Navigating the Empty Spaces of Care: A Feminist Political Economy Analysis of the Care Experiences and Work Practices of Women Living with Cancer

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ABSTRACT

Advances in cancer treatment are improving survival rates and, in so doing, transforming the nature of cancer from an acute to chronic illness. Within the Canadian health care system, there has been increasing policy acknowledgment of and support for a culture change in care that promotes a stronger chronic care agenda and yet the Canadian health care system continues to operate within a predominantly medical model that favours acute care and treatment. The Princess Margaret Cancer Centre has shown some evidence of their commitment to a chronic care model through the implementation of ELLICSR Health, Wellness and Cancer Survivorship Centre. While this appears promising, understanding how these changes are operationalized in a predominantly acute health care setting remains an underdeveloped area and the implications for patients remain unknown. In this study, I apply critical ethnography and various data collection methods (document analysis, participant observation, semi-structured interviews and photo elicitation) in order to explore the patient experience within this changing health care milieu, paying particular attention to patients' care experiences and work practices. As informed and framed by feminist political economy, this project explores the everyday care and work experiences of women diagnosed with cancer as situated within the broader social, political, and economic contexts in which cancer care and work are anchored. Analysis traces key tensions and conflicts between policy directions and the everyday environments where care takes place. The findings illuminate that, in the absence of suitable and sustained institutional and funding support, ideological changes that appear to be in line with improved patient autonomy and control (e.g., person-centeredness, patient involvement and self-management) more closely resemble increased individual responsibility and work for which little choice is given. In the empty spaces between policy promises and care practices, the findings reveal a new responsibility and accountability circuit wherein access to good quality care increasingly rests on patient action/inaction, thus rendering opportunities for care more inequitable. The delivery of psychosocial and supportive care through ELLICSR made a critical difference in the care experiences of study participants; however, the precarity of this space demonstrates the lack of commitment to the proposed goals of reforms. As our health care system changes, we must take up a context-sensitive approach that invites engagement with the messiness and complexity of cancer care as conceptualized, practiced, and lived.

DEDICATION
For Mom

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My years as a doctoral student brought a number of remarkable people into my life and I consider myself truly fortunate to have worked with, learned from, and built relationships with these people. First and foremost, my deepest appreciation to the twelve women who participated in this study; the information and insight they shared provides the foundation upon which this research rests and I hope that in writing this dissertation I have extended our discussions in a manner that remains faithful to their experiences. Several ELLICSR staff also shared their experiences and insights, and these helpful contributions expanded my understanding and contributed to my analysis. I am most grateful for their input.

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CHAPTER ONE
INTRODUCTION

Care has been recognized as a significant issue in the fight for women's equality (Luxton, 2006). Feminists in particular have been integral to the debate surrounding how care ought to be understood, organized and practiced – often in an effort to maximize its equitable delivery to ensure that people are given appropriate support and care when they need it and that no one is coerced into providing (often unpaid) care work (Armstrong & Armstrong, 2010; Armstrong & Braedly, 2013; Baines, Evans, & Neysmith, 1992; Daly, 2012; Day, 2013; Green & Lawson). These debates about care have important implications for feminist scholars and activists, for health care systems, for paid and unpaid care workers, and for those who rely on the services they provide. They also have consequences for how we structure and organize our society as well as how we see ourselves as citizens within that society (e.g., care as an individual responsibility vs. an entitlement of citizenship) (Armstrong & Braedley, 2013). In other words, these debates and their implications are relevant and important for all of us and demand our concerted attention (Armstrong & Braedley, 2013). This dissertation seeks to join the conversation and contribute to this debate by exploring the cancer care system in Ontario, the changing care needs (chronic vs. acute) and care reforms that have this system in a – albeit necessary – state of flux, and the care and work implications for 12 women living with cancer. In doing so, I engage with current systems of care and ask questions that can guide our thinking about how best to conceptualize, organize, and provide care in ways that maximize the equitable delivery of good quality care, ensure that patients do not become overburdened by the demands of care work, and do so in fiscally manageable ways.

The Canadian health care structure continues to operate in a system that was designed to deal with 19th century problems, treating acute and infectious disease and delivering care that is short, episodic, urgent, and treated with cure as the goal (Mair, 2014; May, Eton, Boehmer, Gallacher, Hunt, MacDonald, Mair, May, Montori, Richardson, Rogers, & Shippee, 2014; Siu, Spragens, Inouye, Morrison & Leff, 2009). These features render the prevailing model of care inappropriate for tackling contemporary care needs, with over 80% of all deaths and 90% of all morbidities stemming from chronic illnesses, such as cancer (Boult, Karm, Groves, 2008). In recognition of the mismatch between care needs and care delivery, calls for addressing the

management of chronic conditions have become increasingly loud in Canada (Pederson & Liwander, 2012). Policy makers have responded with the implementation of policies that push a stronger chronic care agenda. For instance, Cancer Care Ontario's[1] (CCO) Ontario Cancer Plan document (2011-2015) and the Princess Margaret Cancer Centre[2] 2013-2018 Strategy Report (*World Class Personalized Medicine: Strategy 2013-2018)* both argue that health care systems will need to increasingly promote attention to individual's specific circumstances and care needs (person-centred care); embrace patient perspectives and facilitate collaborative partnerships between patients and providers (patient involvement); provide holistic care and integrated service delivery (collaborative care); and provide care on a long-term (as oppose to episodic) basis. According to these documents, these shifts are situated as key priorities and strategies in cancer care reform and are promised to improve quality care for all cancer patients (CCO, 2011; Princess Margaret Cancer Centre, 2015). These approaches align well with many of the aims of women's health reformers and health advocates (Hills & Mullett, 2005; Peterson & Donner, 2007; Thurston & O'Connor, 1996) who have long called for greater patient-provider partnerships in the delivery of medical care as well as health care systems that include attention to the social determinants of health (SDOH). Further, in view of the rates of chronic conditions among women, a care system that is more attuned to chronic condition management is both welcomed and necessary to improve women's health (Pederson & Liwander, 2012).

The Princess Margaret Cancer Centre, recognized as one of the top five comprehensive cancer centres in the world (Princess Margaret Cancer Centre, 2015), has shown some evidence of integrating these policies into practice. One such action has been the implementation of the Electronic Living Laboratory for Interdisciplinary Cancer Survivorship Research (ELLICSR), a hospital-based cancer health and wellness centre (CHWC) that adopts a 'whole person' approach to the delivery of psychosocial and supportive care for people living with cancer (ELLICSR,

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[1] Cancer Care Ontario (CCO) is the provincial agency responsible for issues related to cancer services for Ontario residence. As the provincial government's cancer advisor, CCO directs pubic funding for cancer prevention, detection, and care at thirteen Regional Cancer Programs across the province (CCO, 2015).

[2] The Princess Margaret Cancer Centre is a scientific research and teaching hospital in Toronto (Ontario, Canada). The hospital is the largest cancer centre in Canada and one of the five largest comprehensive cancer centres in the world; offering care in the fields of surgical and medical oncology, bone marrow transplantation, radiation oncology and radiation therapy, medical imaging, and psychosocial oncology (Princess Margaret Cancer Centre, 2015; Princess Margaret Cancer Foundation, 2016).

2015). While the aforementioned policies and the inclusion of more diverse forms of care delivery within the hospital appear promising, understanding how these are operationalized in a predominantly acute care setting remains an underdeveloped area; the implications of these policies and this type of care integration for patients thus, remain unknown.

Recognizing and engaging with these shifts in health care is important as the manner in which care is conceptualized, organized, funded and practiced helps to shape the parameters of care responsibility and accountability between citizens and the state (Armstrong & Braedley, 2013). In doing so, they frame the scope of unpaid care work that individuals, usually women, are expected to assume in the management of such things as health and illness (Day, 2013). The aforementioned care reforms thus hold important implications not only for women's care experiences but also for their work practices. The tendency in mainstream cancer literature, policy, and practice to synonymize work with paid employment and to situate the problem of work within 'return to work' discourse however, limits our capacity to fully recognize and interrogate the vast amounts of work that patients perform during the upheavals of illness, the conflicts and struggles that they experience in doing so, and the gendered nature of this work. Indeed, it propels an oversimplified assumption of work as something that ends, for most, once diagnosed and is to be resumed following cancer treatment (Parsons, Eakin, Bell, Franche, Davis, 2007).

When considerations of work are limited to issues of paid employment, the time consuming, demanding and skilled nature of unpaid work that continues during and emerges as a result of a cancer diagnosis remain largely invisible from a systems perspective. Also missing from this view are the social and material contexts that give rise to work projects and through which this work unfolds. For instance, it overlooks the time consuming and hard work of social reproduction[3] – work traditionally performed by women – and in turn also overlooks the

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[3] Social Reproduction is defined as "the activities and attitudes, behaviours and emotions, responsibilities and relationships directly involved in the maintenance of life on a daily basis, and intergenerationally. Among other things, social reproduction includes how food, clothing, and shelter are made available for immediate consumption, the ways in which the care and socialisation of children are provided, the care of the infirm and elderly, and the social organization of sexuality. Social reproduction can thus be seen to include 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." (Luxton, 2006, p. 35-36).

gendered implications of this work on access to prerequisites of health such as time for personal growth and leisure, adequate income, and equity (Clow & Kemp, 2012; Luxton, 2006). In this vein, limited perceptions of work also negate attention to the potential for 'work conflicts' that might arise for women as they seek time, resources and energy to engage in their own need for self-care within the family context (Mackenzie, 2014). Here we might better understand the ways in which work might act as a constraint on women's opportunities for care at times of illness and as a vehicle through which inequities in care between women emerge. The invisibility of unpaid work in mainstream cancer literature, policy and practice thus limits our capacity to fully and critically understand the work experiences, conflicts, and struggles of women diagnosed with cancer; identify the implications of existing care arrangements and proposed policy changes on the scope of their work practices; and the forms of care and support that women require to manage and/or lessen the burden of work at times of illness.

Study Purpose and Research Questions

In researching these topics and unknowns, I applied critical ethnography and various data collection methods (document analysis, participant observation, semi-structured interviews and photo elicitation) in order to answer the overarching question: How does ELLICSR facilitate women's work, for which women and in what ways? Four sub-questions were derived from this major focus, further framing the inquiry undertaken:

1. What are the work and care experiences of women with cancer?
2. What are the social, political and material conditions under which experiences of cancer, care and work occur?
3. What brings women to ELLICSR and/or what keeps them away?
4. What activities do ELLICSR staff pursue in facilitating women's work at times of illness?

In this dissertation, the concepts of care and work serve as entry points into the broader political and economic issues surrounding cancer care and care reform in Ontario, Canada. Through the use of a feminist political economy framework, I explore the everyday care and work experiences of women diagnosed with cancer but also pull back to scan the horizon. Indeed, the broader social, political, and economic contexts in which cancer care and work are anchored are essential to the analysis, facilitating understanding about how particular (neoliberal) policy

decisions and institutional/organizational systems – including the ELLICSR centre – influence individuals' everyday experiences of cancer, frame their care needs, and shape their work practices. My objectives were to illuminate the complex (tensions and contradictions) and often invisible aspects of cancer care and work, to explore the implications of existing and changing health care practices on the everyday care and work experiences of 12 women living with cancer, and to better understand ELLICSR's role in framing these individual experiences. I consider participants' personal narratives in terms of how they relate to or reflect broader systems and structures, and the ways in which any inequities or challenges resulting from social determinants can be meaningfully addressed through changes in policy and/or practice.

I developed, designed and analyzed this study according to several assumptions. First, I assumed that people make choices about their health, care and work based on a number of complex and intersecting factors, influenced primarily by the social and material resources that are available to them. Put differently, people make choices about their health and care, but not in conditions of their choosing. Second, I worked under the assumption that care is a collective responsibility rather than an individual one and that access to care should be conceived of as a right of citizenship as oppose to an individual responsibility. By this, I do not mean to suggest that all care must or should be provided in a collective manner, but rather that it is a "public responsibility to ensure that appropriate care is provided when needed and that failures of care are addressed." (Armstrong & Braeley, 2013, p. 10). Lastly, I assumed that gender holds important implications for our health, work, opportunities for care (and expectations of care provision), and our everyday lives.

Contents of the Dissertation

Chapter Two sets the theoretical landscape for the dissertation and outlines core themes and topics as they relate to the chosen area of study. The chapter begins with a discussion of the defining principles of feminist political economy and an explanation of why this was an appropriate theoretical lens for this project. The chapter proceeds with a review of the feminist political economy of health literature, including a brief discussion of the history of health care and health care reform in Canada. Following this discussion, I take up an analysis of the care literature through a feminist political economy lens, and discuss three overarching domains

through which care is defined, understood, and practiced: 1. social policy (the family model); 2. health care systems (the medical model); and 3. care work organizations (the market model).   I then apply these theoretical understandings to the analytic tasks of this thesis which include an improved understanding of: 1. the macro-social, -political and -economic contexts in which cancer care is conceptualized, governed and funded; 2. the meso-level (including hospital and ELLICSR) approaches to cancer care and support, as informed by the broader social, political and economic context; and, 3. the micro-level day-to-day lives of women with cancer whose health-related *work* practices and *care* experiences are situated within and framed (in part) by these macro- and meso-level processes.

In Chapter Three, I outline the qualitative methods used in this research. I designed a critical ethnography in order to query how Canada's political economic system contributes to conceptualizations of care; to explore how it informs cancer care policies and practices in Ontario Canada; to better understand the implications of these policies and practices on individuals experiences of cancer, care needs (and 'choices') and work; and to better understand ELLICSR's role in framing these individuals experiences. I describe critical ethnography, unpack its ontological and epistemological underpinnings, and highlight the connections between theory and methodology. I discuss the processes of site selection and participant recruitment and outline the methods used for conducting my research and interpreting my findings. In the final sections of the chapter, I situate myself in the research process, I evaluate the methodological choices I have made, and discuss the quality of the research, including relevant ethical considerations.

Chapter Four engages with the study findings in two stand-alone manuscripts organized according to the two overarching themes of this dissertation, work practices and care experiences. In Manuscript One: ""It's Hard Work:" Re-conceptualizing 'Work' in the Cancer Context," I take up a review of the psychosocial oncology and cancer survivorship literatures to identify conceptualization of *work*. I find that within these bodies of scholarship, work is typically characterized as being synonymous with paid employment and the problem of work is thus usually addressed within 'return to work' discourse. Endeavouring to expand conceptualizations of work in the cancer context, I draw on a feminist political economy conceptualization of work as consisting of paid and unpaid tasks that require intent, time, effort

and skill (Smith, 2005, as cited in Sinding et al., 2011). I pursue the theme of 'work' from this perspective as it unfolds in relation to women's experiences with cancer and care. I consider how the rearrangement of care and care practices within the Ontario health care system frame the depth and breadth of patient's work. I further examine the gendered nature of work in this context and the implications of offloading care from health care institutions onto individuals; focusing specifically on the implications for women who are themselves living with cancer and in need of care. Throughout the manuscript, I identify and explore six distinct forms of work performed by participants: 1) illness work; 2) body work; 3) identity work; 4) everyday work; 5) paid employment and/or the work of maintaining income; and 6) coordination work in order to elaborate upon the complexities of work practices, tensions, and negotiations and to illuminate the often invisible social and material resources that lay the foundation for these work tasks.

In Manuscript Two: "Putting Psychosocial Care on the Prescription Pad: The Successes and Challenges of Integrating Psychosocial Care into Routine Cancer Care Practice," I engage the literature to trace the changing landscape of cancer as a disease and explore notions of care in the context of a changing health care milieu marked by conflicting care commitments between health policy (with an increasing emphasis on the need for chronic care) and health care structures (which remain entrenched in acute care operations). In review of patient interviews and photographs, I explore how dominant institutional care practices frame patients' illness experiences, focusing specifically on the ways in which they fail to meet patients' care needs. Alongside this discussion of unmet needs, I identify and explore the ways in which the provision of psychosocial and supportive care and resources through the ELLICSR centre helps to fill patient-identified gaps in care. Lastly, in review of participant noted barriers to ELLICSR, I explore how the ongoing dominance of acute conceptualizations of care and a medical/market model approach to care organization impact upon the coordination and integration of care across the hospital. I further consider how existing power arrangements reinforce the precarity of ELLICSR and limit the scope and reach of care it provides.

Chapter Five pulls together the analyses from preceding chapters in order to illuminate and discuss the overarching tensions of the dissertation, identify key contributions and recommendations, and to provide closing thoughts. The chapter begins by organizing major findings of the dissertation into two key overarching tensions and contradictions that emerged

within and between the manuscripts. These include the tensions that emerged between 1. policy directions and health care settings, and 2. medicalized discourses of self-management and the practicalities of women's everyday lives. The chapter continues with consideration of the contributions that this thesis makes to psychosocial oncology and cancer survivorship literatures as well as to feminist political economy scholarship and illuminates the implications of this work for health policy and clinical practice. Recommendations informed by these contributions and areas worthy of further research are also discussed. The following chapter begins this discussion with an overview of feminist political economy theory and critical feminist perspectives on conceptualizations of health, care and work.

CHAPTER TWO
THEORETICAL FOUNDATIONS

Introduction

> What is happening to care in Canada is troubling. At the broadest level,
> we are moving from *caring and sharing* as widely held public ideals to *greedy
> and mean*, not only in practice but, increasingly, as policy goals. At the level of the
> health care system, we are more narrowly defining which care services are a
> collective responsibility, while shifting responsibility to those least able to care for
> themselves (Armstrong & Braedley, 2013, p.9)

This critical ethnography takes as problematic the conflicts, contradictions, and consequences for women that are embedded in the troubling shifts in care, work, and responsibility described above. In this chapter, I turn to some of the theoretical understandings related to the analytic tasks of this thesis which include: 1) an understanding the macro-social, -political and -economic contexts in which care is conceptualized, governed and funded; 2) the unpacking of meso-level (including hospital and ELLICSR) approaches to cancer care and support, as informed by the broader social, political and economic context; and, 3) an exploration of the micro-level day-to-day lives of women with cancer whose health-related *work* practices and *care* experiences are situated within and framed (in part) by these macro- and meso-level processes. Locating this project within the tradition of feminist political economy scholarship, the chapter begins with consideration of the defining features of this theoretical position. The chapter proceeds with a review of the feminist political economy of health literature, including a brief discussion of the history of health care and health care reform in Canada. Following this discussion, I take up a review of the care literature through a feminist political economy lens, and discuss three overarching domains through which care is defined, understood, and practiced: 1. social policy (the family model); 2. health care systems (the medical model); and 3. care work organizations (the market model). In the final section, I highlight the absence of a feminist political economy analysis of cancer, including analysis of emerging trends in cancer care (e.g., cancer health and wellness centres), and explore how feminist political economy and feminist conceptualizations of care can help expand our understanding of the lived experiences of women with cancer and enliven our approach to notions of care and work in the cancer context.

Feminist Political Economy

The political economy refers to the institutions and relations that encompass not only political and economic systems but also social, ideological, and cultural ones (Armstrong & Armstrong, 2010; Clement, 1997; Jackson, 2012). Political economy has amassed several branches of theoretical thought in its long and varied history. The constant changes to, and outgrowths of, this theory are partially the result of historical developments, emerging evidence, and because of debates among its practitioners (Clement & Vosko, 2003). Feminist political economy for instance is a theoretical current that emerged from feminist critique of what was perceived of as a problematic shortcoming in the political economy tradition (Vosko, 2002). It is thus worth briefly examining the underlying orientations and principles of the political economy perspective, particularly as it has been developed in Canadian scholarship.

Political economy adopts the perspective that the whole cannot be developed from the separate study of individual parts. Social relations are thus seen as being shaped by vast and complex interconnections between politics, economics, and ideology – none of which can be meaningfully understood in isolation (Clement & Williams, 1989). Political economy is also a materialist perspective, wherein social relations are constructed by the mode of production, which is itself historically, politically and socially rooted, and driven by significant inequalities in power (Clement, 1997). The capitalist mode of production, its profit-driven logics, and the inequities that flow from these arrangements are thus conceived of as being neither natural nor inevitable, but rather a socially constructed set of relations that emerged within a specific historical context. The socially constructed and historically rooted nature of social relations render them amenable to processes of change; often marked by tensions, conflict, and resistance (Armstrong, Armstrong & Scott-Dixon, 2008). From this perspective, the state (and its institutions) is viewed as both an instrument of class rule and a contested terrain where struggle can make a difference (Armstrong, Armstrong & Coburn, 2001). The aim of political economy is thus to produce a critical account of how social relations are socially and historically shaped, who benefits from and who is disadvantaged by the existing organization of social relations, and how social relations might be transformed into more equitable arrangements.

Early political economy analysis was primarily focused on class and economic relations as the defining feature of capitalism and as the source of inequitable social relations. The absence of gender garnered extensive feminist critique (Luxton, 2006; Mutari, 2000). In focusing on class and economic relations of paid work, feminists critiqued political economy for overlooking matters of gender and for the ways in which it further perpetuated gender-blindness in mainstream scholarship (Vosko, 2002). Initially this critique focused on illuminating the ways in which the 'formal' capitalist economy sustained and relied upon the provision of unpaid labour in the home – the division of which rested on inequitable gender relations that situated women as primarily responsible for this work (Bezanson & Luxton, 2006). Focusing on the link between public and private as well as paid and unpaid labour led feminist political economists to construct the concept of social reproduction wherein drawing attention to the importance of the household and of unpaid domestic work (e.g., the production, preparation and/or maintenance of food, clothing, and housing; child care and rearing; elder care; and care of the sick/infirm) to the family and to the capitalist economy (Bezanson & Luxton, 2006; Jackson, 2012). Endeavouring to explore the link between private troubles and public issues, feminist political economists recast unwaged labour – often conceived of as existing outside of the capitalist mode of production – as *work* and as work upon which the formal economy rests (LeBaron, 2015). In so doing, feminist political economists have contributed to a broader understanding of labour under capitalism, revealing the inadequacy of analyzing capitalist class and social structure without examining gender and the economy of social reproduction (Bezanson & Luxton, 2006; Jackson, 2012; Luxton, 2006).

In addition to identifying the social construction of gender and its varied cultural and historical meanings, feminist political economy has also played a vital role in expanding the scope of political economy analysis to consider multiple and intersecting axes of identity – including (but not limited to) gender, class, race, age, geographic location – and oppression (Mutari, 2000). Feminist political economy is thus concerned with multiple dimensions of inequality that are produced, reproduced, and sustained by the interconnected whole. Context and the tension between structure and agency are central to this concern. This tension deals with the assumption that while people possess agency and the ability to exercise choices; choice is confined to and made from within the limits of historically-contingent social, political and material boundaries

(Clement & Williams, 1989; Coburn, 2001). Feminist political economy offers an extended view of the ways that multiple and intersecting inequities on the basis of such things as gender, class, and race, further frame the structural conditions that are not of one's choosing and yet are instrumental in framing the "choices people are presented with and the choices they make from those available" (Coburn, 2001, p. 45). In doing so, feminist political economy highlights the importance of acknowledging differences among women and recognizing the many ways that multiple axes of oppression can come together to differentially frame women's experiences, opportunities, and choices (Armstrong, Armstrong & Coburn, 2001).

The Political Economy of Health Care Reform

The political and economic orientations of the state, the parameters of public and private responsibility, and the entrenchment of gendered divisions of labour have a significant influence how we conceptualize and practice health and care as well as how we organize and fund our health care system (Armstrong & Armstrong, 2008). From a feminist political economy perspective, the structure of the health care system is understood within the historically specific context in which it exists, and is seen as being shaped by social, political and economic imperatives – thus offering a far more "integrated approach to the study of health than one that examines health care as an institution largely separated from the rest" (Armstrong & Armstrong, 2010, p. 5). In order to understand current reforms and their impact, it is necessary to explore the development and structure of public health care. While a comprehensive historical review of Canada's health care system falls beyond the scope of this dissertation, it is important to briefly unpack the significance of the *CHA* and to trace what has happened to health care since its inception. This analysis is vital to an understanding of the entrenched powers in and the principal assumptions of the current system. In what follows, I provide a brief discussion of the history of Canada's health care system with the *Canada Health Act* (1984) as a starting point. I also discuss the foundational logics of neoliberalism (the governing ideology of the state) and adopt a feminist political economy lens to explore its impact on health care reform in Canada.

The federal government passed the *CHA* in 1984, a thirteen-page legislative document that sets out the five principles of accessibility, universality, comprehensiveness, portability, and public

administration that the provincial governments are required to meet in order to be eligible for federal funding. Under this Act, the provinces are required to provide universal coverage for all medically necessary hospital and physician services – while charging for these services is prohibited and subject to penalty (see http://laws-lois.justice.gc.ca/PDF/C-6.pdf for a copy of the *CHA* legislation including a full summary its five principles). In this regard, the *CHA* marked a significant turning point in Canada that provided both symbolic and practical value. It represented a commitment to collective care and recognized that we have a shared responsibility as well as a shared risk of ill health. It also symbolized a commitment to health care as both a human right and a defining aspect of citizenship (Armstrong & Armstrong, 2008; Romanow, 2002). Its symbolism was strengthened by its practical value in that it did indeed provide reasonable access to uniformly good care. Further, in providing access on the basis of need rather than ability to pay, universal Medicare played a major role in redistributing the costs of illness – contributing to more equitable distributions of access to health care between rich and poor citizens as well as between rich and poor provinces – as poorer provinces lack resources to provide reasonable access on their own. For these reasons, among others, the *CHA* is frequently demarcated as Canada's most famous piece of legislation (Armstrong & Armstrong, 2008).

Despite its fame as well as its symbolic and practical value however, since its inception, the *CHA* has been subject to debate among politicians and policy makers and countless attempts have been made to 'chip-away' at and undermine the system in ways that are often difficult for Canadians to see or oppose (Armstrong & Armstrong, 2013). Neoliberalism[4] lies at the crux of this dismantlement project. With a keen focus on privatization and relaxing of economic rules and regulations; neoliberal policies attempt to halt the growth of public sector expenditures, largely through the commodification of public goods (Armstrong & Armstrong, 2010; Fuller, 1998; Struthers, 2013; Williams, Deber, Baranek & Gildiner, 2001). While these changes are often positioned as a response to citizen demand and in the interest of improved care and choice, there has never been widespread support in Canada for cutting social services. Indeed, polls frequently and consistently show greater popular support for social services than tax cuts (Connell, 2010).

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[4] There are several key principles to neoliberalism: free markets without government interference provide the most efficient and socially optimal allocation of resources and thus states should provide a minimum of public goods (e.g., public education and social welfare programs); privatization removes inefficiencies of the public sector and improves consumer choice; and individualism, individual responsibility, and entrepreneurial initiative are necessary to protect the 'natural order' of the market (Chomsky, 1999; World Health Organization, 2014).

As such, when cost-cutting and privatization strategies do become visible to the public, they are justified by governments as the only way to save the system while, at the same time, improve our overall health (see Government Report: *When Less is Better* for a full discussion of this position (Deputy Ministers of Health, 1994)). Feminist political economists have been instrumental in the collection of evidence to the contrary, demonstrating that privatization and greater reliance on the market correlates with inequity in access to care, inefficiency in the delivery of care, high cost (to both the state and to its citizens), and public dissatisfaction with the quality of care (Armstrong & Armstrong, 2008; Evans, 1997).

In the early 1990's, policy change in Canada led to a degree of fiscal constraint that was dramatic from both historical and comparative perspectives (National Coordinating Group on Health Care Reform and Women, 2003; Naylor, 1999). According to Armstrong & Armstrong (2010) "Debts and deficits provided the major justification for reforms as Canadians were told that health care resources were scarce, spending was out of control, and that costs would need to be contained in order to 'preserve the sacred trust'" (p. 2). Cutbacks in federal transfers to the provincial acute health care (i.e. hospital) systems fostered a push toward deinstitutionalization. There have been profound transformations in the institutional sector as a result, with hospital care being increasingly focused on short-term acute care and outpatient services while many psychiatric, rehabilitative and chronic care hospitals have closed, increasing intensive care needs outside of the hospital (Armstrong & Armstrong, 2010; National Coordinating Group on Health Care Reform and Women, 2003; Naylor, 1999). This neoliberal restructuring has resulted in the downloading of care from hospital (public care provision) to the community, often in the form of home care. Because criteria of the *CHA* do not clearly apply when patients leave the hospital, governments can avoid the "prohibition against user charges and extra-billing" by steering people away from doctor and hospital care (Armstrong & Armstrong, 2008, p. 4; Aronson, 2004). The simultaneous clawing back of state-funds in community-based care and support services resulted is an inadequately resourced community sector required to support the deinstitutionalization project (Aronson & Neysmith, 1997). The result is that people typically have fewer supports and resources available to them at the same time that they are expected to assume greater responsibility over their health and care, thus making personal caregiving even more challenging.

Provincial responses reflect not only a pressure to cut costs, but a philosophy emphasizing the limits of government responsibility, promotion of the involvement of the for-profit sector in health care and the limitations of the public health care system (Jenkins Jayman & Willson, 2012). The central assumptions underpinning this privatization initiative are that provision of services by governments are "inefficient and costly, that reliance on state services weakens individual initiative and undermines family and community ties, and that caregiving is best arranged through voluntary family and community networks" (Luxton, 2010, p.166). At the crux of these neoliberal ideologies is the belief that individuals *ought* to take greater ownership over their health and assume a more active role the delivery of care (Day, 2013). From this perspective, not only is it assumed that those who are ill will have someone to care for them in the home and that this is the best and safest place for caregiving to take place, but also that the provision of care is an individual, rather than a collective, responsibility – a far departure from the logics underpinning the *CHA* which sought to decommodify care through collectivist arrangements (Armstrong & Armstrong, 2008). Within the current neoliberal climate, care is increasingly positioned as an individual responsibility and health as a commodity (as opposed to a right of citizenship). As such, neoliberalism's largest impact in Canada has been on the erosion or 'hollowing out' of the welfare state that has traditionally decommodified citizens' relations with the market (Coburn, 2004; Salter & Salter, 1997).

The Political Economy of Health and Care

Feminist political economy operates according to assumptions and principles that counter the logics of neoliberalism (Riley, 2008). For instance, feminist political economists adopt the perspective that health is profoundly political in nature. According to Bambra, Fox & Scott-Samuel (2005), health is political because: 1) it is socially produced with some groups having greater opportunities for health than others; 2) the social determinants that frame opportunities for health are amenable to political action (or inaction) and intervention; and 3) "the right to 'a standard of living adequate for health and well-being' is, or should be, an aspect of citizenship and a human right" (p. 187). This broader understanding of health acknowledges that health is largely socially, politically, and economically determined. The social determinants of health perspective coincides with feminist political economy by foregrounding the importance of factors such as gender, income, race, ethnicity, age, education, employment, housing, food

insecurity, geographic location, immigration status, social support, access to health care services and countless intersections thereof in creating the conditions upon which health and illness rest (Laxer, 2013; Mikkonen & Raphael, 2010). Health is also seen as being determined by the care provided for those who become ill. While care relates to a special set of health concerns, it is not separate from the determinants of health. Indeed, money, security, safety, and social and psychological care are even more important (and arguably under greater threat) to those confronted by illness (Armstrong & Armstrong, 2010; Raphael, 2004).

From this broader contextual perspective health is not confined to medical institutions; it also frames and is framed by families and communities, policy documents, economies, and many other significant, but frequently overlooked spaces. In other words, feminist political economists understand 'health' as being far more than the absence of illness; it refers to the well-being of the whole person that comes from such things as secure employment and reasonable incomes; from safe physical and social environments; and from access to high quality health care and necessary social and psychological support (Mikkonen & Raphael, 2010). Health then is fundamentally linked to the distribution of power and resources as well as to social relations – in short it is linked to the political economy (Armstrong & Armstrong, 2010; Bambra, Fox & Scott-Samuel, 2005). The importance of SDOH in framing health and inequities in health are significantly under-acknowledged in dominant health and political discourses.

In the proceeding section, a feminist political economy lens is applied to explore three core models of care identified by Day (2013) and to unpack how these shape the way care is defined, organized, funded, and practiced. The implications of these conceptualizations for women's health are also considered. Further, this section explores the question: what values do these models reflect not only about governance and power but also about notions of gender, care, and work? In taking up these issues, feminist political economy draws attention to the (layered) meanings of terms we frequently take for granted when thinking about care, broadly, and cancer care, specifically; terms such as 'home,' 'family,' 'work,' 'responsibility,' 'accountability,' 'empowerment' and 'choice'.

Conceptualizing care through a feminist political economy lens. The priorities and organization of neoliberal societies have enormous implications for the ways in which we come to conceptualize and understand care, care practices, how we make decisions around what constitutes 'necessary care' and, in turn, what types of care get funded through the public purse. They further instruct who is responsible and accountable for the provision of care (Armstrong & Armstrong, 2010; Armstrong & Braedley, 2013). In turn, feminist political economists have taken up the concept of care to ask a broad range of questions about its social arrangements – many of which have particular relevance to this study. For instance, how can we make sure that people are cared for? How can care be organized in ways that promote efficiency while preserving, or even increasing, quality? What contributes to the invisibility of care work in dominant discourse and everyday life? Why is care work so unvalued in the broader political economy? How does this undervaluing inform how care is understood and what care supports are provided? And how do care conceptualizations, practices and supports (or lack thereof) inform the health and work of women from various social locations?

Among the possible variations of care models, there are three identified by Day (2013) that hold particular importance in a feminist political economy analysis of the cancer care experiences and work practices of women living with this illness; these include the family model, medical model, and market model. These care models do not exhaust all possible models theorized in the care literature, however, they do capture converging categories of care that contain important gendered implications for care practices and experiences. As Day (2013) acknowledges, the separation of these discussions is somewhat misleading as they function together to define and sustain understandings and practices of care. For instance, the health care system is constructed and governed according to public policy, and practices in the market are often informed by 'evidence-based' medicine and 'expert' knowledge of care in the health profession. Below, I explore these models of care wherein I highlight dominant conceptualizations of care and care practices, the intersections between care models, and the implication of these intersections for women and women's health.

Conceptualizing care in social policy: The family model. The gendered nature of caring is not only the result of cultural tradition but is also deeply ingrained in society through official

laws and policies (Radina, Armer & Stewart, 2014). Social policy has been problematized in care literature for the ways in which it implicitly relies upon and sustains a 'family model' of care; a model that often assumes the presence of a woman who will take on the task of caring in the home (Aronson, 2004; Day, 2013; Morris, 2004). Situating care within the home and conceptualizing it as an individual concern (rather than a governmental and/or collective responsibility) ensures that care, including *responsibility* and *accountability* over the provision of care, is cemented within the private sphere (National Coordinating Group on Health Care Reform and Women, 2003). Home-based policies that define care as a private responsibility idealize care in the home as the 'preferred model of care', wherein people can expect to receive the best possible care, associated with feelings of "love and security" (Day, 2013, p. 22).

Positioning the shift from hospital to home as a response to public demand, politicians and policy makers claim that home care is better suited to meet the needs a growing elderly population with chronic conditions and insists that such a shift will lead to improved quality care and patient 'choice.' This claim is based, however, on a series of normative assumptions about the nature of home as a safe space and a 'natural' location for giving and receiving care (Armstrong & Kits, 2004). It overlooks the fact that some people do not have homes to go to or that some homes may be unsafe or unsuitable spaces for the provision of appropriate care. Unsafe home environments, characterized by violence, poverty, poor social safety nets and other positions of marginalization, threaten to contribute to worsened health. Even when homes provide safe locations for care, "many people cannot count on having a stable or caring support network and, even if this network exists, it can quickly become overwhelmed and overtaxed" (Morris, 2001, p. 35). Claims to care within the home can be additionally difficult for women who are most often the ones who take up the work of social reproduction and health/illness management (Luxton, 2006; Morris, 2001).

A second interrelated assumption is that that there exists a care 'crisis' (Day, 2013). Home-based care is contextualized within this care crisis discourse, with governments asserting the need to "cut back on burgeoning care costs" and that families (usually women) are obligated to step in to fill the gaps (Aronson & Neysmith, 1997 as cited in Day, 2013, p.22). This crisis rhetoric has been particularly popular in policy of chronic diseases, whereby the ushering of non-acute care

to the home is more often than not presented as a policy solution rather than a policy problem by governments that see such a shift as an uncontroversial and sensible way of responding to the needs of people with chronic conditions, such as cancer, while also averting demographic and fiscal 'crisis' (see Drummond, 2012, p. 167). The perceived sensibility of this shift is, at least in part, connected to a historically rooted belief that care provision in the home is a naturalized part of family relations that has seldom been considered work (other than by feminist and some socialists) but rather a form of "moral and spiritual vocation" (Struthers, 2013, p. 161). This demonstrates an undervaluing of what is predominantly women's work and fails to recognize the critical role women play in sustaining health and care, particularly during times of fiscal restraint and health care cuts (Struthers, 2013). Further, it is women, as the majority of health care users who suffer worsened care either as a result of unsafe and unsuitable homes or at the hands of overworked, under-compensated, and increasingly undertrained care providers (Armstrong, 2007).

In this regard, nation-states play a critical role in gendering health, care and care work. They help structure what is done in the formal economy and the private household, what in turn, frame the parameters of public and private responsibility over health and the provision of care (Armstrong, 2001; Armstrong et al., 2008). The public/private binary in care policy contributes to a narrow definition and understanding of care that is fragmented and compartmentalized because of the ways that the family, market, and the state are conceptualized and analyzed as separate domains – rather than interconnected parts of the 'whole.' Policies that "sustain a fictitious division between private lives and public matters cannot account for the complex realities in which care in practice always blurs private/public boundaries" (Day, 2013, p. 23). This dichotomized approach to care in social policy develops out of and informs particular social, structural, and discursive contexts. Indeed, this same binary approach is applied to conceptualization of care in the health care system (Day, 2013).

   Conceptualizing care in the health care system: The medical model. The medical model of care assumes dominance within the health care system, providing a narrow definition of care needs in biomedical (and technological) contexts (Armstrong & Armstrong, 2010; Day, 2013). Functioning within this model, health care is structured according to the understanding that

health and illness are purely physiological and biological; "the fixing of body parts" thus becomes the solution to health problems (Armstrong & Armstrong, 2010, p.41), obscuring the possibility of conceptualizing care as a long-term/ongoing process. Instead, care is seen as acute and resources are deployed to cure acute symptomology. Under such conceptualizations of care, once life threat is abated, health care payment and delivery systems do not recognize that the patient is still ill, recovering and/or in need of care and support (Day, 2013). In turn, chronic care needs and the psychosocial and material impacts of illness are often ignored. This narrow approach to understanding and practicing care does not align well with the state of contemporary care needs, with over 80% of all deaths and 90% of all morbidities stemming from chronic illnesses requiring ongoing physiological as well as psychosocial supervision and support (Boult, Karm & Groves, 2008).

Furthermore, the medical model fails to acknowledge the difference between standards and a standardized approach to care (Day, 2013). Adopting a standardized approach to care aimed at eliminating variation, the medical model encourages the same procedures, practices, and supports for all patients (Day, 2013). The result is a conceptualization of care focused almost exclusively on bodies at the expense of the social, political and historical contexts in which these bodies are situated (Armstrong & Armstrong, 2010). Within such standardized approaches to care, two popular assumptions emerge: 1. that people enter in to the system with similar (if not identical) baseline resources and opportunities for health and access to health care; and/or 2. the social, political and contextual circumstances of people do not affect their opportunities for health and access to health care within a universal care delivery system. In both cases, the medical model supports neoliberal logics of individual responsibility for care in ways that are similar to those embedded in social policy, such that health problems or illness are perceived of as being the result of an individual's biology and/or 'choice', while the social, political, and environmental circumstances (including mutagenic damages to an individual's genes/physiology) that impact upon one's health and illness are largely overlooked (Lippman, 1998; Raphael, 2000).

This approach frames the individual as the agent of prevention whereby not only is society's obligation to remove the adverse circumstances damaging to health left unexplored, but illness is

transformed into a private problem (Lippman, 1998). Here we might see how social policy, focused on the individual responsibility to provide care in the home overlaps with the intense focus on the individual within the medical model. Indeed, both models presume that people are educated about health and healthful (risk averse) behaviours and foreground an expectation that they will make 'responsible' choices regarding such things as diet, exercise, doctor's visits, and so forth. The assumptions underpinning this perspective are of course, that everyone is able to access necessary information; that they will be able to understand it; that they are able to translate this information to their specific circumstances; that they possess sufficient confidence to question their doctor; that they have the resources required to access a wide array of choices; and that they will, and/or have the capacity to be risk averse in their decision-making. This repeated focus on individuals as the site of health risk management overlooks the broader contexts through which individual agency is framed. Thus, in addition to oversimplifying the complexity of healthful action/inaction at the micro-level, it also discourages a collective response to conditions that influence health and thus collective responses to care solutions (Day, 2013).

An approach to care that locates health within individual physiological contexts and individual action or inaction situates the need for care within "individual variation or dysfunction". This individualization of health and care presents important problems for women (Day, 2013). For instance, Canadian women are less likely than men to have access to health-promoting resources, such as income, and thus possess fewer opportunities for health and access to health care (Johnson & Repta, 2012). Further, women's role as care provider in the home, as implicitly prescribed through the family model of social policy, can influence the amount of time they have to spend on health-promoting behaviors and activities, including self-care or illness-management (Bird & Rieker, 2008). When these social realities are not accounted for, it is women who are at an increased risk of being pathologized for making 'poor health choices' and who are less likely to be able to surmount barriers to all forms of care (including those provided in the health care system). When we see health as being framed by more than just the individual's physiology and 'choice', we are pushed to envision not only new kinds of social policies that extend beyond the familial 'duty' to care, but also health care supports that are broader in scope than individual-level solutions (Day, 2013; Mol, 2008).

Conceptualizing care organizations: The market model. Reverberating economic 'crises' in Canada go "hand-in-glove with projects of reframing governance and reinvigorated discourses of personal responsibility which serve to limit public provision of social supports," such as health care (Green & Lawson, 2011, p.646). In the context of thinning federal funds, provinces have been forced to deal with depleted budgets, often resulting in service cuts and the use of 'efficiency-based' market (economic) models to define the parameters of what constitutes care, what types of care come to be defined as 'medically necessary,' and of the kinds of care that receive funding through the public purse (Armstrong, 2001). The value of care within this model thus "becomes a matter of whether services deemed *appropriate* have been delivered or not, and the financial aspects of care take center stage in care decisions" (Day, 2013, p. 26). The result is a "slimmed-down" system of care (Evans, 1997, p. 449).

The methods applied to determine the 'appropriateness' of service provision and medical necessity within this slimmed-down system of care tend to rely predominantly (if not entirely) on numerical data collected using methods within the positivist/quantitative tradition (Raphael, 2000). Feminists and other critical scholars have critiqued this approach for its assumptions of objectivity on the basis that evidence constructed within this paradigm has tended to ignore the intricacies and complexities of social location (including, but not limited to gender, income, race, age), as well as the social and political contexts within which health and illness are produced and maintained (Armstrong, 2001). As such, these measures are abstracted from the broader context in which care is received and provided, and from which health emerge. Further, the voices of those who live with and negotiate care decisions (including, but not limited to: patients, caregivers, and health care providers) are muted and their perspectives on quality largely ignored (Armstrong, 2001). Yet, the majority of evidence upon which health policy and care practices are based continues to privilege a narrow range of positivist methods, and tend to rely excessively on particular kinds of numerical/quantitative data. If the provision of state-funded care rests on a conceptualization of 'necessary care services' that is informed by such evidence, then the conceptual environment for creating alternate understandings of care and care needs (e.g. psychosocial and supportive care) is greatly restricted (Day, 2013).

Another market model approach to care has been to shift care provision from public providers to private markets. From the state's perspective, care delivered through the private market is positioned as a care solution wherein the state transfers public services to the market on the basis of state-provided care being deemed 'too costly' while private companies provide the same services at reduced costs (Armstrong & Armstrong, 2010; Day, 2013). This shift is justified not only in terms of saving the government money but also as a means of controlling for inappropriate "care dependence" (Knijn, 2000, p. 234). For instance, supporters of the private market argue that market-based approaches (e.g. user fees) to the delivery of care will reduce costs to the system by discouraging the ('unnecessary') utilization of services and encouraging more 'responsible' consumptions of care. The assumption underpinning this logic is that we place a greater value on those things we pay for directly and that implementing user fees will discourage their 'inappropriate' use (Evans, 1997). As such, the goal under the market model is about keeping people out of care as oppose to facilitating access (Day, 2013).

International research and experience over the last half century has demonstrated that privatization and greater reliance on the market correlates with inequity in access to care, inefficiency in the delivery of care, high cost (to both the state and to its citizens), and public dissatisfaction with the quality of care (Armstrong & Armstrong, 2008; Evans, 1997). Yet, market-based approaches result in "distributional advantages for particular influential groups. A more costly health care system yields higher prices and incomes for suppliers – physicians, drug companies, and private insurers…and private payment costs wealthier and healthier people less than finance from (income-related) taxation" (Evans, 1997; 427). As such, Evans (1997) argues that assumptions about care in the private market on the basis of "value-neutral" economic theory are indeed far from value-neutral; rather they simply overlook the fact that not all individuals' access paid care from a level playing field. Embedded in this 'oversight' are particular assumptions about who is considered deserving of care (and health) and who is not. While Evans' (1997) analysis remains focused on a discussion of economics and class inequities, the inclusion of other (intersecting) determinants of health further complicates this discussion. For instance, women are more likely than men to live in poverty, they earn less than men in the paid workforce, are situated in more precarious employment and are less likely to possess private health insurance coverage through their employer (Armstrong & Armstrong, 2001; Jackson,

2012); thus, the wealth/health split is thus surely also a gendered concern (Day, 2013). Under the market model of care, patients are conceptualized as a homogenous group by overlooking the impact of social location. In turn, much in the same way the medical model standardizes approaches to care, within the market model, there is little consideration for the variation within and between groups of people.

In summary, the way care is defined, re-defined, understood, and practiced through these models of care reflect not only ideas about what constitutes necessary, appropriate, effective and efficient care but also produce and reify ideas about gender, individual and family responsibility, citizenship, and dependency. For instance, the discussions above reveal that care is deeply gendered both because of the gendered responsibility to care and because of the gendered consequences of unequal caring responsibilities and inequitable opportunities to receive care (Day, 2013). By examining care models and their relationship to the organization, governance, financing and delivery of cancer care, this research seeks to better understand women's care and work experiences within the context of the changing health care system in Ontario.

How Can Feminist Political Economy Contribute to Cancer Scholarship?
In review of these key conceptualizations of care, we are able to better understand how the broader political economy and guiding neoliberal ideologies inform conceptualizations of care, care practices, how decisions are made around what constitutes 'necessary care' and in turn, what types of care and care technologies get publically funded and supported. This provides the basis from which to examine the case of women with cancer who must navigate changing (and increasingly complex and converging) health care systems and who are engaged in many, and sometimes conflicting, processes of care including care pursued, provided, exchanged and received. It further permits opportunities to explore the impact of care conceptualizations, practices and state funding arrangements on the types of work that patients are expected to take-up and maintain at times of illness and the types of supports they can expect to receive in facilitation of this work. Below, I discuss key gaps in the psychosocial oncology and cancer survivorship literature and address how insights from feminist political economy theory can be helpful in permitting us to critically fill these gaps in understanding.

Advances in cancer treatment are improving survival rates and, in so doing, transforming the nature of cancer from an acute to chronic illness. While the Canadian health care system continues to operate within a predominantly medical model that favours acute care and treatment, there has been increasing policy acknowledgment of, and support for, a culture change in care that promotes a stronger chronic care agenda. Proposed reforms suggest the need for greater attention to the complex and ongoing biomedical and psychosocial care needs of patients living with chronic conditions; the importance of involving patients in their care and rooting care practices in the unique needs and preferences of individual patients; and the need for supports to assist patients in the self-management of their conditions. The Princess Margaret Cancer Centre has shown some evidence of their commitment to a chronic care model through the implementation of ELLICSR Health, Wellness and Cancer Survivorship Centre. While this appears promising, understanding how these changes are operationalized in a predominantly acute health care setting remains an underdeveloped area and the implications for patients remain unknown. Indeed, relatively little research, particularly in the fields of psychosocial oncology and cancer survivorship, has critically interrogated these shifts. Far more frequently, the focus of investigation within these fields has been on how to promote and facilitate proposed reforms that encourage such things as patient-involvement, person-centred care, and self-management. These investigations are of course rooted in (albeit reasonable) assumptions that see such shifts in care as generally positive; possessing the potential to improve quality care and the patient experience by promoting greater choice and opportunities for empowerment. The macro- and meso-level motivations that drive these reforms; the tensions, conflicts, and contradictions that emerge when new models of care are implemented into institutions (e.g., hospitals) that are historically entrenched in a medical model and the power relations therein; and the everyday micro-level experiences of patients who are left to navigate these crossroads in care are less frequently discussed.

The guiding tenets and underlying assumptions of feminist political economy provide a framework through which to critically interrogate these gaps in understanding. By situating care reforms within broader social, political, and economic shifts, feminist political economy provides a clearer view of the contexts and conditions through which reforms emerge; thus providing insight into the potential motivations underpinning policy proposed changes in health care. This

understanding is important as the motivations behind macro-level reforms (and the funding arrangements that accompany them) inform how policies percolate within meso-level institutions and micro-level worlds. Attune to the interconnections between macro-, meso-, and micro-levels, feminist political economy encourages the identification of and engagement with tensions, conflicts, and contradictions that emerge within and between macro-, meso-, and micro-levels of practice. According to feminist political economy, acknowledgement of, and engagement with, tensions and contradiction in health care provides a crucial first step to constructing more equitable care policies and practices (Armstrong & Braedley, 2013). A key tension in this study comes from the existence of ELLICSR in an otherwise predominantly acute hospital setting. Exploring the impact of this space as a potential site of challenge, resistance, and change to the dominant medical/acute care model helps to fill a substantial gap in the care integration literature. Lastly, political economy "situates individuals within particular social and physical locations, relations, discourses, and understandings of the world" that differentially shape their opportunities (and choices) for and experiences with such things as care (Brassolotto & Daly, 2016, p. 140). Attuned to these differences, we might better understand who benefits and who is disadvantaged by proposed reforms. This provides a more complex understanding of the patient experience than one that is masked by assumptions (held within much mainstream cancer literature and clinical practice) of a level playing field. In other words, feminist political economy permits and indeed encourages the researcher to explore the complexity and messiness of peoples experiences as they navigate the crossroads of an equally complex and messy health care system.

Feminists political economist recognize that the manner in which care is conceptualized, organized, funded and practiced help to shape the parameters of care responsibility and accountability between citizens and the state (Day, 2013). Conceptualizations of care thus frame the scope of unpaid care work that individuals, usually women, are expected to assume in the management of such things as health and illness. Care reforms thus hold important implications not only for women's care experiences but also for their work practices. In psychosocial oncology and cancer survivorship research there is a synonymization of work with paid employment and the problem of work is situated within 'return to work' discourse. This propels an oversimplified assumption of work as something that ends (for most) once diagnosed and is to

be resumed following cancer treatment, thus obscuring the work that both continues during and emerges from a chronic illness such as cancer (Parsons et al., 2007). The invisibility of unpaid work thus limits our capacity to fully and critically engage with and unpack the work experiences, conflicts, and struggles of women diagnosed with cancer; identify the implications of existing care arrangements and proposed policy changes on the scope of their work practices; and to develop an adequate understanding of the forms of care and support that people require to manage, and/or lessen, the burden of work at times of illness. Further, it masks the ways in which work might act as a constraint on women's opportunities for care at times of illness and as a vehicle through which inequities in care between women emerge.

By centralizing the productive and reproductive tasks of daily life, feminist political economy has contributed to "a much broader understanding of labor under capitalism than other forms of thought; an understanding that includes the relations of unwaged labor, not directly waged and highly precarious labour, as well as other forms of work (such as domestic work) often imagined to exist somehow outside of the capitalist mode of production" (LeBaron 2015, p. 7). This broader conceptualization of work offers important insights needed to more fully and carefully unpack the work practices and experiences of patients and the implications of care shifts from hospital to home. Drawing on differences in gender socialization and the historical context of caregiving as women's work, feminist political economy explains how normative gender expectations stress female nurturing and encourage women's participation in care work (Day, 2013). Feminist political economy further acknowledges the complex ways that gender intersects with other facets of identity (e.g., class, race/ethnicity, and age) to differently frame women's opportunities for care and expectations of care work. This sensitization to the gendered divisions of labour, the acknowledgement of women's heavy responsibilities in the provision of unpaid care work, and to the ways that gender intersects with other categories of social location to differently frame opportunities and choices, provides an apt lens through with to explore the gender and equity implications embedded in existing and proposed shifts in care from publically-funded institutions to privately resourced homes. In short, feminist political economy offers a theoretical lens through which to illuminate the often invisible elements of work that patients assume and continue during the upheavals of illness; to probe for differences in the expectation to provide unpaid care work (between women and men but also within groups of women); to

explore the implications of deeply entrenched gendered divisions of labour on the health and care experiences of women who are living with illness; and to view work as a vehicle through which inequities in care can emerge.

Chapter Summary

In this chapter, I outlined key principles and assumptions of feminist political economy and I engage with scholarship that applies this theoretical lens to the study of health care and health care reform, conceptualizations of health, and theorizations of care. I explored key gaps in the psychosocial oncology and cancer survivorship literatures and discussed how insights from feminist political economy theory can be helpful in permitting us to critically fill these gaps in understanding and enliven our approach to notions of care and work in the cancer context. Because I used feminist political economy as a theoretical lens, it informed my research design and practices, shaped the questions that I asked and, in turn, the types of responses that I obtained, and provided a specific lens through which interpretations were made. In the proceeding chapter, I outline the methodology and methods of this study.

CHAPTER THREE
RESEARCH METHODS AND PROCEDURES

Study Purpose and Research Questions

In attempts to address the research gaps identified in the previous chapter, this study employed critical ethnography to query how Canada's political economic system contributes to conceptualizations of care, informs the development of cancer care policies and practices, and to better understand the implications of these policies and practices on individual's experiences of cancer, care, and work. Situated within this broad focus, the specific aim of the present study was to develop an improved understanding of ELLICSR Health, Wellness, and Cancer Survivorship Centre and of how this space impacts women's everyday experiences with cancer, care, and work. In pursuit of this aim, one overarching question guided the design and conduct of the study: How does ELLICSR facilitate women's work, for which women and in what ways? Four sub-questions were derived from this major focus, further framing the inquiry undertaken:

1. What are the work and care experiences of women with cancer?
2. What are the social, political and material conditions under which experiences of cancer, care, and work occur?
3. What brings women to ELLICSR and/or what keeps them away?
4. What activities do ELLICSR staff pursue in facilitating women's work at times of illness?

In this chapter, I describe critical ethnography, unpack its ontological and epistemological underpinnings, and highlight the connections between theory and methodology. I further outline the methods used for conducting my research and interpreting my findings. In the final sections of the chapter, I situate myself in the research process, evaluate the methodological choices I have made, and discuss the quality of the research, including relevant ethical considerations.

Critical Ethnography

Ethnographies are designed to explore, describe and interpret the life-worlds of those who have some common connection or pattern in their lives – frequently referred to as a cultural group (Creswell, 2012). Ethnographers aim to better understand people's activities within specific situations, settings, or fields and seek to learn "*about* people by learning *from* them" (Roper &

Shapira, 2000, p. 1; italics in original). The insider perspectives offered through an ethnographic approach help to provide insight into the ways that people view and take action in their worlds, for instance, during the upheavals of illness (Creswell, 2012). Ethnography thus provides a way of accessing beliefs and practices, allowing these to be viewed in the contexts in which they occur and thereby aids understanding of the array of contextual factors surrounding a particular phenomenon, such as illness (Savage, 2000). Critical ethnography is not at odds with traditional ethnography, rather "it offers a more direct style of thinking about the relationships among knowledge, society, and political action" by foregrounding critical social theory (Thomas, 1993 p.vii). A critical ethnographic approach unites critical theory with ethnographic research and allows the researcher to situate his or her findings in a theoretical worldview (Creswell, 2009; Thomas, 1993). The application of theory at each stage of the research process is done so that the findings can be contextualized and the research problem can be addressed in transformative ways – moving beyond simple description of *what is* to explore *what could be* (Thomas, 1993; italics in original). In this way, critical ethnography is marked by its emancipatory intent; seeking to uncover issues of injustice and oppressive ideologies in society and by its commitment to changing social conditions in the interest of those who are rendered marginal by the dominant culture (Carspecken, 1996).

Philosophical Assumptions

 In the proceeding sections, I outline the ontological, epistemological, and methodological assumptions underpinning critical ethnography and draw connections between the ontological and epistemological foundations of critical ethnography and feminist political economy. I then connect this back to the design, implementation, and interrogation of the present study.

Ontology. In critical ethnography, reality extends beyond what is known by members of a cultural group (Georgiou & Carspecken, 2002). Like feminist political economy, critical ethnography recognizes "that claims to truth are always discursively situated and implicated in relations of power" (Hardcastle, Usher & Holmes, 2006, p. 152); and are thereby concerned with *constructions* of reality and of what or who regulates and organizes reality. Strong emphasis is placed on seeking reality through understanding the relationship between culture and the broader systemic structures and social relations that inform people's beliefs and actions, inform

opportunities, and frame individual agency (Georgiou & Carskpecken, 2002). In other words, it is believed that people are influenced by cultural conditions, social resources and relations, as well as broader power relations and their reality is thus viewed as symbolically and inter-subjectively mediated (Georgiou & Carspecken, 2002; Harrowing et al., 2010). Material conditions arise from these social arrangements. For instance, people live out policies and social discourses in very material ways. Illuminating the social contexts and conditions that might be beyond an individual's awareness are important in critical ethnography because lack of awareness promotes the continuation of repetitive and often habitual routines and knowledge constructions that are deeply immersed in existing relations of power and in doing so reproduce a particular type of knowledge that is taken up as 'truth' (Thomas, 1993). Critical ethnography is empirically grounded in explicit prior evidence of a variety of inequitable and unjust social conditions that provide the departure point for research. As such, the ontology of critical thought includes the conception that there is something better and that the goal of knowledge should be to work towards it (Thomas, 1993).

      Epistemology. A critical ethnographic ontology relies on "the native's point of view, as filtered through the data collector's interpretive framework, to provide a detailed 'thick' description that lets the natives 'do the talking'" (Geertz, 1973 as cited in Thomas, 1993, p. 34). This provides for unconventional ways of knowing (Cook & Fonow, 1986; Denzin & Lincoln, 1994) and considers the ordinariness of everyday lives as a bona fide source of research (Campbell & Bunting, 1991; Charmaz, 1983). As such, critical ethnographers reject positivism which see objectivity as the basis for knowledge (Speziale & Carpenter, 2007), assuming instead that knowledge is highly subjugated (Jackson, 2012; Stanley & Wise, 1990) and that "valid knowledge is obtained, in part, through shared understandings, reflexivity, sensitivity to insiders' points of view, deprivileging the researcher/author voice, and the consensual basis of truth claims" (Jungck, 1996, p. 623). Critical ethnographies are thus guided by, and carried out according to, many of the same epistemological assumptions as those guiding feminist political economy, including the beliefs that: 1) study participants are experts of their own experiences and, as such, their voices should be situated at the core of the research project; 2) subjective data can constitute valid and legitimate sources of knowledge; 3) knowledge is always relational and contextual; and 4) efforts at knowledge production must account for the specific conditions in

and locations from which we experience, observe, and interpret reality (Campbell & Bunting, 1991; Harding, 1988; Jackson, 2012; Smith, 1987). Both critical ethnography and feminist theory regard study participants as respected chroniclers of their own experiences, aim to learn as much as possible about the multiple realities that people construct, and seek to promote mutual creation of data by the researcher and participant (Denzin & Lincoln, 1994; Kasper, 1994; Thomas, 1993).

Methodology. Critical ethnography is a research methodology informed by the underpinning assumption that truth(s) is located in personal and subjective accounts of individual experience as situated within particular cultural and historical contexts, as well as power relations and practices (Speziale & Carpenter, 2007; Thomas, 1993). Participants and researchers are both "subjects in the dialectical task of unveiling reality, critically analyzing it, and recreating that knowledge" (Scotland, 2012, p.14). The researcher is the data collection instrument, collects artifacts and tangible trace evidence, locates stories, rituals, and myths, and/or uncovers cultural themes (Creswell, 2012). They identify, interpret, and analyze the perspectives of the cultural group through interviewing, observing, and recording of cultural data (Thomas, 1993). Participants are also involved in the research process – contributing to such things as the collection of data, framing the interview process, and the interpretation of information (Creswell, 2009). Critical methods – including semi-structured and open-ended interviews, document analysis, participant observation, and arts-based approaches, such as photo-elicitation – allow realities to be critically explored from social, cultural, historical and political perspectives (Scotland, 2012; Thomas, 1993). Analysis often involves analytic interpretation which places values on the data. Given the researcher's depth of involvement in the collection, interpretation and construction of knowledge, critical ethnographers are encouraged to be reflexive about the biases and assumptions that they might bring to their work (Bryman & Teevan, 2005). In other words, a sound ethnography rests on a transparent foundation of the epistemological and ontological assumptions of the researcher – which ultimately shape his or her own personal frame of reference (Dey, 2001). Acknowledgment and discussion of my biases, values and experiences and their impact on the research will be had later on in the chapter in the section titled "Researcher Reflexivity"

Fit of the Methodology to the Research Question

 In pursuit of understanding how ELLICSR facilitates (or not) women's work, I wanted to understand women's need for a resource space like ELLICSR and the broader social, political, and economic influences underlying and differentially framing these needs. I wanted to uncover the social constructions surrounding notions of care and work, to understand the micro-social organization involved, and to learn about the influences of larger socio-political processes in the construction and organization of care and work. As such, the methodological basis of the study required a design incorporating an experiential approach to data collection which began with, but extended beyond, the lived experiences of women with cancer. Ethnographic inquiry that explores the activities of particular individuals and how they are influenced by, and operate in conjunction with, broader social, political and economic influences are particularly well suited to this aim. Furthermore, the depth of understanding sought with ethnographies typically requires multiple data collection methods; in the context of this project, this included participant observation, semi-structured interviews, photo elicitation, and document analysis (Harper, 2002; Higginbottom, Pillay & Boadu, 2013). The application of such methods permits opportunities to *experience* (participant observation), *inquire* (interviewing and photo elicitation), and *examine* (document analysis) conceptualizations and experiences of cancer, care, and work at macro-, meso- and micro-levels of understanding (Thomas, 1993). As such, critical ethnography was perceived as the best approach with which to capture an in-depth understanding of the views and experiences of women with cancer and how these exist within the structure of public (e.g., hospital) and private (e.g., home) care systems.

In addition to capturing the relationships between structure, agency and lived experience, a critical ethnographic approach also permitted opportunities to capture the nuances and complexities of individual experience. As noted above, among the ontological orientations in which ethnography is grounded is the view that people create a multitude of realities that are complex and that change across time and space. As such, ethnographic research seeks to represent reality, rather than to faithfully reproduce every detail, and thus welcomes multiple descriptions and explanations of the same phenomenon (Hammersley, 1992). This allows for the unveiling of multiple realities that permits attention to the complexity and difference in individual's experiences. This sensitivity to the multivocality of experience is well aligned with

my intention to capture the similarities and differences in women's understanding of, and experiences with, care and work, the health care system, and the ELLICSR centre.

Lastly, with the goal of improving women's access to needed cancer care and supports, as well as their equitable distribution across women, I sought to explore the ways in which challenges and inequities resulting from social determinants could be meaningfully addressed through existing CHWCs, such as ELLICSR. I further sought to explore the ways in which dominant conceptualizations of the terms care and work map (or fail to map) onto the lived experiences of women with cancer. A qualitative critical ethnography was the best approach for pursuing these lines of inquiry because the philosophical underpinnings of the methodology permit (and indeed, encourage) the researcher to uncover the political and contextual factors that contribute to challenges and inequities, as well as to unpack, problematize, and re-conceptualize taken for granted notions that help maintain inequitable arrangements – including conceptualizations of care and work.

In short, the methodological foundations of critical ethnography were well aligned with this study because it allows for the in-depth description of a phenomena for which little is known, promotes attention to the social organization of everyday life, and because of its commitment to use findings for change. Conceptualizing the present study as a critical ethnography rooted in a feminist political economy framework bore implications for sampling, procedures, and analysis. In the following sections, I describe the project's research design including site selection, sampling and recruitment methods, data collection procedures, and analysis.

Research Design

Research Setting

About the research setting. ELLICSR was initially proposed in a 2006 Canadian Foundation for Innovation (CFI) grant. The application was led by a small group of research scientists and clinicians working at Princess Margaret Cancer Centre who argued that such a centre is necessary to help address pressing problems and care gaps within the Canadian health care system. Key problems and gaps included: 1) a lack of knowledge to guide the identification, prevention, and treatment of persistent and long-term adverse effects of a cancer diagnosis; and,

2) an outdated and inefficient model of acute and episodic care delivery inappropriate for treating chronic conditions such as cancer (Canadian Foundation for Innovation grant proposal, 2006). ELLICSR was eventually made possible through the receipt of grants from CFI and the Ministry of Research and Innovation, along with additional funding support from the Princess Margaret Cancer Foundation (PMCF). ELLICSR opened its doors in the summer of 2010 in the Toronto General Campus of the University Health Network (UHN) and has since acted as a care branch of the Princess Margaret Cancer Centre (ELLICSR, 2015). ELLICSR continues to operate with funding support through the PMCF, competitive research and innovation grants, and through private funding support (ELLICSR, 2015). Funding for the centre is not built into the hospital's operating budget.

According to its stated goals, ELLICSR adopts a participatory and community oriented approach to cancer care, aiming to: 1) advance understanding of the chronic effects of cancer and its treatment; 2) support and guide patients and their families in the management of cancer-related symptoms and side-effects, health, and wellness; 3) integrate effective and patient-driven education into models of care delivery; 4) create collaborative partnerships among health care providers and survivors to study and improve the quality of survivors' care; and 5) harness the power of communities to drive and accelerate innovation in cancer survivorship programs and services (Canadian Foundation for Innovation grant proposal, 2006; ELLICSR, 2015). ELLICSR proclaims its commitment to working collaboratively with cancer survivors, drawing on their embodied experiences and care preferences in the development and implementation of various clinics, programs, classes and events offered within the centre (ELLICSR, 2015). Informed by these and other collaborative relationships with clinicians, educators, research scientists, and community partners, the centre offers: 1) expert-led support groups and counselling services; 2) clinics, programs, educational workshops and wellness classes aimed at fostering hope, coping, illness management strategies, and rehabilitation; and 3) events aimed at facilitating connections between survivors and community partners to help extend the scope and reach of care available to patients and their families (see the ELLICSR calendar of events for a full list of classes, programs, and events: https://www.ellicsr.ca/en/classes_events/Pages/events_calendar.aspx). Virtual forums also permit patients the opportunity to participate in online programs (e.g., ELLICSR Kitchen's virtual

platforms), pursue online support, and gain information designed to support people throughout their cancer journey.

Site selection. My knowledge of the literature as well as my own Master's research experiences[5] told me that in spite of the universal nature of the Canadian health care system, people continue to struggle to attain the care they need when they need it. I was similarly aware of "crisis" rhetoric within health care literature, policy, and practice and that such discourse was being increasingly used to justify and support shifts in responsibility and accountability for health and care from hospital to home. Such shifts put new and challenging demands on the patient and their families when they are in the greatest need of care and support. With strong beliefs in the *right* to health care for all, this troubled me. I pursued a PhD to further my understanding of the impact of these shifts as lived in the everyday and to creatively explore feasible strategies to improve the scope and reach of cancer care for women living with this illness. I was aware that pursuing equity-based research with a focus on SDOH and psychosocial care ran counter to neoliberal logics of individualism and the techno-medical logics that construct and govern most cancer care policies and practices. I saw ELLICSR Health, Wellness and Cancer Survivorship Centre as a space that operates at the nexus of this tension. A centre that adopts a collective approach to the delivery psychosocial care and support, located within a predominantly acute care hospital. Its location made it an opportune environment through which to assess how the tensions and contradictions between models of care are negotiated and the ways in which patients live out these tensions. Further, an in-depth critical ethnographic exploration of the centre itself facilitates an improved understand of the impact of such a space for the care and work experiences of women diagnosed with cancer.

Despite the potential restrictions on generalizability, focusing on a single CHWC is beneficial in containing the study to one system of care and one geographical area, both of which help to enhance the rigour of data collection while remaining within the parameters of limited study resources. ELLICSR was purposively chosen as the most appropriate setting with which to focus

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[5] This research explored the impact of income on lived experiences of cancer and access to cancer care for women living in the Greater Toronto Area. The pathways through which income frame cancer and care were explored and results revealed significant gaps in access to care, quality care, and perceived quality of life between women of varying economic positions.

this ethnography because: they proclaim a commitment to participatory approaches to research and in the development of their programming (ELLICSR, 2015); because of the vast and diverse services offered within the space; and because of its (somewhat contradictory) location within a predominantly acute care hospital. I carried out the present ethnographic research at ELLICSR between 2013-2015.

Access to the research setting. Access to the research site was negotiated with the Research Director at ELLICSR and later, the research review committee which consisted of ELLICSR's founding Director (who was also the Medical Director of the Cancer Survivorship Program at Princess Margaret Cancer Centre) along with Directors from the various departments at ELLICSR, including research, patient education, and web and digital. They expressed interest in encouraging a study that would provide insight on the care experiences of patients and on the perceived benefit of ELLICSR programs for people attending the centre. Committee members seemed to be equally enthusiastic about the potential of the proposed study to contribute to improved care delivery – as informed by patient needs and wants – within the centre. My study was accepted by the research review committee on March 4, 2013.

Sampling and Recruitment Methods

As opposed to random sampling procedures, purposive sampling is congruent with the aim of selecting individuals and situations where aspects of the phenomenon one wishes to consider are most likely to be present (Creswell, 2009). In this instance, the views, actions, and experiences of women with cancer as well as the broader health care structures – including ELLICSR – that frame them, were of interest. A purposive sample was thus generated by recruiting women with cancer who attended ELLICSR as part of their cancer journey. Women were recruited through a wide range of sampling strategies. These included: email outreach using ELLICSR's patient contact database[6] (see **Appendix A** for "ELLICSR class registration" forms and "patient consent for correspondence and email communications" form, **Appendix B** for patient recruitment email,); research recruitment posters displayed at ELLICSR and the Princess Margaret Cancer

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[6] When patients come to ELLICSR, they are asked to fill out several documents which have, among other things, check boxes which indicate whether or not patients' wish to be contacted for research purposes. From this information, a database of people who are interested in taking part in research is developed.

Centre (see **Appendix C** for recruitment poster); snowball sampling[7]; and through the Princess Margaret Cancer Centre blog and ELLICSR's social media outlets, namely Facebook and Twitter (see **Appendix D** for recruitment blog).

I aimed to recruit a mix of people who had both positive and negative experiences at ELLICSR. In this vein, in addition to recruiting within ELLICSR, attempts were also made to recruit outside of the ELLICSR space – via the Princess Margaret Cancer Centre, through social media, and snowball sampling – in an effort to extend outreach to those who have, but no longer, attended ELLICSR. Valuable information about the usefulness, inclusiveness, and accessibility of the centre can be obtained from women who no longer attend; thus it was seen as important to speak with these women, in addition to those currently attending. Despite my efforts, the majority of women (n=8) who took part in the study were actively attending ELLICSR at the time they were interviewed and reported a high degree of satisfaction with the centre. The other four women, all of whom had completed active treatment (e.g., chemotherapy and radiation) at the time of our interview, stopped coming for a number of reasons, none of which seemed to suggest negative experiences. For instance, one woman explained that as she moved into the recovery phase of her illness, she no longer felt an urgent need for the supports being offered at ELLICSR. Another woman expressed that she wanted to put her cancer behind her and, because ELLICSR was such a big part of her cancer journey, this included leaving ELLICSR behind. The last two women suggested that they would have liked to continue their attendance at ELLICSR, but could not justify the lengthy and costly travel given that they no longer had to come downtown for biomedical treatments. One woman described being connected with a CHWC closer to her home. The other woman described her desire to continue participation in psychosocial programs but highlighted the relative scarcity of these programs, and CHWCs more specifically, in the geographic outskirts of the Greater Toronto Area (GTA) where she lived. This woman described periodic use of the virtual ELLICSR Kitchen program, but explained that she missed the social elements of the program and the ELLICSR space more generally. Despite discontinued attendance, all four of these women used a number of programs, services and supports at ELLICSR and found the space to be beneficial when they did attend.

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[7] A strategy whereby existing study participants share information about the study with new participants (Vogt, 1999).

ELLICSR staff were also purposefully selected. Staff members were selected by the researcher based on site observations and document research, with the aim of having a representative sample of the departments, programs, and services offered at the centre. Staff selection was also influenced by patient narratives – this was particularly true when programs or people where mentioned frequently. Staff members and programs that were frequently discussed by women in the interviews were invited to take part in the research as informants. Chosen staff represented a variety of disciplines at the centre, including research, patient education, social work, nutrition, exercise and rehabilitative therapy, and web and digital (virtual ELLICSR[8]). An administrative team member responsible for coordination across departments/programs and a primary point of contact for in-coming patients also took part in the study. Outreach to chosen staff occurred in person at ELLICSR and/or by email (see **Appendix E** for staff recruitment email). Staff who took part as interview participants were also invited to share information about the study with cancer patients attending the centre.

All participants who demonstrated interest in the study were provide with written information about the study (see **Appendix F** for study information sheet (patients) and **Appendix G** for study information sheet (ELLICSR staff)) outlining the study purpose, procedures, benefits, and risks associated with the project as well as their role in the study. Once interview appointments were arranged, participants were given a copy of the study consent form (see **Appendix H** for patient consent form and **Appendix I** for ELLICSR staff consent form) in person or via email so that they could review the contents prior to the interview. Participants were asked to read through the document, and were encouraged to discuss it with family, friends, and/or their physician, and to direct any remaining questions or concerns to the researcher before signing the document.

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[8] Virtual ELLICSR is an interactive website that allows patients to access information; learn about ELLICSR classes, events, and programs; access program content; learn about ongoing research and research projects; participate in certain programs without needing to be present at the centre (ELLICSR Newsletter, 2012).

Key Informants

The intent of this study was to engage in lengthy, robust and follow-up discussions with a relatively small number of participants. Twelve women with varying cancer types and from a range of social positions along with eight health care and service providers working at ELLICSR took part in the study. While the participant sample is small and selective in nature, thus limiting the representativeness of the data, the data are nonetheless rich and document the lived experiences of cancer, care and work with tremendous depth and detail, capturing a diversity of experiences and perspectives. Demographic and clinical information for these participants is summarized in Table 1 and discussed in detail below.

Table 1- Demographic and Clinical Characteristics*

Characteristic	Frequency n (%)
Age	Range 36 − 73 years old
Living Arrangements	
With spouse or partner:	8 (67)
Alone:	4 (33)
Family Structure	
No children household:	7 (58)
Household with children:	5 (42)
Education	
High school:	2 (17)
Some post-secondary:	1 (8)
Post-secondary diploma:	3 (25)
Post-secondary degree(s):	6 (50)
Employment status during treatment	
Employed full or part time:	4 (33)
Not employed:	2 (17)
Retired:	2 (17)
Sick leave:	2 (17)
Full-time homemaker:	1 (8)
Volunteer:	1 (8)
Total Household Income	
< $19,999:	2 (17)
$20,000 − $59,999:	4 (33)
$60,000 − 99, 999:	2 (17)
> 100,000	3 (25)
Unknown:	1 (8)
Private health insurance	
Yes:	7 (58)
No:	5 (42)
Immigrants to Canada	8 (67)
Cancer type	
Breast:	8 (67)
Brain:	1 (8)
Lung:	1 (8)
Lymphoma:	1 (8)
Ovarian:	1 (8)

* Because the site of the ethnography is disclosed and given its relatively small size, demographic information was grouped rather than presenting it as individual profiles in an effort to protect participant anonymity.

Patient participants.

Demographic and clinical characteristics. Table 1 highlights selected demographic and clinical information about the twelve women who participated in this study. As mentioned previously, the sampling strategies were geared to promote heterogeneity of demographic and clinical characteristics. The resultant sample was mixed in terms of cancer type and status (e.g., recently diagnosed, in treatment, in remission, and cancer free), age, marital status, and geographic location (as measured by proximity to ELLICSR). Given the multicultural nature of the city in which the study hospital resides, a multitude of different ethnic and cultural backgrounds was also possible, despite the small sample size. Their socioeconomic and educational statuses also varied. Below, I summarize and contextualize this information[9]. While efforts are made to situate the sample in national cancer averages, this was not always possible or appropriate. Additional efforts were made to situate the sample in relation to the demographic characteristics of patients who attend ELLICSR, however no such demographic records existed.

Cancer type and status. Most of the women who participated in this study (n=8) were diagnosed with breast cancer. The remaining four women were diagnosed and treated for brain cancer (n=1), lung cancer (n=1), lymphoma (n=1), and ovarian cancer (n=1). Of these twelve women, 9 were receiving medical treatment at the time of the interview, while 3 had finished treatment within the year prior to the interview. Some of the women interviewed described multiple cancer diagnoses; the cancer type recorded in the demographics table pertains to their most recent diagnosis.

Age. Women ranged in age from 36 to 73 years. Three (25%) women fell between the ages of 36-49 years, four (33%) between the ages of 50-59 years, 3 (25%) between the ages of 60-69 years, and 2 (17%) who were 70 years or older. While cancer can occur at any age, national averages suggest that cancer incidence is most prevalent among Canadians aged 50 and older (Canadian Cancer Society, 2015) – an average represented in this sample with 75% of the women being 50 years of age or older.

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[9] Pseudonyms/code names have been omitted from the following demographic/clinical category descriptions: cancer type and status, age, and country of origin. This was done in order to protect participant anonymity.

Living situation. Of the three women in the first age range (36 – 49 years of age), two (P7 and P10) had young children living at home while P11 (age 36) was actively seeking fertility treatments but did not yet have any children. In addition to having young children in the home, P7 also had an ill mother-in-law living in the home for whom she was the primary caregiver. Of the five women in the second age range, three (P2, P6, and P9) had children while two (P4 and P8) did not. P2's daughter was grown and no longer lived at home. While P2's parents did not live with her, she would visit them multiple times per week to provide care and considered them to be dependents. Both P6 and P9 had children (young adults) living at home. P4, while once married, had been widowed for over 20 years. She never had children and lived alone with no dependents. P8 did not mention children in our conversation but did cite her mother, who lives in South America, as a (financial) dependent. Among the remaining four women (P1, P3, P5 and P12), two had children and two did not. For the two women with children, one (P3) lived with and was caring for her adult son with an autism spectrum disorder and the other (P5) had no children living at home.

Household income, employment, and private health benefits. The yearly household income of women ranged from under $15,000 to over $100,000, with women belonging to nearly every income category in-between. Given that annual family income rather than annual individual income was collected through the demographic questionnaire, there is an observable relationship between marital status and annual income. Eight of the twelve women were married or common-law. Four of the women were living without spouses, two of whom identified their marital status as widowed, one single (never married), and one divorced. The annual family incomes of those women who were partnered ranged between $50, 000 and >$100,000. The remaining four women who were not partnered reported annual incomes that fell between <$15, 000 - $49,999.

Two of the non-partnered women reported household incomes of below $20,000. Of these women, one (P4) lived alone while the other (P3) lived with and cared for, her adult son. Both women were unemployed and had no sick benefits, relying solely on government assistance. P1, also non-partnered, reported an annual income between $30,000 - 39,999. She was retired and relied entirely on her work pension. None of these three women had extended health benefits (beyond those offered through the Ontario Health Insurance Plan (OHIP)). P5, also living alone,

reported an annual income of $40,000 – $49,999. She was retired and receiving her late-husband's federal government pension, which included fairly comprehensive health benefits/coverage.

Two of the partnered women (P2 and P11) reported having annual household incomes of $50,000 – 59,999. P2 had lost her job just prior to the cancer diagnosis and was adjusting to a single income household, made additionally difficult by the diagnosis and added expenses associated with her cancer care; a burden lessened slightly by the health coverage she received through her husband's insurance plan. P11, also within this income bracket, balanced part-time work with graduate school. While her decision to work part-time was not influenced by financial strain, she did frequently discuss the financial burden associated with out-of-pocket treatment costs – she had no health insurance to help cover such costs. Another partnered woman (P10) reported an annual household income of $70, 000 – 79,999. She was casually employed in a family-run business but suggested that most of her time was spent engaged in 'homemaking,' which included the care of her three young children. P8, also partnered, reported an annual household income of $80,000 – $89,999. She was on sick leave and receiving long-term disability through her insurer before being promptly "cut off." Relying solely on the income of her husband (reflected in the range provided above) P8, similarly to P2, described the struggle to adjust to a single income household, and the guilt of no longer being able to afford to send money to her relatives back home (South America) who relied on these funds. Neither P8 nor P10 had private health insurance. The final three women reported annual family incomes of >$100,000. Of these women, two were married (P9 and P12) and one was common-law (P6). P6 was on sick leave while P9 was a homemaker. Both women had private insurance through their husbands' insurance plans. P12 was a retired teacher who continued supply teaching on a casual basis. She did not have additional health insurance. Lastly, P7 declined to give financial information but did state that she had private health coverage.

Education. Half of the women in this study had university degrees. Of these, two (P1, P9) held undergraduate degrees and four (P8, P10, P11, P12) had obtained graduate degrees (Master's and PhD). Four of the women (P3, P5, P6, P7) had received college training, three of whom had received diplomas. Finally, two of the women (P2, P4) had completed high school.

Country of origin. Eight of the 12 participating women in this study had immigrated to Canada in their young- to mid-adult lives. Three were born in European countries, including Hungry, England and Czech Republic. Two women were born in Asia, specifically, Israel and India. The other three women immigrated from Kenya, Columbia, and Jamaica. The remaining four women were born in Canada. All of the women spoke English fluently.

Geographic location at time of diagnosis. At the time of diagnosis, most women lived relatively close to the Princess Margaret Cancer Centre and ELLICSR. Nine of the 12 women lived within 9km of the hospital and ELLICSR, and most travelled to the centre by foot, hospital shuttle, or via public transit. The remaining three women, P10, P7 and P9 lived 35.2km, 40km, and 75km respectively. These women drove and/or took public transit. Only one woman (P4) cited barriers imposed by the financial cost of transportation. While this sometimes limited the frequency with which she could attend ELLICSR, it did not appear to interrupt her attendance with biomedical appointments. None of the other women cited barriers to transportation, although some did highlight it as inconvenient and costly.

ELLICSR Staff. Efforts were taken to ensure that ELLICSR staff participating in the study were representative of the variety of programs (i.e., research, patient education, social work/psychology, web and digital, etc.) as well as services and supports offered at ELLICSR. Demographic information was not collected from this group and given the small nature of the centre, I chose not to include the job titles of those who participated in interviews in the interest of protecting anonymity.

Data Collection

Data collection took place over a period of approximately 20 months between July 2013 and February 2015. The study protocol was reviewed and approved by the Research Ethics Boards at UHN and York University, both of which are located in Toronto (Ontario, Canada). Consistent with critical ethnography, data were collected using multiple methods including: participant observation, document analysis, semi-structured interviews (with eight ELLICSR staff members and 12 cancer patients), and photo elicitation. Code numbers were assigned to participants in order to protect the confidentiality and anonymity of participants and their information.

Participant Observation

Participant observation (PO) involves gathering data through exposure to, or involvement in, the day-to-day lives or routine activities of people in a particular research setting (Schensul, Schensul & LeComple, 1999). PO is a starting point in data collection because it, in part, permits the researcher to operate in the environment of key informants, providing "an intuitive as well as an intellectual grasp of the way things are organized and prioritized within a given space, how people relate to one another, and the ways in which social and physical boundaries are defined" (Schensul, et al., 1999, pg. 91). This can assist the researcher in sorting out major social and cultural dimensions in the field being observed and afford them the capacity to produce written accounts and descriptions for others. Indeed, documenting experiences and activities through written fieldnotes turns them from passing events, to accounts that can be revisited (Geertz, 1973). PO also permits the researcher to establish direct relationships with the members of the culture – in this case, ELLICSR staff as well as women with cancer seeking support through ELLICSR programs and services. This provides the researcher with cultural experiences that can later be discussed with key informants (Gobo, 2008; Schensul et al., 1999). Further, observing, recording (e.g., written fieldnotes) and reflecting on these events, activities, and interactions enables the researcher to gain valuable insights into additional areas not addressed, or discussed with less detail, during individual interviews and/or in institutional documents (Schensul, et al., 1999).

Initial observations were made with the intent of gaining a 'general feel' for ELLICSR. In turn, the first few months in the field were spent getting oriented within the ELLICSR space. Consistent with this attempt, initial observations were paid to space (the location of the research), actors (the people who take part in the setting), activity (the actions of people), objects (things located in the setting), events (what was happening in the setting), and time (sequencing of activities). During this time, observations were made mostly throughout open spaces, including the waiting room and library as opposed to scheduled classes, programs, and events. These preliminary observations set the groundwork for more detailed observations that occurred later on in the research process – slightly before, during, and after the interviews. These more targeted observations were recorded during programs, classes, and events in which I paid close attention to the organization and prioritization of service delivery, how people relate and interact with one

another, and the degree to which the issues patients deem to be important are addressed by providers. Observations were also made in more private spaces, including weekly staff meetings, research rounds and national research consortiums (held both at ELLICSR and the Princess Margaret Cancer Centre) to capture a broader picture of the cancer care agenda and ELLICSR's place within this broader scope as well as to assess the degree to which issues that patients deem to be important were being represented. All observations were transformed into written accounts and descriptions in the form of fieldnotes.

It is important to mention that the ELLICSR space is not used by members of the oncology care team (e.g. oncologists, fellows, and oncology nurses) in the delivery of medical care and treatment; as such, no first-hand observations were made pertaining to patient's clinical care. While I received invitations to 'sit in' on private patient consults (held by social workers or psychologists), I opted not to accept these invitations. I am aware that valuable information regarding patient's challenges and struggles could have been garnered in observing these appointments; however, I felt that the presence of a researcher in the room could have swayed patients and/or their family members from discussing sensitive, taboo or stigmatizing topics, such as financial strain, thus potentially compromising their care.

Fieldnotes. In ethnographic research, fieldnotes are used to capture social situations in their various dimensions (Hammersley & Atkinson, 2007). Fieldnotes were carefully recorded and reflected upon while, or shortly after, the observation took place. Following the model proposed by Schensul and colleagues (1999), my fieldnotes were recorded with attention to: 1) detailed and descriptive observations of the ELLICSR space, programs, classes, events, staff meetings and research rounds, as well as 2) my own inferences and personal reflections, hunches and emotional reactions, as the field researcher. In facilitation of these efforts, two separate notebooks were used. One was titled "primary record" and was used during times of intensive observation (detailed information of events). In this notebook I recorded observations and informal discussions in a descriptive fashion. A second notebook, referred to as "field journal" was used to record personal reflections on the described events, points to clarify during interviews, analytic thoughts, and any emergent ideas that I did not want to forget, including reminders to consult specific bodies of literature (Lofland, Lofland, Snow & Anderson, 2006).

While recorded in separate notebooks, observations and reflections on those observations were later electronically recorded and stored in a single Word document. An example of this recording process can be seen in Table 2.

Table 2: Fieldnote Template

Location: ELLICSR, private consult room	**Date/Time:** September 25, 2013	**Event:** Initial interview

Observational Notes	**Field Researcher Perceptions and Comments**
- The participant was wearing a brightly coloured pin on the left side of her sweater with the words "cancer sucks" written on it. - She pointed to this button frequently throughout our conversation	- I was struck by what appeared to be tension between the participants narrative and the words inscribed on the button. She spoke at length about the opportunities that having cancer afforded her: "a new lease on life" and the development of a caring and supportive network. - She was additionally critical of those who "bellyached" about their diagnosis and urged the importance of being positive and optimistic. **Future Considerations** - Probe deeper when tensions between loss and opportunity emerge during the interviews. • e.g., when opportunity is foregrounded, ask participants if they have always perceived it this way, if they think it is important to be positive and why, etc. - Be mindful of this tension in the follow-up interview with P4 and probe accordingly. - When conducting observations around ELLICSR, pay attention to the tone surrounding positivity (look at paintings, books in the library, etc.). Also pay attention to the way optimism is addressed in programs and the role that patient and providers play in framing expectations around cheerfulness, if indeed they do. **Analytic Thoughts and Further Reading** - Consider how these positive accounts might be a function of keeping up appearances in relation to the tacit knowledge of the tyranny of cheerfulness surrounding cancer survivorship. Might she have felt a pressure to portray herself this way in the interview? Could there be a relationship between her social marginalization (poverty) and her presentation of optimism – strategic repositioning, fear of being further marginalized if a negative attitude is adopted, perhaps? Might she have minimized this in the same ways, and for the same reasons, that she downplayed her history of cigarette use? - Read Samantha King's Pink Ribbons Inc. and other literature on the optimistic cancer survivor identity and/or of the tyranny of cheerfulness surrounding cancer.

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I filled 78 typed, single-spaced pages with fieldnotes containing detailed descriptions, which I used for data analysis and self-reflection. Further, by keeping an on-going record of analytic notes and memos, this helped to point out important things to continue to observe or ask participants about during subsequent observations or interviews. I established the habit of writing detailed records and carefully reflecting on the research meetings, events, programs, actions, and interactions taking place within the ELLICSR centre; this helped to improve my understanding of the operational priorities of ELLICSR and of the relationships that patients form with and within the space. These notes provided a rich and reflexive context against which to analyze and better understand interviews and document material.

Documents

Document analysis involves a methodical review of text documents in order to achieve an improved understanding of a particular program, organization, experience, event, or phenomenon (Atkinson & Coffey, 1997; Stake, 1995). In this study, I aimed to gain a richer and more thorough understanding of the cancer care system in Ontario and of how care and work are discussed and represented within this structure. Documents were collected with the intention of developing insights about ELLICSR as well as the broader cancer care structures (the Princess Margaret Cancer Centre locally and CCO provincially) in which ELLICSR operates. Documentary research served four key functions in the project: 1. provided data on the contexts in which research participants' manoeuver; 2. helped inform research questions and situations which required observation; 3. provided a way of tracking change and development within the Ontario cancer care system and ELLICSR; and 4. helped to contextualize the data from other sources – including observations and in-depth interviews (Bowen, 2009). While document analysis alone cannot reveal the lived reality of health care systems, it can provide important historical, institutional, and policy data to contextualize the broader systems in which patients receive, and sometimes fail to receive, care. This method also permitted me to situate local institutions (e.g., the hospital, ELLICSR) and the everyday experiences of individuals within the broader health care policy context.

Documents were collected in several stages, similarly to those performed during observations. Initial document collection focused on material that would provide a general understanding of

ELLICSR. Publically accessible documents produced by ELLICSR and/or written about the space that: mapped the development of the centre (from its launch in 2010); highlighted ELLICSR's mandates, goals, and visions; listed programs, services and supports offered at the space; as well as those that addressed issues of funding were collected to facilitated this general understanding. More detailed documents were later collected on the programs, services, supports, and events offered at ELLICSR. These documents included monthly calendars that outline the availability and frequency of the programs and services offered. Pamphlets on classes and programs were also collected to better understand their purpose, what they offered to patients, and to whom they were available (as some programs were limited to patients receiving care at the Princess Margaret Cancer Centre). Blank documents used by staff in the delivery of care, such as the "survivorship consult template" used by social workers in private patient consults, were also collected. Such documents were crucial as they provided a glimpse into private patient/provider interactions. Documents provided to patients, such as the cooking demonstration recipe handouts (outlining detailed recipes, nutritional information, costs, and substitutions) as well as blank patient feedback forms (assessing the perceived benefit of the classes), were also collected.

In order to situate ELLICSR (and ELLICSR-related documents) within the broader structure of the local and provincial cancer care system, policy, and other official and publically accessible documents and reports that address and govern the health care system and cancer care practices were also collected. These included CCO's 2011-2015 Ontario Cancer Plan and the Princess Margaret Cancer Centre's 2013-2018 Strategies Report 2013-2018. These documents were chosen because they illustrate the structure of the cancer care system; the goals, mandates and priorities of governing organizations; and because they highlight the ways in which care and work (and divisions of responsibility therein) are represented in these contexts. I reviewed these documents to help build an improved understanding of how macro-health care policies and priorities permeate ground-level hospital management policies and practices.

Interviews

Interviews were conducted in order to understand the experiences of individuals who are situated at the ground level of cancer care and the meaning that they attach to their experiences. Twelve

women with varying cancer types and from a range of social positions each took part in two interviews (lasting between 60 -120 minutes each), a photo-elicitation exercise, and completed a demographic questionnaire. Further, eight ELLICSR staff members participated in a single interview (lasting between 45 – 90 minutes). This yielded an exceptionally rich dataset for analysis consisting of 30 individual interviews and 189 photographs. The participants in this study were all experiential experts on the study topic; coming forth with a wide range of experiences and areas of expertise. The range of participants allowed me to explore issues of cancer, care, and work from various perspectives. This variety proved useful for comparing and contrasting perspectives. The interviews were digitally recorded and later transcribed by either myself (14 interviews) or a professional transcriptionist (16 interviews) – I reviewed all transcripts for accuracy. During and shortly after the interviews I noted where the interview took place, my impressions of participant's comments and body language, as well as the conversations that sometimes emerged after the tape recorder was turned off. These notes supplemented the interview transcripts.

Interviews with patients. The twelve women who took part in this study were viewed and valued as expert 'knowers' of their own experiences and were encouraged through reflective dialogue and photo taking to discuss their perceptions of and experiences with cancer, care, and work broadly, as well as the ELLICSR space more specifically. Interviews took place at a location of women's choosing and a date and time that was convenient for them. All women chose to meet and conduct the interviews at ELLICSR; this was likely the place of greatest convenience given that most women were undergoing treatment at the Princess Margaret Cancer Centre most days of the week and/or frequently attended classes and events at the centre. These meetings were held in private spaces throughout ELLICSR and interviews were conducted in a one-on-one fashion. My credentials, relationship to the ELLICSR centre (e.g., not an ELLICSR employee), and the nature of this project (e.g., doctoral study) were discussed at the onset of the interview before the informed consent forms were signed. An honorarium of $25 was provided to patient participants following each interview as thank you gesture, but also to help offset any costs associated with such things as travel, child or family care, and/or work absence.

Initial interviews. The initial interview began with reviewing and signing the informed consent form. Women also filled out a brief demographics questionnaire (see **Appendix J**) to provide additional context for their responses. The initial interview was semi-structured and guided by a series of open-ended questions and prompts. This interview was designed to obtain information about women's everyday worlds' pre-cancer diagnosis and to acquire descriptions of their post-diagnostic experiences. This included questions about their day-to-day experiences with cancer, care, and work as well as ELLICSR's role in framing these experiences. The intention was to gain an improved understanding of the women's lives (i.e., routines, activities, social/familial relationships, responsibilities, hobbies, etc.) prior to illness, in order to better understand how cancer onset impacted their lives. Women were also asked to speak about how they heard of ELLICSR and what prompted their decision to enter the centre (see **Appendix K** for the initial interview guide).

Upon completion of this interview, women were provided with a disposable camera, pre-loaded (and pre-paid) with 27 exposure film, and asked to capture images that they felt reflected their daily experiences of cancer and the most significant aspects of their care and work. Some women declined the disposable camera, opting instead to use their own personal devices. Women were also provided with an instruction page outlining the photo elicitation exercise (see **Appendix L** for the photo elicitation instruction page). On this instruction page, women were asked to imagine they had been invited to mount a photographic exhibit entitled "My Life with Cancer" and to capture images accordingly; they were encouraged to make it as personal as they felt comfortable. An explanation of the use of photographs in the study was discussed and participant questions were answered. Photos were taken by the participants prior to the second interview and were integrated into the interview process to stimulate conversation in a method known as photo elicitation (Harper, 2002; Oliffe & Bottorff, 2007).

It was expected that this process of photo taking would take on average one month and that the lag-time between the initial and follow-up interview would therefore be roughly 4-5 weeks. It was quickly realized however, that the time required to engage with this exercise varied from woman to woman for a number of reasons. Given the sensitive nature of the exercise, some women suggested that the time needed to be right in order to capture the photographs – a process

which was not always possible within a four-week timeframe. Other women were confronted with very difficult life situations including the death of a friend, sudden illness or worsening health of a family member (which required their caregiving locally and abroad), as well as personal issues of health and illness. These women needed more time to complete the photo exercise as these moments of crisis took priority. Efforts were taken to make sure that the participants had the time they felt they needed to capture images of their experiences. As a result, the lag-time between initial and follow-up interviews ranged between two weeks to four months. I would occasionally contact the participants to see how they (and their loved ones) were doing and how the photograph exercise was coming along. In the process, and in addition to the interviews, I learned a great deal about these women's lives, their perspectives and beliefs, concerns and struggles, and about their vast work commitments. Relationship building with these, and other women in the study, was an unanticipated privilege arising from the research.

The follow-up interview. The follow-up interviews began with questions designed to re-establish rapport and clarify discussions had in the initial interview (see **Appendix M** for the follow-up interview guide). Aside from these few introductory questions, the follow-up interviews were guided predominantly by the women and the photographic images they took. In this way, and consistent with critical ethnographic methodology, women contributed to the collection of data and the framing of the interview process. The participants discussed their experiences as they saw fit following two questions I posed: "Can you please walk me through your images?" and "In the review of these photos, what stands out for you?" As each topic was raised, I followed-up with probes to encourage elaboration, adhering to the structure of the woman's unfolding narrative. Images were used to elicit discussion of the issues they represented; however, the photographs themselves were not analyzed. In the proceeding sections, I describe photo elicitation as it was used in the current study; I explore the fit between photo elicitation, health research, and the theoretical/methodological tenets of the project; and, highlight the benefit of this approach for the study and study participants alike.

Photo elicitation. In qualitative research, "visual methods are emerging as an innovative approach to understanding health experiences" (Brooks, Poudrier & Thomas-Maclean, 2008). As an adjunct to in-depth initial and follow-up interviews, participant-produced

photos can provide a rich and reflexive source of data on the day-to-day care experiences of participants and the work they perform in managing chronic illness. When research participants are actively engaged in the development and interpretation of photographs, the process can result in a more thorough understanding of *their* perspectives and experiences, *their* beliefs, and how *they* understand their worlds at times of illness (Maclean & Woodward, 2012). Feminist theorist, including feminist political economists, suggests that "power accrues to those who have voice, set language, make history, and participate in decisions" (Smith, 1987 as cited by Graziano, 2011, p. 2).

Photo elicitation aims to capture the world through the eyes of the individual and seeks to make their voices heard directly and not just through the words and interpretations of a researcher. In this way, participants are 'empowered' as they become involved in the research process by: 1) taking photographs that represent their ideas; 2) reflecting and giving titles and captions to the images; and 3) constructing and directing interview topics and discussions (Oliffe & Bottorff, 2007). There is strong agreement and compelling evidence that photo elicitation methods can produce captivating empirical data and provide distinctive insights into diverse phenomena (Olliffe & Bottorff, 2007). It has been further theorized that these methods can help to empower and emancipate participants by bringing their experiences into view, by disrupting excising power relations, and by building shared approaches (between researcher and participant) to the production of knowledge (Clements, 2012; Oliffe & Bottorff, 2007). These various tenets of photo elicitation are well aligned with the ontological and epistemological tenets and aims of critical ethnography and feminist political economy (Jackson, 2012; Thomas, 1993), making this a particularly well suited method of inquiry.

The benefits of photo elicitation methods. All 12 participating women took part in the photo elicitation component of the study, providing between 3-54 photographs each, for a total of 189 photographs. Participants who take part in a photo elicitation exercise are able to reflect on the pre-reflexive aspects of their everyday lives as they contemplate what photographs they want to take, capture photographic images, and as they elaborate upon the images in conversation (Angus, 2009). The thoughtfulness, creativity, and reflexivity that was invested in the creation of women's photographs in this study was astounding. There were three overarching ways in

which this method was of benefit, to both the study participants and research project alike. The strengths and benefits of photo elicitation in this study closely align with those identified by Oliffe and Bottorff (2007) who engaged in photovoice research with men living with prostate cancer. Specific to this study, the benefits included: supporting recall and reflexivity across temporal and spatial planes, facilitating conversations rich in descriptive detail, and extending observation beyond the confines of ELLICSR into everyday worlds. These are discussed in greater detail in the proceeding sections.

       Supporting recall and reflexivity across temporal and spatial planes. The women in this study had creative control to produce a storyboard of images that would eventually be narrated in an interview; allowing them to structure the direction of dialogue by highlighting aspects of their lives and illness that they considered important. This exercise required women to engage in processes of "planning, introspection, and reflection" as they thoughtfully considered what photographs would capture their cancer experiences and work practices as well as what they might discuss at the interview (Oliffe & Bottorff, 2007, p. 851). In the process, past experiences and 'foggy' memories were brought to the fore of participants' consciousness, promoting temporal and spatial shifts across the different moments of their cancer journey. This was particularly beneficial in cases were women had completed active cancer treatment up to a year before our initial meeting, which can render recall of the treatment experience difficult. Further, many of the women were told that they were "in remission," "cancer-free," or "cured" – although most of these women were still receiving radiation treatment and/or were on adjuvant hormone therapy medications (e.g., Tamoxifen) – at some point prior to the initial interview. Temporal distance from the treatment experience along with a positive health outcome can effect women's present accounts of past experiences (Halldorsdottir & Hamrin, 1996).

The photo taking exercise often required women to revisit past events through the lens of a camera, a process that brought up memories that women had either forgotten or chose not discuss during the initial interview. The resurgence of these memories along with accompanying feelings (e.g., disappointments, fears, anxiety, and struggles) brought to light the experiences had, and/or feelings felt, during these more uncertain times. This may be one reason why follow-up interviews tended to offer far more detailed and emotional accounts of the cancer

journey. For instance, P9 had been told three months prior to our initial interview that she was cancer-free. She explained that capturing images permitted her the opportunity to revisit past events pertaining to her cancer journey when her future was not as certain. She captured a photograph of the Princess Margaret Cancer Centre (Photograph 1), where she received all stages of treatment, and recounts her experiences of walking into this space for the first time:

> P9: This for me represents the first time I entered Princess Margaret. All of a sudden reality hits you. I couldn't get in. I was beside Mount Sinai. We were walking and I just lost it. I couldn't walk in the door [interview is paused as P9 becomes visibly upset – crying]. Anyway, so I guess all of a sudden recapturing it, it just brought back all the memories. There were one or two good ones, but this was a hard one for sure. It's part of the journey I don't usually talk about, it was an awful time, but it's important because it is part of my journey.

This photograph of the Princess Margaret Cancer Centre brought P9 back to a significant moment where the "reality" of her cancer diagnosis was realized and triggering otherwise potentially suppressed memories and emotions that were not as present in our initial conversation. In turn, important thoughts and experiences were prompted by the photographs that women took and were drawn on to provide specific details during the interview which produced accounts of lived experience which may have been absent otherwise.

Photograph 1

While the process of photographing these intimate experiences and memories was potentially confronting, all of the women agreed that capturing, reflecting on, and discussing these images out loud was somewhat therapeutic. Some women explained a lack of opportunity to 'tell their stories' and explore/reflect on their broader cancer experiences and struggles in medical encounters and within the home (usually to protect family members from their emotional hardships). These women explained that taking photos permitted reflection and that being able to tell their stories through the narration of photographs permitted a sort of emotional release – one woman explained "feeling lighter" and "less burdened" after taking part in the photo-exercise. Indeed this was, for many of the women, the first time they felt they had the opportunity to reflect on their experiences as they described the diagnostic, surgery, and treatment phases as a process that necessitated a 'go, go, go' response with little time to think, let alone reflect. There was also little time for reflection following these phases, as the work entailed in restoring and returning to (a new) 'normal' was equally demanding. This photo taking exercise allowed time for such reflection, through which the women often realized, and were surprised by, how far they had come – something for which they were very proud. For example, P2 captured images that emphasized work tasks along with life changes and sacrifices that were prompted by her illness. When asked what it was like to photograph these experiences, she describes a sense of pride in her resilience in the face of crisis:

> P2: I went into this [photo elicitation exercise] thinking of it as a project and I was surprised at the emotions that came with some of the pictures. Some of it brought me back to that time, that dark time, and I think, "Look how far I've come." I look at these pictures and I think, "Look how much I've been through." I had never had the time to really think about that before. So, I feel like a champion!

She continues by stating the therapeutic benefit of the exercise and potential utility of the images as a means of inspiration and hope in the event that the cancer ever returns:

> P2: I think we will print them out like you have and I think I'd like to make a poster and put them in the order that it happened, so then I have a visual thing and if anything else happens, I can say "This is what I have to do and I'll get there."

For most women, the photographs became a tangible representation of all their work; it was something that they created and could keep following their participation in the study. For some women, the photos represented their accomplishments and became a tool with which to cope

with their cancer experiences (including emotions that they had not previously confronted). In turn, not only did the photo elicitation exercise support women's efforts in (re)constructing their experiences across temporal and spatial planes, thus enriching the data, but it also provided women with the time to reflect on their journey – something all women described as cathartic.

Facilitating interviews that were rich in descriptive detail. Photographs can help reduce the strangeness of the interview as well as any discomfort that may result from the uncertainty of the interview questions (Oliffe & Bottorff, 2007). Indeed, similarly to Oliffe & Bottorff (2007), it appeared that the process associated with taking the photographs resulted in a certain readiness to talk. Participants also appeared to be more excited about, and within the interview. As discussed above, women put tremendous thought into the photographs they captured and, in the process, engaged in reflection about the images and why they were important to them. In turn, similarly to the works of Schwartz (1989), I found that participants engaged in discussion of these images without "hesitation in a task similar to viewing a family album" (Oliffe & Bottorff, 2007, p. 852). Participants often appeared eager to look at and talk about the photographs along with the process involved in capturing the images. While lived experience can be difficult to articulate, as it is often an unconscious process, photos helped to draw these ideas out and move beyond the limitations of the spoken or written word (Oliffe & Bottorff, 2007). Indeed, participants tended to take on a leadership role in the interview; directing topics and highlighting issues that were of greatest important to them. Letting participants take photos of their everyday worlds allowed them to take control over and make decisions about what to include in, or exclude from, the photographic records of their lives (Smith & Barker, 2004).

Participant-produced photographs also ensured that the data was collected inductively (Wang, 1999). In other words, topics were chosen and data collected by participants, informed by their perceptions of what was important to share, rather than being informed by responses to a pre-determined (and researcher produced) interview guide. To quote one of the participants (P3), "No one knows a cancer patient better than a cancer patient," and so this inductive approach proved to be invaluable in identifying the issues that the women themselves deemed important for discussion. Lastly, "photographs demand description, detail, and explanation, which help to

reduce assumptions about shared researcher-participant understandings of specific phenomena" (Oliffe & Bottorff, 2007; p. 853). This was particularly helpful with respect to experiences of treatment and the treatment process, which many of the women assumed I was familiar with given my position as a researcher in a cancer centre.

When asked to highlight what stood out for her in the photo, P2 spoke at length about Photograph 2, which she titled: "Although you have lots of support, cancer is still a lonely journey." She contextualized the title, explaining that this image represented her radiation treatments and spoke to all of the support she received during this tumultuous time in her life. She singled out her daughter, mother, and husband; pointing to the stick figures that represented each of these people in the photo. She says: "So, it's like I had these three people who were all like "Bring it on, we're ready for it. Get behind us, we're your first line of defense here." To have that means everything, it makes things more manageable and less scary."

Photograph 2
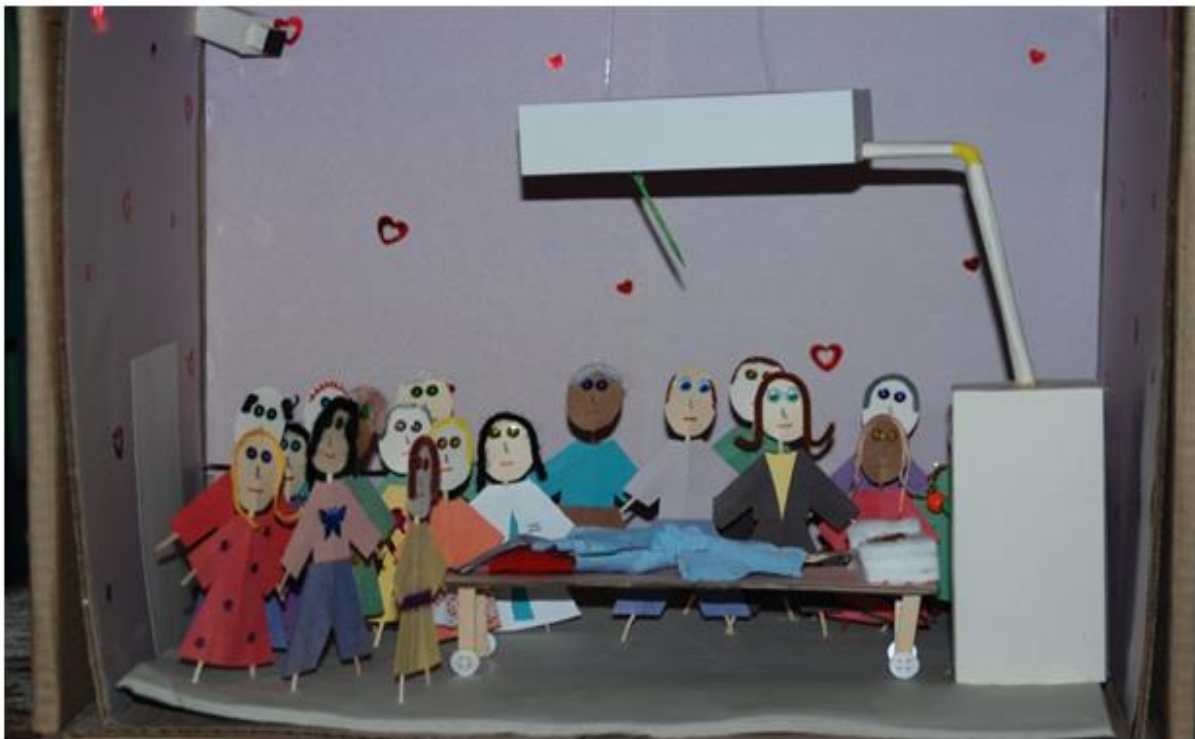
When asked why she perceived cancer to be a lonely journey, she suggested that while she experienced tremendous support from friends, family and her health care team (all represented in the stick figures captured in Photograph 2), she argued that support is quite different from understanding and that, despite unwavering support, no one could truly understand what it was like to have breast cancer, to suffer with treatment related side-effects (in her case, pain) and stigmatizing stares, as well as what it is like to make difficult decisions about treatment and reconstruction following treatment. She drew on a single example to illustrate this seeming tension between being surrounded by support networks and feeling alone. She says:

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P2: My husband was a rock, an absolute rock, but he's of this
temperament [motioning a horizontal line with her hands] and I'm of
this temperament [motions peaks and valleys with her hands]. So, all
throughout it [referring to the cancer journey], we had some different
ideas about difficult decisions. Even now, he say's "Ok, if it's going
to get rid of the pain, then go ahead with the [reconstructive]
surgery" but has his reservations because he doesn't want to see me…I
mean I didn't finish treatment that long ago and I guess he doesn't
want to see me confined to the couch for another six months. But I
think I'm looking more into the future. I can't live with this pain, so
if the reconstruction works…don't get me wrong, it wasn't an easy
decision and I know he just doesn't want to see me laid up again, but
it's a decision I had to make alone.
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P2 was able to communicate a complex and, at points seemingly contradictory, set of experiences framed by treatment, social support, and feelings of solitude. In other words, the use of this diorama (which she crafted as part of another arts-based study, but photographed for this project) facilitated "communication difficulties that might have occurred in a purely verbal interview" (Oliffe & Bottorff, 2007, p.854). Further, complex and sometimes contradictory experiences, such as the tension between having satisfactory support yet feeling alone, were foregrounded. Not only did participants reflect deeply on the specific circumstances captured in their photos, but they also made surprising connections while narrating the images.

Extending observation beyond the confines of ELLICSR into everyday worlds.
Snapshots taken by participants can incorporate significant aspects of illness experiences which cannot always be directly observable in real time and place (Oliffe & Bottorff, 2007). For instance, in the case of this study, observations were confined to the ELLICSR space and thus it was not possible to visually observe how cancer connected with women's everyday lives and work tasks performed outside the centre. Participant-produced photographs of everyday fields

(such as home, hospital, workplace, etc.) made otherwise un-observable moments visible and discernable. For instance, women provided images representing significant places (including parks, recreation centres, religious buildings, etc.), events (fundraising galas, weddings, etc.) and people (family, friends, co-workers, health care and service providers, etc.), along with social and holiday gatherings, medical treatments/technologies and embodied aspects of their cancer (e.g., pictures of hair loss, bodily changes and assistive devices, such as canes to assist with walking).

Participant-produced photographs were crucial in contributing to observational data outside of the ELLICSR space. For instance, in photograph 3, P2 captures the undergarments she wore pre- and post-mastectomy, drawing attention to aesthetic and functional body changes that resulted from this surgery. Beyond aesthetic changes resulting from a radical mastectomy, P2 also experienced surgery-related pain that she described as "excruciating", made worse by the physical pressure of certain articles of clothing, such as a bra. As she pointed to the left side of the image, she said:

> P2: I have to wear undershirts, I can't wear bras and that really puts me into boy mode and having short hair, it's just something from when I was young that has just come back. That's hard, I think that's one of the harder things [begins to cry]. Aside from the pills, this is up there. This is how I start my morning. So, every morning starts off on a bit of a bad note. And this isn't getting any easier. Some of the other pictures are getting easier, but not this one. This is a big reason why I decided I'm going to get the [reconstructive] surgery. I have to tell myself "It's temporary" and that's how I put them on and I put on bright colours and try to be happy.

Photograph 3

This image prompted P2 to share intimate details about the struggles of breast cancer, focusing specifically on physical markers left by the illness (the removal of her breast and the pain that resulted from the surgery). Her narration of this image provided a foundation for discussing the connections between work, optimism, gender, and body/identity repair. In addition, the image allowed me the opportunity to observe an everyday practice – getting dressed – of P2 in the context of her home, and highlighted the different forms of work involved in previously taken-for-granted tasks of everyday life. As illustrated in the quote, this 'simple' everyday task became imbued with meaning and was characterized by challenges. It was an activity that required P2 to confront the reality of her cancer and its lingering effects (effects which, for her, brought her femininity into question by thrusting her into "boy mode"). P2's vulnerability was privately experienced and publicly concealed as she made considerable effort to hide the physical markers of her illness from others; the photograph permitted her to share these experiences, revealing only that which she felt comfortable with. In turn, the use of photo elicitation permitted a glimpse into a significant component of P2's ongoing journey that would not have been possible through participant observation at ELLICSR. Observations within the home via photographic images provided untapped visual and verbal insight into women's home

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environments – including, the management of illness, social relations and divisions of labour, along with the care they received and provided (for themselves and others) within this space. Given women's heavy involvement in the household, observation within the home were essential in capturing the extent of women's care experiences and work practices.

Interviews with ELLICSR staff. The activities and experiences of health care and service providers as well as administrators/organizers at ELLICSR involved in the care of women with cancer were solicited during interviews with eight staff members. All of the staff worked at ELLICSR, some of whom had cross appointments at the Princess Margaret Cancer Centre. The primary focus in these one-on-one, semi-structured interviews was to inquire about their experiences with ELLICSR, the day-to-day work they perform with patients attending the centre and how they believe this work facilitates women's own work demands, what possibilities and/or constraints ELLICSR offers for the treatment and recovery of women with cancer, as well as future plans for the centre (see **Appendix N** for ELLICSR staff interview guide). The interviews took place at times and locations that were convenient for the respondents. All staff decided to conduct the interviews at ELLICSR in a private consult room, the boardroom, or in their personal office space.

Conversations with both patients and staff were ongoing and informal dialogue continued outside transcribed interview processes. Some of the interviewed patients and staff members would raise further issues as they had time to reflect on questions raised during interviews and these discussions were recorded in fieldnotes. In this way, research participants were active contributors and creators of the research process as they became involved in conversations and voiced their thoughts about care experiences and work practices.

Analysis of Data

All interviews were audio-recorded and transcribed verbatim. In the transcribing of interviews, notation of such details as: long or short pauses, emotional responses (including laughter or crying), and words or phrases that were said with particular emphasis were made. Special attention was also paid to moments of hesitation in participants' responses. This was done to better understand the emotional content of these moments and the difficulty of particular discussions (Taylor, Bogdan & DeVault, 2016). Interviews were printed and read in their entirety

and notes were made regarding my impressions. Transcripts were later entered into NVivo 8 to assist in the organization of data and for producing a report of relevant interview quotations.

Collecting, coding, and initial stages of analysis were concurrent. While this approach has some resemblance to the grounded theory approach (Strauss & Corbin, 1990), the intention was not to develop a theory, but rather a detailed description of: women's experiences of cancer, care, and work at times of illness; how social relations involving women, health professionals and others (e.g., family, friends, fellow-cancer patients) are coordinated; and ELLICSR's role in facilitating work processes and practices and framing care experiences. A Constant Comparative Method (CCM) was applied to analyze the data. CCM promotes a thorough assessment of cases in relation to one another to highlight differences and similarities (Fram, 2013; Glaser, 1965; Creswell, 2009; Strauss & Corbin, 1990). Given that this study seeks to capture the complexities of experiences among women with cancer as well as to explore similarities and differences between women's accounts and those of ELLICSR staff and broader institutional practices/policies, this method of analysis was seen to be most appropriate and fitting.

Informed by Boeije's (2002) step-by-step approach to constant comparative analysis, a four-step procedure was derived and implemented across the data:

1. Comparison within a single interview
2. Comparison between interviews within the same group (i.e., patients and ELLICSR staff)
3. Comparison of interviews from different groups (looking at similarities and differences between the narratives of staff and patients)
4. Comparison across interviews, fieldnotes, and documents.

Step 1: Comparison within a Single Interview

In this initial stage of analysis, individual transcripts were read and re-read until important sections or *passages* were marked and descriptive names or codes were added to fragments of data. There were two types of comparison that took place in this initial step. The first was comparison between codes within a single participant's interview(s). For instance, if reference was made to the same code more than once in the course of the interview (for instance, "luck" was a code that came up frequently within patient transcripts), I would compare the various fragments of data pertaining to that code, looking for similarities and differences in those

discussions and would then adjust the code description accordingly to reflect the diversity of discussion had around that particular code. The second form of comparison within this initial stage of analysis was comparison between different passages of the interview, with the intention of examining consistency across the interview as a whole. For instance, a common inconsistency that arose in women's individual interviews was between the central narrative of the Princess Margaret Cancer Centre functioning as a "well-oiled machine" whereby women described receiving optimal care, juxtaposed with accounts that critiqued the health care system as being tiered and full of barriers, highlighting the many moments where they nearly "fell through the cracks." When inconsistencies such as these were identified in the initial interview through the comparison of passages, it was often raised in the second interview as a follow-up question. When women were asked why they had these two seemingly conflicting care experiences, most women clarified that the Princess Margaret Cancer Centre did in fact work as a 'well-oiled machine' in their particular circumstances, but that this was only because they had the resources, confidence, and 'know-how' to navigate through institutional obstacles and to traverse a terrain riddled with deep cracks.   Emerging from this apparent inconsistency then was an understanding that patients saw their own capital, savvy, and hard work as the oil that greased a sometimes rusty machine.

From this initial analysis and comparison, I acquired: the ability to address some of the apparent inconsistencies within individual's interview(s) and a list of provisional codes[10]. This list of codes was analyzed for similarities and grouped into categories based on their common properties. For instance, the codes "it takes a toll," "I felt so loved and supported," and "everyone relied on me," were collapsed into the emerging category "costs and rewards of caring work." Further examples from the women's interviews include codes of "I am still a mom," "I became cancer," and "loss and opportunity" which were later collapsed into the emerging category "identity." In this regard, the initial analysis also yielded an emerging set of categories that helped to refine the individual interview into a conceptual outline, which became particularly beneficial as I began to engage in the other analytic steps discussed below.

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[10] Patient and provider code lists were kept separate.

This initial phase of coding was facilitated by the participation of a fellow qualitative researcher and PhD student at York University. She read the first four transcripts and coded them according to my preliminary scheme. We reviewed our coding of these transcripts together. Although this might be interpreted as an attempt to establish "inter-rater reliability" (Uebersax, 1987, p.140) in the quantitative sense, it was actually an exercise in cross-referencing my own understanding of the women's narratives with that of another qualitative health researcher. We discussed the similarities and differences in our coded transcripts and she suggested some coding refinements. For instance, while I had noted the prevalence of discussions around everyday housework in the women's transcripts, she alerted me to the complexities of the emotional work that the participants described doing on behalf of loved ones and for themselves.

Step 2: Comparison Between Interviews within the Same Group

All individual interviews were analyzed in accordance with the above. After this stage of analysis was conducted, the comparative process between interviews began. The comparison in this step was between interviews within the same group, which, in the case of this study, included: 1. women living with cancer, and 2. ELLICSR staff. Within this stage of comparison, codes and categories (along with the fragments of information attached to them) from different interviews were compared. New codes and categories emerged and others were further refined and honed. This process yielded an inventory of characteristics of each category, which helped to uncover a coherent system of meaning and provided criteria for the systematic comparison across interviews (Boeije, 2002). For instance, to draw on categories discussed above, "identity" and "costs and rewards of caring work," were used as criteria for comparison. Through this comparison, interviews were grouped together according to similarities and differences with regard to identified criteria. From these comparisons, patterns of experience were noted. Interviews that did not fit the pattern (i.e., negative or outlier cases) were actively sought and criteria on which some interviews differed from others were identified and notations (memo) were made. In this way, I began to group the data into typologies of experience (Hammersley & Atkinson, 2007), and later compared key contextual differences using the lens provided by feminist political economy (with a focus on SDOH) in order to tease out the interplay between structure and agency (Thomas, 1993). This stage involved a search for explanations that projected beyond lay accounts of experience and into the social and structural realms.

Step 3: Comparison of Interviews from Different Groups

In this third step, interviews from two different groups were compared with regard to the topics of cancer, care, work, and ELLICSR. While the interview process was somewhat different between patients and ELLICSR staff, attempts were made in both cases to gain improved understanding of ELLICSR and attention was paid across the interviews to understandings of care, the nature of care provided within and beyond the ELLICSR centre and the capacity of this space to facilitate the work that patients perform at times of illness. Contrary to the aims cited by Boeije's (2002), in this study, the aim of this comparative stage was not to "*validate* the patient's story either confirming the story or casting doubt on it." (p. 399, emphasis in original). Rather, my intent in pursuing comparison across patients and providers was to better understand the similarities and differences in their conceptualizations of care and work as well as to provide a deeper understanding of the institutional (ELLICSR and the hospital) context in which women's narratives unfold. Staff provided different accounts than patients and discussed issues that helped to situate the patients' experiences in the broader health care context. For instance, ELLICSR staff spoke frequently about how funding arrangements within the hospital and budget cuts within the ELLICSR space impacted their programs and the extent of psychosocial services they could offer patients. Some spoke with tremendous frustration about significant cuts to the services they offer within their programs and/or the frequency with which their programs ran, while others spoke about, with equal frustration, pilot programs that were terminated when grant funds ran dry. These narratives provided a contextual backdrop for the few patient narrative accounts of frustration around changes to program frequency as well as their confusion around why some programs simply disappeared. This comparison did not yield a new directory of codes – although, new memos and analytic notes were constructed.

Step 4: Comparison across Interviews, Fieldnotes and Documents

In the fourth step, interviews were compared with fieldnotes (generated through observations) and document material. Observations and documents underwent a process of open coding similar to the process performed in stage 1 with participant interviews. Provisional codes attained through the first and second stages of interview analysis were then compared to codes from observational fieldnotes and documents. Specific attention was paid to comparisons between the fragments of data belonging to each code. For instance, how did document material address the

concept of support and how was this similar or different to the ways in which patients spoke about support? The types of codes that emerged and the frequency with which they were used was also compared. For instance, the category of "identity" was of central focus in the women's narratives and yet was scantily discussed in many of the provincial and hospital documents reviewed (e.g., CCO's Ontario Cancer Plan 2011-2015 and the Princess Margaret Cancer Centre Strategies Report 2013-2018). Observations and document review of ELLICSR programs, such as "Getting Back on Track," however revealed increased attention to identity; specifically, the need for identity 'repair'. In this regard, observations and document material were compared with interview transcripts to illustrate moments of potential similarity and difference between the provincial and local care agendas and women's lived experiences of cancer, care, and work.

In addition to comparing and contrasting these bodies of data, I also used the emergent categories and themes captured in my observations and documents to contextualize the patient and provider interviews. For instance, a central theme that emerged from my fieldnotes was "promoting the positive patient." Perhaps the most explicit application of this theme in practice was during a staff meeting in preparation for a patient engagement event, titled "For Me, With Me," held at the ELLICSR centre. In this meeting, a central topic of discussion was how "we" (ELLICSR staff involved in the event) were going to "deal" with people who wanted to share negative experiences of their cancer and care. While I, and another qualitative health researcher colleague, raised objections to the idea of 'enforced positivity,' we were outnumbered by those who felt that "negativity in this context would be unproductive" and "would bring down the tone of the event." The plan was thus to redirect or deflect non-positive experiences shared by cancer survivors on that day.

These and other similar observations provided a conceptual backdrop with which to better understand women's accounts during the interview. For instance, these broader expectations of positivity were perhaps most evident when women apologized for "dwelling" on negative accounts of their cancer experiences in the interview. Furthermore, drawing on the example of P4 described in the previous section on "fieldnotes" (see p. 49 of this dissertation), the "tyranny of cheerfulness" that penetrates the institutional sector and beyond (see King, 2006) offers one potential explanation for her positive account of cancer (despite the number of hardships she has

endured as a result) and her explicit disapproval for people who "bellyache" about their cancer experiences. It also provides insight into the tension between her "cancer sucks" button and her framing of cancer as an opportunity for self-reflection and improvement. This tension might be, at least partially, explained by her location in the hospital and by the expectation to perform in an institutionally 'appropriate' (i.e. optimistic) manner. By comparing document and observational data with participants' individual narratives, I was better attuned to the manner in which broader social, political, and institutional ideologies might influence the thoughts and activities of participants.

The above analytic strategies were often simultaneous and recurring. Throughout the analysis, extensive memos were kept to track my ongoing interpretations of the interviews, to challenge these interpretations, to identify emerging codes, categories, and themes, and to record decisions about which themes to keep and which to discard. Memos also tracked my engagement with the literature and theory, producing a record of the ongoing dialogue that ensued between literature, theory, and data. These memos were kept and used as a tool to aid in the facilitation of self-reflexivity.

Researcher Reflexivity

As mentioned previously in the chapter, reflexivity is an important part of critical ethnography that serves to remind the researcher that they are part of the social world they study and that their values and worldviews position them to perceive, and explore, the research problem in a particular way (Creswell, 2012; Hammersley & Atkinson, 2007; Thomas, 1993). Below, I position myself within the research by declaring my social location and illuminating my assumptions; at least those of which I was consciously aware. I have attempted to be as transparent as possible about the ways this has influenced the study, including the theoretical, methodological, and analytic choices made.

Philosophical assumptions of the researcher. I chose to frame this study according to the tenets of critical ethnography and feminist political economy because of the thematic synergies in their ontological and epistemological positions, but also because of the fit between their philosophical underpinning with my own values and worldviews. I am a relatively young

and healthy Caucasian woman born in Canada to a working class family. I am a feminist, I am left-leaning in my political views, and I am university-educated in a socio-cultural health sciences stream. While I myself have not had cancer, I have an intimate understanding of the process and its impact. I have watched family members be transformed into patients; I have sat in waiting rooms, doctors' offices and next to hospital beds; and I have watched as some have lost their lives to these illnesses. My experiences and observations – as informed by my social location, theoretical orientations, political commitments, and lived experiences – situate me in a specific context that has shaped my worldview and has framed the beliefs and assumptions that underlie all aspects of this research. It is to these assumptions and their influences that I now turn.

I developed and carried out this project with the fundamental assumption that, contrary to neoliberal logics of individualism, there exists a dialectical relationship between the structural constraints on individuals and the relative autonomy of human agency. I thus entered this research with the belief that health is political. I believe that health is shaped by inequities in power; that the social determinants that frame opportunities for health are amenable to political action (or inaction) and intervention; and that health, and a standard of living adequate for health and well-being, should be an aspect of citizenship and a human right. Likewise, I believe that as much as health is political, so too is illness and that those with power are less likely to fall ill, more likely to have access to care when illness strikes, and are more likely to survive illness. I also held on to the assumption that there are important differences between women and men (as well as within these groups) when it comes to issues of health and illness as well as those of work and care; specifically, that the division of care labour holds particular consequences for women and women's health. I entered this study being personally and professionally committed to capturing inequitable arrangements and to bridging such inequities and social injustices.

I further conducted this study from the perspective that illness is multifaceted and far reaching, and that it is not constrained to the physical body and thus is not always amenable to techno-medical fixes alone. I believe that illness unfolds in complex and inequitable circumstances and that this complexity is often ignored, or minimized, by the institutions that treat illness; institutions that are more often than not interested in the pursuit of universal truths, 'objective'

medical knowledge, and one-size fits all solutions to care. I believe that objective approaches to the construction of knowledge and determination of what constitutes 'medical necessity' often fail to capture the nuances of the live experiences of illness and that one-size fits all approaches to treatment are bound to leave some people on the margins of care. In this way, I entered this research under the assumption that health care systems can, and frequently do, act as key social sites wherein inequities are both constructed and maintained. Finally, I entered and carried out this research with the belief that knowledge about health and illness can be derived from various sources and that inter-subjectivity rather than objectivity is needed to capture the complex, holistic, multiple, dynamic, and context-dependent nature of people's everyday lives and illness experiences.

My personal experiences, academic training, as well as my social and political positionalities have informed these assumptions which have in turn shaped the topic I chose, the questions I asked, the cultural group I sought to better understand and work with, and framed the lens through which I collected and interpreted the data. Throughout analysis, I became keenly aware as I recorded analytic memos and wrote in my reflexive journal of how my position (e.g., beliefs, values, social location, academic training) impacted the literature I chose and of how this assemblage of personal life and academic texts informed the ways I interpreted the data during the data analysis process. For instance, during data analysis, I struggled with a deeply inculcated disposition to highlight the devastation of cancer, poor and uncompassionate care experiences, and inequities in health and access to care. These stories were there and they were plentiful; however, this deep inculcation to 'critique' sometimes made it difficult see and tease out patient's more positive accounts of their experiences, such as those of a caring physician who went "above and beyond" or of the perceived opportunities for personal growth that resulted from their cancer diagnosis and journey. In other words, I paid close attention during data analysis to participants who told negative accounts of, and/or challenged mainstream health care practices and models of care. This was partly because these participant accounts provided a counter-perspective to popular understandings of universal, free, and accessible health care and also because their experiences of struggle resonated with some of my own lived experiences as well as the body of critical qualitative literature that I was immersed in at the time (Mauthner & Doucet, 2003).

Acknowledging this tendency, I proceeded in my analysis with caution so as to not favour one set of data over another. Instead, I consciously wrestled with the messiness of varying and conflicting perspectives toward care (within and between interviews) in order to represent the experiences of the women in this study with complexity. I further sought out and frequently discussed my emerging interpretations with some of the women who participated in the study, my research supervisor and committee members, as well as those involved in a research development group I attended at the Princess Margaret Cancer Centre consisting of qualitative and quantitative researchers as well as clinicians and bioethicists. I expressed my reflexive struggles with these various groups and sought out their varied and diverse perspectives. These conversations were helpful in not only identifying positive accounts, but also in fleshing them out and situating them within broader social, political, and institutional contexts.

Social and emotional connection to the participants. Being immersed in ELLICSR for nearly three years, many of the participants (patients and staff) became close friends of mine. In the process, I became more attuned and sympathetic to their problems; seeing the cancer care system from their perspective. Although the research was focused predominantly on the experiences of women living with cancer, there was the possibility that I might be excessively critical of health care providers and judge their behavior as rigid and uncaring in situations that were far more complex. This may partially explain why I searched for cases of hardship as discussed above. Situating these accounts within the larger social, political, and institutional/organizational context offered through feminist political economy often permitted me to extend analysis beyond a focus on uncaring people, to explore the ways in which these people's choices and actions are also constrained by broader structural arrangements.

Quality of the Research

Numerous authors have offered benchmarks or guidelines through which the quality or credibility of qualitative research can be judged (Lincoln & Guba, 1985; Morse, Barrett, Myan, Olson & Spiers, 2002; Patton, 1999; Tracy, 2010). The quality of a study is established, in part, through thorough disclosure (Patton, 1999). Ethnographers thus ought to account fully for their own presence in the work, the investigative approaches and strategies they employed, and for the

limitations of their findings. It is important to provide evidence not only of the quality of the research findings, but also of the research process itself, as the quality of knowledge is deeply grounded in its methods. With this in mind, throughout this chapter, I have described the conduct of the research with careful attention to the sampling methods, data collection procedures, and analysis. In so doing, I aimed to provide a full and transparent account of the investigative approach so that the reader is able to assess the quality and credibility of this study. To assist the reader, I foreground some of the strategies I undertook during my own research in the proceeding sections. I have structured this discussion according to Tracy's (2010) eight "big-tent" criteria for assuring quality in qualitative research: worthy topic; rich rigor; sincerity; credibility; resonance; significant contribution; ethics; and meaningful coherence. While these criteria are still hotly debated among qualitative researchers (a debate which falls beyond the scope of this chapter), I adopted them because of their close alignment with other discussions of validity, credibility, and quality in qualitative research and because they are well-suited to the epistemological foundations of this project.

Worthy topic

Tracy (2010) asserts that good qualitative research is "relevant, timely, and significant" (p. 840). As I have discussed in the current and preceding chapters, Canada's health care system is in a state of flux. The use of "crisis" discourse – emphasizing the unsustainability of a government-supported health care system – has been increasingly used to justify service cuts and shifts in responsibility and accountability for health and health care from hospital to home. Acknowledging the ways that health care systems are changing and the connection between these changes and the broader political economy are crucial to contextualizing the everyday lived realities of people who are impacted deeply by such changes in policy and practice. Through these broader policy and structural shifts, "we can see the beginnings of a wholesale re-arrangement of the work of being sick and the beginnings of a reworking of the social contract between sick people and the clinicians and organizations that care for them" (May, n.d., p. 2). An improved understanding of the quality of care and quality of life implications, as well as potential consequences for the inequitable delivery of care embedded in such changes and shifts, are relevant, timely, and significant.

Rich Rigor

Tracy (2010) suggests that a researcher with a case full of abundant data, retrieved through multiple means, is best prepared to see nuance and complexity and that this contributes the richness of the research. While the collection of varied and diverse sources of data is discussed in greater detail in the section on "credibility," it is worth highlighting here that data were collected through documents, observations, interviews, and photographs. The collection of data through written text, observed action, narration of lived experience (of both patients and providers), and imagery provided a more kaleidoscopic view of cancer care and work from micro, meso, and macro perspectives. These various, and often diverse, perspectives facilitated a fuller understanding of the issues as well as the complexities and nuances therein. Rigor was further supported through the use of a fieldwork journal and through the identification and analysis of outlier or negative cases, both of which are described in further detail below.

Fieldwork journal. Tracy (2010) further suggests that rigor is judged by the care and practice of data collection and analytic practices. In the pursuit of transparency, I have documented throughout this chapter the processes through which varying bodies of data were collected, interpreted, and applied. Throughout the study I kept an on-going record of analytic notes and memos, this signaled important things to continue to observe and/or to ask participants about in interviews. The fieldwork journal was also used to record personal thoughts and feelings, including sadness, anxiety, astonishment, and confusion. I recorded, read, and reflected on these thoughts and emotions frequently in order to understand, among other things, how my thoughts and feelings impacted my relationship with participants, how they informed the ways I was reading the data, and the ways in which this informed my inculcation to weigh some data more heavily than others (Hammersley & Atkinson, 2007). This journal also provided an audit trail of research activities.

Negative or outlier cases. The search for participants who fit the eligibility criteria, but represented a multitude of social locations, was a strategy applied to increase the breadth of participant experience and insights. Further, functioning under the assumption that "any given finding usually has exceptions", a search for instances of "negative or outlier cases" was undertaken within and across interviews (Miles & Huberman, 1994, p. 270). Engagement with

negative or outlier cases can test and improve the findings by encouraging the search for alternative meaning (Miles & Huberman, 1994; Patton, 1990). For example, outlier cases might represent instances of contradictions to emergent interpretations of the data, or instances of important diversities among participants. The diversity and complexity between participants can offer an important glimpse into the broader complexities of the world within which we situate our research. In short, consideration of outliers promotes exploration of complexity as oppose to simplicity within our research – thus, providing further explanation and confirmation of evolving conclusions (Tracy, 2010). During analysis, I was mindful of being open to negative cases; however, in review of the data I did not overtly identify any negative cases per se. Rather, highlighted in the findings where varying shades of difference, and by following a feminist political economy lens, I was able to contextualize the different social and material resources participants had to demonstrate this variability in participants' experiences of cancer, care and work. None of the cases necessarily constituted a negative case but, by highlighting the contextual differences between cases, it helped to enhance the credibility and rigour of the findings.

Sincerity

Tracy (2010) argues that sincerity is achieved through "honesty and transparency about the researcher's biases, goals, and foibles as well as about how these played a role in the methods, joys, and mistakes of the research" (p. 841). As qualitative researchers, we seek to make sense of the collective experiences of our participants by investing countless hours into reading, re-reading, and analyzing our texts (i.e., interview transcripts, fieldnotes, documents, etc.). Throughout this process, we call on our subjectivity surrounding the phenomenon under study and personal understanding of our relationship with research participants to make sense of those things they have told us as well as to probe for meaning in those things that they have not (Stein & Mankowski, 2004). In other words, we map our understanding of the world – as informed by our epistemological, ontological, and theoretical assumptions as well as our personal, social, and institutional influences – onto the voices of participants (Bourdieu & Wacquant, 1992; Mauthner & Doucet, 2003). This subjectivity is not in and of itself a bad thing; indeed, ethnography relies on personal involvement with participants and collaboration between researcher and participant in the construction of knowledge (Thomas, 1993). Rather, it becomes a problem when we fail to

acknowledge the ways in which subjectivity guides the research. Reflexivity provides opportunities for investigative transparency by offering a platform through which researchers can declare their beliefs, assumptions, and practices (Stein & Mankowski, 2004). The declaration of my positionality and contextualization of my assumptions discussed in the previous section on reflexivity thereby make them transparent and open to judgment and evaluation. In this way, I take ethical responsibility for my own subjectivity.

Credibility

Credibility refers to the trustworthiness, dependability, and plausibility of the research findings, achieved through such practices as thick description and crystallization (Lincoln & Guba, 1985; Tracy, 2010). **"**Credibility in qualitative research measures how vivid and faithful the description of the phenomenon is" (Beck, 1993, p. 264). My goal was to represent the voices of study participants in an honest, open and respectful manner. In telling their stories, I acknowledge that people can choose how to construct their stories and that these accounts are thus authentic representations rather than absolute truths (Nunkoosing, 2005). Thick description and crystallization, were used to assist in accurately recording participant's stories as well as the broader phenomena under study.

   Thick description. A defining feature of ethnography is thick description (see Geertz, 1973). Indeed, this is a crucial component for achieving credibility in qualitative research as it moves beyond participant descriptions of their actions to illuminate the context in which those actions take place (Bouchner, 2000; Geertz, 1973; Roper & Shapira, 2000; Tracy, 2010). In doing so, thick description offers the reader a detailed and rich description of the phenomena under study and participant's experiences therein, and facilitates interpretation of the broader and contextual significance of participants' actions and experiences (Patton, 2001).

Geertz (1973) argues that ethnographers need not enter into thick description with an empty head, encouraging that they bring theory and theoretical understandings to provide a necessary lens and language through which to understand and describe the meanings of social actions. In this way, the application of theory in ethnography helps the researcher to immerse themselves into the contextual factors of the field, which facilitates an improved understanding of patterns

within the data (Hammersley & Atkinson, 2007). In this study, I entered the arena of health care and lived experiences of illness with the theory of feminist political economy in hand. I drew on the tenets of critical ethnography and feminist political economy, including a feminist political economy conceptualization of work, in an effort to raise more than a description of participants experiences, but also a theoretical grounding and interpretation of those experiences (Tracy, 2010).

Crystallization. Crystallization encourages researchers to adopt numerous methods, collect various types of data, and employ multiple analysts; the goal is not to provide researchers with "a more valid singular truth, but to open up a more complex, in-depth, but still thoroughly partial understanding of the issue" (Tracy, 2010, p. 844). Consistent with the tenets of crystallization, multiple methods, data sources, and analysts were pursued to provide greater depth and breadth to the analysis; a more kaleidoscopic view of the social practices under study. It was not however, aimed at pursuing an 'objective truth' or a 'truer' representation of events (Barbour, 2001; Flick, 2007). For instance, I applied a multitude of data collection methods – wherein I considered participant narratives alongside observations and documents –to glean a deeper understanding of the cancer care structure, health care policy, and ELLICSR as well as how women's experiences are informed by these fields of practice. In other words, the application of multiple methods permitted a wider view of the phenomena under study and also provided a (albeit partial) context through which to situate women's narrative accounts of care and work. All forms of data were viewed as distinct and equally valued sources of data for analysis.

To further enhance the credibility of the study, narrative data was sought from two different sources, patients and ELLICSR staff. This use of multiple data sources provided a more complete picture as it allowed me to gain critical insight into the issues from the perspectives of those providing care as well as those receiving it. In the interest of capturing varied perspectives and the complexities entailed in accounts of care and work, further attempts were made to speak with women of varying social locations and with different cancer diagnoses. The perspectives of different providers and of women who are variously positioned (socially, economically, and clinically) were useful for comparing and contrasting perspectives and allowed me to view and

interpret the data from varying points of view; thus providing a broader and deeper understanding of the research (Banik, 1993, as cited in Hussein, 2009).

Lastly, due to the independent nature of the research as well as time and financial constraints, the inclusion of multiple researchers and/or analysts was not possible; however, assistance was sought by qualitative and quantitative colleagues at the Princess Margaret Cancer Centre and York University to facilitate multiple ways of seeing the data and to help illuminate things I might be missing in the analysis. Opportunities for feedback on the study by colleagues, peers, and more senior academics were further sought out through the delivery of multiple presentations at various stages of the research. Feedback received during presentations and/or in conversation with colleagues were frequently recorded in an analytic memo journal; which I revisited throughout analysis.   Emergent themes were further discussed with members of the doctoral supervisory committee and with participants (patients and ELLICSR staff) from the study when they would inquire about the progress of the research. In what Tracy (2010) terms "*member reflections*" I would share and dialogue with participants about the emergent findings, offering the opportunity for questions, critique, and feedback. The fresh, and varied, perspectives of all these individuals helped me to reflect upon and challenge my assumptions and emergent analysis.

Resonance

Tracy (2010) uses the term resonance to refer to the research and research's ability to evocatively reverberate and move an audience. Researchers can, and are encouraged to, engage in practices that help to promote "empathy, identification, and reverberation" of the research by people who are both affected and not affected by the topics discussed with the intention of both moving the "heart and belly" as well as the "head"" (Bochner, 2000, as cited in Tracy, 2010, p. 845). In the interest of moving the heart, belly, and head, in this study I have attempted to use qualitative narratives that are "vivid, engaging, and structurally complex" (Tracy, 2010, p. 845), and have whenever possible accompanied such narratives with images; providing both verbal and visual insight into women's experiences, struggles, and successes as they relate to living with cancer.

Significant contribution

When assessing the significance of a study's contribution, Tracy (2010) suggests that researchers ought to "gauge the current climate of knowledge, practice, and politics, and ask questions such as 'Does the study extend knowledge?' 'Improve practice?' 'Generate ongoing research?' 'Liberate or empower?' The answers to these questions point to the ways in which the research will contribute to our understanding of social life, bring clarity to confusion, make visible what is hidden or inappropriately ignored, and generate a sense of insight and deepened understanding" (Tracy, 2010, p. 846). While the contributions of this research will be discussed in greater detail in Chapter Five of the dissertation, there are a few points pertaining to the practical and theoretical significance of this work that warrant mention here.

Practically significant research. According to Tracy (2010), "practically significant research asks whether the knowledge is useful" (p.846). The motivations driving this research, from construction, to collection, to dissemination, have been to extend knowledge and improve practice in the delivery of cancer care. I believe that by casting a wide ideological net with respect to concepts of health *care* (as occurring in homes and communities, not just in hospital) and *work* (as consisting of both paid and unpaid labour) have permitted me to extend knowledge of these concepts in the cancer context in a manner that showcases the potential pathways through which people experience unmet care needs, poor and inequitable quality care, and poor quality of life during the upheavals of illness. By rendering these often invisible pathways visible, I believe this research has the potential to not only improve our understanding of care experiences but also to improve care practices.

Theoretically significant research. Tracy (2010) argues that "theoretical significance usually requires that we go beyond mere (re)application of existing theory" (p. 846). Feminist political economy has been ground-breaking in its efforts to highlight the importance of unpaid work (including, but certainly not limited to, the work of social reproduction and the provision of care for those fall ill) in the formal economy. This work is often women's work and feminist political economists are interested in identifying the implications of such divisions of labour for women and women's health. Much of this research has rightly explored the health consequences for women who provide such care for others. In this study, I sought to extend this focus by

exploring the ways in which such divisions of labour affect women who are themselves in need of care in the home.

Ethics

The tasks discussed above, while contributing to improved quality, are also significant in constructing ethical research. Below, I discuss additional efforts employed to ensure strong ethical conduct.

      Procedural ethics. Procedural ethics are those incorporated by the Institutional Review Boards and include such mandates as avoid deception, do no harm, ensure *informed* consent (including potential risks and benefits of participation), protect privacy and confidentiality (Tracy, 2010). Miles and Huberman (1994) argue that "such procedures not only attend to ethics but also lead to more credible data" as with strong consent processes, participants are less likely to experience mistrust of the researcher and the research process (Tracy, 2010, p.847). As previously described, all participants who demonstrated interest in the study were provide with written information about the study outlining the study purpose, procedures, benefits and risks associated with the project as well as their role in the study. Once interview appointments were arranged, participants were given a copy of the study consent form in person or via email so that they could review the contents prior to the interview. Participants were asked to read through the document, and were encouraged to discuss it with family, friends, and/or their physician, and to direct any remaining questions or concerns to the researcher before signing the document. This not only permitted them opportunities to thoroughly review the contents of the form, but also encouraged opportunities for relationship building between the researcher and participants. All of the data collected was kept strictly confidential.

All hard copies, including transcripts, photographs, fieldnotes, and memos, were stored in a locked filing cabinet at ELLICSR in the research area which is protected by electronic key access during non-business hours. All electronic data and audio-recordings were also kept on a password protected institutional server at ELLICSR. Transcripts were anonymized by removing identifying information such as people's names and places, and code numbers replaced participant names in order protect the confidentiality and ensure the anonymity of all participants along with the information they shared. Audio-files were erased once they were transcribed.

Situational ethics. Tracy (2010) explains that "a situational ethic assumes that each circumstance is different and that researchers must repeatedly reflect on, critique, and question their ethical decisions" (p. 847). An ongoing consideration of whether or not the means justify the ends is crucial to ensuring situational ethics (Tracy, 2010). Given the sensitive nature of my research along with my location in a care setting, it was important that I continuously engaged with these considerations – an incredibly personal and challenging task. For instance, as noted earlier in this chapter, I received invitations to 'sit in' on private patient consults (held by social workers or psychologists) and had the institutional ethics approval to do so. While the social worker emphasized that these kinds of 'sit-ins' occur frequently in her consults, I ultimately opted not to accept these invitations. I am aware that valuable information regarding patient's challenges and struggles could have been garnered in observing these appointments. However, I felt that the presence of a researcher in the room could have swayed patient and/or their family member from discussing sensitive, taboo, or stigmatized topics such as financial strain, thus potentially compromising their care. In other words, after careful reflection, I decided that the means did not justify the ends.

Relational ethics. Relational ethics refer to an "ethic of care that recognizes and values mutual respect, dignity, and connectedness between researcher and researched, and between researchers and the communities in which they live and work" (Ellis, 2007, as cited in Tracy, 2010, p. 847). Similar to a relational ethic is the concept of "feminist communitarianism" introduced by Christians (2005, p. 151); a concept that promotes promise keeping, the primacy of relationships, compassion, nurturance and caring, collaboration, emotionality, and connectedness (Tracy, 2010). Relationship building with the participants in my study is not something I necessarily sought out from the onset of the project, but was rather an unexpected privilege arising from the study. As women shared their stories and images, I felt a sense of connection to women and a compassion for their often challenging circumstances. When women were explicit about some of the challenges they were facing, I acted. For instance, one woman explained that she had been battling a persistent flu made worse by her level of food insecurity and that both of these things were negatively affecting her cancer treatment (and other related work tasks). I explained to her that ELLICSR supplies free Ensure supplement drinks to patients

and that she was welcome to take as many as she would like. She came to ELLICSR a week later and had me called to the front desk – she thanked me for the Ensures and for the kindness and wanted me to know that she was feeling much better.

Meaningful coherence

The use of "methods and representation practices that partner well with espoused theories and paradigms" is at the crux of meaningful coherence (Tracy, 2010, p. 848). Establishing methodological coherence (Morse et al., 2002) entails ensuring that the research question matches with the methodologies, including types of data collected, process of analysis, and theoretical underpinning. In designing the research, I was conscientious of making the link between critical ethnographic methodology and feminist political economy theory. I collected document, observational, interview, and photographic data to answer my research questions because it is a fundamental aspect of feminist political economy ethnographic research that aims to understand meanings and everyday practices to generate knowledge that begins with, but extends beyond, the lived experience. As such, I maintained methodological coherence in adhering to the principles of both critical ethnography and feminist political economy theory.

Chapter Summary

This chapter has outlined the study methodology and considered its implications in terms of its epistemological and ontological assumptions. The chapter began with a description of the methodological framework (CE) guiding the study. Sampling and data collection procedures were discussed, and issues surrounding the quality of the research were illuminated. The aim of this ethnographic study was to uncover the experiences and implications of cancer care and work as conceptualized and practiced in the Canadian context, specifically, Toronto, Ontario. I employed a research design in which qualitative data were collected using critical ethnographic methods, including observations, document analysis, interviews and photo elicitation. The findings were analyzed using feminist political economy as a theoretical guide. These findings are discussed thematically in the following chapters.

CHAPTER FOUR
STUDY FINDINGS

Manuscript One[11]
"It's Hard Work": Re-conceptualizing 'Work' in the Cancer Context

Introduction

The Canadian health care system is organized according to a medical model through which care is seen as short-term and resources are deployed to cure acute symptomology (Armstrong & Armstrong, 2010). Cancer is largely regarded and treated within this acute illness framework whereby patients receive techno-medical assistance, but rarely have government funded access to ongoing psychosocial and supportive care (Boult, Karm & Groves, 2008; Foster & Fenlon, 2011). Within a medical model of care, the work of managing cancer and treatment, late and long-term side-effects, and the personal, social, psychological, and economic consequences that emerge from, or are exacerbated by, this illness fall predominantly, if not entirely, on the shoulders of the individual. Health care and social policies have been instrumental in shifting accountability for this work onto patients (Armstrong, 2013; Day, 2013; May et al., 2014). This shift in accountability mirrors emerging shifts in care responsibilities whereby patients are increasingly expected to take on "new and growing demands to organize and co-ordinate their own care, to comply with complex treatment and self-monitoring regimens, and to meet a whole range of expectations of personal motivation, expertise and self-care" (May et al., 2014, p. 283). As people undertake this illness-related work, they are often simultaneously engaged in the work of maintaining their (changing) daily lives in terms of tasks, roles, and responsibilities (Charmaz, 2006; Corbin & Stauss, 1985; Emslie, Browne, MacLeod, Rozmovits, Mitchell & Ziebland, 2009; Mackenzie, 2014; May et al., 2014; Townsend, Wyke & Hunt, 2006). The navigation of these varying domains and tasks are perceived by many patients as hard, burdensome, and sometimes overwhelming *work*; typically characterized as a 'full time job' (Nelson, 2010; Parsons et al., 2007; Sinding, 2010; Sinding, Miller, Hudak, Keller-Olaman, & Sussman, 2012).

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[11] The manuscript titled ""It's Hard Work": Re-conceptualizing 'Work' in the Cancer Context" will be submitted to Social Science and Medicine. It has been structured according to the requirements of this journal; however, word limits have been exceeded in the interest of providing a more robust analysis that ties more fully into the broader topics of the dissertation.

These accounts of work are seldom acknowledged as such in psychosocial oncology and cancer survivorship literatures, policy documents, and health care practice. Within these fields, 'work' is typically characterized as being synonymous with paid employment and the problem of work in the cancer context is usually addressed within discussions of 'return to work.' This propels an oversimplified assumption of work as something that ends (for most) once diagnosed and is to be resumed following cancer treatment, rather than seeing the crisis of illness as marking the beginning of a new 'job' in which patients must actively engage and frequently struggle (Parsons et al., 2007). While employment is critically important to many cancer patients for a multitude of economic and personal reasons (see Stergiou-Kita, Grigorovich, Tseung, Milosevic, Hebert, Phan & Jones, 2014), this is merely one aspect of work for which support is needed. Furthermore, the synonymization of work with paid employment promotes a limited conceptualization of work that is removed from the everyday contexts of people's lives and the social and cultural factors that permeate their everyday experiences and inform work projects. For instance, it overlooks the time consuming and hard work of social reproduction – work traditionally performed by women – and in turn also overlooks the gendered implications of this work on access to prerequisites of health, including time for self-care (Clow & Kemp, 2012; Luxton, 2006). In this vein, limited perceptions of work also negate attention to the potential for 'work conflicts' that might arise for women as they seek time, resources, and energy to engage in their own needs for self-care within the family context (Mackenzie, 2014; Radina et al., 2014). Attuning to social roles and the division of labour helps to identify and illuminate the circumstances wherein "doing gender" and "doing health" become problematic (Dale, Angus, Seto Nielson, Kramer-Kile, Pritlove, Lapum, Price, Marzolini, Abramson, Oh & Clark, 2015)**.** These complexities and nuances are often overlooked in cancer research focused on paid employment and 'return to work'.

While the synonomization of work with paid employment is most common in mainstream cancer literature, the argument that chronic illness involves challenging and demanding work is not new (May et al., 2014). Indeed, as Parsons and colleagues (2007) have pointed out, social scientific research has been far more attuned to the complexity of work for people living with chronic illnesses. This literature is filled with accounts of the challenges that patient's face to endure the symptoms of chronic illness and of the vast effort that people invest in: actively engaging in

medical contexts and with health care providers (Sinding et al., 2011); self-managing illness and care (May et al., 2014; Rukeyser, Steinbock & Agins, 2003); 'repairing' disrupted identities (Charmaz, 1983) and bodies (Moss & Dyck, 1996); and of maintaining daily life, roles, and routines (Mackenzie, 2014) – including employment (Rasmussen & Elverdam, 2008). This literature provides important insights into the many types of work that patients take on as they manage and adjust to life with a chronic condition. It also showcases the depth and breadth of work tasks inherent in each of these fields. However, with few notable exceptions of scholars who have explored the intersecting nature of the various types of work described above for people with chronic illnesses (Corbin & Stauss, 1985; Parsons et al., 2007; Mackenzie, 2014; Townsend, Wyke & Hunt, 2006), the majority of scholarship on work does not explicitly address their interplay nor does it fully contextualize the source of patient's struggles. In this regard, little is known about the simultaneous demands of various forms of work, the challenges of coordinating this work and navigating tensions between work tasks, prioritizing resources to satisfy work demands and the consequences of being unable to do so. Further, much of this literature does not fully embed discussions of work within the broader social and political relations of gender and other key determinants of health (including health care) that frame people's opportunities to successfully perform work tasks and navigate through work tensions. It is within these nuanced interactions and social positions that we might better understand the intricacies of work and everyday work struggles at times of illness, and therein begin to understand an important pathway through which inequities in care emerge.

In this paper, I draw on a feminist political economy conceptualization of work as consisting of paid and unpaid tasks that require intent, time, effort and skill (Smith, 2005 as cited in Sinding et al., 2011). I pursue the theme of 'work' from this perspective as it unfolds in relation to 12 women's experiences with cancer and care. Informed by a feminist political economy lens, I consider how the rearrangement of care and care practices within the Ontario health care system frame the depth and breadth of patient's work. I further examine the gendered nature of work in this context and the implications for women diagnosed with cancer. I identify and explore six distinct forms of work performed by participants: 1) illness work; 2) body work; 3) identity work; 4) everyday work; 5) paid employment and/or the work of maintaining income; and 6) coordination work, in order to elaborate upon the complexities of work practices, tensions, and

negotiations and to illuminate the often invisible social and material resources upon which these work tasks rest. The aim of this paper is to re-conceptualize work in the cancer context so that the vast paid and unpaid work that patients perform at times of illness, the work struggles they encounter, and the health consequences (and inequities) therein are brought to the fore.

Feminist Political Economy of Health Care

Feminist political economists often turn to the state to explain the health care context as well as broader care policies and practices (Day, 2013). Canada's political economy is guided by the ideological orientations of neoliberalism. Neoliberalism promotes a focus on individual solutions as opposed to social and systemic change in ways that have been increasingly taken-up in discourses of cancer and health care practice (King, 2006; Laxer, 2015). This contributes to an understanding of why, despite Canada's universal health care system, our approach to care provision is increasingly shifting toward community and family-based care as well as for profit-care (Armstrong, 2013). The relegation of care to the home is typically presented as a policy solution rather than a policy problem (Day, 2013). Governments see this shift as an uncontroversial and sensible way of responding to the needs of people with chronic conditions, such as cancer, while also averting fiscal "crisis" (see Drummond, 2012, p. 167). The perceived sensibility of these shifts is, at least in part, connected to a "historically rooted belief that care provision in the home is a 'naturalized' part of family relations that has seldom been considered 'work' (other than by feminist and some socialists), but rather a form 'moral and spiritual vocation' – usually provided by women" (Struthers, 2013, p. 161). As such, care work often goes unacknowledged or is inadequately supported (Struthers, 2013). In this regard, nation-states play a critical role in gendering health, care, and work. They help structure what is done in the formal economy and the private household, and in doing so, frame the parameters of public and private *responsibility* over health and the provision of care (Armstrong, 2001). As care delivery and cost become increasingly privatized; the social determinants of health assume even greater significance in the context for cancer care insofar as they differentially frame opportunities for care and care practices (Clow, Peterson, Haworth-Brockman & Bernier, 2009; Jackson, 2012).

Drawing on a feminist political economy conceptualization of work – as consisting of paid and unpaid tasks that require intent, time, effort and skill (Smith, 2005 as cited in Sinding et al.,

2011) – I examine the notion of work from the perspectives of 12 women who have been diagnosed with cancer. The conceptualization of work projected through feminist political economy provides a unique lens through which to explore the complex and vast work of patienthood and therein, permits the identification of challenges, tensions, and conflicts embedded within and between different forms of work that might limit women from getting the care they need when they need it.

Methods

The analysis presented in this paper emerged from a broader qualitative ethnographic study exploring the impact of a hospital-based CHWC (ELLICSR) on patient's cancer care and work experiences. Informed by critical ethnography and feminist political economy theory, a variety of data were collected and analyzed using: fieldwork (participant observation), document analysis, semi-structured interviews (with ELLICSR staff and cancer patients), and photo elicitation. This paper focuses specifically on data gleaned from patient interviews and photographs to better understand these participants' conceptualizations of, and experiences with, care and work at times of illness. Ethics approval for this study was granted by York University and UHN Research Ethics Boards.

Recruitment and Participant Sample

A purposive sample (Creswell, 2009) was generated by targeting recruitment of women with cancer who came to ELLICSR as part of their cancer journey. Participants were recruited through email outreach using ELLICSR's patient contact database, recruitment posters, snowball sampling, and through the Princess Margaret Cancer Centre blog and ELLICSR's social media outlets (namely Facebook and Twitter). Written consent was obtained and code numbers were provided to ensure the confidentiality and anonymity of participants and the information they provided. Twelve women with varying cancer types and from a range of social positions took part in the study. Demographic information for these participants is provided in Table 1.

[Insert Table 1 Here]

Data Collection

Each of the 12 woman took part in two semi-structured interviews for a total of 24 interviews. The first interview was designed to elicit accounts of women's day-to-day experiences pre- and post-cancer diagnosis and of their relationships with the ELLICSR centre, staff, and other attending patients. Following the initial interview women were provided with pre-paid disposable cameras and asked to capture images pertaining to their daily experiences with cancer. Women captured between 4 and 54 photographs each for a total of 189 images. A follow-up interview was scheduled once the participants had completed the photo elicitation exercise. Capturing images associated with an experience as personal as cancer takes time (Brooks, Poudrier & Thomas-MacLean, 2008) and the time required to engage with this exercise varied between participants depending on a number of life and illness related factors. Efforts were taken to make sure that the participants did not feel rushed and that they had the time they felt necessary to complete the photo-taking exercise. Accordingly, the time between initial and follow-up interviews ranged between two weeks and four months. The follow-up interviews were guided predominantly by the women and the photographic images they took. In a similar approach to that taken by Angus and colleagues (2009), as each topic was raised in relation to the photographs, I asked questions to encourage elaboration but adhered to the structure of woman's unfolding narratives.

Analysis

The analysis followed the tenets of critical ethnography (Thomas, 1993) and feminist epistemology (Alcoff & Potter, 1993; Jackson, 2012) in obtaining women's accounts in their own terms, privileging their perspectives and foregrounding their lived experience (Angus et al., 2007). Interviews were transcribed verbatim and analysis occurred simultaneously with data collection. Transcripts were coded line by line in order to identify emergent codes, categories, and themes and derive analytic thoughts/memos. Following this process of thematic coding, a constant comparative approach was applied to thoroughly assess and better understand influences that contributed to differences and similarities in the circumstances of participants but also to identify similarities and differences across various forms of data. This comparative approach was informed by Boeije (2002) and unfolded with: 1. comparison within a single interview; 2. comparison between interviews within the same group; 3. comparison of interviews

from different groups (survivors and ELLICSR staff); and lastly, 4. comparison across interviews, field notes, and documents. This comparative strategy enabled an understanding of a range of work and care experiences and set the foundation to begin to compare women's key contextual differences using the lens provided by feminist political economy. By examining the data through a feminist political economy lens, I was able to explore the social, political, and economic relations of work at macro-, meso-, and micro-levels of insight (Vosko, 2002).

Limitations

There are several limitations to this study. First, all of the participants were living in the GTA at the time of diagnosis and treatment. Living in a major urban setting meant that they were often in close proximity to their family physician/walk-in clinic; multiple hospitals providing cancer care (including Princess Margaret Cancer Centre – one of the top 5 comprehensive cancer centres in the world); as well as various cancer wellness centres and support services including ELLICSR, Wellspring, Gilda's club, and Nanny Angels to name only a few. Public transportation further eased women's access to these spaces. In contrast, people living in rural spaces often confront geographic isolation, inadequate transportation, and hospital/health professional shortages (Ahmed & Shahid, 2012). In turn, the findings of this study do not necessarily capture the experiences of Ontarians residing outside of the GTA for whom access to care services and supports may be additionally challenging. Further, all of the women who took part in this study attended ELLICSR Health, Wellness, and Cancer Survivorship Centre and thus had access to, and made use of, the various psychosocial resources, services, and supports offered within this space. Access to additional forms of care, services, and resources help to support women in some aspects of their work (see findings in Manuscript Two of this dissertation, p. 125); it can thus be reasonably extrapolated that given the participant's proximity to, and use of, health/cancer care and psychosocial supports, that the findings of this study may actually underrepresent the care hardships and work struggles of women living with cancer. Another limitation is the relatively small sample size. This can often be an issue in case studies given that there are a limited number of people to speak with within an single organization. Notwithstanding this limitation, the group of participants in this study includes representation from a variety of ages, ethnic/racial, educational and economic backgrounds, cancer types, and captures a diversity of living arrangements and family structures. Theoretical saturation of the

concept of work with participants from these varied demographic backgrounds helped to reinforce the extent and challenges involved with the work of patienthood. Also, conducting multiple interviews with women along with the collection of data from other sources (including photo elicitation, participant observations, interviews with health care/service providers, and relevant document analysis) lends additional credibility to the findings (Tracy, 2010).

Findings

All of the participants in this study agreed that cancer constituted a significant crisis in their lives, one which necessitated considerable work as they actively sought to recover, adjust, reconcile, and repair the many aspects of their lives that changed in the wake of the words "you have cancer." In recounting the diagnostic and treatment phases of their illness, six types of work were most frequently discussed: 1. illness work; 2. body work; 3. identity work; 4. everyday work; 5. paid employment and/or the work of maintaining income; and a higher-level order of work, 6. coordination work. In the proceeding sections, each of these forms of work are unpacked, exploring the tasks inherent to each kind of work; how these work tasks are done, delegated, or not done; the conditions in which work tasks unfold; and, the consequences of engaging or not engaging in these forms of work. While this paper divides the work accounts of respondents into six separate sections, the women's accounts of illness and the work it necessitated were inextricably connected and intricately intertwined. For instance, the work of maintaining everyday life, valued social roles, and identities revealed tensions that permeated illness work, yet were also often required in order for illness work to take place. Further, perceived body failures were connected to a disrupted self /self-image and body work was done, in part, to reconcile aspects of one's identity as well as to improve functional capacity to perform everyday and employment activities. Despite their reliance on one another, not all work was given equal weight all of the time. There was an order to these work tasks and the importance of each type of work varied across the illness trajectory as women were called upon to attend to different aspects of their illness. Moreover, the performance of work seemed to be better tolerated by women who were well equipped with resources to manage work tasks. In this vein, the order of work prioritization also varied according to women's social locations, their access to required resources, and the difficulty and/or ease with which work tasks could be done.

Illness Work

As women recounted their diagnostic and treatment experiences, they emphasized the "consuming" nature of illness work. They described the need to coordinate and attend multiple medical appointments, adhere to complex treatment regimens, and to engage in practices of self-care. Learning to communicate in techno-medical terms and managing their care/symptoms at home was part of this work.

"Move over life:" The consuming nature of illness work. Illness work began upon suspicion of cancer. Women described this pre-diagnostic phase as marking the beginning of an impetuous and demanding amount of activity that included making and attending appointments for diagnostic testing, consulting with specialists, and securing time off work to be able to accommodate these appointments and their long waits. Given that health care appointments are scheduled during typical working hours (9am-5pm), this required some creative manoeuvering for those women who needed time off work to attend appointments but did not yet want to disclose the potential of illness to their employer. Once diagnosed, health care teams drafted treatment plans outlining what types of therapy should be given and when. Consults, lab tests, surgeries, and treatments (chemotherapy and radiation) where scheduled – often across multiple medical institutions. While some women described health care providers who took the time to coordinate schedules with them – working around, wherever possible, such things as child care issues, work schedules, transportation arrangements, and other medical appointments – most women were simply provided treatment plans and were expected to arrange other domains of life to accommodate. Attending appointments was a time consuming and exhaustive component of illness work. This was perceived as highly demanding, sometimes stressful, and always tiresome. Below, P9 highlights the continuous sequencing of chemotherapy treatments, blood work, medical consultations, and administering of Neulasta medication to help cope with the side-effects of chemotherapy treatments:

> P9: I had 6 chemo sessions, 1 every 3 weeks. Monday was blood work. You have to go and get your blood checked, and then they send it up [to the lab]. And then you have an oncologist appointment. And Wednesday was chemo. It was more or less around 10:00 - 10:30, and they lasted 1 hour. My husband took me every Wednesday. Other people took me the Monday. And Thursday, I had to get the Neulasta shot, the $3,000 shot. They scheduled that one close to my home.

P8 similarly speaks to the work of attending medical appointments, emphasizing the consuming and exhaustive nature of this work in her photograph and accompanying narrative where she highlights, among other things, its conflict with other valued (and valuable) activities:

Photograph 4
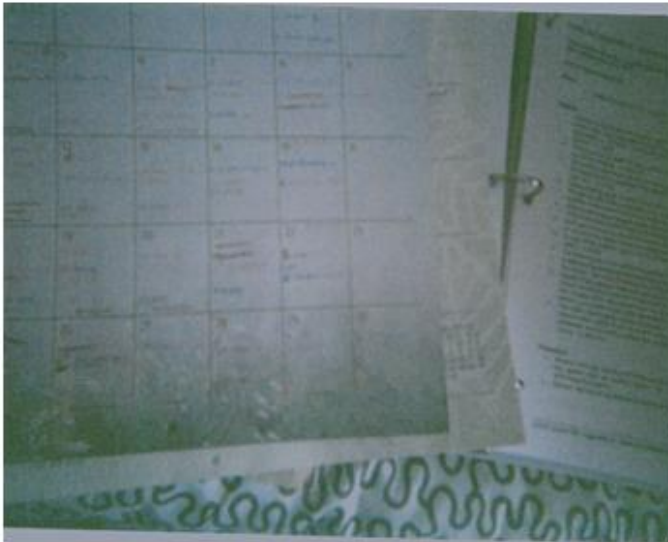
P8: Everything in red is the medical appointments, the therapy appointments. Things in blue are the classes I attend to help me manage the effects of the things in red. Sometimes I need to cross the things in blue because there is no energy, there is no time. But if you see, it is a calendar full of activities. So that is what I did, going for appointments, therapies, follow-up's and so not much time for fun. It's consuming.
I: Yes, I can see that from the calendar. You look very busy.
P8: Everyday, Cheryl. Therapy there and therapy there, appointments and lab tests, you name it. It's very tiresome work.

The work of involved patienthood. Many of the women in this study acknowledged the demand to engage in their medical care, including treatment-related decision making. Women described the active learning that was involved in adjusting to, and succeeding within, this new environment. P5 explained that she bought books, did internet research, and read countless pamphlets in order to "learn how to ask questions to doctors in a language they understood and would respond to." P2 similarly highlights the work involved in communicating with members of her oncology care team and learning to 'speak the same language', but goes beyond the discussion of research and skill development to emphasize the ways in which patienthood marked the beginning of a "new life" which required considerable adjustment. Below, she highlights the preparation involved in attending medical consultations, including the development of questions to facilitate engagement in time-sensitive consultations as well as that involved in researching physician's recommendations and treatment options in order to enter an informed discussion with the provider and to make informed treatment-related decisions:

Photograph 5
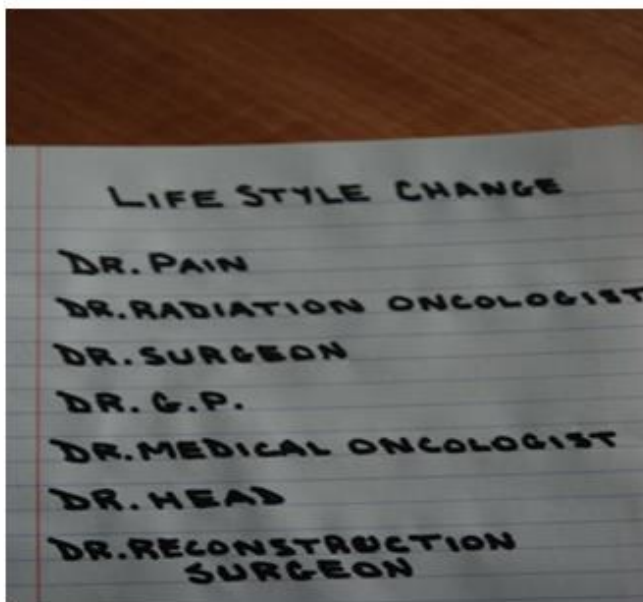
P2: This is my new life. That's how I refer to them in my mind [laughs] because it's hard to remember all these names, they just keep throwing doctors at you. So all of a sudden the calendar is just filled with this and umm, each one of them addresses a separate issue you're dealing with and so there is a lot of new information being thrown at you in a very small window of time. I usually bring my notebook because I usually have questions and they would bring up new information or issues and they would tell me the different things we'd be doing with medications and you don't always understand what they're saying and there's no real time to break it down, so I liked to be able to write those down to help me remember and sometimes I need to decode what's being said [laughs], so it helps with that too. It's like "move over life."

Many women felt that the logics embedded in the health care system rested on the ability of patients to leave other commitments and valued activities to attend day appointments and to spend time: 1. preparing scripts prior to appointments so as to not "waste the doctors' time" (while, ironically, patients were expected to wait for indefinite periods to see providers); 2. "decoding" the specialized and fragmented languages of health care professionals; 3. 'quilting' these knowledge's together; and 4. applying them within the context of their everyday lives and social circumstances. While this was described as challenging work for all of the women, those who had insider knowledge – including past experiences as a patient, caregiver, or health care provider – of the health care system appeared to be better prepared for this work; they expressed greater confidence in communicating with health care providers as well as locating and manoeuvering through complex and fragmented systems of care. Those who had family physician advocates (usually the result of long-term doctor-patient relationships prior to diagnosis) to assist them with such tasks were also able to attend to this work with greater ease and confidence.

'Too much, too soon': Managing illness work at home. Illness work was not just about the work women undertook within and between medical institutions, but was also about monitoring and managing their symptoms at home, including adhering to complex treatment and

pharmaceutical regimens. In this regard, home quickly became an extension of the health care system. P9 describes being thrust into care work within 24 hours of her surgery. She perceived this as technically challenging work, made additionally difficult by the physical impairments (surgical pain/discomfort and limited mobility) she experienced post-surgery and the "lightheadedness" of her family around providing this type of care:

> P9: My surgery was at 11:00am. The time after my surgery, I was up at 3:00pm in my room. By 9:00am, the next morning, "Hi Mrs.[participant name], let's take your vitals and you're on your way home"…not even 24 hours and I was sent home and I don't think that's enough…I had 2 tubes coming out of me and taking care of it and the whole thing; it just wasn't possible. I couldn't do it and my family is really lightheaded with that kind of stuff.

Most women agreed that care responsibilities and tasks were 'too much, too soon' and felt ill-equipped and prepared to perform them. P9 was able to pay for a private nurse to perform techno-medical tasks, such as draining fluids and changing bandages. She explained that the nurse came everyday for the first week and every-other day after that until she felt this care was no longer needed. She emphasized that this assistance was necessary to ensuring she receive "proper care", but acknowledged that this was an incredibly expensive option not available to most and that as hard as her experience was, there are others who have to work even harder to manage these types of self-care. Indeed, most women described doing internet research and/or seeking advice from family and friends with medical training/expertise on how to perform this work. Others engaged in processes of trial and error and some ended up back in hospital with what they perceived as "avoidable complications."

Body Work

Most women struggled with the depth and breadth of illness-related work; work rendered additionally difficult to perform amidst multiple, and sometimes debilitating, changes in the body. The bodily changes that resulted from illness, surgeries, and treatments were significant and acted as a physical reminder of their illness. Learning to cope with these bodily changes was an important aspect of women's work.

> **Betrayal of/by the body.** As women endured cancer treatment (surgery, chemotherapy and/or radiation) they described in vivid detail the bodily changes that altered their physical functioning and appearance. Some women spoke of an aged body – being thrust into menopause

years before they expected – and the need to confront, and adjust to, these changes in a relatively short period of time. Other women's 'body talk' revolved around the presence of tremors, limited range of motion, pain, and fatigue – all of which altered the nature of their pre-illness body. Women provided pre-diagnostic accounts of their bodies as strong and dependable; however, illness and treatment recast these bodies as different and unfamiliar – weak, unpredictable, and unreliable. Women emphasized the impact of physical dysfunction on their lives, including a reduced capacity to engage in mundane activities of everyday life. P7 spoke of the long lasting impact that chemotherapy treatment had on her body. She described experiencing her body as "new" and different than the body she once had, and in such, she experienced a changed capacity to "get things done" in the context of everyday life:

> P7: Well, it's been one year since I completed my chemo and the confidence is gone completely because of such a trauma in your life. You know, body aches, muscle aches. Everything I do, every activity I do. Like, it's a complete new person from what I was. The energy level has dropped dramatically which makes it hard to get things done. I was a very active person, never stopped. And now I have to think, you know, okay, now my energy is running out so I have to plan my day accordingly. I have to do more activities in the morning and less in the evening. If it's a back-to-back, I have to plan it so I have a day of rest in-between. Whereas before, I was just go, go, go, go.

In the case of P7 and many other women in the study, engagement in everyday mundane activities that were easily accomplished prior to their illness, suddenly became a challenging project that demanded thought, creativity, and sacrifice. Some women felt their bodies had betrayed them and were angry that their bodies let them down. Others perceived that they had betrayed their bodies – by not eating well enough, exercising enough, sleeping enough, or by stressing too much. In both cases, a mistrust of the body emerged. P12 speaks to this mistrust and its consequences: "All my activities were gone. I didn't go anywhere. I lived like a nun at home because I was afraid of getting sicker, I was afraid that my body would let me down again."

The body as a newfound site of work. While women told accounts of the struggles of illness and of a body that could no longer be trusted, they also told paralleled accounts of what they did to deal with and manage bodily changes and symptoms. Indeed, most women were adamant about not 'giving-in' to the failing body, and described working hard to locate solutions that helped them to manage and repair bodily changes. For instance, women spoke about: learning to manage their diet in order to cope with chemotherapy and treatment side-effects (e.g., nausea, weight loss/gain, taste changes, etc.); engaging in cancer-specific exercise programs to

regain mobility and reduce pain resulting from treatment; learning to manage medications and their various side-effects in order to minimize bodily effects and harms; and participated in counseling sessions and support groups to better understand their illness and to learn how to trust their bodies again. This body work took time and demanded flexible schedules as classes and programs often took place at fixed times throughout the day/week. Knowledge of how to conduct research – deciphering between reliable and unreliable evidence – was also a necessary aspect of this work. In a broader discussion of the toll that treatments and medications had put on her body, P6 describes doing research and developing strategies to cope. She emphasizes the difficulty she experienced managing medications, the bodily consequences she suffered, and the work *she* did to prevent future bodily harm:

> P6: I found out that I wasn't supposed to take two of my meds together. One was supposed to be on an empty stomach and one on a full stomach. I was taking both together and no one told me differently. I got sick; my body collapsed and ended up in the emergency department. Then I did the research and found out I wasn't taking it right. My husband didn't do the research. I know as a wife and mother, anytime my husband or my kids have an issue, there I am doing the research. In addition to me talking to the doctor and taking notes, I am doing my own homework. Support would be nice because of my memory issues, but it's just not going to happen, so I've taken it on myself – I've developed strategies, putting meds all around my house to remind myself.

Here P6 describes an initial difficulty self-managing her medications and highlights the bodily/health consequences therein. This discussion sparks conversation around the responsibility of body work specifically, and of care work more broadly. She explains that in the absence of strong support, *she* did the research and developed strategies to efficiently and safely manage her medications. She emphasizes her experience and expertise in the 'role' of care provider, connects this to a history of caregiving within the home, and positions herself as being the most suitable person within her family to provide the level of care that her condition requires. Indeed, her experiences as the caregiver for her husband and children aptly prepared her to take on the work of managing her own medications (e.g., researching, consulting with doctors and taking notes, and developing creative strategies to manage medications in the home). Taking control over this work, and being able to do so well, connects to a sense of agency and empowerment. However, by emphasizing that this work was taken-up in the absence of good quality care and support alternatives, P6 hints to the pressure she felt to know about, and be in control of, an overwhelming amount of health knowledge and care. In this way, agency and empowerment might be reasonably recast as responsibility and obligation.

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'Repairing' the gendered body. Women identified several ways in which cancer, and its bodily markers, affected their sense of themselves as women. For these participants, femininity was associated with strength, good health, and a particular body shape and weight. Women spoke frequently about the prevalence and power of stigma that resulted from bodily markers of illness, including surgical scars left from surgery and hair loss resulting from chemotherapy treatments. Women explained that the practical problems of the body and visible markers of the illness appeared to shape other peoples' perceptions of them, which sometimes impacted women's own sense of self. P10 describes what it was like to lose her hair, how this informed other's perceptions of her and framed social interactions, and hints to a lost self. In discussion of the wig captured in the photograph below, she describes an effort to balance treatment and its side-effects with a 'normal' life – one that does not contain visible bodily-signs of her illness:

Photograph 6

P10: It [hair loss] was a hard thing for me to deal with, you know, in terms of image, in terms of being able to socialize, go to work. You know, you're meeting people and all they see is cancer. It's just hard; you lose yourself a bit. I just wanted to know what's the best way for me to deal with this diagnosis but also to lead a normal life.

Many women recounted feeling that illness transformed not only their bodies, but their personalities, perceptions, and social relationships as well. In this regard, the practical problems of the body informed women's sense of self and their position in the social world. Negotiating and elaborating the meaning of these changes and how to cope with them was very much part of the work that women did. They spoke frequently of concealing bodily markers of their illness by wearing wigs and prosthetics, and of walking without their canes in order to avoid stares of sympathy and awkward social interactions. The bodily changes that women described were

perceived as threatening to women's sense of self and to the development and maintenance of their social relationships. In turn, many worked hard to conceal them.

Identity Work

Managing physical symptoms and coping with the emotional challenges of a changed body was closely connected to identity work. When women's bodies kept them from being able to engage in pre-illness activities and continue in valued social roles (e.g., as mother, wife, friend, and dependable employee), a recognizable sense of 'self' was lost. Women described the hard work of coping with loss and of wrestling with how to define themselves following a diagnosis of cancer.

  Identity lost and found: the work of 'quilting' identities. During treatment, women described being almost entirely removed from their daily routines (e.g., employment, running errands, etc.) and activities they loved (e.g., reading a book, going for a bike ride or a run, gardening, playing with their children, spending time with family and friends, etc.) – both because illness work had taken over and because their bodies were no longer able to engage in these routines and activities. For instance, P4 notes that: "One thing you need to learn is that your life does change, overnight. You can't do the things you used to do. Like, I used to love to go for runs and now I can't even walk long distances. I don't have the time or the energy." All of the women emphasized the discrepancies between their former healthy lives and their lives revised by illness. They spoke frequently about what life was like in the past, what hopes and dreams were interrupted or changed by their diagnosis, and what this meant for them now and in the future.

Entangled in women's discussions of cancer and treatment were experiences of loss. For many women these losses occurred rapidly and triggered anxiety, stress and, for some, depression. When asked if life had changed after her cancer diagnosis, P3 emphasized the loss that she endured – a loss of employment, physical function, cognitive acuity, and independence:

P3: I couldn't work. I had to stop working, you know and things like that. I couldn't function properly because when you're getting chemo your mind, you forget things, your mind goes crazy. Most of the time I didn't feel well enough to do anything, so I always had to be asking…and I had a lot of trouble asking for help, it's not who I am…because I'm used to doing my own thing, I did things for myself and then asking people for help, it was like 'OK' all of a sudden your independence seems to be gone and you become this person whose always bothering people.

Discussions of loss were prevalent in women's interviews; however, women also emphasized their efforts in coping with these losses and of "reconstructing" themselves during and following the throws of illness. Indeed, discussions of identity disruption were frequently followed by accounts of identity repair. Identity disruption and repair were cornerstones of P6's interview, as she discussed who she was, who she became, and who she would like to be, and how she worked toward reconciling these temporal elements of self. Below, she describes the impact of her brain tumor on her cognition as well as the loss of a highly valued facet of her identity (being a wordsmith) – something she, and others, had come to define her by. This perceived loss of self triggered a disrupted, unfamiliar, and uncomfortable identity which ultimately drove action:

P6: People have always known me to be well-spoke, articulate, and now this thing [tumor] that I have happens to sit on my memory and language centre, so it really was cutting me in half. It was like "who am I?" If I cannot express myself, then I am just a body, disrobed from the thoughts and all of that. I had to reinvent myself because, I am dying yes, but I'm still conscious during the day so you have to reassemble what you're left with. I suppose, visually if I think about it, it's like you've been in a car accident and then you're picking up the pieces and trying to put them together and if you are constantly trying to get back to what was, it can be very frustrating. This is what I tried to do, you see? I had the pieces but could not put them back together in a way that made any sense. Then I found ELLICSR. Coming here helped me sort through the pieces. I went to the Brain Fog class and this was prime. Because, as I said, this thing [tumor] sits on my memory and language centre, so the skills I learned here were very instrumental...And so ELLICSR has been crucial in helping me put the pieces back together. Not as they were, I'll never be the same and this is something I've come to terms with, but at least it makes sense now.

P6's describes a loss of identity, intense self-reflection, and the exertion of effort as she sought to make sense of and come to terms with the changes brought on by her illness. She engaged with the changes in how she viewed herself as well as how others viewed her; worked to put the pieces "back together in a way that made sense;" and attended a cancer wellness program to support this task. Relating who she was to who she would like to be, she employs a conscious effort to redefine herself by reconciling these aspects of identity. Similarly to P6, most women found ways of 'quilting' new identities onto old ones – an attempt to return to 'normal' while acknowledging that they were also changed by their illness experiences. In response to disrupted

lives, some women worked to preserve important aspects of their pre-diagnostic identities in an effort to remain connected to a 'normal' sense of self. This most often meant engaging in pre-illness tasks and activities, including those in the employment and everyday spheres.

Navigating the tension between loss and opportunity. Women frequently balanced stories of loss with those of opportunity. For instance, below P8 highlights the trauma of cancer but also explains the opportunity to "rethink and to rewrite" her life as a result:

```
It [cancer] was a big trauma. So it was like facing mortality. So well, who
knows, who knows, tomorrow maybe I'm not here. So how am I spending my time?
...  if I have a few days, a few months, a few years, how do I want to spend
them? Where do I want to put, you know, the emphasis?...Trying to see more of
life by pushing the boundaries of who I was into the person I wanted to be.  So
it was a big opportunity to really rethink. Yeah, to rethink and to rewrite.
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Finding the silver lining in their otherwise traumatic illness experiences was situated as an important part of identity work because it was in this recasting of loss to opportunity that women described responding to and/or coping with the losses. Indeed, many women in this study highlighted important lessons learned, wisdom gained, and positive moments experienced (e.g., the rallying of supportive friends and family) from having had cancer and therein expressed what I believe were genuine feelings of opportunity. However, the work of recasting loss as opportunity also appeared for some women, some of the time, to be closely connected to the ways in which the health care system and society more broadly encourage an inspirational cancer survivor identity – someone who is able to see the 'gifts' that come with illness and is able to turn the painful experiences of illness into opportunities for personal development. The work that women performed in managing these broader expectations of optimism and opportunity were perhaps most evident in the interviews themselves when women apologized for "dwelling" on negative accounts of their cancer experiences. This led to a different kind of work – the work of convincing others (and sometimes themselves) that they were fine, hopeful and optimistic – that they had successfully adopted the inspirational cancer survivor identity.

Negotiating the tensions between past selves and new roles/responsibilities. Women also highlighted tensions that emerged between past selves and new roles and responsibilities as women described needing to revisit and reconstruct identities in order to engage more effectively in other work-spheres. For instance, nearly half of the women described wrestling with the

tension between broader social, cultural, and gendered expectations of feminine comportment and 'patient involvement' – an important aspect of illness work that women felt was deeply embedded within the health care system and crucial to securing optimal care. P6 explains: "I got completely derailed and had to reinvent myself because my old self no longer functioned within the confines of my new life and new responsibilities." Elaborating on the nature of these new responsibilities, she spoke of illness work; specifically that of communicating her needs within medical encounters. She explains the need to negotiate a disconnect between the social and cultural expectation of a self-sacrificing womanhood juxtaposed with that of the involved patient. She saw this disconnect as irreconcilable and instead explains the need to reconstruct the self by acting more "like a man":

> P6: Growing up as a girl in India and even after coming to Canada, you're told you should be quiet and un-bothersome [sic], you're led to believe your needs are less important than others. So I lived that way, and never really thought much about it until I got sick. I noticed that the fellow next to me [a cancer patient in the hospital bed next to her] was assertive, sometimes even aggressive, and I felt that he was getting everything he needed, just because of the way he presented. I saw that and really thought about how complacent I had been and I thought, no. After that I was able to say, you are no more important than me. Something in me changed to present differently, like a man, and I notice I've got differently. I'm sure some people didn't think much of me for acting that way, but I didn't care.

The examples provided above illustrate the ways in which identity disruption and repair constitute 'work;' it entailed self-reflection, effort, action, and struggle as they sought to come to terms with illness, cope with the challenges it brought, and 'quilt' together various aspects of self in the construction of a meaningful and comfortable identity. In this way, women foregrounded the work that goes into (re)defining the self, coping, and carrying on. Finding the silver lining in an otherwise traumatic experience was part of this work.

Everyday Work

In describing their everyday social worlds, women presented themselves as busy, needed, and reliable. Most, though not all, women were active in familial networks and described working hard to sustain the wellbeing of close others and ensure the future security of the family. They emphasized the 'duty' to manage illness alongside obligations in daily life and the importance of being able to do this work 'well.'

Domestic labour and caregiving work. All of the women in this study emphasized the difficulty or struggle to continue physical tasks of daily living such as doing laundry, getting dressed, going grocery shopping, and cooking, and most spoke of the challenge of balancing self-care needs with the care needs of others (e.g., parents, partners, children, and friends). Everyday tasks themselves often remained the same, however, engaging with these activities became substantially more difficult in the face of physically debilitating illness and treatment. Despite this difficulty, most of the women in this study described continuing to do the majority of domestic tasks and caregiving work – often with greater intention and purpose than before their cancer diagnosis. Indeed, the desire to protect a sense of 'normalcy' appeared to ignite action. P9 speaks to the increased difficultly of previously taken-for-granted tasks in the home, but highlights her need "push through" and resume her role as mom and matriarch of the home:

Photograph 7

P9: Unfortunately life does not stop when you're sick. Because we're 5. My kids graduated from university and they moved back home. Which I'm very, very, very happy about. But as I said, the weekly grocery shopping, the cooking and cleaning and everything; it's a lot.
I: right
P9: …There was a few times that after the grocery shopping, on the way home, I was, even in the car, really, really out of it, and he [son] had to help me back into the house. And I had to lie down, and he put everything away…During chemo, yeah, it was tough. Everyday chores is a big one, they need to get done and much harder to do. Much, much, much harder... You know, there were many of those moments but on the overall, I tried just to show them, you know, okay, I may not have hair but I can still do the laundry kind of thing

The ability to continue with everyday activities held practical and symbolic importance for many women – reinforcing the necessity of this work. For instance, P9 explains the need to buy groceries and feed herself and the family, but also describes feeling a greater sense of independence, control, and 'normalcy' by maintaining the routines of everyday life and the family dynamic therein. This sense of contributing to the collective and of 'fighting back' against cancer by continuing with 'normal' activities was a frequent sentiment among the women. Despite the symbolic and practical value that these women received from continuing

these tasks, many also described conflicts created by the convergence of family responsibilities and personal health/care needs. Indeed, performing work in the domestic sphere sometimes threatened to aggravate women's illness by pushing their bodies too hard, as evidenced in the example above.

Many women continued to look after dependent relatives during their treatment and experienced a great deal of satisfaction in doing so. But for some women the 'choice' seemed to be more constrained. For instance, rather than being cared for and absolved of their 'duties' to provide care for others, some women described an expectation and moral pressure to continue providing this care in addition to their own care. P2 highlighted the potential for conflict as she sought to meet the care needs of her parents alongside her own health struggles and care needs. She explains: "That's a struggle, looking after my parents because my sister won't or doesn't, so it's up to me. But they were there for me when I was little, so now it's my time to care for them. But it's hard on me physically [brief pause] and emotionally." P2 provided care for her parents both because she felt it was her responsibility (a reciprocal act for the years of caregiving she received as a child) and because there did not appear to be any suitable care alternatives. Similarly to P2, many women in the study highlighted the struggle of simultaneously occupying the roles of both patient and caregiver. P6 discusses this in an explicit way, highlighting the moral and practical responsibility to provide care for her family. She also explains that not only do these care responsibilities remain at times of illness, but that they are compounded by new responsibilities for self-care. She couches both of these discussions in a broader account of gender:

> P6: So even when you're the patient, you're still the caregiver. Actually, you have to do even more work really. I really found out that if I didn't continue the housework and all that other stuff, my family would fall apart…We'll [wives/mothers] do the research on what's best for them [husband/children] to eat, we'll ask the pharmacist about their medications, potential side-effects and all that. That has not been my experience; I do all that for them AND for myself.

Each of these three women, along with many others in the study, emphasized the necessity of domestic labour and caregiving work and explained not wanting, or being unable, to offload these care responsibilities onto other family members. In the absence of other suitable options, many of women continued to provide care for both themselves and for others despite the conflicts.

Emotional work. The need to place the priorities of others, particularly those of the family, in front of their own was discussed frequently. This was perhaps most evident in women's accounts of "emotional housework" (Doyal, 1995, p.46), where emphasis was frequently placed on the importance of being 'selfless,' managing social relationships, and promoting the emotional health of others (often by minimizing/downplaying their emotional hardships) – even if this meant jeopardizing one's own emotional health. For instance, P11 recounts spending "a lot of time consoling people; so much so that I couldn't begin to process what I was feeling and what this [diagnosis] meant for me." Cancer triggered a multitude of emotions for the women in this study that continued throughout the course of their illness (and for some, beyond) including fear, anxiety, depression, a sense of loss, anger, and frustration. Many women described a sense of guilt for 'burdening' the family with their cancer and sought to protect them from additional worry by not sharing these emotions. In the photograph and supporting narrative below, P2 describes the need to adopt two separate selves, one who conceals emotions in the interest of others' well-being and another left to cope with feelings of sadness, worry, and fear:

Photograph 8

P2: That's me! The black one represented how I was feeling and the top one was what I was projecting to people. I always went in to my doctor appointments perky; I don't know why, usually after talking they realized where I was mentally, but I would always put on a smile because it's like they don't want to see that. Especially to my parents I put on that smile, but that's not how I was feeling. These are the two versions of me, the two different personalities that I have to take on. You present a happy face when you're out and then you can go home and be sad...The parental care is really hard to do right now and it's not getting better, but I don't want to throw my worries and fears on them, so I have to remember that.

The women in this study explained that they spent exhaustive amounts of time providing emotional care for family and friends. They also alluded to avoiding conversations about their

illness when speaking with others because it was emotionally exhaustive work to try to explain to others what they were going through.

Paid Employment and/or the Work of Maintaining Income

Six women were employed at time of diagnosis, four of which continued paid employment throughout their cancer treatment. Some of these women explained that they preferred to remain in the workplace because it helped take their mind off of cancer by giving them something else to think about and kept them connected to an important aspect of their pre-illness lives. Other women described taking on this work out of financial necessity and/or as a means of future planning and security. Those women who were not employed or took sick time, frequently focused on another component of work, the work of maintaining income/financial solvency.

Employment as a means of connecting to a pre-illness self. The women who continued paid employed during cancer treatment explained that the workplace was one of the few places where they felt things had not changed and that being there helped connect them to their pre-illness lives amidst drastic life changes. For those women who continued paid work, flexibility within the workplace was highly valued and often necessary to accommodate other forms of work that sometimes conflicted with the time demands of the employment sphere. Supportive workplace environments, including supportive co-workers and employers, were also valued. P7, who continued her paid work on a full-time basis, speaks to the importance of supportive colleagues and employers, the necessity of a flexible work schedule and tasks, and the capacity of the workplace to keep her grounded in her pre-illness life, juxtaposed the other aspects of her life that had been completely rearranged by illness:

> P7: Luckily I have a wonderful team. Again, it's the [Downtown Toronto Hospital]. So I'm in the perfect environment. They completely understand what I'm going through. They've been very supportive at work…They didn't change my position. They let me take time off. And actually, during chemo, I worked. So I would stay home for a week and then… It just brought me back to myself, like being me again. Because everything else at home and hospital was not me. During my illness, you know, they cut back. It was lighter duties. But now I'm… But they do not impose on me. There's no pressure. As soon as I say… Like today I said I had an appointment. No questions asked, you know. So that helps. And I guess they've seen in the past that I'm always a very dedicated person, I've worked hard, and I've never let them down… I'm very responsible.

The financial necessity of employment. In addition to feelings of 'normality' that often accompanied continued involvement in the paid workplace, some women described continuing employment out of financial necessity and as a means of future planning/security. For instance, P11 had just secured a contract job prior to being diagnosed with breast cancer. While describing supportive workplace policies and a flexible work environment, she explains that she rarely took time off work assuming that this would position her unfavourably within the workplace. She did not want to be perceived as unreliable as it may have jeopardized her chances for a promotion or full-time employment upon the completion of her contract. In this regard, paid work sometimes took precedence over illness work:

> ```
> Unfortunately for me, I was working. The whole situation was very strange.
> Just before I got the confirmation of my diagnosis, I accepted a position.  It
> was just a 6 month contract at the [Provincial health organization].  So it was
> difficult for me to attend some of the workshops that help you manage your
> cancer, you know, healthy eating or lymphedema, social support or what have you
> because I was working.
> ```

Instead of attending valuable programs to assist with illness-management during paid-work hours, P11 opted to remain at the workplace in an effort to be seen as a reliable and dependable employee who, even in the face of cancer, 'gets work done'. She struggled with this decision because she felt she had much to gain from attending illness-management programs and that not going could threaten the ease of her recovery. As such, she was torn between the benefits of attending these programs and the potential risks of taking time off work. While both women described supportive workplace policies, P11 did not have the same job security and co-worker buy-in (e.g., willingness to take on additional workload in her absence) as P7 who had a sense of job security that was apparently unavailable to P11. This possession of social support and job security afforded P7 the time she needed to attend medical appointments and illness-management programs, and thus allowed her to juggle multiple work tasks with greater ease.

The work of maintaining income/financial solvency. Three of the women who took time off work or dropped down to casual hours explained being ineligible for sick-leave benefits and one was cut-off long-term disability benefits before being able to return. These women suffered a tremendous loss of income as a result, made additionally taxing by the slew of out-of-pocket costs associated with treatment and other forms of illness work. Women who were unemployed (and un-partnered) at the time of diagnosis described living on low fixed incomes; they had limited or no access to private health benefits; and were frequently unable to pay for

privatized costs (e.g. treatment medications). Locating necessary supports and financial assistance was described as challenging work. For instance, those who sought out financial assistance services frequently described complex and fragmented administrative systems, and discussed the challenges associated with completing forms. P1 drew on her own experiences of struggle to critique how difficult securing financial assistance can be at times of illness:

> P1: We need types of assistance, financial assistance, and it's not available…ahh, well, that which is available, you need to know where to look for it and if you find it, what to do with it. And that is a really bad problem. But no one is going to do it for you, so you've got to do it yourself.

P1 highlights the scarcity of financial supports, the work of locating those supports which are available, and of the importance of having adequate knowledge to complete tasks (e.g., completing forms) required to qualify for the receipt of financial assistance. Many women who were partnered had private drug benefits under their spouses and, while money was much tighter within the home, they had enough to make ends meet. Those women who were not partnered and had no drug benefits were most vulnerable. Most explained being able to secure Trillium drug benefits and some form of social assistance but this was rarely enough to cover living and illness-related expenses. Further, because few where told about these programs by their health care teams, this assistance often came long after treatment began. In the absence of financial solvency, women struggled to adhere to other fields of responsibility and work.

Coordination Work

The accumulation and intersection of the above cited work tasks and activities added up to a considerable workload for women. Women emphasized that "life doesn't stop when you get cancer," and that if life is to go on they would need to find ways of coordinating these work tasks so that time, energy, and other resources are allotted for each. This required the performance of a higher-level order of work, that Corbin and Strauss (1988) have termed "coordinating work." Coordinating work includes identifying the types of work and associated tasks to be done; giving priority to tasks in terms of their importance; making arrangements for who will do them and when; and calculating the need for resources (e.g., money/time, social and practical support, knowledge and skills), obtaining them, and ensuring their maintenance amidst constant (and sometimes competing) demand (Corbin and Strauss, 1988). Below, I draw on two exemplary cases of women from different social locations to illustrate the extent and complexity of patient's

work and of the challenges of coordinating these work demands. While managing various forms of work was difficult for all of the women in this study, the challenges appeared to be more salient for some than for others. The narrative examples discussed below illuminate the importance of social and material resources (that are often invisible from a systems perspective) in performing work and coordinating various work tasks.

Narrative I: coordinating work with sufficient resources. When asked how life changed post-diagnosis, P10 emphasized the need to reprioritize tasks, activities, and roles. Below she describes how life changed in the wake of illness, the (re)development of a 'work hierarchy', creative manoeuvering within this hierarchy, and the resources that helped to enable successful engagement with work tasks:

> P10: Before, you're stressed with work and stressed coming home. You don't have a chance to really take time out for yourself. I had to change my priorities a little bit. The work [employment] aspect was really brought down. So instead of going five days a week, I would maybe go one day a week for just a few hours…when I was undergoing chemo, work was not there for me. So I was lucky that my husband [employer/business owner] was able to find someone else to do the work. So you know, spending a little more time looking on the health issues but then it was also important for me to be able to coordinate family responsibilities together with the treatments. But it has helped me realize the support I have. Like a lot of family members when they were aware of the diagnosis were there to help in any which way… My sister, my sister-in-laws, my in-laws, my parents would take the girls when I was really tired, and they would spend days with them or they would sleep over. And that really helped me just rest and kind of grasp the whole idea of going through what I was going through and what that meant for me, what had changed and what this meant in the long run. It just made it so comforting knowing that everyone was supportive. They were there to help with food or they would bring food over. They would drive me to the appointments and spend the day with me at the chemo sessions. And it just helped me stay positive and kept me going.

As cancer, its side-effects (e.g., pain, fatigue), and illness work took over, P10 highlights the need to reprioritize work tasks and roles. In these accounts she discusses assigning priorities to needs in terms of their immediacy and importance. For instance, she describes sorting out a flexible schedule at work so that she could take time off to focus on treatment and accompanying illness work without disrupting (or jeopardizing) the family business. A steady and adequate family income permitted this kind of flexibility. She emphasizes her focus on cancer and its treatment but also highlights the importance of remaining active within the family and attending to household responsibilities. When the coordination of these work tasks became too challenging, she explains drawing on a vast social network to assist with childcare and other domestic tasks. This support with everyday work allowed her time for rest (an important

component of body and illness work) and for self-reflection (an important facet of identity work). While P9 possessed an abundant amount of social and material resources, they were not limitless and thus managing resources became an important aspect of P10's work. For instance, while drawing on a vast social network of family and friends to assist with such things as caregiving, grocery shopping, meal preparation, and transportation to and from medical appointments, she explains elsewhere in the interview that she was very careful not to "overburden" her social network with these tasks; accepting offers of help only when necessary. Surely there are a multitude of reasons one wishes not to overburden their loved ones, one of which may be to ensure their ongoing assistance and support – an act of managing and maintaining social capital. P10 describes the difficulty of juggling these various types of work and of keeping some sense of balance between illness management, everyday life, and a sense of self. While challenging, she describes being able to successfully obtain and maintain the resources necessary to perform work demands.

Narrative II: coordinating work with insufficient resources. Work was made additionally challenging, disruptive, and/or impossible when the resources needed to perform work tasks were unavailable. This lead to competition between various types of work wherein priorities needed to be identified and difficult decisions made about how to distribute limited resources. P3, a single mother living on a low fixed income, highlights the real potential for 'work conflicts' that arise when the need for resources is high, but the availability of those resources is low. In the absence of sufficient resources to juggle illness, body and everyday work, she describes the need for sacrifice, prioritization, and strategy. In the broader narrative from which the quote below emerged, she highlights the tension between her experiences of struggle and her physician's 'prescription' to "focus on your health and your treatment, nothing else." P3 understood this as a well-intentioned message from doctor to patients – an attempt to absolve her of other responsibilities without guilt. However, despite its well-intentioned nature, she saw this prescription as being oversimplified, unrealistic, and out of touch with the contextual circumstances of her everyday life. Below, she illustrates a hierarchical order of work, the vast resources required to fulfill this work, and the consequences of being unable to do so:

> P3:They [doctors] tell you to stop working, to focus on your health and
> treatment, nothing else…[When I was diagnosed]I had to dip into my savings and
> then that ran out; then I dipped into my RRSP and then that ran out. So then you
> have the little money that you have, the senior check I get, and I have to first
> make sure I have a roof over our heads. I need to make sure I have a phone in
> case the doctor calls me...But then you skip on food and so you're health goes
> down. You get your medication and you know you may not be able to afford it next
> month, it's not in the budget, so you start to find ways of making it last
> longer; you only take it every three days when you're supposed to be takin' it
> everyday. So, some of us would save pills. It causes more stress on you and then
> when you're in pain and not feeling well and you're trying to do all that, you
> need nutrition, you need peace of mind at the same time to try and fight to get
> well. So that's how it is…besides being sick and all the problems that come with
> that - it's a huge stress [bangs her hands on the table]. You don't want to be
> sitting on the street corner while you're sick, cause that's not gonna do you any
> good. You don't have anyone to help you if you're single person or something, you
> don't have anybody to help you, sometimes people are just seniors and seniors
> don't get anything, you get your check and that's it and that's only once a
> month. You have to work with what you've got. You can't do any more than that.

In the absence of abundant resources, P3 frequently found herself at a crossroads – forced to make difficult decisions of which aspects of work to prioritize. As material and human resources were exhausted, she describes an inability to focus on treatment and explains a pragmatic hierarchy of work prioritization - assigning priorities to needs in terms of their immediacy and importance. For instance, the everyday work of securing nutritious food and shelter were often prioritized over illness work; not because P3 failed to see the importance of this work, but rather because she recognized that the maintenance of everyday life (e.g., housing, a phone, and food) set the foundation for illness work to take place. Herein lies a tension between the doctor and patient perspective; her doctor sees *extending* her life through a singular focus on illness work as the utmost priority, whereas she – while not to take away from her very real concern about, and efforts to manage, her cancer – is concerned with *living* her life (and managing her health) in an immediate and sustainable way. That said, P3 does highlight attempts to juggle as many aspects of work as possible, implementing strategies within each field to free-up resources for the next. For instance, paying the phone bill to communicate with the doctor and coordinate appointments meant that she would need to sometimes ration food or go without eating all together, and changes in her monthly budget resulting from unexpected costs meant she frequently had to ration medications. Similarly to P10, P3 identifies the vast work of patienthood, the development of a 'work hierarchy' (although the order of work tasks varied drastically), and describes the difficulty of juggling various lines of work. However, unlike P10, despite a great deal of effort and creative manoeuvering, P3 was not always able to garner sufficient resources to overcome

the challenges inherent in juggling work tasks. This usually meant that her needs within one or more of these fields were insufficiently met.

Discussion

The work of patienthood, as described by the women in this study, cut across multiple fields of practice and included both paid and unpaid labour. In their photographic and narrative accounts, they foregrounded the intent, skill, time and effort that goes into accessing care and resources, providing care for self and others, defining and redefining the 'foreign' self, and 'carrying on' with everyday life (both during and following active treatment). This depiction of work is very different from the way it is typically understood in psychosocial oncology and cancer survivorship literature, policy documents, and clinical practice wherein work is seen as being synonymous with paid employment and the problem of work is situated within 'return to work' discourse. This study confirms the findings of others who have discussed the hard and heavy work associated with chronic illness (Charmaz, 1983; Corbin & Stauss, 1985; May et al., 2014; Parsons et al., 2007; Sinding et al., 2011; Townsend, Wyke & Hunt, 2006). It adds to the existing cancer literature by making explicit the many (and intersecting) types of work that patients must coordinate and perform at times of illness and by highlighting the gendered nature of this work. By developing a detailed description of the tasks and activities that a diverse sample of women did to fill gaps in care and manage their health alongside everyday life, this study illuminates the nuanced work and work struggles that women may encounter and the health consequences (and inequities) therein.

The women in this study explained that the work of patienthood was time consuming, required constant (re)prioritization, demanded resource planning and management, and called for high levels of health literacy and knowledge. Those women who were living on low incomes, socially isolated, responsible for providing care to dependents (and lacked time for personal care as a result), had low health literacy or little practical knowledge of the health care system, and/or were physically or cognitively impaired were less likely to succeed in this context. Indeed, the women who were unable to perform work in other fields found it difficult, if not impossible, to follow clinical guidelines – struggling to adhere treatment recommendations and medication regiments along with other forms of illness work. These findings echo the results of other critical

scholars in the field who acknowledge that the management of chronic illness is both supported and constrained by much broader social, economic, and institutional contexts (Angus et al., 2007; May et al., 2014; Sinding et al., 2010). This finding also complicates prevalent medicalized discourses of self-management that assume that people struck by illness *ought* to (and are able to) temporarily abandon all other tasks and activities in the interest of restoring health – this belief extends back to Parsons' (1951) conceptualization of the 'sick role'. This expectation not only undermines the reality that personal health may be only one of several priorities, but also reflects the assumption that all people enter the health care system from a level playing field – possessing sufficient social and material resources and/or are aptly able to delegate tasks of everyday living to others at times of illness in order to focus entirely on their health. This study provides evidence that complicates the simplicity of these prescriptive logics and problematizes care discourses and practices that overlook SDOH and treat health concerns with a limited behavioural and biomedical approach.

Medicalized discourses of self-management that promote the expectation to abandon everything in the face of cancer are particularly disconnected from women's gendered, political, economic and socio-cultural lives. Indeed, 'sick role' logics can present a troubling tension for women. On one hand, there is the un-problematized expectation, projected both within and outside of the health care system, that patients will focus entirely on 'getting better' when confronted by illness. On the other hand, are gendered expectations of responsibility and behavior woven tightly into the larger social and political fabric in which women live that situate the pleasing of others, taking care of others, and giving to others as woman's work and as work that holds far greater moral and social importance than attending to one's own needs (Radina et al., 2014). In turn, women who become sick are confronted with incompatible expectations – as patients they are expected to engage in degree of 'selfishness' that conflicts with the 'selflessness' demanded of women. Negotiating this tension was part of women's work and often included efforts to minimize assistance from friends and family by assuming the bulk of care work for both themselves and for others – this was taxing on all women and proved to be unbearable for some. The work of self-managing was thus significantly more complex than simple compliance with illness-related tasks. However, the vast and complex nature of work, the gendered divisions of

care labour, and the social and material resources needed to perform work tasks are rendered largely invisible in discourses of self-management and biomedical care practices.

The tension that women experience as they negotiate self-care alongside numerous obligations to others is consistent with other cancer studies that have found that traditional gender roles can conflict with women's cancer care and recovery, as they attempt to manage different responsibilities and care tasks, and locate the necessary time and space to prioritize their own care needs (Emslie et al., 2009; Mackenzie, 2014; Radina et al., 2014). However, the findings of this study also suggest that the provision of care for others was not always so straightforward, and that women performed this work for reasons beyond those of 'selfless sacrifice' for the collective. Given the way that discourses around caring are gendered, the performance of care work is often closely intertwined with meaningful and valued gendered identities (Emslie et al., 2009). In this study, ongoing care provision for others helped some women to reconstruct and reaffirm their identities – thus facilitating aspects of identity work. Further, being able to perform domestic tasks alongside other forms of work (including illness-management) also gave some women a sense of independence and control in broader circumstances in which they felt they had none. In this regard, the work that women performed was not always conceived of as bad of burdensome. Of course, the conditions and circumstances in which women's domestic work and care tasks are performed and the nature of the social relations that underpin these contexts, frame women's agency in taking on this type of work and inform the ease (or difficulty) with which this work, and other work tasks, were done. In order for the shifting of care and work from the hospital to the home and community to be beneficial for patients, increased techno-medical, psychosocial, and material supports should be provided and must be accessible and available to patient who need them. The availability of such supports would afford patients greater agency over their work and would in turn, ensure more equitable opportunities for quality care and improved quality of life.

By re-conceptualizing notions of work in the cancer context, I have made the scarcity of institutional supports for this work more visible. This signals the need for a higher level of care and support than that which is currently provided within the Ontario cancer care system. In addition to the policy changes described above, I suggest that members of the oncology care team (e.g., oncologists, fellows, and oncology nurses) must recognize the concerns and priorities

of their patients and consider the more complex ways that gender and other SDOH affect patients' pathways throughout the cancer journey. To this end, additional questions need to be raised in clinical encounters. For example: Does the patient have the financial solvency to pay for a visiting nurse or do they have private benefits to cover these costs? How is the patient adjusting to his/her altered body and self? What kinds of support does the patient feel they have available to them within the home? What is the employment status of the patient and, for those who are actively engaged in paid employment, are there any time constraints or barriers that prevent them from accessing care? Does the patient appear to be overwhelmed or overtaxed? And, does the patient need help filling out forms, finding transportation, and/or securing financial aid? From the information garnered through such questions, members of the oncology care team will be better prepared to assist their patients in locating appropriate care and supports.

Members of the oncology care team will need to work collaboratively with, and refer their patients to, other care providers and support programs both inside and outside of the hospital. This collaborative approach to multidisciplinary care and support can limit/facilitate the amount of work that patients themselves currently take-up and could thus reduce the burden of patient's workload. Further, if the capacity to successfully engage with illness work is contingent on women's successful involvement in other work processes, it stands to reason that access to a diversified set of care services and supports aimed at other aspects of women's work (e.g., nutrition and exercise programs to assist with body work; psychological/social work services to support identity work; childcare/cleaning services to assist with everyday work; and financial counselling and support to assist with money management) could improve illness outcomes, bridge inequities in care, and improve overall quality of life. Making use of psychosocial and material resources already available in the hospital and community (e.g. cancer health and wellness centres) offers a practical, feasible, and immediate solution.

Conclusion

Work, as it has been discussed here, has traditionally been invisible from a systems perspective. Indeed, within the health care system there is limited knowledge of and attention to the extensive and exhaustive work that patients perform within and outside of the hospital, the gendered nature of this work, and the vast and inequitably distribution of resources upon which this work rests. In

this way, the care work that patients perform is both decontextualized and de-politicized. The findings of this study suggest that the work of patienthood is political, it is gendered and classed and most importantly, it is amenable to change. A feminist political economy approach makes this work visible, reveals the interplay between structure, agency, and individual experiences of cancer, care, and work, and highlights the gender-specific challenges that women face in the management of illness alongside everyday life. The findings of this study thus disrupt popular conceptualizations of work as being synonymous with paid employment. Rather, the exploration of different forms of work in this article – illness work, body work, identity work, everyday work, paid employment and the work of maintaining income, and coordination work – demonstrate the profound need to re-conceptualize our understanding of work in the cancer context.

By examining the complexity of patient's work from everyday perspectives, 'work' and the gender and equity issues associated with it come to the fore and provide a deeper understanding of informal care systems that are often overlooked in policy and practice that seek to push care out of hospitals and into homes. This knowledge can generate a deeper understanding of the breath of care people require at times of illness and the work necessitated by this care. Managing work could be eased if the broader social, political, and economic conditions in which patients live are acknowledged and addressed by policy makers, practitioners, and health care programs. While certain populations are particularly vulnerable due to socioeconomic factors, everyone is at risk for becoming overburdened by the work required in managing cancer.

Putting Psychosocial Care on the Prescription Pad: The Successes and Challenges of Integrating Psychosocial Care into Routine Cancer Care Practice

Introduction

Approximately two in five Canadians will develop cancer in their lifetime (Canadian Cancer Society, 2015). Advances in biomedical treatment are changing the nature of cancer as an illness, with individuals increasingly surviving the acute phases of illness and prevailing against physically challenging surgery and treatments (Adler & Page, 2008). Throughout the trajectory of their illness, cancer patients are increasingly living with the consequences of their disease, including the side-effects of its treatment (Gould, Sinding, Mitchel & Fitch, 2009; Matheus, Buhler & West, 2009; Nelson, 2010; Soothill, Morris, Thomas, Harman, Francis & McIllmurray, 2003). In turn, cancer has become an "illness that has all the hallmarks of a chronic condition requiring continued, long-term management not only in the biomedical arena, but in the psychological, behavioural, and social arenas as well" (Turnbull Macdonald, Baldassarre, Brown, Hatton–Bauer, Li, Green, & Lebel, 2012, p. 209).

Despite the shifting landscape of cancer from an acute to chronic illness, the provision of cancer care continues to operate predominantly in a health care system that was designed to treat acute and infectious disease; delivering care that is short, episodic, urgent, and treated with cure as the goal (Mair, 2014; May et al., 2014; Siu et al., 2009). Within an acute care model, once the threat to life is abated, health care payment and delivery systems no longer see the patient as ill and in need of care and support (Day, 2013). As such, in cancer care, and in the health care system more generally, the provision of psychosocial care, information, and support is typically regarded as secondary to the treatment of disease, and oftentimes these care needs are overlooked altogether (Howell, Mayo, Currie, Jones, Boyle, Hack, Green, Hoffman, Collacutt, McLeod & Simpson, 2012; Trussler, 2007). This narrow approach to understanding and practicing care does not align well with the state of contemporary care needs, with over 80% of

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[12] The manuscript titled "Putting Psychosocial Care on the Prescription Pad: The Successes and Challenges of Integrating Psychosocial Care into Routine Cancer Care Practice" will be submitted to the Journal of Cancer Survivorship: Research and Practice. It has been structured according to the requirements of this journal; however, word limits have been exceeded in the interest of providing a more robust analysis that ties more fully into the broader topics of the dissertation.

all deaths and 90% of all morbidities stemming from chronic illnesses requiring ongoing physical as well as psychosocial supervision and support (Boult, Karm & Groves, 2008).

The conflicting direction between care needs and care delivery has meant that people with cancer continue to experience an array of psychosocial and supportive care needs that are not currently being met (Howell et al., 2012; Jones, Ferguson, Edwards, Walton, McCurdy & Howell, 2012). Patients report dissatisfaction with such things as the amount and type of information they receive about their cancer, its treatments and side-effects, as well as ways to manage their illness and health (Adler & Page, 2008). Even when information is provided, patients report that physicians are ineffective in communicating this information rendering it difficult to understand and act upon (Adler & Page, 2008; Jones et al., 2012). Moreover, patients commonly report that physicians do not adequately recognize, treat, or provide referral for emotional and psychological problems resulting from their illness (Adler & Page, 2008; Ashbury, Findlay, Reynolds, & Mckerracher, 1998; Bultz & Holland, 2006); pay sufficient attention to the social, familial, and employment changes and challenges that emerge during the upheavals of illness; and inquire about their financial circumstances and/or provide assistance with material struggles (Adler & Page, 2008; Canadian Cancer Society, 2003; Trussler, 2007).

In recognition of this mismatch, calls for addressing the management of chronic conditions have become increasingly loud within government agencies and institutional care settings. In the case of cancer care in Ontario for instance, both CCO's 2011-2015 Ontario Cancer Plan and the Princess Margaret Cancer Centre's 2013-2018 Strategy Report stress the need for a culture change in care that is more closely aligned with a chronic care model[13]. For instance, both documents acknowledge and support that cancer patients require ongoing access to biomedical and psychosocial care, delivered by a wide range of health care providers working together in the delivery of care, and that these actions should be embedded within a system that promotes and

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[13] While there is no general consensus in the literature regarding the structure of a chronic care model, the definition provided Nolte and McKee (2008) touches on those elements for which there is general agreement across multiple bodies of literature. They argue that a chronic care model needs to provide a "complex response over an extended time period that involves coordinated inputs from a wide range of health professionals and access to essential medicines and monitoring systems, all of which need to be optimally embedded within a system that promotes patient empowerment."

adheres to each patient's unique circumstances and care needs. These documents thus appear to promote increased attention to individual's specific circumstances and care needs (person-centred care); patient perspectives and collaborative partnerships (patient-involvement); holistic and integrated care services (collaborative care); and long term care delivery as opposed to that which is episodic. These proposed changes to the health care system appear to celebrate a more relational and equitable approach to care.

One response to, and in recognition of, the various challenges associated with living with cancer is reflected in the trend toward the delivery of psychosocial and supportive care through CHWCs (Fitzpatrick & Remmer, 2011). CHWCs generally reside in the community, outside of mainstream medicine institutions, and possess ideologies that sometime conflict with medical discourse. Adopting 'whole person' approaches to cancer care, these centres foreground physical, social (family, social relationships, employment, and the stigma of disability), psychological, emotional, and practical care needs (Dubbin, Chang & Shim, 2013; Turnbull et al., 2012). In Canada, CHWCs have been steadily growing in popularity. For example, Wellspring, began with a single location in Toronto, Ontario in 1992, and now has nine satellite programs across Canada (Fitzpatrick & Remmer, 2011). The growth in CHWCs has paralleled growing criticisms of the biomedical and technological focus of cancer care and is a testament to the need and demand for comprehensive care programs for people living with this illness (Routledge & Robinson, 2009).

While CHWCs have traditionally existed on the periphery of medical institutions, current policy and institutional emphasis on the importance of chronic care models improves the likelihood that such spaces (and/or the psychosocial and supportive care services they provide) will increasingly be integrated into hospital settings. The Princess Margaret Cancer Centre, located within Toronto (Ontario, Canada), offers an innovative case in which policy proposed care integration has been taken up in practice; largely through the development and implementation of ELLICSR: Health, Wellness and Cancer Survivorship Centre – a space that adopts a 'whole person' approach to the delivery of psychosocial and supportive care for people living with cancer (ELLICSR, 2015). While chronic care policies and the inclusion of more diverse forms of care delivery within the hospital appear promising, understanding how these are operationalized in a predominantly acute care setting remains an underdeveloped area; the implications for patients thus, remain unknown.

ELLICSR's location within a predominantly acute cancer care hospital make it an opportune environment through which to explore how changing policy discourse is operationalized within conventional care systems and to better understand the impact of these changes on the patient experience. This paper presents a critical ethnographic account of ELLICSR with the aim of exploring: 1. the care experiences of 12 women in the context of a changing health care milieu; 2. the impact of ELLICSR on these care experiences; and 3. the extent to which ELLICSR is integrated into the everyday clinical care practices of the hospital.

Methods

Research setting

The ELLICSR centre was initially proposed in a Canadian Foundation for Innovation Grant (CFI) to help address pressing problems and care gaps within the Canadian health care system. These included: 1. lack of necessary knowledge to facilitate the identification, prevention, and treatment of persistent and long-term adverse effects of a cancer diagnosis; and, 2. outdated models of acute, episodic care delivery inefficient in treating people with chronic conditions, such as cancer (Canadian Foundation for Innovation grant proposal, 2006). ELLICSR was eventually made possible by grants from CFI and the Ministry of Research and Innovation, along with additional funding support from the Princess Margaret Cancer Foundation. ELLICSR opened its doors in the summer of 2010 in the Toronto General Campus of UHN and has since acted as a care branch of the Princess Margaret Cancer Centre (ELLICSR, 2015).

ELLICSR adopts a participatory and community oriented approach to cancer care that aims to: 1. advance understanding of the chronic effects of cancer and its treatment; 2. support and guide patients and their families in the management of cancer-related symptoms and side-effects, health, and wellness along the entire trajectory of care; 3. integrate effective and patient-driven education into models of care delivery; 4. create collaborative partnerships across health care providers, cancer survivors and community centres/programs to enhance the quality of survivors' care; and 5. to harness the knowledge of different communities – including communities of survivors, clinicians, educators, and research scientists – to drive and accelerate innovation in cancer survivorship programs and services (ELLICSR, 2015).   Informed by these collaborative

partnerships, the centre offers: 1. expert-led support groups and counselling services; 2. clinics, programs, educational workshops and wellness classes aimed at fostering hope, coping, illness management strategies, and rehabilitation; and 3. events aimed at facilitating connections between cancer patients and community partners to help extend the scope and reach of care available to patients and their families (see the ELLICSR calendar of events for a full list of classes, programs, and events: https://www.ellicsr.ca/en/classes_events/Pages/events_calendar.aspx).

Site selection. The collective approach taken by ELLICSR in the development of their programming, the vast and diverse services offered within the space, as well as its (somewhat contradictory) location within a predominantly acute cancer care hospital, make ELLICSR an opportune environment to explore how changing policy discourse is operationalized within conventional care systems and to better understand the impact of integrative models of care on the patient experience.

Research Process and Analysis

Fieldwork for this critical ethnographic study was conducted over 20 months between July 2013 and February 2015. Methods included semi-structured interviews, photo elicitation, document analysis, and participant observation. This paper draws primarily on interviews (including photographs) with 12 cancer patients to garner an understanding of their care experiences as well as interviews with 8 ELLICSR staff to gain an improved sense health care organization and delivery from a systems perspective. Ethics approval was granted by York University and UHN Research Ethics Boards.

A purposive sample (Creswell, 2009) was generated by recruiting women with cancer who came to ELLICSR as part of their cancer journey. Patients were recruited through email outreach using ELLICSR's patient contact database[14], recruitment posters, snowball sampling, and through the Princess Margaret Cancer Centre blog as well as ELLICSR's social media outlets (namely Facebook and Twitter). In order to capture a diversity of perspectives, the aim was to recruit women with different cancer types, different stages of illness/treatment (e.g., recently diagnosed,

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[14] A database of patients who have previously consented to being contacted for research purposes.

in treatment, in remission, and cancer free), and different social locations (e.g., income, age, education, race/ethnicity, geographic location). This was done to facilitate a wide array of understandings to emerge. Demographic and clinical information for these participants is provided in Table 1.

[Insert Table 1 Here]

ELLICSR staff members were also purposefully selected by the researcher to ensure that those participating in the study were representative of the various disciplines (e.g., research, patient education, social work, and web and digital) and programs/classes/events (e.g., the ELLICSR Kitchen, Healthy Steps, Brian Fog, and Community Connections) offered at ELLICSR. Patient narratives also influenced staff selection with those people (or programs) mentioned most frequently being contacted to take part in the research as interviewees. All potential participants were provided with an information sheet pertaining to the study and a copy of the informed consent. They were encouraged to read these documents and ask questions pertaining to their content before agreeing to participate. Each participant signed an informed consent form prior to their participation.

Semi-structured interviews were conducted with 12 women with cancer who attended the ELLICSR centre at some point throughout their cancer journey. Each woman took part in two interviews for a total of 24. Initial interviews were designed to elicit women's experiences with cancer, care, and work and the importance of ELLICSR in framing these experiences. Following the initial interview women were provided with cameras and asked to capture images pertaining to their cancer journey; women captured between four and 54 photographs each for a total of 189 images. Follow-up interviews were scheduled once the participants had completed the photo elicitation exercise and were guided predominantly by the women and the photographic images they took. As each topic was raised, I asked questions to encourage elaboration, adhering to the structure of the woman's unfolding narrative. Eight ELLICSR staff participated in a single semi-structured interview. Staff interviews were designed to inquire about their experiences with ELLICSR, their role in patient care, what possibilities and/or constraints ELLICSR offers for the treatment and recovery of women with cancer, and future plans for the centre.

The interviews lasted between 45 and 120 minutes each. All interviews were digitally recorded and transcribed verbatim. Transcripts were coded line by line to explore emergent themes and derive analytic concepts, often by identifying unique terms used by the participants themselves (e.g., "cancer friends"). Special attention was paid to codes, categories and themes that related to the study objectives, were discussed consistently within an individual interview, as well as those that were discussed repeatedly between participant interviews. Efforts were also taken to identify outlier or contradictory cases. Following this process, the transcripts were critically analyzed using Boeije's (2002) approach to the constant comparison method to better understand influences that contributed to differences and similarities in the circumstances of participants. A feminist political economy framework was applied to illuminate who benefits from and who is disadvantaged by current health care policy/institutional changes and to tease out the conditions through which these inequities emerge (Armstrong, Clow, Grant, Haworth-Brockman, Jackson, Peterson & Seeley, 2012).

Limitations

There are several limitations to this study that warrant consideration in review of the study findings. First, this ethnography presents a snapshot of a specific place and time. The documents that were analyzed and several of the interviews with ELLCISR staff have painted a broader picture of the system, but the findings of this study are still specific to the timeframe in which the ethnography occurred (July 2013 to February 2015). Secondly, it is possible that self-selection resulted in the recruitment of women who were particularly positive about their experiences at ELLICSR. All of the women in this study were very open to discussing their experiences, with many interviews taking longer than the expected one hour. It is possible that their willingness and eagerness to participate in the interview may have affected the amount and type of information they gave and that other women might have had very different experiences. It is also possible that those people who choose to go to a CHWC may not be representative of the needs and wants of the cancer population as a whole. Those who are not interested in research participation or who had negative experiences at ELLICSR may have important insights that are not captured in this study. Lastly, given my declared interest in the ELLICSR centre, the omission of outside health care providers was a conscious decision I made in designing the study. However, as participant accounts extended the purview of this study into other fields of

practice, such as the hospital, members of the oncology care team became central actors in the stories that unfolded. While patients and ELLICSR staff shared their perceptions about physician's beliefs, practices, motivations, and challenges, the perspective of clinicians themselves regarding such things as their challenges, their beliefs about psychosocial and supportive care, and their understanding of patient needs/unmet needs, are not represented.

Findings

Most women in this study were generally happy with the biomedical care they received but felt that their psychosocial and supportive care needs were poorly addressed within medical encounters. The five overarching domains identified most frequently by patients as being crucial to their cancer care yet under- or unaddressed in hospital included: 1. information about their illness and its treatments, side-effects, and available support services; 2. assistance with self-managing illness and care; 3. assistance with managing disruptions in everyday life; 4. support with emotional trauma accompanying illness and treatment; and 5. financial advice and/or assistance, including access to practical and material resources. In this section, I outline findings related to these five overarching domains. In so doing, I address the areas of care that the patients in this study found to be lacking. I then outline the ways in which the patients found ELLICSR to have helped bridge these care gaps. Lastly, I illuminate ongoing tensions that limit the scope and reach of care provided at ELLICSR, and unveil barriers to its fuller integration in the conventional care system.

Care Needs

1. **Access to information.**

Information pertaining to cancer and its treatment. Many of the women in this study acknowledged the demand put on patients to engage in their medical care, including treatment-related decision making. However, few felt they had the necessary information to make appropriate treatment decisions and care arrangements that were consistent with their lives and preferences. When information was provided, women explained that it was usually written and packaged for mainstream audiences and was not always easily translatable to their specific circumstances. Short medical appointments and rushed care providers further limited women's opportunities to communicate these challenges. This often truncated discussions of the broader

everyday contexts in which women's illnesses unfolded and through which care decisions were made. For instance P11, who was 32 years of age at time of diagnosis explained that much of the breast cancer information she received from the hospital was written for women much older than her and thus tended not to include information about family planning and fertility. This left her with a significant knowledge gap that rendered it difficult to make treatment related decisions:

> P11: We wanted someone to talk to us about, you know, what are the experiences like for someone who has had fertility preservation and is trying to figure out, okay, should they use a surrogate or should they, you know, try it for themselves, and what are the impacts of that for my health; because I would need to get off Tamoxifen earlier than the standard five years. They [oncologists] wouldn't even entertain the conversation. 'We can't advise you against best medical evidence' is a response I heard a lot. I didn't need a green light, I just wanted to have a conversation. I needed that information, the pros and cons, to make an informed decision and if you don't have that information you need to refer me to someone who can help.

From the information she garnered, P11 understood that a five-year post-treatment Tamoxifen regiment was standard, but explained the conflict of this information with a desire to have children and wondered if there were safe exceptions to the standard. Translating dominant medical and treatment recommendations to her familial circumstances proved challenging and she felt that few doctors were able (or willing) to comment on health-related issues that did not relate directly to her cancer and that none provided referrals to specialists who could help fill this information/knowledge gap.

Countering the strict temporal constraints they experienced in traditional medical encounters, women described ELLICSR as a place that permitted time in and for care. In a broader discussion of her experiences with a psychologist at ELLICSR, P11 continues the discussion of fertility addressed above, but offers a far different care experience:

> P11: I'm at a different life stage than most women with breast cancer, and of course my priority is my health but it is also important for me to carry on with my life and part of that means having kids. Having someone you can trust to talk to about making decisions or dealing with situations... And also for me dealing with my own fears and, you know, concerns about if I do this [stop Tamoxifen treatments], what are the pros and cons type thing. Like I said, there was this resistance [from the oncologist] to talk to me about my fertility. You wouldn't believe how hard it was to get this information, it took me probably a year of consistently trying to find someone who would talk to me seriously about it. Dr. X [psychologist at ELLICSR] was so helpful. She listened to my situation and she connected me with a fertility specialist who works with young adults with cancer so that I could make the most informed decision that made the most sense for me and where I'm at.

P11 described the benefit of being able to participate in a more holistic conversation that took both her physical health and psychosocial wellbeing into consideration. Being connected to, and having the opportunity to consult with, a fertility specialist in advance of treatment decision-making provided P11 with important *technical* and *professional* knowledge that she needed to make an informed decision about the treatment path that was best for her.

     Information pertaining to the side-effects of diagnosis and treatment. Many women in the study explained that they lacked sufficient information about side-effects they might experience and about how to cope with such things as fatigue, pain, neuropathy, extreme weight loss/gain, and cognitive struggles. For instance, P12 describes the onset of side-effects as a shock and explains that this provoked additional, and avoidable, distress:

> P12: Of all the different doctors and fellows that I saw, none prepared me for what to expect in terms of changes. I mean, I knew that I was going to probably be nauseous and that my hair was going to fall out because of the chemo, and ok, well that's more common knowledge stuff, but I had no clue that I would lose feeling in my fingertips and that I would struggle to remember where I put my keys or that I wouldn't be able to concentrate to read a book. No one prepared me for that, so when it happens you think something is going wrong, that the cancer is getting worse or that it's spreading. Your mind races in a million directions, none of them pleasant.

Many women in this study suggested that if they were going to effectively manage side-effects, they needed to know what to expect and be provided information on how to cope. Few felt that there were adequate opportunities to garner this information in hospital.

In describing efforts to manage treatment related side-effects, most women discussed the importance of being able to connect with and learn from those that they perceived to be "in the same boat" and explained that ELLICSR permitted them with opportunities to foster these connections in ways that medical waiting rooms did not. They explained that the *experiential* and *embodied* knowledge of "cancer friends" was highly valued, providing them with "trustworthy" and reliable information about the course of cancer and treatment. In a broader discussion of an informal support group of cancer friends, P8 emphasizes the importance of embodied knowledge as a source of information and highlights the emotional benefit of being prepared for the side-effects of treatment:

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P8: It helped me to understand and to be less worried about symptoms or signs that I was going to be experiencing. For example, with the chemo, people told me that I was going to lose my hair, lose sensation in my mouth, my nails were going to get brittle and all those things were going to happen, so, now I know rather than panicking about them when they happen.

Many women also described the benefit of being able to share health information with others, including advice, personal experiences of medical events, and personal accounts of learning to cope with or adjust to the side-effects of treatment:

P3: It's comforting to speak to people who have gone through it because they can relate to your experiences. So you'll tell your doctor 'I have tingling, numbness in my fingers' and they brush it off, 'Oh yeah, that's normal' kinda thing. But a cancer patient will say 'Oh yeah, I had that, it was awful but I did this and it helped.' They've found ways of managing it.

P3's narrative is one of many that emphasized the value of embodied knowledge. The information generated through lived experience was perceived to offer practical assistance in ways that others, including health care providers, could not.

Information pertaining to support services. Nearly all of the women in this study stressed their need for information about insurance coverage and financial support, additional clinical supports (e.g., psychological, pain, and fertility), sources for obtaining wigs and prosthetics, and/or information on how to 'break the news' of their diagnosis to family and friends (particularly children). Most women felt that their medical team was unaware of available support services in the hospital and community. Instead, most explained "stumbling" upon this information too late and emphasized that standardized delivery of this information early on in the treatment process would have been beneficial:

P12: I don't know how much attention is paid to the ways this diagnosis completely changes your life and so there doesn't seem to be a big awareness around that. I know they're [medical providers] busy, but I just needed some information, like a list of different support programs; and what would that take, 10 seconds? Instead, I ended up finding most of the information on my own, but didn't always know what to trust or what programs were worth following-up on.

P12 explains that one's life often becomes unhinged in the face of a cancer diagnosis and that there is a need for care and support that extends beyond the biomedical realm to address these life changes and challenges. While she took on the work of locating this information herself, she

explained that she did not always know what information to trust and which programs were best suited to her particular needs.

Referred to by some women as "knowledge brokers," ELLICSR staff were discussed frequently for their authority and expertise in the area of psychosocial oncology, care programs, and support services. Below, P11 highlights the difficulty she experienced with securing information on support services within the hospital and emphasizes the benefit of ELLICSR in filling this information gap:

> P11: I got an appointment with a social worker here at ELLICSR and that was very helpful in thinking through some of the ways I could get additional supports. That's probably where I got the bulk of my resources from. So that was very helpful because I found that it was very hard to come by, at least it was for me and it wasn't until I came here that I started to get answers and really see things happening.

Staff assisted women in locating information suited to their specific support needs. In a photograph she titled "A Warm Environment Filled with Information," P10 explains that she secured most of her information at the ELLICSR library and emphasizes the value of having expert staff on-hand to assist with locating appropriate materials:

Photograph 9

P10: I told [ELLICSR staff member] that I was really scared to tell my children about my cancer and within minutes she found one of the most important books I read; it was about how to tell your kids you have cancer. When I first found out about the diagnosis, I was keeping it from my children. They knew something was up. But then reading the…I actually read the book before I read it to them. I realized that if I involved them and keep them in the loop, they would be supportive and it's not like a hush, hush. Like, I really….this is something that mommy's going through. And to be quite honest, they've been the most supportive. Like every day they'll get up and say "good luck with your radiation. I'll see you after school, mommy". Or they'll say things like, "mommy, you look great bald!" So, that book was a god send.

P10 emphasized the importance of sharing her diagnosis with her children and of doing so with care and sensitivity; access to reliable and expert-endorsed information permitted her the opportunity to do so with confidence. Similarly to P10, many women in the study experienced worry about 'breaking the news' to their children, with some situating this pressure in relation to their position in the home as a mother. For instance, P6 explains:

> P6: As a woman, a mom, you are the pillars of your household; everyone depends on you for everything – the cooking, the cleaning, the help with school work – and so when you get sick I think it is more present in the home…I mean to say, in the routine of the home because the whole house is under threat. Because of this, you need to be very careful in how you approach these situations [disclosure of diagnosis to the members of the household].

P6 alludes to the different anxieties women might experience when disclosing their diagnosis to their children and of how (and why) the receipt of this news might be taken-up differently by the children themselves.

2. Self-management support. Many of the women in this study described processes of indoctrination into a medicalized discourse of illness-management that promoted adherence to specific practices associated with diet, exercise, medication regiments, and stress management. However, the need to manage serious illness was, for most women, unchartered territory and many explained needing instruction and hands-on support in developing new skills to manage their illness effectively and safely. Despite this need, many women cited a lack of institutional instruction, education, and support to assist them with the tasks that were being prescribed. For instance, women described being told by their doctors about the importance and benefit of healthy eating and exercise, but were rarely provided with necessary instruction and support on how to adhere to these prescriptions:

> P8: I found that my doctors were very vague in their recommendations. So, exercise for instance. What about exercise? Should I try low impact or high impact? Do I do weights or not because of the lymphedema? Should I avoid exercising during treatment? There is a need to understand that this isn't common sense stuff. I want to do everything possible to support myself and help to maintain my health, but we need some more instruction and support.

The women in this study spoke frequently about the importance of ELLICSR classes and programs that focused on the development of skills to help them cope with their illness. They stressed the importance of learning new and alternative ways to deal with their cancer, to optimize their health during treatments, and to help carry on with life as best as they could. Many women described histories of physical activity, food preparation, and good nutrition. These were

cornerstones of their pre-illness lives and were perceived as key to maximizing their health during treatment. However, these women explained that changes to their bodies (including, but not limited to pain, fatigue, mobility issues, and eating difficulties) resulting from cancer surgery, treatment, and medications altered their capacity to participate in these activities as they once had. For instance, they explained needing to learn new and less vigorous exercise techniques that targeted very specific health and wellness goals including improved range of motion, reduced swelling and pain, improve physical balance, and stress management:

> P9: Okay. The Healthy Steps, as I said, compared to what I used to do at the gym, this is almost like next to nothing. But right now in my life, I am in bad shape. I feel like physically I'm in bad shape, I was always exhausted. During treatment weeks I didn't leave the house. I couldn't even walk up the stairs. Seriously, I couldn't walk up the stairs; my husband had to carry me. If you could believe it, that someone who did so much exercise couldn't even walk up the stairs. They [Healthy Steps] do exercises that are good for my left side, which had the surgery and now radiation and everything. I have some issues with that arm now. There's some pain and movement problems, and the program is really helping with it. So it's really good. I'm hoping to get the basics and then be able to go back to the gym. But you don't want to push it.

In addition to physical activity, women stressed the need for nutritional information, cooking skills, and recipe tips to assist with compromised immunity; help overcome appetite loss, taste changes, difficulty swallowing, and digestive complications; and to help reduce the effects of treatment-related side-effects including fatigue and cognitive challenges. In discussion of the photograph below, P9 emphasizes the nutritional information and culinary skills that she received through her participation in the ELLICSR Kitchen program and explains how this helped her to execute self-management prescriptions provided in hospital:

Photograph 10

P9: The nutritionist and chef are friendly, approachable, and well-educated and know the cooking methods and nutritional aspects extremely well. They do different themes, so I went the other week and it was about how to fight fatigue with food. I found that very helpful. I've found I have more energy for sure. This week was brain healthy foods and I need to enhance my memory due to cancer [brain] fog [laughs].

Many women explained that ELLICSR programs and classes provided them with reliable information and hands-on support to assist them in developing new skills to manage their illness and illness-related side-effects effectively and safely. Managing the side-effects of their illnesses gave women a sense of control, confidence, and reintroduced elements of familiarity and normality into their otherwise disrupted lives. Managing 'well' held practical importance insofar as it permitted women to continue those tasks that they and their families relied upon, improved their capacity to adhere to physician prescriptions of behaviour change, and signalled their ability to 'fight back' against the cancer.

3. Assistance managing disruptions in everyday life. While managing illness through the adoption of prescribed behaviours was seen as important, most women described the work of 'self-managing' as being much more complex than simply complying with clinical guidelines and performing medically-inscribed self-care activities (e.g., diet, exercise, stress reduction, and medication regimens). The burden of self-management work was not only about the performance of illness-related activities; indeed, the most challenging components of this work emerged through efforts to implement and maintain such tasks alongside the demands of everyday life. Few felt that the everyday world factored into medicalized conceptualization of self-management that appeared to be focused exclusively on illness. Indeed, in a broader discussion of short hospital stays following surgery, P10 highlights the invisibility of everyday care from a systems perspective and the unavailability of practical care supports:

>P10: It was hard to go grocery shopping and I couldn't stand there and start cooking dinner or start…I mean even walking up and down the stairs to do laundry was a big event. But they [medical team] don't see this; I don't think they see this as part of it, so you don't get very much support from the system after leaving the hospital.

Similar to P10, P7 remarked, "I don't think the system, doctors think seriously enough about 'Ok after treatment, after she leaves the hospital, this woman has to go home and feed herself and her family.'" Both P10 and P7 illuminate the ways in which the patient experience is decontextualized and in the process, how important aspects of care go unnoticed and untreated. Not all participants were immediately at liberty to relinquish taxing chores or responsibilities, nor were all of them interested in doing so. While women had varying amounts of informal support to assist with these tasks, many still described reaching a point of exhaustion and reported the need for additional help with cooking, cleaning, shopping, and caregiving (for children and dependent others) so that they could find time for personal needs and illness-management tasks. Systemic support for women with childcare and domestic responsibilities was frequently needed, however, women explained that such services were too costly or unavailable and in turn, inaccessible.

Most women described ELLICSR as a space that recognized individual difference and the importance of rooting care within the context of people's everyday lives and struggles. Women felt that this space was more attuned to the diverse requirements (and challenges) of self-managing and that the community/collective approach to care delivery was better in line with their care needs. For instance, Community Connections events at ELLICSR were discussed for the ways they introduced women to local community programs and services geared toward a broad spectrum of their psychosocial and supportive care needs. P10 recounts her experiences at a Community Connections event and describes connecting with what she perceived as a pivotal organization, "Nanny Angel." While she expressed having a large and supportive circle of family and friends who were willing to help, she felt uncomfortable passing domestic work (specifically cooking, cleaning, and childcare) onto others who she perceived had already done "too much." Taking on the brunt of the domestic work herself, P10 provided detailed accounts of the difficulty she experienced balancing domestic responsibilities with her own health needs. Below,

she emphasizes the need for additional support with cooking, cleaning, and caregiving and describes how the Nanny Angel organization helped her fill this care need:

> P10: It was at one of these [Community Connections] events that I met the Nanny Angel people. Like who knew we had these types of services? it's just great! Anyway, they've come to my house a few times now. And so it gave me a chance to rest, and they would have activities with the kids. So it gives the kids a bit of… You know, because I'm still tired. I don't have the energy to be… even though my kids are older, they're not baby, baby toddlers. We had a great nanny that would come in and bring in some great activities or different fun things to do which maybe, you know, I'm too tired to do at this stage. So that was great; having someone that I know my children really enjoyed. I think it was really good for them and me.

ELLICSR helped many women locate the programs, services, and supports they actively sought out, but could not find and/or were unable to afford.

4. Support with emotional trauma accompanying illness and treatment. All of the women emphasized the emotional consequences of a cancer diagnosis and its treatment. They explained that cancer brought a multitude of emotions that endured over the course of their illness including, but not limited to, fear; anxiety; depression; a sense of loss; isolation; anger; and frustration. Some women reported efforts to confront these emotions with their oncologists or ask for referral to services that might be able to help; however, few found that oncologists were adequately responsive to these needs. Some women spoke of well-intentioned clinicians who reassured them of the 'normalcy' of psychological and emotional distress following a cancer diagnosis as well as those who emphasized the importance of a positive and optimistic outlook. However, very few women spoke of providers who referred them to psychologists, social workers, and/or cancer support groups to help cope with their emotional challenges:

> P2: We've been brought up in a culture, and I'm sure it's changing, that doctor knows best and you just follow him and do what he says. If you get the sense that this [psychological/emotional distress] is normal or not important, then it must be so. But doctor doesn't always know best, I know that now!

Other women spoke about the tendency of their medical care team to confuse familial support for emotional care, rendering their claims to emotional/psychological care even more fragile. In review of the photograph below, P2 explains that despite experiencing tremendous support from friends, family and her health care team (all represented in the stick figures captured in photograph 11), she argued that support is quite different from understanding and that, despite

unwavering support, these people could not truly understand what it was like to have breast cancer, to suffer with treatment related side-effects (in her case, pain) and stigmatizing stares, as well as what it is like to make difficult decisions about treatment. In turn, her emotional care needs remained unmet.

Photograph 11

P2: Photograph Title: "Although you have lots of support, cancer is still a lonely journey."

Similar to P2, several women in the study highlighted the salient difference between having a support network and having access to emotional care supports. Indeed, nearly all of the women in this study explained that they felt a need to be emotionally strong for their loved ones and that it was important for them to not further "burden" family and friends with their emotional struggles. In an effort to protect loved ones, some women described concealing their emotional challenges, which often left them feeling isolated and alone – even when they were surrounded by large networks of supportive others:

> P8: I need to be strong for THEM. I was protecting THEM. My family is in South America, so I would talk to them over the phone and they would say "How are you doing?" and I would say "Oh, I'm doing fine and everything is fine" and then after talking to them I would start crying. I remember sitting on the floor against the wall, crying inconsolably, thinking I'm NOT fine. I'm terrified, I have anxiety, I am depressed. Am I going to be able to make it? Am I going to survive? If I don't survive, what is going to happen to them? I am the economic support for them, I cannot die. I CANNOT die. This was adding to my fear and worry. In the process of protecting them, I realized there was no one to care for me.

Many women foregrounded the need to provide emotional care to loved ones in order to protect them from the distress of their illness. For instance, P11 recounts spending "a lot of time consoling people. So much so that I couldn't begin to process what I was feeling and what this

[cancer diagnosis] meant for me." These findings suggest that women's claims to emotional care for themselves are often fragile, and that this might be particularly true for women with families who are often tasked with maintaining care for themselves *and* others, and who may not receive necessary medical attention or referral due to the assumptions that familial support ensures emotional care.

Assistance with coming to terms with a cancer diagnosis along with the uncertainty it entails and of being given opportunities to connect with others who have been through a similar circumstance were consistently cited as prominent unmet needs. ELLICSR was discussed by many women in this study as an alternate care environment that provided them with an safe and caring space where they could foster friendships with people who were living with, or had lived through cancer. The shared experience of cancer opened opportunities for empathy and connectivity within the group, promoting an environment of compassion and acceptance. As P1 noted "Even though we only knew each other for a few weeks, we had more in common than we had with people whom we had known for a lifetime…It is a point of recognition where you stop and think [sigh of relief] 'These people get me.'"

Having a place to go where they could connect with others facing similar circumstances was highly valued; affording them opportunities for debriefing and consciousness raising. Indeed, many women found comfort in shared discussions about their experiences and through the collective acknowledgement that their feelings of fear, anxiety, depression, and isolation were common and not suggestive of inadequacy or 'abnormality'. Indeed, the connections that women built with others were discussed for the ways they promoted a sense of 'normalcy' and belonging during times where they described felling "stigmatized," "abnormal," and "broken." The safe, empathetic, and caring nature of this environment encouraged open and honest emotional expression, permitting opportunities for sadness, anger, and vulnerability (as oppose to an expectation of positivity and cheerfulness) – emotions they often did not feel comfortable expressing in the hospital and home.

The emotional care received in interaction with cancer friends was perceived by most women to fill an important care gap; however, these relationships took on additional and nuanced importance for those women that possessed little social support in the context of their everyday

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lives. For instance, P4 described the lack of familial support she received and wanting to give up on treatment as a result. She explained that the emotional support and encouragement she received from cancer friends was not only therapeutic and beneficial in addressing her emotional challenges, but it also gave her the confidence and motivation to carry on with treatment:

> P4: They [her brother and sister-in-law] would just put me in the car and wave bye-bye and I would have to come home by myself [tears up]. I mean that is one of the reasons why I just wanted to give it up, I wanted to stop the treatment, stop fighting, because I couldn't get their support. It's lonely, cancer is a lot to take on by yourself and the treatments just wipe you right out, so I was done and then I realized that I didn't need their support, I need to support myself, be strong, and never give up. I got a lot of that strength from the cancer support group here [ELLICSR]. Sometimes you just need to know that people give a damn and when someone else thinks your worth something so do you and so you fight. And those people [cancer friends] gave a damn.

P4's experiences highlight the consequences that can emerge when emotional care needs are left unmet and of how appropriate emotional supports can assist people in effectively coping with the vast (and changing) emotional challenges they encounter throughout the diagnostic, treatment, and post-treatment phases of this illness.

5. **Financial advice and assistance with logistical and material resources.** While the Canadian health care system provides universal access to care deemed 'necessary', many women felt that there were gaps in financial coverage for needed care and supports. Some felt that there were few opportunities to dialogue about financial challenges in hospital (often because of short medical appointments and/or the taboo nature of income, particularly poverty) and that locating and assessing financial assistance programs was difficult terrain to navigate.

The most frequently discussed out-of-pocket-expenses included transportation (e.g., public transit costs and hospital parking), medications/pharmaceuticals, dispensing fees, wigs and prosthetics, home health aides (e.g., nursing), house cleaning and childcare, as well as alternative medications and supplements. Women emphasised the salience of private insurance in these discussions and hinted to their shock at the extent to which care is privatized:

> P9: I mean I was lucky enough that I was able to afford it [Neulesta injections]. My husband's insurance covered everything and it was about $18,000 for the shots. And the only thing I feel bad is for those who can't afford it or don't have the insurance. So there's monetary restriction to care in Canada. That's a big one. To me, government, the Ontario government, that's something that should be covered by OHIP.

While out-of-pocket costs associated with treatment were stressful for many of the women, it was particularly problematic for those who had to do without as a result. Low-income women without private insurance struggled to meet the financial needs of everyday life and often did not have the resources to pay for out-of-pocket medical costs:

> P3: We think we're not like the States, but we've got a lot of the same struggles. Even if you think you've got a good job and so forth, BAM, your cancer won't let you go back to work…then you have to fight with your insurance, that is, if you're lucky enough to have insurance – which I didn't have because I got sized down to part time and then I didn't have benefits anymore, so when the cancer came, I was already in turmoil. I mean the medication costs alone will just kill you. I had to dip into my savings and then that ran out; then I dipped into my RRSP and then that ran out. I had nothing and so I worried about paying rent, I couldn't afford the medication, sometimes I couldn't even afford to eat…and you start to think, 'Am I going to die because of this?'

The women's experiences discussed above reveal that coping with financial issues can make dealing with a difficult disease even more challenging and that financial circumstances are influential in framing patients' 'choices' about adherence to treatment. More generally, they show that there are vast inequities in access to care based on one's ability to pay and these inequities are not adequately recognized or supported within the medical model.

Women spoke about the ways that ELLICSR assisted them with financial challenges and the associated fallout of financial hardships. For instance, P4 described connecting with the Money Matters program (offered at Wellspring Cancer Support Network) through a Community Connections event held at ELLICSR. She explained that it was through this connection that she received the necessary financial advice and navigation support needed to locate and secure income replacement and drug coverage programs. P4 emphasizes the value of Community Connections, stating: "I was at rock bottom financially, so getting connected with the Money Matters program was beyond helpful in getting medications and getting on with other things."

P3 offers a more nuanced account of how ELLICSR assisted her in overcoming some of the struggles that she experienced as a result of economic marginalization:

> P3: When the wellness chef and dietitian are talking about nutrition, they're not only telling us about what is healthy for us; the dietitian tells us what to eat and why it's good for us and the chef really pays attention to cost. He brings in farmers and tells us where we can get cheap homegrown food. When he does a recipe, he breaks it down, he tells us how to make a healthy meal for $1.35 – I can do that, I can budget for that. I never knew I could eat healthy for $10 dollars a week. If you're a senior, you only get money once a month, so you try to find ways to deal. It's a good program to give you ideas on how to shop and how to buy the healthy food to keep you better…Because money is a

The Kitchen Program provided her with more than 'cancer-friendly' nutritional advice and cooking tips. It helped her overcome issues of food insecurity, which became even greater in the face of additional costs associated with her cancer and cancer care.   P3's narrative speaks to how the program's recognition of and sensitivity to issues of cost and food accessibility allowed her to implement the nutritional advice and culinary skill being offered, and of how this helped her cope more successfully with treatment and the tasks of everyday living. What made ELLICSR so impactful in this case was its acknowledgement and responsiveness to SDOH in the structuring and delivery of care.

Barriers to ELLICSR

For the women in this study, ELLICSR is a space that made a critical difference in care experiences and one that appears to fall closely in line with policy promises of integrative and ongoing care that adheres to each patient's unique circumstances and care needs. However, the findings of this study also unveiled challenges to the integration of this centre within everyday operations of the hospital. In this section, I explore those elements that appeared to limit the scope and reach of the cancer care and support that ELLICSR provides.

Most women described "stumbling" upon ELLICSR through word of mouth, posters in the hospital or through internet searches. Many women explained that they did not find this space until later into the course of their treatment and wondered why such an important service was not provided from the beginning:

        P12: My only regret is that I didn't find this place sooner. I've found so many
        resources here that I thought 'That would have been really helpful when I was
        getting chemo' or 'Oh, transportation services, I wish I knew about that when I
        was coming to the hospital every day for radiation' And so, yeah, I wish I
        found out about this space earlier on.

Women explained that earlier access would have helped them adapt and better prepare to confront their illness and argued that there should be a more concerted systemic effort to increase the coordination of this information to ensure more consistent referral procedures. In the absence of systemic notification of and/or referral to the centre, some women described taking it upon themselves to advertise the space:

> P1: I've met countless people with cancer who need help and they have no clue
> that these centres exist, and I think 'WOW, why?' It's an absolute shame. So
> now I carry around information about ELLICSR and hand it out… I know that so
> many people are just completely lost, so I've taken it upon myself to promote
> it [ELLICSR].

P1 draws on her experiences with fellow cancer patients to illuminate the extent to which psychosocial supports are needed and emphasizes her shock over the disconnect between available psychosocial and supportive care within (and outside of) the hospital and knowledge of this availability. Endeavouring to close this gap, she takes it upon herself to inform patients of the ELLICSR centre.

The system/clinician barrier. Both patients and ELLICSR staff explained that referral to psychosocial and supportive care did not appear to be built into hospital norms and routines and that attention to these elements of care is the exception rather than the rule in standard clinical practice. In a broader discussion of ELLICSR's outreach efforts to inform hospital staff about the centre, the services provided within the space, and of the benefits to patients, E7 explained that there continues to be low levels of collaboration between systems of care delivery in the hospital and identified this as a major barrier for patients:

> E7: The clinicians not knowing about us, or they know about us, but they don't
> really understand what we do or they don't think it's important so they don't
> really sell it much. So that is probably the biggest barrier for people wanting
> to come [to ELLICSR] or that could benefit from coming. People happen upon the
> centre. How they hear about that is not really systematically done, and it
> shouldn't be like that. There needs to be more collaboration.

E5 also identified poor collaboration as a significant barrier to ELLICSR use and explained that she perceived this reluctance was due in part to the subjective norms of oncologists that psychosocial and supportive care is not integral to routine oncology practice. She notes that "Many of the oncologists that I've worked with, they think the centre is nice but not necessary. They have different priorities when it comes to care, I guess."

E6 echoed these perceptions, going further to suggest that physicians were not only reluctant to refer their patients to ELLICSR, but that this reluctance extended to psychosocial and supportive care services more generally:

> E6: It's not just ELLICSR, I think its psychosocial care more broadly. So I've
> done some work over at POPC [psychosocial oncology and palliative care centre,
> located in the Princess Margaret Cancer Centre], and it's the exact same thing
> there, there is just this reluctance to work with us [psychosocial care

> providers] and I don't know…maybe they [oncologists] don't think this is
> important, and I think that's a major barrier for patients because they rely on
> their doctors to provide this information and sometimes they need referrals; so
> the doctor is very much the gatekeeper to their care.

E5, E6 and E7 all emphasize the importance of oncologist 'buy-in' to patient knowledge of, and access to, ELLICSR and other psychosocial and supportive care programs. Their comments further illuminate that even within progressive health care centres designed according to integrative models of care, traditional care hierarchies that privilege acute orientations and the authority of acute care providers remain relatively unchanged.

Although there was talk about good and bad providers, cancer patients and ELLICSR staff tended to attribute fault to the health care system rather than to individual people. Indeed, it was common for participants to follow their comments about unsupportive providers or rushed medical appointments with an acknowledgment that the health care system does not afford providers the necessary time to inquire about their everyday lives and their psychosocial struggles. Indeed, some stressed that system imposed quotas and packed waiting areas made it difficult for even the best providers to focus on anything other than tumour-related/biomedical care delivery.

The funding barrier. Drawing on their experiences within the health care system, a number of women hinted at two separate systems of care; an acute/curative care system which appeared to be very well funded and the other, an inadequately resources chronic/psychosocial care system. Below, P9 problematizes the funding trends between these two systems of care:

> P9: So yeah, it kind of surprised me that all of this money. There's lots of
> money being raised for cancer research, and I'm not saying that it's not
> necessary. But I think we need to… We, meaning we as a society, need to
> recognize that this thing, cancer, is not going away any time soon. So until we
> find a cure, we need to be thinking more seriously about putting attention and
> money towards the struggles that people face when they're living with this
> disease, because people are struggling. I don't know that the promise of a cure
> is good enough for these people. Don't get me wrong, I am forever in debt to
> this place [Princess Margaret Cancer Centre]for saving my life, and I'm not
> minimizing that or the importance of the care I received, but we can't keep
> overlooking the impact of this disease. It's about quality of life in the end,
> right?

P9 emphasizes her understanding of the importance of acute cancer care and the delivery of techno-medical treatments; however, she also highlights the importance of looking beyond 'the

cure' to ensure the availability and accessibility of psychosocial and supportive care for people living with cancer.

Funding trends were discussed frequently by ELLICSR staff and some patients, both of whom suggested that current funding practices impose significant barriers to the scope and reach of care ELLICSR provides. E3 and E7 both explained that ELLICSR was founded on, and continues to operate within, soft and unstable funding arrangements gained predominantly through Princess Margaret Cancer Foundation fundraising dollars, research grants, and private donations that fluctuate from year-to-year. This lack of stable funding sometimes made it difficult to ensure the ongoing delivery of programs and supports and often made it challenging to accommodate the volume of patients who could benefit from attending the centre:

> E7: I think the exercise program [WE-CAN] is going to bring a lot of people here. It's going to…we're actually already quite worried about the volume of patients. That's the double edged sword, we want whoever can benefit from this centre to come, and we want physicians on board with what we do here, but we don't have the staff and resources or the space to accommodate everyone who could probably benefit from coming here.

This rising demand on limited resource was echoed by P12 who described a growing wait list for the Healthy Steps exercise program. Despite the need for, and ability to benefit from the program, she describes "holding-off" on registration so as to not fill a spot that could be used by a new patient:

> P12: There is a lot of interest in the exercise program and that's great, they've even got a waitlist going. And so I would love to be able to take the program again because the pain in my chest and arm has come back and this program really helped me the first time around but I know there are other people who need it, so I've held-off on signing up.

P12's experiences speak to the ways in which, despite its commitment to a chronic approach to the delivery of care over the long-term, ELLICSR does not entirely succeed in its efforts to offer ongoing care and support following active treatment. Here we see the ways in which limited funds make it impossible to act sufficiently on discourses and commitments to chronic care, even when necessary infrastructures are in place. In addition to growing wait-lists for some programs, some ELLICSR staff expressed frustration about program cuts as well as the diminished frequency with which programs were being offered. As E5 notes: "It's a bit frustrating. I've seen a bunch of great programs get cut. I've also helped lead some really exciting pilot programs and

the response from patients has been outstanding, but after the research nothing gets done because there just isn't the money to sustain the program."

Despite the perceived benefit of this space and its alignment with proposed policy changes (for more integrative, holistic, and person-centred care that adheres to each patient's unique circumstances and care needs), acknowledgement of these barriers illuminate the challenges of implementing an alternate, and more collective-oriented model of care, in a health care structure that is predominated by an acute care orientation and a funding system that remunerates acute medical services (Daly, 2012). In other words, it appears that ELLICSR's very alignment with policy promises is what reinforces the precarity of this space.

Discussion

This study explored the micro-level care environments through which macro- and meso-level policies are enacted and lived. Provincial policy and institutional agencies are increasingly demonstrating their political commitment to a culture change in care that is more closely aligned with a chronic-centred approach to care delivery through the development of policies that enforce greater person-centeredness, patient involvement, and holistic care integration (Pederson & Liwander, 2012). While these changes appear promising in their capacity to resolve current conflicts between chronic care needs and acute care delivery, the findings of this study reveal important tensions as policies percolate from macro- and meso-levels to the micro environments where care is delivered and received. The findings of this study confirm that through standard hospital care, cancer patients continue to cite insufficient or inappropriate information, rushed and fragmented care delivery, inadequate emotional support, and insufficient assistance to manage their illness, cope with changes in everyday life, and to adjust to financial challenges. These findings reinforce decades of quantitative and qualitative evidence about the unmet needs of cancer patients in the Canadian context (Ashbury et al., 1998; Canadian Cancer Society, 2003; Jones, et al., 2012; Soothill et al., 2001), but do so in a different and still changing health care milieu that increasingly pledges its political commitment to chronic care, but that remains both systematically and economically focused on the delivery of curative efforts, treatments, and technologies.

Patients are currently operating at the nexus of this crossroads in health care and the findings of this study show that to bridge the gap between promise and practice, patients themselves must organize and coordinate their own care, translate standardized messages into standards of care, develop the necessary expertise needed to obtain, review and understand information about their illness, ask the 'right' questions and make informed decisions, comply with prescriptions of behaviour change and expectations of personal motivation, and navigate complex and fragmented care systems in pursuit of non-biomedical care. Participants emphasized systemic constraints – including brief consultations and fragmented care systems – which hampered communication efforts and prevented their oncology care team from adequately inquiring about their social circumstances and struggles; limited opportunities for dialogue and shared decision making; and diminished opportunities for meaningful collaboration with other essential care providers and/or programs. Some women also explained that provider assumptions of care provision in the home, for instance emotional support and assistance with self-management tasks, limited their opportunities for, and claims to, appropriate care. In other words, women explained that their experiences were either decontextualized or rooted in normative assumptions (rather than facts) and in the process, important aspects of care went unnoticed and untreated. Patients themselves were left to fill these gaps in care, a task that was described as challenging by all of the women in this study and proved to be unbearable for some. This finding echoes May and colleagues (2014) who found that in the current era of restructuring, health care systems shift an ever growing list of management and care coordination responsibilities and tasks on to patients, and in doing so, increases the burden of their illness and perpetuate increased opportunities for inequities to emerge between patients.

Women described ELLICSR as an alternate care environment to that of the hospital; as a space that recognized individual difference and the importance of rooting care within the context of people's everyday lives. Indeed, the very design and delivery of care at ELLICSR seems to counter assumptive neoliberal logics that are frequently embedded in policy documents (see for example, *Ontario Cancer Plan 2011-2015*; *Public Services for Ontarians: A Path to Sustainability and Excellence)* and hospital practice; assumptions that project the belief that people know how to care for and support themselves during the upheavals of illness, that appropriate care support is available in the home (particularly for patients with families), and that the home is always the most desirable and appropriate site for care delivery (Luxton, 2010; Day,

2013; Armstrong & Armstrong, 2010; Armstrong and Kits, 2004). Breaking with these assumptions was important, as women illuminated the many instances in which they mapped poorly onto the realities of their lives and circumstances. For instance, women described managing illness and illness related side-effects as uncharted territory for which they felt poorly prepared to address. Further, women described active efforts to protect the stability of the home by resuming care responsibilities and by downplaying their own suffering and need for care. The time spent caring for others paired with their reluctance to request/accept care support from family and friends, rendered women's access to care in the home fragile. Lastly, for women whose households already rested on shaky ground due to such things as poverty, the added responsibility and cost of providing illness-related care threated to further disrupt the foundation of the home. We see this with P3, for whom the added cost associated with care-related expenses threated to worsen already present food insecurity issues. For these women, home was not a desirable and appropriate site for care.

ELLICSR was described as being attuned to the diverse challenges of cancer and its collective approach to care delivery was well aligned with women's support needs. The space was praised for the ways in which it acknowledged the devastating and far reaching impact of cancer and of the vast need for psychosocial and supportive care services. The women in this study explained that ELLICSR provided time for and in care, permitting them opportunities to express their challenges and concerns and to dialogue about suitable care directions. It offered a space that allowed women to better locate reliable information and where assistance was available to help assess their applicability. It provided opportunities for important skill development that rendered the uncharted terrain of illness-management easier to navigate. It facilitated connections and collaboration with "cancer friends" and health care professionals (social workers, psychologists) in ways that helped the women to cope with the emotional fallout of their diagnosis as well as adjust to the various side-effects of treatment. Lastly, it facilitated connections to community programs and providers that afforded women opportunities to seek out vast networks of supportive care (including homemaking support through Nanny Angels and financial counselling and advice through Wellspring's Money Matters). Such programs helped women to maintain a suitable level of care within the household (without overburdening themselves and others) and helped ensure adequate financial and material resources needed to meet medical and everyday living costs. In short, the participant's accounts of ELLICSR suggest that this centre adopted a

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broader approach to health and health care that took such things as gender, income, and other SDOH into account. In doing so, it helped to facilitate the work necessitated by patienthood and offered the necessary supports to help fill what they perceived as important care gaps in the conventional cancer care system.

ELLICSR is a space that made a critical difference in the care experiences of the women in this study and one that appears to fall closely in line with policy promises of integrative and ongoing care that adheres to each patient's unique circumstances and care needs (see *Ontario Cancer Plan 2011-2015; World Class Personalized Medicine: Strategy 2013-2018).* The findings of this study however, also highlight the challenges of implementing an alternate, and more collective-oriented, model of care organization in a structure that is predominated by a "funding system that remunerates acute medical care and favours hospital services that are brief, biomedical, and episodic" (Daly, 2012, p. 93). Within this care environment, ELLICSR operates as a care silo (as oppose to an integrated component of the standard care structure), existing on the periphery of an already fragmented health care system. While navigating such systems are challenging for all patients, they are particularly challenging for women who are marginalized (Gould et al., 2009). As such, it stands to reason that the fragmentation of ELLICSR and other psychosocial and supportive care services will disadvantage those who are likely in the greatest need of, and stand to benefit most from, such services.

Recommendations

Throughout this paper, I explored the lives of 12 women with cancer and critically engaged with the complexity and messiness of their illnesses, care experiences, and care needs as they unfolded in an equally complex and messy health care system. The findings of this study hold important implications for policy and clinical practice.

Policy. This paper unveils the tensions and conflicts that can emerge when chronic care policies are implemented into what remain predominantly acute care environments. The tensions that underlie care policies and practices must be recognized and balanced in order for effective equity-promoting strategies to be developed (Armstrong & Braedley, 2013; Smele & Seeley, 2013). Bridging these tensions will require a re-conceptualization of care at the level of policy in ways that reflect its complexity as lived and practiced in everyday contexts. This will require

bottom-up policy development as oppose to top-down strategies currently employed (Gould & Gardner, 2009). The inclusion of various stakeholder (including, but not limited to patients from different social locations, diverse health care and service providers, and hospital administrators) experiences will help to move policy from consideration of what should work in theory to explore what can be reasonably applied in practice. The findings of this study also confirm a 'silo-ization' of cancer care and hint to the ways that chronic care solutions (such as ELLICSR) get tacked onto – rather than integrated into – existing health care structures. Fuller integration of care systems on the ground will require critical and creative thinking at the policy level to resolve tensions between models of care. More equitable and stable funding arrangement between departments will be crucial to this effort. Indeed, policies that call for greater chronic-centred approaches to care delivery in the absence of necessary resources to facilitate these changes will likely be ineffective in improving systemic care integration as well as improvement in the delivery of good quality care that is equitably available.

Clinical practice. Health care providers frequently find themselves at a conflicting crossroads between medically-driven evidence and the lived experiences of their patients. Increasing, rates of cancer diagnosis along with a medical culture that sets shorter appointment times as a goal of efficiency-based care can result in the development of a system that render the negotiation of this tension challenging for physicians (Armstrong & Armstrong, 2008; Evans, 1997). This study recognizes that oncology care teams are working within an incredibly restrictive system that places limits on what they are (un)able to accomplish in the delivery of care. While it is understandable that in very short medical appointments oncologists 'choose' to focus on tumour-related care, the findings of this study show that this is not acceptable or sufficient in the delivery of good quality care. To be truly helpful to their patients, health professionals must recognize the concerns and priorities of those they endeavour to help (Townsend et al., 2006). This will include the need to consider the complex ways that gender and other SDOH affect patients' care needs throughout the cancer journey. A brief conversation about how the patient is coping will not only likely improve doctor-patient relationships but will also better prepare oncologists (or other members of the oncology care team – e.g., fellows and nurses) to work collaboratively with, and refer their patients to, appropriate care providers and support programs. Working collaboratively with other health care systems, such as ELLICSR,

may free up time in clinical oncology appointments (as patient's psychosocial care needs, concerns, and questions will be addressed elsewhere), but will also ensure that patients receive the necessary care from the most appropriate providers. Broader structural changes will need to occur to facilitate greater oncologist involvement and collaboration; however, future research will need to further consider what forms these changes should take.

Conclusion

This paper illuminates important gaps in care that emerge when ideological models of care shift but practical care systems and supports remain relatively unchanged. The existence of ELLICSR demonstrates an acknowledgement of major structural gaps in the conventional cancer care system, a commitment to addressing these gaps and improving quality care, and reinforces that positive systemic change is possible. However, the precarity of this space (through low levels of collaboration and unstable funding commitments) demonstrates a lack of commitment to the professed goals of reform. While it is reasonable that major shifts in the organization of health care will be met with the challenges and growing pains of any evolving context, I argue that these conflicts and tensions need to be acknowledge, engaged with, resolved and/or balanced – rather than ignored or dismissed as a 'natural' or inevitable side-effect of change. Indeed, we will need to tackle these tensions head-on if we hope to construct a true partnership between CHWCs (and psychosocial and supportive care more broadly) and biomedical/acute care system in the effort to better serve the growing number of those living with cancer.

CHAPTER FIVE

DISCUSSION, RECOMMENDATIONS AND CONCLUSION

Introduction

The study presented throughout the pages of this dissertation has moved through multiple settings and stages. Reflecting back on my original impetus, I expressed an interest in joining an ongoing dialogue concerning the lived experiences of cancer, care, and work in the Ontario health care context. I chose ELLICSR as the site through which to engage in this dialogue endeavouring to answer the question: How does ELLICSR facilitate women's work, for which women and in what ways? The women chose additional sites of focus: the hospital, the home, the community, and for some, the paid workplace – situating their interview responses and photographic images within these particular fields of practice. In these instances, I was reminded of the boundless nature of cancer and its consequences as well as the work it necessitates. As women's accounts of ELLICSR refracted into discussions of hospital, home, community, and workplace I was reminded that ELLICSR does not operate in a vacuum and that women's stories of care and work extended far beyond the confines of this space alone. As women recounted their experiences of care and work within and between these fields, important tensions and conflicts emerged. In line with feminist political economy and critical ethnography, I sought to pursue these tensions and conflicts further as they related to the topics of work and care.

In Manuscript One: ""It's Hard Work:" Re-conceptualizing 'Work' in the Cancer Context", I adopted a feminist political economy conceptualization of the notion of *work* as consisting of paid and unpaid tasks that require intent, time, effort, and skill (Smith, 2005 as cited in Sinding et al., 2011). I pursued the theme of work from this perspective as it unfolded in relation to 12 women's experiences with cancer and care. The findings of this manuscript contributed to a foundational understanding of: the far reaching impact of cancer; the limits of the medical model in attending to the vast care and support needs of women living with this illness; and the various gendered consequences and equity concerns that emerge when care is commodified, when the responsibilization of care provision shifts to individuals and their homes, and/or when inadequate care supports are provided to help individuals and their families to manage the vast

burdens of illness. In illuminating and engaging these tensions and conflicts, I enlivened the various roads that bring women with cancer to spaces like ELLICSR.

In Manuscript Two: "Putting Psychosocial Care on the Prescription Pad: The Successes and Challenges of Integrating Psychosocial Care into Routine Cancer Care Practice", I explored notions of care in the context of a changing health care milieu marked by conflicting care commitments between health policy (with an increasing emphasis on the need for chronic care) and health care structures (which remain entrenched in acute care operations). Within this manuscript, I endeavoured to better understand the care experiences of women in the context of this changing health care milieu, the impact of ELLICSR in framing these care experiences, and the extent to which ELLICSR is integrated into the everyday clinical care practices of the hospital. The findings revealed that not only do long cited unmet care needs remain but suggest that access to good quality care may be even more challenging in the context of current policy changes. The findings further revealed that ELLICSR's holistic and collective orientation to care delivery helped to fill many of the care gaps that patients experienced through conventional health care channels. Despite the perceived benefit of this space and its alignment with proposed policy changes, the findings of this study highlighted the challenges of implementing an alternate, and more collective-oriented model of care, in a structure that is predominated by a "funding system that remunerates acute medical care and favours hospital services that are brief, biomedical, and episodic" (Daly, 2012, p.93). As such, in an ironic twist, the findings of this study revealed that ELLICSR's alignment with policy promises is what reinforces the very precarity of this space.

Reflecting on the findings of these manuscripts and in consideration of the tensions and contradictions that emerged within and between them, a topsy-turvy health care climate is more clearly revealed. This topsy-turvy environment closely resembles the Looking Glass World described in Louis Carroll's novel *Through the Looking Glass, and What Alice Found There* (Carroll, 1871). The Looking Glass is the mirror that permits Alice entry into a world both clear and recognizable, yet turned sideways – a backward reflection of the world in which she resides. This parallels women's own experiences as they journeyed from a state of health to illness but also provides an appropriate metaphor for the tensions in care that surfaced throughout this dissertation; where care was provided in ways that opposed, and sometimes, evaded policy

promises as well as women's own care philosophies and needs. Feminist political economy contends that the tensions that underlie care policies and practices must be recognized and resolved (or balanced) in order for effective equity-promoting strategies to be developed (Armstrong & Braedley, 2013; Smele & Seeley, 2013). As such, in what follows I organize the major findings of this study according to the two key overarching tensions that emerged throughout this dissertation: 1. policy directions and health care settings; and, 2. medicalized discourses of self-management and the practicalities of women's everyday lives. In identifying and unpacking these tensions, feminist political economy provides a lens through which to view the topsy-turvy landscape of cancer care policy and practice and to illuminate the implications for women's health, care, and work.

Major Findings

Tension 1: Policy Directions and Health Care Settings

> Now, if only you'll attend, Kitty, and not talk so much, I'll tell you all my ideas about Looking-glass House. First, there's the room you can see through the glass – that's just the same as our drawing-room, only the things go the other way…Well then, the books are something like our books, only the words go the wrong way: I know *that*, because I've held up one of our books to the glass, and then they hold up one in the other room (*Carroll, 1871, Chapter* 1, p. 4).

Document analysis of guiding provincial and institutional cancer policy documents in Ontario (e.g., CCO's 2011-2015 Ontario Cancer Plan and Princess Margaret Cancer Centre's 2013-2018 Strategy Report) revealed an increased acknowledgement of, and support for, a model of care that attends to the complexity of illness and provides care over an extended period of time. A system that provides biomedical and psychosocial care, includes a wide range of health care providers, facilitates their collaboration in the delivery of care, and where efforts are taken to promote and adhere to each patient's unique circumstances and care needs. These documents thus promote a health care system that provides attention to individual's specific circumstances and care needs (person-centred care); embraces patient perspectives and collaborative partnerships (involved-patient); provides holistic care and integrated service delivery (collaborative care); and where care is delivered on an on-going/long-term (as oppose to episodic) basis. These approaches align well with many of the aims of women's health reformers

and health advocates (Hills & Mullett, 2005; Peterson & Donner, 2007; Thurston & O'Connor, 1996) who have long called for greater patient-provider partnerships in the delivery of medical care as well as health care systems that include attention to SDOH (Pederson & Liwander, 2012). The barriers that women confront in securing necessary health care are often related to SDOH and tend to be far greater for women as compared to men (Hill & Mullett, 2005 as cited in Pederson & Liwander, 2012). Further, given the high rates of chronic illness among women, a care system that attends to chronic illness and illness-management is both important and necessary to improve women's health (Pederson & Liwander, 2012). As such, the proposed policy changes possess strong potential to improve the likelihood of addressing some of the foundational factors that influence women's health, their access to care, and care outcomes.

Through the Looking Glass: A topsy-turvy health care climate marked with tensions and contradictions. While a thorough analysis of the issues that have led to support for such policy shifts is beyond the scope of this dissertation, it is important to situate these changes within the political economy context. In Ontario, where this research took place, chronic care has emerged as a policy position of "governments preoccupied with both limiting public provision of the needs of citizens (particularly of the aging baby boomers as well as those living with chronic illnesses) and facilitating the expansion of private-sector methods and delivery across care sectors" (Smele & Seeley, 2013, p. 145). Within this political and economic climate, health care systems are hyper-focused on efficiency, market-based practices, and numeric/quantifiable evidence – all of which come to frame the parameters of 'necessary care.' As the financial aspects of care take centre stage, the result is a 'slimmed-down' approach to care delivery and a strengthened commitment to shorter hospital stays as well as care appointments (Armstrong, 2001; Day, 2013). Within this system, primacy is given to 'consumer choice,' while collective rights and responsibilities to care are downplayed (Mol, 2008). The neoliberal logics (and economic crunch) fuelling the reorganization of health care systems appear to be in conflict with the ideological foundations of person-centred care, involved patienthood/collaborative partnerships, and integrated models of care delivery.

In this study, women's accounts of hospital care brought these large-scale policy shifts to the individually lived level and, in the process, illuminated tensions between policy promises and care practices; tracing a crossroads that helped to reveal a topsy-turvy health care landscape

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where seemingly positive and equity-promoting commitments (e.g., person-centred care, patient involvement, and integrated care) took alternate forms. For instance, women described a health care system where standards were replaced with standardization in a way that seemed to counter commitments to person-centeredness. Indeed, some women identified approaches to care that aimed to eliminate variation between patients; encouraging the same medicalized procedures, practices, and supports across all care recipients – even when these approaches were explicitly in discord with the patients' circumstances and preferences. For instance, in "Putting Psychosocial Care on the Prescription Pad: The Successes and Challenges of Integrating Psychosocial Care into Routine Cancer Care Practice," we see how P11's concerns about fertility were left unaddressed by the common physician response "We can't advise you against best medical evidence."

According to many women in the study, few oncologists deviated from tumour-related treatment and talk; most were unaware of (or at least did not endorse) psychosocial and supportive programs; and few worked collaboratively with other care providers (e.g., fertility specialists, psychologist, social workers) to explore different types of evidence and consider safe care alternatives that aligned more appropriately with patient preferences and needs. Indeed, far from a person-centred approach – focused on individual circumstances and preferences – women explained that their social and material contexts were rarely discussed in clinical encounters. Women worked hard to counter the effects of 'one-size fits all' approaches, including obtaining relevant health information, reading and assessing their quality, preparing questions for providers in advance of medical appointments, locating the appropriate specialists and 'making a case' for referral, "decoding" specialized and fragmented languages of health care professionals, and 'quilting' this knowledge together in ways that were applicable to their everyday lives and social circumstances. In these conversations, many emphasized the constant struggle to stay one step ahead of the system's version of person-centred care, which appeared to rest almost entirely on the hard work of patients themselves to "decode" and personalize what were otherwise standardized medical messages and approaches to care delivery. In this topsy-turvy health care climate, the body is individualized yet the individual is decontextualized and person-centred care more closely resembles individual responsibility.

In Manuscripts One and Two, women emphasized the work they performed within the health care system: they managed countless appointments across various care settings, sought out and read enormous volumes of information, learned a 'new (techno-medical) language' to facilitate communication with health care providers, prepared scripts and well-researched questions; made (often unsupported) treatment decisions, and often fought for referral to other health care providers (e.g. psychologists, fertility specialist). This finding echoes those of Sinding and colleagues (2011), who found that patient 'involvement' is increasingly being positioned as a *requirement* (rather than a choice) to ensure the appropriate coordination, quality, and safety of patient care. This is captured in ""It's Hard Work:" Re-conceptualizing 'Work' in the Cancer Context," when, in a broader discussion of locating and coordinating psychosocial and material supports, P1 says "No one is going to do it for you, so you've got to do it yourself." Such statements seem to suggest that patient 'involvement' in care is frequently performed as a result of inappropriate or unavailable care and support alternatives. This counters involvement discourse (reified in both policy documents and in hospital systems) that evokes language of empowerment, autonomy and choice.

This new-found 'authority' of the patient in the health care system and in treatment decision making offers a counter narrative to the medical dominance that feminists have long critiqued (Doyal 1995); however, it appears that while this shift has afforded patients a greater role in their care, it has done so at the expense of adequate institutional support and guidance with respect to care and care-related decision making – particularly when patient care decisions deviated from biomedical philosophies and medical evidence. Furthermore, this policy shift comes with tangible shifts in both responsibility and accountability from organization to individual wherein patients are not only held responsible for making 'good' choices, but are also held accountable if they make the 'wrong' ones. These findings support Sinding and colleagues (2011; 2012) who found that discourses of patient involvement promote the message that good care is the result of patient action and effort; obscuring the social and material resources that facilitate successful involvement and undermining the importance of having a health care team that understands and is responsive to these issues. In confirming these findings, this dissertation contributes to a growing body of literature that argues that involved patienthood can make securing good quality care additionally challenging and complex; ultimately, worsening health inequities between patients (Mair & May, 2014; May et al., 2014; Sinding et al., 2011; 2012).

In review of the lived tensions of person-centeredness and involved patienthood, we are able to trace the patient experience through a new responsibility and accountability circuit that better positions us to understand the implications for patients when ideological models of care shift, but practical care systems and supports remain the same. For instance, the aforementioned tensions can be partially ascribed to the dominance of evidence-based medicine in the health care system; informed by a focus on the body and activities that can be quantified and measured (Armstrong, 2001; Sinding et al., 2011). The intricacies and complexities of gender, as well as the social, political, and economic contexts in which health and illness are produced and maintained however, are largely overlooked in the production of such evidence. Furthermore, the voices of those who live with and negotiate care practices and decisions (including, but not limited to: patients, caregivers, and health care providers) are muted and their perspectives on quality are largely ignored (Armstrong, 2001). It is suggested here, that the application of evidence that excludes consideration of the personal, social, political, and economic conditions of life completely obscures the possibility of providing person-centred care and engaging in truly collaborative patient/provider partnerships during medical encounters. Instead, professionals are limited to offering a series of standardized "statistical 'likely-to-happens'" based on medically-driven positivistic and numerical population studies (Sinding et al., 2011, p.95). Examples of this were tightly woven in the narrative accounts of many women in this study as they recounted the need and expectation to translate standardized medical messages to their specific (personal, social, and material) circumstances and to make care 'choices' accordingly. This was a process that demanded tremendous work for which few women in this study felt prepared.

As noted succinctly by Armstrong (2010, p. 198):

> Accountability is defined in bureaucratic terms and numerical measures become the basis of accountability and choice. Not only what can easily be measured but what it is important to measure is decided by particular interest pretending to value-free assessment that allows public input. Written "objectives" and reports based on these measures replace the messier processes of democracy and debate. This "cult of efficiency," to use Janice Stein's term (2001), is actually self-referential. Like the Romanow Report on the future of Canadian health care (Canada, 2002), Stein draws our attention to the need to begin with fundamental human and social values in any system of accountability rather than with numbers and dollar signs.

The above quote by Armstrong (2010) resonates with this study's analysis and findings, as cancer care and the work of managing illness are complex, demanding, and indeed 'messy.' Efforts to confront and erase the messiness through statistically informed population studies and numerically calculated methods is understandable; after all, engaging with the complexities of individuals' experiences of illness is not easy. However, the application of medically-driven evidence does not change the above-mentioned realities of struggle and inequity – it simply ignores them.

The organization of knowledge about care holds important implications for how care services are understood, organized, and delivered (Armstrong & Braedley, 2013). When our understanding of essential care services rests on medically-driven positivistic and numerical evidence, the conceptual environment for developing alternative conceptualizations of care and care needs is greatly restricted (Day, 2013). ELLICSR challenges the existing conceptual territory by providing more collective approaches to care and through the delivery of care services that are typically devolved to the individual and provided in the home (e.g., emotional care, diet/nutritious, and exercise/rehabilitation). This space made a critical difference in the care experiences of the women in this study. However, a system predominated by medically-driven evidence and resultant funding arrangements contributes to a conceptual environment that systematically undervalues psychosocial and supportive care services such as those offered at ELLICSR (Daly, 2012; Day, 2013). Thus, while the implementation of this space within the hospital demonstrates clear commitments to change and quality improvements within the Princess Margaret Cancer Centre, the findings of this study support that without challenging and changing the foundational ideologies (as well as evidence and funding) that govern existing health care systems, fuller care integration will remain a significant challenge. Instead, as the participants in this study illuminate, it is far more likely that these systems will remain on the periphery as silos within acute care systems. Because navigating fragmented health care systems are particularly challenging for women who are marginalized (Gould et al., 2009), it stands to reason that the fragmentation of psychosocial and supportive care will disadvantage those who are likely in the greatest need of, and stand to benefit most from, such services.

In summary, patients are currently operating at the nexus of a crossroads in health care erected by tensions between policy directions and practical care environments. The findings of this study show that policy commitments that cannot be reasonably applied in practice are likely to be ineffective and potentially counter-productive in ensuring good quality care that is equitably accessible. This is a simple, yet critical point as it is within the empty spaces between conflicting care commitments that we find a reimagined patient and reengineered sense of patienthood. To bridge the gap between promise and practice, patients themselves must organize and coordinate their own care; translate standardized messages into standards of care; develop the necessary expertise needed to obtain, review, and understand information about their illness; ask the 'right' questions and make 'good' decisions; and comply with expectations of motivation and optimism. These requirements assume, of course, that everyone is able to access necessary information; that they will be able to understand it; that they are able to translate this information to their specific circumstances; that they possess sufficient confidence to question their doctor; that they have the resources required to access a wide array of choices; and that they will, or have the capacity to, be risk averse in their decision-making. The hard and often overwhelming nature of patient's work and the resources and supports required to satisfy its demands are minimized by assumptions of a level playing field and can be masked by promises of choice, autonomy, and empowerment. Thus, while I am not suggesting that people should have no responsibility for their health, I do argue that there exists a need for greater awareness of the fact that the resources and supports needed to engage in the work of patienthood (and to promote health more generally) are vastly inequitable. In short, this study found that while proposed policies offer hope for a more relational and equitable health care system, if the tensions between policy and practice are not adequately attended to, it is also possible (and likely more probable) that person-centeredness, involved patienthood, and integrative medicine will come to represent "political slogan[s] to identify a user-based approach to care" (Edvarddsson, Featherstonhaugh & Nay, 2010, p. 2612, as cited in Smele & Seeley, 2013).

Tension 2: Medicalized Discourses of Self-management and the Practicalities of Women's Everyday Lives.

Neoliberalism promotes self-help rhetoric focused on individual change rather than social transformation in ways that have been increasingly taken-up in health care discourse and practice (Laxer, 2015; Sinding et al., 2011). We see hints of this in provincial cancer policy documents that increasingly pledge their commitment to "bring cancer care as close to home as quality permits for more Ontarians" (CCO, 2011, p. 2). The ushering of cancer care to the home is often presented as a policy solution rather than a policy problem by governments that see such a shift as an unproblematic and logical way of responding to the needs of people with chronic conditions, such as cancer. The assumption embedded within such shifts is that the best and preferred care is delivered at home and that families want to and can provide good quality care (Day, 2013). The ability to self-manage thus goes unquestioned as a desirable and possible attribute. Here we see a continuation of the logics of patienthood discussed in the previous tension wherein the 'expert' autonomous patient is perceived of as the ideal patient and where shifts in responsibility are carefully masked by promises of choice and empowerment. Drawing on the experiences of those who live with and negotiate through such policy decisions and shifting care expectations, the findings of this study unsettle the legitimacy of the positive proclamations shared in such assumptions.

Through the Looking Glass: "You must run at least twice as fast as that!" if you hope to self-manage. Once again, the Looking Glass provides a fitting metaphor for the tensions that emerged between policy commitments and the practicalities of the micro-level environments through which care is provided and received.

> 'Well, in our country,' said Alice, still panting a little, 'you'd generally get to somewhere else – if you run very fast for a long time, as we've been doing.' 'A slow sort of country!' said the Queen. 'Now, here, you see, it takes all the running you can do, to keep in the same place. If you want to get somewhere else, you must run at least twice as fast as that!' 'I'd rather not try, please!' said Alice. 'I'm quite content to stay here-only I AM so hot and thirsty!' 'I know what YOU'D like!' the Queen said good-naturedly, taking a little box out of her pocket. 'Have a biscuit?' (*Carroll, 1871, Chapter 2, p.16*)

Most of the women in this study told accounts of running at full speeds before being diagnosed; juggling various paid and unpaid work activities to ensure the everyday care and wellbeing of themselves and others. The foundations of medicalized self-management concealed these lives of obligation, emphasizing instead personal responsibility for the management of illness. In this regard, the foundations of self-management closely resembled 'sick role' (Parsons, 1951) logics of the past that undermine the reality that personal health may be only one of several priorities and that assume everyone is suitably situated to juggle, or delegate, non-illness related work at times of illness. The women in this study described the work of 'self-management' as being far greater than simply adhering to clinical guidelines and medically-inscribed prescriptions of behavior change (e.g., diet, exercise, stress reduction, and medication regimens).

The burden of self-management work was not only about the performance of illness-related activities; indeed, the most challenging components of this work emerged through efforts to implement and maintain such tasks alongside the demands of everyday life. Balancing these work tasks was complex. For instance, the work of maintaining everyday life, valued social roles and identities, as well as financial solvency revealed tensions that permeated illness work, yet were also often required in order for illness work to take place. Further, perceived body failures were connected to a disrupted sense of self /self-image and body work was done, in part, to reconcile aspects of one's identity as well as to improve functional capacity to perform illness-related work as well as everyday and employment tasks. Similar to the findings of Corbin and Strauss (1988), the women in this study emphasized the importance and necessity of identifying the types of work and associated tasks to be done; giving priority to tasks in terms of their importance; making arrangements for who will do them and when; and calculating the need for resources (e.g., money/time, social and practical support, knowledge and skills), obtaining them, and ensuring their maintenance amidst constant, and sometimes competing demands. The extent of work and the relational manner in which work tasks took place were invisible from a systems perspective that promoted a medicalized discourse of self-management. The invisibility of women's hard work and the resultant lack of government-funded care supports to facilitate this work prompted them to *run twice as fast* in the wake of serious illness as they sought to juggle multiple work tasks, perform new activities of self-care, and obtain and maintain the necessary resources to do so.

"I know what YOU'D like…Have a biscuit?" The tension for women in bringing cancer care closer to home. Women's accounts supported the notion that the home was, in part, a place of work for most women, rather than a restorative space, as experienced by most men (Aronson, 2004; Bezanson & Luxton, 2006; Luxton, 1997; Morris, 2004). Some women, particularly those who lived alone, encountered a void within the home – the absence of someone to organize and perform the activities of everyday work (e.g., grocery shopping, cooking, and cleaning) and to assist them with new self-care tasks. More frequently, however, the women in this study described receiving varying amounts of care support from loved ones; yet, gendered divisions of labour within the home frequently meant that even when support was available, women often continued to perform most of the everyday care work themselves, including new activities associated with illness work. Women couched these decisions within the broader economy of the home. They explained that, given their histories of caregiving, they were often best suited to provide good quality care; they felt discomfort with close loved ones providing intimate care (changing bandages, draining fluids, and bathing); and they reconnected to a disrupted sense of self through the resumption of a caregiver identity. Many women also foregrounded the need to continue with care tasks in order to protect those they cared about (from the distress of their illness and what they perceived as a burden of care) as well as to protect their relationships.

These findings support the argument that gender socialization, which stresses women's selflessness and caregiving responsibilities, informs women's sense of entitlement to care (Atkins, 2016). The absence of family and/or the difficulty accepting help from family members and close others meant that women often went without necessary care, took on the brunt of care work for themselves, or sought out supportive relationships with "cancer friends" who were able to identify with their experiences and with whom they could reciprocate acts of care. Absent from medicalized discourses of self-management are these everyday practices and conditions which may constrain the efforts of women to practice self-care. The ideologies that underpin these policy shifts thus reveal there disconnect from the social, political, and material realities of women's lives.

While the findings of this study illuminate the ways in which self-management discourses are disconnected from women's gendered, political, and socio-cultural lives as a whole, they also

confirm that gender is complex and intersects with other key SDOH (e.g., age, social class, social support, and geographic location) to differently frame women's opportunities for care and shape the burden of their work (Jackson, 2012). While self-managing was difficult for all of the women in this study, the challenges appeared to be more salient for some than for others. This is perhaps most vividly seen through the experiences of P3 (an un-partnered senior living on a low fixed income, providing care and financial support for her ill adult son, but with little social support of her own) who frequently found herself at a crossroads. With insufficient resources to meet the demands of self-management she was forced to make difficult decisions of which aspects of work to prioritize. As material and human resources were exhausted, she describes assigning priorities to needs in terms of their immediacy and importance. For instance, the everyday work of securing food and shelter were often prioritized over medically-inscribed self-care activities, such as securing medications and following pharmaceutical regimens.

The principles and practices of self-managing illness fell out of view as P3 attended to living life in an immediate and sustainable way. These were not 'choices' she made because she failed to see the importance of this work, but rather because she recognized that the maintenance of everyday life (e.g., housing, a phone, and food) set the foundation for illness work to take place. In other words, while P3 ultimately made decisions around what aspects of work to prioritize, they were not in conditions of her choosing. These decisions were not without consequence. As P3 explains in "It's Hard Work:" Re-conceptualizing 'Work' in the Cancer Context", the difficulty she experienced managing illness-related tasks in the home (both because of their complexity and because of conflicting work obligations/depleted resources) often sent her back to hospital with what she perceived as avoidable complications. Here we see how gender, poverty, age, and social support (or lack thereof) intersect with expectations of self-management to render already vulnerable lives even more 'topsy-turvy.'

P3's experiences illuminate the ways in which the financial status of the home and the care capacities of individuals and their family members can have a significant impact on one's ability to adhere to the tenets of self-management in ways that are overlooked or taken-for-granted in medicalized discourses of the term. Further, we are reminded through her narrative that choice is a precarious and context-specific concept and that "the circumstances under which we make

choices, the choices and alternatives made available to us, and the boundaries around the 'care products' we may or may not opt for" (Henwood, Balka & Green, 2009, p. 83) can resituate the meaning of 'choice' in more problematic terms. The framing of self-management policies that promote increased choice and foreground the language of empowerment can covertly displace greater responsibility for care onto individuals, often performed by women in the home, and away from state-funded health care institutions (Lawn, McMillan & Pulvirenti, 2011; Mol, 2008; Pederson & Liwander, 2012). From this perspective, contrary to policy promises couched in medicalized discourses of self-management, under some conditions, self-managing may ironically lead to less choice and to circumstances that can be rather disempowering.

In review of the lived experiences of self-managing illness, we can identify an important tension between women's preferences for how they *ought to be* treated/cared for and how they *are* treated/cared for in a way that resembles the tension between Alice and the Red Queen. The findings of this study show that the discourse of self-management is taken up in everyday life in complex ways, marked with challenges and barriers. Most women needed support in ways that extended beyond the prescriptions of well-intentioned doctors to self-manage by changing their diet, incorporating exercise, controlling stress levels, and closely monitoring drug regiments. Women emphasized circumstances of exhaustion, and similarly to Alice, they described becoming hot and tired from running twice as fast as they sought to juggle vast amounts of work as well as manage the resources needed to do so. Embedded in these accounts, they emphasized their metaphorical need for *water* and described a health care system and well-intentioned providers that responded with the provision of *biscuits* and promises of empowerment.

This study extended the focus of self-management beyond the management of illness alone; it viewed self-management as political and analyzed the tasks of self-managing through the lens of work; and explored the role of gender and other SDOH in framing the scope of self-management work and shaping opportunities to successfully adhere to its requirements. In doing so, the findings of this study enliven the ways in which the current shift towards self-management reflects a broader trend toward a domestication of health, the clawing back of state-funded health care services, and an increased reliance on individuals (usually women) and their unpaid care work in the maintenance/restoration of health. This emphasis on individuals as the site of 'health

risk management' overlooks the broader social, political, and material contexts through which agency is framed. Thus, in addition to oversimplifying the complexity of healthful action/inaction at the micro-level it also discourages a collective response to conditions that influence health and thus collective responses to care solutions (Day, 2013).

ELLICSR as an important site of self-management support, but is self-management support enough to ensure good quality care? The women in this study found that the knowledge, skills, and connections gained within the ELLICSR space allowed them to better locate reliable information and assess their applicability; manage their illness in the context of a changed body and life; cope with a disrupted sense of self, an uncertain future, and the associated emotional fallout of this uncertainty; adjust to and 'carry on' with everyday life (including the need to balance care for self and others); and maintain financial and other material resources needed to meet medical and everyday living costs. Specifically, the value of this centre is captured in the experiences of P3 who explains how the ELLICSR Kitchen program helped her to overcome issues of food insecurity that she experienced as a result of economic marginalization. It is further illuminated through the experiences of P4 who describes being connected to the Money Matters program at Wellspring where she received the necessary financial advice and navigation support to locate and secure income replacement and drug coverage. P6's experiences highlight the ways in which Brain Fog classes at ELLICSR helped her to "put the pieces back together" and, in so doing, helped her to rebuild important elements of her identity and provided opportunities to move on with life as best she could. Its value is further showcased in the experiences of P1 and P4, who described connecting with "cancer friends" and of how this provided emotional support and encouragement, promoted a sense of normalcy and belonging at times where they felt stigmatized and alone, and offered confidence and motivation to carry on when they wanted to give up. Its value is emphasized by P9 who described how the Healthy Steps program helped her to reduce levels of pain and fatigue as well as increased her mobility so that she could safely reintroduce her previous exercise regimen and be better able to attend to tasks of everyday living. And for P10, its value was contained in the pages of a book she found at the ELLICSR library that gave her the information and confidence she needed to gently break the news of her diagnosis to her three small children. Indeed, the

pages of this dissertation are replete with examples of how ELLICSR supported women's self-management.

The multitude of reasons women sought out a space like ELLICSR (as illustrated through the vast care needs highlighted above) and the varying benefits they derived through their participation in this space, further reinforce the importance of incorporating consideration of SDOH in the design and delivery of cancer care. In attending to the specific physical, psychosocial, and material concerns of patients, ELLICSR not only facilitated women's self-management work but also offered more equitable opportunities to pursue self-management options. Ironically however, their intense focus on the individual as the vehicle of change leave untouched the systemic problems that contribute to inequitable opportunities to self-manage in the first place. To reiterate my previous claim, I am not suggesting that people should be completely absolved of any responsibility for their own health and care; in fact, the findings of this study show that some patients do indeed derive an improved sense of control in doing so. Rather, I argue that it is not reasonable to ask patients to *run twice as fast* in the wake of major illness and that access to care should not be dependent on patients and what they are able or unable to accomplish. While ELLICSR provides an important first step, the findings of this study also reinforce the need for adequate and appropriate (and state funded) care and care supports aimed at reducing patient workloads. The availability of such supports would afford patients greater agency over their work and would in turn, ensure more equitable opportunities for quality care and improved quality of life.

Limitations of the Study

At multiple moments throughout the conduct and presentation of this research, I have been asked the question, why women? It has been pointed out that little is known about men's cancer experiences and psychosocial needs and that much could be gained from comparing men's and women's patterns of work during the upheavals of illness. Given women's significant overrepresentation in positions of marginalization such as poverty, their increased interactions with health care systems, and that care work, both paid and unpaid, most frequently falls on the shoulders of women (Armstrong, 2012a; Armstrong, 2012b; Jackson, 2012), it was seen as both fitting and appropriate to make women the primary concern in a study on (in)equity, care, and

work. Informed by the literature, I was aware that there are considerable similarities and differences among women and that a comparative focus between women and men (while also attending to the similarities and differences among men) would prevent me from capturing the complexity within a single gender category. More to the point, understanding whether or not the organization of health care and expectations of work were comparatively more challenging for women than for men was not the issue I cared to explore. That said, one limitation of the study is that in focusing solely on women's experiences, I was unable to capture the experiences of women's families and close others. Most women's narratives of care and work revolved around broader discussions of their spouses, children, friends and other loved ones. A modification to the design of the study would thus be to interview family members or close others to gain a fuller understanding of the social relations (and environments) through which care and work are done and to gain an improved sense of how others might also be better supported.

Given my declared interest in the ELLICSR centre, the omission of outside health care providers was a choice I made in the design of this study. However, as participant (ELLICSR staff and patients) accounts extended the purview beyond the confines of this space, the oncology care team and the hospital setting became important focal points of the dissertation. While patients and ELLICSR staff shared their perceptions about physician's beliefs, practices, motivations, and challenges, the perspectives of clinicians themselves are not represented. The challenges that they confront in the delivery of care, their understanding of psychosocial/supportive care and perceptions of ELLICSR, their understanding of patient needs/unmet needs, as well as their understanding of patient's work (and the gendered nature of this work) offer a valuable, yet underexplored, perspective that warrants further attention and research.

It is possible that self-selection resulted in the recruitment of women who were particularly positive about their experiences at ELLICSR. All of the women in this study were very open to discussing their experiences, with many interviews taking longer than the expected one hour. It is possible that their willingness and eagerness to participate in the interview may have affected the amount and type of information they gave and that other women might have had very different experiences. It is also possible that those people who chose to go to a CHWC, may not be representative of the needs and wants of the cancer population as a whole. Those who are not

interested in research participation, those who felt they had little need for psychosocial and supportive care, and/or those who had negative experiences with ELLICSR may have important insights that are not captured in this study.

All of the participants were living in the GTA at the time of diagnosis and treatment. Living in a major urban setting meant that they were often in close proximity to: a family physician/walk-in clinic; hospitals and clinics providing cancer care and services; as well as various cancer wellness centres and support services including ELLICSR, Wellspring, Gilda's Club, and Nanny Angels. Public transportation further eased women's access to these spaces. In contrast, people living in rural spaces often confront geographic isolation, inadequate transportation, and hospital/health professional shortages (Ahmed & Shahid, 2012). In turn, the findings of this study do not necessarily capture the experiences of Ontarians residing outside of the GTA for whom access to care services and supports may be additionally challenging. While I cannot say with any generalizable certainty, key findings of this dissertation do suggest that access to additional forms of care, services, and resources supported women in various aspects of their work. Given the participants' proximity to, and use of, health/cancer care and CHWCs, the findings of this study may actually underrepresent the care hardships and work struggles of women living with cancer.

While I foreground issues of gender, class, and to a lesser extent age, there are other important facet of identity and experience that are not represented in this dissertation. This is in part because of the demographics of the participants I interviewed, the discussions that they foregrounded, but is also framed by my own social location. For instance, while the study had a racially and ethnically diverse sample of women, discussions of race and ethnicity are noticeably absent in the presentation of my findings. Discussions of race and ethnicity were not prevalent in women's interviews and when these issues did come up, they appeared (at least to me) to be couched as gender issues as oppose to racial ones. For instance, in one of the few discussions where race/ethnicity/culture were raised, P6 states: "Growing up as a girl in India and even after coming to Canada, you're told you should be quiet and un-bothersome [sic], you're led to believe your needs are less important than others. So I lived that way, and never really thought much about it until I got sick." Because she suggested gendered similarity between the two

countries I did not think to probe the issue of race, ethnicity, culture, nationhood, immigration/migration further. My personal and professional interest in issues of gender and social class informed the topics that I was sensitive to (and keenly aware of) and may have framed the topics I probed for as well as those I did not – and in turn shaped the information I received.

Furthermore, this dissertation provides a dominant heterosexual representation of gender, womanhood, and experiences with care and work therein. Given that the study participants were predominantly (if not entirely) heterosexual and gender-conforming, I was unable to capture the experiences of women with cancer who identify as non-heterosexual, transgendered, and/or non-gender conforming. As such, I was unable to capture their views on gendered identity, perceptions of womanhood, gender relations and divisions of care labour, and the influence of these views and perceptions on experiences of care and work in the cancer context. Given how prominent gender identity and division of labour in the home factored into women's experiences with care and work in this study, additional insights might be gained from the care and work experiences of those women who identify as non-heterosexual, transgendered, and/or non-gender conforming. This is an important area for future research.

Lastly, this ethnography presents a snapshot of ELLICSR at a specific time. For instance, more recent observations at ELLICSR reveal marked differences in the pattern of program delivery. New programs, such as WE-CAN (an exercise intervention) have been introduced and programs such as a "Spoon Full of Laughter" and "Laughter Yoga" have been cut, while others, including the ELLICSR Kitchen, are offered less frequently. Given that women's accounts revolved heavily around programs and opportunities to connect with similar others during and after these programs, it stands to reason that changes in the type of programs and frequency of program delivery might also change patient's perceptions of this space. In turn, the findings presented throughout this dissertation may not be representative of current patient experiences at ELLICSR.

Contributions and Recommendations

Despite the limitations discussed above, this research contributes to scholarship in several ways and holds preliminary implications for health policy and clinical practice.

Contributions to Feminist Political Economy Theory

Feminist political economy theory was central to this dissertation. It informed my choice to use a theoretically grounded ethnography and to analyze conceptualizations of, and experiences with, care and work at macro-, meso-, and micro-levels. It provided a lens through which to explore constructions and relations of gender and the intersection of gender with other SDOH. My findings confirm feminist political economy theory and have also extended its application in the field of cancer care.

The complexities of care work for women with cancer. Drawing on differences in gender socialization and the historical context of caregiving as women's work, feminist political economy explains how normative gender expectations stress female nurturing and encourage women's participation in caring labor (Day, 2013). Feminist political economy led me to explore the relations of unpaid care work. My findings contribute to our understanding of the gendered and complex ways that care work is performed in the management of chronic illness and support the unpaid care work literature by documenting the extent of care work that women perform and by highlighting the negative health effects that this can bring. The focus of this scholarship has tended to be on the unpaid care work that women perform to sustain the health of the family and on the caregiving that women provide when others are confronted by illness. Less frequently, however, is feminist political economy applied to consider how the tendency to identify women as nurturers and caregivers impact their capacity to receive care from others when they themselves are sick. This study extends this view by providing insight into the work experiences of women living with cancer.

This dissertation takes into account how gender expectations affect women's capacity to focus on themselves and shape their expectations about care. The women in this study did refer to the support of spouses, children, friends and neighbours; however, they portrayed care work (including the management of illness) as a predominantly individual pursuit. They did not deny

that support was important to them, but chose to emphasize their own agency in managing the performance and coordination of various work tasks. Making a determination about what was an appropriate level of commitment to themselves was wrought with tension and conflict between notions of womanhood and expectations of patienthood. Women were required to strike a balance between a degree of 'selfishness' projected in medicalized discourses of the 'good' patient (e.g., the 'expert' autonomous patient who prioritizes the management of illness and is involved in their care) and 'selflessness' demanded of women. Norms that expect women to sacrifice their own needs and prioritize the needs of others meant that women often struggled to place limits on what they provide to others and frequently needed to rely on themselves for care in order to minimize the distress of their illness on family and close others. The findings of this dissertation thus suggest that women's access to care in the home during the upheavals of serious illness is complex and often fragile. The absence of care support, and more frequently, the difficulty accepting help from family and close others meant that women often went without necessary care, took on the brunt of care work for themselves, or sought out supportive relationships with "cancer friends" who were able to identify with their experiences and with whom they could reciprocate acts of care.

Unpaid care work in public institutional settings. This dissertation contributes to feminist political economy scholarship that addresses the shifting of care from publicly funded institutional settings to individuals, usually women, in the private sphere. It confirms the negative effects that these broad neoliberal policy trends have on unpaid care providers and reveals the ways in which the ideologies that inform these policy shifts are at odds with the social, material, and contextual realities of women's lives. The findings of this study extend the unpaid care work literature by exploring women's increasing provision of unpaid care work in the public health care setting. By foregrounding the reengineered patient who is increasingly held both responsible and accountable for engaging in and monitoring their care in the hospital, this dissertation illuminates the ways in which informal and unpaid care extends beyond the private sphere. The responsibility of patients to increasingly provide care within and outside of the hospital can threaten quality care and promote inequities between patients.

Contributions to Psychosocial Oncology and Cancer Survivorship Research

The findings of this study offer several contributions to psychosocial oncology and cancer survivorship literatures. In Manuscripts One and Two, I identified several gaps in the literature, including: limited conceptualizations of work in the cancer context; little attention explicitly paid to gender and other SDOH; limited acknowledgement of converging and conflicting systems of care and their implications for patients; and an underdeveloped understanding of how chronic care policies are operationalized in acute care settings. This critical ethnography provides qualitative content that speaks to each of these under-researched aspects of cancer care.

Reconceptualization of work in the cancer context. Within psychosocial oncology and cancer survivorship literatures, 'work' is typically characterized as being synonymous with paid employment and the problem of work in the cancer context is usually addressed within discussions of 'return to work.' This propels an assumption of work as something that ends (for most) once diagnosed and is to be resumed following cancer treatment. This conceptualization of work limits our ability to understand the ways in which work might act as a constraint on women's opportunities for care at times of illness and as a vehicle through which inequities in care emerge. This study drew on a feminist political economy conceptualization of work as consisting of paid and unpaid tasks that require intent, time, effort, and skill (Smith, 2005, as cited in Sinding et al., 2011). In doing so, six types of work were identified: 1) illness work; 2) body work; 3) identity work; 4) everyday work; 5) paid employment and/or the work of maintaining income; and 6) coordination work. The reconceptualization of work provided in this dissertation adds to the existing cancer literature by making explicit the many types of work patients must coordinate and perform at times of illness. Further, it highlights the gendered nature of this work and the implications for women when care is narrowly defined as the "fixing of body parts" (Armstrong & Armstrong, 2010, p.41), and other important aspects of care shift from hospital to home. By examining the complexity of patient's work from everyday perspectives, work and the gender and equity issues associated with it came to the fore and provided a deeper understanding of informal care systems that are often overlooked in scholarship on cancer and work. In recognizing various forms of care provision as *work*,

particularly work that is gendered, this labour can be made more visible and its challenges can be better identified and supported by health care professionals and policymakers.

Recommendation. Approaches to scholarship that reinsert gender and social context into investigations of cancer care and work are essential. The findings of this study traced a shift in care responsibility from hospital to home that resulted in the concealment of much of women's work. As such, the vulnerability that women confront in the management of various work tasks at times of illness is often privately experienced and publicly concealed. In turn, it is important to note the unique benefits of observational research and/or novel arts-based approaches (e.g., photography) to the collection of data. These permit for increased opportunities to bring forward patients' work practices and care experiences that are increasingly taking place in the private spaces, such as the home. In this study for instance, participant-produced photographs of everyday fields (e.g., home, hospital, workplace, etc.) made otherwise un-observable moments more visible and discernable. Observations within the home via photographic images provided untapped visual and verbal insight into women's home environments – including, the management of illness, social relations and divisions of labour, along with the care they received and provided (for themselves and others) within this space. Given women's heavy involvement in the household and family maintenance, observation within the home, and in everyday life more generally, are essential in capturing the extent of women's care experiences as well as their work practices, tensions, and challenges. As such, I recommend observational and arts-based research to bring forward what patients are experiencing in the everyday practical realities of their lives.

Troubling discourse. In review of cancer policy documents (namely, CCO's 2011-2015 Ontario Cancer Plan document and the Princess Margaret Cancer Centre 2013-2018 Strategy Report) as well as much of the psychosocial oncology and cancer survivorship literatures, I found that discussions of person-centeredness, patient involvement, self-management, and empowerment often rested upon a number of assumptions. Among them were that everyone understands, experiences, and benefits from these terms in the same way. As such, in the context

of much policy and research, these terms represent condensation symbols[15]. The power of condensation symbols rests in their "ability to represent a value-laden discourse as generally accepted, thereby silencing meaningful debate and obscuring taken-for granted assumptions" (Bundon & Hurd Clarke, 2015, p. 354). Important foundational questions that interrogate the terms themselves, the contexts in which they unfold, and the people for whom they affect are thus frequently overlooked while queries regarding how best to adopt and implement them are foregrounded. Drawing on the example of self-management for instance, queries pertaining to this term in much of the cancer literature and in policy documents are focused on how we can promote improved adherence to self-management? How should self-management interventions be designed? And, how do we enable and empower people to self-manage? Three prominent assumptions underpinning such questions are that self-management is a generally positive thing, that all patients stand to benefit from self-managing, and that all patients will become 'empowered' in doing so. Resting on these assumptions, we fail to engage sufficiently with questions that promote our understanding of how self-management is conceptualized by those who are expected to self-manage? How is self-management experienced in everyday contexts of the hospital and home? How do gender and other SDOH inform peoples understanding and experiences of self-management? How do gender and other SDOH frame people's desire and ability to self-manage? And who benefits and who loses in existing arrangements of self-management?

Engaging with some of these foundational questions, this study illuminates the complexity and consequence embedded in terms such as self-management in ways that are not captured in taken-for-granted assumptions of the term. Firstly, the women in this study offered conceptualizations of self-management that extended far beyond medicalized discourses. Indeed, most felt that medicalized discourse of self-management undermined the many other work tasks that emerged, remained, and changed during the upheavals of serious illness. While some did foreground an improved sense of control in self-managing, most (including those who derived a sense of control) emphasized the ways in which self-management demanded time, knowledge, skill,

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[15] A Condensation symbol is defined as "concept or maxim that evoke an emotional reaction in the audience and that is assumed to be a desirable objective without ever being properly defined." (Edelman, 1985 as cited in Bundon & Hurd Clarke, 2015, p. 354).

social support, and boundless resources. This was challenging for all of the women in this study and proved impossible for some despite tenacious efforts to self-manage. In engaging foundational questions, I unveiled the ways in which the uncritical promotion of self-management may fail to serve the best interests of patients and can exacerbate existing inequities in health, access to care, and expectations of work. Thus, while questions of adoption and implementation are important we cannot reasonably and responsibly engage with such questions until we more fully understand the terms themselves as experienced by those that bring such language to life. While I have elaborated on the example of self-management here, similar cases can be made with terms like person-centeredness, patient involvement, and empowerment.

Recommendations. The value-neutral or universally positive representation of terms such as person-centeredness, patient involvement, self-management, and empowerment can result in unintended consequences as they enter into lived realities and a complex nexus of gender, health, and government. I strongly encourage researchers to consider these as ideological terms that are complex and debatable and I encourage researchers to engage these debates. In order to do so effectively, researchers will need to first engage in foundational questions that explore what these terms mean to, and how they are experienced by, patients.

Contribution to Health Policy

This dissertation identifies important tensions between care policy and the everyday environments through which care provision occurs. For instance, women's experiences in hospital illuminate a crossroads in health care erected by tensions between policy commitments to a chronic care model and the practical realities of institutional care systems that remain both systematically and economically devoted to the delivery of acute care. To bridge this gap between policy and practice, it is patients themselves who are tasked with new and growing demands. The work involved in filling gaps between policy and practice was described as complex, time consuming, and stressful and not all women – particularly those of a low socioeconomic status as well as those with low levels of social support – were suitably positioned to adhere to the demands of these tasks. Further tensions were revealed in discussion of policy efforts to bring care "as close to home as quality permits" (CCO, 2011, p.2). This shift in policy rests on a domestication of health and gendered assumptions about the feasibility of

unpaid care work that did not map neatly onto the contextual realities of women's lives who are themselves confronted with a serious illness. This tension was intensified by the lack of care supports and resources to accompany shifts in care responsibility from hospital to home. These tensions illuminate one of the major findings of this dissertation: if care policies and commitments cannot be reasonably applied in practice, they are likely to be ineffective and potentially counter-productive in ensuring good quality care that is equitably accessible.

Recommendation. The tensions that underlie care policies and practices must be recognized and balanced in order for effective equity-promoting strategies to be developed (Armstrong & Braedley, 2013; Smele & Seeley, 2013). Bridging these tensions will require a reconceptualization of care at the level of policy in ways that reflect its complex reality as lived and practiced in both public and private care spaces. When we situate care as a constructed concept and practice that is entrenched in relations of inequality and power, we are better able to understand that while care is something that everyone needs – particularly during the upheavals of serious illness – not everyone has equal access to opportunities to be cared for (Day, 2013). Reflecting on participants' accounts of care throughout this dissertation, we might easily draw parallels between *care* and the conditions that render *health* a political construct (Bambra, Fox & Scott-Samuel, 2005). Indeed, like health, care is also: 1. socially produced with some social groups having greater opportunities to access it than others; 2. the social determinants that frame opportunities for care are amenable to political action (or inaction) and intervention; and 3. "the right to 'a standard of living adequate for health and well-being' (including access to wide-ranging forms of care) is, or should be, an aspect of citizenship and a human right" (p. 187). Broadening the definition of care by asking political questions about care conceptualized in policy provides a crucial first step in confronting existing tensions. Day (2013) suggest that we might begin with such foundation questions as: When the state retreats from supporting health care, what happens to the organization of care, which care services are made available, and what elements of care become the responsibility of individuals and their families? And, what are the material and relational aspects of care and how do these fit with the medical model's framework? Such questions will improve opportunities to more fully consider the link between private experiences of care and the public organization of care supports.

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Rooting policy development in the practical environments where care takes place is another crucial step in confronting these tensions. One way in which this might be accomplished is through an increased reliance on individual "voice" in policy making; assuming that if policy is to become more inclusive of the multitude of care contexts and experiences that people living with illness confront, it must be informed by the complex, relational, and messy circumstances through which care is provided and received. This will require bottom-up policy development as oppose to top-down strategies currently employed (Gould & Gardner, 2009). The inclusion of various stakeholder experiences will help to move policy from consideration of what *should* work in theory to explore what *can* be reasonably applied in practice. However, because perspectives and experiences of care can sometimes be competing and contradictory, including a limited number of members from a particular stakeholder group (e.g., cancer patients, caregivers, health care providers) on policy advisory boards (an increasing trend in policy organizations and health care institutions) will likely not suffice. Rather, rigorous and large scale qualitative research that "begin with fundamental human and social values…rather than with numbers and dollar signs" (Armstrong, 2010, p. 198) will need to be implemented into the collection of evidence that informs the development of care policies and funding arrangements. In short, the findings of this study support the importance of including qualitative health research that is grounded in human experience when developing 'evidence' and conceptualizing best-practice in cancer care.

Fuller integration of care systems on the ground will require critical and creative thinking at the policy level to resolve tensions between models of care. More equitable and stable funding arrangement between departments will be crucial to this effort. Indeed, policies that call for greater chronic-centred approaches to care delivery in the absence of necessary resources to facilitate these changes will likely be ineffective in improving systemic care integration and widespread improvement in the delivery of good quality care that is equitably available.

Clinical Contributions

This dissertation has argued that what is considered valid and reliable evidence in health care practice is quite limited; overlooking the complex social, political, and economic conditions that frame health. In doing so, it has illuminated the ways in which health care providers might find

themselves at a conflicting crossroads between medically-driven evidence and the lived experiences of their patients. The application of practical and experiential knowledge in clinical practice has been argued to result in the delivery of more effective treatments and more efficient use of scarce health care resources (Sandelowski, 2004). As such, in order to improve the quality of health care for cancer patients, while also maintaining the financial sustainability of the cancer care system, care practices must incorporate knowledge that is grounded in patient experience. Throughout this dissertation I have grappled with the complexity and messiness of women's experiences with cancer, care, and work and in doing so offer crucial evidence that holds important implications for clinical practice.

This study offers a reconceptualized understanding of work as lived and negotiated in the everyday lives of women with cancer. It further revealed that there is a lack of institutional consideration and support for this work and that institutional constraints prevent patients from voicing their concerns and/or having these concerns heard. This study, and many of those who participated in it, recognized that oncology care teams are working within an incredibly restrictive system that place limits (particularly in the way of time constraints) on what they are able/unable to accomplish in the delivery of care. While it is understandable that within very confined medical appointments that clinicians would focus on the delivery of tumour-related care; this study found that while understandable it is not acceptable and threatens to compromise overall quality care. To be truly helpful to their patients, oncology care teams must recognize the concerns and priorities of those they endeavour to help and consider the more complex ways that gender and other SDOH affect patients' pathways throughout their cancer journey.

Recommendation. Leaving a place for dialogue about such things as the emotional fallout and identity disruptions associated with the diagnosis of cancer, the experience of bodily deprivation, and the experiences of managing care in the home, will likely enable providers to know more about, and better serve, patients. To this end, additional questions need to be raised in clinical encounters. For example, Does the patient have the financial solvency to pay for a visiting nurse or do they have private benefits to cover these costs? How is the patient adjusting to his/her altered body and self? What kinds of support does the patient feel they have available to them within the home? What is the employment status of the patient and, for those who are

actively engaged in paid employment, are there any time constraints or barriers that prevent them from accessing care? Does the patient appear to be overwhelmed or overtaxed? And, does the patient need help filling out forms, finding transportation, and/or securing financial aid?

These conversations need to begin in clinical appointments with a member of the oncology care team. These providers are often the first and sometimes only point of contact for patients and for many they are considered the foremost experts on the topic, making them a trusted source of information and advice. A brief conversation about how the patient is coping will not only likely improve doctor-patient relationships but will also better prepare oncologists (or other members of the oncology care team – e.g., fellows and nurses) to work collaboratively with, and refer their patients to, appropriate care providers and support programs. Working collaboratively with other health care systems, such as ELLICSR, may free up time in clinical oncology appointments (as patient's psychosocial care needs, concerns, and questions will be addressed elsewhere), while also ensuring that patients receive the necessary care from the most appropriate providers. This collaborative approach to multidisciplinary care and support can facilitate the amount of work that patients themselves currently take-up and could thus reduce the burden of patient's workload. Engaging with diverse care systems that are already in place provides a realistic, feasible, and immediate solution to many of the care gaps addressed in this study. Oncology care teams have a direct stake in facilitating collaboration since, as this research has shown, the capacity to successfully engage with illness work is contingent on women's successful involvement in other work processes. Thus, it stands to reason that access to a diversified set of care services and supports aimed at other aspects of women's work (e.g., nutrition and exercise programs to assist with body work; psychological/social work services to support identity work; free childcare/cleaning services to assist with everyday work; and financial counselling and support to assist with money management) could improve patient compliance with physician prescriptions of illness-management and thus help to improve illness outcomes.

This degree of provider involvement and action would help address three problems noted in this study. First, health professionals would learn more directly about their patients' everyday lives, encouraging more personalized care support. Second, it could facilitate earlier referral to psychosocial programs and material supports and ensure stronger consistency in access to these

programs and resources across patients. Thirdly, and intersecting with the first two points, it could assist patients in their struggles to translate the information offered by health professionals into everyday practice. Broader structural changes will need to occur to facilitate greater oncologist involvement and collaboration. The implementation of cancer-centric Family Health Teams[16] could present one potential solution; however future research will need to further consider what forms these changes should take.

Rethinking rhetoric. Most women's experiences countered policy and institutional claims that 'involvement' in care and self-managing illness are key to improved patient autonomy and empowerment. The hard and sometimes overwhelming work that women described in narrating their experiences of involvement and self-management supports that the "virtue of patient empowerment has a correlative vice—the relocation of responsibility for health care away from social and political realms and onto the shoulders of patients" (Juengst, Flatt & Settersten, 2012, p. 3). In promoting self-management and other forms of involved patienthood, health professionals – including ELLICSR staff – support the notion that people have considerable influence over their own health and that they are equitably able to secure and manage high quality care. It further assume that patient involvement and management always yields positive and empowering outcomes with little consideration of how these concepts might be differently experiences in practice as they intersects with gender and other categories of marginalization. This study explored the application of such terms in practice, and similar to Sinding and colleagues (2011), found that policies and practices that promote individual responsibility for the provision, management, and coordination of care can compromise patient's access to quality care and ignite inequities between patients.

Recommendation. To limit the shifting of responsibility to patients in ways that threaten to compromise their care, I echo the recommendations put forth by Sinding and colleagues (2011) as well as those proposed by Juengst and colleagues (2012) in stating that providers need to be mindful in their encouragement of patient involvement and use of patient empowerment rhetoric. While likely well-intentioned, the application of patient involvement and empowerment

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[16] Family Health Teams are "primary health care organizations that include a team of family physicians, nurse practitioners, registered nurses, social workers, dietitians, and other professionals who work together to provide primary health care within the community" (Ontario Ministry of Health and Long Term Care, 2016).

discourse could reinforce for patients that they are indeed responsible to provide, manage and coordinate their own care. By avoiding the use of such terms, providers might encourage a different message; that access to high quality care is a right of citizenship and collective responsibility rather than an individual one.

Concluding Remarks

Throughout this dissertation I have explored notions of care and work in the context of a changing health care milieu marked by conflicting care commitments between health policy (with an increasing emphasis on the need for chronic care) and health care structures (which remain entrenched in acute care operations). In illuminating the empty spaces between conflicting commitments to care I traced a new responsibility and accountability circuit. I paid close attention to the manner in which this new set of responsibility and accountability relations contributed to the reorganization of patient's work practices and the reframing of their care experiences, including their claims to care. Informed by feminist political economy, I sought and located tensions and conflicts between policy frameworks and the everyday private and public environments where care takes place. I considered the impact of these tensions and conflicts for patients, paying particular attention to the gender and equity implications. I explored ELLICSR as a pocket of resistance and change within the broader health care setting.

The findings of this study confirmed the far reaching impact of cancer and identified the limits of the medical model in attending to the vast care and support needs of women living with this illness. They revealed the ways in which holistic and collective approaches to care delivery through the ELLICSR center helped to fill many of the care gaps left through conventional health care channels and yet there remained significant political and economic barriers that limited the scope and reach of care this centre provided. The findings further illustrated that in the absence of institutional and funding changes, policy shifts that appear to facilitate improved patient autonomy and control (e.g., person-centeredness, patient involvement and self-management) more closely resemble increased individual responsibility and work for which little choice is given. Lastly, the findings illuminated the various gendered consequences and equity concerns that emerge when care is commodified, when the responsibilization of care provision shifts to individuals and their homes, and/or when inadequate care supports are provided to help individuals and their families to manage the vast burdens of illness.

From this perspective, the arguments made throughout this dissertation are quite simple. I argue that acute care delivery is insufficient in the treatment of chronic illness. I argue that when ideological models of care shift but practical care systems remain relatively unchanged, important gaps emerge within the health care system. I further argue that we increasingly look to patients and their families to navigate, negotiate, and fill these systemic care gaps and that in doing so, quality care increasingly rests on what individuals do or do not do. To this point, I argue that it is inappropriate and ineffective to solve systemic problems with individual-level solutions. I also argue that the privatization of care in its many forms (e.g., the privatization of cost and the responsibility of care work) is a gender and equity concern and that women as a group, as well as specific groups of women, are more harshly affected by care discourse and practice that overlook SDOH. And for all of these reasons, I argue that care and work are political constructs. On the other hand, the arguments offered throughout this dissertation are quite complex. They are complex because they require an understanding of the medical model, the determinants of health, and the political economy in order to recognize care and work as political constructs and to interrogate them accordingly; to unpack the tensions, conflicts, and contradictions integral to health care; and to critically engage with and problematize reforms made in the name of improving health care and expanding choices. As our health care system changes I encourage others to take up a context-sensitive approach that invites engagement with the messiness and complexity of cancer care as conceptualized, practiced, and lived. We must begin to redirect our focus away from the individual as the site of health and health care solutions, to account for the social, political, economic, and institutional settings in which patient care and work are anchored.

Bibliography

Adler, N.E. & Page, E.K. (Eds.) (2008). *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. Washington, DC: National Academies Press.

Ahmed, S. & Shahid, R.K. (2012). Disparities in Cancer Care: A Canadian Perspective. *Current Oncology, 19*(6), e376-e382.

Alcoff, L. & Potter, E. (1993). *Feminist Epistemologies*. Abingdon, Oxon: Routledge

Angus, J., Rukholm, E., Michel, I., Larocque, S., Seto, L., Lapum, J., Timmermans, K., Chevrier-Lamoureux, R., Nolan, R.P. (2009). Context and Cardiovascular Risk Modification in Two Regions of Ontario, Canada: A Photo Elicitation Study. *International Journal of Environmental Public Health, 6*(9), 2481-2499.

Angus, J., Paszat, L., McKeever, P., Trebilcock, A., Shivji, F., Edwards, B. (2007). Pathways to Breast Cancer Diagnosis and Treatment: Exploring the Social Relations of Diagnostic Delay. *Texto Contexto Enferm, 16*(4), 591-598.

Armstrong, H. (2013). Neoliberalism and Official Health Statistics: Toward a Research Agenda. In Pat Armstrong and Susan Braedley (Editors), *Troubling Care: Critical Perspectives on Research and Practices* (p.187-189). Toronto, ON: Canadian Scholars Press.

Armstrong, P. (2012a). Introduction. In, P. Armstrong, B. Clow, K. Grant, M. Haworth-Brockman, B. Jackson, A. Pederson & M. Seeley (Eds), *Thinking Women and Health Care Reform in Canada* (p. 1-14). Toronto, ON: Women's Press.

Armstrong, P. (2012b). *Unpaid health care: An indicator of equity*. (Pan American Health Organization Report). Retrieved from the Canadian Health Coalition Website http://healthcoalition.ca/wp-content/uploads/2013/12/CHC-Article-Pat-Armstrong.pdf

Armstrong, P. (2007). Relocating Care: Home Care in Ontario. In O. Hankivsky, C. Varccoe, & M.H. Morrow (Eds.), *Women's Health in Canada: Critical Perspectives on Theory and Policy* (p. 528-552). Toronto, ON: University of Toronto Press.

Armstrong, P. (2001). Evidence-based health-care reform: Women's issues. In H. Armstrong, P. Armstrong, & D. Coburn (Eds.), *Unhealthy times: Political economy perspectives on health and care in Canada*. New York, NY: Oxford University Press.

Armstrong, P. & Armstrong, H. (2010). *Wasting Away: The Undermining of Canadian Health Care* (Second Edition). Don Mills, Ontario: Oxford University Press.

Armstrong, P. & Armstrong, H. (2008). *About Canada: Health Care*. Nova Scotia: Fernwood Publishing.

Armstrong, P., Armstrong, H. & Coburn, D. (2001). *Unhealthy Times: Political Economy Perspective on Health and Care in Canada*. Oxford University Press: Canada

Armstrong, P., Armstrong, H. & Scott-Dixon, K. (2008). *Critical to Care: The Invisible Women in Health Services*. Toronto, ON: University of Toronto Press.

Armstrong, P., Boscoe, M., Clow, B., Grant, K.R., Guberman, N., Jackson, B., Pederson, A., Willson, K. (2012). Woman-Defined Quality Care. In, P. Armstrong, B. Clow, K. Grant, M. Haworth-Brockman, B. Jackson, A. Pederson & M. Seeley (Eds), *Thinking Women and Health Care Reform in Canada* (p. 215-232). Toronto, ON: Women's Press

Armstrong, P. & Braedley, S. (2013). Introduction. In P. Armstrong & S. Braedley (Eds.), *Troubling Care: Critical Perspectives on Research and Practices* (p. 9-16) .Toronto, ON: Canadian Scholars Press.

Armstrong, P. & Connelly, P. (Eds.). (1999). *Feminism, political economy and the state: Contested terrain*. Toronto: Canadian Scholars' Press.

Armstrong, P. & Kits, O. (2004). One hundred years of caregiving. In K. Grant, C. Amaratunga, P. Armstrong, M. Boscoe, A. Pederson, & K. Willson (Eds.), *Caring For/Caring About: Women, Homecare, and Unpaid Caregiving* (p. 45-74). Aurora, Ontario: Garmond Press.

Aronson, J. (2004). "Just Fed and Watered:" Women's Experiences of the Gutting of Home Care in Ontario. In K. Grant, C. Amaratunga, P. Armstrong, M. Boscoe, A. Pederson & K. Willson (Eds.), *Caring For/Caring About: Women, Home Care and Unpaid Caregiving* (p. 167-184). Aurora, ON: Garamond Press.

Aronson, J. & Neysmith, S.M. (1997). The retreat of the state and long-term care provision: implications of frail elderly people, unpaid carers and paid home care workers. *Studies in Political Economy*, *53*, 37-66.

Ashbury, F.D., Findlay, H., Reynolds, B. & McKerracher, K. (1998). A Canadian survey of cancer patients' experiences: are their needs being met? *Journal of pain and symptom management, 16*(5), 298-306.

Atkins, L. (2016). Half the Battle: Social Support Among Women with Cancer. *Qualitative Inquiry, 22*(4), 253-262.

Atkinson, P. & Coffey, A. (1997). 'Analysing Documentary Realities', in Silverman, D. (Ed.) *Qualitative Research Theory Method and Practice* (p.45-62). London: Sage Publications.

Baines, C.T., Evans, P.M., & Neysmith, S.M. (1992). Confronting Women and Caring: Challenges for Practice and Policy. *Affilia, 7*(1), 21-44.

Bambra, C., Fox, D. & Scott-Samuel, A. (2005). Towards a politics of health. *Health Promotion International*, *20*(2), 187-193.

Banik, B. J. (1993). Applying triangulation in nursing research. *Applied Nursing Research, 6*(1), 47-52.

Barbour, R. S. (2001). Checklist for Improving Rigour in Qualitative research: A case of the tail wagging dog? *British Medical Journal, 322*, 1115-1117.

Beck, C. T. (1993). Qualitative research: The evaluation of its credibility, fittingness, and auditability. *Western Journal of Nursing Research, 15*(2), 263-266.

Bezanson, K. & Luxton, M. (2006). Introduction: Social Reproduction and Feminist Political Economy. In, K. Bezanson & M. Luxton (Eds.), *Social Reproduction: Feminist Political Economy Challenges Neo-Liberalism* (p. 3-10). Montreal & Kingston: McGill-Queen's University Press.

Bird, C.E. & Rieker, P.P. (2008). *Gender and Health: The Effects of Constrained Choices and Social Policies.* New York, NY: Cambridge University Press.

Boeije, H. (2002). A purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Quality and Quantity, 36*. 391-409.

Bochner, A. (2000). Criteria Against Ourselves. *Qualitative Inquiry, 6*, 266-272.

Boult, C., Karm, L. & Groves, C. (2008). Improving Chronic Care: The "Guided Care" Model. *The Permanente Journal, 12*(1), 50-54.

Bourdieu, P. & Wacquant, L.J.D. (1992). *An invitation to reflexive sociology*. Chicago: University of Chicago Press.

Bowen, G. A. (2009). Document Analysis as a Qualitative Research Method. *Qualitative Research Journal, 9*(2), 27-40.

Brassolotto, J. & Daly, T. (2016). Scarcity discourses and their impacts on renal care policy, practices, and everyday experiences in rural British Columbia. *Social Science & Medicine, 152*, 138-146.

Broadie, J. (2009). Putting Gender Back In: Women and Social Policy Reform in Canada. In Y. Abu-Laban (Ed.), *Gendering the Nation State: Canadian and Comparative perspectives*. Vancouver, BC: UBC Press.

Brooks, C., Poudrier, J., Thomas-MacLean, R. (2008). Creating Collaborative Visions with Aboriginal Women: A Photovoice Project. *Social Indicators Research Series, 34,* 193-211.

Bryman, A. & Teevan, J.J. (2005). *Social Research Methods* (Third Edition). Oxford University Press.

Bultz, B.D. & Holland, J.C. (2006). Emotional distress in patients with cancer: the sixth vital sign. *Community Oncology, 3*, 311-314

Bundon, A. & Hurd Clarke, L. (2015). Honey or Vinegar? Athletes with Disabilities Discuss Strategies for Advocacy Within the Paralympic Movement. *Journal of Sport and Social Issues, 39*(5), 351-370.

Canadian Cancer Society. (2015). *Cancer Statistics at a Glance*. Retrieved from Canadian Cancer Society Website, http://www.cancer.ca/en/cancer-information/cancer-101/cancer-statistics-at-a-glance/?region=on

Canadian Cancer Society. (2003). *Breaking Down the Barriers: Study of Cancer Patient and Caregiver Needs in Ontario*. Ontario: Canadian Cancer Society.

Cancer Care Ontario. (2011). *Ontario Cancer Plan 2011-2015*. Retrieved from Cancer Care Ontario Website https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=84204

Campbell, J. & Bunting, S. (1991). Voices and paradigms: Perspectives on critical and feminist theories in nursing. *Advances in Nursing Science, 13*(3), 1-15.

Carrol, L. (1871). *Through the Looking Glass and What Alice Found There*. United Kingdom: MacMillan

Carspecken, P. (1996). *Critical ethnography in educational research: A theoretical and practice guide*. Routledge: London.

Cederstrom, C. & Spicer, A. (2015). *The Wellness Syndrome*. Cambridge, MA : Polity Press

Charmaz, K. (2006). *Good Days, Bad Days: The Self in Chronic Illness*. Rutgers University Press, New Brunswick, NJ.

Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness, 5*(2), 168-195.

Chomsky, N. (1999). *Profit over People: Neoliberalism and Global Order.* Toronto, Ontario: Seven Stories Press.

Christians, C. G. (2005). Ethics and politics in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed., pp. 139-164). Thousand Oaks, CA: Sage.

Clement, W. (1997). Whither the New Canadian Political Economy? In W. Clement (Ed.), *Understanding Canada: Building on the New Canadian Political Economy* (p. 3-18). Montreal & Kingston: McGill-Queen's University Press.

Clement, W. & Vosko, L (Eds.). (2003). *Changing Canada: Political Economy as Transformation.* Montreal: McGill-Queen's University Press.

Clement, W. & Williams, G. (1989). Introduction. In W. Clement & G. Williams (Eds.), *The new Canadian political economy* (pp. 3-15). Kingston, Ontario: McGillQueen's University Press.

Clements, K. (2012). Participatory action research and photovoice in a psychiatric nursing/clubhouse collaboration exploring recovery narrative. *Journal of psychiatric and Mental Health Nursing, 19*(9):785-91

Clow, B. & Kemp, K. (2012). Caring at Home in Canada. In, P. Armstrong, B. Clow, K. Grant, M. Haworth-Brockman, B. Jackson, A. Pederson & M. Seeley (Eds), *Thinking Women and Health Care Reform in Canada* (p. 139-165). Toronto, ON: Women's Press.

Clow, B., A. Pederson, M. Haworth-Brockman & Bernier, J. (Eds.). (2009). *Rising to the Challenge: Sex- and Gender-Based Analysis for Health Planning, Policy and Research in Canada*. Halifax: Atlantic Centre of Excellence for Women's Health.

Coburn, D. (2004). Beyond the Income Inequality Hypothesis: Class, Neo-Liberalism, and Health Inequalities. *Social Science and Medicine, 58*, 41-56.

Coburn, D. (2001). Health, health care, and neo-liberalism. In P. Armstrong, H. Armstrong, & D. Coburn (Eds.), *Unhealthy times: Political economy perspectives on health and care in Canada* (pp. 45-65). Toronto, Ontario: Oxford University Press.

Collier, J. (1979). Visual anthropology In J. Wagner (Ed.), *Images of information* (pp. 271-281). Beverly Hills, CA: Sage.

Cook, J.A. & Fonow, M.M. (1986). Knowledge and Women's Interests: Issues of Epistemology and Methodology in Feminist Sociological Research. *Sociological Inquiry, 56*(1), 2-29.

Corbin, J. & Strauss, A. (1985). Managing chronic illness at home: Three lines of work. *Qualitative Sociology, 8*(3), 224-247.

Cornwall, A., Gideon, J., & Wilson, K. (2008). Introduction: Reclaiming Feminism: Gender and Neoliberalism. *IDS Bulletin, 39*(6), 1-9.

Coughlan, R. & Ward, L. (2007). Experiences of recently relocated residents of a long-term care facility in Ontario: Assessing Quality Qualitatively. *International Journal of Nursing Studies*, 44(1), 47-57.

Creswell, J.W. (2012). *Qualitative inquiry and research design: Choosing among the five approaches* (Third Edition). Thousand Oaks, CA: Sage.

Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks: Sage.

Dale, C.M., Angus, J.E., Seto Nielson, L., Kramer-Kile, M., Pritlove, C., Lapum, J., Price, J., Marzolini, S., Abramson, B., Oh, P., Clark, A. (2015). "I'm no superman": Understanding diabetic men, masculinity, and cardiac rehabilitation. *Qualitative Health Research,* doi:10.1177/1049732314566323

Daly, T. (2013). Imagining an Ethos of Care within Policies, Practices, and Philosophy. . In P. Armstrong & S. Braedley (Eds.), *Troubling Care: Critical Perspectives on Research and Practices* (p. 33-46) .Toronto, ON: Canadian Scholars Press.

Daly, T. (2012). The politics of women's health equity: Through the looking glass. *Canadian Woman Studies*, *29*(3), 84-94.

Day, S. (2013). The Implications of Conceptualizing Care. In P. Armstrong & S. Braedley (Eds.), *Troubling Care: Critical Perspectives on Research and Practices* (p. 21-32). Toronto, ON: Canadian Scholars Press.

Denzin, N. K. & Lincoln, Y. S. (Eds.). (1994). *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage Production.

Deputy Ministers of Health. (1994). *When Less is Better: Using Canada's Hospitals Efficiently*. A paper written for the Conference of Federal/Provincial/Territorial Deputy Ministers of Health. Retrieved from http://medicine.dal.ca/content/dam/dalhousie/pdf/faculty/medicine/departments/core-units/DME/medical-informatics/when_less_is_better.pdf

Dey, C. (2001). Methodological Issues: The use of Critical Ethnography as an Active Research Methodology. *Accounting, Auditing and Accountability, 15*(1), 106-121.

Doyal, L. (1995). What Makes Women Sick: Gender and the Political Economy of Health. New Brunswick: Rutgers University Press.

Doyal, L. (1979). *The political economy of health*. London: Pluto Press.

Drummond, D. (2012). *Public Services for Ontarians: A Path to Sustainability and Excellence.* Final Report of the Commission on the Reform of Ontario's Public Services. Queens Printer for Ontario. ISBN: 978-1-4435-8898-0.

Dubbin, L.A., Chang, J.S., Shim, J.K. (2013). Cultural health capital and the interactional dynamics of patient-centered care. *Social Science and Medicine, 93*, 113-120.

Edvardsson, D., Fetherstonhaugh, D. & Nay, R. (2010). Promoting a continuation of self and normality: person-centred care as described by people with dementia, their family members and aged care staff. *Journal of Clinical Nursing, 19*(17-18), 2611-2618.

ELLICSR: Health, Wellness & Cancer Survivorship Centre. (2015). Retrieved from, http://www.ellicsr.ca/

Ellis, C. (2007). Telling secrets, revealing lives: Relational ethics in research with intimate others. *Qualitative Inquiry, 13*, 3-29.

Emslie, C., Browne, S., MacLeod, U., Rozmovits, L., Mitchell, E. & Ziebland, S. (2009). 'Getting through' not 'going under': A qualitative study of gender and spousal support after diagnosis with colorectal cancer. *Social Science & Medicine, 68*, 1169-1175.

Evans, R. G. (1997). Going for the Gold: The Redistributive Agenda Behind Market-Based Health Care Reform. *Journal of Health Politics, Policy and Law*, *22*(2), 427-465.

Fitzpatrick, T.R. & Remmer, J. (2011). Needs, expectations and attendance among participants of a cancer wellness centre in Montreal, Quebec. *Journal of Cancer Survivorship: Research and practice, 5*(3), 235-246.

Flick, U. (2006). An Introduction to Qualitative Research (3rd Edition.). London, Thousand Oaks, New Delhi: Sage

Foster, C & Fenlon, D. (2011). Recovery and self-management support following primary cancer treatment. *British Journal of Cancer, 105*, S21-S28.

Fram, S.M. (2013). The constant Comparative Analysis Method Outside of Grounded Theory. *The Qualitative Report, 18*(1), 1-25.

Fuller, C. (1998). Caring for profit: How corporations are taking over Canada's health care system. Ottawa, Ontario: Canadian Centre for Policy Alternatives and New Star Books Ltd.

Geertz, C. (1973). *The interpretation of Cultures*. New York, NY: Basic Books.

Georgiou, D. & Carspecken, P. F. (2002). Critical ethnography and ecological psychology: Conceptual and empirical explorations of a synthesis. *Qualitative Inquiry, 8*(6), 688-706

Glaser, B. (1992). *Basics of grounded theory analysis*. Mill Valley: Sociology Press.

Glaser, B. (1965)**.** The constant comparative method of qualitative analysis. *Social Problems, 12*(4), 436-445.

Glenn, E.N. (2010). *Forced to care: Coercion and Caregiving in America*. Cambridge, MA: Harvard University Press.

Gobo, G. (2008). *Doing Ethnography*. London, Sage Publication.

Gould, M. & Gardner, B. (2009). *Mental Health and Well-being*. Prepared for the Ministry of Health and Long-Term Care. Toronto, Ontario: CMHA Ontario and Wellesley Institute Report.

Gould, J., Sinding, C., Mitchel, T. & Fitch, M.I. (2009). Listening for Echoes: How Social Location Matters in Women's Experiences of Cancer Care. In, J.J. Nelson, J., Gould & S. Keller-Olaman (Eds.), *Cancer on the Margins: Methods and Meaning in Participatory Research* (pp.75-101). Toronto, ON: University of Toronto Press.

Graziano, K.J. (2011). Working with English Language Learners: Preservice Teachers and Photovoice. *International Journal of Multicultural Education, 13*(1).

Green, M. & Lawson, V. (2011). Recentring care: interrogating the commodification of care. *Social and Cultural Geography, 12*(6), 639-654.

Halldorsdottir, S. & Hamrin, E. (1996). Experiencing existential changes: the lived experiences of having cancer. *Cancer Nursing, 19*(1), 29-36.

Hammersley, M. (1992). *What's wrong with ethnography? Methodological explorations*. New York, NY: Routledge.

Hammersley, M., Atkinson, P. (2007). *What is ethnography? Ethnography, Principles in practice* (3rd edition). New York, NY: Routledge.

Hardcastle, M-A., Usher, K., Holmes, C. (2006). Carspecken's Five-Stage Critical Qualitative Research Method: An Application to Nursing Research. *Qualitative Health Research, 16*(1), 151-161.

Harding, S. (1988). *Feminism and Methodology*. Indiana: University Press.

Harper, D. (2002). Talking about pictures: A case for photo elicitation. *Visual Studies, 17*(1), 13-26.

Harrowing, J. N., Mill, J., Spiers, J., Kulig, J., & Kipp, W. (2010). Critical ethnography, cultural safety, and institutional nursing research. *International Journal of Qualitative Methods, 9*(3), 240-251.

Hatten, K., & Forin, T. R., & Adams, R. (2013, June), *A picture elicits a thousand meanings: Photo elicitation as a method for investigating cross-disciplinary identity development* Paper presented at 2013 ASEE Annual Conference, Atlanta, Georgia. https://peer.asee.org/19103

Henwood, F., Balka, E. & Green, E. (2009). Informing gender? Health and ICTs in context. In E. Balka, E. Green, and F. Henwood (Eds.), *Gender, health and information technology in context* (p. 1-16). Hampshire: Palgrave Macmillan.

Higginbottom, G.M.A., Pillay, J.J. & Boadu, N.Y. (2013). Guidance on Performing Focused Ethnographies with an Emphasis on Healthcare Research. *The Qualitative Report, 18*(17), 1-16.

Hills, M. & Mullett, J. (2005). Primary health care: A preferred health service delivery option for women. *Health Care for Women International, 26*(4), 325-339.

Howell, D., Mayo, S., Currie, S., Jones, G., Boyle, M., Hack, T., Green, E., Hoffman, L., Collacutt, V., McLeod, D. & Simpson, J. (2012). Psychosocial health care needs assessment of adult cancer patients: a consensus-based guideline. *Supportive Care in Cancer, 20*(12), 3343-3354.

Hussein, A. (2009). The use of Triangulation in Social Sciences Research: Can qualitative and quantitative methods be combined? *Journal of Comparative Social Work, 1*, 1-12.

Jackson, B. (2012). Theory and Methods for Thinking Women. In, P. Armstrong, B. Clow, K. Grant, M. Haworth-Brockman, B. Jackson, A. Pederson & M. Seeley (Eds), *Thinking Women and Health Care Reform in Canada* (p. 15-36). Toronto, ON: Women's Press.

Jackson, B., Pederson, A. & Seeley, M. (2012). Assembling the Evidence for Thinking Women. In, P. Armstrong, B. Clow, K. Grant, M. Haworth-Brockman, B. Jackson, A. Pederson & M. Seeley (Eds), *Thinking Women and Health Care Reform in Canada* (p. 65-84). Toronto, ON: Women's Press.

Jenkins Jayman, A. & Willson, K. (2012). Women and Private Health Insurance. In, P. Armstrong, B. Clow, K. Grant, M. Haworth-Brockman, B. Jackson, A. Pederson & M. Seeley (Eds), *Thinking Women and Health Care Reform in Canada* (p. 233-264). Toronto, ON: Women's Press.

Jnuncck, S. (1996). Photovoice Evaluated: An Appropriate Visual Methodology for Aboriginal Water Resource Research. *Anthropology & Education Quarterly, 27*, 623-624.

Johnson, J. L. & Repta, R. (2012). Sex and gender: Beyond the binaries. In J.L. Oliffe & L. Greaves (Eds.) *Designing and conducting gender, sex, and health research* (p. 17-37). Thousand Oaks: Sage Publications.

Jones, J.M. Ferguson, S., Edwards, E., Walton, T., McCurdy, N. & Howell, D. (2012). Experiences of care delivery: endometrial cancer survivors at end of treatment. *Gynecologic Oncology, 124*(3), 458-464.

Juengst, E.T., Flatt, M.A. & Settersten, R.A. (2012). Personalized Genomic Medicine and the Rhetoric of Empowerment. *Hastings Centre Report, 42*(5), 34-40.

Kasper, A.S. (1994). A Feminist, Qualitative Methodology: A study of women with breast cancer. *Qualitative sociology, 17*(3), 263-283.

Kincheloe, J., & McLaren, P. (2003). Rethinking critical theory and qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research: Theories and issues* (p.220-235). Thousand Oaks, CA: Sage.

King, S. (2006). *Pink Ribbons, Inc. Breast Cancer and the Politics of Philanthropy*. Minneapolis, MN: University of Minnesota Press.

Knijn, T. (2000). Marketization and the struggling logics of (home) care in the Netherlands. In M. Harrington Meyer (Ed) *Care Work: Gender, Labor and the Welfare State* (p. 232-248). London: Routledge.

Laslett, B. & Brenner, J. (1989).Gender and Social Reproduction: Historical Perspectives. *Annual Review of Sociology, 15*, 381-404.

Lawn, S., McMillan, J. & Pulvirenti, M. (2011). Chronic condition self-management: Expectations of responsibility. *Patient Education and Counseling, 84*, e5-e8.

Laxer, K. (2015). Who Counts in Care? Gender, power, and aging populations. In P. Armstrong and A. Pederson (Eds.), *Women's Health: Intersections of Policy, Research and Practice, 2nd Edition*. Toronto: Women's Press.

LeBaron, G. (2015). Unfree Labour Beyond Binaries. *International Feminist Journal of Politics, 17*(1), 1-16.

Liamputtong, P. (2007). *Researching the Vulnerable: A Guide to Sensitive Research Methods*. Thousand Oaks, CA. Sage Publications.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications.

Lippman, A. (1998). The Politics of Health: Geneticization Versus Health Promotion. In Susan Sherwin (Coordinator) *The Politics of Women's Health: Exploring Agency and Autonomy* (p. 64-82). Philadelphia: Temple University Press.

Lofland, J., Lofland, L., Snow, D.A. & Anderson, L. (2006). *Analyzing Social Settings: A Guide to Qualitative Observation and Analysis* (4th Edition). Belmont, CA: Thomson, Wadsworth.

Luxton, M. (2010). Doing Neoliberalism: Perverse Individualism in Personal Life. In S. Braedley & M. Luxton, *Neoliberalism and Everyday Life* (p. 163-183). Montreal & Kingston: McGill-Queens University Press.

Luxton, M. (2006). Feminist Political Economy in Canada and the Politics of Social Reproduction (p. 11-44). In, K. Bezanson & M. Luxton (Eds.), *Social Reproduction: Feminist Political Economy Challenges Neo-Liberalism*. Montreal & Kingston: McGill-Queen's University Press.

Luxton, M. (1997). The UN, women and household labour: Measuring and valuing unpaid work. *Women's Studies International Forum, 20*(3), 431-439.

Mackenzie, C.R. (2014). 'It is hard for mums to put themselves first': How mothers diagnosed with breast cancer manage the sociological boundaries between paid work, family and caring for the self. *Social Science and Medicine, 117*, 96-106.

Maclean, K. & Woodward, E. (2012). Photovoice Evaluated: An appropriate Visual Methodology for Aboriginal Water Resource Research. *Geographic Research, 51*(1), 94-105.

Mair, F.S. & May, C. (2014). Thinking about the burden of treatment: Should it be regarded as an indicator of the quality of care? *British Medical Journal, 349*, 6680-6681.

Maroney, H. J. & M. Luxton (1987). From feminism and political economy to feminist political economy. In H. J. Maroney & M. Luxton (Eds.), *Feminism and political economy: Women's work, women's struggles* (pp. 5-28). Toronto, Ontario: Methuen Publications

Martin, P.Y. (2004). Gender as social institution. *Social Forces*, *89*(4), 1249-1273.

Mathews, M., Buehler, R. & West, S. (2009). How important are out-of-pocket costs to rural patients' cancer care decisions? *Canadian Journal of Rural Medicine, 14* (2), 54-60.

Mauthner, N. and Doucet, A. (2003) Reflexive Accounts and Accounts of Reflexivity in Qualitative Data Analysis. *Sociology* 37(3); pp. 413-431.

May, C. (n.d.). The Burden of Treatment and the Burden of Symptoms: The problem of workload and institutional boundaries in chronic disease. *Working Papers in Health Science,* 1(9), 1-2.

May, C.R., Eton, D.T., Boehmer, K., Gallacher, K., Hunt, K., MacDonald, S., Mair, F.S., May, C.M., Montori, V.M., Richardson, A., Rogers, A.E. & Shippee, N. (2014). Rethinking the patient: Using Burden of Treatment Theory to understand the changing dynamics of illness. *BMC: Health Services Research, 14*, 281-292.

May, C., Montori, V.M. & Mair, F.S. (2009). We need minimally disruptive medicine. *British Medical Journal, 339,* b2873.

Mikkonen, J., & Raphael, D. (2010). *Social Determinants of Health: The Canadian Facts*. Toronto: York University School of Health Policy and Management.

Miles, M.B. & Huberman, A.M. (1994). *Qualitative Data Analysis* (2nd Edition). Newbury Park, CA: Sage.

Mol, A. (2008). *The Logic of Care: Health and the Problem of Patient Choice*. London: Routledge

Morris, M. (2004). What research reveals about gender, home care, and caregiving: Overview and the case for gender analysis. In K. Grant, C. Amaratunga, P. Armstrong, M. Boscoe, A. Pederson & K. Willson (Eds.), *Caring For/Caring About: Women, Home Care and Unpaid Caregiving* (p. 91-113). Aurora, ON: Garamond Press.

Morris, M. (2001). *Gender-sensitive home and community care and caregiving research: A synthesis pape*r. Retrieved from Health Canada Women's Health Bureau or the Government of Canada, http://www.womenandhealthcarereform.ca/publications/synthesis.pdf

Morse, J.M., Barrett, M., Myan, M., Olson, K. & Spiers, J. (2002). Verification Strategies for Establishing Reliability and Validity in Qualitative Research. *International Journal of Qualitative Methods, 1*(2), 1-19.

Moss, P. & Dyck, I. (1996). Inquiry into environment and body: women, work, and chronic illness. *Environment and Planning: Society and Space, 14*, 737-753.

Mutari, E. (2000). Feminist political economy: A primer. In *Political economy and contemporary capitalism: Radical perspectives on economic theory and policy*. R. Baiman, H. Boushey, & D. Saunders (Eds). New York: ME Sharpe.

Mykhalovskiy, E., & Weir, L. (2004). The problem of evidence-based medicine: Directions for social science. *Social Science and Medicine, 59*(5), 1059–1069.

National Coordinating Group on Health Care Reform and Women. (2003). *Reading Romanow: The Implications of the Final Report of The Commission on the Future of Health Care in Canada for Women*. Toronto: National Coordinating Group on Health Care Reform and Women.

Naylor, C.D. (1999). Health Care in Canada: Incrementalism Under Fiscal Duress. *Health Affairs, 18*(3), 9-26.

Nelson, C. (2010). *The Financial Hardship of Cancer in Canada: A Literature Review.* Retrieved from http://www.ccanceraction.ca/wp-content/uploads/2010/11/FinancialHardshipofCancerInCanada-Literature-Manitoba.pdf

Nunkoosing, K. (2005). The problems with interviews. Qualitative Health Research, 15(5), 698-706.

Oliffe, J.L. & Bottorff, J.L. (2007). Further than the eye can see? Photo elicitation and research with men. *Qualitative Health Research, 17*(6), 850-858.

Ontario Ministry of Health and Long-Term Care. (2016). Family Health Teams. Retrieved from the Ontario Ministry of Health and Long-Term Care Website, http://www.health.gov.on.ca/en/pro/programs/fht/

Parsons, J.A., Eakin, J.M., Bell, R.S., Franche, R.L. & Davis, A. (2008) "So, are you back to work yet? Re-conceptualizing 'work' and 'return to work' in the context of primary bone cancer. *Social Science & Medicine, 67*, 1826-1836.

Parsons, T. (1951). *The social system*. Glencoe, IL: The Free Press.

Patton, M.Q. (1999). Enhancing the Quality and Credibility of Qualitative Analysis. *Health Services Research, 34*(5), 1189-1208.

Pederson, A. & Liwander, A. (2012). Primary Health Care for Women in Canada. In, P. Armstrong, B. Clow, K. Grant, M. Haworth-Brockman, B. Jackson, A. Pederson & M. Seeley (Eds), *Thinking Women and Health Care Reform in Canada* (p. 37-64). Toronto, ON: Women's Press.

Peterson, A. & Donner, L. (2007). Beyond vectors and vessels: Reflections on women and primary health care reform in Canada. *Pan American Journal of Public Health, 21*(2/3), 145-154.

Prainsack, B., Reardon, J., Hindmarsh, R., Gottweis, H., Naue, U. & Lunshof, J.E. (2008). Personal genomes: Misdirected precautions. *Nature, 456*, 34-35.

Princess Margaret Cancer Centre. (2015). *World Class Personalized Medicine: Strategy 2013-2018* (2015 Edition). Retrieved from the University Health Network Website http://www.uhn.ca/corporate/AboutUHN/OurHospitals/Documents/PMHCP_StrategyReport.pdf

Princess Margaret Cancer Foundation. (2016). *About Us*. Retrieved from the Princess Margaret Cancer Foundation Website http://www.thepmcf.ca/About-Us/About-the-Cancer-Centre/Message-From-The-Cancer-Centre-Leaders.

Radina, M.E., Armer, J.M. & Stewart, B.R. (2014). Making self-care a priority for women at risk of breast cancer related lymphedema. *Journal of family nursing, 20*(2), 226-249.

Raphael, D. (2009). *Social Determinants of Health: Canadian Perspectives* (2nd edition). Toronto, ON: Canadian Scholar's Press.

Raphael, D. (2004). Introduction to the Social Determinants of Health. In D. Raphael (Ed.) *Social Determinants of Health: Canadian Perspectives*. Toronto, ON: Canadian Scholar's Press.

Raphael, D. (2000). The Question of Evidence in Health Promotion," *Health Promotion International*, *15*(4): 355-367.

Rasmussen, D. M. & Elverdam, B. (2008). The meaning of work and work life after cancer: an interview study. *Psychosocial-Oncology, 17*(12), 1232 – 1238.

Richardson, L. (2000). Evaluating ethnography. *Qualitative Inquiry, 6*, 253-256.

Riley, M. (2008). *A Feminist Political Economy Framework*. Retrieved from the Centre of Concern Website, https://www.coc.org/files/Riley%20-%20FPE_0.pdf

Romanow, R. (2002). *Building on Values: The Future of Health Care in Canada* (CP32-85/2002E-IN). Retrieved from the Government of Canada Website http://publications.gc.ca/collections/Collection/CP32-85-2002E.pdf

Roper, J. M. & Shapira, J. (2000). *Ethnography in nursing research*. Thousand Oaks, CA: Sage Publications.

Rukeyser, J., Steinbock, C. & Agins, B.D. (2003). Self-management of chronic disease. *JAMA, 289*(12), 1508-1509.

Sandelowski, M. (2004). Using Qualitative Research. *Qualitative Health Research, 14*(10), 1366-1986.

Savage, J. (2000). Ethnography and health care. *British Medical Journal, 321*, 1400-1402.

Schensul, S.L., Schensul, J.J. & LeCompte, M.D. (1999). *Essential Ethnographic Methods: Observations, Interviews, and Questionnaires*. Walnut Creek, CA: AltaMira

Scotland, J. (2012). Exploring the Philosophical Underpinnings of Research: Relating Ontology and Epistemology to the Methodology and Methods of the Scientific, Interpretive, and Critical Research Paradigms. *English Language Teaching, 5*(9), 9-16.

Simon, R.I. & Dippo, D. (1986). On Critical Ethnographic Work. *Anthropology & Education Quarterly, 17*(4), 195-202.

Sinding, C. (2010). Using Institutional Ethnography to Understand the Production of Health Care Disparities. *Qualitative Health Research, 20*(12), 1656–1663.

Sinding, C., Aronson, J., McGillicuddy, P. & Rochon, A. (2011). The Right to be Involved: Contexts and Contradictions. *Canadian Social Work Revue, 28*(1), 69-88.

Sinding, C., Miller, P., Hudak, P., Keller-Olaman, S. & Sussman, J. (2012). Of time and troubles: Patient involvement and the production of health care disparities. *Health, 16*(4), 400-417.

Siu, A.L., Spragens, L.H., Inouye, S.K., Morrison, R.S., Leff, B. (2009). The ironic business case for chronic care in the acute care setting. *Health Affairs, 28*(1), 113-125.

Slater, L. & Slater, R. (1997). The New Infrastructure. *Studies in Political Economy, 53*, 67-102.

Smele, S. & Seeley, M. (2013). Balancing the Tensions in Resident-Centred Care. In P. Armstrong & S. Braedley (Eds.), *Troubling Care: Critical Perspectives on Research and Practices* (p. 143-154) .Toronto, ON: Canadian Scholars Press.

Smith, D.E. (2005). *Institutional Ethnography: A Sociology for People*. Toronto: AltaMira Press.

Smith, D.E. (1990). Women's Experiences as a Radical Critique of Sociology. In D. Smith, *The Conceptual Practices of Power: A Feminist Sociology of Knowledge*. Toronto, ON: University of Toronto Press.

Smith, D. (1987). *The everyday world as problematic: A feminist sociology*. Boston: Northeastern University Press.

Smith, F., & Barker, J. (2004). Contested spaces: Children's experiences of out of school care in England and Wales. *Childhood*, *7*(3), 315-333.

Soothill, K. Morris, S.M., Thomas, C., Harman, J.C., Francis, B. & McIllmurray, M.B. (2003). The universal, situational, and personal needs of cancer patients and their main carers. *European Journal of Oncology Nursing, 7*(1), 5-16.

Speziale, H. J. S., & Carpenter, D. R. (2007). *Qualitative research in nursing: Advancing the humanistic imperative* (4th ed.). Philadelphia, PA: Lippincott Williams & Wilkins

Stake, R. (1995). *The art of case study research* (pp. 49-68). Thousand Oaks, CA: Sage Publications.

Stanley, L. & Wise, S. (1990). Method, methodology and epistemology in feminist research processes. In L. Stanley (Ed.), *Feminist praxis* (p.20-60). London: Routledge.

Statistics Canada. (2014). *Education Indicators in Canada: An International Perspective, 2013*. Retrieved from Statistics Canada Website: http://www.statcan.gc.ca/daily-quotidien/140107/dq140107b-eng.htm

Stein, J. (2001). The *Cult of Efficiency*. Toronto, ON: House of Anansi Press Inc.

Stergiou-Kita, M., Grigorovich, A., Tseung, V., Milosevic, E., Hebert, D., Phan, S. & Jones, J. (2014). Qualitative meta-synthesis of survivors' work experiences and the development of strategies to facilitate return to work. *Journal of Cancer Survivorship: Research and Practice,* 8(4), 657-670.

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage Publications.

Stein, C.H. & Mankowski, E.S. (2004). Asking, witnessing, interpreting, knowing: conducting qualitative research in community psychology. *American Journal of Community Psychology, 33*(1-2), 21-35.

Struthers, J. (2013). Historical Perspectives on Care and the Welfare State: The Rise, Retreat, Return, and Reframing of a Key Concept. In P. Armstrong & S. Braedley (Eds.), *Troubling Care: Critical Perspectives on Research and Practices* (p. 159-170) .Toronto, ON: Canadian Scholars Press.

Sulik, G.A. (2007). The Balancing Act: Care Work for the Self and Coping with Breast Cancer. *Gender & Society, 21*, 857-877.

Schwartz, D. (1989). Visual ethnography: Using photography in qualitative research. Qualitative Sociology, 12(2), 119-154.

Taylor, S.J., Bogdan, R. & DeVaul, M.L. (2016). *Introduction to Qualitative Research Methods: A Guidebook and Resource* (Fourth Edition). Hoboken, NJ: John Wiley & Sons, Inc.

Thomas, J. (1993). *Doing Critical Ethnography*. Newbury Park, CA: Sage Publications, Inc.

Thorne, S. (2000). Data Analysis in Qualitative Research. *Evidence-Based Nursing, 3*, 68-70.

Thurston, W. & O'Connor, M. (1996). *Health promotion for women*. Paper prepared for the Canada-USA Forum on Women's Health. Ottawa: Health Canada.

Townsend, A., Wyke, S., Hunt, K. (2006). Self-managing and managing self: practical and moral dilemmas in accounts of living with chronic illness. *Chronic Illness, 2*, 185-194.

Tracy, S.J. (2010). Qualitative Quality: Eight "Big-Tent" Criteria for Excellent Qualitative Research. *Qualitative Inquiry, 16*(10), 837-851.

Turnbull Macdonald, G.C., Baldassarre, F., Brown, P., Hatton–Bauer, J., Li, M., Green, E. & Lebel, S. (2012). Psychosocial care for cancer: a framework to guide practice, and actionable recommendations for Ontario. *Current Oncology, 19*(4), 209-2016.

Uebersax, J. S. (1987). Diversity of decision making models and the measurement of inter-rater agreement. *Psychological Bulletin*, *101*(1), p. 140–146.

Vosko, L. (2002). The pasts (and futures) of feminist political economy in Canada: Reviving the debate. *Studies in Political Economy*, *68,* 55-83.

Wang, C. (1999). Photovoice: A Participatory Action Research Strategy Applied to Women's Health. *Journal of Women's Health, 8*(2), 185-192.

Williams, A. P., Deber, R., Baranek, P., & Gildiner, A. (2001). From Medicare to home care: Globalization, state retrenchment, and the profitization of Canada's healthcare system. In P. Armstrong, H. Armstrong, & D. Coburn (Eds.), *Unhealthy times: Political economy perspectives on health and care in Canada* (pp. 7-30). Toronto, Ontario: Oxford University Press.

World Health Organization. (2014). *Trade, foreign policy, diplomacy, and health: Neoliberal ideas.* Retrieved from http://www.who.int/trade/glossary/story067/en/

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Optional Email Subscriptions:

Please indicate if you would like to subscribe to any of the email lists below. You can unsubscribe at any time by emailing patienteducation@uhn.ca.

Would you like to receive an email version of the Patient & Survivorship Education Newsletter and Calendar of Events?   ☐ Yes ☐ No

Would you like to be contacted about research studies into Patient & Survivorship Education?   ☐ Yes ☐ No

Privacy Notice:

Princess Margaret Cancer Centre respects your privacy. All information provided is collected and used for the purposes of the providing and improving services offered by the Patient Education Program at the Princess Margaret.

Please note that the security of email messages is not guaranteed. Messages sent to, or from, your care provider may be seen by others using the Internet. Email is easy to forge, easy to forward, and may exist indefinitely. For this reason, do not use email to send, receive, or discuss information you think is sensitive or to contact us in an emergency.

Signature: _____   Date: _____

UHN Princess Margaret Cancer Centre

PATIENT CONSENT FOR CORRESPONDENCE AND E-MAIL COMMUNICATIONS

Dear Patient:

Your care team at the Cancer Survivorship Program would like to send you information about the program, events, volunteer opportunities and potential research studies related to cancer survivorship.

E-mails are:
- Not encrypted
- Not guaranteed for security. Although every effort will be made to protect your information and keep it private there are things you should know about communicating with e-mails
- Not used for communicating sensitive information including test results
- Not used to communicate urgent matter

Please check below if you would like to be contacted by care team by phone, mail or e-mail:

Phone
- ☐ Information on up coming events
- ☐ Research
- ☐ Clinical Programs
- ☐ Volunteer opportunities

E-Mail
- ☐ Information on up coming events
- ☐ Research
- ☐ Clinical Programs
- ☐ Volunteer opportunities

If you have checked any of the above, please provide your e-mail address

_____

I have read and agree with the above terms.

_____   _____
Please Print Patients Name   Signature of Patient

                                                         Date: _____

Required Interpreter *(Please Check)* ☐   If there is a substitute decision maker, see chart for proper documentation.

The Princess Margaret Hospital Foundation

Appendix B
Patient Recruitment Email

Hello,

You are receiving this email as you have expressed an interest in being contacted for ELLICSR-based research projects.

My name is Cheryl Pritlove and I am a PhD student conducting my doctoral research at ELLICSR. I am conducting research on the potential of ELLICSR to impact women's experiences with cancer, cancer care, and cancer recovery. Specifically, the study is interested in better understanding how the programs, services, resources and supports offered at ELLICSR help to facilitate the day-to-day work that women perform in managing their cancer.

If you attend, or have attended, ELLICSR as a woman with cancer, you are eligible to take part in this research study.

For more information on this study, please see the attached study information sheet.

If you are interested in taking part in the study or have any questions please do not hesitate to contact me directly at ████████ or by responding to this email. You may also contact the Principle Investigator of the study, **Jennifer Jones,** by phone ████████ or via email ████████

You will be compensated for your time for participation in this study.

Thank you in advance for considering this request.

Kind Regards,
Cheryl

* Please note email is not a secure method of communication. Please do not send any personal health information over email

Appendix C
Recruitment Poster

Princess Margaret Hospital

Research Study:
Putting Health Work on the Prescription Pad:
Exploring the Potential of ELLICSR to Facilitate Women's Health
Work.

What does ELLICSR mean to you?

If you attend, or have attended, ELLICSR as a woman with cancer, you are
eligible to take part in this research study.

I am interested in better understanding your relationship with ELLICSR and how
it has impacted your day-to-day experiences with cancer and cancer care.
Participation in this study involves **two 60-90 minute interviews** and a **photo
taking exercise** (a disposable camera will be provided).
You will be compensated for your time for participation in this study.
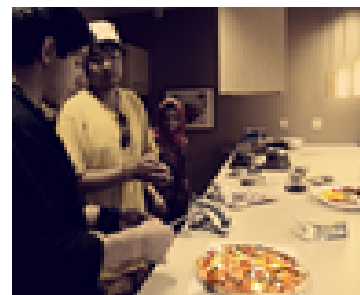
To learn more about this study, please call Cheryl at [   ] or email [   ]

How Does ELLICSR Help You Manage the Day-to-Day? Help Us Find Out (Study)

Written By [Cheryl Pritlove](#)

Life is busy. Isn't that what everyone is always saying? Well, just try fitting cancer into your day-to-day! You can't simply put life on hold. Sure, some things get dropped or put off for a while, but new obligations take their place. Medical appointments, treatment, arranging child care and other activities get added to daily routines. It can be tough.

Hi, my name is Cheryl Pritlove and I'm a PhD student here at ELLICSR. I'm interested in better understanding the struggles and successes that women experience managing day-to-day life with cancer. I also want to know how the programs, services, resources and supports we offer at [ELLICSR](#) may have helped you. Which programs and services do, or did, you find most useful? Is there something you need or want that we do not offer?

If you are a woman who has come to ELLICSR anytime between your diagnosis and the end of your treatment, join our study and help us make ELLICSR even more useful to women like yourself! I'd like to talk to you whether you've only come to ELLICSR once or if you come here often. With this study we hope to improve the quality of cancer care and support that women receive at times of illness.
To help us with our research, you will be invited to talk with me in 2 separate one-on-one interviews. After the first interview you'll get a disposable camera so that you can take pictures that reflect your day-to-day experiences. We'll use these photographs for our discussion during the second interview.

To Join the Study
If you would like to join this study, or if you have any questions about it, please get in touch! Contact me or Jennifer Jones, this study's Principal Investigator.

We appreciate the time you take to help us with our research, and we will compensate everyone who takes part in this study.

Cheryl Pritlove
Phone: ▉▉▉▉▉▉▉▉
email: ▉▉▉▉▉▉▉▉▉▉▉▉

Jennifer Jones
Phone: ▉▉▉▉▉▉▉
email: ▉▉▉▉▉▉▉▉▉

Appendix E
ELLICSR Staff Recruitment Email

Body of the recruitment email to ELLICSR staff

Hello [insert staff name],

My name is Cheryl Pritlove and I am a PhD student conducting my doctoral research at ELLICSR. I am conducting research on the potential of ELLICSR to impact women's experiences with cancer, cancer care, and cancer recovery. Specifically, the study is interested in better understanding how the programs, services, resources and supports offered at ELLICSR help to facilitate women's health work.

The work of health professionals can provide a critical link between the experiences of cancer patients and the broader organization of health care. As such, I am interested in learning more about your work with patients who attend the centre as well as your role in the development and delivery of services at ELLICSR.

For more information on this study, please see the attached study information sheet.

If you are interested in taking part in the study or have any questions please do not hesitate to contact me directly at ██████████ or by responding to this email. You may also contact the Principle Investigator of the study, **Jennifer Jones**, by phone (██████████ or via email ██████████

Thank you in advance for considering this request.

Kind Regards,
Cheryl

Appendix F
Study Information Sheet (Patients)

Study Information Sheet

Date:
Project Title: Putting Health Work on the Prescription Pad: Exploring the Potential of ELLICSR to Facilitate Women's Health Work

Principle Investigator: Jennifer Jones (Associate Director, ELLICSR Princess Margaret Hospital, UHN)
Lead Researcher: Cheryl Pritlove (York University, ELLICSR)

I am conducting research on the potential of ELLICSR to impact women's experiences with cancer, cancer care, and cancer recovery. Specifically, the study is interested in better understanding how the programs, services, resources and supports offered at ELLICSR help to facilitate women's health work. **Health work** in this study refers to the added tasks and activities that often accompany a cancer diagnosis, including such things as communicating with health providers, seeking information, locating community programs and supports, traveling to and from clinics, finding ways to meet uninsured costs of care, navigating complex forms, and maintaining self-care for other health problems. Health work may also refer to changes in everyday living that often occur at times of illness, including such things as child or family care, house work, obtaining and preparing food, managing finances, and coordinating schedules.

It is the **purpose** of this research project to: 1) highlight the struggles and successes that women with cancer confront at times of illness; 2) better understand the potential of ELLICSR to ease the burden of women's health work as they confront and negotiate cancer, treatment, and recovery; and 3) improve the quality of cancer care and support that women receive at times of illness.

As a participant in this study, you will be asked to take part in **two 60-90 minute one-on-one in person interviews** that will be audiotaped and transcribed. You will be contacted one month following the first interview to plan a second meeting for a follow up interview. You will also be asked to take part in a photo taking exercise where you will capture images that reflect your day-to-day health work (a disposable camera will be provided to you free of charge upon completion

of the first interview). These photographs will act as the focus of the second interview. You will be asked to provide a copy of the photos to the researcher. Please note that there will be no cost to you for the development of the pictures as the costs are built into the cost of the disposable camera. The photos you provide will be scanned by the interviewer following the second interview and will be edited (cropped or blurred) using photo editing software to remove all faces and/or other potential identifying features captured in the photographs to protect anonymity. After the images have been scanned and edited, the original photographs will be returned to you, or if you prefer, they will be destroyed. Should you consent, the edited photos may be used in presentations or publications resulting from the study. If you prefer that your photographs not be included in presentations and/or publications and that they only be used by the researcher for analytic purposes, they will not be used in the dissertation write-up or any presentations/publications that may result from the study. You can stop the interview at any point in time or decline to answer any specific question.

Spaces such as ELLICSR are under-researched in Canada, and your involvement with this project will help us better understand their role in the delivery of cancer care in Canada. Your perspective on this research topic would be invaluable, and I would greatly appreciate your consideration of participation in this project. Although there are no obvious harms associated with taking part in this study, every effort will be made to be sensitive to any personal information that you share and to make you as comfortable as possible as you discuss your experiences.

In appreciation of your time a **$25 honorarium** will be provide following each interview. The decision to participate or not is **completely voluntary**. Your decision not to participate will not affect your relationship with the researcher, York University, ELLICSR or any other group associated with this project.

If you would like more information or are interested in participating, please feel free to contact me by email at █████████████████████ or by phone at ██████████. You may also contact the principle investigator of this study, Dr. Jennifer Jones, by phone ██████████ or via email █████████████████
Thank you in advance for considering this request.

Sincerely,

Cheryl Pritlove, PhD (c)

Study information

Date:
Project Title: Putting Health Work on the Prescription Pad: Exploring the Potential of ELLICSR to Facilitate Women's Health Work

Principle Investigator: Jennifer Jones (Associate Director, ELLICSR Princess Margaret Hospital, UHN)
Lead Researcher: Cheryl Pritlove (York University, ELLICSR)

Dear ELLICSR staff,

I am conducting research on the potential of ELLICSR to impact women's experiences with cancer, cancer care, and cancer recovery. Specifically, the study is interested in better understanding how the programs, services, resources and supports offered at ELLICSR help to facilitate women's health work. **Health work** in this study refers to the added tasks and activities that often accompany a cancer diagnosis, including such things as communicating with health providers, seeking information, locating community programs and supports, traveling to and from clinics, finding ways to meet uninsured costs of care, navigating complex forms, and maintaining self-care for other health problems. Health work may also refer to the changes in everyday living that often occur at times of illness, including such things as child or family care, house work, obtaining and preparing food, managing finances, and coordinating schedules.

It is the **purpose** of this research project to: 1) highlight the struggles and successes that women with cancer confront at times of illness; 2) better understand the potential of ELLICSR to ease the burden of women's health work as they confront and negotiate cancer, treatment, and recovery; and 3) improve the quality of cancer care and support that women receive at times of illness.

The work of health professionals can provide a critical link between the experiences of cancer patients and the broader organization of health care. This study is interested in learning more about your work with patients/survivors as well as your role in the development and delivery of services at ELLICSR. Spaces such as ELLICSR are under-researched in Canada, and your involvement with this project will contribute to filling this gap in the literature and may help the future practice and delivery of cancer care in Canada. It is believed that your perspective on this research topic would be invaluable, and I would greatly appreciate your consideration of participation in this project.

As a participant in this study, you will be asked to take part in **one 60-90 minute interview** which will be audiotaped and transcribed. You can stop the interview at any point in time or decline to answer any specific question. Because ELLICSR consists of a limited number of staff, anonymity may not be possible. Should you wish to remain anonymous, every effort will be made to insure that no identifying characteristics be included.

The study has minimal risks and the decision to participate or not is **completely voluntary**.

If you would like more information or are interested in participating, please feel free to contact me by email at ░░░░░░░░@░░░░░ or by phone at (░░░) ░░░░░ You may also contact the principle investigator of this study, Dr. Jennifer Jones, by phone (░░░░░░░░ or via email ░░░░░░░░░░

Thank you in advance for considering this request.

Sincerely,

Cheryl Pritlove, M.Sc.; PhD (c)

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

STUDY TITLE: Putting Health Work on the Prescription Pad: Exploring the Potential of ELLICSR to Facilitate Women's Health Work

NAME OF PRINCIPAL INVESTIGATOR: Jennifer Jones, PhD. Director of Research, Cancer Survivorship Program Princes Margaret Hospital / University Health Network.

NAME OF CO-INVESTIGATOR: Cheryl Pritlove, Doctoral Student, York University.

CONTACT INFORMATION: You may contact the lead researcher of the study, **Cheryl Pritlove**, via email at ██████████████████ or by telephone (███████████. You may also contact the Principle Investigator of the study, **Jennifer Jones**, by phone (███████████ or via email ██████████████

INTRODUCTION:

You are being asked to take part in a research study. Please read this explanation about the study and its risks and benefits before you decide if you would like to take part. . You should take as much time as you need to make your decision. You should ask the study staff to explain anything that you do not understand and make sure that all of you questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish, including your friends, family, and family doctor. Participation in this study is voluntary.

BACKGROUND/PURPOSE:
You are being asked to participate in this research study because your opinions, experiences and thoughts as a woman with cancer who attends, or has attended, ELLICSR will be invaluable in furthering our understanding of women's day-to-day lives at times of illness and the usefulness of cancer health and wellness centres, ELLICSR specifically, for women with cancer.

Women being treated for cancer are often very busy with activities related to their care. As part of this health work, women must take on a number of tasks including, but not limited to: communicating with health providers, seeking relevant and personalized information, locating community programs and supports, traveling to and from clinics, making difficult decisions, finding ways to meet uninsured costs of care, filling out complex forms, and maintaining self-care for other health problems. Canadian research has shown that access to resources including such things as income, social networks, time, and knowledge/education have a rather large influence on a cancer patient's ability to perform health work, which can impact patient's quality of life and care. Yet, attention to patient resources is lacking in the development of cancer care plans – something that patients have themselves often criticized. Cancer health and wellness centres, such as ELLICSR, apply a patient-centred approach to care whereby programs and services are developed around the wants and needs of the patient. In this way, cancer health and wellness centres may help patients overcome some the challenges and barriers that they face throughout their cancer journey, which may help improve patient's quality of life and care.

The **purpose** of this study is to better understand how ELLICSR impacts women's experiences with cancer, cancer care, and health work. Up to 20 women with cancer will participate in this study along with 10 ELLICSR staff. This study will take 1 year complete..

STUDY DESIGN:
This is a qualitative study. Qualitative research is interested in better understanding people's experiences as told through their voice. As such, this study includes two one-on-one interviews (and a photo taking exercise) tailored to better understand your day-to-day experiences (with an emphasis on health work) as a woman with cancer as well as your experiences of, and thoughts about, ELLICSR. . I will observe and participate in some of the classes and programs held at ELLICSR in order to gain a better understanding of what these classes and programs offer. I will also be observing the interactions that take place within ELLICSR – both the interactions that happen among patients as well as between patients and ELLICSR staff. I will verbally notify attendees of ELLICSR and ELLICSR staff of my presence in the space and purpose for being there. Documents specific to ELLICSR, including things like websites, event posters, and educational material will also be included in the study to gain a better understanding of ELLICSR (including their goals and mandates) and the connection this space establishes with patients.

PROCEDURES:
If you agree to participate in this study, you will be asked to take part in two one-on-one and in-person interviews. These will last approximately 60-90 minutes, and they will be recorded to insure that all information discussed in the interview is accurately captured. During the interviews you will be asked about your day-to-day experiences of cancer, the challenges and successes you've experienced throughout your cancer journey, and your relationship with ELLICSR. You will be able to decide the location and time of the interview. You will be given a

disposable camera free of charge at the end of the first interview and will be asked to capture your daily activities and health work, including but not limited to your participation at ELLICSR. The second interview will take place approximately one month following the initial interview and is intended to follow up on discussions had in the first interview as well as to discuss the events and activities that you captured in your photographs. You will be asked to provide a copy of the photos to the researcher. Please note that there will be no cost to you for the development of the pictures as the costs are built into the cost of the disposable camera. Immediately following the second interview, where the photos will be seen and discussed by you and the interviewer, the photos you provide will be scanned by the interviewer and will be edited (cropped or blurred) using photo editing software to remove all faces and other potential identifying features captured in the photographs to protect anonymity. The edited photographs will be kept in a locked filing cabinet, accessible only to the research team. After the images have been scanned and edited, the original photographs will be returned to you, or if you prefer, they will be destroyed. Should you consent, the edited photos may be used in presentations or publications resulting from the study. If you prefer that your photographs not be included in presentations and/or publications and that they only be used by the researcher for analytic purposes, please indicate this prior to consent (below) and they will not be used in the dissertation write-up or any presentations/publications that may result from the study. A brief demographic questionnaire (including such things as year of birth and annual income) will be completed at the end of the first interview.

VOLUNTARY PARTICIPATION:
Your participation in this study is **completely voluntary.** You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time without affecting your care. We will give you new information that is learned during the study that might affect your decision to stay in the study. You may refuse to answer any questions you do not want to answer, or not answer an interview question by saying "pass".

WITHDRAWAL FROM STUDY:
You can stop the interview at any point in time or decline to answer any specific questions **without consequence**. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with the researcher, York University, ELLICSR or any other group associated with this project. Should you decide to withdraw from the study; all data collected as a result of your participation will be destroyed.

RISKS:
Although there are no obvious harms associated with taking part in this study, every effort will be made to be sensitive to any personal information you share and to make you as comfortable as possible as you discuss your experiences.

BENEFITS:
You may not receive direct benefit from being in this study, however, your involvement in this study will add to research which may better the overall health and well-being of women with and recovering from cancer. Your experiences will contribute to an increased awareness of the lived experiences of cancer and how we might better support women with and recovering from cancer. Your thoughts and experiences will inform recommendations that could be used to improve the delivery of cancer care.

ALTERNATIVES TO BEING IN THE STUDY:
You do not have to join this study to receive treatment for your condition.

CONFIDENTIALITY:
All the information obtained during the study will be held in strict confidence and stored in a secure cabinet in a locked office. You will be identified with a study number only. No names or identifying information will be used in any reports, publications or presentations that may come from this study. No information identifying you will be transferred outside this hospital or to anyone besides the investigators in this study.

The information collected during this study will be destroyed securely 7 years after the end of the study is complete. The audio-recordings will be destroyed and/or deleted immediately upon transcription.

Representatives of the University Health Network Research Ethics Board may look at the study records and at your personal health information to check that the information collected for the study is correct and to make sure the study followed proper laws and guidelines.

If you decide to leave the study at any point, you may request that your information (including your interview transcripts) be removed from the study. No new information will be collected without your permission.

COSTS:
In appreciation of your time and any costs that you may incur in order to take part in the interview (i.e., costs associated with such things as transportation and possibly child or family care), you will be provided with an honorarium of $25 following each interview. The honoraria will be provided regardless of whether you complete the interview.

RIGHTS AS A PARTICIPANT:
By signing this form you do not give up any of your legal rights against the investigators, sponsor or involved institutions for compensation, nor does this form relieve the investigators, sponsor or involved institutions of their legal and professional responsibilities.

CONFLICT OF INTEREST:

The researchers of this study (Jennifer Jones and Cheryl Pritlove) have an interest in completing this study. Their interests should not influence your decision to participate in this study.

QUESTIONS ABOUT THE STUDY

If you have any questions, concerns or would like to speak to the study team for any reason, please call: **Jennifer Jones at** ▮▮▮▮▮▮▮▮ **or Cheryl Pritlove at** ▮▮▮▮▮▮▮.
If you have any questions about your rights as a research participant or have concerns about this study, call the **Chair of the University Health Network Research Ethics Board (UHN REB) or the Research Ethics office number at** ▮▮▮▮▮▮▮▮ The REB is a group of people who oversee the ethical conduct of research studies. These people are not involved with the research project in any way and calling them will not affect your participation in the study. Everything that you discuss will be kept confidential.

CONSENT

I would like the photographs that I have taken for this study to be used in:
Please check any of the boxes that apply.

- ☐ Analysis only
- ☐ Presentations that may result from the study
- ☐ Publications that may result from the study

This study has been explained to me and any questions I had have been answered. I know that I may leave the study at any time. I agree to take part in this study.

_____   _____   _____
  Print Name of Participant   Signature   Date

My signature means that I have explained the study to the participant named above. I have answered all questions

_____   _____   _____
  Print Name of Person   Signature   Date
   Obtaining Consent

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

STUDY TITLE: Putting Health Work on the Prescription Pad: Exploring the Potential of ELLICSR to Facilitate Women's Health Work

NAME OF PRINCIPAL INVESTIGATOR: Jennifer Jones, PhD. Director of Research, Cancer Survivorship Program Princes Margaret Hospital / University Health Network.

NAME OF CO-INVESTIGATOR: Cheryl Pritlove, Doctoral Student, York University.

CONTACT INFORMATION: You may contact the lead researcher of the study, **Cheryl Pritlove**, via email at ▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮ or by telephone at ▮▮▮▮▮▮▮▮▮▮. You may also contact the Principle Investigator of the study, **Jennifer Jones,** by phone ▮▮▮▮▮▮▮▮ or via email ▮▮▮▮▮▮▮▮▮▮

INTRODUCTION:

You are being asked to take part in a research study. Please read this explanation about the study and its risks and benefits before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the study staff to explain anything that you do not understand and make sure that all of you questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish – including your friends, family, and family doctor. Participation in this study is voluntary.

BACKGROUND/PURPOSE:

You are being asked to participate in this research study because your expertise as an ELLICSR employee will provide a valuable link between what happens to service users and the broader organization of care systems.

Women being treated for cancer are often very busy with activities related to their care. As part of this health work, women must take on a number of tasks including, but not limited to: communicating with health providers, seeking relevant and personalized information, locating community programs and supports, traveling to and from clinics, making difficult decisions,

finding ways to meet uninsured costs of care, filling out complex forms, and maintaining self-care for other health problems. Canadian research has shown that access to resources including such things as income, social networks, time, and knowledge/education have an immense influence on a cancer patient's capacity to perform required health work, which can impact patient's quality of life and care. Yet, attention to patient resources is lacking in the development of cancer care plans – something that patients have themselves often criticized. Cancer health and wellness centres, such as ELLICSR, apply a patient-centred approach to care whereby programs and services are developed around the wants and needs of the patient. In this way, cancer health and wellness centres may help patients overcome some of the challenges and barriers that they face throughout their cancer journey.

The **purpose** of this study is to better understand how ELLICSR impacts women's experiences with cancer, cancer care, and health work. Up to 10 ELLICSR staff will participate in this study along with up to 20 women with cancer. The study will take 1 year to complete.

STUDY DESIGN:
This is a qualitative study. Qualitative research is interested in better understanding the realities of people's experiences as told through their voice. As such, this study includes a one-on-one interview tailored to better understand your day-to-day work with patients and survivors attending ELLICSR. I will observe and participate in some of the classes and programs held at ELLICSR in order to gain a better understanding of what these classes and programs offer. I will also be observing the interactions that take place within ELLICSR – both the interactions that happen among patients as well as between patients and ELLICSR staff. I will verbally notify attendees of ELLICSR and ELLICSR staff of my presence in the space and purpose for being there. Documents specific to ELLICSR, including things like websites, event posters, and educational material will also be included in the study to gain a better understanding of ELLICSR (including their goals and mandates) and the connection this space establishes with patients.

PROCEDURES:
If you agree to participate in this study, you will be asked to take part in 1 one-on-one and in-person interview. The interview will last approximately 60-90 minutes, and it will be recorded to insure that all information discussed in the interview is accurately captured. You will be able to decide on the location and time of the interview. During the interview you will be asked about your professional role at ELLICSR, your day-to-day work with patients and survivors attending the centre, resources available through the centre, as well as your understanding of future directions at the centre.

VOLUNTARY PARTICIPATION:
Your participation in the study is **completely voluntary.** You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time

without affecting your employment status or academic standing. We will give you new information that is learned during the study that might affect your decision to stay in the study. You may refuse to answer any questions you do not want to answer, or not answer an interview question by saying "pass".

WITHDRAWAL FROM STUDY:
You can stop the interview at any point in time or decline to answer any specific questions **without consequence**. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with the researcher, York University, ELLICSR or any other group associated with this project. Should you decide to withdraw from the study, all data collected as a result of your participation will be destroyed.

RISKS:
Although there are no obvious harms associated with taking part in this study, every effort will be made to be sensitive to any personal information you share and to make you comfortable as you discuss your experiences.

BENEFITS:
You may not receive direct benefit from being in this study, however, your involvement in this study will add to research which may better the overall health and well-being of women with and recovering from cancer. Your experiences will contribute to an increased awareness of how we might better support women with and recovering from cancer. Your thoughts and experiences will inform recommendations that could be used to improve the delivery of cancer care.

CONFIDENTIALITY:
All the information obtained during the study will be held in strict confidence and stored in a secure cabinet in a locked office. Because ELLICSR consists of a limited number of staff, anonymity may not be possible. Should you wish to remain anonymous, every effort will be made to insure that no identifying characteristics be included in any reports, publications or presentations that may come from this study. Further, should you wish to remain anonymous, no information identifying you will be transferred outside this hospital or to anyone besides the investigators in this study.

The information collected during this study will be destroyed securely 7 years after the end of the study is complete. The audio-recordings will be destroyed and/or deleted immediately upon transcription.

Representatives of the University Health Network Research Ethics Board may look at the study records and at your personal health information to check that the information collected for the study is correct and to make sure the study followed proper laws and guidelines.

If you decide to leave the study at any point, you may request that your information (including your interview transcripts) be removed from the study. No new information will be collected without your permission.

COSTS:
While the study does ask you to invest 60-90 minutes of your time, it is not anticipated that your involvement in this study will have any additional financial costs.

RIGHTS AS A PARTICIPANT:
By signing this form you do not give up any of your legal rights against the investigators, sponsor or involved institutions for compensation, nor does this form relieve the investigators, sponsor or involved institutions of their legal and professional responsibilities.

CONFLICT OF INTEREST:
The researchers of this study (Jennifer Jones and Cheryl Pritlove) have an interest in completing this study. Their interests should not influence your decision to participate in this study.

QUESTIONS ABOUT THE STUDY
If you have any questions, concerns or would like to speak to the study team for any reason, please call: **Jennifer Jones at** ▮▮▮▮▮▮▮▮▮ **or Cheryl Pritlove at** ▮▮▮▮▮
If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the University Health Network Research Ethics Board (UHN REB) or the Research Ethics office number at ▮▮▮▮▮▮▮▮▮ The REB is a group of people who oversee the ethical conduct of research studies. These people are not involved with the research project in any way and calling them will not affect your participation in the study. Everything that you discuss will be kept confidential.

CONSENT
This study has been explained to me and any questions I had have been answered. I know that I may leave the study at any time. I agree to take part in this study.

_____   _____   _____
         Name of Participant   Signature of Participant   Date

My signature means that I have explained the study to the participant named above. I have answered all questions.

_____   _____   _____
         Name of Person   Signature   Date
         Obtaining Consent

Appendix J
Demographic Questionnaire

UHN Princess Margaret Cancer Centre

Demographic Questionnaire
(to be completed by study personnel)

1. Birthdate: _____
                    Year

2. What is your living situation (check all that apply)
[ ] alone   [ ] spouse/partner   [ ] common law
[ ] divorced/separated   [ ] married   [ ] single
[ ] other, specify _____

[ ] child(ren) living at home - if so, how many? _____

[ ] Adult dependent(s) - if so, how many? _____

3. Education
(highest level of education completed)
[ ] < high school   [ ] some post-secondary education   [ ] completed high school
[ ] college diploma   [ ] undergraduate degree   [ ] graduate degree or greater

4. What is your current employment status:
[ ] full-time   [ ] part-time   [ ] casual
[ ] unemployed   [ ] disabled   [ ] homemaker
[ ] retired   [ ] sick leave
[ ] other _____

5. Income
a) Participant's own personal before-tax income in 2012?
    (hand page of income ranges to participant)
[ ] A = < $15, 000   [ ] B = $15,000-19, 999   [ ] C = $20, 000-29, 9999
[ ] D = $30,000-39, 999 [ ] E = $40, 000-49, 999   [ ] F = $50, 000-59, 999
[ ] G = $60, 000-69, 999 [ ] H = $70, 000-79, 999   [ ] I = $80, 000-99, 999

[ ] J = > $100, 000

b) Participant's total before-tax family income in 2012?

[ ] A = < $15, 000   [ ] B = $15,000-19, 999   [ ] C = $20, 000-29, 9999
[ ] D = $30,000-39, 999   [ ] E = $40, 000-49, 999   [ ] F = $50, 000-59, 999
[ ] G = $60, 000-69, 999   [ ] H = $70, 000-79, 999   [ ] I = $80, 000-99, 999
[ ] J = > $100, 000

6. Were you born in Canada?

[ ] yes [ ] no   If no, where? _____

If no, year of arrival/immigration to Canada? _____

7. Resources:

a) Do you have additional health insurance coverage (Other than OHIP)?

[ ] yes [ ] no   If yes, specify _____

b) Access to a Primary Care Provider (e.g., family doctor, nurse practitioner):

[ ] yes [ ] no

c) Distance from participant's home to the hospital/ELLICSR: _____

d) Mode of transportation to hospital/cancer clinic/ELLICSR:

[ ] private car   [ ] hospital provided transportation   [ ] taxi
[ ] public transit   [ ] walk/bike
[ ] other, specify_____

e) Do you tend to travel alone?

[] yes   [] no   If no, who do you usually travel with? _____

Appendix K
Initial Interview Guide (Patient)

Schedule of Questions for 1st Interview

1. Perhaps we could start off by speaking a little about yourself and your life before you were diagnosed with cancer (i.e., what was an average day like - your daily routines, tasks, activities, responsibilities, hobbies, etc.)

2. How did your diagnosis with cancer add to or change these daily routines, tasks, activities, etc.?
    Prompts
 • Did you find yourself with new or added responsibilities after the diagnosis? If, so what were they?
        Probes: Things to probe for if participants do not mention should include side-effects of cancer treatment and/or medication; the **financial impact** of the diagnosis, including transportation costs, affordability of medications**, changes to paid work**; and **caregiving responsibilities** (i.e., children, parents, relatives).

2. a) How have you responded to these changes/added responsibilities and tasks?

        o What **resources** (i.e., social networks, financial resources, etc.) have you drawn on in order to attend to these tasks?

3. What initially brought you to ELLICSR?
    Prompts
 • How did you hear about the centre?
 • **Why did you believe the centre would be beneficial?**
        Probes: Things to probe for if participants do not mention should include any barriers encountered in the hospital throughout the cancer treatment process, including unmet physical, emotional, informational, and/or financial needs.

4. Have you experienced any barriers to ELLICSR, and if so, what have these barriers been? (i.e., transportation difficulty, time constraints/conflicts, disconnect between programs and services offered and your needs/wants, etc.)?

5. Why do you no longer attend ELLICSR? [This question will only be asked to patients who no longer attend ELLICSR]

6. What have your experiences at ELLICSR been like?
    Prompts

- What resources have you attained through your participation at ELLICSR?
- What programs/courses do you attend?
- Which programs/courses do you find **most beneficial** and why?

7. **Has ELLICSR helped you overcome any barriers or added responsibilities you experienced in relation to your cancer care and/or your day-to-day experiences as a woman with cancer?**

8. **Is there anything else that you would like to talk about that we didn't get a chance to address?**

9. **Do you have any questions that you would like to ask me?**

Instructions for photo taking exercise

As part of your involvement in this study, you are asked to take part in a photo taking exercise. For this exercise you are asked to imagine that you have been asked to mount a photographic exhibition entitled *Living with Cancer*, an exhibition that would show what it is like to manage cancer in day-to-day life, from your own perspective and drawing on your personal experiences.

You are encouraged to capture any images that hold meaning for you. These images can be taken within or outside of ELLICSR.

These photographs will act as the focus of the second interview.

Please note that there will be no cost to you for the development of the pictures as the costs are built into the cost of the disposable camera. Simply bring the camera to any **Black's Photography** to develop your images.

Please do not hesitate to contact me by phone at ███████████ or by email at ██████████████████ should you have any questions about the photo taking exercise or about the study more broadly.

Appendix M
Follow-up Interview Guide (Patient)
<u>**Schedule of Questions for 2nd Interview**</u>

The second interview will be a continuation and elaboration of the issues discussed in the first interview. The photographs will be reviewed and discussed with the participant to better understand their day-to-day cancer experiences, their patterns of engagement with ELLICSR, and any major issues they encountered in their everyday health work.

Introductory Questions
In our last discussion you told me about your experiences with cancer and your participation at ELLICSR. How have things been for you since we last spoke?

Did you have any additional thoughts after our discussion that you would like to share?

Before we spend some time looking at and discussing your photos, I wonder if you would like to share what it was like to capture your daily cancer experiences/activities for that week.

Photo Specific Questions
Can you please walk me through some of your images, telling me a bit about the activities/work that you have captured in the photographs that you brought for me today?
- In the review of these photos, what stands out for you?
- I notice in this photo you have captured _____, can you tell me more about that?

Concluding Questions
- After capturing these images and reflecting on the day-to-day health work that you perform, I wonder is there anything you would change about, or add to, ELLICSR, and if so, what would it be and how do you think this would help to ease the burden of your health work and potentially improve the quality of care that you currently receive?
    Probes: Things to probe for if participants do not mention should include any barriers they may face in terms of getting to the centre and attending the programs and courses as well as classes, programs, services and/or counseling that they would like to see added to the program.

- Would you recommend ELLICSR to other cancer patients, and if so, what would you tell them about the centre?

- Is there anything else you would like to tell me concerning your experiences with cancer or ELLICSR?

- Do you have any questions that you would like to ask me?

Appendix N
ELLICSR Staff Interview Guide ELLICSR Staff

<u>**Schedule of Questions**</u>

1. Perhaps we could begin by discussing what brought you to ELLICSR and your role here at the centre?
   <u>Prompts</u>
   - What drew you to ELLICSR?
   - What does an average day here look like for you? (i.e. roles/responsibilities)

2. Can you tell me a little about your involvement with the patients who attend the centre?
   <u>Prompts</u>
   - In what capacity in your role as _____ do you interact with the patients/survivors at ELLICSR?
   - What are your individual goals in your role as _____ to improve the patient experience, and how do you think these align with the broader goals of ELLICSR?

3. What do you think brings patients/survivors to ELLICSR?
   <u>Prompts</u>
   - What does this centre provide to patients/survivors that hospitals, and/or other cancer centres, do not?

4. What do you believe some of the barriers to ELLICSR might include for patients? (i.e., lack of knowledge about the centre, competing demands faced by patients, temporal or financial barriers, etc.)
   <u>Prompts</u>
   - How do you think ELLICSR could help patients/survivors overcome these barriers?

5. Do you believe that ELLICSR helps patients overcome the added tasks and activities that often accompany a cancer diagnosis (i.e. health work)?
   a. If so, in what ways?

6. What are the future directions for ELLICSR and how do you think these will make the patient experience better?

7. Is there anything else you would like to tell me about ELLICSR, your role at ELLICSR, or your experiences with the patients here at ELLICSR that we did not get a chance to discuss?