ontario more generally (Statistics Canada, 2007b).

In both locations, more women lived with a spouse than in other household arrangements (50 percent in Ontario and 45 percent in New York). A slightly higher percentage of women interviewed in New York lived with a spouse and children (18 percent compared to 15 percent in Ontario). A higher percentage of the women interviewed in New York lived with children as a single parent (18 percent compared to none in Ontario).

Interview participants in both locations varied in terms of their health insurance coverage. Variation in coverage was particularly striking in the 22 interviews conducted in New York, where health insurance histories changed from one person to the next. New York participants' health insurance coverage during treatment is summarized in the chart below. The following chart provides a 'snapshot' of participants' main forms of coverage during treatment:

New York Participants' Health Insurance Coverage During Treatment

Type of Coverage	New York Participants N = 22
<b>Private health insurance</b>	
Through own employment	5 (23%)
Through spouse/partner's employment	3 (14%)

Through spouse's employment with supplemental private health insurance	1 (5%)
<b>Total private health insurance</b>	<b>9 (41%)</b>
<b>Medicare + private health insurance</b>	
Through own employment	0 (0%)
Through spouse's employment	2 (9%)
<b>Total Medicare + private health insurance</b>	<b>2 (9%)</b>
<b>Medicare + Medicaid</b>	
Medicare + Medicaid Excess Income Program	1 (5%)
Medicare + Medicare Savings Program	1 (5%)
<b>Total Medicare + public program</b>	<b>2 (10%)</b>
<b>Medicaid</b>	
Medicaid Cancer Treatment Program	7 (32%)
Medicaid Cancer Treatment Program following a private plan	1 (5%)
Medicaid following Family Health Plus	1 (5%)
<b>Total Medicaid</b>	<b>9 (41%)<sup>15</sup></b>

During breast cancer treatment, nine participants relied on private health insurance obtained through their own employment or their spouse's or partner's employment to finance care. Four more participants relied primarily on Medicare to finance breast cancer treatment, with two of these women also holding private health insurance coverage and the other two supplementing Medicare coverage with coverage through a public program. Nine participants primarily relied on Medicaid during their breast cancer treatment.

In Ontario, all participants had OHIP coverage during their breast cancer treatment and at the time of their interview. Ontario participants' health insurance coverage during treatment is summarized in the chart below, which offers a 'snapshot' of participants' main forms of coverage during treatment:

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<sup>15</sup> Percentage totals are not exact due to rounding off.

### Ontario Participants' Health Insurance Coverage During Treatment

Type of Coverage	Ontario Participants N = 20
<b>Public coverage through OHIP</b>	<b>20 (100%)</b>
OHIP only	3 (15%)
OHIP + Ontario Drug Benefit	3 (15%)
OHIP + Ontario Disability Support Program	1 (5%)
<b>Public coverage only</b>	<b>7 (35%)</b>
<b>OHIP coverage + private health insurance</b>	
Through own employment	2 (10%)
Through spouse's employment	3 (15%)
<b>Total OHIP coverage + private health insurance</b>	<b>5 (25%)</b>
<b>OHIP coverage + ODB + private health insurance</b>	
Through own employment	3 (15%)
Through spouse's employment	3 (15%)
<b>Total OHIP coverage + ODB + private health insurance</b>	<b>6 (30%)</b>
<b>OHIP coverage + private health insurance through own employment + other private plan(s)</b>	
+ second private plan through spouse's employment	1 (5%)
+ second private plan private plan through spouse's employment + individually purchased plan	1 (5%)
<b>Total OHIP coverage + private health insurance through own employment + other private plan(s)</b>	<b>2 (10%)</b>

During breast cancer treatment, three Ontario participants had OHIP coverage only, three had OHIP and the Ontario Drug Benefit (ODB) and one had OHIP and public coverage through the Ontario Disability Support Program (ODSP). Five participants had OHIP coverage as well as supplementary private health insurance coverage obtained through employment (their own or a spouse's). Six participants had OHIP, ODB, and private health insurance coverage as well. Two participants had OHIP coverage as well as more than one supplementary private health insurance plan.

### **Strengths and limitations of methodological choices**

The present study focuses on understanding how the different health insurance systems in Ontario and New York affect women's health insurance experiences in relation to breast cancer care. It concentrates on contrasting these systems and their implications rather than on contrasting the experiences of individual women within each jurisdiction. The overall aim is to develop a feminist political economy analysis of the health insurance systems in question. In this context, the emphasis is on understanding the possibilities and constraints facing women in the systems under investigation and the political economic circumstances within which this occurs. Participants' experiences of breast cancer care are approached as offering valuable insight into the systems within which they occur.

All methodological choices involve limitations as well as strengths. There are limitations inherent in the sample of interview participants obtained in the present project. Due to recruitment challenges discussed above, referrals from past study participants played an important role in recruiting participants in Leeds Grenville in particular, contributing to the homogeneity of a sample in which older white women with higher incomes figure prominently. In St. Lawrence County, greater support for the study from a wider variety of sources meant referrals from past study participants played a relatively smaller role in recruitment. While participants were still predominately white, somewhat younger women and those with lower incomes are more represented.

In a number of ways, study participants in both Ontario and New York can be seen to represent a good case scenario within the health insurance systems in which they



live. All of the women I spoke with were healthy enough to complete an interview, having had access to breast cancer care. The bias of this study in focusing on living women able to access treatment first became clear to me when several New York participants with Medicaid coverage remarked that although they would have liked to help by finding other women for the study, all of the women they had known with breast cancer *had died*. In New York State, most of the participants who had Medicaid coverage accessed this coverage through the New York State Medicaid Cancer Treatment Program, which, as will be discussed at greater length in subsequent chapters, focuses on breast, cervical, colorectal and prostate cancer. Participants were thus eligible for this program precisely *because* they had been diagnosed with breast cancer. Had my research focused on another condition in studying women's health insurance experiences, those interviewed would not have had access to this particular Medicaid program and the public health insurance coverage it provided.

With interview participants almost exclusively identifying as white, the analysis provided focuses on the experiences of women of a privileged racialized group. While access to health insurance can pose problems for women of all racialized groups, African American and Latina women in the United States have, as previously discussed, been found to have even higher rates of uninsurance than their white counterparts (Ranji & Salganicoff, 2011: 14). Anti-racist feminist literature dealing with circumstances in Canada confirms relations of race that privilege white women operate in this context as well (Bannerji, 1995; Dua & Robertson, 1999; Razack, Smith & Thobani, 2010). In focusing predominantly on the experiences of white women in both Lanark and Leeds

Grenville in Ontario and St. Lawrence County in New York, this study addresses the experiences of particularly privileged women. This focus is useful as participants' experiences can be seen to reflect some of the best of what their respective health insurance systems offer women in terms of breast cancer care. Health insurance problems apparent even among women in this privileged group could thus be even more extreme for women of less privileged racialized groups.

The age of participants can also be seen to contribute to their privilege. Overall, 98 percent of study participants (all but one woman) were 41 years of age or older and 76 percent were over 50 years of age. As such, many participants belonged to a generation in which workers, particularly white workers, and their dependants enjoyed relatively good employment-based private health insurance coverage and retirement packages that that included private coverage. With employment-based private health insurance in decline (Gibson & Fuller 2006; Keene & Prokos, 2007; Glied, Jack & Rachlin, 2008), younger generations of workers and their dependants face more difficult circumstances. With structural changes resulting in more jobs in sectors of the economy that have low pay and offer rates for private health insurance coverage (Wyn et. al. 200; Cubbins & Parmer, 2001), younger workers and their dependants may not be able to look forward to hard won benefits enjoyed by previous generations.

In focusing largely on white women middle aged or older, this study not only focuses on a group of women particularly likely to be diagnosed with breast cancer (Canadian Cancer Society, 2013: 27; American Cancer Society, 2011: 2-4), but on those that have historically enjoyed good access to private health insurance coverage relative to

other women. This can be seen to bias this study towards understanding some of the best of women's experiences within the health insurance systems considered. It also means that challenges identified are best approached as 'the tip of the iceberg' when it comes to problems that the health insurance systems studied pose for women who use them.

The purposeful sampling strategy used in this qualitative study is clearly not effective for exploring all of the differences among women suggested by quantitative scholarship about health insurance or feminist political economy scholarship about women. This strategy does, however, provide rich data to which the critical insights of feminist political economy scholarship are applied in order to advance knowledge of two different health insurance systems and their consequences. Following Sandelowski's (1995: 182) advice on sampling for homogeneity as a way that for researcher working alone with limited resources to produce credible findings, my sampling choices focused on relatively homogenous samples of women from rural and small communities who were English speaking and who were largely white and not immigrants. All could broadly be considered working class in the sense that all either worked or had worked in the past or were in relationships with men who worked or had worked in the past, yet personal and household incomes varied. All of the women interviewed were age 40 or older. While sampling did not pursue *variation* among respondents, this does not mean that the *significance* of gender, race, class, age, language or immigration status is not considered in this study. Feminist political economy provides a robust framework in which to examine the significance of social relations in these areas in this study. Ultimately, focus on women privileged along a number of axes has the advantage of allowing for attention

to the experiences of women well positioned to encounter some of the best of what health insurance systems of Ontario and New York offer in terms of financing breast cancer care.

### **Quality in Qualitative Research**

Assessment of quality in qualitative research remains controversial. A key issue relates to whether concepts central in evaluating quantitative research—validity, reliability and generalizability—are relevant for qualitative studies, and if not, where appropriate alternatives are to be found. Those working in different qualitative paradigms take different positions on this matter, leading to differences in emphasis as well as terminology (Patton, 2002: 542). While those such as Lincoln and Guba (1986) propose naturalistic inquiry is best assessed with trustworthiness and authenticity criteria, authors such as Mays and Pope (2002), Tobin and Begley (2004) and Ritchie and Lewis (2003) maintain that validity, reliability and generalizability remain important concerns for qualitative researchers, but argue that these concepts need to be operationalized differently in the context of qualitative inquiry.

In attempting to navigate what have been described as the “turbulent waters of the meaning of quality in qualitative studies” (Ali & Yusof, 2011: 27), concerns about validity, reliability and generalizability have shaped the design, conduct and presentation of the results in this thesis. Traditionally, validity has been understood to refer to the “correctness” of a particular research reading (Ritchie & Lewis, 2003: 273). As Hammersely (1992: 69) suggests, “an account is valid or true if it represents accurately those features of the phenomena that it is intended to describe, explain or theorize”. In

research employing qualitative methods, validity concerns can be addressed through forms of triangulation. This may involve use of multiple methods, sources, analysts or theories to contribute to the validation of qualitative analysis (Patton, 2002: 555). The present study has utilized methodological triangulation in exploring the question of how the different health insurance systems in Ontario and New York affect women's health insurance experiences in relation to breast cancer care through drawing on review of relevant literature, attention to legislation and policy documents, and in-depth semi-structured interviews conducted with 42 women diagnosed with breast cancer. Use of these sources of information together arguably allows for a richer—and more valid—approach to answering the research question than would any of them alone.

Reliability is generally understood to relate to the replicability of research findings (Ritchie & Lewis, 2003: 270). The idea of replication is not well suited to qualitative research, however, in which the phenomena being studied *and* the contexts within which they are being studied are complex and dynamic and, therefore, unlikely to ever be precisely reproduced (Ritchie & Lewis, 2003: 270). Ritchie and Lewis (2003: 272) write of the importance of carrying out internal checks on the quality of data and interpretation and providing sufficient information for readers to assess the reliability of the research conducted. In the present study, time and care has been taken to maintain records of the material analyzed. To ensure accurate recording of participants' responses to interview questions, all interviews have been audio-recorded and supplemented by notes written both during and as soon as possible after each interview. Interviews were

carefully transcribed by this researcher in full and were listened to and read multiple times to ensure accuracy.

The material used in this study could, as Emerson, Fretz & Shaw (1995) suggest, be coded and interpreted differently by researchers with different theoretical orientations.. In this context, concerns about reliability demand the consistent application of theory in guiding the analysis of data in order to address the research question developed. Care has been taken to describe the research question, theoretical and methodological commitments, research methods, and procedures used in analysis in order to provide a transparent account of the research conducted.

Generalization may take empirical or theoretical forms. While empirical generalization addresses the application of research findings to populations and settings beyond the particular sample used in a study, theoretical generalization involves an attempt to contribute to advancing theoretical understanding (Ritchie & Lewis, 2003: 264). In quantitative research, claims about empirical generalization from samples to populations hinge on systematic random probability sampling. Random probability sampling has not been used in the present study, and empirical generalization is not possible. Instead, this project strives to examine the different health insurance systems in Ontario and New York through the lens provided by the materials analyzed. The aim is to contribute to advancing theoretical understanding of the health insurance systems that exist in the jurisdictions in question and to provide a rich picture through the lens of a comparative qualitative study. In this way, this study seeks to enrich understanding of

two health insurance systems in which public and private health insurance play different roles and their implications.

## **Conclusion**

In addressing the methodology and methods used in the present study, this chapter responds to calls for greater transparency about the theoretical and philosophical underpinnings of qualitative research (Coyne, 1997: 624). It also responds to interest in detailed accounts of sampling procedures and obstacles encountered along the way (Abrams, 2010: 547). The discussion is intended to provide readers with a basis for understanding why, how, when, where and from whom the data analyzed in subsequent chapters have been obtained, and the circumstances under which this occurred.

Guided by the theoretical insights from feminist political economy scholarship, the methodological underpinnings of the present study fall within a critical theory paradigm of qualitative research, reflecting the understanding that an historical, material reality can be discerned and interpreted, that both researcher and research participants are linked through their interaction, and that research is shaped by values rather than removed from them. As is characteristic of feminist research more generally the present project seeks to both valorize and problematize women's experiences, which are approached as an important yet not unproblematic source of information about the health insurance systems within which they occur.

Ontario and New York have been chosen as neighboring jurisdictions that feature different roles for public and private health insurance: while health insurance is largely public in the former, it is largely private in the latter. Within their respective countries,

neither New York nor Ontario exemplifies an extreme *laissez faire* approach to private health insurance. Both jurisdictions are relatively active in regulating the health insurance industry in the context of different health insurance systems that offer different roles for private coverage. In studying the health insurance systems in these jurisdictions, this thesis draws on secondary literature about histories of health insurance reform in Canada and the United States more generally, legislative and policy documents related to health insurance in Ontario and New York in particular, and in-depth semi-structured interviews with 20 women in Lanark and Leeds Grenville as well as 22 women in St. Lawrence County about their health insurance experiences in relation to breast cancer care.

This chapter has discussed sampling and recruitment as well as participant characteristics in order to explain the methodological choices made. Coming from rural and small communities, the English-speaking women interviewed for this study were forty years old or older and largely identified themselves as white. Few were immigrants, and most had some form of post-secondary education. While all could broadly be considered working class, personal and household incomes varied. In many ways these women can be seen to occupy positions of relative privilege—suggesting their experiences may reflect a good case scenario in exposing some of the best of what the health insurance systems in Ontario and New York offer women when it comes to financing breast cancer care. In addition to considering participants, this chapter has addressed strengths and limitations of the present study as well as matters of validity, reliability and generalizability in order to contextualize the analysis which follows.



## **Chapter 4: Health Insurance Reform in Canada and the United States**

### **Introduction**

This chapter considers the historical context that frames women's contemporary health insurance experiences in relation to breast cancer care in Ontario and New York. It begins by situating health insurance reform in Canada and the United States more generally within transformations in the broader political economy, tracing developments from the postwar period through subsequent decades with the rise and retrenchment of welfare states in the context of global capitalism. Against this background contemporary health insurance arrangements in Ontario and New York are examined as constituting the more immediate context for women's health insurance experiences. While the specifics of health insurance reform have historically differed in Canada and the United States, with the emergence and consolidation of neoliberalism as a political economic project reforms in both contexts have expanded the scope for commodified health insurance, responsibilized individuals in relation to coverage, and led to gradations in coverage.

### **Postwar Welfare States and Collective Commitments**

Canada and the United States have been described as "parting at the crossroads" when it comes to health care reform (Maioni, 1998). Yet health insurance histories in these countries reveal commonalities as well as differences when considered from a feminist political economy perspective. With the hardships of the Great Depression and the Second World War and the specter of popular unrest, the post-war period in both countries was marked by expansions in social programs that came to be associated with

the 'golden years' of the welfare state. As Brodie (2008: 150) explains, welfare states of the time "were grounded on the principle that the market could and should be regulated by democratic governments with the goal of maximizing economic and political stability and the collective welfare of all citizens." This compromise hinged on a particular relationship among households, states and markets. It was constructed on the basis of a male breadwinner family model that "both assumed and reinforced a position of dependency for women", as Porter (2003: 232) among others has observed. It must be noted that this particular breadwinner model was not universal; it did not capture the experiences of many poor, unmarried, lesbian or minority women among others (Brodie, 2008). Nevertheless, social policy reforms promoting collective responsibility helped all, albeit not necessarily in equal ways.

### ***Early Steps towards National Health Insurance***

Emphasis on collective responsibility characteristic of post-war welfare states in both Canada and the United States extended to the realm of health insurance. The 1930s had witnessed the growth of private health insurance as a commodity as well as calls for public health insurance programs in both countries (Hurley & Guindon, 2008: 11; Jost, 2009: 8-9). At the time, private health insurance was largely employer-based and involved non-profit and for-profit insurers. For-profit insurance grew, however, as rising post-war incomes promised attractive profits (Tuohy, 1999: 50-51). In the health insurance market of the 1940s, non-profit plans began to have difficulty competing with commercial insurers who brought an actuarial approach to bidding for contracts and offered lower premiums to lower risk groups (Geyman, 2008: 8). Coverage was far from

even. In gendered labour markets, women faced exclusion from employment-based private health insurance schemes and the majority of women were not employed full-time (Fuller, 1998; Dutton, 2007: 11, 49; Murray, 2007: 100).

Between 1945 and 1952 proposals for national health insurance were presented to the U.S. Congress with presidential support but did not pass (Boychuk, 2008: 42). In 1945, most regulation of the insurance industry was ceded to states in the *McCarren-Ferguson Act* (Geyman, 2008: 14). Subsequently, the 1946 *Hill-Burton Act* provided for federal cost-sharing of hospital reconstruction (Boychuk, 2008: 42). In Canada, the Federal government expressed interest in extending conditional grants to the provinces for health care costs at the 1945 Dominion-Provincial Conference on Social Reconstruction, yet this was seen to infringe on provincial jurisdiction. *The British North America Act* of 1867 had set out health care as a provincial responsibility while granting significant powers to raise revenue to Canada's federal government, making health care financing a source of conflict between these levels of government. In the face of disagreement, Saskatchewan nevertheless moved to implement universal hospital insurance in 1947. Subsequently, the National Health Grants Program of 1948 provided federal grants for provinces for a range of health related activities, including hospital construction (Taylor, 1978: 62-65).

Saskatchewan offers an important case of health insurance reform. Its status as the first province in Canada—and the first jurisdiction in North America—to introduce a universal system of hospital insurance is often attributed to the visionary leadership of provincial premiere Tommy Douglas of the Co-operative Commonwealth Federation

(CCF). A broader account must, however, consider the importance of grassroots activism in both electing Douglas and in supporting universal public hospital insurance despite opposition from medical and industry interests. As Ostray (2009: 277) writes, this change “was built on the back of a rural tradition of co-operative economic and institutional development which evolved in the first half of the 20th century in the province of Saskatchewan.” Seen from this perspective, Saskatchewan’s innovation is a popular achievement rather than merely a technical or bureaucratic success or a visionary leader’s achievement. Its success enabled the province to demonstrate a universal system of hospital insurance grounded in one’s relationship to the state rather than the market, effectively relieving individuals and households of the responsibility to obtain this form of coverage through employment or individual purchase. This success can be seen as offering inspiration for subsequent reforms in other Canadian provinces.

Throughout the 1950s, proposals for national public health insurance programs remained on political agendas in both Canada and the United States. In 1957, legislation for public health insurance for the elderly was introduced in the United States but failed to pass (Boychuk, 2008: 60). In Canada, in contrast, the *Hospital Insurance and Diagnostic Services Act* of the same year marked a significant turning point in the development of public health insurance. Instead of coverage for a specific population, such as the elderly or the poor, it covered services for all. Under the Act, provinces were to design and operate their own health care services with the federal government paying for half of specified services within hospitals provided federal standards were respected (Armstrong & Armstrong, 2003: 148). While reformers in the United States spent the

1950s struggling unsuccessfully to achieve public health insurance for part of the population, Canadians enjoyed public hospital insurance by the end of the decade. Significantly, this development was not ‘socialized medicine’, but rather “a government organized scheme to pay for existing services” (Armstrong & Armstrong, 2003: 52). The role of the Canadian state in providing public hospital insurance instead of presiding over commodified coverage can be seen to mark an important step in the development of the post-war welfare state in Canada, relieving individuals and households of responsibility for obtaining and maintaining this form of coverage through the market but leaving significant areas open for private health insurance coverage.

The 1950s were a time of expansion for the private health insurance industries in both Canada and the United States. Between 1950 and 1960, the number of Americans with health insurance grew from 77 to 132 million with commercial insurers gaining the largest share of this increase (Andrews, 2006 as cited in Geyman, 2008: 10). This growth in commercial insurance changed the competitive landscape, heightening the focus on profit (Geyman, 2008: 10). Some state governments began to look more closely at the practices of commercial insurers in this period and some took measures to limit the ability of insurers to cancel or refuse to renew policies (Jost, 2009: 13). Meanwhile, private coverage was making “considerable inroads” among middle class Canadians (Hurley & Guindon, 2008: 14).

### ***National Health Insurance Reform in the 1960s***

National health insurance reform occurred in both Canada and the United States in the 1960s. In 1965, Medicare was incorporated into the *Social Security Act* signed by

President Johnson. The “Medicare package”, as it is sometimes known, had three parts: Part A and Part B addressed hospital and physician insurance for social security beneficiaries, while Medicaid provided for federal grants to states for health insurance for low income individuals and nursing home care (Boyчук, 2008: 68-69). This reform reflected concessions to both service providers and private insurers. Not only was the existing delivery system left in place, but hospitals were allowed to nominate “fiscal intermediaries” for the administration of their participation in Medicare Part A and private insurers could be appointed as carriers of Medicare Part B coverage (Touhy, 1999: 60). Moreover, due to limitations on coverage, deductibles and co-payments, the program financed only part of the medical expenses of those insured (Marmor & Morone, 1983 as cited in Touhy, 1999: 61). The most significant health insurance reform in the post-war period in the United States thus provided for some public coverage for only some elements of the population—those least likely to obtain health insurance through the market. For the majority of Americans, this reform did not alter the primacy of commodified health insurance coverage. Nor did it relieve working individuals and households of the responsibility of getting and keeping health insurance through employment, relationships with those employed, or individual purchase of a private policy. Nevertheless, with the introduction of Medicare and Medicaid, the federal government became the largest single insurer of health care in the United States (Relman, 2007: 24).

In Canada, Saskatchewan again led the way with provincial medical insurance in 1961. This expansion of public health insurance coverage was a hard won

accomplishment achieved despite bitter opposition from detractors including the medical establishment and the insurance industry (Taylor, 1978). It was not until 1966 that national medical insurance legislation was introduced in Canada, again in the face of opposition from medical and industry opponents (Taylor, 1978). Under its auspices, the federal government would cover half the cost of physician services, of dental surgery done in hospitals, and of a limited number of services provided by other professionals. This Act was based on the principles of comprehensive coverage of physician services, universality, portability and non-profit administration (Armstrong & Armstrong, 2003: 54). As with hospital insurance in Canada, this reform addressed payment for medical care rather than its structure, leaving responsibility for services in provincial and territorial hands (Armstrong & Armstrong, 2003: 54). By 1972 each of the provincial and territorial plans had been extended to include these services (Taylor, 1978: 375).

Offering broad coverage for the population rather than targeted plans for limited groups, public health insurance dramatically expanded Canadians' access to care (Enterline et al. 1973 as cited in Armstrong et al., 2002: 15). For services deemed medically necessary, this reform eliminated "the commercial insurance concepts of deductibles, non-insurable conditions, limitations with respect to age, employment, or membership in groups and experience rating—all designed to protect insurance funds but frequently at the expense of individual hardship" (Taylor, 1987: 235). The framework created was crucial in establishing the idea of health insurance as a social right of citizenship in Canada. It was, moreover, important in working to "squeeze out virtually any form of private payment for most hospital, physician, and diagnostic services"

(Bhatia, 2010: 40-41). In extending universal public coverage to encompass not only hospital but medical care, the Canadian state worked to transform this coverage from a commodity to an entitlement, relieving individuals and households of the responsibility of obtaining and maintaining these forms of insurance through the market and promoting equality rather than gradation in health insurance coverage among Canadians. With these reforms, Canadians no longer needed to assume the burden of obtaining coverage for hospital and physician care through employment, relationships with those employed, or individual purchase. Instead, they could acquire coverage on the basis of legal residency whatever the state of their work, personal relationships, or income.

### ***Post War Welfare States, Health Insurance and Social Reproduction***

Although often portrayed as a compromise between capital and labour, welfare state policies of the 1960s can also be seen to address “crises in care” in which “networks of family and kin, church and community proved incapable of underwriting the social reproduction of mass industrial societies” (Brodie, 2008b: 168). Health insurance reforms in both Canada and the United States in this era can be seen as underpinned by recognition that the financial costs of health care were too onerous for individuals, households and charitable organizations to shoulder in the face of the vicissitudes of the market, but required state intervention via the establishment of public health insurance programs to combat gradations in coverage and associated inequalities in health care financing and access.

Canada’s public health insurance system took on a much broader role in redistributing the costs of illness, sharing these costs widely across society (Williams et



al. 2001: 12). Women—who made greater use of health services, were generally poorer than men and were less likely to have their own private insurance though paid work—benefited from the introduction of the public system (Armstrong & Armstrong, 2004: 15). The Canadian state's role in providing public coverage for hospital and physician care can be seen to relieve women in particular—as well as individuals and households more generally—from the responsibility of obtaining and maintaining these forms of health insurance through the market. Yet in limiting public coverage to these areas, reforms still left significant scope for private health insurance coverage—and pressure for individuals and households to obtain and maintain this coverage via employers, personal relationships with the employed, or individual purchase of private policies.

Health insurance reform in the United States in this period can also be seen to benefit women, more likely to number among the elderly and the poor. Yet the reforms undertaken there established a precedent for allowing public coverage for only those least able to obtain health insurance as a commodity in the market. This policy direction, which upheld commodified coverage as standard and placed responsibility on individuals and households to obtain it through the market, did far less to address gradation in health insurance coverage by providing only residual public coverage for a few groups. Reforms did far less than those in Canada to relieve individuals and households of responsibility in relation to health insurance coverage, which in all but exceptional cases continued to be tied to employment, personal relationships whereby coverage could be gained as a dependant, and individual purchase of private policies. Tensions within welfare states and public health insurance programs they gave rise to in this period were not resolved,

however, before new forces emerged to fundamentally alter the political economic landscape and with it the direction of health insurance reform in Canada and the United States.

### **Neoliberalism and Welfare State Retrenchment**

With liberalization of the international political economy, growing competition from newly industrializing countries in a context of globalizing capitalism and climbing energy prices, welfare states of the 1970s grappled with issues including rising unemployment, inflation, and burgeoning government deficits (Brodie, 2008b: 169). Solutions were sought in welfare state retrenchment and restructuring, with implications for health insurance reform in both Canada and the United States. In this context, the rise and expansion of neoliberalism as a political economic project came to shape social policy in both countries, with significant implications for the health insurance systems constructed during the post-war period.

In broad terms, neoliberalism can be understood as “a thoroughgoing adherence to the virtues of a market economy and, by extension, a market society” (Coburn 2001: 53). As a governing philosophy, it “prioritizes economic growth and market logics” and pursues these ends through strategies including privatization, deregulation, marketization, decentralization and fiscal austerity with respect to social expenditure (Brodie, 2008b: 169-170). From this perspective the role of the state is to support and expand the role of the market. In rejecting notions of collective responsibility and focusing on the figure of the “the self-sufficient and genderless individual” (Brodie, 2008: 154) as a consumer and the market actor, neoliberal ideals can be seen to present a fundamental challenge to the

theoretical underpinnings of post-war welfare states, the vision of collective responsibility advocated and the social entitlements extended. This can also be seen to challenge feminist theory and practice.

Yet while neoliberal dogma has been understood to eschew the significance of gender, as well as class, race and other social relations, neoliberal reforms were from their beginnings underpinned by a “complex restructuring of family-market-state relations” that left “women with major responsibility for addressing the needs of social reproduction in the home and for obtaining an income in the marketplace” (Porter 2003: 236). Thus while neoliberal rhetoric can be seen to minimize the importance of gender and other social relations, neoliberal reforms can be seen to intensify the significance of these very relations. As Brodie (2008: 161) has written,

as gendered income gaps grow, as migrant women and women of colour endure the weight of social exclusion...the iconic subjects of the new governing order, struggling to balance work–life commitments, discover that neoliberalism’s promise of choice and self-sufficiency are, although not named as such, masculinist constructs.

Neoliberal reforms can thus be seen as involving significant tensions.

### ***The Rise of Neoliberal Health Insurance Priorities***

With the rise of neoliberal priorities in Canada and the United States, health insurance reform began to take on a different meaning. In this environment public spending on health care, as on social programs more generally, came to be understood not as an objective to be pursued but a problem to be solved. In Canada, the federal government moved to redefine its role in financing public health insurance in the 1970s. In 1975, Ottawa unilaterally established upper limits for increases in the hospital and

medical costs it would share with the provinces. In 1977, the existing system of conditional grants was replaced with block transfers under Established Programs Financing (EPF). This move eroded federal power to make health care funding conditional on meeting national standards, with user fees and extra billing in some provinces undercutting the national principles of public health insurance in this period (Boychuk, 2008: 136-37). Weakening of the federal role in enforcing standards for public health insurance threatened the system in place without officially altering its principles, while user fees and extra billing challenged these principles in practice.

In 1970, the Nixon administration proclaimed rising health care expenditures a crisis in the United States and made the private sector the central focus of health care reform (Relman, 2007: 69). During this period large corporate entities came to dominate the health care sector within an increasingly entrenched system of employer-based private health insurance (Tuohy, 1999:71-72). The key Medicare reform issue of the era was not expansion but rather cost control (Boychuk, 2008: 73-75). An incremental expansion did occur in 1972, however, when Social Security amendments passed allowing people under age 65 with long-term disabilities and end stage renal disease to qualify for Medicare coverage, continuing the U.S. tradition of extending public health insurance only to those least able to obtain coverage through the market.

Meanwhile, Medicaid went from a “glittering symbol of the ‘Great Society’ to a political liability” (Stevens & Stevens 1974 as cited in Boychuk, 2008: 75). Reforms focused on restricting eligibility and reducing levels of payment, with states cutting back Medicaid programs (Boychuk, 2008: 75; Maioni, 1998: 167). In 1973, the *Health*

*Maintenance Organization Act* encouraged the development of private health maintenance organizations (HMOs) through federal grants, contracts and loans (Relman, 2007: 72). A kind of managed care organization, HMOs were ostensibly developed to address escalating health care costs.<sup>16</sup> To ensure cost control and in most cases, be profitable, however, these organizations limited the freedom of users to consult physicians and used financial incentives and penalties to encourage physicians to practice in “a cost-effective style” (Relman, 2007: 73). In the 1970s, state coverage mandates, which required private health insurers to cover “specific persons, services or providers” become more common (Jost, 2009: 13). In 1974, however, the *Employee Retirement Income Security Act* (ERISA) changed the regulatory environment by exempting benefit programs provided by employers, including health insurance, from state regulation (Boychuk, 2008: 76).

### ***The Entrenchment of Neoliberal Health Insurance Priorities***

The advent of the Reagan administration in 1980 effectively removed national health insurance from the political agenda in the United States. In 1983, this administration introduced a system of “prospective payment” for hospitals under Medicare as a “cost-containment” measure (Tuohy, 1999: 73). In contrast to the traditional fee-for-service system, the prospective payment system saw hospitals paid a set amount for each Medicare patient treated depending on the diagnosis. In 1986, the *Emergency Medical Treatment and Active Labor Act* (EMTALA) required hospitals participating in Medicare to screen and stabilize all persons using their emergency rooms

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<sup>16</sup> Managed care sees insurers assume “some degree of legal responsibility for both the financing and management of care delivery” (Weiner et al., 2008: 1109).

regardless of ability to pay. The same year, the *Consolidated Omnibus Budget Reconciliation Act* (COBRA) contained provisions allowing those who lost jobs to continue with their health plan for 18 months. At the state level there was a variety of private health insurance reform efforts in the 1980s and early 1990s, which included restrictions on the use of pre-existing condition limitations and various types of community rating, however in several cases proposals were scaled back or not implemented (Tuohy, 1999: 85). Such efforts suggest that by this time practices within the private health insurance industry—practices better suited to increasing the wealth of investors than to offering people protection from health care costs—had become a matter of concern for some policymakers. Yet reforms restricting profit-making in private enterprise ran contrary to neoliberal idealization of the role of the market, and more specifically to the priorities of an increasingly powerful industry.

The late 1980s and early 1990s was a time of change in the private health insurance industry in the United States. Private managed care plans became increasingly popular with employers focused on containing health insurance costs, many older indemnity type mutual and not-for-profit insurance companies were converted to for-profit managed care plans, and acquisitions and mergers created large health insurance firms (Relman, 2007: 75). Between 1995 and 2005, more than 400 mergers took place involving insurers and managed care organizations, with industry giants gaining leverage (Geyman, 2008: 15). Changes in state regulation of private health insurance thus occurred alongside growth and consolidation within an increasingly powerful health insurance industry. While regulatory efforts in this period can be seen to address some of the more

egregious practices of a profit-hungry industry, piecemeal reforms did not fundamentally challenge the primacy of commodified health insurance in the United States or the growing power of the health insurance industry. Nor did reforms alter the burden of responsibility on most individuals and households to obtain coverage through the market. Indeed, cuts to, and restrictions on, the public health insurance coverage offered through Medicaid further restricted the already limited role of this public health insurance program in offering protection from the costs of ill health.

In the context of separatist sentiment in Quebec and practices of extra-billing and user fees in some provinces, Canada's federal government adopted the *Canada Health Act* in 1984. Replacing previous legislation on hospital insurance and medical insurance, this Act "restated, clarified, and tightened up the conditions of the two existing programs" (Boychuk, 2008: 138). It featured five criteria that provincial and territorial health insurance plans needed to meet in order to qualify for federal funding: public administration, comprehensiveness, universality, portability and accessibility. Although penalties for violation of these criteria were discretionary, dollar-for-dollar reductions in federal funds were mandated for revenue collected in provinces through user fees and extra billing (Boychuk, 2008: 139). The *Canada Health Act* has been assigned tremendous symbolic significance (Tuohy, 1999: 90; Armstrong & Armstrong, 2008: 33), and deservedly so given its importance in setting out basic criteria for public health insurance in Canada. Yet while the Act set standards, funding cuts in the context of neoliberal pressure for public sector austerity worked to undermine the very system it aimed to consolidate.

In the 1980s and 1990s, the role of Canada's federal government in health care frayed as public sector spending cuts were prioritized in keeping with neoliberal ideals. From 1983-1993, the Conservatives in power worked to limit federal financial contributions to provincial health insurance plans (Tuohy, 1999). Upon gaining power, the federal Liberals introduced the Canada Health and Social Transfer (CHST) in 1995, replacing the EPF and the Canada Assistance Plan (CAP) with a single—significantly reduced—block payment for health, education and social services. This block payment scheme further eroded federal power to enforce national health insurance standards. In this context, cutbacks and restructuring occurred at the provincial level with governments embracing various forms of privatization.

Literature on privatization in health care in Canada devotes particular attention to trends visible by the 1990s (Armstrong et al., 1994; Armstrong et al., 2000; Armstrong et al. 2002; Gilmour, 2002; Armstrong & Armstrong, 2003). Although the nature and extent of privatization differed across the country, patterns have nevertheless been identified (Armstrong & Armstrong, 2008; Armstrong et al. 2002). Privatization in the costs of health care, of central concern in this chapter, occurred through a range of strategies. One strategy was delisting: the selective de-insuring of services formerly insured under provincial health insurance plans (Gilmour, 2002). Meanwhile, growing emphasis on care outside of hospitals in the context of cuts to hospital budgets and technological change increasingly placed health care and its financing beyond the purview of the *Canada Health Act* and its equalizing criteria (Armstrong et al., 2002). As Armstrong and Armstrong (2008: 121) point out, privatization in costs also occurred through government



failure to fund services needed to address new issues. Collectively, such measures weakened public health insurance coverage in Canada, effectively transferring increasing responsibility for health care costs to individuals and households. This can be seen as transferring these costs to women in particular, given women's greater use of health care (Forget et al., 2005) and prominence in unpaid care giving (Armstrong & Armstrong, 2004). Meanwhile, moves to privatize health care costs expanded the scope for private health insurance coverage as a commodity in Canada. The growing role of private health insurance coverage in supplementing public health insurance plans can be seen to increase pressure on individuals and households to take responsibility for obtaining and maintaining this supplementary coverage through employment, personal relationships with the employed or individual purchase in order to finance health care not publicly insured.

In the 1990s, the issue of national health insurance reemerged in the United States in the face of escalating health care costs, rising private health insurance costs for employers, and growing numbers of un- and under-insured Americans (Tuohy, 1999: 73). Against the background of an economic downturn, this period saw the rise and fall of the *Health Security Act* under the Clinton Administration. Clinton's market-oriented approach to reform in 1993-4 was based on "managed competition" and sought to "further privately run and financed managed care" (Skocpol, 1997: 15). Although this Act has been characterized as "designed to get around and through the anti-government and fiscal legacies of the Reagan era", it became a target of anti-government protest itself and was eventually defeated (Skocpol, 1997: 178). Significantly, this ill-fated reform did

not seek to rollback the role of the market in health insurance, but rather to extend its reach.

More limited reforms occurred in the United States over the course of the 1990s. Nationally, the 1990 *Breast and Cervical Cancer Mortality Prevention Act* established the Centers for Disease Control and Prevention's National Breast and Cervical Cancer Early Detection Program to provide breast and cervical cancer screening exams to underserved women, including older women, those with low incomes, and members of racial and ethnic minority groups (Centers for Disease Control and Prevention, 2013a). In 1996, the *Health Insurance Portability and Accountability Act* (HIPAA) restricted use of pre-existing conditions in some private health insurance coverage determinations and set standards for medical records privacy (U.S. Department of Labor, 2004; Centers for Disease Control and Prevention, 2010). The same year, the *Personal Responsibility and Work Opportunity Act* delinked Medicaid and cash assistance eligibility. In 1997, the *State Children's Health Insurance Program* (S-CHIP) was enacted to allow states to extend Medicaid coverage to uninsured children in low income families that earned too much to otherwise qualify for Medicaid (Branch et al., 2003). These reforms continued the U.S. tradition of providing public health insurance for only some of the most vulnerable while according private health insurance a primary role in financing health care for the working population. The “Medicare + Choice” provision of the 1997 *Balanced Budget Act* established Medicare payment for provider-sponsored managed care organizations and contained specific financial rules for these organizations (Jost, 2009: 11). This development carved out a larger role for private health insurers in one of

the country's most important public health insurance programs, further expanding the role of the market in health insurance coverage in the United States.

The 1998 *Women's Health and Cancer Rights Act* provided specific protections relevant for women using health insurance in relation to breast cancer care. This Act required coverage for post-mastectomy breast reconstruction, applying to group health plans, health insurance companies, and HMOs where the plan in question covered costs for mastectomy. It specifically addressed:

- (1) reconstruction of the breast on which the mastectomy has been performed;
- (2) surgery and reconstruction of the other breast to produce a symmetrical appearance; and
- (3) prostheses and physical complications all stages of mastectomy, including lymphedemas; in a manner determined in consultation with the attending physician and the patient (Women's Health and Cancer Rights Act, 1998: H11161)

As Wilkens and Alderman (2004: 148) have cautioned, however, "Due to the lack of provisions addressing payer compliance and enforceable penalties for infractions, the law has more bark than bite." Coverage mandates increased in this period, as state governments moved to further regulate the health insurance industry (Jost, 2009: 14). Whereas in 1981, only one state (Illinois) required insurers to cover mammograms, by the end of May 2000, the District of Columbia and all states except Utah had mandated health insurance coverage for mammograms for breast cancer screening for women covered by health insurance (Centers for Disease Control and Prevention, 2000). Health insurance reform in the United States in this period thus continued in a piecemeal fashion in the context of support for commodified health insurance coverage for most of the

population. While mandates sought to enforce some similarities in coverage for some specific procedures, gradation in coverage continued alongside un- and under-insurance.

### ***Neoliberalism, Social Reproduction and Health Insurance Coverage***

Health care reform in both Canada and the United States from the 1970s through the 1990s can be seen as one aspect of a broad attempt to reshape state, market and household involvement in social reproduction along neoliberal lines in the context of globalizing capitalism. As Braedley and Luxton (2010: 15) explain, proponents of neoliberalism built into its theory and implementation an “insistence that individuals and their families are responsible for social reproduction.” This involves “pressure on families, and given women’s role within the home, on women in particular, in terms of being able to both meet financial needs and look after domestic concerns”, as Porter (2003: 241) has observed. In this period, cuts to public health insurance funding, moves to roll back public coverage, and failures to expand public coverage to new populations in the United States or to new services in Canada can all be seen to privatize costs related to health care financing. Such moves strengthened the roles of private coverage as well as the health of insurance firms profiting from the sale of this commodity. Meanwhile, these measures placed increasing responsibility on individuals and families to acquire and maintain health insurance coverage through the health insurance industry whether via employment, relationships with those employed, or individual purchase of private health insurance policies. These trends were more extreme in the United States in the context of a system centered on primary private coverage and residual public coverage.

Nevertheless, they were also apparent in Canadian efforts to undermine the coverage achieved through the country's universal public health insurance system.

### **21<sup>st</sup> Century Reforms and the Normalization of Neoliberal Priorities**

The normalization of neoliberal social policy priorities can be seen to underpin health insurance reform in the Canada and the United States in the 21<sup>st</sup> century. In the United States, market-oriented reform in health insurance continued to advance with some limited expansions in public health insurance coverage. With the restrictions imposed in HMO-style managed care beginning to chaff and exposés of industry abuses inciting controversy, a less restrictive form of managed care, known as “preferred provider organization” (PPO) insurance came to be promoted by the health insurance industry (Relman, 2007: 77).<sup>17</sup> The industry, which continued to oppose state mandates, brought increasing pressure to bear, with fewer state mandates adopted and some repealed in this period (Jost, 2009: 16).

In 2000, the *Breast and Cervical Cancer Prevention and Treatment Act* gave states the option to extend Medicaid coverage to eligible women screened for and found to have breast or cervical cancer, including precancerous conditions, through the National Breast and Cervical Cancer Early Detection Program (Centers for Disease Control and Prevention, 2013b). This option was subsequently taken up by all states, however some set more restrictive eligibility requirements than others and per capita spending on

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<sup>17</sup> As explained by Relman (2007: 77), in PPO plans members select a primary care provider from a panel of physicians approved by the insurance plan, but are free to consult specialists considered preferred providers without advance approval from their primary care physician.

treatment varied (Salganicoff, Ranji & Beamesderfer, 2012: 5). This extension of public health insurance coverage for breast cancer treatment was thus both limited and uneven.

The 2003 *Medicare Prescription Drug, Improvement, and Modernization Act* established Medicare Part D, an outpatient prescription drug benefit. Outsourcing the administration of this benefit to private insurance companies, it specifically empowered them—not Medicare—to negotiate prices with drug companies and brought large profits for drug manufacturers (Relman, 2007: 85). The Act included funds for private Medicare managed care plans, now known as “Medicare Advantage” plans. It also authorized tax subsidies for health savings accounts (HSAs) coupled with high deductible health plans.<sup>18</sup> While the Act did not preempt state regulation of these plans, it did specify that tax incentives would only be available in states that permitted HSAs and thus encouraged states to allow them (Jost, 2009: 24). Described as the “Medicare Middleman Multiplication Act” (Krugman, 2007: A17), this Act has been assessed as “largely designed to benefit the corporate health care sector without containing costs or significantly reducing the threat of rising health care costs to the economic security of current and future retirees” (Polkiva & Kwak, 2008: 340).

Subsequently, the 2005 *Deficit Reduction Act* increased flexibility for states’ Medicaid programs (Coughlin & Zuckerman, 2008). States moved to limit costs by changing benefits and eligibility (Relman, 2007: 86). Some introduced fees such as

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<sup>18</sup> As defined in plain language by the IRS (2012: n.p.), a “health savings account” is a “tax-exempt trust or custodial account that you set up with a qualified HSA trustee to pay or reimburse certain medical expenses you incur”. To qualify, one must be covered under a “high deductible health plan”. This type of plan features a “higher annual deductible than typical health plans” and a “maximum limit on the sum of the annual deductible and out-of-pocket medical expenses that you must pay for covered expenses” (IRS, 2012: n.p.).

premiums and co-payments, privatizing costs for those enrolled (Coughlin & Zuckerman, 2008). Several directly privatized parts of their Medicaid programs through reliance on private managed care plans. Other measures included the creation of public-private partnerships in the employer-based insurance market, premium assistance in which states subsidized individual's employer-sponsored insurance premiums, new Medicaid only public-private insurance products, other types of public-private partnerships, and health savings accounts for Medicaid beneficiaries (Coughlin & Zuckerman, 2008: 225-29). Changes to both Medicare and Medicaid in this period can be seen to increase the involvement of the private (for profit) sector in the main forms of 'public' health insurance coverage available in the United States. Collectively, these reforms point to the role of the federal and state governments in using public health insurance programs as new markets for the health insurance industry, in keeping with neoliberal emphasis on state support for markets.

By the late 2000s, health insurance in the United States had again reached a crisis in the face of rising premiums and declining coverage. Geyman (2008: xv) went as far as to describe the health insurance industry as "dying" due to increasing costs and decreasing access to health insurance for more and more Americans. In this context, reform strategies came to focus on decreasing the ranks of the uninsured, but largely ignored the issue of underinsurance "providing little security against the costs of necessary health care" (Geyman, 2008: 22). Yet underinsurance had become an important problem. In a study of illness and injury as contributors to bankruptcy, Himmelstein and colleagues (2005) found roughly three quarters of participants *had* insurance at the onset

of their illness, underlining the failure of health insurance policies to adequately protect the insured from financial hardship.

### ***Overt Market-Oriented Reform in the United States***

National health care reform in the United States re-emerged as a priority under President Obama with the 2010 *Patient Protection and Affordable Care Act* (ACA). Popularly known as ‘Obamacare’ by both proponents and opponents, this Act has been characterized as “designed to accomplish comprehensive market-based health reform” (American Public Health Association, 2012: 1). Infamous for its length and complexity, the ACA has been summarized as setting out reforms including:

- Medicaid expansion to 138% of the federal poverty level for those under age 65;
- Creation of health insurance exchanges through which those who do not have access to public coverage or affordable employer coverage can purchase insurance, with premium and cost-sharing credits available to some;
- New regulations on all health plans to prevent health insurers from denying coverage and from charging higher premiums on the basis of factors such as health status and gender;
- The requirement that most individuals purchase health insurance beginning in 2014;
- Penalties for some employers that do not offer affordable coverage to their employees (The Henry J. Kaiser Family Foundation, 2012c).

The ACA was subject to legal challenges (American Public Health Association, 2012: 1), however the U.S. Supreme Court ultimately upheld its constitutionality in 2012. Different



provisions come into force at different times, with the bulk of change scheduled between 2010 and 2014 (U.S. Centers for Medicare and Medicaid Services, n.d.; The Henry J. Kaiser Family Foundation, 2013e.).

The American College of Obstetricians and Gynecologists (2012: 2) has suggested the ACA “has the potential to improve access to care for millions of underserved women” across the United States.. The National Women’s Law Center (2013) has highlighted its role in offering women greater protections against insurance company abuses. Provisions that will take effect in 2014 have been praised for working to stop insurance companies from denying women coverage on the basis of pre-existing conditions, end the practice of charging women more for coverage than men, and ensuring insurance companies include maternity coverage in health plans (National Women’s Law Center, 2013). This organization has also highlighted the importance of the ACA in improving women’s access to affordable preventative care, making it easier for children and young adults to get and keep health insurance, offering senior women more affordable access to services, and making health care more affordable beginning in 2014 (National Women’s Law Center, 2013). The Act is expected to expand coverage for breast cancer screening in particular through reducing the number of uninsured people and by requiring private insurance and Medicare to cover breast and cervical cancer screening without cost-sharing (Levy et al., 2012). Services relevant to breast cancer care to be covered without cost-sharing include: mammography for women 40 or older, genetic (BRCA) screening and counseling, and preventative medication counseling (The Henry J. Kaiser Family Foundation, 2012d).

While the ACA is expected to require that health insurance in the United States better serve more women, it is vital to recognize that it does not fundamentally alter the market-centered health insurance system in place. With the primacy of private health insurance in financing health care for the working population long established, the ACA bolsters its role and extends its reach. While the Act does expand Medicaid, it nevertheless requires most people to buy private policies and in some cases offers public subsidies for this coverage, channeling additional people and money into the country's market-driven health insurance system (Himmelstein & Woolhandler, 2010; Light, 2011). If the health insurance industry was indeed dying, as Geyman (2008) contended, the ACA can be seen as providing a complex life support system through an infusion of public funds, regulation and an "individual mandate" requiring most Americans to purchase private policies. Far from challenging the primacy of commodified health insurance in the United States, the ACA entrenches it, holding most individuals and households responsible for obtaining and maintaining coverage through the market via employment, relationships or individual purchase of a private plan. While the Act is expected to result in more coverage for more people, by no means does it promise comprehensive coverage for all.

### ***Covert Market-Oriented Reform in Canada***

With reforms proposed to reinvigorate the federal role in public health care in Canada by the late 1990s, federal initiatives in the 21<sup>st</sup> century included some increases in funding (Boychuk, 2008: 148). In the 2000 Health Accord and the 2003 Accord on Health Care Renewal, federal-provincial negotiations centered on planning for health

system renewal (Health Canada, 2006). Increased funding can be seen to strengthen services insured under public health insurance programs. Yet despite official commitment to the *Canada Health Act* by political leaders and energetic proclamations of support even from representatives of the private health insurance industry in Canada (Canadian Life and Health Insurance Association, 2009), more covert moves to undermine the foundations of the Act have become apparent. As Bhatia (2010: 38) has underlined, despite the relative stability of the institutional structures and networks in this era “ideational factors, particularly discursive practices and strategies, have had an important role to play in shifting the consensus away from health care as a right of social citizenship”—the idea that has underpinned Canada’s public health insurance system since its inception.

With the enduring popularity of public health insurance in Canada (Nanos Research, 2011; Soroka, 2011), those bent on a larger role for commodified coverage have seldom challenged it overtly. Having learned from the failure of heavy-handed propaganda to dissuade Canadians from supporting public health insurance in the 20th century, efforts to undermine the public health insurance system in the 21<sup>st</sup> century have become more sophisticated. Thus the Canadian Life and Health Insurance Association (2009: ii), in advocating for a larger role for the private health insurance industry, recommends not the immediate demise of public health insurance but that “governments seize more opportunities for strategic partnering with the private sector” in the interests

of moving “towards a sustainable, accessible, quality public health care system”<sup>19</sup>. This rhetoric, which casts Canada’s current public health insurance system as unsustainable and the health insurance industry as a helpful partner, effectively directs attention away from the true *raison d’être* of the health insurance industry in Canada and elsewhere: profit-making.

Those seeking to expand the role for private health insurance in Canada have turned to the courts to challenge legislative restrictions on private coverage. This strategy met with success in 2005, when the Supreme Court of Canada ruled in *Chaoulli v. Quebec* that the province’s legislation banning private health insurance for publicly insured services was in violation of the *Quebec Charter of Human Rights and Freedoms* (Flood, Roach & Sossin, 2005). The Quebec government subsequently allowed private coverage to duplicate public coverage for a limited number of procedures in certain circumstances (Bhatia, 2010: 54). The ruling inspired similar challenges in other provinces, including Ontario (Flood & Xavier, 2008; Picard, 2012).

Collectively, these cases center on the idea that prohibiting purchase of private health insurance for publicly insured health care unjustly interferes with individual rights and freedoms. At their core, they can be seen as attempting to fundamentally shift understandings of social rights “away from collective obligations and toward competing claims of individuals” (Bhatia, 2010: 38). The abstract individual at their center calls to mind “the self-sufficient and genderless individual” discussed by Brodie (2008: 154) as the archetypal neoliberal consumer and market actor. While many of these cases remain

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<sup>19</sup> “Towards a Sustainable, Accessible, Quality Public Health Care System” is in fact the title of the 2009 Canadian Life and Health Insurance Association report discussed.

to be decided, their existence has contributed to normalizing debate about private payment for health care in Canada and to the creation of a higher profile for private health insurance in particular.

### ***Tensions in Health Insurance Reform and Social Reproduction in the 21<sup>st</sup> Century***

Health insurance reform in Canada and the United States in the 21<sup>st</sup> century has occurred within the context of a broader shift in responsibility for social reproduction. This shift has involved normalizing the transfer of responsibility for social reproduction to individuals and households as well as the expectation that state support for the invisible hand of market can ameliorate difficulties thereby created. Far from offering a new direction, reforms have served to entrench neoliberal policy priorities as the unquestionable norm. Yet, as Brodie (2008b: 171) has observed “pressures on social reproduction have intensified as neoliberal governments divert ever more caring responsibilities from the public sphere to the private sphere.” This author has cautioned that advanced liberal democracies, including Canada and the United States, are “poised at the edge of a crisis in social reproduction” (Brodie, 2008b: 183), a warning that has also been extended by others (Fudge & Cossman, 2002a, 2002b; Peterson, 2003; Luxton, 2006a; Bezanson, 2006a, 2006b; Vosko, 2006; Katz, 2008). Collectively, health insurance reforms in Canada and the United States can be seen to contribute to this situation through efforts to normalize commodified coverage, the burden of responsibility assumed by individuals and households in relation to obtaining and maintaining it, and gradation in coverage among citizens unequally positioned in relation to the market.

Underpinned by transformations within the broader political economy, health insurance reform in Canada and the United States has been a long, complex and controversial process. From similar beginnings, reforms in the post-war period brought universal public health insurance coverage for medically necessary hospital and physician care to Canadians, and a far more limited system of residual public health insurance for some groups in the United States. While subsequent reforms in Canada largely focused on consolidating existing public health insurance gains rather than expanding on them, reforms in the United States focused on extending public health insurance to marginalized groups in an incremental way and piecemeal regulation of an increasingly powerful private health insurance industry. Yet with the rise and entrenchment of neoliberal priorities, both systems were subjected to public sector austerity measures and reforms that advanced the role of the market in health insurance and responsibilized individuals and households in relation to coverage.

In the United States, reforms came to focus largely on regulating, protecting and expanding the existing system of commodified health insurance. Public health insurance continued to be a last resort reserved for those unable to gain coverage through the market. For most, obtaining and maintaining health insurance coverage through the market, whether via employment, relationships with those employed, or individual purchase of a private policy, became entrenched responsibilities of individuals and households. In this context, gradations in coverage among those unequally positioned in relation to the market continued to be the rule rather than the exception.

In Canada, ongoing support for public health insurance in theory came to be undercut to some extent in practice by austerity at federal and provincial levels, failures to enforce adherence to *Canada Health Act*, forms of privatization in health care costs and legal challenges expanding the role of private health insurance and normalizing debate about its role in financing health care. These developments can be seen not only as *not* challenging the scope for private health insurance within Canada's health care systems but as expanding this scope incrementally. Longstanding focus on whittling down rather than expanding public health insurance coverage in Canada and gradual increases in the scope of private coverage have further responsibilized individuals and households in relation to supplementary private health insurance—albeit to a lesser extent than south of the border.

While the nature of individual and household responsibilities in relation to private health insurance coverage can be seen as broadly similar in Canada and the United States in the sense of needing to obtain and maintain private coverage through the market via employment, relationships with the employed, or individual purchase of a private policy, they differ significantly in scope. As public health insurance in Canada has continued to operate as a primary form of health care financing, private health insurance and the burden of responsibly entailed is accorded a supplementary role rather than the primary one accorded in the United States. Thus Canadians have not been responsibilized in relation to health insurance coverage to the extent Americans have been. Yet while Canada's provincial and territorial systems of universal public health insurance for medically necessary hospital and physician care continue to present a contrast to reliance

on private health insurance and restricted public coverage in the United States, both systems have nonetheless been marked by market-oriented priorities characteristic of neoliberal reform.

### **Contemporary Health Insurance Systems in Ontario and New York**

Shaped by health insurance reforms enacted in the context of welfare state transformation in Canada and the United States, the contemporary health insurance systems in Ontario and New York form the more immediate context for the present study. Having considered broad trends toward commodified health insurance, responsibilized individuals and households in relation to coverage and gradation in coverage offered under different programs and policies unfolding over time, this section examines the impact of these trends in addressing the state of health insurance in Ontario and New York. As a detailed account of all aspects of all programs and policies is beyond the scope of this section, attention is devoted to central features of forms of health insurance useful for understanding participants' accounts of their health insurance experiences in relation to breast cancer care.

#### ***New York: Medicaid***

Women make up nearly 56 percent of Medicaid beneficiaries in New York State (The Henry J. Kaiser Family Foundation, 2013b). Since the inception of New York State's Medicaid program in the 1960s, administration has been shared by levels of government. The federal government is involved in setting rules, issuing State Medicaid Director Letters, the State Plan approval process and waivers, and oversight through central and regional offices (New York State Department of Health, 2010a). The New



York State Department of Health is responsible for policy development, ensuring compliance with federal requirements and administration of New York Medicaid (New York State Department of Health, 2010a: 5). The state has traditionally downloaded significant financial and administrative responsibilities to the county level. County duties have included processing applications, determining eligibility for initial coverage and recertification, enrolling beneficiaries in Medicaid managed care and authorizing the use of services such as non-emergency transportation (New York State Department of Health, 2010a: 5). Medicaid managed care began in New York on a voluntary basis in 1988, but in 2007 state law authorized the mandatory enrollment of certain beneficiaries into managed care plans. By 2010, nearly 69 percent of New York Medicaid beneficiaries were enrolled in managed care (New York State Department of Health, 2010a: 20). The same year Medicaid was the single largest mandated budget item in every county in the state (New York State Association of Counties, 2010: 3). In 2010, legislation was enacted to transfer administrative responsibilities involved with Medicaid to the state level, with the transfer to be complete by 2016 (New York State Department of Health, 2010a: 2)

Although typically referred to in the singular, New York State Medicaid is not one program but several. With coverage varying by population, income level and benefits, eligibility differing by population group, and several different application pathways, it is extraordinarily complex. The program includes Medicaid Medical Assistance, as well as Family Health Plus, Child Health Plus, Emergency Medicaid, Medicaid Prenatal Care Services, Family Planning Benefit Program, the Medicaid Buy-In Program for Working People with Disabilities, the Medicaid Cancer Treatment Program

and the Medicare Savings Program. It also includes the Medicaid Excess Income Program. Types of Medicaid coverage relevant for understanding participants' experiences using health insurance in relation to breast cancer care are discussed below.

#### *Medicaid Medical Assistance*

In New York State, Medicaid Medical Assistance, also known as 'regular' or 'county' Medicaid, is available to children, caretaker adults and the elderly and disabled, as well as single adults and childless couples (at lower income levels) (De Jung, 2009). The types of services covered under this form of Medicaid include: hospitalization, outpatient care, mental health care, dental care, physical therapy, diagnostic tests, home care, medical equipment and prescription drugs. This type of Medicaid may provide for up to three months of retroactive coverage for unpaid medical bills (New York State Department of Health, 2013a). Individuals have traditionally applied for this form of coverage through local departments of social services (New York State Department of Health, 2013a).

#### *Medicaid Excess Income Program*

This program is sometimes referred to as the "Spenddown" or "Surplus Income Program" (New York State Department of Health, 2010b). Federal law allows states to use a "spenddown", basically a deductible, to extend Medicaid coverage to the "medically needy" in certain categories (children, caretakers, elderly and people recognized as disabled) whose income or resources are above the eligibility level for 'regular' Medicaid (De Jung, 2009). Under this program applicants can qualify for Medicaid once their income and resources—less medical expenses—fall below the

specified level. Those enrolled must mail or bring in their medical bills or spenddown amounts on a monthly basis to their local department of social services to maintain Medicaid coverage (New York State Department of Health, 2010b)

*Family Health Plus (FHP)*

The Family Health Plus program was started in 2001 as part of New York's Medicaid expansion to cover parents up to 150 percent of the federal poverty level and childless adults up to 100 percent of the federal poverty level (New York State Department of Health, 2010a: 20). In this program, services are provided through managed care plans. FHP does not provide retroactive coverage (De Jung, 2009).

*The Medicaid Cancer Treatment Program (MCTP)*

The Medicaid Cancer Treatment Program (MCTP) targets those determined to require treatment for breast, cervical, colorectal or prostate cancer or precancerous conditions. Since 2002 the program has provided for full Medicaid coverage during treatment for eligible men and women diagnosed with breast cancer and for women diagnosed with cervical cancer, or a pre-cancerous breast or cervical condition, with coverage for colorectal and prostate cancer beginning in 2007 (New York State Department of Health Cancer Services Program, 2013: 5). As explained by the New York State Department of Health Cancer Services Program (2012: 1), to be eligible for coverage under MCTP in relation to breast or cervical cancer, individuals must be:

Screened for and diagnosed with breast or cervical cancer, or a pre-cancerous breast or cervical condition, by a New York State-licensed health care provider, or, if diagnosed with such in another state, were screened and/or diagnosed by that state's National Breast and Cervical Cancer Early Detection Program;

Not covered under any creditable insurance<sup>20</sup> at the time of MCTP application;  
In need of treatment for breast or cervical cancer or pre-cancerous breast or cervical conditions;  
A resident of New York State; and  
A United States citizen or an alien with satisfactory immigration status.

To enroll in MCTP, a prospective beneficiary must complete an application with a New York State Department of Health Cancer Services Program trained designee.

Recertification is required yearly for those still in need of treatment, at which time eligibility is reassessed. Coverage is limited to the individual enrollee and cannot be extended to family members or dependants (New York State Department of Health, 2010c).

#### *Medicare Savings Program*

The Medicare Savings Program encompasses several different programs designed to assist individuals to meet costs involved in Medicare coverage. The program encompasses full Medicaid coverage for “dual eligibles”, those eligible for both Medicaid and Medicare, extending to medical care, services and supplies as well as premiums, coinsurance and deductible payments for Medicare beneficiaries (New York State Department of Health, 2013b). The Qualified Medicare Beneficiary Program targets those at or below 100 percent of the federal poverty level. This program covers Medicare Part A and Part B premiums as well as deductibles and co-insurance but it is not

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<sup>20</sup> For the purposes of the MCTP, those with the following types of plans would be considered to have “creditable” insurance: a group health plan, health insurance benefits consisting of medical care under any hospital or medical service policy or certificate, hospital or medical service plan contract or health maintenance organization contract, Medicare, Medicaid, or Armed Forces Insurance, or a state health risk pool. Those who have lost their health insurance or who have health insurance that does not cover the cost of eligible cancers or pre-cancerous conditions can apply for coverage under the MCTP (New York State Department of Health Cancer Services Program, 2013: chapter 7 page 4- 5).

retroactive. The Specified Low Income Medicare Beneficiary Program, which targets those with incomes between 100 and 120 percent of the federal poverty level, covers only Medicare Part B premiums but is retroactive, providing coverage for three months prior to application.

The Qualified Individual Program targets those with incomes between 120 percent and 135 percent of the federal poverty level, will cover Medicare Part B premiums only and is retroactive. Unlike the first two programs, this final program cannot be held in conjunction with other Medicaid coverage. The Qualified Disabled and Working Individual Program targets disabled workers under 65 who have lost Medicare Part A benefits due to returning to work (New York State Department of Health, 2013b). Individuals enrolled in a Medicare Savings Program are automatically enrolled for the Low Income Subsidy for Medicare Prescription Drug Coverage, also known as “Extra Help”, which is a subsidy paid by the federal government to the drug plan in which the eligible Medicare beneficiary is enrolled (Centers for Medicare and Medicaid Services, 2009: 5). This subsidy basically makes Medicare more affordable by having no deductible, coverage for the gap in Medicare drug coverage between initial coverage and catastrophic coverage informally known as the Medicare ‘donut hole’, a subsidized premium, and lower co-payments (De Jung, 2009; U.S. Center for Medicare and Medicaid Services, n.d.).

### ***New York: Medicare***

Women make up 58 percent of Medicare beneficiaries in New York State (The Henry J. Kaiser Family Foundation, 2013c). Medicare in the United States is, as

previously discussed, a federal health insurance program that provides coverage for those 65 years of age and older, those under 65 with certain disabilities, and people with End-Stage Renal Disease (U.S. Centers for Medicaid and Medicare Services, 2013: 13).

Medicare Part A offers hospital insurance, while Medicare Part B offers medical insurance. Together, Medicare Part A and Medicare Part B make up what is sometimes referred to as ‘original’ Medicare. Medicare Part C refers to “Medicare Advantage” plans offered by private insurance companies that include the benefits covered under Medicare Part A and Medicare Part B and often include Medicare Part D coverage as well.

Medicare Part D is Medicare prescription drug coverage offered by Medicare-approved private health insurance companies (U.S. Centers for Medicaid and Medicare Services, 2013: 13).

Medicare plans can change costs and coverage each year, with a specified enrollment period for coverage for the following year. Those who are 65 or over and receive benefits from Social Security or the Railway Retirement Board receive Medicare Part A and B automatically, as do those who are under 65 and recognized as disabled (U.S. Centers for Medicaid and Medicare Services, 2013: 17). Individuals who need to sign up for Part A and B include those nearing 65 who will not receive Social Security benefits and those with end stage renal disease (U.S. Centers for Medicaid and Medicare Services, 2013: 17). While Medicare Part A coverage is premium free for those who paid Medicare taxes while working, it can also be purchased by those not eligible to receive it premium free for a cost of \$441/month in 2013. Medicare Part B coverage does involve a premium, amounting to between \$104.90 and \$335.70 in 2013 depending on income

(U.S. Centers for Medicaid and Medicare Services, 2013: 25) Where individuals have other health insurance coverage, such as private health insurance coverage through employment, Medicare offers primary health insurance coverage in some circumstances and supplements private primary coverage in others (U.S. Centers for Medicaid and Medicare Services, 2013: 22).

### ***New York: Private Health Insurance***

In New York State, 56 percent of non-elderly women hold employer-based private health insurance coverage, obtained through their own employment or as a dependant, and 5 percent hold individually purchased private health insurance coverage (The Henry J. Kaiser Family Foundation, 2013f). It is important to understand that regulation of the health insurance industry differs significantly between states as well as within states depending on the health insurance market in question. In regulating private health insurance states differentiate between the large group (typically over 50 members), small group (typically greater than one but less than fifty members) and the non group markets (individuals and individual families) (Hall, 2000: 174). As Hall (2000: 173) points out, these markets are “not simply points on a continuum; they constitute entirely different product lines, often sold by different sales forces and serviced by different insurers or corporate divisions” and are “distinct in their economic and legal characteristics”. Regulation of the large group market is shaped by ERISA, which, as previously noted, exempts employers that self-insure (typically large companies) from “the core of state law insurance regulation” regarding financial matters, consumer protections and coverage content (Hall, 2000: 174).

New York State is relatively active in regulating the health insurance industry. Indeed, industry advocates such as Novak (2003: 11) have bemoaned New York's status as "one of the most heavily mandated states in the nation". For the purpose of regulating private health insurance, New York State defines a small group as 2 to 50 people. Guaranteed issue is applied to all products in the small group market, meaning small employers cannot be turned away by an insurer based on the health status of their group (Kaiser Family Foundation, 2013g). A community rating system is imposed, which does not allow for rating for factors including gender, health status, age, tobacco use or industry (Kaiser Family Foundation, 2013h). New York is one of 40 states to have expanded COBRA continuation coverage for small firm employees, with the maximum duration of this coverage set at 36 months (Kaiser Family Foundation, 2013i).

In the non-group (individual) market, New York is one of only six states requiring guaranteed issue of all products. All individual market insurers must issue all individual market plans that the insurer sells to all applicants, who cannot be turned down on the basis of health or risk status (Kaiser Family Foundation, 2013j). New York State does not permit "elimination riders", which are amendments to individual health insurance contracts that allow health problems disclosed at the time of application to be permanently excluded from coverage (Kaiser Family Foundation, 2013k). Moreover, unlike in some other states, the label of "pre-existing condition" can apply only to conditions for which someone actually received medical advice, diagnosis, care or treatment prior to enrollment (Kaiser Family Foundation, 2013k).



New York State has a history of legislating health insurance coverage relevant to breast cancer care. By 2000, it had mandated reimbursement for breast reconstruction or prosthesis (1984), length of in-patient care following mastectomy (1984) and breast cancer screening (1990) (Centers for Disease Control and Prevention, 2000: 6-7). Yet since insurance offered by employers who self insure is not regulated at the state level due to ERISA, women with these plans have not necessarily been able to enjoy the benefits set out in state law.

***Ontario: The Ontario Health Insurance Plan***

Most women who reside in Ontario are entitled to coverage under the Ontario Health Insurance Plan (OHIP). As with other provincial and territorial health insurance programs in Canada, OHIP falls under the 1984 *Canada Health Act*. As explained, this Act applies to medically necessary hospital and physician services and sets out five criteria that provincial/territorial plans need to meet in order to qualify for federal funding: universality, accessibility, comprehensiveness, portability, and public administration. *Universality* demands that all residents have access to public health insurance and insured services under the same terms and conditions. *Comprehensiveness* requires that provinces and territories actually insure services defined as “insured health services.” *Accessibility* involves ensuring that all insured people have reasonable and uniform access to insured health services. *Portability* requires coverage of insured services for those temporarily absent from their province or territory of residence. In order to satisfy the criterion of *public administration*, each provincial and territorial

health care insurance plan must be administered and operated on a non-profit basis by a public authority that is accountable to the provincial government.

In Ontario, the 1990 *Health Insurance Act*, the 1990 *Independent Health Facilities Act* and the 2004 *Commitment to the Future of Medicare Act* reflect the principles of the *Canada Health Act* in maintaining a single system of public payment for services insured under OHIP. OHIP focuses on insuring medically necessary care from physicians and prescribed practitioners and care in hospitals and prescribed health facilities. Coverage under OHIP is available to individuals who reside in Ontario. As summarized by the province's Ministry of Health and Long-Term Care, to be eligible for this coverage one must:

- be a Canadian citizen, permanent resident or among one of the newcomer to Canada groups who are eligible for OHIP as set out in Ontario's Health Insurance Act and
- be physically present in Ontario for 153 days in any 12-month period; and
- be physically present in Ontario for at least 153 days of the first 183 days immediately after establishing residency in the province; and
- make your primary place of residence in Ontario. (Ontario Ministry of Health and Long-Term Care, 2012a: n.p.)

OHIP coverage generally takes effect three months after residency in Ontario is established (Ontario Ministry of Health and Long-Term Care, 2012). In hinging on recognition of legal residency, the terms of eligibility for OHIP coverage are broad.

Certain groups are, however, excluded. Provincial and territorial plans that fall under the *Canada Health Act* exclude groups that include members of the military, Royal Canadian Mounted Police, prisoners and aboriginals, who are covered by the federal government (Hurley & Guindon, 2008: 6). The undocumented, individuals within the three month

waiting period, and international students are also not eligible to receive OHIP coverage. In addition, as previously mentioned, recent reforms have also excluded refugees (Citizenship and Immigration Canada, 2012)

For the insured, OHIP provides first-dollar coverage for insured services and as such is free of co-payments and deductibles. The program is financed primarily through taxes levied by the federal and provincial governments. Ontario is one province that retains a health care 'premium', established in 2004. This is applicable to Ontario residents with taxable income over \$20, 000 and is deducted from employee pay and pension checks through the personal income tax system (Ontario Ministry of Finance, 2012a). Depending on income it can range up to \$900 (Ontario Ministry of Finance, 2012a). This 'premium' is essentially a tax: it is neither linked to OHIP nor to an individual's eligibility to receive health care in Ontario (Ontario Ministry of Finance, 2012a). The province also collects a health specific payroll tax (Ontario Ministry of Finance, 2012b). Thus while New York State has numerous public health insurance programs that in some way address hospital and physician care for certain groups that can involve various types of fees for usage, Ontario has one public program that addresses these aspects of health care for most legal residents of the province and there are no co-payments or deductibles for care.

One area not included under OHIP is drug coverage outside of hospitals. Ontario has six public drug programs: Ontario Drug Benefit, which is for seniors, as well as New Drugs Funding Program for Cancer Care, Special Drugs Program, Inherited Metabolic Disease Program, Respiratory Syncytial Virus (RSV) Program for High-Risk Infants, and

the Visudyne Program (Ontario Ministry of Health and Long-Term Care, 2013b). One must live in Ontario and be insured under OHIP in order to be eligible for these programs; however further conditions apply as they target particular groups and conditions. Public drug coverage is also available for those receiving social assistance through Ontario's Ministry of Community and Social Services, as in the case of Ontario Works (Ontario Ministry of Community and Social Services, 2012), and the Ontario Disability Support Program (Ontario Ministry of Community and Social Services, 2013).

#### ***Ontario: Private Health Insurance***

As Hurley and Guindon (2008: 15) explain “no single source summarizes the number and characteristics of Canadians who hold private health insurance”, making it difficult to ascertain the precise number of women in Ontario with forms of private health insurance coverage. Data from the 2005 Canadian Community Health Survey (CCHS) Cycle 3.1, reportedly the most recent CCHS with data on non-dental health insurance coverage, suggests approximately 47.5 percent of women surveyed in Ontario reported having “employer-sponsored” health insurance coverage for hospital charges for a private or semi-private room, while approximately 3.6 percent of women surveyed in the province reported having “private” coverage for such charges. Data from the same CCHS suggests approximately 55.5 percent of women surveyed in Ontario reported having “employer-sponsored” health insurance coverage for all or part of the cost of

prescription medication while approximately 4.3 percent of women surveyed in the province reported having “private” coverage for these costs.<sup>21</sup>

In Canada, private health insurers are subject to two general types of regulation, with the first focused on ensuring financial solvency and the second on the types of policies offered and the terms and conditions under which they are sold. Financial regulation is conducted by the Office of the Superintendent of Financial institutions at the federal level and provinces regulate the provision of private health insurance (Hurley & Guindon, 2008: 22). At the provincial level, Section 14 of the Ontario’s *Health Insurance Act* expressly prohibits other insurance from covering services insured under OHIP. The preamble to the *Commitment to the Future of Medicare Act* reaffirms the province will “Continue to support the prohibition of two-tier medicine, extra billing and user fees in accordance with the *Canada Health Act*” and bans physicians in Ontario from opting out of the public plan.<sup>22</sup>

As private health insurance in Ontario is limited to covering what OHIP does not, it is confined to a supplementary role. Thus, as in other provinces, this commodity plays a significant role only outside of the physician and hospital sectors (Hurley & Guindon, 2008: 9). Drug coverage represents an important area for private health insurance among those who do not have some form of public coverage for prescription drugs outside of hospitals.

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<sup>21</sup> Data from the 2005 CCHS Cycle 3.1 was obtained with the assistance of York University librarian Walter Giesbrecht.

<sup>22</sup> As Hurley and Guindon (2008: 23) note, however, physicians who had already opted out as of September 2004 were “grandfathered” in this legislation.

In Canada, private health insurance is sold by for-profit life and health insurance companies, non-profit insurance organizations and for-profit property and casualty insurers (Hurley & Guindon, 2008: 16). The market is dominated by for-profit life and health insurance companies. Although data are limited, these for-profit insurers are estimated to account for 80 percent of the market (Hurley & Guindon, 2008: 16). Private insurers offer nine types of health insurance products: extended health care insurance, hospital supplemental insurance only, prescription drug insurance only, dental care insurance, disability income insurance, accidental death and dismemberment, long term care insurance and travel insurance (Hurley & Guindon, 2008: 17). Extended health care insurance plans, the source of most supplementary hospital, prescription drug and travel coverage, address “a range of hospital and other health care expenses not covered by a provincial health insurance plan, including hospital amenities, prescription drugs, non-physician providers, vision care, medical devices, travel insurance and ambulance service” (Hurley & Guindon, 2008: 19). These policies typically feature deductible and “co-insurance” provisions and annual or life-time maximums for different types of services with “cost sharing” on the increase (Hurley & Guindon, 2008: 19). The market for this type of insurance is dominated by group contracts provided by employers or purchased by members of professional orders, associations or unions (Hurley & Guindon, 2008: 19).

While the roles of public and private health insurance are clearly delineated in Ontario, the coverage offered is not static. The scope of private health insurance has been expanding through “delisting”, which refers to decreasing coverage for, and even the

complete removal of, procedures, devices, and drugs from the list of “medically necessary” services that are publicly funded through OHIP (see Ontario Health Coalition, 2003; Stabile & Ward, 2006). Chiropractic, optometry, and community-based physical therapy services are among those that have been “delisted” (see Landry et al., 2006). When services are no longer covered by OHIP they become the preserve of private health insurance plans, expanding the scope of the coverage that private insurers can provide in the province.

## **Conclusion**

In establishing the context within which women in Ontario and New York use health insurance in relation to breast cancer care, this chapter has considered both the forms of health insurance offered in these jurisdictions and health insurance reform in Canada and the United States more generally in the context of broader welfare state transformations. While the specifics of the health insurance systems that have developed do differ, the rise and consolidation of neoliberalism as a political economic project has conditioned arrangements in both settings, with commodified coverage, shifts in responsibility for health insurance coverage to individuals and households, and gradations in coverage among different programs and policies apparent to varying extents in histories of reform in both Canada and the United States.

At the present juncture, forms of public and private health insurance in Ontario and New York play different roles. In New York, public health insurance programs under Medicare and Medicaid play a residual role in targeting specific groups unable to obtain private health insurance through the market. Private health insurance is the main source

of coverage for the employed population, with large group, small group and non-group markets feeding a complex and powerful health insurance industry. In Ontario, universal public health insurance coverage is available to legal residents of the province under the terms set out in the *Canada Health Act*. Public health insurance offered through OHIP plays a primary role in financing the medically necessary hospital and physician care central in treating breast cancer. Private health insurance, prohibited from covering services that are publicly insured, is confined to supplementing OHIP through coverage of things such as prescription drugs, medical devices, and the services of practitioners not publicly covered. Thus while common pressures have shaped health insurance reform in Canada and the United States, women in Ontario and New York confront different health insurance systems when using forms of coverage. Women's experiences in this regard are the focus of the following chapter, which examines participants' accounts of health insurance experiences in relation to breast cancer care in Lanark and Leeds Grenville in Ontario and St. Lawrence County in New York.



## **Chapter 5: Commodified Coverage, Responsibilized Individuals and Gradation in Consequences of Financing Breast Cancer Care**

### **Introduction**

This chapter draws on interviews conducted with women in Lanark and Leeds Grenville in Ontario and St. Lawrence County in New York to develop a comparative account of participants' health insurance experiences in relation to breast cancer care. Grounded in a thematic analysis of forty-two interviews, it seeks to understand participants' experiences within the context of the health insurance systems examined in the preceding chapter. The discussion provided in this chapter is organized in three sections that address three overarching themes connecting participants' accounts that are based on categories emerging from feminist political economy insights and analysis of the interviews conducted. Interview findings are presented within the themes of 'commodified coverage', 'responsibilized individuals', and 'gradation in consequences' of financing breast cancer care. Sub-themes are highlighted in bold font and sub-sub-themes are underlined in order to ensure finer details of the interview findings are not lost in the account provided.<sup>23</sup> It is argued that in the context of private health insurance as the primary form of health care financing in New York, participants faced more commodified coverage, were more responsabilized in relation to coverage and confronted more gradation in consequences than in Ontario, where public health insurance played a primary role in financing breast cancer care.

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<sup>23</sup> Sub-themes are highlighted in bold font and sub-sub-themes are underlined the first time they appear but appear in regular font thereafter.

### **Commodified Coverage: Access to Health Insurance in Differing Landscapes**

The overarching theme of ‘commodified coverage’ addresses participants’ experiences of health insurance as a commodity, namely something bought and sold. It is concerned with how states and markets as well as individuals and their households were implicated in participants’ access to health insurance coverage, with ramifications for conditions of access, stability of access and variation in coverage. In this section it is argued that participants’ accounts suggest they experienced health insurance as far **less commodified** in Ontario than in New York, with inclusive, stable and uniform public health insurance through OHIP financing the bulk of participants’ breast cancer care and private coverage playing only a supplementary role. In New York, with private coverage assigned a primary role in health care financing and public coverage accorded a residual role, participants’ accounts suggest they experienced health insurance as **more commodified**, with more exclusive conditions of access, precarious access and varied coverage the rule rather than the exception.

In Ontario, participants’ access to health insurance coverage depended not on their relationship to the market through employment, a family member’s employment, or insurance purchasing decisions as is the case in New York State, but rather on their relationship to the state. Residency was the most apparent condition for OHIP coverage for participants: as one participant’s husband put it, “It’s part of living in Ontario”.<sup>24</sup> OHIP coverage was seen by participants as inclusive: it was described as something “everyone has”<sup>25</sup>, “regular”<sup>26</sup> and “the *norm*”<sup>27</sup>. In addition to being inclusive, OHIP

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<sup>24</sup> This was discussed by the husband of ON17.

<sup>25</sup> This was discussed by ON3, ON13 and ON20.

coverage was stable. Participants discussed having had OHIP since it started<sup>28</sup> all their lives<sup>29</sup> or since moving to Ontario.<sup>30</sup>

In contrast, Ontario participants' access to private health insurance coverage was conditional on their own employment, their husband's employment, or individual purchase of a private policy. Of the 20 women interviewed, five had private coverage through their own employment during breast cancer care,<sup>31</sup> six had coverage through their husband's employment,<sup>32</sup> one had coverage through both her own employment and her husband's employment,<sup>33</sup> and one had coverage through her own employment, her husband's employment and an individually purchased plan.<sup>34</sup>

Seven participants in Ontario did not have private health insurance during breast cancer care, reflecting the more exclusive nature of private coverage.<sup>35</sup> Exclusivity of private coverage was especially apparent in experiences with travel and other individually purchased policies, with six participants having encountered breast cancer-related denial or restriction of coverage.<sup>36</sup> ON18 dramatically described how an attempt to clarify details of a travel insurance policy resulted in its abrupt cancellation, explaining: "And I mentioned something about my radiation treatments. And there was

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<sup>26</sup> This was discussed by ON2.

<sup>27</sup> This was discussed by ON9.

<sup>28</sup> This was discussed by ON1, ON5, ON10, ON11 and ON20.

<sup>29</sup> This was discussed by ON2, ON3, ON8, ON9, ON12, ON13, ON15, ON17 and ON19.

<sup>30</sup> This was discussed by ON4, ON6, ON7, ON14, ON16 and ON18.

<sup>31</sup> ON1, ON6, ON10, ON13 and ON19 had private coverage through their own employment.

<sup>32</sup> ON2, ON4, ON5, ON8 ON15 and ON17 had private coverage through their husband's employment.

<sup>33</sup> ON3 had private coverage through both her own and her husband's employment.

<sup>34</sup> ON12 had private coverage through her own employment, her husband's employment and private plan she had purchased individually.

<sup>35</sup> (ON7, ON9, ON11, ON14, ON16, ON18, ON20 did not have private health insurance during breast cancer care.

<sup>36</sup> ON7, ON9, ON10, ON11, ON12 and ON18 discussed being denied or restricted in travel or other individually purchased insurance coverage.

this silence at the other end of the phone. And he said, “Radiation treatments?” And I said, “Yes, I had breast cancer. And I had radiation treatments.” And he said, um, “Your insurance policy is null and void as of this conversation right today” [laughs]. ON9, who discussed being rejected for privately purchased supplementary insurance she had tried to buy, summed up the situation by observing “You’re, you’re kind of on the naughty list as soon as you get cancer [laughs] or any kind of illness, yeah, any kind of illness.” When a breast cancer diagnosis did not result in denial of coverage, the plan in question specifically excluded breast cancer, making its coverage useless in this regard.

Beyond being more exclusive than public coverage, private health insurance in Ontario was also more precarious. Dependent on employment and income, access was tied to participants’ and their husbands’ labour market participation. Its continuation required success in obtaining and maintaining employment or retirement packages offering health insurance and paying premiums—or maintaining relationships with those who could. Reported changes in participants’ private health coverage between being diagnosed and being interviewed in 2012-2013 are summarized in Appendix E. The longest running employment-based coverage discussed was 48 years old (held by ON6 through her own employment and later in her retirement package), and the shortest discussed was six months old (gained by ON13 when her husband started a new job). While no participant reported having lost OHIP coverage since obtaining it, a few participants did report actual or impending loss of private coverage. ON4, a widow, described cancelling her private coverage at the point when she would have had to begin paying a premium following her husband’s death. ON12, who had separated from her

husband, considered the loss of coverage under his plan imminent, explaining, “Once we’re divorced, um, my lawyer told me that there isn’t an insurance company on the planet that’ll cover me.” ON15 believed coverage through her husband’s employment would end or change with his impending retirement in 2013. Compared to OHIP coverage, private coverage was thus not only more exclusive, but more precarious.

In addition to being inclusive and stable, OHIP coverage was uniform. In all interviews, participants reported full coverage for physician and hospital care related to breast cancer. As ON2 succinctly explained, OHIP had covered “any of the hospitals or the doctors’ appointments or specialists’ appointments.” When participants had appointments with doctors, tests, surgery, chemotherapy or radiation, they reported without exception that OHIP had financed these aspects of their breast cancer care. Moreover, although participants varied in the specific care they discussed having received, OHIP had played the primary role in financing care for everyone. As ON19 explained, “OHIP is the main help that you get. Not your private coverage. Because, if there’s any balance over and beyond the OHIP, that’s what your coverage comes in.” The uniformity of OHIP coverage was explicitly acknowledged by some. ON9, for instance, remarked that, with OHIP coverage she had been treated “like a normal person would be I guess. Not less or more.” ON11, bemused by my eagerness to interview additional women, asked “Yeah, but, are you not finding the same thing that I’m telling you?” In this case, she could not understand why I would want to interview more women who would presumably provide the same responses she had.

In contrast to the uniformity that characterized OHIP coverage, there was variation in specifics of supplementary private coverage. Of the 13 participants who had private coverage, only 12 reported using it for breast cancer related care. As ON6 succinctly explained, “the private one just adds on to whatever the provincial one is doing.” Private plans were mainly used to cover prescription drugs and equipment related to breast cancer care beyond that covered by OHIP and other public programs. Drug coverage varied in level of coverage, with those participants who had private health insurance reporting coverage of prescription medication ranging from 80 to 100 percent. The operation of private drug coverage also varied. While the majority of the women who had private coverage had drug costs covered directly, two participants, ON3 and ON4, reported needing to pay at the point of purchase and submit claims for reimbursement.

Private coverage was used by six Ontario participants to cover breast prosthesis costs beyond those paid by OHIP, in most cases covering the balance. Five had used private coverage to pay for a wig, and one was in the process of making a claim for a wig. Coverage of wigs varied, however, and was reported to range from roughly \$80 to \$400. Four participants had used private coverage to pay for limited massage therapy.<sup>37</sup> One, ON15, had used private coverage to pay for physiotherapy costs. Her coverage was capped at \$750, which she estimated had amounted to coverage for seven sessions. Unlike private drug coverage, which often operated directly, private coverage for

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<sup>37</sup> ON2, ON4, ON13 and ON15 had all used private coverage for massage therapy to prevent lymphedema. ON4 had attended only one \$75 session. ON13 and ON15 had plans capped at \$500. However, since her husband had started a new job with private coverage ON13 had come to have two plans with \$500 worth of coverage through each.

equipment and services typically functioned on a reimbursement system, with women paying the initial costs and being reimbursed for varying portions of the total cost of a good or service depending on the specifics of their policies. Finally, three participants discussed using private coverage for a private room when hospitalized.

Differences in the expenses associated with maintaining and using private coverage were also apparent, with participants sometimes struggling to recall the details of their plans. Of the 13 participants with private coverage, seven did not have, or were not aware of having, a deductible. Where participants had them, deductibles were estimated to range from \$10 to \$200 a year. Participants sometimes did not know the cost of their health insurance premiums, which tended to be deducted automatically at their place of employment or their husband's. Three didn't know how much they had paid.<sup>38</sup> Three reported paying nothing for their coverage.<sup>39</sup> Among the seven other women with private health insurance coverage, who either were confident about knowing their premium or were able to check, costs ranged from approximately \$260 to \$1500 a year. The cost of private coverage—when known—was generally not considered a burden. As ON2, for instance, remarked, "It would be *very* low in terms of our family budget", noting "I haven't even thought of it. That it comes off. It is a cost somewhere, and it comes off his paycheck, but I, I can check that out." Variation in the cost, extent and operation of coverage among women with private plans stands in contrast to the uniformity apparent in participants' accounts of OHIP coverage. Yet, in the context of the

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<sup>38</sup> ON13, ON17, ON19 did not know how much they paid for their coverage.

<sup>39</sup> ON1, ON8 and ON15 reported paying nothing for their private coverage, the cost of which was to the best of their knowledge fully covered by employers.

restricted role of private health insurance coverage in supplementing the public coverage that financed the bulk of participants' breast cancer care, the variation wrought by commodified coverage was relatively limited in participants' accounts overall.

Commodified health insurance was experienced to a far greater extent by participants in New York State, where private health insurance assumed a primary role in financing health care and public health insurance a residual one. The role of the market was privileged in this context: participants' access to private health insurance was conditional on their own employment, their husband's or partner's employment, or individual purchase of a private policy. Of the 22 women interviewed in St. Lawrence County, 12 had some form of private health insurance coverage during some part of their breast cancer treatment. Six participants held private coverage through their own employment,<sup>40</sup> and three had private coverage through a partner or husband's employment.<sup>41</sup> One had private coverage through her husband's employment combined with a supplementary individually purchased plan.<sup>42</sup> Two had private coverage through a husband's employment that supplemented Medicare.<sup>43</sup> Ten participants had not had private health insurance coverage at or since the time of their breast cancer diagnosis, underlining the exclusive nature of private coverage.<sup>44</sup>

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<sup>40</sup> NY3, NY4, NY7, NY16, NY17, NY19 had private coverage through their own employment for some part of their breast cancer treatment. NY16 began her treatment with private coverage but finished it with public coverage under circumstances discussed later in this chapter.

<sup>41</sup> NY1, NY2 and NY5 had private health insurance coverage through their husband's employment during breast cancer treatment.

<sup>42</sup> NY9 had private coverage through her husband's employment combined with a supplementary individually purchased plan.

<sup>43</sup> NY10 and NY11 had private coverage through a husband's employment that supplemented Medicare.

<sup>44</sup> NY6, NY8, NY12, NY13, NY14, NY15, NY18, NY20, NY21 and NY22 had not had private health insurance coverage at or since the time of their breast cancer diagnosis. Please note that for the purposes of



With private health insurance as a primary source of health care financing conditional on participants' employment, marital or common-law relationships, or individual purchase of a private policy, access was precarious and insurance status unstable. Reported changes in participants' private health insurance between being diagnosed and being interviewed in 2012 are summarized Appendix F. Of 12 participants with private health insurance at the time of their diagnosis 10 reported subsequent change either in or between plans. While these changes had generally occurred after treatment, as NY4 underlined "People sometimes think....that cancer is just cancer. And when you're done with it, you're done with it. And they don't realize that cancer damages your body for life and you have long term issues, health issues." Thus change in health insurance coverage after treatment should still be seen as relevant to participants' breast cancer-related care.

Participant NY16 reported dramatic change in her private coverage during breast cancer treatment itself. As she recounted, "Right in the middle of the procedure for my cancer, they totally dropped me. Completely. Because I was off work. And that's their policy, for I had to pay more money than what I could afford to do." She went on to explain: "They gave me a letter to say they wanted me to pay them over a thousand dollars a month to keep their premium....And I can't afford that. So, with me not havin' that income, they had to drop me completely." Her plight illustrates the exclusive nature

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this analysis I classify Medicare as public coverage even though, as discussed, this public coverage is sometimes privately administered.

of private health insurance that requires employment and income precisely at a time when breast cancer treatment makes this particularly difficult for women to manage.

The exclusive nature of private health insurance coverage is also apparent in the experiences of NY12, who was uninsured at the time of her breast cancer diagnosis and tried unsuccessfully to purchase private coverage as an individual. As she explained with input from her husband,

NY12: Well I did call around to see if I could get insurance. We couldn't touch it. You know, health insurance for myself. Ungodly prices.

NY12's husband: Well, the minute that you mentioned that she had breast cancer...

NY12: You can't lie.

NY12's husband: And, "Nope, we can't cover you".

NY12: Exact words, yes.

NY12's husband: And then the Mutual of Omaha guy, come here, he said, "I could put you straight through, no problem". He says, "I guarantee I'll get you both covered". It came back "Denied, because high risk". Yeah, for both of us. Yup.

NY12: We tried. [pause]

In reflecting on her experience NY12 recalled, "Rudeness, people were *rude*. They are *rude*, the insurance company. You know, more or less, 'Don't bother'. 'Click.'". Her account underlines both the issue of unaffordable coverage and that of outright rejection on the basis of being labeled "high risk" by insurers.

Public coverage in New York State also tended to be both exclusive and precarious, with women needing to meet multiple conditions in order to qualify for coverage. Of the ten participants without private health insurance coverage during breast cancer care, seven were uninsured at the time of diagnosis. These women subsequently obtained coverage for limited periods of time under one Medicaid program or another. Access to "regular" Medicaid depended on income. Access under the Medicaid Excess Income Program, as discussed in the previous chapter, involved a deductible termed a

“spenddown”, with participants needing to qualify for coverage from month to month. As previously explained, those accessing Medicaid coverage in this way must submit medical bills or spenddown amounts to re-qualify for coverage each month. Access to Medicaid coverage under the MCTP depended on lacking insurance coverage and being treated for an eligible form of cancer that included breast cancer. As NY12 bluntly put it, “The minute I stop my cancer pill, I’m dropped.” This coverage was renewed yearly, but participants reported it could only be held for a maximum of five years.

Two other participants had Medicare coverage, available to those 65 years old or older and to some recognized as disabled that they supplemented with other forms of public coverage conditional on income. Of these women one was deemed eligible for additional Medicaid coverage with a spenddown during certain months of her breast cancer treatment, and the second described receiving a Medicare supplement through the State of New York based on her low income. Although she did not identify the program by name when asked, based on her description this coverage appears to have been obtained through the Medicare Savings Program branch of New York State Medicaid which, as explained in the preceding chapter, offers subsidies for Medicare coverage for low income individuals. The final participant was covered at the time of her diagnosis under Family Health Plus, a public health insurance program conditional on income, but discussed obtaining ‘regular’ Medicaid coverage thereafter and later holding Medicare and Medicaid coverage (sometimes with a spenddown) together at times.

Forms of public coverage were precarious in this context as women gained and lost eligibility for different types of coverage. Changes in participants’ public health

insurance histories are summarized in Appendix G. All New York State participants with public health insurance had had some kind of change in public health insurance coverage since being diagnosed with breast cancer. While Medicare covered participants age 65 and older or recognized as disabled, eligibility for Medicaid coverage changed with financial circumstances or health status. NY8, whose public coverage had changed several times, reported:

It was a bit of a roller coaster ride, really. Because, start out knowing that this is going to cover this. Family Health Plus will cover this much. Then Medicaid will cover this much. Then Medicare and Medicaid will cover this much....Then going to the Medicare only, [pause] but knowing that I have it and knowing what it covers. But yeah, you kinda went through this, "Alright, I know exactly what I've got" to "Oh gosh, what do I have now". Okay, then "I've got exactly what I want", and then, "Oh goodness, I gotta change again". So I want to say it was a roller coaster. Yeah.

Overall, precarious coverage was the rule rather than the exception with public coverage in New York State.

Variation in coverage was apparent in participants' accounts of their experiences of public as well as private health insurance in New York State. Public programs offered varying levels of coverage for breast cancer related expenses. Medicare offered comparatively limited coverage. As NY6 observed, "They cover, what is it, 80 percent. 80 percent, with the rest of it my responsibility." As NY7 pointed out, "You think, '80 percent coverage, this is really good!' Un-un. Because everything is so prohibitively expensive." NY6 matter-of-factly discussed the Medicare "donut hole", the infamous gap in Medicare prescription drug coverage. As she explained,

....if you have a prescription plan coverage, and you spend up to a certain point, then after that you encounter what they call a "donut hole". A donut hole is that point in which you have *no* coverage for prescriptions. If

you've met up to a certain amount, like I think it's \$2500 or \$3000, I don't even know the amount. But beyond that point, for a time, then you have no coverage at all, and you become responsible for 100 percent of your prescription.

Limits and gaps in Medicare meant that, as NY6 put it, there was a need to "pick up the pieces elsewhere." Moreover, along with a premium of nearly \$100 a month<sup>45</sup> Medicare involved varying co-payments for breast cancer related care and prescription drugs.<sup>46</sup>

Participants reported more comprehensive and affordable coverage for breast cancer care under the MCTP. This program covered physician and hospital care as well as prescription drugs with lower co-payments.<sup>47</sup> Unlike other Medicaid, coverage under this program was never reported to involve a "spenddown". Participants with MCTP coverage typically took care to specify they were covered under this particular program and compared it favorably to other Medicaid programs. NY18, for instance, bluntly described MCTP coverage as "better". Thus even when women were covered under the umbrella of "Medicaid", coverage was not necessarily commensurate but varied between programs. Under these circumstances, participants in New York State faced variation rather than uniformity in public coverage for breast cancer care.

Variation was also apparent in participants' accounts of private health insurance in New York State. Premiums varied, as did co-payments, deductibles and levels of coverage, with participants also varying in their knowledge of these details. Two

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<sup>45</sup> This premium was reported by NY6 and NY20.

<sup>46</sup> NY20, who used Medicare coverage in conjunction with what she described as a low income supplement, reported co-payments for office visits and hospital care ranging from \$5 to \$20 and prescription co-payments as low as \$1.04. NY6, who was initially using only her Medicaid Advantage Plan for breast cancer care, reported co-payments for office visits of \$15 and up. She mentioned a prescription co-payment of nearly \$300 a month for anti-depressant medication, and described obtaining breast cancer-related medication through the manufacturer in order to avoid the "donut hole" in her coverage.

<sup>47</sup> Participants with MCTP reported co-payments of \$1-\$3 for medication.

participants, who had used a combination of Medicare and secondary private health insurance coverage through husbands' employment during breast cancer care (NY10 and NY11) knew they paid a private health insurance premium but did not know what it was.<sup>48</sup> Three participants, NY3, NY9 and NY19, reported they did not have to pay premiums. Among the remaining participants with private coverage, the premiums reported ranged from \$600 a year, which NY4 paid to cover herself and her son, to \$2931.12 year, which NY5's husband paid for family coverage. Co-payments varied in size and application. Participants discussed co-payments ranging from \$0 to \$40 for appointments with various kinds of doctors in the course of breast cancer care. NY3 mentioned a \$75 co-payment for surgery, which she described as "very cheap". Prescription co-payments discussed ranged from \$3 to \$88, varying within plans depending on the drug in question as well as between different plans. Co-payments for various kinds of tests were discussed as ranging from \$10 to \$35. Significantly, different plans were discussed as imposing co-payments on different things. For instance, while NY3 and NY9 reported not having co-payments for radiation, for instance, NY17 had faced \$40 co-payments for each of her radiation treatments.

Co-payments needed to be paid repeatedly over the course of breast cancer treatment, adding up over time. NY1 indignantly remarked there were

....too many of them. Repetitive ones. When you go through cancer treatments, the one thing that you probably have more than anything is lab work. And, if it's not tied to a specific. You know, like, every two weeks, when you have chemo, they check your blood counts to make sure they are not in dangerous levels. So you might have blood work once a week or

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<sup>48</sup> As NY11 ruefully observed, "That is a sad story that my husband has paid all of the bills and handled all of the finances all our married life."

every two weeks. And to get hit with a 20 dollar or 15 dollar co-pay, as good as my insurance is, I just think that's unfortunate. Because they're not, you know I mean, it's not like an abuse of service. You know, this is to diagnose or to evaluate your health. Um, so to get hit with multiple co-pays continuously every week because of the follow up and the monitoring that's going on I think is unfortunate.

Beyond specified co-payments, some private plans only partially covered medical costs. NY19's policy, for instance, covered 80 percent of eligible treatment until she had paid a \$250 deductible that applied to some services and not others. Thereafter the plan provided 100 percent coverage. In contrast, NY16's private plan had only ever covered 80 percent of eligible services. Deductibles, which not all participants could recall, were reported to range from \$0 to \$500.

Some private plans placed limits on where treatment would be covered. Several participants discussed either coverage of particular local doctors or facilities but not others or suggested differences in coverage in-state compared to out-of-state. NY9 and NY10 mentioned receiving lists of doctors covered under their private insurance plan. NY4 approached this issue from the opposite direction, noting there were "people" who were "not participating" in her plan. Both NY3 and NY4 raised the issue of being uncertain about their coverage out of the state. NY3, who had initially considered having treatment while staying with a relative in a different state, recalled having been told by an insurance company representative "they might be able to work something out." Two participants, NY5 and NY7, explained that their plans would fully cover the cost of breast cancer treatment only at designated centers, which were all outside of the county. Their plans offered some reimbursement for travel, meals and accommodation related to breast cancer care, things not covered under other private plans.

Participants themselves did not typically understand their plans as restricting choice in health care providers—only NY5 discussed her coverage in this light—instead focusing on the fact that the providers they had used had accepted their coverage. In confining participants to certain providers these plans can, however, be seen to restrict where participants could obtain care, with the specifics of participants' private plans reflecting variation rather than uniformity in this regard. Overall, variation in plans combined with changes between plans over time made for complicated health insurance histories among privately insured participants as well as publicly insured participants in New York State.

Although participants in both Ontario and New York accessed public and private forms of health insurance in the course of their breast cancer care, they did so under different conditions and on very different terms. In New York State, commodified coverage figured far more prominently in participants' accounts of access to health insurance coverage. With the primacy of private health insurance coverage bought and sold in the market, participants' access to coverage was conditional on their own employment or a spouse's as well as on having sufficient income to afford associated costs or being in a recognized relationship with someone who did. These conditions of access excluded participants who were either not offered health insurance through employment or were unable to afford the coverage offered, as well as those not in recognized relationships with men able to obtain coverage. When participants did have private health insurance, their coverage was only as stable as employment, relationships and income, with coverage emerging as precarious and varied in content. Public coverage



was confined to a residual role in that it was for those unable to obtain private health insurance in the market. With conditions for eligibility for different public programs related to age, ability, income and treatment, participants' experiences suggest this coverage was also exclusive, precarious and varied.

In Ontario, in contrast, where participants described less commodified health insurance coverage, access to public health insurance under OHIP as a primary source of financing for breast cancer care was characterized by greater inclusivity and stability as well as by uniformity in coverage. Access to private health insurance through the market was conditional along the same lines as in New York, with this coverage characterized by exclusivity, precariousness and variation in Ontario as well. Yet, with the limited scope of private coverage in supplementing public health insurance coverage in this jurisdiction, on the whole commodified coverage figured far less prominently in Ontario participants' accounts of accessing health insurance for breast cancer care.

### **Responsibilized Individuals: Health Insurance Responsibilities in the Context of Commodified Coverage**

With the theme of 'commodified coverage' addressing the terms on which participants accessed health insurance coverage for breast cancer care, the theme of 'responsibilized individuals' encompasses ways participants assumed responsibility in using health insurance coverage. In this section it is argued that individuals were **less responsibilized** in relation to health insurance coverage for breast cancer care in Ontario than in New York State in the context of less commodified health insurance. Awareness of health insurance coverage and unpaid work involved in utilizing coverage underpin this theme. With public health insurance coverage in Ontario often taken for granted,

participants' accounts suggest this coverage operated automatically, involving relatively minimal responsibility for unpaid work on their part in terms of health insurance *learning, intervening or addressing bills and cost-related paperwork*. Private health insurance did, however, involve greater awareness and more work in these areas. Yet individuals were **more responsibilized** in New York in the context of more commodified coverage, with health insurance awareness more acute and more onerous work involved in using public and private health insurance coverage.

Awareness of health insurance coverage varied among Ontario participants. Although OHIP had financed the bulk of the breast cancer care that all participants received, comments suggest its existence and functioning were often simply taken for granted. Several times during the course of recruiting, potential participants cautioned they might not be suitable—because they didn't have health insurance. Yet, all turned out to have OHIP coverage when questioned in detail. Roughly a third of the women interviewed were forthright in stating that they *had not thought about* OHIP during the course of their breast cancer care. This is illustrated in the following exchanges:

Alison: In your view, has your health insurance coverage through OHIP, has it met your needs in terms of breast cancer care?

ON20: Yeah, yeah.

Alison: Okay, and why or why not?

ON20: Why or why not? It just has. It's met my needs. I've never, ever, really thought so much about OHIP [laughs].

Alison: Okay.

ON20: You know, you've been having away on it, and I just, I never even think about it.

Alison: Okay. Well, I'd like to ask now, overall how has your health insurance, um, how has it affected your experience with breast cancer care? And, I guess, starting with your OHIP coverage?

ON17: How has it?

Alison: How has it affected your experience, or what has it meant for your experience with breast cancer care?

ON17: Nothing. Like I say, you don't have to worry about it. So we never even think about it.

ON17's husband: Yeah. There's no correlation between it, because it just, it's there, you know.

ON17: Yeah.

ON17's husband: You don't have to think about it.

ON17: And you never had to worry about it or think about it.

ON17's husband: Yeah. And you're at a point, you don't think "OHIP is doing this." You don't think that.

In addition to describing lack of thought given to OHIP coverage, discussion of assumptions about OHIP was common. Half of Ontario participants spoke of *assuming* OHIP had covered one aspect of their breast cancer care or another. ON4, for instance, when asked whether she had used OHIP during breast cancer care replied, "I suppose. I have no idea. When you go to the hospital, you give them your card. And I guess that's it, sure. It would have paid for all that. It would have paid for chemo and everything else. Radiation and everything. I would assume they paid for all that." Or, as ON8 suggested, "It's all paid for. By the government I assume." ON13 reasoned, "I didn't pay for it, so it must have been paid through OHIP." Such responses reflect taken for granted assumptions about public health insurance coverage in Ontario.

Some Ontario participants demonstrated greater awareness of what OHIP did *not* cover than what it did. Three were strongly issue-oriented: while willing to answer interview questions they repeatedly returned to particular limits of OHIP coverage or aspects of breast cancer not covered under OHIP. ON10 spoke at length about her disappointment that OHIP had not provided for reconstructive surgery immediately

following her mastectomy. ON9 returned again and again to the matter of lack of OHIP prescription drug coverage outside of hospitals. ON12 focused on the limits to homecare. In these accounts participants tended to attach little importance to whatever OHIP had covered, even while noting it had financed the bulk of their breast cancer care. ON10, for instance, explained “everything that happened to me was covered totally by OHIP”. She was, however, almost entirely critical of her public coverage, explaining “I resent the fact that I wasn’t offered reconstruction at the time of removal.” Declaring “we don’t think big enough, because we, I, for instance, have only ever known OHIP”, she repeatedly praised a relative’s private health insurance coverage in the United States. ON10 went on to describe her own private health insurance plan in glowing terms—despite the fact it had covered relatively little in relation to her breast cancer care compared to OHIP.

In contrast to the taken for granted nature of OHIP coverage, Ontario participants were more aware of the private health insurance coverage they possessed. Individuals not only *knew* definitively whether or not they had supplementary private health insurance coverage but discussed private coverage with *enthusiasm* if they had it. Private coverage was especially praised for covering breast cancer related medication considered expensive, particularly *Neulasta* and *Neupogen*. Praise was apparent in comments such as:

Well, until I had breast cancer I wasn’t too pleased with it, but since I’ve got the breast cancer and, you know, and this \$3000 needle, I’m quite pleased with it [laughs]. And I think I’ll keep it up! (ON5)

Well, it’s been a benefit, for sure. For sure. Because, I mean, they just, the, um, cost of the drugs. I mean, I knew that the injections were about a \$2900 for the one single injection. (ON13)

It has been fantastic. *Fantastic*. To cover the expensive drugs that I've been taking. (ON15)

Such enthusiastic praise for specific benefits of private coverage provided a contrast to the off-handed taken-for-granted way that many spoke about the public coverage under OHIP that had financed the bulk of their care.

Ontario participants took on minimal responsibility for unpaid work in utilizing their OHIP coverage. This public coverage tended to be seen as *automatic* in the sense of operating largely without intervention by participants as is typical of a public good. Aspects of unpaid health insurance-related work—learning about coverage, intervening between insurers and providers, and addressing bills and other cost-related paperwork—were all either minimal or entirely absent in participants' accounts of OHIP coverage.

More than half of Ontario participants (13 of 20) reported that they had not sought out information about OHIP coverage for breast cancer care. ON9, reflecting a common sentiment, described OHIP coverage as “just common knowledge”. ON17's husband explained:

We know as a Canadian citizen, or a resident of Ontario, that everything, you know, things are covered. We can go see a doctor and that's covered by OHIP. Go into the hospital, and the surgeons and whatever's covered by OHIP. It's just, it's just a known fact.

As ON4 observed, “I never questioned. I mean, they just covered everything, so I didn't call and say, ‘Are you gonna cover this?’, ‘Are you gonna cover my chemo?’ I didn't enquire.” Among the participants who had sought information, five had obtained information from their health care providers and two had looked up information on

online. Overall acquiring knowledge of OHIP was not characterized as onerous, with most participants reporting they had not even undertaken this task.

Use of OHIP coverage to finance breast cancer care was reported to require minimal intervention by participants. As ON19 put it “Everything’s automatic.” Or, as ON13 explained, “Everything just went through.” In terms of intervention, participants mainly focused on showing their health card and renewing it as required. As ON4 observed, “You walk in, and you just, *cha-ching*, and that’s the end of it”. ON15 explained in more detail,

OHIP, I, that’s why I was curious about what you would ask about OHIP. Because it, I do nothing. It is just an assumed coverage benefit, when you live here. And, um, other than carry around a health card.... I’ve had my health care renewed. Which is newly updated with a photo and that sort of thing. So, other then, every time we move, you update your address for OHIP.

Other forms of intervention were largely absent from accounts of OHIP coverage. One exception was women who had had a prosthesis covered in part by OHIP who had to complete paperwork in order to submit a claim. ON13 described the process as “Very simple. Because the store where you buy it, fills out most of your purchase. And just marks where to fill in, and you send, that was no trouble, to just mail it in.” Paperwork had to be filled out meticulously, however, as ON1 had learned the hard way. She explained, “Um, and then when I sent it in, I missed filling out one date on one column so they sent it back to me. And I had to put that date in and send it back.” Paperwork was, however, otherwise conspicuously absent from women’s accounts of using their OHIP coverage.

Nor did bills or other cost-related paperwork—or the work of understanding, negotiating or paying them—figure in participants’ accounts of their OHIP coverage. As ON1 explained,

So, you know, if something does go wrong, here, you can feel, if you’ve got the OHIP coverage, that all your major bills, you’re not even, you don’t even see them. I couldn’t tell you what my treatments and that have cost. You don’t know. You don’t get any kind of a bill. You just get looked after.

ON6 was more succinct, simply observing “We don’t see what the costs are in Canada. They’re just paid.” Thus the task of addressing costs and bills did not feature in women’s use of OHIP coverage for breast cancer treatment. Overall, participants had to take on few responsibilities in using OHIP coverage, which operated largely automatically without their intervention and often with little awareness on their part.

Ontario participants took on more responsibility for performing unpaid work in using private health insurance coverage. Of the 12 participants who reported using their private coverage for breast cancer care<sup>49</sup>, all but one had taken steps to learn the specifics of their coverage. Typically, this involved reading manuals and calling or emailing to confirm details. ON13, for instance, described her private plan as involving “a lot of research on going back to what your coverage covers, and, um, what department to go through for, you know, wigs and prosthesis is this, and something else is this...”. ON2 spoke of consulting “Just the standard book. That my husband brings home. And I was always checking back, and saying, and then there’s the number. So you phone.... and they would give you the information. You know, saying, “Is this covered, is that

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<sup>49</sup> One participant, ON6, who had private coverage reported she had not used it in relation to her breast cancer care.

covered?” Participants had thus taken responsibility for educating themselves about the nature and workings of their private coverage.

Private coverage varied in terms of the intervention required of participants. Most participants had drug coverage that involved showing an insurance card, but needed to pay at point of purchase for other goods and services and complete and submit claims for reimbursement. Two participants, ON3 and ON4, reported needing to submit claims for drug costs and other eligible expenses as well. Submitting claims involved the work of obtaining and completing forms appropriately, saving and enclosing receipts, and mailing or emailing the claim and supporting documentation to the appropriate place. ON3 described the claims process as a “nuisance”, noting, “I hate doing the forms. I really do hate it [laughs]. It’s stupid, but I hate it [laughs].” ON13 acknowledged the knowledge and skills needed to prepare and submit claims. She observed “A lot of it was computer stuff. Which, I said, to me, I’m computer, not very literate, but I can work a computer. Whereas a lot of people wouldn’t have access to a computer, or, older people wouldn’t know how to, you know.” She mused, “I can’t imagine, you know, a little old lady being able to do all this and, and feeling really rotten on top of it, you know. Or maybe being alone and not having people to help her.”

Although participants typically reported the reimbursement process operating smoothly, this was not always the case. As ON1 recounted:

I submitted a claim to Sunlife actually, for the two prostheses. They sent it back, saying “No, you’ve got to go through the Ontario government first.” But they had wanted the original receipts. And then they, but I asked for them back, they said they destroy them. They sent me copies, which hopefully the Ontario government will accept. Once I get the money from the Ontario government, I will resubmit to my own insurance.



This situation had delayed reimbursement, which ON1 had not received at the time of her interview. Where participants did need to submit claims for reimbursement from private insurers this meant more work for them, work all but absent in using OHIP coverage.

In contrast to OHIP, bills and cost-related paperwork featured in participants' use of private health insurance coverage in Ontario. ON5 and ON12, who were interviewed at home, both brought out examples of such paperwork to discuss during their interviews. ON5 did so in order to support her point that her private plan offered limited coverage:

Okay, this one should tell me here. [pause] Oops. There, deductible \$120. That would be a year I suppose.....And \$29.99 co-insurance, whatever that is. You see, they get you comin' and goin'. See, your claim is \$412.97. So the total eligibility is \$269. So, they don't pay, they don't pay no 100 percent.

ON12 referred to such paperwork to emphasize her point about the expense of Neulasta:

ON12: Like, as an example, I took, um, Neulasta.

Alison: Mhm.

ON12: I don't know how to spell it. [Gets up to get paperwork.]

Alison: Okay.

ON12: I think this is. I took that, after every treatment. See the cost of it?

Alison: Oh gosh, well it says, it's, um, \$2,146.50. Is that the total?

ON12: It's the two of them together. There's your total.

Alison: Oh gosh, okay, I'm not even reading the right part here! So the total would have been \$2,684.13?

ON12: For one needle.

These examples are significant not because participants routinely brought out cost-related paperwork to discuss—most did not. They are significant because they represent an aspect of health insurance work absent from OHIP coverage of physician and hospital care, under which women did not have to see this kind of paperwork, much less decode it or negotiate or pay outstanding bills. With OHIP covering most aspects of breast cancer

care in Ontario, much of participants' coverage operated in a largely automatic way, without individuals needing to take on responsibility for the work of learning about coverage, intervening in its functioning, or addressing bills and other cost-related paperwork. While the reports of those who used private plans during breast cancer care suggest participants took on more responsibility for health insurance awareness and unpaid work in using these plans, the limited scope of private coverage in Ontario restricted the scope of this responsibility.

Individuals emerged as more responsabilized in New York participants' accounts of using their health insurance coverage. In the context of more commodified health insurance, health insurance awareness was obvious and participants assumed responsibility for more onerous unpaid work related to learning about health insurance coverage, intervening in its functioning, and addressing bills and other cost-related paperwork. While all participants were acutely aware of their health insurance coverage, whether private or public, in this context the work of using coverage varied.

The ideal of responsabilized individuals in relation to health insurance coverage was explicitly expressed in interviews conducted in New York State. This was, perhaps, most clearly distilled in the declaration "you have to be your own advocate", made by NY2 and echoed by two other participants with private coverage. The power of this ideal was, however, no less apparent in the words of those who saw themselves as failing to live up to its demands. NY14, describing her experience applying for Medicaid coverage, recalled,

I about flipped right out. You gotta walk in there and ask somebody to help you. Cause I already took care of myself. I mean, I've always been

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I about flipped right out. You gotta walk in there and ask somebody to help you. Cause I already took care of myself. I mean, I've always been

able to do that. And then you have to walk in there. And I know a lot of people that work there. And they look at you like, “What are you doing here?” And it’s embarrassing.

For this woman, use of public health insurance coverage was not “the norm”, as for Ontario participants, but a source of shame. In a similar vein, NY21 observed, “I didn’t want to feel like one of these people that use the system. Just because they can.” It was NY12, however, who put it most starkly, saying, “You know, the last resort was going to Medicaid. I hate begging, but I’d do it in a heartbeat.” In this context, individual responsibility for health insurance coverage was held up as an ideal to aspire to, both by women with private and public coverage.

In New York State, participants were acutely aware of whether or not they had health insurance. All could immediately explain what health insurance they had—or didn’t have—and were very aware of the importance of health insurance coverage in financing breast cancer care. Rather than being taken for granted, as was often the case in Ontario, public coverage was discussed with *enthusiasm* by those who had had it. Women with MCTP coverage particularly praised this program, underlining its role in financing care that would have otherwise been unaffordable:

You know, without it, I probably wouldn’t have gotten the amount of care that I did. Because if you don’t have insurance, I mean, it’s very expensive. If you can’t afford to pay for it, you don’t get it. And you die. I mean, that’s just the way it is. So, that’s why the Medicaid program that they have up here in New York State is awesome. (NY15)

I think it’s important. Because there’s going to be a lot of women out there that will do the same thing that I was going to do, and just let it go. Because they have no way to pay for it. (NY13)

I could *have* treatment [laughs]. It meant that I *could* have treatment. And I didn't have to, you know, just go home and say "Oh wow, can't do anything about it, I don't have insurance." (NY22)

The role of Medicare in this respect was also acknowledged:

Medicare has been, just, our, you know, our lifesaver. We would have lost our house. And everything else probably. If, you know, if we'd had to pay for everything. (NY11)

This participant had supplemented her Medicare coverage with private coverage. NY6, who had had Medicare coverage alone for part of her treatment before qualifying for Medicaid with a spenddown during certain months, was more circumspect in her assessment of the program, noting, "Well, it's been there, you know. I can't complain really. It covered a substantial amount of what my expenses were." The importance of public health insurance in financing breast cancer care was, however, recognized by women with public coverage of all kinds.

Women with private health insurance in New York also discussed their coverage with *enthusiasm*. Indeed, private plans were resoundingly praised regardless of the coverage they had provided. Only one participant, NY16, was outspoken in her criticism of a private plan—and this was after her coverage had been terminated in the middle of her breast cancer treatment. Those who still had private policies discussed them in glowing terms, describing coverage as "fabulous"<sup>50</sup>, "very good"<sup>51</sup>, "fantastic"<sup>52</sup>, "phenomenal"<sup>53</sup>, "a model"<sup>54</sup> and "probably the best anywhere".<sup>55</sup> When asked about the

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<sup>50</sup> NY1 used this term.

<sup>51</sup> NY2, NY3, NY10 and NY19 used this term.

<sup>52</sup> NY4 used this term

<sup>53</sup> NY5 used this term.

<sup>54</sup> NY7 used this term.

<sup>55</sup> NY9 used this term.

reasons for such assessments, participants generally explained that, as NY2 put it, their plan had covered “a lot of stuff”. In addition to coverage of breast cancer related expenses, private plans were also praised for providing information,<sup>56</sup> having “very few qualification or stipulations”,<sup>57</sup> or working well with doctors and hospitals.<sup>58</sup>

In discussing their private health insurance coverage, seven participants declared themselves “fortunate”<sup>59</sup> and two others described themselves as “lucky”.<sup>60</sup> Over the course of interviewing, it became apparent that these enthusiastic assessments occurred in the context of participants comparing their own circumstances to those of women with less coverage or no health insurance coverage at all. Comments reflecting such comparisons included:

Um, and quite honestly, if I am being completely honest, it angers me that I probably got additional care that others could not get, because they wouldn't have been able to afford it. (NY1)

I have had friends who were not covered, particularly for the Neulasta. At \$1500 to \$1800 a shot. I've had other friends who, you know, not necessarily this insurance won't pay for this cause, you know, they consider the reconstruction cosmetic. Or they consider this whatever. I mean, I've heard. And then just in general. I mean, I went on several blogs on the web at the time, and you know and stuff. And there were women who were really battling.... I mean, there were all kinds of issues that were floating around at the time. And I was amazed that none of those were applicable to me. (NY7)

I feel guilty, for, I can still tear up about it [pause], people who aren't as fortunate as me. That's not fair, you know. It's like a survivor's guilt sometimes. It's for people who may have not had health insurance or not as good as health insurance as you had. So their care wasn't as good. So

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<sup>56</sup> NY5 and NY7 praised this aspect of their plans.

<sup>57</sup> NY9 praised this aspect of her plan.

<sup>58</sup> NY10 praised this aspect of her plan.

<sup>59</sup> NY1, NY2, NY3, NY5, NY7, NY9 and NY19 used this term.

<sup>60</sup> NY and NY10 used this term.

their long term prognosis, or even short term prognosis, may be quite different than mine. So, you know, you do think about that. (NY4)

Notions of good fortune in relation to private coverage can thus be understood in the context of awareness of un- and under-insurance in the United States.

One interaction in particular raised questions about freedom to criticize private health insurance in this context. Before beginning her interview, NY5 asked what would happen to interviews conducted for my study. She listened politely to a lengthy description of the research process before clarifying that her actual concern was whether I would be *reporting what she said to her insurance company*.<sup>61</sup> NY5 was alone in bringing up this issue; however her concern does raise the possibility that she—and other participants—may not have felt at liberty to speak critically of private coverage that could be lost. In New York State, awareness of health insurance and its role in financing breast cancer was acute and pervasive. Far from suggesting they had not thought about health insurance coverage, participants' enthusiastic accounts of private and public coverage alike emphasized acute awareness of the importance of health insurance in financing breast cancer care.

Participants' discussions of using health insurance coverage in New York State suggest they were not only acutely aware of health insurance coverage and its role in financing breast cancer care but also assumed more responsibility for unpaid work involved in utilizing public and private health insurance coverage than did participants in Ontario. Aspects of health insurance work—learning about coverage, intervening in its

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<sup>61</sup> I emphasized that this was not the purpose of the study and carefully explained about confidentiality as outlined in the informed consent document NY5 had signed. She appeared satisfied, and we proceeded with the interview.

functioning, and addressing bills and other cost-related paperwork—varied among participants, with those with private health insurance in particular taking on more responsibilities in these areas in using their coverage.

The theme of ‘responsibilized individuals’ in learning about private health insurance coverage was clearly captured in words that NY17 recalled an insurance company representative once using to admonish her: “Well, it’s your coverage. You should know”. Learning about the details and operation of coverage was a task undertaken by most participants with private health insurance, often repeatedly. Of those with private coverage, ten discussed taking steps to learn about their plans. Literature was not, however, characterized as helpful in this respect. As NY4 explained, “It’s all in lingo that you cannot understand.” Or, as NY17 described having told her insurance company representative, “Well of course you send me that paper, and it means nothing to me when you look at that. You know, it’s all technical whatever. It means nothing to me.” With the terms of private coverage both complex and variable, participants were most likely to call their insurance company directly<sup>62</sup> and sometimes consulted human resource departments of employers as well.<sup>63</sup> A few women discussed obtaining information at the offices of health care providers.<sup>64</sup> One didn’t discuss the issue.<sup>65</sup> Only NY16 described herself as not seeking out information about her plan, saying “I didn’t. I was sort of like blind on that part.” This was the woman whose private plan had been terminated during her breast cancer treatment.

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<sup>62</sup> NY1, NY2, NY3, NY4, NY5, NY6, NY9, NY17, and NY19 described having done this.

<sup>63</sup> NY4, NY7, NY9, NY17 and NY19 described having done this.

<sup>64</sup> NY1, NY2 and NY11 described having done this.

<sup>65</sup> NY10 did not discuss this.



Participants described receiving different levels of support in efforts to learn about their coverage over the course of their breast cancer care. Two participants, NY5 and NY7, were assigned a particular nurse, an insurance company employee, who, as NY7 put it, acted as a “liaison with the insurance company”. As NY5 explained, she “answers a whole ton of questions for you. Helps you make your decision. Gives you all kinds of questions to ask the doctor.” Others, such as NY4 and NY9, dealt with particular health insurance representatives. NY4 explained, “We have a representative at our health insurance office, and I made a lot of phone calls to her. We really bonded. And in fact she gave me her home number, so if I was somewhere and I couldn’t get a hold of anybody at the health insurance office, it was after hours, I could call her up at home, and say, you know, “Is this covered?” Others simply reported calling a general information line and speaking with different representatives each time. Overall, participants’ accounts underlined both the need to assume personal responsibility for knowing the precise details of their coverage and the ongoing nature of this work involved in learning these details over the course of breast cancer care.

Women with private coverage in New York often needed to take responsibility for intervening between insurers and health care providers. In this context, maintaining and presenting a health insurance card was typically the most straightforward task discussed but not the only one. Participants’ accounts pointed to various kinds and quantities of paperwork, with some placing more emphasis on this than others. Roughly a third of New York State participants with private health insurance suggested they had done little

or no insurance paperwork in relation to breast cancer care,<sup>66</sup> yet answers to more detailed questions about activities revealed unpaid work of this nature was often simply taken for granted. Women routinely received “explanation of benefit” (EOB) papers, outlining the costs their insurer had covered—or not. Where no money was owed, these statements could be and were looked over and filed away. As NY7 explained,

I had, I received, mounds actually, of, oh god, what do I want to call them. Sheets that told me what had been paid. You know, this was for the radiology, this was for the chemo, and this was for the whatever, so on. But it was more informational. I didn’t have to deal anything with that. So what I did is, I just took them, I put them in my thing, you know “patient responsibility zero”. That’s it, thank you very much, put it in my little thing so I had it.

When money was owed, however, participants needed to take responsibility for paying or negotiating outstanding bills. NY5, who had one of the highest incomes among New York State participants, described simply paying bills. As she put it, “We receive them in the mail...just put a cheque back in the mail, and that’s it.” Other participants described questioning and negotiating particular bills they received. NY1, for instance, discussed challenging a bill for a test she had taken care to have her doctor’s office obtain pre-approval for, explaining,

...ironically, I got a bill much later. A month later. It was like a \$1500 bill. And I called my insurance company, and I said, ‘*Why* did you deny this?’ And they said ‘Well, this is a new....’. It was like cutting edge MRI, some diagnostic something they did. And they said, ‘We don’t cover it.’

NY1 described how she had pursued the matter with the hospital, explaining “So, I called....and I said, “‘It would have been nice to know that this was gonna cost me 1500 bucks out of pocket’. And they said ‘No, it’s not. You don’t have to pay for it.’ In this

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<sup>66</sup> NY3, NY10, NY11, NY16, NY17 and NY19 made comments to this effect.

case the hospital did not pursue the matter further. NY4 described a similar situation surrounding her insurer's failure to pay for a pre-approved consultation about genetic testing, explaining how in the end she had successfully applied to the hospital for "medical emergency relief of bill". NY9 also discussed confusion surrounding payment for genetic testing, which was ultimately not covered although she had petitioned her insurance company to do so after the test was performed. In the end the hospital required her to pay only part of the bill. NY7 recounted needing to intervene when bills arrived unpaid because providers sent them to the wrong branch of her insurance company, with this mistake occurring repeatedly.

One participant, NY2, spoke at length about the work involved in monitoring her explanation of benefits forms (EOBs) and bills, carefully detailing how she uncovered and challenged errors:

...each time I get a bill I'll go through it and I'll look, I'll connect it to the last one. And see, well this was paid, that was paid, why is this one here again? And I, you know, I go through it, you notice, I have a highlighter marking that that was paid, and why are you giving it back to me?

[Showing a bill] So I take care of those....

Alison: Who would you have to deal with? With the billing office yourself, or the insurance?

NY2: Well, I'll talk to the insurance people first. Because each time you get a bill, you do get some kind of documentation from the insurance company. So you put them together. You know, like if you have a deductible, or you know, whatever it is. There is a connection with both of them. This is what the insurance cover, this is what it did not cover. So, the doctor's office bill should correspond with that particular document. So I'll have those connected together, I have a filing cabinet, so things are filed in my two drawer cabinet. So things are in order. If you don't have them in order, then you have no idea what's going on. So, sometimes you'll have more problems with the doctors' offices payments, than the insurance itself. Sometimes you think you're having problems with the insurance, but it's really the doctor's billing office....

Alison: Were there times when you found discrepancies, or differences, between what you should have paid...

NY2: Yes, yes. And they have to, um, what they call it now, do over all the paperwork. I don't remember what's the correct word for it at this time. But they'll have to, the doctor's office have to send back in a new bill and fix it. 'Oh, we had a wrong code, we put in the wrong code'. And this thing cost \$400, why was I charged \$2000?' You know. Or, '\$150, why was I charged \$1500? This is not right. Will you please give me an explanation. Why is this different? Cause all the other drugs I've taken, they're for this price.' It was a computer error, sometimes. Or, they put a wrong code in. There was a wrong code. Instead of paying \$150, it was \$1500. And it's like, what if you don't check it? ....So, I made sure that things were okay. So there was a lot of errors, in the office, more office bill problem than the insurance itself. So you really have to be on top of it, and make sure each time you get a chemo treatment, it's the same thing your getting each time you go, so it should be the same, it's not a different medication, so why should you pay a higher price? 'Why is it different this time, from my last time? It doesn't make any sense. You know, so, would you please explain that to me.'

NY2 was the only participant to discuss tasks involved in dealing with EOBs and bills at this level of detail. Her step-by-step description of her activities meticulously decoding statements and challenging errors is useful, however, in exposing aspects of health insurance work others glossed over. Thankful for what they saw as their good fortune to have private coverage, participants did not necessarily recognize or attach importance to the work involved in using their private coverage. When discussing activities they had taken responsibility for completing, they sometimes minimized their significance rather than reflecting on their importance.

Participants using forms of public coverage in New York State also needed to take responsibility for intervening in its functioning. With variation in public health insurance coverage, participants needed to learn about the details of specific programs. Those with MCTP coverage resoundingly praised the local Cancer Services Program

Coordinator, who was responsible for program enrollment, for her assistance in this regard. As NY16 put it, “She tells me everything I need to know.” This coordinator was exceptional in bringing information to participants rather than leaving them with the responsibility to seek it out.

Participants with other kinds of public coverage rarely reported this level of support. NY8 had learned about her Family Health Plus and “regular” Medicaid coverage through her social services case worker. NY6 reported reviewing her booklet and calling the company administering her Medicare Advantage plan, but seemed to have learned about her Medicaid coverage primarily through the patient navigator at the hospital where she was receiving her treatment. NY11 and NY20 relied on doctors’ offices for information about Medicare coverage. Thus even participants with public coverage sometimes needed to assume responsibility for learning about the details of specific programs and plans.

Other interventions involved in using public health insurance typically revolving around qualifying and re-qualifying for coverage as required. Those with MCTP coverage largely relied on the assistance of the Cancer Services Program Coordinator described above, who not only helped them to enroll in the program but provided ongoing support over the course of their coverage. NY15 characterized the MCTP enrollment process as “Very easy. I mean, I met with K---- the first time, filled out paperwork....And then after, once I got approved, every year she just calls me over the phone, asks if I’m doing okay. Sends me a form, or I go over to her office and sign it, and

that's it. Very simple." NY14 bluntly told me, "That's why I call her my angel, because she did everything."

Other forms of Medicaid coverage emerged as more labour intensive in participants' accounts, involving the need to qualify and re-qualify more frequently. NY6 drew attention to the work of organizing, copying and submitting paperwork related to income and medical expenses, necessary for establishing that she had met the monthly "spenddown" required of her under the Medicaid Excess Income Program. Having brought boxes of paperwork to our interview, she reflected,

You sit there for hours [laughs], trying to sort this mess out. And what's fun, is when you apply for a program, like when I was applying for Medicaid. Yeah, you know, my navigator did the sending the stuff in, but I had to go through all the paperwork to sort out what was what. And make copies and dadada.

With the need to continue to re-qualify for Medicaid and establish having met her spenddown from month to month, such work was ongoing.

While individuals' tasks in using public coverage largely revolved around routine paperwork for many participants, NY12 and her husband described waging a protracted struggle to obtain and maintain Medicaid coverage. As they explained,

NY12's husband: We had to fight to get it.

Alison: The Medicaid?

NY12: Oh *yes*. It took me seven months before I could even start my chemo.

Alison: Oh gosh, what happened?

NY12: The papers were on their desk. And it took 'em *seven* months.

NY12's husband: They didn't want to give it to us at first. The way it really started was, I didn't have no insurance neither. And she was trying to get help. And then I ended up had a heart attack. And I went to [the hospital], and they wanted, they were big bucks. They weren't little thousands of dollars.

NY12: Yeah.

NY12's husband: And I tried to apply for it, well, "You can't get it". So, I got hold of [Senator] Darrel Aubertine, and Governor Pataki, and I tried them all. And that was the

*only two* that helped us. So we got coverage. And then she ended up, they weren't going to put her on. So I got hold of Darrel Aubertine again, and he got her on to it. NY12: That's the only way. We had to *fight*. We really did.

NY12's husband explained NY12's Medicaid coverage had later been cancelled when her income was incorrectly recorded, an error that had to be addressed in order for her coverage to be reinstated. In discussing their experiences, NY12 and her husband emphasized the difficulty of gaining coverage and the persistence of NY12's husband in researching options and actively seeking out assistance that was all too often denied. Their experience is a testament to the fact that Medicaid coverage did not always function smoothly, at times requiring sustained and labour-intensive intervention.

The final aspect of health insurance work considered, addressing bills and other cost-related paperwork, did not feature in discussion of all public health insurance coverage in New York State. This did not figure in accounts of using MCTP coverage. As NY22 succinctly stated, "It was all covered. Never had a bill. Never saw a bill." However, medical bills and related paperwork did figure in accounts of other Medicaid coverage. NY6 and NY8 needed to meet "spenddowns" for medical bills in order to qualify for Medicaid from month to month. NY6 described her process for submitting bills for Medicaid coverage as follows:

Okay, so now, what I do, is I take this bill, which I just got, and this amount, and I send it to Medicaid.... Medicaid says, "We'll send this, we'll process this, and you don't have to pay anything on it, we'll determine how much of this you really will have to pay." So, that's what I do."

Gesturing to stacks of bills and statements she had piled on the table between us NY6 confessed, “I try to organize it. I try to keep it, but you know, I miss my anti-depressants [laughs]. To tell you the truth.” Bills were —literally—a central feature in this interview.

The work of Medicare coverage consisted in part of obtaining and maintaining additional coverage to fill its gaps, whether through private plans (NY10 and NY11) or public plans (NY6 and NY20). With “basic” Medicare as well as privately administered Medicare Advantage Plans, it also consisted in choosing and enrolling in an appropriate plan. As NY6 described it, “when you become eligible for Medicare, you also become eligible for one of the [privately administered] Medicare Advantage plans. They send you a booklet, a notice, and then once a year, you can sign up for a plan, okay.”

Choosing between plans was not always a straightforward matter. NY20 recounted how she had switched from “basic” Medicare to a privately administered Medicare PPO because a friend “*swore* it was a better program, she was getting so much more out of it than she did with Medicare....And I listened to her. And, next month, when you can change back, *I’m goin’ home*.” NY20 was planning to “go home” to “basic” Medicare coverage because her Medicare PPO was requiring her to use a preferred provider for a prosthesis that she had found she could purchase less expensively from an on-line supplier. This participant was, however, overt in her praise for Medicare more generally precisely because of work it had not involved. She observed, “It was excellent, covered everything. No problems, no glitches. Actually, better than Blue Cross.....Didn’t have to fight them about drugs or coverage. They just paid it....Which is a lot better.” Having earlier financed treatment for another type of cancer using private health



insurance and battled for coverage of a life-saving drug, NY20 appreciated that Medicare coverage of her breast cancer care had not involved this kind of struggle.

Overall, participants' accounts of their health insurance experiences in relation to breast cancer care in New York State suggest more highly responsibilized individuals than do the accounts of participants in Ontario. In the context of a more highly commodified health insurance system in which coverage was exclusive, precarious and varied, participants with both public and private insurance coverage were more acutely aware of the role of health insurance coverage in financing breast cancer care and took more responsibility for performing unpaid work related to its functioning. Health insurance was not something that any New York State participant could afford to take for granted, as participants in Ontario often did with public coverage through OHIP. The work of using coverage did not begin and end with maintaining and presenting a health insurance card, as it was largely considered to under OHIP, but involved ongoing efforts to learn about coverage, intervene in its functioning, and in some cases to address bills. While health insurance work varied among New York participants with different public and private plans, assumption of individual responsibility for clarifying details of coverage, intervening, and addressing bills and cost-related paperwork was more apparent overall. Whether public or private, coverage in New York State did not function automatically, as OHIP coverage was largely seen to do in Ontario, but required time and effort from participants and in some cases their family members.

While public coverage through MCTP involved relatively little work compared to other forms of coverage in New York State, NY12's harrowing struggle for Medicaid

coverage underscores that obtaining and maintaining public insurance was not always easy in this jurisdiction. Moreover, while participants who felt fortunate to have private coverage sometimes attached little importance to responsibility they took on for unpaid work involved in using their health insurance in relation to breast cancer care, details of their activities suggest the scope of their work in this regard was larger and effort more continuous than in the accounts of Ontario participants with private plans. While the work of using private health insurance coverage in Ontario was similar in form, the restricted scope of private coverage in the province meant this work was much more limited in scope and volume. Ontario participants were often more aware of private coverage than public, lauding private coverage that had played a relatively minor role in financing breast cancer related expenses while devoting relatively little attention to the public health insurance program that had financed the bulk of their care automatically. Although the theme of ‘responsibilized individuals’ in relation to health insurance for breast cancer care was apparent to varying degrees in the accounts of Ontario participants, individuals were more pervasively and onerously responsibilized in New York State.

### **Gradation: Extreme Consequences in New York and Broad Protection in Ontario**

The overarching theme of ‘gradation in consequences’ addresses differences in participants’ experiences of the consequences of methods of financing breast cancer care. Thus while the theme of ‘commodified coverage’ addressed the terms on which participants accessed health insurance and the theme of ‘responsibilized individuals’

addressed its usage, this theme concerns participants' experiences of the repercussions of coverage—or lack thereof. The focus in this section is on participants' accounts of the material and psychological ramifications of health insurance coverage, encompassing financial, practical and emotional implications as well as concerns in looking toward the future. In the context of more commodified health insurance and more responsabilized individuals in New York State, **more extreme gradation** in the consequences of financing breast cancer care was apparent in this setting. In Ontario, with less commodified health insurance and less responsabilized individuals in relation to coverage, **less pronounced gradation** in participants' experiences was apparent, with participants reporting broad protection from unwelcome consequences in financing breast cancer care.

In the context of inclusive, stable and uniform public coverage through OHIP, Ontario participants' accounts of the implications of funding breast cancer care were broadly similar. OHIP coverage had financed physician and hospital care for everyone, with little unpaid work and often little awareness on the part of participants themselves. In this context lack of worry about costs of breast cancer treatment was pervasive. This matter was explicitly discussed in most (17 of 20) interviews and evident in comments including:

Because of the insurance there wasn't the worry about, you know, whether money was going to be an issue. I could go ahead and concentrate on the fact that I needed it done, and get it done. (ON1)

Um, because, the last thing you want to worry about when you're sick is nickeling and diming and "Can I afford this, or can I afford that? Or do I have to wait 'til next month 'til we've got a little surplus in the budget? You don't think of those things. (ON2)

You don't, it's not, I mean, I think you have enough things to worry about, and that, for me, for us, in this province and this country, are simplified. (ON4)

Well it just relieves the stress. I mean, it's stressful enough to have the disease, but to have a financial burden as well must be terrible. Because that would really overload you. I would just be, really, really stressed if I thought I had to pay money, you know, for this, or to get the treatment I need. Because some people, I guess you wouldn't be able to have that if you didn't have the money. (ON8)

Well, it gives you, um, a feeling, of, um, security that everything's covered. That suddenly somebody's not gonna turn up on the fifth session and say "Oh well, now you have to pay \$10, 000 or \$2, 000." I know it's gonna be covered. (ON14)

It's taken the challenge of dealing with the breast cancer, it's taken the negativity away from it. Because you can concentrate on your health. And getting better. Rather than worrying about the next \$50, you know. (ON16)

The three participants who did not touch on the idea of not having to worry about costs covered by OHIP had other preoccupations. ON9 focused on the difficulty of paying travel and living expenses without income coming in from her small business. ON10 focused on lack of OHIP coverage for reconstructive surgery at the time of her mastectomy. ON13 focused on shortcomings in psychological support for breast cancer survivors under OHIP.<sup>67</sup> The details of these participants' accounts did not reflect different OHIP coverage. Rather, these participants did not discuss the importance of the costs covered by OHIP as most other participants did.

In aspects of breast cancer care not covered by OHIP, gradation was more apparent in consequences of financing breast cancer. As not all participants had private

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<sup>67</sup> Interestingly, the role of OHIP in financing psychological support was grudgingly praised by ON10.

insurance coverage and not all of those with private coverage had the same coverage, out of pocket expenses varied. Participants with public and private coverage reported spending varying amounts of money on prescription drugs and breast cancer related equipment such as prostheses, wigs, bras and things like clothing and nutritional supplements. Public programs beyond OHIP were reported to have covered some costs related to prescription drugs for some participants both with and without private coverage. The following nine participants had ODB coverage: ON1, ON4, ON5, ON6, ON7, ON8, ON11, ON19 and ON20. One participant, ON16, had prescription drug coverage under ODSP. Four participants, ON3, ON9, ON10 and ON18, reported receiving lower cost medication through the intervention of a hospital or local Community Care Access Centre but were unclear about the details of how public payment had functioned. ON3, for instance, remarked, “And I don’t even know who came and talked to me. Whether it was, I don’t really know who they were [laughs]. I was sittin’ in the waiting room and they come over and talked to me. Okay! [laughs] There must have been some way they did it [laughs].” ON9, ON14 and ON18, who had OHIP coverage only, reported out of pocket expenses related to prescription drugs beyond co-payments.

Neither public nor private health insurance in Ontario was reported to cover the expense of travel related to breast cancer care. While Ontario’s Ministry of Health and Long Term Care does offer the Northern Health Travel Grant Program to assist Ontario residents in some designated northern communities who need to travel to access medical specialists or health care facility services that are not available locally, Lanark and Leeds

Grenville are not located in the northern areas covered under this program (Ontario Ministry of Health and Long Term Care, 2012b). Travel costs dominated participants' discussions of out of pocket expenditure related to breast cancer care. As Lanark and Leeds Grenville is largely an area of rural and small communities, breast cancer care involved trips to larger centres for treatment, typically Kingston or Ottawa. Participants reported paying various out of pocket costs associated with travel, including gas, parking, meals and sometimes lodging. With the repetitive nature of treatments such as chemotherapy, radiation, and ongoing tests, these costs added up even when participants were able to keep receipts and use them to claim some income tax deductions (Canada Revenue Agency, 2013).

Travel expenses affected participants' budgets to varying extents, with some finding them more burdensome than others. At one end of the spectrum, ON11 and ON18, who had among the highest household incomes reported by Ontario participants, considered out of pocket expenses insignificant. As ON11 quipped, "I mean, a few tanks of gas to go to Kingston is not excessive. You know, it's in most people's capabilities." At the other end of the spectrum, ON9, who was self-employed and unable to work during treatment, found out of pocket expenses such as those for travel difficult to manage in the context of struggling to pay her bills:

Oh it was hard. Very hard. I mean, each, you know, I would always have to think, like, "Okay, am I gonna have enough money to, you know, pay for this?" So, yeah, it was stressful. Like I always looked to my family to help me out. I mean, I'm happy that they were there to help us out with whatever I needed to pay for. Um, there wasn't really anything, yeah, like I said, it was just, you're always thinkin' ahead, to make sure that you have the money to pay for stuff. That was pretty much it. So yeah, it was very stressful. Very stressful.

Between these extremes, participants were aware of and budgeted for out of pocket costs, including those related to travel, but were able to pay them. As ON17's husband said of expenses related to her care,

We've had to add it in to our budget. It's still something we've gotta factor in when we do our budget. Ah, but right now, like I said, my income's gone down a lot, 'cause I'm off of work 'cause of this [serious illness]. And I'm on EI right now. Ah, so it's affected us. But, so, this point in time, yes, we're thinking of it. But, everything's still doable.

Thus out of pocket expenses were more of a burden for some participants than they were for others.

Out of pocket expenses related to breast cancer care were sometimes partially offset by financial or other limited assistance from the voluntary sector in Ontario. Nine participants reported they had not received any kind of financial support from charitable programs or non-governmental organizations. Four participants had used drivers provided free of charge by the Canadian Cancer Society. Three participants had received financial or in-kind support from other groups. ON2 had received a quilt. ON13 and ON15, both mothers of young children, had received money or gift certificates for food and gas through fundraising involving friends, co-workers and/or family members. Additionally, four participants reported that part of the cost of some drugs had been paid for through the Victory Program, which the pharmaceutical company Amgen describes as a "patient assistance program".<sup>68</sup> Overall, financial support provided through charitable programs

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68 Significantly, ON4 challenged the idea that such assistance was purely altruistic. As she explained, "I was thinking about how nice that was, until I started talking to my daughter. And she says, 'Well of course. They want you to take the drug. So they're gonna make a lot of money on it.'"

and non-profit organizations was not especially extensive or widespread, playing at most a minor role in participants' accounts of financing breast cancer care.

When discussing the non-profit sector, most of Ontario participants who had not received support from this sector simply made a comment to this effect. ON11 elaborated by noting "I'm the one in the charitable organizations [laughs]. Doing the fundraising. No. No, I haven't received. I don't need it." ON14 observed that she had not received support "Cause I haven't asked for it [laughs]." Such comments suggest support was not received because it was not sought out or needed.

Only ON12 discussed having sought assistance from non-profit organizations without success. This participant recounted requesting transportation from branches of the Canadian Cancer Society only to find she lived just outside of the zone covered by one and in an area which did not have drivers. As she explained,

When I called, the woman said, "Well, we don't have a driver in [that location]. So, it'll depend, I'll post it on the board, and see if somebody wants to go." And I'm like, "When do I find out. You know, that's not been picked up by somebody?" "Well, I can let you know 24 hours before." I said, "That's not going to help me. Where am I going to find somebody to take me in less than 24 hours?"

ON12 subsequently organized drivers for each trip by asking people she knew. During treatment she struggled with basic daily activities including cleaning, laundry and meal preparation while ill and requested support from a local independent living organization. She found, however, that she was not old enough qualify for assistance. As she explained, "everybody kept saying to me, "Well, there's this [organization]" And so when I contacted them they said, "No, you don't qualify. You're too young." And I'm like, "But



I'm the one with cancer!" In this case, assistance from the non-profit sector was not forthcoming even when requested.

Overall, the accounts of most Ontario participants suggest the expense of breast cancer care itself posed relatively little financial strain. Of the 20 women interviewed, 16 reported experiencing little or no financial fallout from breast cancer. Succinct comments reflecting the absence of financial burden included "It really hasn't affected us" (ON19) and "It really hasn't made any difference" (ON7). ON1 addressed this issue at greater length, explaining,

And again, knowing that there wasn't going to be any financial restraint that would make you say, "Oh, better not take a holiday." We could go ahead and do that. I think that's pretty darn good [laughs]. So, yeah, I think that the fact that we have this coverage. You know, may have some that are, relatively, let's face it, minor bills when it comes to medical expenses, compared to the actual cost of the surgery and the treatment and that. It literally did not interfere with us going on the cruise in the Caribbean.

In this case, expenses related to breast cancer care were not significant enough to interfere with the luxury of a vacation abroad.

The four participants who did discuss being affected financially by breast cancer, ON3 ON9 ON13 and ON15, focused on loss of income from employment rather than on medical bills. Comments on this topic included:

It didn't cost me money to have breast cancer other than being off work.  
(ON3)

Like I say, when you own your own business, you're, you know, you can't, you got no income coming. You can't fall back on an appointment. Um, things like that. So, yeah, financially, it's very, very hard. I don't wish it upon anybody. I don't wish it upon anybody to get their own business. Because you never know what's around the corner, you could get sick. (ON9)

Such remarks underlined that breast cancer had imposed financial strain beyond the expense of care itself, as illness had resulted in inability to work and lost wages.

Looking forward, Ontario participants expressed few worries about the future in relation to their public health insurance coverage. Most (15 of 20) simply stated this was not a concern. The sense of complacency apparent in most responses was captured in ON9's comments about OHIP: "I don't, right now I don't have any worries about it. I'm assuming it should be there for me, if I ever needed it again. Like if I needed to get into the hospital or go see my doctor. I'm assuming that it's always going to be there, so no, I don't, I'm not worried about that at all, no." In the context of participants' accounts of lack of thought about, and assumptions regarding OHIP coverage, such lack of concern is not particularly surprising. Concerns, when expressed by a few participants, focused on its continuation, forms of privatization, and the impact of cost-cutting. Comments included:

I hope they don't stop it [laughs]. (ON19)

Well, the health care system is in, um, a bit of a bind really, because the population's aging. I mean, we're all living longer. And there are less employed people to cover this. So, I hope we never go to a two tier health system, but it could possibly happen. (ON11)

Well I just wonder if government funding, and if it's going to become too expensive for it to be continued as it is. And whether or not there will be more privatization. (ON8)

Um, I would hate to think it would be privatized. Because I have a real problem with our tax dollars are training doctors. And then if those doctors are trained with our taxpayers' money and they go off in work in a private clinic, then, I think they should repay the money [laughs]. I really do. (ON14)

I just hope that they don't mess with it too much [laughs]. You know, again, it's, it's the kind of thing where, I think, um, I understand, you know, it's, there are people [pause]. OHIP is a huge government program. It costs the government a lot of money. There will be efforts, you know, going forward to try and, and keep those costs reasonable. Um, and I hope they manage to do that without diminishing the, the program itself. So, fingers crossed they'll be able to do that. (ON18)

Private coverage was a concern for a few participants. One participant, ON1, worried about the \$15,000 lifetime cap on her coverage. Another, ON11, was concerned about being able to obtain travel insurance. Two more, ON8, ON15 worried about the stability of private coverage in retirement. ON18 stood out in expressing concern about the role of private companies in health insurance in Canada more generally, stating:

I've got a bad feeling about the insurance companies. Let's put it that way. I just have a bad feeling about them. Because I think that they are, again, they're in the business of trying to, to make as much money and spending as little money as possible. And, hey, they're a business, and they're allowed to do that. It's just I think it's, it's not at all transparent. Insurance companies aren't even remotely transparent. And I think that's wrong. I think that's very wrong.

As she went on to explain,

Well, it's just that, it's, I do not want, ah, Canada to, to, I know there's probably lots of private industry out there that would like Canada to go the way of the United States. And I think that's a huge mistake. And what I don't understand it why it would be, the lack of health care, proper health care in the United States, causes huge problems for their industry and for their companies, so why would they want to go that way? I don't understand it.

Her analysis was exceptional in considering broad problems posed by the privatization of health insurance in Canada. More generally, however, Ontario participants' comments reflected a sense of complacency about a health insurance system centered on public health insurance coverage with less commodified health insurance, less heavily

responsibilized individuals in relation to coverage, and less gradation in health insurance and its consequences.

‘Gradation in consequences’ of financing breast cancer care was more extreme in the accounts of participants in New York State. In this context, variation in financial, emotional and practical consequences was very apparent. At one extreme, participants who were un- or underinsured at the time of their diagnosis reported great hardships of financial loss, emotional distress and delay in care in cases where Medicaid was not obtained promptly and maintained consistently throughout treatment. When Medicaid was obtained expeditiously enough to cover the expense of treatment, however, this averted hardship at least during the limited duration of coverage. At the other extreme, women with comprehensive private insurance plans and sufficient financial resources to cover the costs associated with maintaining and using them considered their plans had offered them complete protection from financial, emotional and practical hardships in financing breast cancer care. Yet as private plans varied in coverage and associated costs and participants’ financial resources differed, having private health insurance coverage when diagnosed did not necessarily fully protect participants from financial, emotional and practical costs associated with paying for breast cancer care. Some participants reported facing incomplete protection from hardship even when they had private health insurance coverage for breast cancer care.

NY12 and NY14 had both been uninsured when diagnosed with breast cancer and had *not* obtained MCTP coverage quickly enough to stave off great hardship. For NY12, the financial, emotional and practical consequences of struggling to fund breast cancer

care were devastating. She began by explaining, “We just couldn’t pay out of pocket, so we used credit cards, and it’s a big mistake in our own.” The results of this “mistake”—her only way to pay for treatment—are captured in the following exchange with her husband:

NY12’s husband: Put us in debt more.

NY12’s husband: *Oh* yeah. We were so far in we didn’t see daylight. It was horrible.

Alison: And how did it end up going, or getting worked out?

Husband NY12: It went to bankruptcy.

NY12’s husband: We filed. We went to a lawyer. Paid him off. Took us six months. Paid him off. Filed bankruptcy.

NY12 went on to report that her delay in acquiring Medicaid coverage had delayed her chemotherapy. Describing her experience as a “nightmare”, she recalled,

The chemo, I had to wait seven months. After the surgery. Seven long months in order to get the Medicaid. Because they would *not*. The chemo is *so* expensive, I can understand. I couldn’t even afford it.

She grimly recounted being told to leave her oncologist’s office, concluding “If you had had no insurance, no money, forget it”. Her ordeal had taken an emotional toll. As NY12 put it, “oh, we were down a lot. Crabby. I’ll be honest, I was a royal you-know-what. You know, you try to struggle day by day. People don’t realize. You’re struggling to figure out where the dollars are going to come from, and where you’re going to spend ‘em.”

NY14—who observed “Breast cancer of any kind is not cheap, believe me. I’m well over \$250, 000.”—faced dramatically reduced financial circumstances as a result of trying to pay for her care. She explained, “At this point, I’m still making payments to doctors and hospitals. You know, I’ve signed my life away to all these different bills that

I owed.” She recounted that she and her husband had had to sell his childhood home, reporting “we had property, and we sold this house.....That’s how I paid a lot of my debt off to cancer.” NY14 went on to say,

It just [begins to crumple plastic water bottle in her hand], it just, well, we don’t have any savings. Our retirement is gone. We don’t have. I mean, we had money when he [her husband] retired. And we were going to travel. Well, that’s gone. I mean, it, people don’t realize. I mean, you don’t even realize, because thank god you never will have it I hope. But it is crazy when you get these bills and they’re not just \$20, they’re like two, three thousand.

Underlining the emotional hardship she had experienced, she spoke of an “awful feeling in the pit of your stomach when these bills come in and you can’t pay it”. She recalled, “all these bills....I’m talking like this high. I mean, they couldn’t even put ‘em in my mailbox. So I would come home with boxes of this, it was just mind-boggling. I just would sit and cry.” Such comments underscore that for NY14 as NY12, breast cancer care was paid for with tragic consequences.

In contrast, women who gained Medicaid coverage before having to pay for treatment or within the three month period that coverage was reported to be retroactive experienced far less hardship emotionally and financially. NY8, who had a series of public plans during treatment, noted, “I would say to a certain extent that they brought a little bit of stress. Um, for example, when certain drugs weren’t covered right away.” However, participants who had obtained MCTP coverage early in their treatment fared better financially and emotionally as this was important in averting hardship, albeit for limited periods of time. These participants described how liberating it was not to have to worry about how they and their families would cover the cost of breast cancer treatment.

As NY13 observed, “Everything’s paid for right, I don’t know how they do it, but I don’t see any of them. So, it makes me happy [laughs].” She elaborated, “It’s put a lot of ease in my mind, knowing that it’s all being paid for. Makes it a lot easier to heal, instead of sittin’ back worrying about how this was all gonna get paid for.” NY15 commented, “It made me feel more at ease. Because it covered everything. And made me feel good that I could get the care that I was getting. So, I mean it helped me mind-wise.” She noted, “I think it’s been a relief. You know, it’s just me and my mom. My brothers and sisters live [in another part of the country]. I think it was a big relief, to her, that this was all going to be taken care of. You know, for me and for her. It was definitely a big relief.” NY18 described her adult children as “tickled pink” about her MCTP coverage, noting this “was the big, um, concern off them too and everything.” NY22 reported, “Um, made it much easier. Made it one less thing to worry about.”

Medicare had also helped to avert financial and emotional hardship—when used in combination with other public and private coverage. NY6, who had initially had Medicare alone, had struggled with the limited coverage offered. She reflected “*How* do you think that affects me psychologically? You know, and they say, “keep a positive attitude.” “Relaaaax”. “Picture yourself in a desert island”. [laughs] You know. That kinda thing. But they send you the Explanation of Benefits for everything”. She described her Medicaid coverage with a spend-down as “nice”, noting, “It takes the stress away, you know, for at least the months that I will be eligible for it.” NY20, who had Medicare in combination with a public supplement reported, “It covered *everything* I needed”. Not one to mince words, she declared, “Cuts out your financial worries, which is a *big* relief

actually. Because you know it's covered, it's taken care of. It's not going to be there, facing you". Women with Medicare supplemented by private plans also avoided hardship. As NY10 explained, "well, being that they did take such good care, it was certainly a burden that was not put on my family, put on myself, my husband or my children."

Among participants with private health insurance, women with private plans offering comprehensive coverage and enough money to comfortably cover costs associated with maintaining and using these plans described being completely protected from hardships associated with funding breast cancer care. NY7, for instance, remarked, "I think my insurance allowed me to forget about the financial repercussions and to concentrate solely on the health part of it. Um, and that, to me, that was an incredible gift. I never worried about it." NY9, who had a private policy through her husband's employment as well as supplementary private coverage from AFLAC during treatment reflected, "I don't have to be concerned about it. I don't even have to give it a thought." While her account of using her plans did indeed reflect thought and intervention, her response nonetheless reflects a lack of concern with health insurance coverage for breast cancer care that few other participants shared. Significantly, her supplementary coverage addressed costs that might otherwise have been a burden: she explained that expense not covered by her primary private plan "was not a hardship because of what AFLAC was paying me."

In other cases, costs associated with breast cancer care were a source of strain for privately insured participants with plans offering incomplete protection from hardship.



This was especially apparent in the case of NY16, whose private plan had covered only 80 percent of costs prior to its termination during her breast cancer treatment. As she recounted, “the insurance [MCTP], like I said, they only go back so far. But I still got bills that POMCO never paid. And I still got that, some of them are in collection agencies and everything else.” Struggling to pay outstanding bills from breast cancer care had had serious financial implications for NY16, affecting her ability to obtain medication for other health conditions. As she explained,

How did it affect me? It put me in the hole. Financially. You know, it was just, cause sometimes I didn’t even have it. Cause I’d come to pay the bills, I didn’t have any money for my medicines. If I didn’t have the money for my medicine they wouldn’t let me charge it. So I would have to wait and not have my medicine.

Underlining that the implications of funding breast cancer care continued to affect her, NY16 quietly told me, “I’m trying to get myself afloat. It’s hard”.

NY17 had a more comprehensive private health insurance plan, however she had not been unaffected by costs associated with using it. In her case the end of her treatment was marked by an unpleasant surprise. As she recounted,

I got the bill at the end. So I, when I went for my initial consultation, they never up front said anything about any co-pays. And it wasn’t until that I got the bill at the end, that they said that your insurance, was a \$40 co-pay every time that I went. So. I do, I’m still paying on it. Because I make \$100 payments. Because even though it was the radiation, it was also the two doctors I see, I saw them through the course of that, and every time I saw them, it was a \$40 payment.

NY17 described subsequently cutting her physiotherapy, which also involved co-payments, because she “didn’t want to start and have another hospital and have another money I had to pay back.” Two years later she was still paying off her debt. Asked about

the consequences, she described “having to cut back on other things because, you know, you’re paying money out of pocket for the medical bills.”

In discussing costs associated with the private insurance plan she had had during breast cancer treatment, NY2 noted she “didn’t really struggle a lot.” She did, however, characterize the premium for the plan she had used as “expensive” and recounted “at that time, that was difficult.” She explained,

I had to pay a percentage ‘cause we’re a couple. And we share the bills. And I had to pay a percentage. So it was difficult at that time, putting my portion, but I make sure that I have it set aside. It would have been easier if it was now [under a different plan]. Because I am not paying a lot, like I did then.

NY2 described paying health insurance related bills in the context of frugality in other areas of life. In her words,

It’s good. Okay, really, ‘cause I don’t pay rent, and I live on my own property and we grow our own food. So, that takes off a lot of burden off whatever the bill is. And we use solar electric. So, we’re very, what’s the word I’m looking for, I don’t know the word, but, you know, economical.

Thus NY2, while not categorizing herself as struggling with the cost of the plan she had used during breast cancer treatment, had handled associated costs in a context of austerity.

Travel expenses, covered under some health insurance plans but not others in New York State, added to already extreme gradations in the consequences of financing breast cancer care. Similar to Lanark and Leeds Grenville in Ontario, St. Lawrence County contains rural and small communities and participants were obliged to travel varying distances to obtain breast cancer treatment. Most travelled to physicians and hospitals in the county. Others went further afield, however, with eight participants

reporting travel out of state for consultation and/or treatment.<sup>69</sup> As discussed, some participants with private coverage made reference to their private plans covering only certain providers within the local area (NY4, NY9, NY10), being uncertain about coverage outside of the state (NY3, NY4), or needing to travel to designated centers outside of the area in order for care to be fully covered (NY5, NY7). Such comments suggest restrictions on the location of treatment covered, which can be seen to shape travel expenses in relation to breast cancer care.

As previously mentioned, NY5 and NY7 had plans that offered some reimbursement for travel, meals and accommodation related to breast cancer care. These expenses were not covered under NY9's primary private insurance plan; however they had been offset by funding from her supplemental private policy. The other participants who had relied on private health insurance had not had these costs covered under their plans and had to pay out of pocket. Five participants with forms of public coverage reported receiving assistance with transportation costs through subsidies offered by the county's Department of Social Services<sup>70</sup> or drivers arranged through the Office for the Aging.<sup>71</sup> There were thus disparities in participants' out of pocket travel expenses in addition to other disparities in the consequences of financing breast cancer care.

The voluntary sector played a somewhat more prominent role in offsetting expenses related to breast cancer care for New York State participants than it did for those in Ontario. Nine participants, including publicly and privately insured women with

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<sup>69</sup> NY3, NY4, NY5, NY7, NY9, NY10, NY19 and NY22 reported travelling out of state for consultation and/or treatment related to breast cancer.

<sup>70</sup> NY13, NY15, NY18 and NY22 reported receiving subsidies for transportation costs through the county Department of Social Services.

<sup>71</sup> NY20 reported arranging drivers through the Office for the Aging.

diverse income levels, reported they had not received any support from non-profit organizations or charitable programs. Thirteen reported receiving some kind of assistance from these sources. Twelve women had received financial support or goods from a local charity, the Gouverneur Business Women Breast Cancer Walk Fund, which bills itself as assisting “people with breast cancer in the greater Gouverneur area, which encompasses St. Lawrence, Jefferson and Lewis Counties, New York” (Gouverneur Business Women Breast Cancer Walk Fund, n.d.). This organization had provided participants with funding for expenses including mileage to and from appointments<sup>72</sup>, health insurance co-payments<sup>73</sup>, medical tests<sup>74</sup>, medication<sup>75</sup>, mortgage payments or other household bills<sup>76</sup>, car repair<sup>77</sup> or care packages.<sup>78</sup> Five participants had received goods, accommodation, or funding for travel or household bills from other charitable organizations.<sup>79</sup> Two participants, with the help of a patient navigator at a local hospital, had successfully applied to a drug company for discounted breast cancer related medication.<sup>80</sup> Seven participants discussed surgeons<sup>81</sup> or hospitals<sup>82</sup> reducing or waiving fees. Yet while assistance from non-profit organizations or charitable programs was mentioned by more participants in New York State than in Ontario, support from this sector appeared to play

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<sup>72</sup> NY1, NY6, NY11, NY13, NY15, NY21 and NY22 reported received funding for mileage.

<sup>73</sup> NY1 and NY11 reported receiving funding for health insurance co-payments.

<sup>74</sup> NY14 reported receiving funding for medical tests.

<sup>75</sup> NY14 reported receiving funding for medicine.

<sup>76</sup> NY4, NY8, NY13, NY16 and NY22 reported receiving funding for mortgage payments or other household bills.

<sup>77</sup> NY15 reported receiving funding for car repair.

<sup>78</sup> NY5 and NY21 reported receiving care packages.

<sup>79</sup> NY3, NY4, NY6, NY8 and NY17 reported funding from other charitable organizations.

<sup>80</sup> NY6 and NY14 reported drug company assistance with the cost of prescription medication.

<sup>81</sup> NY12 and NY14 discussed surgeons reducing fees when they were uninsured.

<sup>82</sup> NY4, NY7, NY9, NY16 and NY19 discussed hospitals waiving or reducing unpaid fees.

a relatively minor role overall in offsetting gradation in the consequences of financing breast cancer care among participants.

Looking to the future, the majority of participants in New York State (17 of 22) expressed concern rather than complacency. The worries most commonly cited all related to worsening health insurance coverage. Loss of coverage was a concern for both privately and publicly insured participants. NY3, when asked if she had concerns about health insurance, simply stated, “Yeah, losing it. [laughs] Yeah, if I ever lost it, it would be awful.” Women covered through employment raised the matter of losing coverage if they lost their jobs<sup>83</sup> as well as changing coverage for retirees.<sup>84</sup> Concerns were also expressed about declines in coverage<sup>85</sup> and rising costs for private coverage.<sup>86</sup> Most participants covered under the MCTP were worried about what would happen after they reached the five year limit for coverage under the program.<sup>87</sup> As NY13 explained, “It’s sort of scary not having it after the five years.” Participants were also concerned about worsening coverage under Medicare<sup>88</sup> as well as unaffordable Medicaid spend-downs.<sup>89</sup> In discussing how changing from the MCTP program to “normal” Medicaid would eventually involve higher costs for their already strained budget, NY12 and her husband came to a terrible conclusion:

NY12’s husband: See, you can’t win. [laughs] There’s no way to win.  
NY12: Don’t get old [laughs].

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<sup>83</sup> This concern was expressed by NY1 and NY19.

<sup>84</sup> This concern was expressed by NY3 and NY9.

<sup>85</sup> This concern was expressed by NY2.

<sup>86</sup> This concern was discussed by NY4 and NY22.

<sup>87</sup> NY13, NY14, NY15, NY18 and NY21 expressed concern about loss of public coverage.

<sup>88</sup> This concern was discussed by NY10, NY11 and NY20.

<sup>89</sup> This concern was discussed by NY8 and NY12.

Although not all participants saw the future this starkly, the majority approached their health insurance prospects with concern rather than complacency.

Participants in New York State also expressed concern about the state of health insurance in the United States more generally. Recognizing inequalities in health insurance coverage, participants spoke of the need for greater equity. NY12 simply stated, “I wish they would make it easier for the women. I really do. I *really do*. There’s some that don’t even have nothin’”. NY9 reflected, “I just wish there was more equity for all of us. Because, I’m fortunate, but you might not be fortunate. I know of people who aren’t. And I know it’s a struggle and I know it’s hard. I know families have had to chip in.” Although not concerned about her own private coverage NY7 was troubled by lack of access to breast cancer treatment among the uninsured, remarking,

I think the biggest issue for me is knowing a lot of people who are not covered. Who have no insurance. And while they receive free mammograms every year and stuff like that, what would actually happen to them if they were diagnosed? I have one friend in particular, who refuses to do mammograms because she says, ‘I can’t afford the treatment’. She said, ‘Why do I wanna to know? I can’t afford the treatment anyway’.

NY7 explicitly framed her discussion of un- and under-insurance in class terms, observing,

I think that, particularly in the underclass that exists in this area as well as certainly in the inner cities and whatever, there’s a definite underclass. Now, I’m talking about the underclass that is between the welfare, and the lower class. Okay. Now the lower class [is] where you start to have spotty coverage. But right underneath the lower class there is a subsistence class. And the subsistence class isn’t necessarily on welfare....my perception that there is in that class, and more and more up into the lower class and even in the middle class, depending on your amount of coverage, where health issues, and the ability to treat those issues and, for breast cancer.

NY16 was even more direct in voicing concern, saying she thought the rich were “treated better” than the poor. Such comments can be seen to underline the significance of class in understanding inequalities in health insurance and its consequences in the context of commodified health insurance and responsibilized individuals unequally positioned in relation to the market.

NY6 concluded her interview by offering a broad vision for health insurance reform in the United States, declaring,

I think health insurance ought to be available to everybody. Everybody, without exception. From the time they’re born ‘til the time they die. Just like it is in Canada, just like it is in the other first world countries. In Europe. And I think it’s disgraceful that this country is lagging so far behind in terms of health care for its people. Not only just women with cancer, but everyone.

Significantly, this vision is one that explicitly considers health insurance in the United States from a comparative perspective, condemning American exceptionalism and calling for change. Like other comments made in New York State, these parting words combine concern about inequalities in health insurance coverage with emphasis on the need for greater equity. In the context of more commodified health insurance and more responsibilized individuals in the use of coverage, more extreme gradation in consequences of financing breast cancer care was apparent in the accounts of participants in New York than in Ontario. This gradation was recognized and condemned by several New York participants themselves, who approached the future of health insurance coverage as a topic of concern for themselves and in the United States more generally.

## **Conclusion**

Collectively, participants' descriptions of their experiences using health insurance in relation to breast cancer care in Lanark and Leeds Grenville in Ontario and St. Lawrence County in New York can be seen to reflect the overarching themes of 'commodified coverage', 'responsibilized individuals', and 'gradation in consequences' of financing care. Yet accounts of experiences in each place reflect these themes to very different extents with the primacy of private health insurance in New York and public health insurance in Ontario. While participants used forms of public and private health insurance in financing breast cancer care in both jurisdictions, they did so on different terms under different health insurance systems with different consequences.

In Ontario, with the public health insurance offered under OHIP operating as participants' primary source of health care financing, health insurance was less commodified. Participants encountered public coverage that was inclusive, stable and uniform in covering most aspects of breast cancer treatment. Private coverage was more exclusive, precarious and varied, yet it was confined to a supplementary role in financing care for those who had it. In New York, where the health insurance was more commodified, exclusive, precarious and varied health insurance coverage was the rule rather than the exception, with private and public coverage both exhibiting these characteristics.

In the context of more commodified health insurance in New York State, participants' accounts suggest individuals were more responsibilized in using their coverage. Those interviewed expressed more acute awareness of their coverage and took on more unpaid work in using their coverage than did participants in Ontario, where



public health insurance was often taken for granted and considered to function largely without individuals' intervention. While private coverage garnered greater awareness and involved more unpaid work for the participants who used it in financing breast cancer care, the volume and intensity of this work was constrained by the limited nature of its supplementary role in Ontario.

Different outcomes were apparent in participants' accounts of financing breast cancer care under the health insurance systems operating in Ontario and New York. Gradation in consequences of financing breast cancer care was particularly striking in the accounts of New York participants. There were women who experienced financial catastrophe, emotional distress and even delay in breast cancer care while others enjoyed protection from such calamities. Yet while some forms of public and private coverage protected some women from financial difficulty and distress, shortcomings in coverage left others without sufficient protection at a time of profound vulnerability. In Ontario, in contrast, the reported financial, emotional and practical consequences of financing breast cancer care suggested far less pronounced gradation. Inequalities were not completely absent in Ontario: beyond the purview of OHIP, some participants faced more out of pocket costs than others, and some were better equipped to address them. Yet, considered as a whole, Ontario participants' descriptions of financing breast cancer care and the implications of doing so did not reflect the extremes apparent across the border mere miles away. The significance of this gradation in consequences in the context of differing levels of commodified health insurance and responsibilized individuals in relation to coverage in Ontario and New York will be considered in the chapter that follows, which

concludes this thesis by reviewing the study conducted and considering implications of the findings presented.

## Conclusion

*“And I mean, the horror stories of people without coverage, or insufficient coverage....I can’t imagine how dreadful that would be.” –ON18*

*“We had to learn the hard way.” –NY12*

## Introduction

This concluding chapter begins by providing a broad overview of the research conducted, situating it in relation to relevant literature and considering its theoretical concerns, methodological choices, context, and results of the interviews completed. It proceeds to suggest limitations of the research undertaken and empirical, theoretical and policy-relevant implications of the analysis presented before proposing directions for future research.

## An Overview

This thesis has explored the question of how the health insurance systems of Ontario and New York impact women’s health insurance experiences in relation to breast cancer care. This question was conceived to address a gap at the intersection of a number of bodies of literature relevant to the sociological study of women’s health and health care. Studies of health insurance identify differences in coverage between women and men and among women, but are often not well suited to exploring the implications for women’s experiences in depth or in historical context. Historical institutionalist accounts of health insurance reform in Canada and the United States are comparative, yet tend to focus on domestic political institutions at the expense of broader social relations and devote more attention to the nature of reforms than to women’s experiences with them.

Qualitative studies about breast cancer explore varied aspects of women's experiences in detail, but seldom focus centrally on health insurance experiences in particular. Feminist political economy scholarship in Canada offers a powerful critique of neoliberal reform and its implications for women as a group and for different groups of women, yet research within this tradition has not extended to a comparative qualitative study focused squarely on women's health insurance experiences within jurisdictions in Canada and the United States.

Theoretical insights from feminist political economy scholarship have guided analysis. This orientation has encouraged attention to historical context, material conditions and change over time in an analysis that understands women's lives and experiences as a crucial topic for critical study. Feminist political economy's emphasis on the importance of considering both similarities and differences among women has been important in underpinning this study. Social relations of gender as well as those of class, race and age have been considered important in shaping women's health insurance experiences within the health insurance systems under study. Moreover, insights from feminist political economy scholarship into states, markets, households and voluntary sectors and their roles in social reproduction in the context of neoliberal reform have been vital in directing analysis of women's health insurance experiences in relation to breast cancer care, women's agency and the contexts within which they act.

Ontario and New York were selected for study due to the different roles of private and public health insurance in these jurisdictions, which are geographically adjacent, connected through links such as trade (Ontario, 2013), and situated within welfare states

classified as “liberal” (O’Connor, Orloff & Shaver, 1999). Comparison at the state/province level has been preferred due to differences in provincial and state health insurance systems in Canada and the United States. Both Ontario and New York are relatively restrictive in regulating private health insurance within their respective jurisdictions, with neither embracing an extreme *laissez faire* approach within their own national contexts. Health insurance in relation to breast cancer care was chosen as the particular focus for this thesis due to the unfortunate prevalence of this form of cancer, its prominence as a women’s health issue, and the focus of treatment on costly medical care making questions of health care financing especially significant. Breast cancer care is arguably a crucial area for health insurance coverage to address, and thus a useful area in which to examine what this form of health care financing offers women under different health insurance systems.

The research strategy involved review of literature about women, health insurance and breast cancer care. It also involved review of scholarship, legislation and policy documents pertinent to the development and transformation of health insurance in Canada and the United States and the current state of health insurance in Ontario and New York in particular. In-depth semi-structured interviews were conducted with 42 women diagnosed with breast cancer within the last eight years. These interviews were conducted in order to gain insight into participants’ health insurance experiences in relation to breast cancer care under the health insurance systems in place in Ontario and New York. The women interviewed lived in two adjacent areas: the counties of Lanark and Leeds Grenville in Ontario and St. Lawrence County in New York. These counties

were selected due to their close geographical proximity and the similar nature of the rural and small town populations they encompass, which are predominantly English speaking, non-immigrant and white (Statistics Canada, 2013a; Statistics Canada, 2013b; U.S. Census Bureau, 2013).<sup>90</sup>

In keeping with feminist political economy's emphasis on understanding historical and material contexts and locating women's activities and experiences within them, this thesis considered the historical development and contemporary structure of health insurance in Canada and the United States. It examined the historical roots of health insurance in both countries, devoting particular attention to twentieth century developments setting the stage for Ontario's system of primary public health insurance coverage and supplementary private coverage and New York's system of primary private health insurance coverage and residual public coverage. In considering more recent history, analysis addressed neoliberal reforms in health insurance in both Canada and the United States. It has been argued that while the systems in these jurisdictions have developed differently, they have both been subject to neoliberal reforms promoting privatization in health care financing within the broader context of global capitalism.

Thematic analysis of interviews, guided by theoretical insights from feminist political economy scholarship, identified three overarching themes in participants' accounts of their health insurance experiences. These have been conceptualized as 'commodified coverage', 'responsibilized individuals', and 'gradation in consequences' of financing breast cancer care. In the context of the primacy of private health insurance

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<sup>90</sup> This is the terminology used by the U.S. Census Bureau (2013); Statistics Canada (2013a; 2013b) uses the term "not a visible minority".

in New York's health insurance system, participants' narratives underlined more commodified coverage, more responsabilized individuals, and greater gradation in the consequences of financing breast cancer care than in Ontario, where public health insurance played a primary role. Participants' accounts of health insurance in the province underlined the inclusive, stable and uniform nature of public health insurance coverage, which differed from supplementary private health insurance that emerged as more exclusive, precarious and varied. With more commodified health insurance in New York State, both private and public coverage emerged as exclusive, precarious and varied in this context, as participants attempted to obtain and maintain coverage through the market or qualify for residual public programs targeting specific groups.

New York State participants' accounts suggest individuals were more responsabilized in relation to the use of health insurance coverage in this setting, with this more apparent both as an ideal and in practice than in Ontario. Participants were not only acutely aware of their health insurance coverage and its role in financing breast cancer, but assumed more responsibility for learning about coverage, intervening in its functioning and addressing bills and cost-related paperwork to varying degrees for both public and private coverage of breast cancer care. In Ontario, by contrast, participants' accounts suggest individuals were less responsabilized in relation to health insurance. Public health insurance coverage was often taken for granted and largely considered to function without individual intervention in financing the bulk of participants' breast cancer care. Supplementary private coverage garnered greater awareness and involved individuals taking on greater responsibility for unpaid work related to its functioning, yet

the scope of participants' work in this regard was limited by the supplementary role of private health insurance in the province.

In the context of more highly commodified coverage and more highly responsabilized individuals in New York State, greater gradation in the consequences of financing breast cancer care was apparent in this setting than in Ontario. In Ontario, participants' accounts point to broad protection from expenses associated with breast cancer care under OHIP and some inequalities beyond its purview. Across the border, more extreme gradation in financial, emotional and practical consequences of funding breast cancer care was evident, with some women facing hardship and distress while others enjoyed protection against such adversity. While the harshest consequences were discussed by women who reported being uninsured when diagnosed with breast cancer, exclusive, precarious and varied coverage from public and private plans meant even women who were insured did not necessarily escape unwelcome consequences in financing breast cancer care.

### **Limitations**

As is the case with all research, this thesis has limitations. The first relates to its general focus on women's reports of their health insurance experiences in relation to breast cancer care. This focus hinges on the conviction that women who use health insurance coverage in relation to breast cancer care are uniquely positioned to reflect on and report their experiences. Participants in this study were indeed willing and able to discuss their experiences with health insurance in relation to breast cancer care. In some cases, however, they did not know or were unable to recall specific details of their



coverage, such as premiums automatically deducted from paychecks or deductibles. This can be seen to speak to the real world complexities of health insurance coverage, where those who use this method of health care financing do not necessarily enjoy the perfect information sometimes assumed in abstract economic models.

In the course of this study others also emerged as knowledgeable about women's health insurance experiences in the jurisdictions considered. Husbands, who were sometimes present during interviews, at times shared knowledge about details participants did not know or could not recall themselves, or contributed comments that spurred participants to reflect further on issues. While the comments of husbands were included in analysis when present, they were not the focus of the study. More broadly, in the course of county-level recruiting, in St. Lawrence County in particular it emerged that a variety of professionals working with women on issues surrounding public and private health insurance coverage for breast cancer care were knowledgeable. While positioned differently in relation to the topic at hand, they were able to share insights about their own experiences working with women using various forms of coverage. The research design, however, did not extend to interviewing such individuals.

A second limitation relates to the sample of interview participants obtained. The analysis offered draws on interviews conducted with 20 women from the counties of Lanark and Leeds Grenville in Ontario and 22 women from St. Lawrence County in New York State who had been diagnosed with breast cancer within the last eight years. While women with a range of income levels and ages were interviewed, participants almost exclusively identified themselves as white, all were English-speaking and few reported

having immigrated to the country in which they currently resided. These characteristics reflected those of populations in their counties more generally (Statistics Canada, 2013a; Statistics Canada, 2013b; U.S. Census Bureau, 2013). The homogeneity of the sample used for this study allows for understanding the experiences of older white, non-immigrant English speaking women in rural and small communities. However, it does not facilitate reflection on the experiences of diverse women. It does not reflect many perspectives from women of colour, with only one participant identifying herself in this way. Nor does it facilitate comparison of racialized health insurance experiences. As all of the women interviewed were 40 years of age or older, the views of younger women with breast cancer are not represented. And, of course, those who had very bad experiences may no longer be alive, or may have been too ill and/or distressed to agree to be interviewed.

Nevertheless, the homogeneity of the sample is also a strength: the prominence of perspectives of relatively privileged older, white non-immigrant English-speaking women, members of the majority in their respective counties, allows for attention to a “good case” scenario when it comes to health insurance coverage in Ontario and New York. Participants’ experiences arguably reflect some of the best of what health insurance systems in these jurisdictions offer women. As such, the challenges faced by participants in *even* this privileged group are best considered only the tip of the iceberg when it comes to challenges women confront with health insurance coverage in relation to breast cancer care.

A third limitation relates to the focus on interviewing women in Lanark and Leeds Grenville in Ontario and St. Lawrence County in New York. Both Ontario and New York are geographically large jurisdictions that contain diverse areas and communities. The counties that were the focus of recruiting in this effort were selected on the basis of their proximity and relative similarity in encompassing rural areas and small communities. This choice has necessarily meant that analysis focuses on the experiences of women in rural and small communities at the expense of considering the experiences of women in other environments, such as large urban centers or suburban areas. The focus on areas with rural and small town communities in both jurisdictions does, however, mean the study is well suited to comparing women's experiences within these types of communities.

A fourth limitation relates to focus on the province of Ontario and the state of New York. While provincial health insurance systems in Canada are all supposed to respect the criteria of public administration, comprehensiveness, universality, portability and accessibility set out in the *Canada Health Act*, public health insurance programs as well as regulations surrounding private health insurance differ between provinces. In the United States, there is even more variation in the specifics of public health insurance programs and the regulation of private health insurance between states. Under the circumstances, Ontario cannot be considered to represent all of Canada, nor New York all of the United States.

Nevertheless, focus on Ontario and New York in particular is useful for comparing women's health insurance experiences in relation to health insurance coverage

for breast cancer care in two jurisdictions that are adjacent and relatively restrictive when it comes to health insurance regulation. Within the United States, New York has been active when it comes to health insurance regulation in areas such as restricting gender rating (National Women's Law Center, 2010b; National Women's Law Center, 2010c) and enacting coverage mandates relevant for breast cancer care (Centers for Disease Control and Prevention, 2000: 6-7). Ontario is one of six provinces to ban private health insurance from covering publicly insured services, and the province is thus not an outlier within in Canada in terms of drawing boundaries between public and private health insurance in this way (Boychuk, 2006: 6). Clearly, the comparison does not address extremes in contrasting a state known for allowing private health insurers a relatively free hand in gender rating, for instance, as a number of Southern states traditionally have (National Women's Law Center, 2010b; National Women's Law Center, 2010c) with a province known for adopting an expanded role for private health insurance coverage as in Quebec. Rather, it is useful in allowing for comparison of two jurisdictions within Canada and the United States that place limits on the operation of private health insurance. Given that some contend that regulation can improve the functioning of private health insurance alongside public health insurance systems (Thomson & Mossialos, 2004; Greb, 2005; Colombo & Tapay, 2004b) this comparison is especially useful in allowing attention to problems that even more restrictively regulated private health insurance pose for women.

### **Analytical Considerations**

This thesis contributes to the project of developing a more nuanced understanding of social relations impinging on health insurance coverage within a feminist political economy framework and suggests insights useful for understanding the role of health insurance in social reproduction more generally. Broadly speaking, the analysis provided underlines the importance of attending to how access to health insurance as well as its use and consequences are shaped by political economic contexts with varied consequences for the daily lives of those in different social, political and geographical locations.

Feminist political economy emphasizes the importance of sex and gender in social life, and this thesis supports this emphasis in understanding sex and gender as relevant to women's health insurance experiences in relation to breast cancer care within the two different health insurance systems examined. The women interviewed used health insurance to finance care for a type of cancer far more common in women than men (American Cancer Society, 2011; Canadian Cancer Society, 2013). Public coverage in Ontario was available to all participants to finance much of their breast cancer care, promoting equality in relation to health insurance coverage.

Yet participants' experiences underline the gendered nature of inequalities in access to private health insurance in particular. Private coverage in both Ontario and New York was directly tied to women's own employment or a husband or partner's employment in gendered labour markets, or, more rarely, to individual purchase of a private policy. In both Ontario and New York, women covered as dependants were literally a man away from losing their health insurance coverage, with coverage conditional not only on their relationship with their husband or common-law partner but

on his continued employment in a job offering coverage and continued ability to afford the costs associated with coverage. Such experiences are in line with previous findings about the gendered nature of access to private health insurance (Miles & Parker, 1997; Dewar, 2000; Wyn et al., 2001; Salganicoff, Ranji & Wyn, 2005; Angel, Lein & Henrici, 2006; Robertson & Collins, 2011).

The findings of this thesis about responsabilized individuals, and specifically the unpaid work that participants performed in using forms of health insurance coverage, support and extend feminist political economy insights about the gendered nature of unpaid health care work that have been explored elsewhere (see, for instance, Grant et al., 2004). While discussion of the gendered nature of unpaid health care work underlines that women disproportionately engage in unpaid work that involves care giving for others, the findings examined here highlight unpaid work for which women interviewed assumed responsibility in using their own health insurance coverage. The findings suggest that private health insurance, especially when used as a primary method of health care financing as it was by many New York participants, placed a particularly heavy burden of responsibility for unpaid work on women when it came to learning about coverage, intervening in its functioning and addressing bills and other cost related paperwork. In contrast, public health insurance coverage as a primary method of health care financing in Ontario was discussed as involving minimal to non-existent work in these areas, suggesting forms of health insurance can increase or lessen the gendered burden of unpaid health care work undertaken by women.

In considering findings about variation in private health insurance coverage among participants and gradation in the consequences of financing breast cancer care, class emerges along with gender as a salient concern. All of the women interviewed were either employed themselves or were married to men who were employed, or else had been employed in the past or were married to men who had been employed. All could broadly be considered working class in sense of working or having worked for a living or being in relationships with men in this position. Yet employment, personal income and household income varied considerably among the women interviewed. In both New York and Ontario, participants with the highest personal and household incomes were those who reported coping most easily with expenses involved in financing breast cancer care.

In New York, women with the very highest personal and household incomes tended to be privately insured and most comfortably able to meet the costs involved in using their insurance for breast cancer care. In contrast, those who reported the most hardship in relation to financing breast cancer care in New York were women with among the lowest personal and household incomes who eventually acquired public coverage. This can also be seen to reflect gendered segregation of labour markets. While concerns of confidentiality preclude discussion of specifics, all but one of the seven women interviewed who were uninsured at the time of their diagnosis had been either employed in stereotypically feminine low wage work generally involving care giving or had not been employed outside of the home. Findings on income-related health insurance divisions among women conform to those discussed in recent literature from the United States (Ranji & Salganicoff, 2011). Between these extremes, women at varying income

levels faced various hardships in New York State—largely depending on whether they or their husbands had employment, or had retired from employment allowing access to coverage. Significantly, lack of health insurance emerged as a problem not only for the neediest working class women interviewed but more prosperous ones as well.

In Ontario, where all of the women interviewed had public health insurance coverage through OHIP, private coverage did not necessarily correspond to personal and household income. Some of the highest income participants had private coverage and some did not. Nor did participants with the lowest incomes in Ontario necessarily report the most hardship in relation to financing breast cancer care. Those with the very lowest incomes were able to depend on a combination of OHIP and other public programs and sometimes had private coverage as well. Class differences—as reflected in income and employment—were thus not as significant in shaping women’s health insurance experiences in Ontario in the context of less commodified coverage and less responsibilized individuals in relation to coverage for breast cancer care.

While the findings of this study do not facilitate comparison of the health insurance experiences of differently racialized women, it is nevertheless important to address the importance of race in understanding them. Acknowledgment of the relative privilege accruing to those identified as white in the United States and Canada allows for recognition that white women enjoy positions of relative advantage. With racialized minority group status having been found to constitute a structural barrier to health insurance in the United States in particular (Montez, Angel & Angel 2009: 133), it is important to recognize the absence of this particular barrier for most of the women



interviewed. In this context, what findings do underline is variation in coverage and gradation in the consequences of financing breast cancer care *even* within a group of relatively privileged white women.

It is also important to consider the significance of age—and more broadly generation—in relation to findings about private health insurance coverage. The women interviewed were, as discussed, all forty years of age or older. The Ontario sample featured nine women 65 years of age or older, while the New York sample featured six women in this age group. The older women interviewed had employment histories, and/or husbands with employment histories, reaching back to welfare state arrangements under which employment was often more stable for white, working class, non-immigrant men in particular and in which such workers were more often able to extract better employment benefits (Porter, 2003:10), including health insurance. The growing precariousness of work and ongoing decline in employment-based private health insurance (see Claxton et al., 2012; Glied, Jack & Rachlin, 2008: 14; Wyn et. al. 2001:47; Cubbins & Parmer, 2001) calls into question whether a younger cohort of women would be able to report the private health insurance coverage enjoyed by the women interviewed.

Beyond encouraging attention to social relations of gender, class, race and age in shaping health insurance coverage, this project contributes insights useful for considering the role of health insurance in social reproduction more generally. Participants in both New York and Ontario acknowledged the crucial role of health insurance in financing breast cancer care considered to be life-saving. Their accounts point to the importance of

health insurance for social reproduction in the basic sense of survival from one day to the next. Participants' experiences in Ontario and New York, did, however, differ in terms of the roles reflected for the state, market, household and voluntary sector in relation to health insurance coverage. With the primacy of private health insurance in New York State, participants experienced more highly commodified coverage, access to which revolved around the vicissitudes of labour market and the position of participants and their households within it, with exclusive, precarious and varied coverage the rule rather than the exception. Health insurance in this context can be understood primarily as a privilege for workers employed in jobs offering coverage as well as sufficient income to obtain and use it for themselves and their families. Dependent on the market, participants were also responsibilized in utilizing health insurance, performing unpaid work in order to use their coverage in relation to breast cancer care.

In New York State, the role of the state can be understood as upholding the market and offering limited health insurance to targeted groups not able to compete within it—those recognized as aged, disabled, needy, and some of the seriously ill. In placing responsibility on individuals and more broadly households for this aspect of social reproduction, this state-market-household arrangement can be seen to burden the ill and their households with health insurance responsibilities at an especially vulnerable time, with some experiencing great hardship and distress as a result. Unpaid work related to learning about coverage, intervening in its functioning and addressing bills and other cost-related paperwork emerged as more onerous in New York State in the context of more commodified health insurance coverage.

Gradation in the consequences of financing breast cancer care can be seen to contribute to stratification in social reproduction (Colen, 1995; Arat-Koc, 2006) more generally by privileging the well being and survival of some over others. While participants were grateful for financial support received from the voluntary sector, this did not play an especially large or systematic role in offsetting gradation in the consequences of financing care, at best curbing but not significantly challenging stratification in this aspect of social reproduction. The extremes in hardship exposed in New York State could be seen as suggestive of a potential crisis of social reproduction in the fundamental sense of survival, most clearly embodied in NY12's bankruptcy, distress, and delay in breast cancer treatment.

In Ontario, participants experienced health insurance as less commodified in the context of a public health insurance system that financed the bulk of their breast cancer care. Health insurance in this setting can be seen as based on participants' relationship to the state in terms of legal residency, with participants experiencing inclusive, stable and uniform public coverage. Private health insurance was limited to supplementing public coverage in this context, constraining the role of the market in this aspect of social reproduction.

Participants were largely not responsabilized in using their public coverage in Ontario. Indeed, many knew little about it and simply assumed it was there. While those who had private coverage did take on more responsibility for awareness and unpaid work in using it, this work was limited by the restricted scope of supplementary coverage in the province. The role of the state in this context can be seen to support social reproduction

through intervening to free health insurance coverage from the market, taking much of the burden of financing health care off of individuals and households at the point of use and providing broad protection from the cost of treating illness. Against this background, gradation in the consequences of financing breast cancer care was far less extreme.

Although out of pocket costs in relation to breast cancer care were reported as a burden by some participants in Ontario, experiences were not so extreme in this context as to suggest a potential crisis in social reproduction in the presence of inclusive, stable and uniform public coverage which covered the bulk of the expense of breast cancer care for all participants. While participants were grateful for support received from the voluntary sector, this did not play an especially large or systematic role in offsetting gradation in the consequences of financing breast cancer care in this context.

### **Empirical Contribution**

This thesis makes an empirical contribution relevant to the sociological study of health insurance as well as the study of breast cancer care. For the study of health insurance, it introduces detailed information about particular women's experiences accessing, using and facing the consequences of forms of health insurance in Lanark and Leeds Grenville as well as St. Lawrence County within the health insurance systems operating in Ontario and New York respectively. Analysis of participants' accounts of their everyday health insurance experiences in relation to breast cancer care adds to empirical scholarship about what health insurance means and involves for women who have and use it. This contribution complements findings about trends in health insurance coverage in the United States and Canada by adding to knowledge about the significance

of different forms of coverage in practice for women in particular social, political and geographical locations. It suggests the importance of empirical study of how health insurance is gendered, classed, racialized and age-related in particular contexts.

For the study of breast cancer, the detailed accounts of health insurance experiences analyzed in this study contribute to better understanding how women in particular social, political and geographical spaces experience the financing of breast cancer care, complementing research on other aspects of women's breast cancer experiences. In examining health insurance experiences in relation to breast cancer care as gendered, classed, racialized and age-related, this thesis suggests the importance of understanding experiences of breast cancer and breast cancer care more broadly as influenced by these relations within different health insurance systems.

Significantly, this thesis does not find that health insurance experiences are more or less gendered, classed, racialized and age-related under different health insurance systems. Rather, it finds the significance of these social relations in creating and entrenching inequalities in access, use and consequences of health insurance coverage differ in the context of different health insurance systems. In the context of the primacy of private health insurance obtained as a commodity through the market in New York State, these social relations can be seen to influence inequalities in experiences of health insurance access, use and consequences more profoundly than in Ontario, where public health insurance coverage as a primary means of health care financing was available through the state on the basis of legal residency to all participants in what can be seen as an achievement promoting equality in health insurance coverage.

### **Theoretical Contribution**

The analysis provided in this thesis connects feminist political economy insights about social reproduction under capitalism to women's experiences within specific health insurance systems. In feminist political economy analysis, social reproduction addresses "how various institutions (such as the state, the market, the family/household, and the third sector) interact and balance power so that the work involved in the daily and generational production and maintenance of people is completed" (Bezanson & Luxton, 2006: 3). In linking feminist political economy analysis of social reproduction and women's health insurance experiences the analysis identifies three overarching themes in women's experiences, conceptualized as 'commodified coverage', 'responsibilized individuals' and 'gradation in consequences'.

Considered more abstractly, the idea of commodified coverage concerns how the market is implicated in social reproduction in the basic sense of financing treatment of illness—and thus access to care and opportunity for survival. More highly commodified coverage ties this aspect of social reproduction among workers tightly to the labour market, while less commodified coverage that comes from the state through taxation allows this aspect of social reproduction to be separated from the market to a greater extent.

Responsibilized individuals, central to neo-liberal dogma, partake in the insurance market with commodified coverage. More abstractly, this addresses what happens in practice when the accomplishment of social reproduction among working people is tied to the market. It concerns placement of the burden of responsibility for unpaid work related to social reproduction on individuals and their households directly. Beyond

gaining coverage through waged work, in this scenario working individuals and their households need to take responsibility for unwaged work in using market-based coverage. A consequence of a system of health insurance that operates via responsabilized individuals in the context of commodified coverage in the market is gradation in consequences, reflecting disparities in coverage and in the implications of financing health care. Gradation in consequences thus addresses social reproduction as occurring unequally among individuals and households in different social, political and geographical locations. Such gradation can be understood as an instance of stratification in social reproduction shaped by relations of class, gender, race and age among others, in which the well being and basic survival of some is privileged over that of others.

The analysis provided suggests the role of the state in relation to health insurance coverage can, at a higher level of abstraction, be understood to either strengthen stratification in social reproduction or lessen it depending on involvement in the provision of public goods, thus tying this work into literature more widely found in political economy. A public good has in this context been broadly understood as one “available for all citizens to consume” (Holcombe, 1997:3). State intervention can be understood to strengthen stratification in social reproduction where the state under neo-liberalism allows and promotes the primacy of the market in health insurance coverage. A more socially accountable state that delivers health insurance coverage as a public good for individuals and households independent of their market positioning and without a burden of unpaid work at point of use can be seen to lessen stratification in social reproduction. This thesis particularly underlines the significance of the role of the state in

averting crisis in social reproduction stemming from commodified coverage, responsabilized individuals, and gradation in consequences. The failure of the market to provide working people in different social, political and geographical settings with broad protection from calamitous consequences in financing treatment for serious illness arguably necessitates consideration of health insurance as a public good with significant implications for public policy.

### **Policy Implications**

The analysis provided has policy implications at different levels. The first and perhaps most obvious is that it is important to recognize that not all ‘public’ and all ‘private’ forms of health insurance are equal. In this study public health insurance in Ontario emerged as inclusive, stable and uniform, while public health insurance in New York emerged as exclusive, precarious and varied. This demonstrates how the specifics of coverage and the terms on which it is accessed matter profoundly in allowing—or precluding—the role of public coverage in offering protection from the costs of ill health. Private coverage emerged as having the same fundamental dynamics in both of the jurisdictions examined: coverage was linked to the labour market either directly through employment and income from employment or indirectly through women’s relationships with the employed. Yet the role of the state in privileging or restricting the role of market-based private coverage made a tremendous difference in the settings considered. While private coverage was exclusive, precarious and varied in both of the contexts studied, in New York it was a primary source of health care financing and in Ontario it was supplementary. Under the circumstances it was relied on to different extents. The



exclusive, precarious and varied nature of this form of coverage affected women most negatively when a first and only option for financing care, and less so when used to supplement inclusive, stable and uniform public health insurance coverage.

The findings considered directly challenge the idea that privatization of health insurance through expanding the role of the market in this form of health care financing should be passively allowed or actively pursued. In both of the contexts examined, private health insurance offered exclusive, precarious and varied coverage, transferred responsibility for unpaid work involved in using coverage to the ill, and involved gradations in the consequences of financing medical treatment that varied from more minimal to more extreme. Private health insurance was not effective in providing broad protection from the cost of ill health, but rather was associated with inequities in coverage that at their most extreme involved financial devastation, emotional distress and delay in care. More broadly, this analysis suggests the failure of the market with respect to health insurance coverage, with market-based private health insurance emerging as ineffective in offering broad protection from the consequences of financing health care.

The findings provide support for the idea that public health insurance—of the kind available in Ontario under the criteria of public administration, comprehensiveness, universality, portability and accessibility set out in the *Canada Health Act*—should not only be protected but expanded in scope. OHIP coverage was found to be inclusive, stable and uniform, and to function so as to relieve the ill of the burden of unpaid work in using their coverage. Within its remit it was reported to provide broad protection from unwelcome consequences of financing health care—arguably the true *raison d'être* of

health insurance as a method of health care financing. However, beyond the scope of OHIP coverage in Ontario and in the absence of this style of universal public health insurance in New York, gradations in the consequences of financing of health care were apparent with varied access and coverage through other public programs and private insurance protecting some individuals more completely than others. Expanding the scope of OHIP coverage in Ontario and introducing OHIP-style coverage in New York could expand the benefits of this inclusive, stable and uniform public coverage and the broad protection offered. In Ontario, one important area for the expansion of OHIP coverage suggested by this study is coverage of prescription drugs outside of hospitals, an important expense associated with breast cancer care. More broadly, this research suggests health insurance is a type of good the state needs to provide in order to ensure broad protection from the consequences of financing health care in the face of the failure of the market to offer broad protection in this regard.

A final policy implication is broader in scope: it relates to the importance of looking beyond borders when drawing inspiration for health insurance reform. In Ontario, OHIP emerged as the assumed status quo, with participants struggling to imagine alternatives or evaluating them on the basis of scant evidence. The occasion to appreciate a good thing when one has it—and not only once it has been dismantled—is arguably one of the most important opportunities presented by comparative research. So too is the occasion to recognize calamity when it occurs in order to learn from and avert it in the future. Comparative research is useful for policymaking precisely because it exposes the existence of actual alternatives, revealing the status quo as a carefully

constructed creation that can be deconstructed and reconstructed along other lines—for better or for worse. No one today need imagine how dreadful it would be to live without health insurance coverage or to have insufficient coverage when faced with a serious illness when there are those who live with these realities on a daily basis. Nor should anyone need to learn the hard way about the consequences of a privatized health insurance system when others already have.

### **Future Research Directions**

The analysis provided and its limitations suggest a number of possible directions for future research. As interviews were conducted with a small and relatively homogenous group of women from two geographical areas, it would be useful to pursue a larger study to learn about the health insurance experiences of more diverse women in relation to breast cancer care across larger and more varied areas in the province of Ontario and the state of New York.

As health insurance arrangements differ among provinces and states, it would be helpful to study women's health insurance experiences in other states and provinces in order to develop a nuanced comparison of women's health insurance experiences in relation to breast cancer care within Canada and the United States as well as between these countries. Even more broadly, it would be instructive to compare women's experiences not only in jurisdictions in Canada and the United States but in Australia and the United Kingdom as well to develop a comparative account of women's health insurance experiences in jurisdictions across liberal welfare states in the context of global capitalism. Differences in the roles of public and private health insurance coverage and in

the scope of coverage could be usefully explored, particularly in relation to public drug coverage. Comparisons encompassing social democratic welfare states in Scandinavia could also be helpful in looking beyond liberal welfare states.

Comparative qualitative scholarship about other kinds of insurance experiences also represents a useful direction for future research. Ultimately, health insurance is but one method of health care financing, and the financing of health care only one of the financial considerations facing those who confront serious illnesses. In the current study, some of the women interviewed raised concerns about other forms of insurance in relation to breast cancer care, pointing to the importance of employment insurance, disability coverage, and long term care insurance in shaping women's financial futures in the face of illness. Future research could usefully explore experiences with these forms of insurance and their interaction in the context of political economic change in Canada, the United States and elsewhere.

## Appendix A: Ethics Approval Memo



5<sup>th</sup> Floor,  
York Research Tower,  
4700 Keele St.  
Toronto, ON  
Canada M3J 1P3  
Tel: 416-736-5201  
Fax: 416-650-8197  
[www.research.yorku.ca](http://www.research.yorku.ca)

Certificate #: STU 2012 - 033

Approval Period: 03/01/12-03/01/13

### **Memo**

To: Alison Jenkins Jayman, Sociology, [ajenkins@yorku.ca](mailto:ajenkins@yorku.ca)

From: Alison M. Collins-Mrakas, Sr. Manager and Policy Advisor, Research Ethics  
(on behalf of Wade Cook, Chair, Human Participants Review Committee)

Date: **Thursday 1<sup>st</sup> March, 2012**

Re: **Ethics Approval**

Paying the Price: Women, Breast Cancer Care and Health Insurance in  
Ontario and New York

I am writing to inform you that the Human Participants Review Sub-Committee has  
reviewed and approved the above project.

Should you have any questions, please feel free to contact me at: 416-736-5914 or  
via email at: [acollins@yorku.ca](mailto:acollins@yorku.ca).

Yours sincerely,

Alison M. Collins-Mrakas M.Sc., LL.M.  
Sr. Manager and Policy Advisor,  
Office of Research Ethics

## **Appendix B: Informed Consent Form**

Study Name:

Paying the Price: Women, Breast Cancer Care and Health Insurance in Ontario and New York

Researcher:

Alison Jenkins Jayman  
Ph.D. Candidate, Department of Sociology  
York University  
2075 Vari Hall, 4700 Keele Street  
Toronto, Ontario  
M3J 1P3  
[ajenkins@yorku.ca](mailto:ajenkins@yorku.ca)

Purpose of the research:

The purpose of this study is to examine women's use of health insurance in relation to breast cancer care in the province of Ontario and the state of New York. Through learning about women's experiences in these two jurisdictions, this study will explore the consequences of health insurance policy for women with breast cancer.

What you will be asked to do in the research:

Participation in this study will involve an interview relating to your use of health insurance in relation to breast cancer care, which will last approximately 60 minutes. Questions will focus on health insurance rather than health. You may be contacted for a brief follow-up interview in the months following the initial interview. All interviews will be audio-recorded by digital recorder, and handwritten notes may also be taken during the interview. An honorarium of \$30 will be provided.

Risks and discomforts:

There are no foreseeable risks or discomforts associated with participation in this research.

Benefits of the research and benefits to you:

This study will improve understanding of how health insurance policy affects women with breast cancer. Your participation in this research will allow you to contribute to

advancing knowledge in this area. A summary of the results of the study will be provided to you upon request.

#### Voluntary participation:

Your participation in the study is completely voluntary and you may choose to stop participating at any time. Your decision not to volunteer will not influence the relationship you may have with the researchers or study staff or the nature of your relationship with York University either now, or in the future.

#### Withdrawal from the study:

You can stop participating in the study at any time, for any reason, if you so decide. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with the researchers, York University, or any other group associated with this project. In the event you withdraw from the study, all associated data collected will be immediately destroyed wherever possible. If you decide to stop participating, you will still be eligible to receive the promised pay for agreeing to be in the project

#### Confidentiality:

Interview data will be collected through audio-recordings and written notes that will be securely stored in a locked cabinet and a password protected computer file. Audio-recordings will be used to create interview transcripts. These recordings will be deleted within two years of completion of the interview transcripts. Interview transcripts and written notes will be securely stored in a locked cabinet and a password protected computer file for ten years following the completion of the study, after which point they will be destroyed. Only the researcher and her supervisor will have access to this data. Confidentiality will be provided to the fullest extent possible by law.

The data collected for this study will be used in writing a doctoral dissertation, academic articles, and academic conference presentations. Neither your name nor any other personal identifying information will be used in communicating the results of this study.

#### Questions about the research?

If you have any questions about this research in general or your role in this study please contact Ms. Alison Jenkins Jayman ([ajenkins@yorku.ca](mailto:ajenkins@yorku.ca)) or her supervisor Dr. Pat Armstrong ([patarmst@yorku.ca](mailto:patarmst@yorku.ca)). You may also contact the Graduate Program in the Department of Sociology at York University, by telephone at (416) 736-5013 or by email ([atokiwa@yorku.ca](mailto:atokiwa@yorku.ca)).

This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, you may contact the Senior Manager and Policy Advisor for the Office of Research Ethics, 5th Floor, York Research Tower, York University, telephone 416-736-5914 or e-mail ore@yorku.ca

Legal rights and signatures:

I \_\_\_\_\_ consent to participate in "Paying the Price: Women, Breast Cancer Care and Health Insurance in Ontario and New York" conducted by Alison Jenkins Jayman. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form.

My signature below indicates my consent.

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Researcher's Signature

\_\_\_\_\_  
Date

My signature below indicates my consent to audio-recording of my interview.

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date



## **Appendix C: Call for Participants**

### **Call for Participants**

#### **Study on Breast Cancer Care and Health Insurance Coverage**

#### **In This Time of Health Care Reform...Make Your Voice Heard!**

The purpose of this study is to examine women's use of health insurance in relation to breast cancer care in the province of Ontario and the state of New York. Through learning about women's health insurance experiences in these two jurisdictions, this study explores the consequences of health insurance policy for women with breast cancer.

In the Ontario portion of this study I am seeking to interview women who:

- \* have been diagnosed with breast cancer within the last seven years
- \* live in the United Counties of Leeds and Grenville or parts of Lanark County within the South East LHIN (including Perth and Smiths Falls)
- \* have used OHIP or private health insurance or no health insurance coverage
- \* are willing to meet for 45-60 minutes to discuss their experiences

Interview questions focus on health insurance coverage rather than health, and an honorarium of \$30.00 is provided to every participant.

All participants' experiences—with or without health insurance—are valuable for this study.

To participate, please call (315) 244-9717 or e-mail:

Alison Jenkins Jayman  
Ph.D. Candidate  
Department of Sociology  
York University  
ajenkins@yorku.ca

This research has been reviewed and approved by the Human Participants Review Sub-Committee of York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines.

## **Call for Participants**

### **Study on Breast Cancer Care and Health Insurance Coverage**

#### **In This Time of Health Care Reform...Make Your Voice Heard!**

The purpose of this study is to examine women's use of health insurance in relation to breast cancer care in the state of New York and the province of Ontario. This study focuses on St. Lawrence County in New York and the United Counties of Leeds and Grenville in Ontario. Through learning about women's health insurance experiences in these two jurisdictions, this study explores the consequences of health insurance policy for women with breast cancer.

In the New York portion of this study I am seeking to interview women who:

- \* have been diagnosed with breast cancer within the last five years
- \* live in St. Lawrence County
- \* have been with or without health insurance coverage
- \* are willing to meet for 45-60 minutes to discuss their experiences

Interview questions focus on health insurance coverage rather than health, and an honorarium of \$30.00 is provided to every participant.

All participants' experiences—with or without health insurance—are valuable for this study.

To participate, please call (315) 244-9717 or e-mail:

Alison Jenkins Jayman  
Ph.D. Candidate  
Department of Sociology  
York University  
ajenkins@yorku.ca

This research has been reviewed and approved by the Human Participants Review Sub-Committee of York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines.

## **Appendix D: Interview Guide**

### **Paying the Price: Women, Breast Cancer Care and Health Insurance in Ontario and New York**

#### **Interview Questions**

##### **General Health Insurance Questions**

- Do you have health insurance coverage? If so, what type(s) of coverage do you have?
  - o Is your coverage public and/or private? What kind of public and/or private coverage do you have?
  - o US:
    - Public: Medicaid? Medicare? Another public plan?
    - Private: A traditional fee-for-service plan? Managed care? A high deductible health plan?
    - Managed care: Health maintenance organization (HMO)? Preferred provider organization (PPO)? Point of service plan (POS)?
- How long have you had this coverage?
- Have you ever been without coverage? If so, when? Why? For how long?
- How did you get your health insurance coverage? E.g. Through your paid work, through your partners, through coverage you purchased yourself, through the government?
- What do you have to do to maintain, or keep up, your coverage?
- What does it cost per year? What does this mean in terms of your budget?

##### **Health Insurance and Breast Cancer Care**

- When were you diagnosed with breast cancer?
- Have you used health insurance coverage for breast cancer care?

- What type, or types, of coverage have you used? (Public coverage? Private coverage? Both? Neither? If public coverage, what kind? If private coverage, what kind?)

(If the participant does not have any coverage, subsequent questions will address lack of coverage)

- How do you feel about your health insurance coverage in relation to breast cancer care?
- What does your health insurance cover in terms of breast cancer care? Screening, care providers, drugs, surgery, radiation, education, prosthesis, wigs, other?
- How do you get information about what your health insurance covers?
- When you want to use your health insurance, what do you have to do? How long does this take?
- When you use your insurance, are there any fees, co-payments or deductibles? If so, how do you pay them? What are the consequences of having fees?
- When using your coverage, do you ever have to pay 'up front' for goods or services and seek reimbursement? How long does it take for you to be reimbursed? How does this affect you?
- Have you had to seek pre-approvals for tests or procedures?
- I would like to also ask about insurance related paperwork that you've done in relation to breast cancer care. What has that been like? Have you had to deal with any errors?
- Are there restrictions or limitations on your coverage in terms of breast cancer care? If so, what are they? How do they affect you?

- Are there expenses associated with your breast cancer care that your health insurance does not cover? What are they? How do they affect you?
- How do you think health insurance has shaped your decisions at different stages in your breast cancer care?
  - o Has your health insurance coverage affected your decisions about breast cancer screening? How?
  - o Has your coverage affected your decisions about the diagnostic process? How?
  - o Has your coverage affected decisions about your primary/family doctor? How?
  - o Has your coverage affected your decisions surrounding use of specialists? How?
  - o Has your coverage affected your decisions around breast cancer treatment? How?
  - o Has coverage affected post-treatment care? If so, how?
- How has your coverage affected how you navigate, or find your way around, the health care system in seeking breast cancer care?
- Have breaks in your coverage or changes in your coverage affected your experience with breast cancer care? When? How?
- In your view, has your health insurance coverage met your needs in relation to breast cancer care? Why or why not?

- Has being diagnosed with breast cancer affected your health insurance coverage in any way?
- Do you have any worries, concerns or anxieties surrounding your health insurance coverage? If so, what are they?
- Has your health insurance coverage affected your decisions about paid work since being diagnosed with breast cancer?
- Has it affected family members' decisions about paid work?
- Has your coverage affected your family? Has it affected life in your household, or the people you live with on a daily basis?
- Has your coverage affected your interaction with voluntary organizations, such as charities or religious groups?
- Overall, how has your health insurance affected your experience with breast cancer care?
- How has having had breast cancer affected you financially?
- Have you ever talked with other women with breast cancer in Ontario/New York about their health insurance experiences? If so, what stories have you heard?
- Have you ever talked with other women about health insurance and breast cancer care across the border? If so, what stories have you heard?
- Are there any other issues related to health insurance coverage and breast cancer care that you would like to discuss?
- Are there any topics we have not discussed that you feel are important?

### **Demographic Questions**

- How old are you?
- Where were you born?
- If you were not born in the country in which you now live, when did you immigrate there?
- What is the highest level of education you have completed?
- What is your marital status?
- How do you classify yourself in terms of race?
- What is your occupation? Has this changed since you were first diagnosed with breast cancer?
- What is your approximate yearly income? Has this changed since you were first diagnosed with breast cancer?
- What is the approximate yearly income of your household? Has this changed since you were diagnosed with breast cancer?
- Who lives with you in your household? Has this changed since you were first diagnosed with breast cancer?
- Finally, how did you find out about this study?

### Appendix E: Changes in Ontario Participants' Private Health Coverage Since Diagnosis

Participant	Changes in Private Health Insurance Coverage
ON1	Covered under private insurance through her former employment at the time of her diagnosis in 2011 and reported no change in her coverage since. Described reduction of her coverage to \$15,000 limit after retirement in 1998.
ON2	Covered under husband's employment-based private health insurance at time of her diagnosis in 2010 and reported no change in her coverage had affected her breast cancer care.
ON3	Covered under private insurance through her employment and her husband's employment at the time of her diagnosis in 2009. Suggested her own plan had "changed somewhat" "through the years", mentioning changes in coverage for drugs and hospital rooms in particular and noting it "used to pay more".
ON4	Covered under private insurance through her husband's former employment at the time of her diagnosis in 2009. Her husband died in 2011, and her coverage was free for the following year. Cancelled her coverage in 2012, when she had to start paying a premium.
ON5	Covered under private insurance through her husband's former employment at the time of her diagnosis in 2011. Described reduction in her drug coverage prior to her diagnosis but reported that no change in her coverage since had affected her breast cancer care.
ON6	Covered under private insurance through her former employment at the time of her diagnoses in 2009 and 2010. Reported no changes in her coverage had affected her breast cancer care. Maintained she had not used her private coverage in relation to breast cancer care.
ON8	Covered under private health insurance through her husband's former employment when diagnosed in 2004, 2010 and 2012. Reported no changes in her coverage had affected her breast cancer care.
ON10	Covered under private health insurance through her former employment at the time of her diagnosis in 2011. Reported no changes in her coverage had affected her experience with breast cancer care.
ON12	Covered under private insurance through her own employment as well as through the employment of her husband, from whom she was separated, at the time of her diagnosis in 2011. Also had a supplementary private health insurance plan, but this specifically excluded breast cancer care. Expected to lose coverage under her husband's plan through divorce.
ON13	Covered under private insurance through her employment at the time of her diagnosis in 2008. Gained additional private health insurance coverage under a plan through her husband's employment in 2012, some six months



	before being interviewed.
ON15	Covered under private health insurance through her husband's employment when diagnosed in 2012. Reported no changes in her coverage had affected her experience with breast cancer care, however was concerned this coverage would end or become more costly with husband's retirement in 2013.
ON17	Covered under private health insurance through her husband's employment when diagnosed in 2010. Reported the plan had since come to involve a health insurance card "in the last year and a half".
ON19	Covered under private insurance through her former employment when diagnosed in 2010. Reported no changes in her coverage had affected her experience with breast cancer care.

**Appendix F: Changes in New York Participants' Private Health Coverage Since Diagnosis**

Participant	Changes in Private Health Insurance Coverage
NY1	Covered under partner's employment-based private health insurance at time of diagnosis in 2008. A little over a year later the relationship ended and she obtained private coverage through her own employment.
NY2	Covered under husband's employment-based private health insurance at time of diagnosis in 2006. Changed to coverage through her own employment when she changed from part-time to full-time hours in 2008. Her employer had changed from one insurance company to another and then back to the first.
NY3	Covered under private insurance at the time of her diagnosis in 2009. Medicare became her primary insurance in 2012 when she turned 65, and her private coverage became secondary insurance.
NY4	Covered under private insurance through her own employment at the time of her diagnosis in 2007. Discussed her coverage changing over time with the addition of various "riders".
NY5	Covered under her husband's employment-based private health insurance at time of diagnosis in 2011 and reported no change in her coverage.
NY7	Covered under private insurance through her own employment at the time of her diagnosis in 2006. Medicare became her primary insurance in 2012 when she turned 65, and her private coverage became secondary insurance.
NY9	Covered under husband's employment-based private health insurance and a supplementary privately purchased plan at time of diagnosis in 2008. Medicare became her primary insurance in 2009 when she turned 65.
NY10	Covered under Medicare with husband's employment-based private health insurance as secondary coverage at the time of her diagnosis in 2010. Reported her coverage had not changed since that time.
NY11	Covered under Medicare with husband's employment-based private health insurance as secondary coverage at the time of her diagnosis in 2008. Reported her private drug coverage had changed since then.
NY16	Covered under private insurance through her own employment at the time of her diagnosis in 2010. Her coverage was terminated during breast cancer treatment. She was subsequently covered under the Medicaid Cancer Treatment Program.
NY17	Covered under private insurance through her own employment at the time of her diagnosis in 2010. Reported no change in her coverage since then.
NY19	Covered under private insurance through her own employment at the time of her diagnosis in 2009. Reported her employer had since changed to a different plan, noting previous coverage was "a little bit better".

**Appendix G: Changes in New York Participants' Public Health Insurance Coverage  
Since Diagnosis**

Participant	Changes in Public Health Insurance Coverage
NY6	Covered under a Medicare Advantage Plan when diagnosed in 2011 and 2012. Granted additional Medicaid coverage in 2012 with a spenddown for months in which her income and medical expenses qualified her for the program.
NY8	Covered under Family Health Plus when diagnosed in 2004. Granted Medicaid coverage in 2005, part way through her treatment. Gained Medicare coverage in 2006, and described having additional Medicaid coverage with a spenddown for months in which her income and medical expenses qualified her for the program.
NY12	Uninsured when diagnosed in 2006 and during part of her treatment. Described gaining Medicaid after a seven month struggle, losing it due to her income being recorded incorrectly, and then regaining it. Later discussed her current Medicaid coverage as ending with her breast cancer treatment, characteristic of the MCTP.
NY13	Uninsured when diagnosed in 2012, described gaining coverage through MCTP, saying "It wasn't very long into when I started."
NY14	Uninsured when diagnosed in 2008 and during part of her treatment. Subsequently covered under "county" Medicaid and later under the MCTP.
NY15	Uninsured when diagnosed in 2008, soon after covered under the MCTP.
NY18	Uninsured when diagnosed in 2007, described gaining MCTP coverage "so fast".
NY20	Covered under Medicare with low income supplement when diagnosed in 2005. In 2011 switched to Medicare PPO and continued to hold low income supplement.
NY21	Uninsured when diagnosed in 2011 and described gaining MCTP coverage in "weeks".
NY22	Uninsured when diagnosed in 2010 and described gaining MCTP coverage "that day".

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