11-11-2014 12:00 AM

Gender Relations in Hospice Palliative Home Care for Clients with Cancer and Their Family Caregivers: A Critical Analysis

Nisha S. Sutherland
The University of Western Ontario

Supervisor
Catherine Ward-Griffin
The University of Western Ontario Joint Supervisor
Carol McWilliam
The University of Western Ontario

Graduate Program in Nursing
A thesis submitted in partial fulfillment of the requirements for the degree in Doctor of Philosophy
© Nisha S. Sutherland 2014

GENDER RELATIONS IN HOSPICE PALLIATIVE HOME CARE FOR CLIENTS
WITH CANCER AND THEIR FAMILY CAREGIVERS: A CRITICAL ANALYSIS

Thesis Format: An Integrated Article

by

Nisha <u>Sutherland</u>

Graduate Program in Nursing

A thesis submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy

The School of Graduate and Postdoctoral Studies
The University of Western Ontario
London, Ontario

© Nisha Sutherland 2014

Abstract

The purpose of this study was to critically examine gender relations in the sociopolitical context of hospice palliative home care for clients with cancer and their family caregivers. Using a critical feminist lens, I employed critical ethnography as a methodology to uncover taken-for-granted attitudes, beliefs, and practices that shape health and health care experiences within the culture of end-of-life at home. The study addressed the following research questions: (a) How do gender relations shape health and health care experiences within the socio-political context of hospice palliative home care for clients with cancer and their caregivers?; (b) How do gendered processes operate to produce gender relations and potential gender inequities in this context?; and (c) What are the social mechanisms and consequences that (re)produce gender (in)equities in hospice palliative home care?

Purposeful sampling was used to gather information-rich data from six triads consisting of a client with cancer, her or his family caregiver, and primary nurse. I employed ethnographic methods of interview, observation, and document review to gain in-depth knowledge of the patterns and dynamics of gender relations. Twenty-five semi-structured interviews were conducted with clients, family caregivers, and nurses. Observations of nine home visits by the nurse contextualized gender social relations in this setting. Program, professional, and public communication documents were analyzed to understand how institutional discourses shaped gendered attitudes, beliefs, and practices and everyday health and health care experiences in hospice palliative home care.

A gender-based analysis revealed that institutional discourses influenced *Gendered Expectations and Exemptions*, disadvantaging both men and women in this

context. Ideological gendered processes of *Normalizing Gender Relations* and *Equalizing Gender Relations* supported the everyday practices of *Regulating Gender Relations*. Finally, socially constructed mechanisms of *Preservation/Destruction of Gender Stereotypes* and *Imbalance/Balance of Power* (re)produced gender (in)equities. Overall, gender inequities were considered low in priority and status within the culture of hospice palliative home care. Recommendations have been made related to policy, practice, education, and research.

Key words: hospice palliative care; home care; gender relations; equity, critical feminist lens

Co-Authorship Statement

Nisha Sutherland conducted this research under the supervision of Dr. Catherine Ward-Griffin, Dr. Carol McWilliam, and Dr. Kelli Stajduhar, who will be co-authors on the publications resulting from Chapters Four, Five, and Six.

Acknowledgements

I would like to acknowledge the participants of the study, who shared with me their time and personal stories. I am grateful and humbled that they permitted me to enter into their lives, sometimes in very private and vulnerable moments.

I have been privileged to have Dr. Catherine Ward Griffin as a supervisor. She has afforded me countless opportunities to flourish, and through her excitement and drive for excellence, she has cultivated in me a dedication and passion for advocacy, research, and education in nursing. I cannot adequately express my gratitude to Cathy for having inspired me to be my best and realize my dreams. I can only attempt to emulate the exemplary teacher and mentor that she has been.

I am truly grateful for all the countless hours, feedback, reference letters, and words of encouragement from my committee members, Dr. Carol McWilliam and Dr. Kelli Stajduhar. I am fortunate to have been under Dr. McWilliam's tutelage and appreciate her excellence and immense wisdom. I am thankful for Dr. Stajduhar's expertise and kindness. Thank you to both for always being available when needed.

I would like to extend my gratitude to the following for financially supporting this work: De Souza Institute, Canadian Association on Gerontology, Nursing Research Interest Group, Registered Nursing Federation of Ontario, Canadian Institutes of Health Research and Ontario Graduate Scholarships. Finally, I would like to acknowledge my family and friends, and particularly my husband, Bill, for the immeasurable support he has given me throughout these years.

Table of Contents

VIII

List of Figures

List of Appendices

1. Chapter One: Introduction

There is evidence to indicate that the type and quality of care given and received in palliative care differs for men and women (Brazil, Thabane, Foster, & Bedard, 2009; Brown, 2004), potentially impacting on health (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Grov, Dahl, Moum, & Fossa, 2005; Grunfeld et al., 2004; Schultz & Beach, 1999) and health care delivery (Clark, Booth, Velikova, & Hewison, 2006; Salander & Hamberg, 2005). However, little is known about how gender relations shape experiences that potentially lead to inequities in health and health care in this context. Most research has examined gender as an individual's masculine or feminine attribute; however, few have analyzed gender relations and the social patterns that shape gender (in)equities (Connell, 2012; Johnson & Repta, 2012).

This dissertation critically examined gender relations and how they shaped client-caregiver-nurse relationships and experiences in the sociopolitical context of hospice palliative home care. For this study, I sought to address the following research questions: (a) How do gender relations shape health and health care experiences within the socio-political context of hospice palliative home care for clients with cancer and their caregivers?; (b) How do gendered processes operate to produce gender relations and potential gender inequities in this context?; and (c) What are the social mechanisms and consequences that (re)produce gender (in)equities in hospice palliative home care?

A critical feminist lens (Smith, 1987, 2005) was used to examine the structural influences on everyday interactions and how dominant and subordinate relationships were (re)produced. A critical ethnographic methodology (Thomas, 1993, 2003) was used to expose gendered attitudes, beliefs, and practices in the culture of hospice palliative home

care. The ultimate goal of this study was to expose gender relations, gendered processes, and mechanisms and consequences of gender (in)equities. This type of analysis is needed to better inform policies and practices that promote strategies for quality, equitable hospice palliative home care for clients with cancer and their family caregivers.

1. 1 Background

1.1.1 The significance of examining gender relations in hospice palliative home care. Although cancer survival rates have been on the rise, cancer death rates remain high because of the growing aging population. New cancer incidence rates occur primarily among Canadians 50 years of age and older (88%), with 95% of the cancer deaths represented within this group (Canadian Cancer Society, 2011). These demographic trends highlight the importance of care during end-of-life, or hospice palliative care for seniors with cancer, and their family members (Canadian Hospice Palliative Care Association [CHPCA], 2012).

The World Health Organization ([WHO], 2011a) defines palliative care as compassionate, quality care for people with life-threatening illnesses and their family members. Care involves assessment and treatment of physical, as well as psychological, social, and spiritual aspects of the illness. While palliative care is available at any stage through the illness trajectory, the focus of hospice palliative care is not on cure of the disease, but rather the quality of life (National Hospice and Palliative Care Organization, n.d.). While often confused with residential places and community-based organizations with a mission to help people to live with life-limiting disease, the term "hospice" in the context of this study is a philosophy of care with an emphasis on quality of life for people with terminal illness and includes family members and friends who are caring for them

(National Hospice Palliative Care Organization, n.d.). The term "hospice palliative care" has been used to unite both hospice and palliative care into one movement (DeMiglio, Dykeman, Williams, & Kelley, 2012) and has been used for this study.

Hospice palliative care is becoming increasingly important for the future, particularly at home. In addition to the growing numbers of older people with chronic illnesses, early hospital discharges (Romanow, 2002) have made it necessary for more care to be provided in the home. Also, technological advancements have permitted more care to be transferred from the institution to home (Ward-Griffin & Marshall, 2003; Wiles, 2005). Many Canadians have indicated a preference to die at home (Brazil, Howell, Bedard, Krueger, & Heidebrecht, 2005; Stajduhar, Allan, Cohen, & Heyland, 2008), as it has been seen as a place where individuals are able to make choices, maintain their privacy, and be comfortable with fewer stresses (Armstrong & Armstrong, 2005; Exley & Allen, 2007). Some have been compelled to stay home because hospital care is perceived to be stressful, inadequate (Stajduhar & Davies, 2005) and unsafe (Gravel et al., 2007; WHO, 2011b). Although the cost and strain of providing hospice palliative care at home has been shifted to families (Cain, MacLean, & Sellick, 2004; Funk et al., 2010; Glazer, 1990; Wiles, 2005), the cost-effectiveness of home care has been promoted as a practical solution to counter deficits by policy makers (Glazer, 1990; Romanow, 2002; Wiles, 2005).

Examining gender relations in hospice palliative home care is important because home is the locus in which the gendered division of labor has been constructed and learned (Angus, 1994; Wiles, 2005). While home is idealized as a site of comfort and support (Exley & Allen, 2007), it is also a place of gendered hierarchies and oppressive

relationships (Armstrong & Armstrong, 2005; Clemmer, Ward-Griffin, & Forbes, 2008). In this context, home is a place of identity, which shapes and organizes social relationships, roles, and normative beliefs and practices (Angus, 1994; Wiles, 2005). In turn, home is shaped by wider social structures such as governments and institutions. For example, government policy to shorten hospital stays and thus reduce health care costs has shifted the burden of care and costs to home, and particularly to women (Armstrong & Armstrong, 2005; Brodie, 2002; England, 2010). Yet, because of the perception that activities occurring within the home are considered as concerns that are private rather than public (Angus, 1994; Wiles, 2005), care and possible inequitable practices within the home are largely made invisible. Thus, home is a physical space as well as a place imbued with symbolic, social, psychological, emotional, and political meanings and implications (Wiles, 2005), particularly in terms of power, relations, and gender.

As such, the provision of care within the home is frequently viewed as a private, family responsibility rather than a collective, public responsibility (Glen, 2010). While Marxist philosophy suggests that waged work has been associated with capitalistic activities outside the home (Armstrong & Armstrong, 2005), scholars argue that family care within the home also must be conceptualized as "work" (Ward-Griffin & Marshall, 2003; Wiley, 2005), differentiating the concepts of "caring about" and "caring for" (Armstrong & Armstrong, 2005; Ward-Griffin, 2004) and thus recognizing and supporting the value of care work within the home (England, 2010). As the concepts of care and home are associated with women and thus highly gendered, it is crucial to examine gender relations within the context of hospice palliative home care in promoting optimal care.

1.1.2 The politics of hospice palliative home care. Broader political forces have an effect on relationships in home care. During the 1990s, in several countries, including Canada, large national debts have been attributed to costly social programs (Armstrong & Armstrong, 2005; Williams, 2006) and have led to cuts in health care spending. Deficit-cutting policy changes of deinstitutionalization and restructuring (Williams, 2006), in turn, have created greater demands on the home care sector, necessitating a restriction of services. At the same time, neoliberal ideologies have emerged, changing the philosophy of government goals from providing services to establishing and maintaining conditions for a market economy. In this context, the notion of independence and autonomy in neoliberal thought has constructed health and health care as an individual, rather than a community responsibility (England, 2010; McGregor, 2001). In terms of hospice palliative care at home, care of a dying relative has been viewed as a private family obligation instead of a collective concern and care and costs have shifted from public to private spaces and from paid to unpaid caregivers (Armstrong & Armstrong, 2005).

While there have been federal, provincial, and regional initiatives to improve quality and access to palliative care, funding has been limited (Gauvin et al., 2013), and few recommendations from a government and organization coalition (Ministry of Health and Long Term Care, Local Health Integration Networks, Quality Hospice Palliative Care Coalition) have been fully implemented (Gauvin, Abelson, & Lavis, 2013). Despite numerous initiatives, palliative care in Canada remains fragmented and inconsistent across settings and regions (DeMiglio et al., 2012; Williams et al., 2010), making it difficult to develop and sustain equitable standards of care. Federal funding transfers to provinces legislated under the Canada Health Act (1984) are enforced separately by each

province, leading to a devolution of funds and differential services across and within provinces (Williams et al., 2010). A Canadian policy on palliative care (The Way Forward: Moving Towards Community-Integrated Hospice Palliative Care in Canada) advanced by the government and community advocacy groups is presently in the stages of development to improve equitable access and quality of care to all Canadians (CHPCA, 2014).

The Canadian Government also has attempted to address caregivers' needs during end-of-life with the Compassionate Care Benefit. However, research has indicated that accessing information and negotiating the application process for this subsidy adds further strain for family caregivers (Crooks, Williams, Stajduhar, Allan, & Cohen, 2007). The Compassionate Care Benefit is a program in which employed family members of terminally ill relatives can take a six-week leave with payment of up to 55% of their insurable earnings (Crooks et al., 2007). However, few can afford to take time off paid employment for less pay, which particularly disadvantages lower income families. Moreover, the people who are unemployed or working part-time, mainly women caring for children and elders at home, are ineligible for this benefit. Thus, this program creates a gendered bias in terms of optimal hospice palliative home care (Armstrong & O'Grady, 2004; Crooks et al., 2007).

The political discourse of limited finances and resources has affected health care professionals' practices in home care. Financial constraints have led nurses to shorten the time they spend with clients and to manage client care using an authoritative top-down approach to care (McWilliam, Ward-Griffin, Sweetland, Sutherland, & O'Halloran, 2001; Oudshoorn, Ward-Griffin, & McWilliam, 2007). Clients and caregivers have experienced

a climate of rationed services, hindering the development of therapeutic relationships (Oudshoorn et al., 2007), and creating situations in which caregivers feel pressured to provide care (Stajduhar, Nickel, Martin, & Funk, 2008). Operating within a constrained system, nurses at times have engaged in exploiting the labor of family caregivers by transferring formal nursing care to family members, particularly those who are less able to resist demands (Ward-Griffin, McWilliam, & Oudshoorn, 2012 b; Ward-Griffin & McKeever, 2000). More specifically, in Ontario, the Community Care Access Centres (CCACs) have contracted out in-home care to private for-profit agencies creating competition and frequent changes in the provision of care (Williams, 2006). These structural changes have led to instability for agency employees, increased workloads, and added stress, often leaving nurses to explain the deficit in services (England, 2010; Williams, 2006). These policy-driven practices not only have compromised care, they have led to differential treatment of clients and family members, possibly privileging some, while disadvantaging others. Moreover, as these practices have occurred within private homes, they are hidden from public scrutiny (Armstrong & Armstrong, 2005). Thus, more investigation is needed to reveal client-family caregiver-nurse interactions in home care, and in particular, the gender enactments and processes that shape the practices and experiences in end-of-life home care.

   1.1.3 The context of hospice palliative home care. Effective hospice palliative home care involves both paid and unpaid caregivers (Stajduhar, Funk, Roberts et al., 2010). Unpaid caregivers are usually friends or family members of the person with a terminal disease. They provide physical, emotional, and psychological support and increasingly assume more medical and technical responsibilities such as the management

of symptoms and treatments (CHPCA, 2012; Funk et al., 2010; Haley, 2003). Dependent upon the physical effects of the disease and treatment, caregiving responsibilities for individuals dying of cancer can vary, ranging from assistance with activities of daily living to extensive care of debilitated individuals (Haley, 2003). Caregiving also includes emotional work involving the management of emotions for persons with cancer and other family members (Thomas, Morris, & Harman, 2002) and intense periods when having to make critical care decisions for loved ones who are dying (Grov et al., 2005).

Social relationships between and among clients, family caregivers, and nurses are essential for optimal hospice palliative home care (Funk et al., 2010; Walsh & Luker, 2010; Ward-Griffin & McKeever, 2000: Ward-Griffin, McWilliam, & Oudshoorn, 2012a, 2012b). Quality hospice palliative home care involves the development of trusting, collaborative relationships in which the caregiver is viewed as a "co-worker" (Ward-Griffin et al., 2012a, 2012b). In turn, family caregivers have expressed their desire for partnerships with health care providers (Funk et al., 2010). Relationships among the "co-partners" in home care have been found to profoundly affect health care experiences (Stajduhar, Funk, & Roberts, 2010; Ward-Griffin et al., 2012a, 2012 b). There is evidence to indicate client-family caregiver-nurse relationships impact on nurses' decisions regarding access to care (Stajduhar, Funk, & Roberts et al., 2010). The amount, type, and quality of service provided also may be affected by social relations of gender.

Research indicates that health care providers spend more time with patients of the same gender (Franks & Bertakis, 2003; Govender & Penn-Kekana, 2008), potentially advantaging some, while disadvantaging others. Also, patients may withhold reporting symptoms such as pain in order to maintain gendered cultural norms (Govender & Penn-

Kekana, 2008). More specific to care related to clients with advanced cancer, research suggests women, more than men, provide intimate care such as bathing and toileting (Brazil et al., 2009; Brown, 2004), possibly because of traditional gendered roles. Rather than assume the reasons for this gender difference in palliative experiences, more research is needed to examine the sociopolitical factors that may contribute to potentially inequitable experiences of this nature.

Although clients and family members have access to specialist palliative care teams, at least in urban settings, everyday care is often provided by generalist paid care providers (CHPCA, 2006; McWhinney et al., 1995). Paid caregivers are health care providers. In most jurisdictions in Canada, including Ontario (Quality End-of-Life Coalition of Canada, 2008), palliative care often involves a specialist team that includes physicians, nurses, personal support workers, and other allied health professionals such as physiotherapists, occupational therapists, and social workers. Members of the specialist teams have additional qualifications to care for people with life-threatening diseases. For example, nurses may complete specialty exams to obtain certification in hospice palliative nursing care (Canadian Nurses Association, 2010).

A newer model of hospice palliative care promotes integration of specialist palliative care services with acute, disease modifying care. In opposition to older models of care in which palliative care is initiated when curative treatment options are exhausted, point of entry in a newer model begins at diagnosis of potentially life-limiting disease and would include greater involvement of palliative care and extension to end-of-life and bereavement as needed (See Figure 1) (Canadian Hospice Palliative Care Association, 2002; Local Health Integration Networks [LHIN] & Quality Hospice Palliative Care

Coalition of Ontario [QHPCCO], 2011; Ontario Medical Association, 2014) . Early

introduction of palliative care facilitates critical transition periods in the illness trajectory,

thereby increasing access to palliative care (Prastana & Junger, 2008) and improving

quality of life (Bakitas et al., 2009; Temel et al., 2010). However, many researchers,

organizations, and palliative care specialists have continued to consider palliative care as

an approach to be introduced at "terminal" stages of illness (Pastrana & Junger,

2008),wherein terminal, or end-stage, is not clearly defined. As such, many clinicians

have referred to palliative services late in the illness trajectory (Bruera & Hui, 2010;

Keating et al., 2010; Partridge, 2014). Reluctance to refer to palliative services early in

the illness trajectory may be because of the predominance of the biomedical, curative

paradigm in health care (Williams et al., 2010)

Despite advancement of early integration of palliative care (LHIN & QHPCCO,

2011), the older palliative care model has been reflected in hospice palliative home care

policies that stipulate entry into programs by prognosis of illness and estimated time to

death. At the start of this study, entry to the CCAC hospice palliative home care program

was one year prognosis to death, which changed to six months to anticipated death,

resulting in less time for the development of relationships between and among health care

providers and clients and caregivers.

Figure 1. Model of Palliative Care
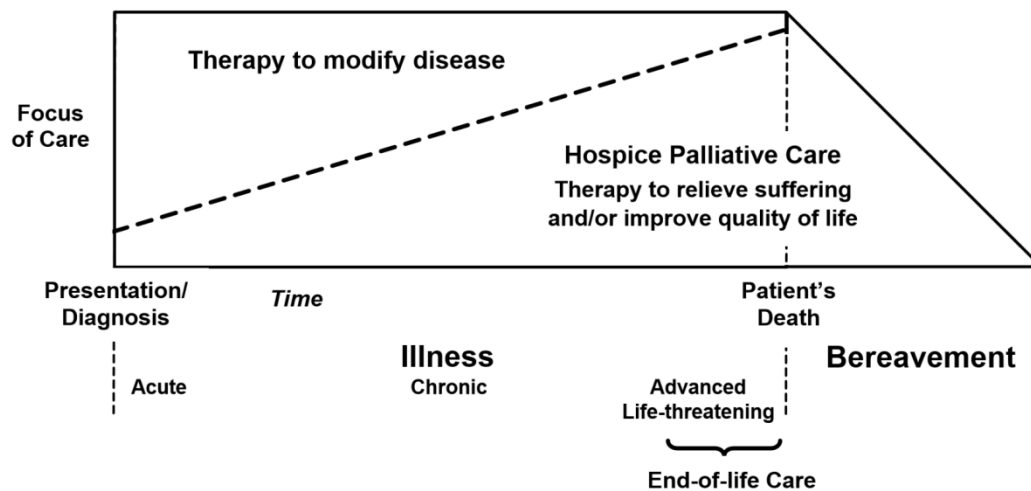
Canadian Hospice Palliative Care Association (2002)

Other models of care delineate how specialist palliative care programs are integrated within the health care system. Specialist palliative care teams enter into care either as consultants, collaborators, or sole providers of care (Luckett et al., 2014; Partridge et al., 2014). In this study, the specialist palliative care teams within hospice palliative care programs played a prominent role in the care of clients and caregivers with collaboration between and among family physicians and oncology specialists, and often alongside disease modifying treatment. Regardless of the type of model used, registered nurses have played a key role within all models of care (Seow, 2014).

Nurses and supportive care workers, such as personal support workers, have the greatest amount of contact with home care clients and their family caregivers (Ontario Home Care Association, 2011). Personal support workers are non-registered health care providers who assist clients with non-medical tasks of daily living. Registered nurses are the primary professional personnel who not only provide direct care, but also coordinate

care among clients, family caregivers, and other health care team members. They assess, educate, counsel, and manage the care of clients and family caregivers, often facilitating and organizing home care services (CHPCA, 2006; Ontario Home Health Care Association, 2011). Home care agencies make an effort to have a primary nurse assigned to the client and family to provide increased continuity and quality of care (CHPCA, 2006). In these roles, nurses are often responsible for care decisions critical to providing access to services (Stajduhar, Funk, & Roberts et al., 2010). While nurses may at times feel powerless because of system constraints, they also may exercise power by managing care with little negotiation among clients (Oudshoorn et al., 2007). Also, nurses' negative feelings or discomfort in relationships with clients and family members may lead to fewer client-nurse interactions and nurse activities (Stajduhar, Funk, & Roberts et al., 2010). As nurse members of the health care team play a central role in home care, it is important to focus on nurses to examine issues of equity in everyday hospice palliative home care.

While there has been evidence to suggest that gender differences exist in hospice palliative home care, little is known of how gender relations are enacted between and among clients, family caregivers, nurses in the context of broader social structures that influence the receipt and delivery of equitable hospice palliative care. This study sought to examine gender relations and the gendered processes, mechanisms and consequences that (re)produce gender (in)equities.

1.2 Conceptualizing Gender

The concept of gender is understood by its differentiation from sex and sex category (CIHR, 2000; Johnson, Greaves, & Repta, 2007; West & Zimmerman, 1987, 2009). Sex is a biological category based on the presence of reproductive organs

(Connell, 2009; Johnson et al., 2007;West & Zimmerman, 1987, 2009). Ironically, the category of sex is represented on a daily basis, not by revealing reproductive organs, but through features of appearance, dress, and gestures that display whether one is male or female, thus pointing towards a social rather than biological organization of what constitutes femininity and masculinity (West & Zimmerman, 1987, 2009). In this context, there is a "doing" of gender that is accomplished through interaction with others (Charlebois, 2011; West & Zimmerman, 1987; 2009).

While gender is conceptualized as a dynamic interaction between individuals, men and women do not freely choose how to "do" gender. Rather, individual agency in "doing" gender is influenced through socially ascribed attitudes, beliefs, and practices of femininity and masculinity (Charlebois, 2011). Thus, gender appropriate behaviours are prescribed and regulated by broader social structures such as institutions (Charlebois, 2011). Social structures are viewed as formal, legal, and governmental institutions as well as informal cultural traditions that determine practices and rules (Sen & Ostlin, 2008).

Others view structures as governed macro or micro interactions (Charlebois, 2011) or organized relationships (Connell, 2009) that dictate behaviours, connections, or limitations. Smith (1987, 2005) refers to structures as "ruling relations," more specifically outlining them as textually mediated relations of corporations, government bureaucracies, academic and professional discourses, or mass media that organize everyday lives. Structures organize and constrain gendered behaviours by dictating responsibilities of home and work, according power and prestige, allocating resources, and organizing relationships (Lorber, 1994). These hierarchal gender differences become everyday taken-for-granted attitudes, beliefs, and practices and are thus institutionalized through

normative images and discourses in government policies, organizational practices, or the media (Ridgeway & Correll, 2004). Embedded within cultural and social structures, gender, then, must be conceptualized as relational, occurring amongst levels of the interpersonal, intrapersonal, and structural and affecting power, economics, emotions, ideologies, and thus attitudes, beliefs, and practices (Botorff, Oliffe, Robinson, & Carey, 2011; Charlebois, 2011; Connell, 2009).

For this study, I conceptualize gender as relational to capture these dynamic, interactional aspects of gender (Connell, 2012). A relational approach to gender moves beyond a dichotomous, categorical view of men and women to an analysis of social interactions that enhance or limit opportunities for health and well-being (Botoroff , Oliffe, Robinson, & Carey, 2011; Connell, 2012; Schofield, Connell, Walker, Wood & Butland, 2000). This type of approach enables an examination of the ways in which gender inequities are created and sustained (Connell, 2012). In the next section, I discuss how gender is related to equity and health.

1.3 Gender, Equity, Social Justice, and the Social Determinants of Health

There has been little agreement of the definition of the term equity in the literature. Conceptualized differently within diverse disciplines such as philosophy, economics, and social sciences, the meaning has been clouded further as it has been used interchangeably with the terms equality, disparity, and social justice. For this study, I employ a "social determinants of health" perspective of equity in which social factors such as gender are considered central to accessing resources that shape health care experiences and thus opportunities for health and well-being (Raphael, 2009).

Inequities in health and health care are differences that are unnecessary and unjust (Whitehead & Dahlgren, 2006). Equity has been regarded as a normative term, meaning that it is value-based (Braveman et al., 2011), the connotations of unfair or unjust derived from ideologies of those in power (Falk-Rafael, 2005). Thus, while an inequality or disparity can be measured, an equity or inequity cannot. Equity is an essential component of social justice (Davison, Edwards, Webber, & Robinson, 2006; Falk-Rafael, 2005), which is widely defined as a concern for the equal distribution of resources (Rawls, 1971). This concept of social justice is economically based and reflects neoliberal ideologies of a free market economy, individualism, and egalitarianism in which conditions are shaped by individual efforts or market forces that are self-regulating and with minimal government intervention (Pauly, MacKinnon, & Varcoe, 2009; Reimer Kirkham, & Browne, 2006). According to this distributive justice, social factors are inconsequential and the failure to cope in end-of-life would be considered a result of personal failure rather than influenced by structural factors (Pauly, 2008; Reimer Kirkham & Browne, 2006).

Social justice within a social determinants of health perspective considers that health is influenced by sociopolitical factors such as income, education, and gender and gives rise to hierarchal differences in power and therefore differential access to social resources (e.g., education, employment, money), ultimately shaping people's health experiences (Graham, 2004; Marmot, Firel, Bell, Houweling, & Taylork, 2008 ; Raeburn & Rootman, 2007; Raphael, 2009). Thus, the redressing of inequities is directed towards public policies and practices that establish and organize social relations and accord material and non-material resources such as status and respect (Raphael, 2012; Reutter &

Kushner, 2010). These non-material resources include political, social, and symbolic means that afford control, time for relaxation, or recognition of care work (Armstrong, 2002). Thus, these resources are the conditions that enhance opportunities for well-being. Analogous to a critical feminist viewpoint of social justice, what determines health in this approach are the social conditions to which people are exposed, requiring an "upstream" solution that addresses the root of the problem.

Gender is one of the most pervasive and influential social determinants of health (Sen & Ostlin, 2008). As resources are distributed through power relations and social structures, social relations of gender can affect health. Cultural and social norms construct gendered rules and roles, creating power differentials and thus constraining men's and women's attitudes, beliefs, and practices and creating obstacles for opportunities of well-being (Doyle, 2000, Marmot et la., 2008; Sen & Ostlin, 2008; Spitzer, 2005). An equity lens using a social determinants of health approach and examining broader social factors that influence social relations such as gender is crucial to better inform policies and practices and promote strategies for gender equity. Furthermore, failure to address gender equity may perpetuate inequitable practices, rendering it particularly unjust for persons in vulnerable situations such as end-of-life.

A significant focus of health promotion is achieving equity (WHO, 2009). Unfair access to resources creates opportunities and disadvantages, helping and hindering people in reaching their life aspirations. Failing to attend to inequities results in the reinforcing of privileges at the expense of the disadvantaged (Raphael, 2012). A critical methodology is needed to uncover everyday social relations of gender and address inequitable practices and policies.

1.4 Health Promotion and Hospice Palliative Care

While the concept of health promotion is often overlooked in the life stage of palliation and death (Stajduhar, Funk, Jakobsson, & Ohlen, 2010), health-promoting palliative care has been advanced as increasing control and support for those living with serious life-threatening illness (Kellehear, 1999). It includes education about death and dying, everyday quality of life, and personal and community support such as decision-making and support groups (Stajduhar, Funk, Jakobsson et al., 2009; Kellehear, 1999). More broadly, health-promoting palliative care involves altering community discriminatory attitudes, adjusting health care services, and developing policies that enhance palliative care (Kellehear, 1999), and in this context, promoting equitable and quality hospice palliative care.

In summary, a major focus of health promotion is to ensure equity in the opportunities for people to access resources, make choices, and achieve their full health potential (Whitehead & Dahlgren, 2006;WHO, 2009). As gender is a power-laden social relation that constrains attitudes, beliefs, and practices, and thus shapes experiences and opportunities for well-being, it is important to examine gender relations in the sociopolitical context of hospice palliative home care.

As hospice palliative home care experiences can be challenging and consuming (Ward-Griffin et al., 2012 a, 2012b; Funk et al., 2010), affecting participants' physical, emotional and financial well-being, this is a time in which few clients and caregivers will recognize or challenge gender inequities, making it essential to ensure strategies for equitable policies and practices. Failure to do so will result in the maintenance of inequities and further disadvantage those in vulnerable situations (Raphael, 2012).

Furthermore, as gendered attitudes and beliefs may be more salient in home and as inequities may be less visible, away from public scrutiny, it is important to expose gender inequities and how they are shaped and sustained in hospice palliative home care. Finally, as increases in the aging population are adding to the rising incidence of cancer deaths (Canadian Cancer Society, 2011), it is both imperative and timely to promote equitable practices and policies in this context.

In terms of study significance, findings from this study add to the understanding of gender relations and how they are constructed at personal and system levels to (re)produce gender (in)equities. This knowledge is important to consider in the development of practices and policies in hospice palliative home care to promote quality and equitable care. Inequitable policies and practices have the potential to negatively impact on clients' and caregivers' health care experiences. Study findings illuminate for nurses and nurse educators gender relations and their impact on health and health care experiences. Furthermore, study findings are particularly valuable to inform standards and guidelines for nursing practice with regard to gender relations. Ultimately, this study contributes to nursing as it urges nursing leaders to ensure that the profession pays attention to gender relations and gender inequities to meet the professional mandate of social justice.

1.5 The Review of the Literature

Having established the importance of examining gender relations in hospice palliative home care, I now turn my attention to what is currently known in this area. I conducted a literature review to examine studies that investigated gender relations in hospice palliative home care. The following terms were used in the preliminary search:

cancer, end-of-life, hospice, palliative care, and terminal care with caregivers, family members, and home care. A second search was undertaken using the terms gender, male, female, and men and women. The following search engines were used: Pub Med, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Proquest Nursing and Allied Health Source, Web of Science and SCOPUS. Reference lists were scanned for further articles and highly relevant articles were searched through Web of Science to recover further literature. Studies that included palliative care in other stages of the cancer illness trajectory were included. No studies were found that examined gender relations between and among clients, family caregivers, and nurses. Studies that examined gender from the perspective of the client, family caregiver, and nurse were included. As such, the literature review has been categorized into three sections: gender relations and clients in hospice palliative home care, gender relations and caregivers in hospice palliative home care and gender relations and nurses. As there were no studies found that specifically examined gender relations of nurses in hospice palliative home care, studies that examined gender in other health care areas were included.

      1.5.1 Gender relations and clients with cancer in hospice palliative home care. While the evidence of how gender shapes clients' experiences is unclear, studies have indicated that cultural relational patterns of gender lead to gender differences and potential inequities. Generally, women have reported more negative health care experiences than men. Women have experienced more feelings of loneliness ($P<0.0001$) and fear ($P<0.0001$) than men (Thome & Hallberg, 2004). Also women have reported more feelings of frustration and perceived that they had fewer choices during the period

of their illness of advanced cancer (Spiroch, Walsh, Mazanec, & Nelson, 2000), perhaps reflecting gender relations that are not ideal.

Additionally, women, but not men, have reported that their complaints of pain have been discounted by health care professionals (Im, 2006). In the examination of virtual case studies, health care providers have tended to rate and treat men's pain higher in comparison to women (Wadner et al., 2014). Clinical studies examining men and women experiencing pain related to advanced cancer have shown that physicians have underestimated pain severity more for women (79%) compared to men (59%) ($P<0.05$) (Anderson et al., 2000). Gendered interactions may have been related to beliefs that "strong" men are reluctant to report pain. Because of this belief, assessment of men's pain has been typically underrated, while it is expected that women's pain is overrated because of assumptions that women have less pain endurance than men (Robinson et al., 2001). These findings suggest men's and women's interpersonal and cultural relations affect gender relations; however, there is a gap in our knowledge of how these gendered attitudes, beliefs, and practices in hospice palliative home care are affected by social structures.

Findings about the quality of life of men with advanced cancer have revealed an association between dependency and depression. Such findings may reflect gender relations shaped by beliefs that men should be traditionally strong and autonomous. Men who have required help with activities of daily living (e.g., eating, toileting, washing, dressing) have experienced more depression compared to their female counterparts (OR 2.3 with 95% CI 1.3 to 4.3, p=0.0006) (Hayes et al., 2012). However, other studies have shown no gender differences in quality of life scores (Hagedoorn Buunk, Kuijer, Wobbes,

& Sanderman, 2000; Husain et al., 2007; Jacobs-Lawson, Schumacher, Hughes, & Arnold, 2010), raising questions about the nature of gendered relations in health care.

In terms of receiving emotional support, men have preferred to receive information (Clark et al., 2006) and have used a problem-solving approach (Fife, Kennedy, & Robinson, 1994). Also, men have tended to rely on support from their partners (Clark et al., 2006; Fife et al., 2004; Graham & Palmer, 2002; Greimel, Padilla & Grant, 1998). In contrast, women with cancer have relied on a wider range of supports including family members, friends, and professionals (Clark et al., 2006), possibly reflecting gendered attitudes and beliefs that women assume caring for others as well as themselves and must seek out care from all sources. Compared to men, women have reported significantly higher needs for emotional and professional support (McIllmurray et al., 2001) and discussion of their journeys (Seale, 2006), again reflecting gender relations are a fundamental consideration in the enactment of health care.

In summary, the evidence related to gender relations from the perspective of clients with cancer may be influenced by interpersonal and cultural gendered attitudes, beliefs, and practices. However, what is not revealed is how broader contextual structures such as government and non-governmental organizations and agencies (e.g., health care agencies) affect clients' daily gendered experiences and how gendered processes operate and unfold within hospice palliative home care. An analysis that includes the relational processes and structural impact of gender will assist in identifying, understanding, and challenging gendered processes and possible inequities in everyday hospice palliative home care. In this way, relevant strategies may be developed to assist in promoting gender equity.

1.5.2 Gender relations and family caregivers in hospice palliative home care.

Research has shown that women have been expected by family members and health care providers to assume responsibility for care of relatives during end-of-life (Clemmer et al., 2008). Women have been positioned by others as expert carers, emotional supporters, and decision-makers (Ussher & Sandoval, 2008). Researchers have concluded that health care providers and family members have influenced and expected women to adopt the caregiver role based on societal ideology that women are natural caregivers (Clemmer et al., 2008; Ussher & Sandoval, 2008). These high expectations during times when women are least able to refuse may account for evidence that indicates female caregivers are more psychologically distressed than their male counterparts during end-of-life care experiences (Brazil et al., 2009; Burridge, Barnett & Clavarino, 2008; Chapman & Peppler, 1998; Dumont et al., 2006; Hoogedoorn, Sanderman, Bolks, Tuinstra, 2008; Mystakidou et al., 2012; Payne, Smith & Dean, 1999; Rivera & McMillan, 2010). Female caregivers have reported significantly higher levels of anxiety ($p<0.01$), depression ($p<0.01$) and unmet needs (<0.01) than men (Ussher & Sandoval, 2008). They also have experienced decreased satisfaction with health professionals ($p<0.01$) and greater burden on their time than their male counterparts (<0.05) (Ussher & Sandoval, 2008).

Additionally, whereas men have provided care mostly to their spouses, women have cared for a broader range of people including partners, siblings, and parents (Perz, Ussher, Butow, & Wain, 2013), possibly because of traditional attitudes and beliefs that women should provide care. Research has shown that women have been more likely to be involved in toilet-related tasks (OR=1.98, p=.044) (Brazil et al., 2009) and personal body

care, whereas men have been encouraged to retrieve supplies and medications (Brown, 2004). This evidence suggests that care may be delegated to, or assumed by, women differently from men because women are considered to be natural nurturers who traditionally provide intimate care.

While research to date has indicated that societal attitudes, beliefs, and practices affect men and women's experiences in hospice palliative home care, a fuller analysis is needed to understand how broader social factors influence gendered practice patterns throughout this care experience. This understanding is needed to identify and challenge gender inequities during this vulnerable time when clients and caregivers focus on end-of-life. Also, the majority of research examining family caregivers during end-of-life has been generated from data derived from individual interviews. As gender and gender inequities are socially constructed, what is needed is an examination of interactive social relations of gender between and among nurses, clients, caregivers and other social structures. A research design such as ethnography is required to capture dynamic gendered attitudes, expressions, and responses.

1.5.3 Gender relations and nurses. No studies have been found that examined nurses' gender relations in hospice palliative home care. Studies that examine gender in other areas of nursing have been included in this review. Research has found that female nurses have reified gendered assumptions of caring attitudes as inherently female (Bolton, 2005). Bolton's (2005) study involving 25 gynecological nurses revealed that female nurses have associated their type of care with "dirty" work, reinforcing societal assumptions of women's devalued work of bodily care for others. In contrast, male nurses have been encouraged by female nurses to move to managerial and highly technical areas

(Simpson, 2009). Male nurses have often been characterized as protectors (Simpson, 2009) as they have been asked to intervene in confrontational interactions with patients (Pullen & Simpson, 2009; Whittock & Leonard, 2003). While female nurses have spent significantly more time (mean=25.17 minutes) than male nurses (mean 15.02) interacting with patients (mean difference=10.14 minutes, $p<0.05$), male nurses have indicated lower job satisfaction when they perceived spending time with a patient (Torkelson & Seed). However, it may be that patients are more receptive and responsive to female rather than male nurses because they view women as having natural tendencies to care. Furthermore, it may be that male nurses are asked to care for more aggressive patients, or that they avoid interactions that may be interpreted as sexual. Clearly, more research is needed that explicates gender relations in the provision of nursing care, particularly in hospice palliative home care.

In caring for female patients, male nurses have been found to be hesitant in their use of touch, concerned that it may be interpreted as sexual (Evans, 2002; Evans & Frank, 2003; Fisher, 2009; O'Lynn & Krautscheid, 2011) and have projected a more authoritative, distant manner in providing care (Pullen & Simpson, 2009). Moreover, because they are expected to be strong, male nurses have tended to show little emotion (Milligan, 2001). This suggests that cultural assumptions of femininity and masculinity shape client-nurse relationships, and everyday practices in the delivery of care.

For female nurses, exposure to sexual harassment has been found to be widespread (Bronner, Pretez, & Ehrenfeld, 2003), and a daily aspect of nurses' jobs (McGuire, Dougherty, & Atkinson, 2006). While many nurses have not been able to recall specific incidents, they have described numerous situations of unwanted sexual

provocations. One study also has indicated that male nurses, more than female nurses, have reported experiencing a threat of assault, emotional abuse, and sexual harassment (Andrews, Stewart, Morgan, & Darcy, 2012). As men are viewed as predatory, they have been accused of "over involvement" with patients (Chiarella & Adrian, 2014). While female nurses have sent holiday cards to patients without judgment, for example, male nurses have been accused of crossing professional boundaries for the same behaviour, indicating discriminatory attitudes that women rather than men assume responsibility for care, bodies, and health (Chiarella & Adrian, 2014). Thus, both male and female nurses are affected by gendered cultural attitudes, beliefs, and practices, at times influencing the way they approach and maintain relationships.

While there has been evidence to indicate nurses' attitudes, beliefs, and practices have been influenced by cultural assumptions of femininity and masculinity, there is little discussion in the literature of how structural organizations and agencies organize and influence gender relations to affect nurses' relationships with clients and caregivers and how gendered processes and gendered inequities are constructed in hospice palliative home care. A gender-based analysis is needed to ensure equitable and high quality care in this context.

1.6 Summary of the Literature Review

This literature review has found that men and women in hospice palliative home care have different experiences because of their gender (Clark et al., 2006; Fife, Kennedy, & Robinson, 1994; Graham & Palmer, 2002; Greimel, Padilla, & Grant, 1998) and that health care providers have reacted and responded to men and women differently (Evans, 2002; Evans & Frank, 2003; Im, 2006; McGuire et al., 2006; Milligan, 2001; Pullen &

Simpson, 2009; Simpson, 2009; Wadner et al., 2014; Whittock & Leonard, 2003). In turn, patients and caregivers have behaved in specific ways in order that health care providers and others may sanction their gendered identities (Brazil et al., 2009; Brown, 2004; Chiarella & Adrian, 2014; McIllmurray, 2001; Seale, 2006; Perz et al., 2011). In essence, gender affects relationships and may contribute to inequities by way of influencing how men and women are treated (e.g., with respect, rewards), how power is accorded, or how resources are allocated. While studies point to interpersonal and cultural factors that influence gendered relations in hospice palliative home care, there is limited exploration about how gendered relations are enacted and how social structures and institutions influence gendered attitudes, beliefs, and practices in this context. It is important to examine social structures in order to address upstream approaches to achieve gender equity.

Instead of examining the interactional dynamics of gender relations, most research has used a categorical approach to compare men's and women's experiences, thus potentially essentializing and reifying femininities and masculinities. Unlike a relational approach in which structural dominant relationships are examined, a categorical perspective fails to address issues of power that lead to hierarchal relations and potential inequities. A gender relational approach permits analysis of the micro and macro social factors that influence gender relations. This type of research is essential to expose how gender relations, processes, and potential inequities are shaped and may be challenged. Moreover, viewing gender as relational is in keeping with a social determinants of health perspective that focuses on the social, cultural, political, and economic conditions that shape inequities.

1.7 Overview of the Dissertation

In this chapter, I have described the context of hospice palliative home care and the salience and importance of gender relations of in-home care. I have outlined the significance of conceptualizing gender as relational and the use of a critical, social determinants of health equity lens to examine power and structural influences on day-to-day health care encounters in hospice palliative care. I also have identified the current knowledge and knowledge gaps in this area.

In Chapter Two, I explain the methodology of the study and include the purpose and utility of using a critical feminist lens and a critical ethnographic methodology. I describe the use of interview, observation, and document review methods for data collection. The sample, setting, data analysis, study rigour, and knowledge translation strategies are also explicated.

In keeping with the integrated article format as outlined in the Western University Graduate Studies and Postdoctoral Studies Department, this dissertation includes in Chapters Three, Four, and Five, three manuscripts prepared for future publication. In Chapter Three, "Gendered Expectations and Exemptions in Hospice Palliative Home Care," I expose the sociopolitical context that shape gendered expectations and exemptions in hospice palliative home care. I shed light on the ideological processes that support the regulating of gender relations in Chapter Four, "Gendered Processes in Hospice Palliative Home Care." For the final manuscript, Chapter Five, "(Re)producing Gender (In)equities in Hospice Palliative Home Care," I illuminate the mechanisms of gender (in)equities: *Preservation/Destruction of Gender Stereotypes* and an '*Imbalance /Balance of Power'* and how they (re)produce gender (in)equities in this context.

Finally, for Chapter Six, I describe the major insights and key implications that have emerged from this study. I discuss the study strengths and limitations and reflect on the methodologies used and the methodological issues that I encountered.

1.8 References

Anderson, K., Mendoza, T., Valero, V., Richman, S., Russell, C.Hurley, J….Cleeland, C.
(2000).

Minority cancer patients and their providers: Pain management attitudes and

practice. *Cancer, 88* (8), 1929-1938

Andrews, M., Stewart, N., Morgan, D., & D'Arcy, C. (2012). More alike than different: a

comparison of male and female RNs in rural and remote Canada. Journal of

Nursing Management, 20, 561-570. doi: 10.1111/j.1365-2834.2011.01195x

Angus, J. (1994). Women's paid/unpaid work and health: Exploring the social context of

everyday life. *Canadian Journal of Nursing Research, 26* (4), 23-42.

Armstrong, P. & Armstrong, H. (2005). Public and private: Implications for care work.

The Sociological Review, 53 (s2), 167-187. doi: 10.1111/j.1467-

954X.2005.00579.x

Armstrong, P., & O'Grady, K. (2004). Compassionate care not compassionate enough.

Canadian Women's Health Network – Network Magazine, 6 (4). Retrieved from:

http://www.cwhn.ca/en/node/39518

Bakitas, M., Lyons, K., Hegel, M., Balan, S., Brokaw, F., Seville…Ahles, T. (2009).

Effects of palliative care intervention on clinical outcomes in patients with

advanced cancer: the project ENABLE II randomized controlled trial. *The Journal

of the American Medical Association, 302* (7), 741-749. doi:

10.1001/jama.2009.1198.

Bolton, S. (2005). Women's work, dirty work: The gynaecology nurse as 'other.'

    Gender, Work and Organization, 12 (2), 169-186. doi: 10.1111/j.1468-

    0432.2005.00268.x

Botoroff, J., Oliffe, J, Robinson, C., & Carey, J. (2011). Gender relations and health

    research: A review of current practices. *International Journal for Equity in*

    Health, 10 (60). Retrieved from http://www.equityhealhtj.com/content/10/1/60

Braun, M., Mikulincer, M. Rydall, A., Walsh, A., Rodin, G. (2007). Hidden morbidity in

    cancer: spouse caregivers. *Journal of Clinical Oncology, 25* (30), 4829-4834.doi:

    10.1200/JCO.2006.10.0909

Brodie, J. (2002). The great undoing: State formation, gender politics, and social policy in

    Canada. In C. Kingfisher (Ed.) *Western welfare in decline: Globalization and*

    women's poverty. Philadelphia: University of Philadelphia Press.

Brazil, K., Howell, D., Bedard, M., Krueger, P., & Heidebrecht, C. (2005).Preferences for

    place of care and place of death among informal caregivers of the terminally ill.

    Palliative Medicine, 19, 492-499.

Brazil, K., Thabane, L., Foster, G., & Bedard, M. (2009). Gender differences among

    Canadian spousal caregivers at the end of life. *Health and Social Care in the*

    Community, 17 (2), 159-166. doi: 10.1111/j.1365-2524.2008.00813.x

Bruera, E., & Hui, D. (2010). Integrating supportive and palliative care in the trajectory of

    cancer: Establishing goals and models of care. *Journal of Clinical Oncology, 28*

    (25), 4013-17. doi: 10.1200/JCO.2010.29.5618

Bronner, G., Pertez, C., & Ehrenfeld, M. (2003). Sexual harassment of nurses and nursing

    students. *Journal of Advanced Nursing, 42* (6), 637-644. Retrieved from:

http://journals2.scholarsportal.info.proxy2.lib.uwo.ca:2048/journal.xqy?uri=/0309
2402

Brown, M. (2004). Between neoliberalism and cultural conservatism: spatial divisions
and multiplications of hospice labor in the United States. *Gender, Place and
Culture, 11* (1), 67-82. doi:10.1080/0966369042000188558

Burridge, H., Barnett, A., Clavarino, A. (2009) The impact of perceived stage of cancer
on carers' anxiety and depression during the patients' final year of life.
Psychooncology. 18, 615-23.doi: 10.1002/pon.1435

Cain, R., MacLean, M., & Sellick, S.(2004). Giving support and getting help: Informal
caregivers' experiences with palliative care services. *Palliative and Supportive
Care, 2*, 262-272. doi: 10.107/S1478951504040350

Canadian Cancer Society's Steering Committee on Cancer Statistics (2011). *Canadian
CancerStatistics 2011*. Toronto, ON: Canadian Cancer Society.

Canadian Hospice Palliative Care Association (CHPCA) (2002). *A model to guide
hospice palliative care.* Retrieved from:

www.chpca.net/uploads/.../model_to_guide.../Table-of-contents-etc.pdf

Canadian Hospice Palliative Care Association (CHPCA) (2006).*The pan-Canadian gold
standard for palliative home care.* Retrieved from: www.chpca.net/pan-
cdn_gold_standards

Canadian Hospice Palliative Care Association (CHPCA) (2012). *Hospice palliative home
care fact sheet, 2012*. Retrieved from:

http://www.chpca.net/media/7622/fact_sheet_hpc_in_canada_may_2012_final.pdf

Canadian Hospice Palliative Care Association (CHPCA) (2014) *The Way Forward National Framework: A roadmap for the integrated palliative approach to care (Second draft for stakeholder feedback)*, The Way Forward initiative, Spring 2014. Retrieved from http://www.hpcintegration.ca/media/54625/TWF-framework-doc-Eng-2014-final.pdf

Canadian Institutes of Health Research (CIHR). (2000). *Gender and sex-based analysis in health research: A guide for CIHR researchers and reviewers*. Retrieved from http://www.cihr-irsc.gc.ca/e/32019.html

Canadian Nurses Association [CNA] (2010) *Social justice: A means to an end, an end in itself*.

Retrieved from www.cna-aiic.ca/Social_Justice_2010

Chapman, K., & Peplar, C. (1998). Coping, hope and anticipatory grief in family members in palliative home care. *Cancer Nursing, 21,* 226-234

Charlebois, J. (2011). *Gender and the construction of hegemonic and oppositional feminism*. Plymouth: Lexington Books

Chiarella, M., & Adrian, A. (2014). Boundary violations, gender and the nature of nursing work. *Nursing Ethics, 2* (3), 267-277. doi: 10.1177/0969733013493214

Clark, S., Booth, Velikova, G., & Hewison, J. (2006). Social support: gender differences in cancer patients in the United Kingdom. Cancer *Nursing, 29* (1), 66-72. Retrieved from:

http://ovidsp.tx.ovid.com.proxy1.lib.uwo.ca/sp3.10.0b/ovidweb.cgi?&S=BNHCF PIOHMDDLKCANCNKJDDCLEHIAA00&Link+Set=S.sh.37.38.42.48%7c12% 7csl_10

Clemmer, S., Ward-Griffin, C., & Forbes, D. (2008). Family members providing home-based palliative care to older adults: The enactment of multiple roles. *Canadian Journal on Aging, 27 (3)*, 267-283.

Connell, R. (2009). *Short Introductions: Gender*. Cambridge: Polity Press.

Connell, R. (2012). Gender, health and theory: Conceptualizing the issue, in local and world perspective. *Social, Science, & Medicine, 74*, 1675-1683.

Crooks, V., Williams, A., Stajduhar, K., Allan, D., & Cohen, R. (2007). The information transfer and knowledge acquisition geographies of family caregivers: An analysis of Canada's Compassionate Care Benefit. *Canadian Journal of Nursing Research, 39* (3), 36-54. Retrieved from:

http://www.ingentaconnect.com.proxy1.lib.uwo.ca:2048/content/mcgill/cjnr/2007/00000039/00000003/art00005

Davison, C., Edwards, N., Webber, J., Robinson, S. (2006). Development of a social justice gauge and its use to review the Canadian Nurses Association's code of ethics for registered nurses. *Advances in Nursing Science, 29* (4), E13-E26

DeMiglio, L., Dykeman, S., Williams, A., & Kelley, M. (2012). Evolution of palliative care in Ontario: The impact of geography, funding, and advocacy. *Journal of Rural and Community Development, 7* (4), 109-121.

Dumont, S., Turgeon, J., Allard, P., Gagnon. P., Charonneau, C., Vezina, L. (2006). Caring for a loved one with advanced cancer: Determinants of distress in family caregivers. *Palliative Medicine, 9* (4),912-921. doi: 10.1089/jpm.2006.9.912

England, K. (2010). Home, work and the shifting geographies of care. *Ethics, Place and Environment, 13* (2), 131-150. doi: 10.1080/13668791003778826

Evans, J. (2002). Cautious caregivers: gender stereotypes and the sexualization of men nurses' touch. *Journal of Advanced Nursing, 40* (4), 441-448. doi: 10.1046/j.1365-2648.2002.02392.x

Evans, J., & Frank, B. (2003). Contradictions and tensions: Exploring relations of masculinities in the numerically female-dominated nursing profession. *The Journal of Men's Studies, 11* (3). Retrieved from: https://www-lib-uwo-ca.proxy1.lib.uwo.ca:2443/cgi-bin/ezpauthn.cgi/login?url=http://search.proquest.com.proxy1.lib.uwo.ca:2048/docview/222640838?accountid=15115

Exley, C. & Allen, D. (2007) A critical examination of home care: End of life care as an illustrative case. *Social Science and Medicine* 65 (11) 2317-2327.

Falk-Raphael, A. (2005). Speaking truth to power: Nursing's legacy and moral imperative. *Advances in Nursing Science, 28* (3), 212-223.

Fife, B., Kennedy, V., & Robinson, L. (1994). Gender and adjustment to cancer: Clinical implications. *Journal of Psychosocial Oncology, 12* (1/2), 1-21.

Fisher, M. (2009). 'Being a chameleon: labor processes of male nurses performing bodywork. *Journal of Advanced Nursing, 65* (12), 2668-2677. doi: 10.1111/j136-2648.2009.05120.x

Franks, P. & Bertakis, K. (2003). Physician gender, patient gender, and primary care. Journal of Women's Health, 12, 73-80.

Funk, L., Stajduhar, K., Toye, C., Aoun, S., Grande, G. & Todd, C. (2010). Part 2: Home-based family caregiving at the end of life: a comprehensive review of published

qualitative research (1998-2008). *Palliative Medicine, 24* (6), 594-607. doi:

1177/0269216310371411

Gauvin, F., Abelson, J., Lavis, J. (2013). *Citizen brief: Improving access to palliative*

care in Ontario. Hamilton, Canada: McMaster Health Forum.

Glazer, N. (1990). The home as workshop: Women as amateur nurses and medical care

providers. *Gender & Society, 4* (4), 479-499. Retrieved from:

http://www.jstor.org/stable/189750

Glen, E. (2010). *Forced to care: Coercion and caregiving in America*. Cambridge,

Massachusetts: Harvard University Press.

Govender, V., & Penn-Kekana (2008). Gender biases and discrimination: a review of

health care interpersonal interactions. *Global Public Health, 3* (S1), 90-103. doi:

10.1080/17441690801892208

Graham, M., & Palmer, A. (2002). Gender difference considerations for individuals with

laryngectomies. *Contemporary Issues in Communication Science and Disorders,*

29, 59-67.

Graham, H. (2004). Social determinants and their unequal distribution: Clarifying policy

understandings. *The Milbank Quarterly, 82*,1, 101-124.

Gravel., D., Taylor, G., Ofner, M., Johnston, Loeb, M., Roth, V.,…Matlow, F. (2007).

Point prevalence survey for healthcare-associated infections within Canadian adult

acute-care hospitals. *Journal of Hospital Infection, 66*, 243e-248e.

doi:10.1016/j.jhin.2007.04.008

Greimel, E., Padilla, G., & Grant, M. (1998). Gender differences in outcomes among

patients with cancer. *Psycho-Oncology, 7*, 197-206.

Grov, E., Dahl, H., Moum, T., & Fossa, S. (2005). Anxiety, depression and quality of life in caregivers of patients with cancer in late palliative phase. *Annals of Oncology, 16*, 1185-1191. doi: 10.1093/annonc/mdi210

Grunfeld, E., Coyle, D., Whelan, T., Clinch J., Reyno, L., & Earl, C. (2004). Family caregiver burden: Results of a longitudinal study of breast cancer patients and their principle caregivers. *Canadian Medical Association, 170* (12), 1795-1801. doi: 10.1503/cmaj.1031205

Hagedoorn, M., Buunk, B.P., Kuijer, R.G., Wobbes, T.., & Sanderman, R. (2000). Couples dealing with cancer: Role and gender differences regarding depressive symptoms and quality of life. *Psycho-Oncology, 9*, 232-242.

Hagedoorn, M., Sanderman, R., Bolks, H., & Tuinstra (2008). Distress in couples coping with cancer. *Psychological Bulletin, 134* (1), 1-30. doi: 10.1037/0033-2909.134.1.1

Haley, (2003). Family caregivers of elderly patients with cancer: Understanding and minimizing the burden of care. *Supportive Oncology, 1* (2), 25-29.

Hayes, R., Lee, W., Rayner, L., Price, A., Monroe, B., Hansford, P., …Hotopf, M. (2011). Gender differences in the prevalence of depression among patients receiving palliative care: The role of dependency. *Palliative Medicine, 26* (5), 696-702. doi: 10.1177/0269216311416035

Husain, A., Stewart, K., Arseneault, R., Moineddin, R., Cellarius, V., Librach, S., & Dudgeon, D.(2007). Women experience higher levels of fatigue than men at the end of life: A longitudinal home palliative care study. *Journal of Pain and Symptom Management, 33* (4), 389-397. doi: 10.1016/j.jpainsymman.2006.09.019

Im, I. (2006). White cancer patients' perception of gender and ethnic differences in pain experience. *Cancer Nursing, 29* (6), 441-450.

Jacobs-Lawson, J., Schumacher, M., Hughes, T., & Arnold, S. (2010). Gender differences in psychosocial responses to lung cancer. *Gender Medicine, 7* (2), 137-147. doi: 10.1016/j.genm.2010.03.002.

Jo, S., Brazil, K., Lohfeld, L., & Willison, K. (2007). Caregiving at the end of life: Perspectives from spousal caregivers and care recipients. *Palliative and Supportive Care, 5,* 11-17.

Johnson, J., Greaves, L., & Repta, R. (2007). *Better science with sex and gender: A primer for health research.* Women's Health Research Network.

Johnson, J., & Repta, R. (2012). Sex and gender: Beyond the binaries. In J. Oliffe, & L. Greaves (Eds.), *Designing and conducing gender, sex, and health research*, (pp 17-39). Thousand Oaks: SAGE Publications Inc.

Keating, N. Landrum, M., Rogers, S., Baum, S., Virnig, B., Huskamp, H….Kahn, K. (2010). Physician Factors associated with discussions about end-of-life care. *Cancer, 116*, 998-1006. doi: 10.1002/cncr.24761

Kellehear, A. (1999). Health-promoting palliative care: Developing a social model for practice. *Mortality, 4*, 75-82.

Local Health Integration Networks [LHIN] & Quality Hospice Palliative Care Coalition of Ontario [QHPCCO] (2011). *Advancing high quality, high value palliative care in Ontario: A declaration of partnership and commitment to action*. Retrieved from

http://health.gov.on.ca/en/public/programs/ltc/docs/palliative%20care_report.pdf

Lorber, J. (1994). "Night to his day": The social construction of gender. In J. Lorber (Ed.). *Paradoxes of gender* (pp 13-36). New York: Vail-Ballou Press.

McGregor, S. (2001). Neoliberalism and health care. *International Journal of Consumer Studies, 25 (*2), 82-89.

McGuire, T., Dougherty, D., & Atkinson, J. (2006). Paradoxing the dialectic: The impact of patients' sexual harassment in the discursive construction of nurses' caregiving roles. *Management Communications Quarterly, 19* (3), 416-460. doi: 10.1177/0893318905280897

McIllmurray, M., Thomas, C., Francis, B., Morris, S., Soothill, K., & Alhamad, A. (2001). The psychosocial needs of cancer patients: findings from an observational study. *Journal of Cancer Care, 10*, 261-269.

McWhinney, I., Bass, M., & Orr, V. (1995). Factors associated with location of death (home or hospital) of patients referred to palliative care team. *Canadian Medical Association, 152* (3), 361-367.

McWilliam, C., Ward-Griffin, C., Sweetland, D., Sutherland, C., & O'Halloran, L. (2001). The experience of empowerment in in-home services delivery. *Home Health Care Services Quarterly, 20* (4), 49-71.

Marmot, M., Friel, S., Bell, R., Houweling, T., & Taylor, S. (2008). Closing the gap in a generation: Health equity through action on the social determinants of health. *The Lancet, 372*, 1661-69. doi: doi:10.1016/S0140-6736(08)61690-6

Milligan, F. (2001). The concept of care in male nurse work: an ontological hermeneutic study in acute hospitals. *Journal of Advanced Nursing, 35* (1), 7-16. doi: 10.1046/j.1365-2648.2001.01818.x

Mystakidou, K., Parpa, E., Panagiotou, I., Tsilika, E., Galanos, A., & Gouliamos, A. (2012). Caregivers' anxiety and self-efficacy in palliative care. *European Journal of Cancer Care, 22*, 188-195. doi: 10.1111/ecc.12012

National Hospice Palliative Care Organization (n.d.). *What is hospice and palliative care?* Retrieved from:

http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3356

Ontario Home Care Association. (2011). *Home care nursing in Ontario*. Retrieved from www.homecare.ca/public/.../ohca-home-care-nursing-in-ontario.pdf

Ontario Medical Association (2014). *Palliative care: Backgrounder OMA's end of life care strategy*. Retrieved from

https://www.oma.org/Resources/Documents/PalliativeCare.pdf

Oudshoorn, A., Ward-Griffin, C. & McWilliam, C. (2007). Client-nurse relationships in home-based palliative care: A critical analysis of power relations. *Journal of Clinical Nursing, 16*, 1435-1443. doi: 10.1111/j.1365-2702.2006.01720.

O'Lynn, C., & Krautscheid, L. (2011). 'How should I touch you?': A qualitative study of attitudes on intimate touch in nursing care. *American Journal of Nursing, 11* (3), 24-31. doi: 10.1097/10.1097/01.NAJ.0000395237.83851.79

Partridge, A., Seah, D., King, T., Leighl, N., Hauke, R., Wollins, D….Von Roenn, J. (2014). Developing a service model that integrates palliative care throughout cancer care: The time is now. *Journal of Clinical Oncology, 32* (29), 3330-6. doi: 10.1200/JCO.2013.54.8149

Payne, S., Smith, P., & Dean, S. (1999). Identifying concerns of informal carers in palliative care. *Palliative Medicine, 13*, 37-44.doi: 10.1097/ANS.0b013e3181a3afaf

Pauly, B. (2008). Harm reduction through a social justice lens. *International Journal of Drug Policy, 19,* 4-10. doi.1016/j.drugpo.2007.005

Pauly, B., McKinnon, K., & Varcoe, C. (2009). Revisiting "Who gets care?": Health equity as an arena for nursing action. *Advances in Nursing Science, 32* (2), 118-127.

Perz, J., Ussher, J., Butow, P., & Wain, G. (2011) Gender differences in cancer carer psychological distress: an analysis of moderators and mediators. *European Journal of Cancer Care, 20*, 610-619. doi: 10.1111/j.1365-2354.2011.101257.x

Prastrana, T., & Junger, S. (2008). A matter of definition – key elements identified in a discourse analysis of definitions of palliative care. *Palliative Medicine, 22*, 222-232. doi: 10.1177/0269216308089803

Pullen, A., & Simpson, R. (2009). Managing difference in feminized work: Men, otherness and social practice. *Human Relations, 62* (4), 561-587. doi: 10.1177/0018726708101989

Quality End-of-Life Care Coalition of Canada. (2008). *Hospice Palliative Home Care in Canada: A Progress Report.* Retrieved from: www.qelccc.ca/.../Hospice_Palliative_Home_Care_Progress_Report-final.

Raeburn, J., & Rootman, I. (2007). A new appraisal of the concept of health. In M. O'Neill, A. Pederson, S. Dupere, I. Rootman (Ed.), *Health promotion in Canada* (2nd ed.). Toronto: Canadian Scholars' Press.

Raphael, D. (2009). Social determinants of health: An overview of key issues and themes. In *Social determinants of health: Canadian perspectives* (Ed. R. Raphael) (2nd Ed.). Toronto: Canadian Scholars Press.

Raphael D. (2012). The importance of tackling health Inequalities. In D. Raphael (Ed.), *Tackling health inequalities: Lessons from international experiences* (pp 1-32). Canadian Scholars' Press: Canada

Rawls, J. (1971) *A theory of justice*. Oxford University Press: Oxford.

Reimer Kirkham, S., Browne, A. (2006). Toward a critical theoretical interpretation of social justice discourses in nursing. *Advances in Nursing Science, 29* (4), 324-339. Retrieved from:

http://journals.lww.com/advancesinnursingscience/Abstract/2006/10000/Toward_a_Critical_Theoretical_Interpretation_of.6.aspx

Reutter, L., & Kushner, K. (2010). Health equity through action on the social determinants of health: Taking up the challenge in nursing. *Nursing Inquiry, 17* (3), 269-280. doi: 10.1111/j.1440-1800.2010.00500.x

Ridgeway, C., & Correll, S. (2004). Unpacking the gender system: A theoretical perspective on gender beliefs and social relations. *Gender & Society, 18* (4), 51-531. doi: 10.1177/0891243204265269

Rivera, H., & McMillian, S. (2010). Predictors of depression symptoms in hospice care. *Journal of Hospice & Palliative Nursing, 12* (6), 345-357. doi: 10.1097/NJH.0b013e3181f184f4

Robinson, M., Riley, Jl, Myers, C., Papas, R., Wise, E., Waxenberg, L., & Fillingim
(2001). Gender role expectations of pain: Relationship to sex differences in pain.
The Journal of Pain, 2 (5), 251-257. doi: 10.1054/jpai.2001.24551

Romanow, R. (2002). *Building on values: The future of health care in Canada – final
report*. Commission on the future of health care in Canada. Retrieved from dsp-
psd.pwgsc.gc.ca/Collection/CP32-85-2002E.pdf

Salander, P., & Hamberg, K. (2005). Gender differences in patients' written narratives
about being diagnosed with cancer. *Psycho-Oncology, 14*, 684-795. doi:
10.1002/pon.895.

Schofield, T., Connell, R., Walker, L., Wood, J., & Butland, D. (2000). Understanding
men's health and illness: A gender relations approach to policy, research and
practice. *Journal of American College, 48* (6), 247-256.

Seale, C. (2006). Gender accommodation in online cancer support groups. *Health An
Interdisciplinary Journal for the Social Study of Health, Illness and Medicine, 10*
(3), 345-360. doi: 10.1177/1363459306064495 1363-4593

Sen, G., & Ostlin, P. (2008). Gender inequity in health: why it exists and how we can
change it. *Global Public Health, 3* (S1), 1-12.

Schultz, R., & Beach, S. (1999). Caregiving as a risk factor for mortality: The caregiver
health effects study. *American Medical Association, 282*, (23), 2215-2219.

Simpson, R. (2009). *Men in caring occupations: Doing gender differently*. NewYork:
Palgrave MacMillan.

Soew, H. (2014). *Rethinking palliative care in the community: A change guide*. Retrieved
from http://www.palliativecareinnovation.com/files/PallativeCareInnovation.pdf

Spiroch, C., Walsh, D., Mazanec, P., Nelson, K. (2000). Ask the patient: A semi-structured interview study of quality of life in advanced cancer. *American Journal of Hospice & Palliative Care, 17* (4), 235-240. doi: 10.1177/104990910001700408

Smith, D. (1987). *The everyday world as problematic*. Massachusetts: Northeastern Press.

Smith, D. (2005). Women's Standpoint: Embodied knowledge versus the Ruling Relations. *Institutional ethnography*: *A sociology for people* (pp. 7-26) Maryland: Alta Mira Press.

Spitzer, D. (2005). Engendering Disparities. *Canadian Journal of Public Health, 96* (2), S78-S96. doi

Stajduhar, K., Allan, D., Cohen, S., & Heyland, D. (2008). Preferences for location of death of seriously ill hospitalized patients: perspectives from Canadian patients and their family caregivers. *Palliative Medicine, 19* (1), 21-32.

Stajduhar, K., & Davies, B. (2005). Variations and factors influencing family members' decisions for palliative home care. *Palliative Medicine, 19*, 21-32.

Stajduhar, K., Funk, L., Jakobsson, E., & Ohlen, J. (2010). A critical analysis of health promotion and 'empowerment' in the context of palliative family caregiving. *Nursing Inquiry, 17*, 221-230. doi: 10.1111/j.1440-1800.2009.00483.x

Stajduhar, K., Funk, L., Roberts, D., Cloutier-Fisher, D., McLeod, B., Wilkinson, C., & Purkis, M. (2010). Articulating the role of relationships in access to home care nursing at the end of life. *Qualitative Health Research, XX* (X), 1-15. doi: 10.1177/104973231037114

Stajduhar, K., Nickel, D., Marin, W., & Funk, L. (2008). Situated/being situation: Client and co-worker roles of family caregivers in hospice palliative care. *Social Science & Medicine, 67* (11), 1789-1797. doi: 10.1016/j.socscimed.2008.09.012

Temel, J., Greer, J., Muzikansky, A., Gallagher, E., Admane, S., Jackson, V….Lynch, T. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. *The New England Journal of Medicine, 363*, 733-42. Retrieved from: http://www.nejm.org/doi/full/10.1056/NEJMoa1000678

Thomas, C., Morris, S., & Harman, J. (2002). Companions through cancer: The care given by informal carers in cancer contexts. *Social Science & Medicine, 54*, 529-544. doi: 10.1016/S0277-9536(01)00048-X

Thome, B., & Hallberg, I. (2004). Quality of life in older people with cancer – a gender perspective. *European Journal of Cancer Care, 13*, 454-463.

Torkelson, D., & Seed, M. (2011). Gender differences in the roles and functions of inpatient psychiatric nurses. *Journal of Psychosocial Nursing, 49* (3), 41. doi: 10.3928/02793695-20110201-02

Trapp, S., Woods, J., Grove, A., & Stern, M. (2012). Male coping processes as demonstrated in the context of a cancer-related social support group. *Supportive Care in Cancer, 21*, 619-627. doi: 10.1007/s00520-012-1565-x

Ussher, J., & Sandoval, M. (2008). Gender differences in the construction and experience of cancer care: The consequences of the gendered positioning of carers. *Psychology and Health, 23* (8), 945-963.

Wadner, L., Heft, M., Lok, B., Hirsh, A., George, S. Horgas, A….Robinson, M. (2014) *International Journal of Nursing Studies, 51*, 726-733. doi: http://dx.doi.org/10.1016/j.nurstu.2013.09.011

Walsh, C., & Luker, K. (2010). District nurses' role in palliative care provision: A realist review. *International Journal of Nursing Studies, 47*, 1167-1183. doi: 10.1016/j.ijnurstu.2010.04.006

Ward-Griffin, C. (2004). Nurses as caregivers of elderly relatives: negotiating personal and professional boundaries. *Canadian Journal of Nursing Research, 36* (1), 92-114.

Ward-Griffin, C., & McKeever, P. (2000). Relationships between nurses and family caregivers: Partners in care? *Advances in Nursing Science, 22* (3), 89-103.

Ward-Griffin, C., & Marshall, V. (2003). Reconceptualizing the relationship between public and private care. *Journal of Aging Studies, 17*,189-208. doi: 10.106S0890-4065(03)00004-5

Ward-Griffin, C., Hall, J., DeForge, R., St. Amant, O., Oudshorrn, A., Forbes, D., & Klosek, M. (2012). Dementia home care resources: how are we doing? *Journal of Aging Research*, 2012. doi: 10.1155/2012/590724

Ward-Griffin, C., McWilliam, C., Oudshoorn, A. (2012a). Negotiating relational practice patterns in palliative home care. *Journal of Palliative Care, 28* (2), 33-40. doi: 10.1177/1074840712462134

Ward-Griffin, C., McWilliam, C., Oudshoorn, A. (2012b). Relational experiences of family caregivers providing home-based end-of-life care. *Journal of Family Nursing, 18* (4), 91-516. doi: 10.1177/1074840712462134

Wessels, H. DeGraeff, A., De Heus, M., Kruitwagen, C., Woltjer, G., Teunissen, S. &Voest, E. (2010). Gender-related needs and preferences in cancer care indicate the need for individualized approach to cancer patients. *The Oncologist, 15*, 648-655. doi: 10.1634/theoncologist.2009-0337

West, C., & Zimmerman, D. (1987). Doing gender. *Gender & Society, 1* (2), 125-151.

West, C., & Zimmerman, D. (2009). Accounting for doing gender. *Gender & Society, 23* (1), 112-122. doi: 10.1177/0891243208326529

Whitehead, M., & Dahlgren, G., (2006). *Levelling up (part 1): A discussion paper on concepts and principles for tackling social inequities in health*. WHO Collaborating Centre for Policy Research on Social Determinants of Health. Retrieved from:

http://www.google.ca/url?sa=t&rct=j&q=&esrc=s&frm=1&source=web&cd=2&ved=0CDgQFjAB&url=http%3A%2F%2Fwww.who.int%2Fsocial_determinants%2Fresources%2Fleveling_up_part1.pdf&ei=auakUrG8EqWyygGdk4GoBQ&usg=AFQjCNE6nRR_6s1kVu5mErF9K-aLBMjsDw&bvm=bv.57752919,d.aWc

Whittock, M., & Leonard, L. (2003). Stepping outside the stereotype. A pilot study of the motivations and experiences of males in the nursing profession. *Journal of Nursing Management, 11*, 242-249. doi: 10.1046/j.1365-2834.2003.00379.x

Wiles, J. (2005). Home as a new site of care provision and consumption. In A. Gauvin, & Phillips (Eds.). *Ageing in Place* (pp. 75-97). New York: Routlege.

Williams, A. (1996). The development of Ontario's home care program: A critical geographical analysis. *Social Science & Medicine, 42* (6), 937-948.

Williams A., (2002). Changing geographies of care: Employing the concept of therapeutic landscapes as a framework in examining home space. *Social Science & Medicine, 55* (1), 141-154. doi: 10.1016/S0277-9536(01)00209-X

Williams, A. (2006). Restructuring home care in the 1990s: Geographical differentiation in Ontario, Canada. *Health & Place, 12*, 222-238. doi: 10.1016/j.healthplace.2004.09.002

Williams, A., Crooks, V., Whitfield, K., Kelley, M., Richards, J., Demiglio, L. & Dykeman, S.(2010). Tracking the evolution of hospice palliative care in Canada: A comparative case study analysis of seven provinces. *BMC Health Service Research, 10* (147). Retrieved from http://www.biomedcenral.com/1472-6963/10/147

World Health Organization [WHO]. (2011a). *WHO definition of palliative care*. Retrieved from http://www.who.int/cancer/palliative/definition/en/

World Health Organization [WHO]. (2011b). *Report on the burden of endemic health care-associated infection worldwide*. Retrieved from whqlibdoc.who.int/publications/2011/9789241501507_eng.pdf

2. Chapter Two: Methodology

In this chapter, I examine the conceptual underpinnings of Dorothy Smith's social feminism (1987) as a critical feminist lens, and the suitability of this framework to examine gender relations in hospice palliative home care for clients with cancer. Second, I reflect on my multiple social locations as a woman, a paid caregiver, an unpaid caregiver, a nurse educator, a student researcher, and an East Indian. Third, I discuss and evaluate the utility of critical ethnography for this study. Then, I describe the setting and sample of the study and detail data collection methods of interview, participant observation, and document review. Finally, I discuss the data management, analysis, ethics, and action towards gender equity for this study.

As the purpose of this critical ethnographic study was to expose gendered attitudes, beliefs, and practices that potentially lead to inequities, it was essential to ground data in the everyday experiences of men and women in hospice palliative home care. While gender relations was the focus of this study, the social political conditions in which other power relations such as race, age, and class came into play were also considered (Gottfried, 1996; Marshall, 1994). As such, a critical feminist lens was employed to uncover these potential inequities. Critical ethnography provided the conceptual foundations and practical methods to examine power relations within the culture of hospice palliative home care. As gendered attitudes, beliefs, and practices are entrenched within culture, inequitable practices and policies that shape health and health care are rendered invisible (Acker, 2012). During such vulnerable time periods, these hidden structural and ideological influences can constrain the actions of individuals with terminal illness and their caregivers. With a focus on power relations and social change,

critical ethnography methods of interview, observation, and document review were used to make visible inequities which have been rendered invisible.

2.1 Theoretical Lens

As the purpose of this study was to critically examine gender relations and practices in hospice palliative home care, a critical feminist lens was important to foreground gender. I was guided by Dorothy Smith's (1987) feminist sociology to begin inquiry with the everyday practices of men and women in this context. While focusing on gender relations, using this lens also permitted me to investigate the conditions within which relationships between and among clients, caregivers, and nurses were embedded. This type of inquiry is crucial to reveal and challenge inequities in the drive towards optimal, quality hospice palliative home care. I first discuss the standpoint and then the process of Smith's (1987, 2005) critical feminist perspective.

2.1.1 The standpoint. Denying that her feminist sociology is a totalizing theory, Smith states that her approach is instead an inquiry (Smith, 1992) that begins with people's lives, a standpoint on which individuals interact and carry through with day-to-day activities. Starting from this standpoint permits the discovery of how everyday subjective perspectives and experiences are influenced by powerful structures such as institutional discourses (Smith, 1997). These structures, or as Smith describes, the '"ruling apparatus," constitute the intersections of governments, laws, health and education institutes, professional organizations and their prevailing discourses that intersperse through, and have control over, actual everyday practices (Smith, 1987, 2005). This level of ruling is an abstract form mediated through texts and instilled into the

consciousness of those who are silent and absent from the powers that shape the actualities in the everyday practical world.

The ruling apparatus is "The Problematic of the Everyday World," the title of Smith's seminal work (1987). The problematic is of concern for Smith, not to deconstruct it, but to reveal how it operates in the everyday world. For example, the familiar practice of teaching family members to give injections to clients in hospice palliative home care may be explored in relation to how texts, ideologies, and implicit understandings from structural institutions such as home care agencies and professional bodies (e.g., College of Nurses) operate to shape this everyday practice. As in this study I aimed to examine the construction of gender relations within a health care system that includes institutional structures of professional organizations (nursing), home care agencies (organizations) and governmental bodies (Community Care Access Centre [CCAC]), a feminist sociological lens was highly relevant to my exploration of gender relations in everyday hospice palliative home care.

In contrast to other feminist standpoint perspectives (e.g., Harding) that privilege the knowledge of the subordinated, the epistemological stance of Smith's (1987, 2005) perspective is that knowledge is relational as it is mediated through institutional texts and materialized in the everyday actualities of people's lives. Beginning with people's day-to-day experiences ensures consideration of the ways in which people manage their lives relative to how structures determine ideologies, rules, and practices that shape everyday lives (Marshall, 1994). Thus, by exposing assumptions that are ensconced in prevailing discourses, this approach was suitable to reveal and challenge the ways in which subordinate relations are formed (Smith, 1987, 2005), and to redress these potentially

hierarchal social relations and injustices (Kushner & Morrow, 2003; Pitre, Kushner, Raine, & Hegadoren, 2013) in hospice palliative home care.

2.1.2 The process. An "Archimedean" position in which the researcher stands outside the world that he or she examines has been the objective scientific approach traditionally employed by positivist researchers (Smith, 1987, 2005). It is a position that is inclined to view those outside the "ruling apparatus" as objects. Using this androcentric, authoritative method is in keeping with the very organizations and governing bodies that constrain and suppress the actions of individuals in the everyday realm. Moreover, a view of the everyday world is not always apparent from a top-down authoritative approach. In order to obtain a clear view of the everyday world, away from the influences of the dominant discourses, a feminist researcher must start from the standpoint of participants, a world of which the researcher is a part (Smith, 1987, 2005).

The shift away from an androcentric approach has implications for the relationship between the researcher and the researched. In employing a critical feminist lens, it is not acceptable for the researcher to stand outside looking in from an omnipotent position; rather, in order to elicit the everyday experience, the researcher is highly reflexive, particularly in attending to the way in which dominant discourses have influenced the inquiry, interview questions, and interpretations (Smith, 1987). Furthermore, the researcher and the participants co-create interpretations through dialogic encounters. In order not to assume an "expert" stance and avoid "gazing" on the researched, I critically reflected on my position, and my beliefs and practices as a doctoral student approaching research "subjects," and placed value on participants' subjective knowledge. Research participants must be viewed as knowers and experts, not as objects

of research (Smith, 1987). I also critically reflected upon my social locations and how they might influence interactions and interpretations (Atkinson & Hammersley; Kincheloe & McLaren, 2005; Suzuki, Ahluwalia, Mattis, & Quizon, 2005; Thomas, 1993, 2003). In essence, I attempted to subvert the traditional expert, objective, and value-free researcher by regarding myself as the object of inquiry or "other" (Foley, 2002).

Through journaling, I was reflexive about my social locations to self-scrutinize any personal biases that may affect interactions and stages of the research process, including data collection and analysis. Reflecting on my social locations also was important to view myself as a "living, contradictory, vulnerable, evolving multiple self who speaks in a partial, subjective culture-bound voice" (Foley, 2002, p.474).

2.2 My Social Locations

Insider and/or outsider status constituted through my social locations have an impact on how data were collected and interpreted (Al-Makhamreh & Lewando-Hund, 2008; Fine, 1994). I am a nurse with previous oncology and palliative care experience. I also have conducted research in oncology and palliative care. By being familiar with medical terminology, treatment, and processes, I was able to easily understand nursing actions and behaviours. This insider perspective as a nurse was advantageous in understanding the language and actions in hospice palliative home care; yet, too much familiarity can obscure perspectives and result in misinterpretations (Roper & Shapira, 2000). Accordingly, I created distance by continually questioning the dominant discourse (Smith, 2005), the everyday routine, and my insider knowledge (Labaree, 2002). I documented how my feelings and attitudes may have affected my interpretations. For example, following interviews and observations, in fieldnotes, I critically examined the

routine practice of incrementally transferring care to female caregivers. By questioning these normative practices, I was open to alternative interpretations (Lather, 1995). As a nurse, I was aware of the "relations of ruling," the sub-conscious professional and organizational discourses that may influence my observations and interpretations (Smith, 1987, 2005). Additionally, I was alert to contradictions between observations of what participants did and what they said (Al-Makhamreh et al., 2008; Larabee, 2002).

I am a daughter of a father who died at home from cancer of the lung. In this context, I had insider knowledge as a family caregiver who had experienced hospice palliative home care for a dying relative with cancer. Yet, for spouses, I was an outsider as a daughter of a father with terminal cancer. From the perspective of the person with terminal cancer, I was an outsider as a person who has never been seriously ill.

My father had received home care, which my family and I found extremely important in order to meet my father's wishes to die at home. Even with this help, however, we found the end-of-life at home challenging. As a female spouse taking on the caregiver role, my mother was fearful that she would not be able to manage symptoms such as shortness of breath. Not knowing what to expect, my mother and sister made a decision to call the ambulance in the case that my father experienced distress, despite my father having requested to die at home. While my family was aware of my father's terminal disease, they were unaware that death was in the near future. Also, there were difficulties navigating the system, such as arranging physician home visits. Because of these challenges, I questioned how the health care system and health care providers could further facilitate quality palliative care, especially to individuals who are vulnerable and disadvantaged because of their social positions (e.g. class, age, gender and ethnicity).

Following through from this experience, I decided to pursue graduate studies and focus on palliative research. Although I have never been employed as a nurse in home-based palliative care, my personal experiences, alongside the present social trend to die at home, has led me to focus on palliative home care.

During the research process of collecting data, being a woman was to me the greatest influence on my insider-outsider status. I aligned several times with female clients, caregivers, and nurses, particularly to discuss care aspects. Most of the time, male participants excluded themselves, or were excluded by female clients, female caregivers and nurses, not only from care conversations, but also from "gendered" conversations (e.g., discussions related to fashion) often initiated by female clients and caregivers, likely in an effort to connect with the female nurse (and me). Male participants were included in care conversations when they were clients from whom critical information had to be obtained. I also learned that client-family caregiver-nurse alignments with men and women were largely based on assumptions of masculinity and femininity.

I also connected with participants in other ways, such as in a sharing of interests, humour, and understandings. As a mature student and nurse, participants were better able to share their stories with me as was indicated to me by one participant who remarked about a young nurse with whom she found challenges in relating intimate feelings and meanings. I connected with nurses, being familiar with their educational background and past nursing experiences. In terms of class, I have recognized my privileged position as a PhD student and realized that this opportunity is not available for many individuals. As a nurse and educator, I have been confident in my ability to seek employment with reasonable pay, thus privileged as a middle-class individual relatively free from financial

worry, and with professional and economical access to additional resources, if needed. I recognized that some participants with less education and money may have been more disadvantaged than me in this regard.

As a researcher, I also was an outsider in several ways. First, I had entered into already established relationships. As a non-practising nurse and a non-family member, I was an addition to the visits. Participants interacted within roles and relationships of which I was an outsider. At the same time, however, because I was an outsider, some participants were more open with me. One male client stated how he was able to express his emotions during our discussions, whereas with the other female support workers and nurses he exerted an effort to show more composure.

All participants, including clients, participants, and nurses were Caucasian. I became aware of my outsider status, as one client asked me if I had graduated from nursing in Canada. While I consider myself an insider, having grown and lived in Canada for the majority of my life (completing all my education in Canada), I am continually made aware of my outsider status because of my color/race. Being a visible minority may have affected my relations with participants. Initially, in an attempt to minimize differences (Manderson, Bennett, Andajani-Sutjahojo, 2006), I approached participants in an agreeable manner. I adhered closely to my preplanned interview guide and likely was less spontaneous in expressing or disclosing aspects of myself.

While I have adopted many Western cultural values and beliefs, I still have deeply embedded East Indian gendered beliefs, actions, and behaviours. Growing up within the backdrop of a male-dominated culture, I may have treated men differently. In interviewing men, I stayed close to the confines of the interview guide, whereas with

women, I felt comfort and freedom to ask more in-depth questions. As a consequence, my conversations with women were free-flowing, eliciting more spontaneous discussions with them.

In summary, positioned through my multiple locations and identities, I held a fluid insider-outsider status, at times simultaneously being both insider and outsider. Through reflexivity, I was aware that the negotiation of these identities may have an impact on others' responses and my interpretations. Throughout the study, reflexivity was important to document my feelings and attitudes and how this may affect stages of the research process.

2.3 Reflexivity

In self-reflecting, I attempted to be consciously aware of my locations and how they shaped the inquiry, data collection, and interpretation (Pillow, 2003). In a journal, I reflected on my social locations and my feelings, interests and attitudes that I brought to the study. I had to reflect deeply on my own gendered assumptions and biases. My tendency to make assertions about stereotypical feminine and masculine roles at times reinforced gendered hierarchies. Based on the assumption that women organize matters in the home, I addressed a female caregiver rather than the male client to arrange a future interview. I realized that I held my own gendered assumptions, and recognized that I had definitive views of what men and women should and should not do. I became aware that these views essentialized gender relations, and only served to maintain the status quo of gender inequities. I continue to be aware of my gendered assumptions as I have learned the difficulty of challenging deep-rooted attitudes and assumptions. Also, in the process of writing fieldnotes and memos, I would routinely stop and question my observations

and interpretations, questioning how my historical perspectives and biases may have influenced my understandings.

Important in using a critical feminist lens, I was cognizant not to form relationships of power in which the expert researcher is the mediator of the observations made on the "objects" of interest (Smith, 1987, 2005). As I started to feel comfortable during observations or interviews, I engaged in a more informal, conversational style of interaction. As is consistent with a feminist approach, I shared personal experiences and stories with participants. For example, I connected with participants when I shared with them my experiences as a nurse, teacher, daughter, or student. Also, in order to show interest and further develop the relationship, I actively listened to participants, and attempted to follow up on their responses to show that I understood and empathized (Sprague, 2005). I maintained eye contact and nodded to acknowledge my comprehension. In addition, I considered participants to be collaborative research partnerships as I viewed them as valuable contributors of knowledge (Angrosino & Rosenberg, 2011; Foley & Valenzuela, 2005; Smith, 1987, 2005). Presenting myself as a learner, rather than an expert, I shared and engaged in discussions regarding the research findings with four participants. However, in conducting a study that examines and challenges dominant groups who hold power and shape the lives of subordinate groups, I recognized that I must be aware of false consciousness, a phenomenon in which people in non-dominant positions may be accepting of dominant ideologies (Lather, 1995; Smith, 2005). For example, a wife may feel it is her obligation and duty as a woman to provide care to her partner with terminal cancer.

In summary, in the process of developing relationships with participants, I subjected myself to the same scrutiny as the participants (McCorkle & Myers, 2003). That is, through reflexivity, I daily interrogated my own position and power in all stages of the research process.

2.4 Critical Ethnography

As guided by Thomas (1993, 2003), critical ethnography was used to uncover taken-for-granted attitudes, beliefs, and practices that reinforce social power relations, and potentially lead to inequities for the men and women in the culture of hospice palliative home care. Critical ethnography has its roots in ethnography, an approach that describes and interprets the attitudes, beliefs, and practices of a culture (Thomas, 1993). While Smith's feminist social lens assists in examining how broader social structures such as government bureaucracies, professional associations, or corporations influence gender relations in everyday hospice palliative home care, critical ethnography brings a social cultural focus to this context. Critical ethnography permitted examination of all levels of interactions in gender relations, including the interpersonal, intrapersonal, as well as the structural (Charlebois 2011; Conner, 2009).

Culture is a system of relations within groups that determines socially acceptable ways of everyday interacting, valuing, knowing, and behaving (Browne, 2005; Kincheloe & McLaren, 2005; Thomas, 1993). Historically constructed, culture establishes what constitutes meanings and values that are to be upheld within a group. As such, knowledge of the culture that has been produced in the past can be changed in the future through transformative actions (Carroll, 2004). Culture is thus a dynamic relational process in

which dominant ideologies or shared beliefs that validate the "what" and "why" of the world (Thomas, 1993) shape practices and social constructs such as gender.

The "critical" component of ethnography begins with a value judgment of social processes, attitudes, beliefs or practices that are considered inequitable. The focus of this approach is to reveal constraining values and practices that disadvantage some, to the advantage of others. Within a culture, power is tacitly diffused through the control of ideologies and institutions. The ideologies of the dominant group infiltrate quietly to control and affect less dominant individuals or groups; it determines the value of knowledge, its legitimacy, and to whom and when it will be disseminated (Eakin, Robertson, Poland, Coburn, & Edwards, 1996; Kincheloe & McLaren, 2005). Ideology and knowledge are viewed to be natural and are left unquestioned as taken-for-granted rules that structure the culture. In hospice palliative home care, the social institutes of marriage and family shape the ways in which productive and reproductive work are divided, influencing family members' and health providers' expectations of who should provide care work.

The ontological premise of critical ethnography is that power relations within a culture produce unfair or inequitable practices and experiences that are hidden within cultural routines and norms (Thomas, 1993). In this methodology, power is exposed by questioning taken-for-granted beliefs, discourses, practices, and policies. Thus, the ordinary routines of commonplace interactions are analyzed to reveal institutional processes, ideologies, and facts that reify accepted norms within the culture (Thomas, 1993). This analysis is congruent with Smith's (1987, 2005) critical feminist lens that views everyday activities in relation to the "ruling apparatus," social institutions that

(re)produce dominant discourses and shape the everyday world. As an example, professional associations, imbued with ideological premises, provide nursing standards to guide daily practices and shape home care experiences, and thus influence nurses` attitudes, beliefs, and practices. A fundamental principle of critical ethnography is to uncover and redress these taken-for-granted "truths" that sustain the power, position, and values of the privileged. Thus, a critical ethnographic methodology permits a viewpoint from which to examine and expose alternate meanings, hidden power imbalances, and inequitable practices (Thomas, 1993, 2003).

Finally, critical ethnography is a call for social justice, the aim being to advance social and political change (Thomas, 1993). This approach is important to problematize and thus challenge social and organizational ideologies, practices, and policies that contribute to gender inequities.

2.5 Methods

2.5.1 Setting and sample. This study was largely conducted in clients' and caregivers' homes. Entry into homes started with contacting two local government agencies that contract home health care services: the Waterloo Wellington Community Care Access Centre [CCAC], and the South West CCAC. Following ethics approval from the Research Ethics Boards of Western University and one agency (see Appendix A), I arranged appointments with the Client Services Managers of each CCAC to explain the purpose and process of the study. I was provided with contact information of hospice palliative home care case managers, as they assess palliative home care clients for eligibility and needs (CCAC, 2011) and could identify potential participants. Case managers gave client-family caregiver participants a notice of recruitment (see Appendix

B) describing the purpose of the study, and the number of visits and personal interviews involved. Clients and family caregivers were informed that the study was voluntary and that they could withdraw from the study at any time. Potential participants were also informed in the notice that all information would be kept confidential and that all reports would be coded with pseudonyms and would therefore be anonymous. To maintain confidentiality with respect to the decision to participate in the study and comply with the Privacy Health Information Protection Act (2004), the case manager asked potential participants for permission for the researcher to call them. I called potential participants to further explain the study and expectations and to arrange a meeting time for the interviews in their homes where they gave and received care. Prior to the first interview, I reviewed with the client and family caregiver the letters of information (see Appendices C-1 and C-2), and obtained written consents (see Appendix D). All clients and caregivers consented to continue with face-to-face interviews.

Primary nurses assigned to care for the client and family caregiver were contacted by the case manager to ask if they would participate in the study and if the researcher may contact them. I called potential nurse participants involved in the care of the consenting client/caregiver and arranged to meet them at a time and place that was convenient to them. I explained the study with the letter of information (see Appendix C-3) and obtained consent (See Appendix D) prior to the face-to-face interview. Following the first interviews, I made arrangements to observe agency home visits in which the primary nurse provided care to the client and family caregiver in their home.

In order to address recruitment issues for individuals experiencing a vulnerable time such as end-of-life, I spent time with case managers (Atkinson & Hammersley,

2007; Mulhall, 2003) so they could become more familiar with the study and with me personally. This enabled case managers to better describe the study and my general attitude and mannerisms to potential participants. However, family members experience the strains of caregiving and emotional distress when their relatives are dying (Funk et al., 2010; Ward-Griffin, McWilliam, & Oudshoorn, 2012a, 2012b). Family caregivers and nurses also often feel the need to protect dying clients. Both of these experiences made recruitment and retention of clients and caregivers in hospice palliative home care challenging (Jo, Brazil, Lohfeld, & Willison, 2007; Morse & Fife, 1998).

To facilitate recruitment of clients with cancer in hospice palliative home care, I emphasized my role as a student and showed genuine curiosity by asking questions and listening attentively. An attempt was made to be non-threatening to assure nurses that my role was not to evaluate their knowledge and skills, but rather to understand how gender may influence everyday hospice palliative home care. I also shared my personal experiences as a nurse and a family member of a relative dying at home receiving home care (Atkinson & Hammersley, 2007; Harrington, 2003; Lofland, Snow, Anderson, & Lofland, 2006). At the same time, to demonstrate competence and mutual interests, I made it known that I have some knowledge and experience of palliative care. These recruiting strategies were in keeping with critical feminist approaches that strive for the building of relationships and flattening of hierarchies, particularly in light of the inherent power of the researcher in the researcher-participant relationship (Olesen, 2005).

Additionally, I attempted to invite clients and family caregivers to participate in the study close to the time of their admission to hospice palliative home care. As advised by case managers, the Palliative Performance Scale (PSS), a validated tool used to

measure progressive decline of dying patients, was used to guide recruitment. The case managers and I agreed that the tool could provide a guide to determine the patient's proximity to end-of-life. By assessing ambulation, disease progress, activity, intake, level of consciousness, and ability to care for self, the nurse provided a score indicating proximity to death. We determined that a score of 60 to 70% on the PPS would be an ideal time to recruit clients, as the patient would be conscious, able to care for her or himself, and make decisions. This would allow time to complete interviews and home visits while the client was still able.

Purposeful sampling was employed to gather information-rich data and allow for an in-depth understanding of gender relations in hospice palliative home care (Patton, 2003). According to Smith (1987, 2005), starting with the men and women in the everyday world is starting with the knowledge experts of their experiences. This point of entry into the inquiry then makes visible the invisible practices and regulations that permeate down to, and shape, the everyday experiences of those who are not part of the "ruling apparatus" (Smith, 1987, 2003).

As the goals of treatment for hospice palliative care are focused on care, rather than cure (Canadian Hospice Palliative Care Association [CHPCA], 2006; Ross, McLean, & Fisher, 2002), the primary criterion for inclusion in this study was being a senior client (over the age of 60 years) diagnosed with terminal cancer who was receiving hospice palliative home care to enhance quality of life. As well, the client had to be alert and orientated to person, time, and place at the initiation of the study. The family caregiver was a family member or friend who identified him or herself as a caregiver. Nurses were registered nurses, since they provide the complex care frequently required in hospice

palliative home care (S. Smith, personal communication, August 31, 2011). All participants were over the age of 18 and able to speak English. However, consistent with ethnographic research, the unit of analysis was the culture of hospice palliative home care, rather than a focus on individuals (Atkinson & Hammersley, 2007; Thomas, 1993). As gender is relational, involving enactment of gendered expressions and responses between and among men and women and social institutions (Botoroff, Oliffe, Robinson, & Carey, 2011; Charlebois, 2011; Connell, 2012; West & Zimmerman, 1987, 2009), the sampling unit was comprised of the triad which included a client, her or his family caregiver, and the primary nurse involved with that particular client and caregiver. Data consisting of individual and conjoint interviews, observations of home visits, and documents were thus gathered from the "natural setting" during 16 months in the field (Allen, Chapman, Francis, & O'Connor, 2008).

In the midst of the study, the criterion for entry into the hospice palliative home care program had changed from a prognosis of one year to one of six months to live. This change in entry to the program made it difficult to recruit patients with higher PPS scores, and necessitated a longer time in the field than originally planned. Consequently, I was in the field from April 2012 to August 2013, achieving the successful recruitment of six client-family caregiver-nurse triads (See Appendix E).

A sample size of six clients, six family caregivers and four nurses (two clients had the same nurse) elicited 25 formal interviews, focused on predetermined semi-structured interview questions, in addition to nine informal interviews, comprised of questions and interactions that arose during field observations, written in the form of field notes for analysis (Roper & Shapira, 2000). As completion of thirty to fifty interviews is deemed to

be adequate for ethnographic research (Morse, 1994, 2000; Sandelowski, 1995), this study was considered to be satisfactory with a total of 34 interviews in addition to observations of home visits and review of documents. These methods generated copious data with a total of 39 hours of observation and 852 pages consisting of typed transcripts and fieldnotes. Furthermore, rather than aiming for a large number of participants, the focus of the study was on the unit of analysis of the triad consisting of the client, family caregiver, and nurse, which permitted examination of the dynamic and interactional quality of gender relations. More significantly, data were sufficient to fully develop concepts and themes and relationships among concepts and themes (Brod, Tesler, & Christensen, 2009) in order to understand and challenge gendered attitudes, beliefs, and practices that inform the culture of everyday hospice palliative home care. In addition to interviewing and observing the triad within the setting of hospice palliative home care, documents were also included (Thomas, 1993) and are discussed under data collection.

2.5.2 Data collection methods. One of the primary features of ethnography is that the researcher collects data by observing people's actions and perceptions in their natural settings for extended periods of time (Atkinson & Hammersley, 2007). In keeping with critical ethnography, multiple data sources were used in order to understand the construction of gender relations in the daily interactions of people's lives (Thomas, 1993, 2003). These sources included the interview, participant observation, and document review (Atkinson & Hammersley; Thomas, 1993), as elaborated in the following sub-sections.

2.5.2.1 Interview. Prior to the first interview, I asked participants to complete a demographic questionnaire. Clients were asked their age, type of cancer, year of

diagnosis, education level, occupation, and income range (see Appendix F-1). For family caregivers, the questionnaire included inquiry about age, education level, occupation, employment status and income range (see Appendix F-2). Nurses were asked about age, education level, nurse status (registered nurse, general classification or extended class), generalist or palliative specialist status, employment status (full-time, part-time, or casual), income range, and number of years employed as a nurse (see Appendix F-3). Obtaining this information was important to consider because of other social locations such as class and age (Kincheloe & McLaren, 2005) that may intersect and influence everyday experiences of gender in this context.

In ethnography, the interview is important to examine people's accounts and views of events (Allen et al., 2008; Atkinson & Hammersley, 2007; Thomas, 1993). I used a semi-structured format to guide the interviews (see Appendices G-1, G-2, G-3) and afforded participants space to elaborate on topics of interest to them (Atkinson & Hammersley; Chavez, 2008). For the formal, pre-determined, semi-structured interviews (n=25), I used open-ended questions to initiate the topic of inquiry and stimulate discussion (Allen et al., 2008; Atkinson & Hammersley; Madison, 2005). In particular, I asked clients, family caregivers, and nurses to describe their relationships in everyday hospice palliative home care, including their feelings and responses to interactions. In keeping with a feminist lens to be attentive to inherent power relations in the participant-researcher relationship and focus on experiences, particularly those of the silenced and marginalized in the everyday world (Hesse-Biber & Leckenby, 2004; Smith, 1987, 2005), I attempted to use probes such as "describe," "explain" and "elaborate" to elicit and foreground participants' experiences (Hesse-Biber & Leckenby, 2004, Smith, 1987) and

information-rich descriptions. Affording space for participants to speak relinquishes the researcher's control over the interview process (Borbasi, Jackson, & Willkes, 2005). However, I also was cognizant of the innate power present in "permitting" the voice of the "other" (Hesse-Biber & Leckenby, 2004).

As a feminist researcher, I engaged in a dialogic interview style (Chavez, 2008; Foley & Valenzuela, 2005) and shared feelings, opinions, and personal experiences with participants to diminish the power differential between the researcher and the researched and counter the expert, authoritative position of the researcher (Smith, 1987, 2005). Critical to feminist research is the development of relationships that avoid objectifying and subordinating individuals and reproducing power relations (Smith, 1987, 2005). Rather, research participants should be respected and valued for their knowledge (Smith, 2005). When appropriate, I shared my own experience of providing care for my dying father at home, creating a receptive environment and thus helping participants to feel at ease. I also shared my experiences as a palliative care nurse. This interview style also allowed me to connect to participants personally as I became a person who had experienced cancer and end-of-life with family members, rather than a person outside looking into hospice palliative care experiences. Sharing of stories mainly occurred with nurses and female participants in part because the culture already present within this context, but also perhaps because of my own cultural background in which females play an inferior role to males.

As I could understand medical terminology and the health care system, participants were able to describe their experiences without explicating background information. However, as too much closeness can obstruct understanding (Sprague,

2005), I was cognizant of the need to question routine practices and dominant discourses. Although I knew as a nurse how to conduct and assess client histories, I questioned nurses on their practices. My inexperience and limited knowledge in community-based nursing care was a catalyst to question attitudes, beliefs, and practices within hospice palliative home care.

However, researcher self-disclosure also can constrain participants, as the researcher may deflect conversation away from the participant and convey a disinterest in the participant's responses. More importantly, in disclosing information, the researcher may reveal dominate narratives that reproduce subordinate relationships (Sprague, 2005). As the researcher brings to the social interaction his or her own cultural attitudes, beliefs, and practices to the research interview, it was important to interrogate and challenge the experiences and narratives that filter my worldview (McCorkel & Myers, 2003). As such, I also was conscientious and reflexive of sharing my personal experiences (Sprague, 2005).

For two triads, more than one interview was conducted with each client with cancer, her or his family caregiver and the primary nurse, and for one triad three interviews were conducted with the client and caregiver. Conducting more than one interview enabled me to capture the patterns and dynamics of gendered relations that occur over time (Atkinson & Hammersley, 2007). Four to eight week time periods between interviews provided enough time for participants to reflect and respond to dynamic relationships, and short enough intervals to avoid attrition due to death. Multiple interviews with each member of the triad permitted follow up questions to address gaps and contradictions noted from the first interview (Thomas, 1993). From a critical feminist

perspective, multiple interviews helped to build trust and comfort in participant-researcher relationships and thus diminish the power inherent in traditional research (Sprague, 2005).

Additionally, a second interview in which findings were shared with participants was important to co-construct knowledge in a dialogic interview style (Lather, 1986, 1995). In accordance with feminist research, having more than one interview permits participants opportunities to benefit from the study and be genuinely involved in data analysis. I returned to participants and sought their opinions on how the study findings reflected their own experiences. Moreover, through multiple interviews, participants had more time to reflect on gender relations, thereby creating potential opportunities towards social change (Kincheloe & McLaren, 2005; Thomas, 1993). I asked participants how participation in the study helped them to reflect on gender relations, affording them an opening to discuss their views. I also shared how this study helped me to question my gendered assumptions and biases. However, because of the uncertain nature of end-of-life, the numbering and the timing of the interviews were contingent on the client's illness progression and family members' desires to continue with the study. For three client-family caregiver-nurse triads, only one interview with each was completed because of clients' deteriorating conditions and the emotional toll it took on participants.

To understand the construction of social interactions, and uncover hidden assumptions and beliefs, it was valuable to conduct both separate and joint interviews with clients and family caregivers. Interviewing in groups provides context, affording a more natural social encounter in which interactions can be captured and in which the balance of power is shifted from the researcher to the participants, leading to a more equal

relationship and thus aligning with feminist principles (Wilkinson, 2004). However, while a joint interview can provide an understanding of the dynamics of relationships (Taylor & deVocht, 2011), separate interviews gave participants an opportunity to freely express their views in a non-threatening environment, unconstrained by the family member's presence (Atkinson & Hammersley, 2007; Taylor & deVocht, 2011).

For this study, the first three clients and family caregivers were given a choice in the initial interview of separate and/or joint interviews. The thought of separate interviews may create apprehension for family members protecting ill relatives (Gysels, Shipman, & Higginson, 2008), and some sense that in requesting separate interviews, the relationships may be perceived as secretive and unsatisfactory (Taylor & deVocht, 2011). Moreover, presence of a second person permits the interviewee to withdraw from the interview during difficult situations such as end-of-life (Pleschberger et al., 2011).

While the first three client-family caregiver dyads agreed to joint interviews, I found that participants' answers were constrained by the presence of family members. Explaining that separate interviews would assist me in the study gave participants the opportunity to interview separately and thus express their views freely. Of the three joint interviews with three triads, one client and caregiver was followed up with separate interviews, and separate interviews were conducted thereafter with each client and caregiver. Observations of interactions between and among family members were also made during formal interviews with clients and caregivers, and documented in the form of fieldnotes.

2.5.2.2 Participant observation. Nine observations of agency home visits involving the triads of client, family caregiver, and primary nurse were conducted.

Agency home visits were made at various times, largely dependent on participants' schedules. During two home visits, husbands of ill wives excused themselves at the time of the agency home visit. I noted the absence of the third participant and any dynamic differences. One client was not home during the time of an arranged visit, and consequently missed it. I always entered with the nurse in order not to interfere further into clients' and caregivers' everyday activities. Because of this, clients and caregivers may have perceived that I was aligned with the home care agencies and the nurses. On the other hand, my role as a researcher was made clear, and I was at once an insider and outsider, as noted previously.

Being present in the natural environment afforded context, and therefore a better understanding of the interactions that occurred between and among clients, family caregivers, and nurses in everyday hospice palliative home care (Atkinson & Hammersley, 2007; Roper & Shapiro, 2000). In particular, I observed the relationships within this setting and how social relations of gender affected experiences. I observed interactions related to care among participants and took notice of verbal and non-verbal expressions that illuminated taken-for-granted positions of dominance and the sources of power underlying those positions. For example, I observed how men would sit to the side or leave during agency home visits.

An attempt was made to make observations of two home visits for each triad to capture the dynamic patterns of everyday interactions; however, the second home visit was not possible for three triads, because of clients' imminent deaths and the strain involved for family members. Thus, two home visits were completed for each of the remaining three triads. As is consistent with feminist research, two visits provided an

opportunity to develop relationships for more collaborative interactions in which participants and I could co-construct understandings (Hesse-Biber & Leckenby, 2004; Smith, 1987, 2005).

During times of observation, I assumed a peripheral membership role in which I interacted with participants without fully participating in activities of those involved in home care (Adler & Adler, 1994). I was clear about my role as a researcher, but, to develop relationships and ease into everyday hospice palliative home care, I also made it known that I was an experienced palliative care nurse (Fontana & Frey, 2005), though I have not worked in home care. I engaged in a peripheral role observing interactions and treatment procedures (e.g. dressing changes), with the exception of one visit in which I assisted with retrieving dressing and cleaning supplies.

During the agency home visits, there were opportunities for informal interviews, or spontaneous discussions that arose during participant observation (Atkinson & Hammersley, 2007). The discussions were interactional in nature compared to the semi-structured interviews. These data were important to acquire an understanding of the complex relations and interactions that occur every day in hospice palliative home care and that are not present within the structure of the formal interview (Fontana & Frey, 2005). The informal interview also permitted questions to be asked about the actions and behaviours that occur, and allowed me to express feelings and answer participants' questions (Adler & Adler, 1994; Baker, 2006), thereby enriching the participant observation data. In four agency home visits, there were interruptions from a son, neighbour, personal support worker, and a friend of the client or caregiver. During these occasions, I was able to ask how these personal and professional relationships were

supportive to the client or caregiver and how gender may play a role, thus gaining further

contextual knowledge of their experiences and relations. I also asked about perceptions

and feelings regarding certain routines and practices, such as how the client or caregiver

prepared for the home visit and how their gender and the female nurse influenced these

actions. In keeping with feminist principles, this time also was valuable to share stories

and develop relationships, particularly when participants shared with me their emotional

experiences in hospice palliative home care. Data collected through participant

observation were recorded in the form of fieldnotes.

As note-taking in the field can be perceived as threatening and disruptive,

observations were recorded following home visits and in the form of fieldnotes for

analysis (Adler & Adler, 1994; Atkinson & Hammersley, 2007; Lofland et al., 2006).

During the home visit, I made mental notes of the setting, the people involved, the order

of events, and the actions and interactions (Lofland et al.). Furthermore, as noted

previously, I reflected on and recorded my role, as well as how my gender, class, age, and

ethnicity influenced the social interactions within the home care visit (Angrosino &

Rosenberg, 2011; Borbasi et al., 2005). As soon as I was alone, I recorded fieldnotes

phrases, quotations, and key words to enhance my memory when writing full fieldnotes.

In order to distinguish between paraphrased and verbatim descriptions, and description

and interpretation (Lofland et al., 2006), I noted different members, quotations,

commentaries, reflections, and reactions, and marked any other notes as theoretical or

methodological (Emerson, Fretz, & Shaw, 2001). I used a fieldnote guide (See Appendix

H) to distinguish descriptions, interpretations, reflections and analytical notes (Emerson et

al., 2001) for further analysis.

2.5.2.3 Document review. As supplementary data sources (Lofland et al. 2006), documents were analyzed to gain an understanding of the sociopolitical context of hospice palliative home care. Documents are traditionally viewed as inert texts referenced to determine "hard facts" and rules (Prior, 2010). However, documents are written by people with specific purposes; they are written words or images that influence social relationships, hierarchies, and practices, and may act as experts, rule-makers, or illustrators (Prior, 2010). Furthermore, documents are created to align with the organizational culture and are shaped by broader taken-for-granted attitudes, beliefs, and meanings (Perakyla, 2008). Similarly, "relations of ruling" (Smith, 1987), or organizations, function and control policies and practices through texts or discourses. It follows that documents should be viewed as actors or agents that structure and clarify understandings of how one should interact and what actions should get done or not (Prior, Hughes, & Peckham, 2012) within an organization. Additionally, further emphasis should be placed on how these documents affect people's everyday lives (Smith, 2005).

Based on this notion of document as actor, I examined the documents to reveal presuppositions, the intended audience, the purpose, the timing, and the included/excluded content. I asked questions such as: "What is taken-for-granted?" "What is omitted?" "Who reads this?" and "For what purpose?" (Atkinson & Hammersley, 2007; Prior et al., 2012). I examined how the document was constructed, used, and circulated and how it functioned to influence social actions and interactions (Prior, 2008) in everyday hospice palliative home care.

From a critical perspective, it was also important to expose ways in which texts reproduced power relations such as gender. As these power relations are often taken-for-

granted, I was alert to dominant discourses that legitimized, denied, or concealed dominance as well as to strategies that may have been used to downplay, understate, or imply power (Van Dijk, 2006). I also examined how people were described and categorized, and the significance of using the selected categories (Perakyla, 2008). Additionally, I was attentive to overall concepts that framed the message of the documents (Fallon, 2006). For this study, I explored the discourses of individualism, familialism, and economic efficiency, and their connections to and influences on everyday interactions (Smith, 1987, 2005).

Virtual public communication documents relevant to hospice palliative care and located on web sites for the agencies to which nurses were employed were examined (see Appendix I), since this mode of information is easily accessed by the public. While research indicates that only 26% of older adults use the internet for health information (Ferguson, 2007; Sidon, 2007), these documents were examined, since they have been shaped by the cultural attitudes and beliefs of the agencies (Perakyla, 2008) and reflect the structure and expected relations and actions in this context (Prior, 2008; Smith, 1992). I also obtained public communication documents that were frequently distributed to clients in hospice palliative home care. Finally, to investigate the prevalence of professional discourses related to gender relations in this context (Smith, 1987, 2005), I examined documents from professional, provincial, and national nursing organizations (See Appendix I).

2.6 Data Management and Data Analysis

All fieldnotes of observations and informal interviews were transcribed as soon as it was possible. Taped interviews were transcribed verbatim and edited for any

identifying elements. Documents were summarized in fieldnotes (Atkinson & Hammersley, 2007). A computer program, NVivo, was employed to aid in data management and included the numbering, coding, filing, and retrieving of interview transcripts, participant observation fieldnotes, and documents. Throughout data collection and analysis, memos were written to capture concepts of emerging themes, the research process, and field work observations and incidents (Lofland et al., 2006). In contrast to objective data that are seen and heard, memos included concepts, reflections, and insights from the data. Memos, thus, were used as part of the data analysis in order to develop theoretical understanding (Lofland et al., 2006; Roper & Shapira, 2000). I also wrote memos in relation to the research process (Lofland et al., 2006). For instance, I questioned my approach when participants doubted that gender had any influence in hospice palliative home care experiences. I re-examined the interview guide questions and queried how I presented myself, questioned others, and affected participants' responses. I decided to first listen attentively to participants' stories and then ask how gender played a role and their thoughts and feelings particular to the gendered experiences described.

As is consistent with qualitative research, data analysis was conducted concurrently with data collection (Atkinson & Hammersley, 2007). To become familiar with the data and make it intelligible (Atkinson & Hammersley, 2007), I wrote a summary detailing each client-family caregiver-nurse triad. The stages of data analysis involved, first, repeatedly reading data line by line to make sense of the data, organizing it into general categories, and coding it in the computer software program, NVivo (Atkinson & Hammersley, 2007).

In coding, I named phenomena, ideas, and patterns observed in the data. In the step of initial coding or open coding, I asked general questions such as, "what is this?" or "what is going on here?" (Lofland et al., 2006, p. 201). More specifically, I asked, "How is gender in play?" ;"How is gender embodied, practiced, displayed, received or transcended?" and "How do assumptions and roles play into interactions?" (Thomas, 1993). Numerous different codes were generated during this process (Lofland et al., 2006) and routine processes and hidden assumptions were made explicit at this time (Thomas, 1993). In the process of initial coding, I noticed more general categories that developed, while others faded, and then I categorized them conceptually (Lofland et al., 2006; Madison, 2005).

The second step encompassed comparing and contrasting each category to others, collapsing similar themes, while developing others (Atkinson & Hammersley). Finally, I examined the data to develop major themes. I described the theme characteristics, asking: "What is this?"; "Who is involved?" ; "How does this evolve?"; "When did this occur?"; and "What is it not?" From a critical perspective (Smith, 1987, 2005; Thomas, 1993), I asked, "Who benefits?"; "Who is disadvantaged?"; "Whose interests are served?"; "How do I account for this contradiction?"; "Who is controlling?"; and "Who is resisting?" Additionally, I questioned taken-for granted gendered attitudes, beliefs, and practices (Smith, 2005; Thomas, 1993, 2003). As categories and themes were interpreted, they were continually compared to the existing data. At this time, relationships among categories were being conceptualized. As an example, in defining specific enactments of power strategies, I found that each one included a form of asserting, maintaining, or resisting power, and that this category was of a higher level theme.

Throughout analysis, relationships were also made with all data sources, including documents, fieldnotes, memos, or journal entries, while comparisons were made among individuals, groups, and organizations to help in clarifying meaning. I also attempted to link everyday actions to institutional texts and discourses (Smith, 1985, 2005). I used the strategies of diagramming and matrix-making to compare and link concepts. By representing findings visually, concepts were refined and relationships were made between concepts (Lofland et al, 2006). In developing a matrix, I was able to cross reference categories to participants, achieving further contrast and comparison of findings.

2.7 Study Rigour

Validity was augmented by the authenticity criteria set out by Guba and Lincoln (1989). An audit trail was maintained by recording key decision points that were used to inform interpretations. An audit trail is used to detail the process through which key points are logically made to reach the conclusions made in the study. Subsequently, one can follow analyses to the data source. The process and method decisions were documented in memos (Guba & Lincoln, 1989), ensuring that interpretations were derived from participants and context, rather than from my biases.

Member checking involved returning to participants with interpretations to co-construct a mutual understanding and thereby validate findings (Guba & Lincoln, 1989). Consistent with the critical feminist paradigm, I also used member checking to promote reciprocal relationships that potentially engage and empower participants (Lather, 1995). While member checking can foster a collaborative, "dialogic encounter" (Lather, 1986, p. 268), it was important to be cognizant of the possibility of false consciousness in critical

research. I also corroborated participants' interpretations with context and other data (Guba & Lincoln, 1989). While conducting second interviews for member checking purposes was attempted, it was not possible with three of the terminally ill clients and their family caregivers. Three formal interviews were conducted for one client and family caregiver. I also returned to two nurses to co-construct and validate knowledge. Additionally, my advisory committee members ensured that interpretations were supported with data.

I also employed Patti Lather's (1993, 1995) transgressive validity, which is specifically relevant to feminist and critical methodology, rather than traditional, positivist research based on theories of truth (Lather, 1995). While Lather's main interest in her postulation is to address how critical feminist researchers can represent research participants' stories, her main goal is to interrogate how researchers can ethically and responsibly be accountable in interpreting others' experiences (Lather, 1995). Lather attends to this "crisis of representation" through a transgressive validity check list that includes: ironic, paralogic, rhizomatic, and voluptuous validity (Lather, 1993, 1995).

To promote Lather's ironic validity (Lather, 1993, 1995), data analysis was viewed critically to problematize everyday events, question contradictions, and ensure that participants' voices were heard. To create ironic validity, data were examined with an assumption that what is perceived fails to represent reality. I did not take at face value what was seen; I questioned what was represented as truth (Lather 1993, 1995), such as nurses' "routine" practices. In other words, it was important to problematize everyday interactions and social norms of home care and interrogate master narratives (Borbasi et al., 2005).

Constructing paralogic validity (Lather, 1995) involved questioning contradictions, hindrances, indecisions, or complications. Rather than accepting narratives that fit tidily, I attempted to place findings in the context of location and time, refusing closure, and remaining open to alternative interpretations. In this way, interpretations were continually interrogated to avoid imposing my "expert" views and therefore prevent a "crisis of authority" (Lather, 1993, p. 683). Knowledge then is created with, for, and from participants, rather than about them (Lather, 1995).

Rhizomatic validity evades a systematic evaluation of a well-ordered structure, and instead is concerned with complexities, connections, and intersections (Lather, 1995). I critically examined power, normality, and conventionality of relationships in home care. Social relations were critically examined to make room for complex understandings of any intersecting social dimensions such as age, ethnicity, class or gender. I attempted to look beyond simple hierarchal structures and dichotomies, such as nurse and patient, male and female, or rich and poor, and look for complex networks of power relations.

Finally, voluptuous validity is concerned with the positionality of the researcher and its influences on participant responses and data analysis (Lather, 1995). I reflected in my journal my social positions that I brought to the end-of-life home encounter. I was constantly aware that, in the process of collecting data, my presence as a researcher may have the potential to shape actions and responses and therefore the data being analyzed (Atkinson & Hammersley, 2007; Smith, 1987). I was alert to hierarchal relationships and questioned if, because of my social locations, how I viewed participants or how participants may have viewed me. In particular, as fellow nurses may have been guarded because they perceived me to have power as a graduate student and nurse instructor, I was

cognizant of my goals in entering relations, whether they were towards advocacy, empathy, or being with (Lather, 1993). I used reflexivity (Lather, 1995) to work against a researcher-imposed analysis.

2.8 Ethics

Ethics approval was obtained (Feb 2012) and renewed (February 2013) from the Research Ethic Boards of the University of Western Ontario Research Ethics Board and Waterloo Wellington Community Care Access Centre (See Appendix A). I ensured that all participants were aware of the voluntary nature of the study and that they could withdraw from the study at any time, even after the study had started. Participants were assured that names and other identifying items would be removed from all documents, interview transcripts and field notes. Pseudonyms were used on all documents (transcripts and reports) to protect individuals. Tapes of interviews were destroyed after they were transcribed verbatim and edited for any identifying elements. Any documents with contact information were shredded following completion of the study. Coded transcripts have been kept in a locked cabinet and will be kept there for 7 years, at which time they will be destroyed.

The purpose of critical research is to strive for social change through social awareness. At times I did question nurses' attitudes and behaviours. For example, I questioned a nurse when she said that women were more naturally inclined to be nurses than men. Upon reflection, I could have challenged nurses more often about their gendered assumptions. Although I shared my own difficulties of reflecting and transforming embedded gendered beliefs to encourage nurses to be more introspective, I did not push this. Attention to gender relations is important to avoid and address gender

inequities. Ignoring inequities only serves to perpetuate them and further disadvantage the already oppressed and marginalized (Raphael, 2012). In terms of clients and caregivers, they were focused on their experiences during this vulnerable time. While I did ask clients and caregivers if the study had sparked and changed thoughts about gender relations, I sought to reveal gender inequities in hospice palliative home care to a wider audience in an effort to set the stage for, and ultimately promote, the initiation of social change.

2.9 Towards Action for Gender Equity in Hospice Palliative Home Care

Action towards change on equity in health and health services requires intervention from various levels and sectors (Baum, 2007; Reutter & Kushner, 2010). There may be intervention at individual, community, and government levels (Baum, 2007; Grol & Grimshaw, 2003), local, regional, and national levels (Evans, 2005) or formal and informal levels (Blas et al, 2008). Evidence indicates that success for knowledge translation of research evidence to practice and policies also involves collaborative approaches involving networks (Armstrong & Kendall, 2010; Dobbins et al., 2009) and alliances (Evans, 2005). Furthermore, a "bottom up, top down" approach is needed for society to drive policy makers towards practices and policies that promote equity (Baum, 2007). To this end, I intend to join community and organizational groups for the purpose of forming alliances and networks towards action for gender equity, particularly during end-of-life home care.

At the individual level, I have attempted to initiate opportunities to co-create stories through reflection on the experiences and challenges in hospice palliative home care. Participants have been engaged in dialogic interpretation of the data during the

second interviews, thereby promoting knowledge translation. Also, I have asked clients, caregivers, and health care providers how participation in the study had altered their views, feelings, or behaviours about gender relations, thereby making an effort to achieve social change at a micro level. Furthermore, by presenting my research findings, I have engaged a wider audience of clinicians, researchers, and educators at international and national conferences such as the 20th Congress of Palliative Care Conference (2014) and the 9th National Community Health Nurses Conference (2014).

Including local people who may benefit from change brings valuable knowledge to inform relevant strategies for change (Blas et al., 2008; Smith, 2005). As such, I will explore and join groups who show concern for gender equity in health and health care, including women's groups, the North West End of Life Network and the Centre for Education and Research on Education and Health. As networks include stakeholders from various sectors (Armstrong & Kendell, 2010; Dobbins et al., 2009), I will attempt to form alliances with caregivers, health care providers, home care agencies, and policy makers. As I continue to conduct research, I aim to make connections with clients and caregivers living with various chronic illnesses (e.g., Alzheimer's disease, congestive heart failure) and conditions (e.g., disabilities) to help address needs and concerns that need to be addressed, particularly in terms of equity. As a feminist researcher, I will attempt to include participants (e.g., clients and caregivers) in all levels of the research project.

Building on a past knowledge translation opportunity (Knowledge Translation in Dementia Care: It Takes a Community), I plan to use the knowledge and skills that I have developed in this endeavor to initiate projects in which there is extensive collaboration amongst key stakeholders. As I grow in this field of equity in health and health care, I

hope to create alliances within different disciplines and sectors. For example, I will explore end-of-life for other chronic diseases and conditions such as persons with disabilities or Alzheimer's disease, and explore linkages with other relevant associations such as the Alzheimer's Society of Ontario. I also will ensure that I remain apprised of activities of interest groups such as the Canadian Caregiver Coalition, the Home Care Association of Canada, and Canadian Association for Retired Persons.

In terms of the "top down" approach, at the policy level, I have been active with the Registered Nurses' Association of Ontario (RNAO), an association that provides tools for advocacy, political connections, and a concern for those disadvantaged. I have taken on an executive position on the Palliative Care Interest Group associated with RNAO to remain up-to-date of current trends and issues in palliative care nursing and be a part of a collective voice to promote change. As people need support to make change (Baum, 2007), being connected to and sharing my research findings with nursing associations involved in the development of standards and guidelines for practice is important to promote awareness and education regarding gender relations.

2.10 References

Acker, J. (2012). Gendered organizations and intersectionality: problems and possibilities. *Equity, Diversity and Inclusion*. 31 (3), 214-224. doi: 10.1108/02610151211209072

Adler, P.A. & Adler, P. (1994).Observational techniques. In N. Denzin& Y. Lincoln (Eds.). *The sage handbook of qualitative research* (pp. 377-392). Thousand Oaks: Sage publications.

Al-Makhamreh, S., &Lewando-Hundt, G. (2008). Researching 'at home' as an insider/outsider: Gender and culture in an ethnographic study of social work practice in an Arab society. *Qualitative Social Work, 7* (1), 9-23. doi: 10.1177/1473325007086413

Allen, S., Chapman, Y., Francis, K., & O'Connor, M. (2008). Examining the methods used for a critical ethnographic enquiry. *Contemporary Nurse, 29*, 227-237.

Angrosino, M., & Rosenberg, J. (2011). Observations on observations. In N.Denzin, & Y. Lincoln (Eds.), *The sage handbook of qualitative research* (4th ed.) (pp. 467-478). Thousand Oaks: Sage Publications.

Armstrong, K., & Kendall, E. (2010). Translating knowledge into practice and policy: the role of knowledge networks in primary health care. *Health Information Management Journal, 39* (2), 9-17.

Atkinson, P., & Hammersley, M. (2007). *Ethnography: Principles in practice* (3rded.).New York: Routledge.

Baker, L. (2006). Observation: A complex research method. *Library Trends, 55* (1), 171-189.

Baum, F. (2007). Cracking the nut of health equity: top down and bottom up pressure for action on the social determinants of health. *Promotion & Education, 14* (2), 90-98. doi: 10.1177/10253823070140022002

Blas, E., Gilson, L., Kelly, M., Labonte, R., Lapitan, J., Muntaner, C….Vaghri, Z. (2008). Addressing social determinants of health inequities: what can the state and civil society do? *The Lancet, 372*, 1684-89. doi:10.1016/S0140-6736(08)61693-1

Botoroff, J., Oliffe, J., Robinson, C., & Carey, J. (2011). Gender relations and health research: A review of current practices. *International Journal for Equity in Health, 10* (60). Retrieved from http://www.equityhealthj.com/content/10/1/60

Borbasi, S., Jackson, D., & Wilkes, L. (2005). Fieldwork in nursing research: positionality, practicalities and predicatments. *Journal of Advanced Nursing, 51* (5), 493-501. doi: 10.1111/j.1365-2648.2005.03523.x

Brod, M., Tesler, L., & Christensen, T. (2009). Qualitative research and content validity: developing best practices based on science and experience. *Qualitative of Life Research, 18*: 1262-1278. doi: 10.1007/s11136-009-9540-9

Browne, A. (2005). Discourses influencing nurses' perceptions of First Nations patients.*Canadian Journal of Nursing Research, 37 (4)*, 62-87.

Canadian Hospice Palliative Care Association [CHPCA]. (2006).*The pan-Canadian gold standard for palliative home care.* Retrieved from: www.chpca.net/pan-cdn_gold_standards

Canadian Nurses Association [CNA]. (2010). *Social justice: A means to an end.* Retrieved from: www2.cna-aiic.ca/CNA/documents/pdf/.../Social_Justice_2010_e.pdf

Carroll, W.K. (2004). Unpacking and contextualizing critical research strategies. In

W.K. Carroll (Ed.) *Critical Strategies for Social Research*. Toronto, ON:

Canadian Scholars' Press.

Charlebois, J. (2011). *Gender and the construction of hegemonic and oppositional*

feminism. Plymouth: Lexington Books

Chavez, C. (2008). Conceptualizing from the inside: Advantages, complications and

demands on insider positionality. *The Qualitative Report, 13* (3), 474-494.

Retrieved from: http:/www.nova.edu/ssss/QR13-3/chavez.pdf

College of Nurses of Ontario (2002). *Professional Standards*. Retrieved from

http://www.cno.org/Global/docs/prac/41006_ProfStds.pdf

College of Nurses of Ontario (2009). *Standards of practice: Ethics.* Retrieved from

www.cno.org/Global/docs/prac/41034_Ethics.pdf

College of Nurses of Ontario (2006). *Standards of practice*: *Therapeutic nurse-client*

relationships. Retrieved from

www.cno.org/Global/docs/prac/41033_Therapeutic.pdf

Connell, R. (2012). Gender, health and theory: Conceptualizing the issue, in local and

world perspective. *Social, Science, & Medicine, 74*, 1675-1683.

Community Care Access Centre [CCAC], (2011). *Careers*. Retrieved from:

http://jobs.workopolis.com/jobshome/db/ccac.job_posting?pi_job_id=9560426&p

i_search_id=682296856&pi_sort=&pi_curjob=2&pi_maxjob=3

Dobbins, M., Robeson, P., Ciliska, D., Hanna, S., Cameron, R., O'Mara, L….Mercer, S.

A description of a knowledge broker role implemented as part of a randomized

controlled trial evaluating three knowledge translation strategies. *Implementation Science, 4* (23), 1-9. doi: 10.1186/1748-5908-4-23

Eakin, J., Robertson, A., Poland, B., Coburn, D., & Edwards, R. (1996). Towards a critical social science perspective on health promotion research. *Health Promotion International, 11* (2), 157-165.

Emerson, R., Fretz, R., & Shaw, L. (2001).Participant observation and field notes. In P. Atkinson, A. Coffey, S. Delamont, J. Lofland, L. Lofland (Eds.), *Handbook of ethnography*. (pp. 352-368). Thousand Oaks, California: Sage Publications

Evans, K. (2005). A guide to feminist advocacy. *Gender and Development, 13* (3), 10-19. Retrieved from: http://www.jstor.org/stable/20053159

Fallon, D. (2006). To 'raise dream and ambition' – the rhetorical analysis of a teenage pregnancy strategy. *Nursing Inquiry, 13* (3), 186-193.

Ferguson, T. (2007). *E-patients: How they can help us heal health care.* Retrieved from: http://www.e-patients.net/e-patients_whitepaper.pdf

Fine, M. (1994). Working the hyphens: Reinventing self and other in qualitative research. In N. Denzin& Y. Lincoln (Eds.). *The sage handbook of qualitative research* (pp. 70-82). Thousand Oaks: Sage publications.

Foley, D. (2002). Critical ethnography. The reflexive turn. *Qualitative Studies in Education, 15* (5), 469-490.

Foley, D., & Valenzuela, A. (2005). Critical ethnography: The politics of collaboration. In N. Denzin, & Y. Lincoln (Eds.), *The sage handbook of qualitative research* (3rd ed.). Thousand Oaks: Sage publications.

Fontana, A., & Frey, J. (2005). The interview: From neutral stance to political involvement. In N. Denzin, & Y. Lincoln (Eds.), *The sage handbook of qualitative research* (3rd Ed.) (pp. 695-728). Thousand Oaks: Sage publications.

Funk, L., Stajduhar, K., Toye, C., Aoun, S., Grande, G. & Todd, C. (2010). Part 2: Home-based family caregiving at the end of life: a comprehensive review of published qualitative research (1998-2008). *Palliative Medicine, 24* (6), 594-607. doi: 1177/0269216310371411

Gottfried, H. (1996). Engaging women's communities: Dilemmas and contradictions in feminist research. In H. Gottfried (Ed.), *Feminism and social change*. (pp. 1-20). Chicago: University of Illinois Press.

Grol, R., & Grimshaw. (2003). From best evidence to best practice: Effective implementation of change in patients' care. *The Lancet, 362*, 1125-30. doi: doi:10.1016/S0140-6736(03)14546-1

Guba, E., & Lincoln, Y. (1989). *Fourth generation evaluation*. Newbury Park: Sage Publications.

Gysels, M., Shipman, C., & Higginson, I. (2008). Is the qualitative research interview an acceptable medium for research with palliative care patients and carers? *BMC Medical Ethics, 9* (7). doi: 10.1186/1472-6939-9-7

Harrington, B. (2003). The social psychology of access in ethnographic research. *Journal of Contemporary Ethnography, 32* (5), 592-625.

Hesse-Biber, S., & Leckenby, D. (2004). How feminists practice social research. In S. Hesse-Biber & L. Yaiser (Eds.). *Feminist perspectives in social research* (pp 209-226) New York: Oxford University Press.

Jo, S., Brazil, K., Lohfeld, L., & Willison, K. (2007). Caregiving at the end of life: Perspectives from spousal caregivers and care recipients. *Palliative and Supportive Care, 5,* 11-17.

Kincheloe, J., & McLaren, P. (2005). Rethinking critical theory and qualitative research. In N. Denzin& Y. Lincoln (Eds.), *Handbook of qualitative research* (pp. 303-342) (3rded.). Thousand Oaks: Sage Publications.

Kushner, K., Morrow, R. (2003). Grounded theory, feminist theory, critical theory: Toward theoretical triangulation. *Advances in Nursing Science, 26* (1), 3043. Retrieved from:

Labaree, R. (2002). The risk of 'going observationalist': Negotiating the hidden dilemmas of being an insider participant observer. *Qualitative Research, 2* (1), 97-122.

Lather, P. (1986). Research as praxis. *Harvard Educational Review, 56* (3), 257-277.

Lather, P. (1993). Fertile obsession: validity after poststructuralism. *The Sociological Quarterly, 34* (4), 673-693.

Lather, P. (1995). The validity of angels: interpretive and textual strategies in researching the lives of women with HIV/AIDS. *Qualitative Inquiry, 1* (1), 41-68.

Lofland, J., Snow, D., Anderson, L., & Lofland, L. (2006). *Analyzing social settings: A guide to qualitative observation and analysis* (4th ed.). Toronto: Thomson, Wadsworth.

McCorkle, J., & Myers, K. (2003). What difference does difference make? Position and privilege in the field. *Qualitative sociology, 26* (2), 199- 231.

Madison, S. (2005) *Critical ethnography: Method, ethics and Performance.* Thousand Oaks: Sage Publications.

Manderson, L., Bennett, E., & Andajani-Sutjahjo, S. (2006). The social dynamics of the
interview: Age, class and gender. *Qualitative Health Research, 16* (10), 1317-
1334. doi: 10.1177/1049732306294512

Marshall, B. (1994). *Engendering modernity: Feminism, social theory, and social change.*
Cambridge, UK: Polity Press.

Morse, J. (1994) Designing funded qualitative research. In N. Denzin& Y. Lincoln (Eds.).
Handbook of qualitative research (pp. 220-235). Thousand Oaks: Sage.

Morse, J. (2000). Determining sample size. *Qualitative Health Research, 10*, 3-5.

Morse, S., & Fife, B. (1998). Coping with a partner's cancer: Adjustment at four stages of
the illness trajectory. *Oncology Nursing Forum, 25*, 751-760.

Mulhall, A. (2003). In the field: notes on observation in qualitative research. *Journal of
Advanced Nursing, 41* (3), 306-313.

Olesen, V. (2005). Early millennial feminist qualitative research: challenges and contours.
In N. Denzin & Y. Lincoln (Eds.) *The sage handbook of qualitative research* (3rd
ed.) (pp 235-278).

Patton, M. (2003).*Qualitative research and evaluation methods*. (3rd ed.). Thousand Oaks,
California: SAGE.

Perakyla, A. (2008). Analyzing talk and text. In N.K. Denzin and Y.S. Lincoln (Eds.),
Collecting and interpreting qualitative materials (pp. 869-885) (3rd ed.). Thousand
Oaks, CA: Sage

Pillow, W. (2003). Confession, catharsis or cure? Rethinking of reflexivity as
methodological power in qualitative research. *Qualitative Studies in Education, 16*
(2), 175-196. doi: 10.1080/0951839032000060635

Pitre, N., Kushner, K., Raine, K., & Hegadoren, K. (2013). Critical feminist narrative inquiry: Advancing knowledge through double-hermeneutic narrative analysis. *Advances in Nursing Science, 36* (2), 118-132. doi: 10.1097/ANS.0b013e3182902064

Pleschberger, S., Seymour, J., Payne, S., Deschepper, R., Onwuteaka-Philipsen, B., & Rurup, M. (2011). Interviews on end-of-life care with older people: reflections on six European studies. *Qualitative Health Research, 21* (11), 1588-1600. doi: 1177/104732311415286

Prior, L. (2008). Repositioning documents in social research. *Sociology, 42* (5), 821-836. doi: 10.117710038038508094564

Prior, L (2010). Documents in health research. In I. Bourgeault, R. Dingwall and R. deVries (Eds.), *The sage handbook of qualitative methods in health research* (pp 417-432). Thousand Oaks, CA: Sage

Prior, L., Hughes, D., Peckham, S. (2012). The discursive turn in policy analysis and the validation of policy stories. *Journal of Social Policy, 41* (2), 272-289. doi:10.1017/S0047279411000821

Raphael, D. (2012). The importance of tackling health inequalities. In D. Rapheal (Ed.), *Tackling health inequalities: Lessons from international experiences* (pp 1-33). Toronto: Canadian Scholar's Press.

Registered Nurses' Association of Ontario (2002). *Nursing best practice guideline: Establishing therapeutic relationships.* Retrieved from http://rnao.ca/sites/rnao-ca/files/Establishing_Therapeutic_Relationships.pdf

Reutter, L., & Kushner, K. (2010). Health equity through action on the social determinants of health: Taking up the challenge in nursing. *Nursing Inquiry, 17* (3), 269-280. doi: 10.1111/j.1440-1800.2010.00500.x

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

Ross, M., McLean, M., Fisher, R. (2002). End-of-life care for seniors: The experience of seniors and informal caregivers. *Canadian Journal on Aging, 21* (1), 137-146.

Sandelowski, M. (1995). Focus on qualitative methods: Sample size in qualitative research. *Research in Nursing and Health, 18,* 179-183.

Sidon, T. (2007). *A comparative analysis of internet health information use between baby boomers and older adults*. (Master's Thesis, Department of Gerontology, Simon Fraser University, Vancouver, BC) Retrieved from www.sfu.ca/uploads/page/02/thesis_sinden.pdf

Suzuki, L., Ahluwalia, M., Mattis, J., & Quizon, C. (2005). Ethnography in counseling psychology research: Possibilities for application. *Journal of Counseling Psychology, 52* (2), 206-214. doi: 10.1037/0022-0167.52.2.206

Smith, D. (1987). The everyday world as problematic. Massachusetts: Northeastern Press.

Smith, D. (1992). Sociology from Women's Experience: A reaffirmation. *Sociological Theory,* 10 (1), 88-98. URL: http://www.jstor.org/stable/202020

Smith, D. (2005). Women's Standpoint: Embodied knowledge versus the Ruling Relations. *Institutional ethnography*: *A sociology for people* (pp. 7-26) Maryland: Alta Mira Press.

Sprague, J. (2005). *Feminist methodologies for critical researchers: Bridging differences*. New York: Altamira.

Taylor, B., & de Vocht, H. (2011). Interviewing separately or as couples? Considerations of authenticity of method. *Qualitative Health Research, XX* (X), 1-12. doi: 10.1177/1049732311415288

Thomas, J. (1993). *Doing critical ethnography*. Newbury Park, California: Sage publications.

Thomas, J. (2003). Critical ethnography, meanings, and symbolic violence. In R.B. Clair (Ed.), *Expressions of Ethnography: Novel approaches to qualitative research* (pp 45-65)*.* Albany: State University of New York.

Van Dijk, T. (2006) Principles of critical discourse analysis. *Discourse & Society, 42*(2), 249-283. doi: 10.1177/0957926593004002006

Ward-Griffin, C., McWilliam, C., Oudshoorn, A. (2012a). Negotiating relational practice patterns in palliative home care. *Journal of Palliative Care, 28* (2), 33-40. doi: 10.1177/1074840712462134

Ward-Griffin, C., McWilliam, C., Oudshoorn, A. (2012b). Relational experiences of family caregivers providing home-based end-of-life care. *Journal of Family Nursing, 18* (4), 91-516. doi: 10.1177/1074840712462134

Waterloo-Wellington Community Care Access Centre [WW-CCAC], 2010. *Waterloo-Wellington Integrated Hospice Palliative Care Program*. Retrieved from: http://www.ccacont.ca/Content.aspx?EnterpriseID=3&LanguageID=1&MenuID=1462

Wilkinson, S. (2004) Focus groups. A Feminist Method. In S. Hesse-Biber & L. Yaiser

    (Eds.). *Feminist perspectives in social research* (pp 271-289) New York: Oxford

    University Press.

West, C., & Zimmerman, D. (1987). Doing gender. *Gender & Society, 1* (2), 125-151.

West, C., & Zimmerman, D. (2009). Accounting for doing gender. *Gender & Society, 23*
    (1), 112-122. doi: 10.1177/0891243208326529)

3. Chapter Three: Gendered Expectations and Exemptions in Hospice Palliative Home Care

3.1 Introduction

There has been considerable attention paid to the hospice palliative care movement internationally, and in Canada, as policy makers and organizations strive towards high quality care (Canadian Hospice Palliative Care Association [CHCPA], 2002; Carstairs, 2010; Dale et al., 2009). As there has been a lack of consensus in the use and definition of the terms to describe palliative care, the term hospice palliative care is used to converge the movements of hospice and palliative care (DeMiglio, Dykeman, Williams, & Kelley, 2012). The goal of hospice palliative care is to maintain the quality of living and dying for persons and their family members with life-threatening illnesses, which may or may not include disease-modifying treatment (CHCPA, 2002).

While there has been a move forward towards policy changes that promote quality hospice palliative care (Carstairs, 2010), there remain challenges to reaching optimal and equitable care in this context, particularly in home care. Aligning with neoliberal ideologies, the move from a welfare state towards a managerial state in Canada has led to health care cost containment policies and thereby shifted care from the institution to the home (Armstrong & Armstrong, 2005; Martin-Matthews, Sims-Gould, & Tong, 2013; Williams, 1996). This policy change is based upon the underlying premise that family members will provide the bulk of care, thus shifting care from the paid to the unpaid caregiver (Armstrong & Armstrong, 2005; Martin-Matthews et al., 2013). Women make up the majority of unpaid family caregivers (Armstrong & Armstrong, 2005; Decima Research Inc., 2002; Morris, 2001); however, even when both male and female family

members jointly provide care, women tend to assume more care responsibilities than their male counterparts (Brazil, Thabane, Foster & Bedard, 2009). This inequitable division of labor in hospice palliative home care is of significant concern because it may negatively affect women's physical, financial, and mental health (Grov, Dahl, Moum, & Fossa, 2005; Grunfeld et al., 2004; Morse & Fife, 1998: Schultz & Beach, 1999), and places them at risk for early death (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Schultz & Beach).

Hospice palliative home care is a unique care setting in which public boundaries blur into private spaces (Armstrong & Armstrong, 2005: Martin-Matthews et al., 2013) and the development of optimal relationships between and among clients, family caregivers, and paid providers is crucial to the quality of care delivered (Funk & Stajduhar, 2011; Stajduhar, Funk, & Roberts et al., 2010; Ward-Griffin, McWilliam, & Oudshoorn,, 2012a; Ward-Griffin, McWilliam, Oudshoorn, 2012b). These relationships are particularly important during this complex and encompassing time when clients and caregivers are often dependent upon care services and emotionally and physically strained (Funk et al., 2010; Ward-Griffin et al., 2012a, 2012b).

Home has been idealized as a place of comfort and safety, or a "haven" from the outside world (Angus, 1994; Armstrong & Armstrong, 2005; Glazer, 1990), for which, because of cultural norms, women are mainly responsible. Home is thus a gendered space in which men, as providers, are situated as the head of the household, and the woman's role is viewed as one of love and care for the family. Home as such is a place of identity and social relations (Angus, 1994; Armstrong & Armstrong, 2005; Glazer, 1990). However, home can also be a place of struggle in which there are constraining choices

(Williams, 2002) and where inequitable gender relations can be (re)produced (Clemmer, Ward-Griffin, & Forbes, 2008). Gender relations occurring within the private spaces of home are largely hidden, rendering care inequities created by gendered expectations and exemptions in hospice palliative home care invisible.

Sex and gender differences in hospice palliative home care have been well documented. Compared to their male counterparts, female caregivers have reported more adverse health effects and increased caregiver burden (Brazil et al., 2009; Burridge, Barnett & Clavarino, 2008; Dumont et al., 2006; Grov et al., 2005;; Grunfeld et al., 2004; Hagedoorn, Sanderman, Bolks, & Tuinstra, 2008; Mystakidou et al., 2013; Rivera & McMillan, 2010; Usher, Sandoval, Perz, Wong, & Butow, 2013). Additionally, evidence has suggested that, women, more than men, provide intimate bodily care such as toileting (Brazil et al., 2009; Brown, 2004). While women have been supported by social networks of family and friends, they tend to receive less help than men (Allen, 1994; Brazil et al., 2009; Morris, 2001). Furthermore, because of gendered assumptions that women are natural caregivers, family members and health care providers have expected women to provide complex technical care, for which they are often ill-prepared (Clemmer et al., 2008). However, research also has indicated that, based on traditional notions of masculinity, men may be disadvantaged as well. Clark, Booth, Velikova, and Hewison, (2006) found that men with cancer generally dismiss the need for emotional care. Furthermore, compared to women, more men have reported difficulties in adjusting to the additional household responsibilities they undertake in providing cancer care (Ussher et al., 2013).

While there is knowledge indicating that men and women may have different experiences in hospice palliative home care, little is known about gendered expectations and exemptions among participants in hospice palliative home care and how these gender relations shape experiences. Emanating from the biological category of sex, gender is a social construction in which men and women express and respond to gender through socially accepted attitudes, beliefs, and practices (Johnson & Repta, 2012; West & Zimmerman, 1987, 2009). Gender relations shape opportunities and constraints by operating through interactions at both personal and macro social levels involving cultural, organizational, or governmental institutions (Bottorff et al., 2011; Connell, 2012; Smith, 2005). Based on ideologies that underpin policies and practices, these sociopolitical influences ultimately shape gendered attitudes and behaviours and organize our everyday lives (Smith, 1987, 2005). Thus, it is important to critically examine and expose the sociopolitical discourses that are used and interpreted in the construction of gender relations. This understanding is crucial to challenge policies and practices that may lead to inequities.

Examining gender relations in the sociopoliticial context of hospice palliative home care is important to make visible and challenge inequities in health and health care. Given that increases in the aging population are adding to the rising incidence of cancer deaths (Canadian Cancer Society, 2011), it is both imperative and timely to promote equitable practices and policies in this context. In critically examining gender relations in the sociopolitical context of hospice palliative home care, this chapter reveals how gendered expectations and exemptions shaped by institutional discourses influenced health and health care experiences. As central members of the health care team who often

assess, educate, and counsel, the health care provider in this study is the registered nurse involved in home care with clients and family members.

3.2 A Review of the Literature

A literature review was conducted to examine studies that investigated clients', caregivers', and nurses' gender issues in hospice palliative home care. The literature review has been classified into sections that consider sex and gender with each category of client, family caregiver, and nurse in hospice palliative home care. Studies examining different stages of the cancer trajectory, including the palliative phase, were included.

3.2.1 Sex and gender and clients in hospice palliative home care. Evidence of how sex and gender shape the experiences of clients with cancer is unclear. Research has shown that women with cancer use a wider range of supports such as family, friends, and professionals, while men rely largely on partners for emotional support (Clark et al., 2006; Fife, Kennedy, & Robinson, 1994; Graham & Palmer, 2002; Greimel, Padilla, & Grant, 1998; Keller & Henrich, 1999; Salander & Hamberg, 2005). Men have reported to prefer receiving information from health care professionals (Clark et al., 2006), and emotional care from their wives. However, there has been contradictory evidence that indicates no significant gender differences in the use of social support networks between men and women (n=100) living with cancer (Jacobs-Lawson, Schumacher, Hughes, & Arnold, 2010). It may be that women are traditionally seen as the ones providing nurturing care and offering more help, or that men are not offered psychosocial or emotional assistance, based on gendered assumptions that men are strong and autonomous (Creighton & Oliffe, 2010; Nicholas, 2000). These findings suggest that a better understanding is needed of how gender expectations and exemptions affect the

emotional support clients receive from both health care providers and their family members, and the contextual factors that shape these relationships and experiences.

Contradictory findings also have been reported in relation to men and women with cancer and their levels of needs and quality of life scores. Compared to men, women have reported significantly higher levels of needs for professional support, access to information, and emotional support (McIllmurray et al., 2001). However, other studies have found no gender differences related to patient needs (Im et al., 2008; Jacobs-Lawson et al., 2010). In terms of quality of life, women have reported lower psychological, physical, and emotional well-being (Jones, Cohen, Zimmerman & Rodin, 2010). Additionally, compared to men, women have reported significantly more nausea and vomiting (Cheung, Le, Gagliese, & Zimmerman, 2011; Kirkova, Rybicki, Walsh & Aktas, 2012), anxiety (Kirkova et al., 2012; Zimmerman et al., 2009), fatigue (Husain et al., 2007), and pain (Avemark, Ericsson, & Ljunggren, 2003). However, men more than women have experienced significantly more problems with sleep (Avemark et al., 2003; Kirkova et al., 2012), appetite (Avemark et al., 2003), and depression when there are greater needs with toileting and dressing (Hayes et al., 2011). Other evidence, however, has indicated no gender differences in quality of life scores (Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2000; Husain et al., 2007; Jacobs-Lawson et al., 2010).

In relation to the provision of care, women have reported that their pain is not taken seriously by health care professionals, family, and friends because of their gender (Im, 2006). Compared to men, women have described more negative experiences with staff and expressed more disappointment in staff relationships (Salander & Hamberg, 2005; Spiroch, Walsh, Mazanec, & Nelson, 2000), reflecting possible gender

discrimination of women. Additionally, women have reported that they are interested in human relationships (Ando, Morita, O'Connor, 2007; Wessels et al., 2010), spirituality (Mystakidou et al., 2008), and preparatory grief (finding meaning) (Mystakidou et al., 2006), whereas men have ranked the receiving of information as an important aspect of care (Klemm, Hurst, Dearholt, & Trone, 1999; Seale, 2006).

In summary, current research to date has suggested that the sex and gender of clients with cancer may affect health care experiences. It may be that, compared to men, women experience more negative encounters (Im, 2006; Salander & Hamberg, 2005; Spiroch et al., 2000) and that the establishment and normalization of emotional support for men is needed (Clark et al., 2006). The majority of studies have measured sex differences (Fife et al., 1994; Graham & Palmer, 2002; Greimel et al., 1998; Hagedoorn et al., 2000; Im et al., 2008; Jacobs-Lawson et al., 2010; Keller & Henrich, 1999; Mystakidou et al., 2006; Mystakidou et al., 2008; Wessels et al., 2010). A focus on sex and gender differences may reify gendered assumptions and stereotypes of male and female preferences and needs and thereby reinforce gendered attitudes, beliefs, and practices related to gendered expectations and exemptions. Clearly, further research is needed that moves beyond sex and gender differences to consider how gendered expectations and exemptions within sociopolitical contexts shape care experiences for clients and care providers, both paid and unpaid, and during the vulnerable time of end-of-life.

3.2.2 Sex and gender and family caregivers in hospice palliative home care.
Study findings have suggested that female caregivers have been more psychologically distressed (Brazil et al., 2009; Burridge et al., 2008; Chapman & Peppler, 1998; Dumont

et al., 2006; Hagedoorn et al., 2008; Mystakidou et al., 2013; Payne, Smith & Dean, 1999; Rivera & McMillan, 2010; Ussher et al. 2013) and experience greater caregiver burden (Ussher & Sandoval, 2008) than their male counterparts. In a study investigating 50 caregivers of persons with cancer in all stages of the disease trajectory, females reported significantly higher levels of anxiety (p<0.01), depression (p<0.01), unmet needs (p=<0.01), and decreased satisfaction in health care interactions (p=<0.01) than men (Ussher & Sandoval, 2008). One exception is a study by Costa-Requena, Cristofol and Canete (2011) that found no gender differences in caregiver distress. It may be that other factors such as coping style (Costa-Requena et al., 2011) and the quality of the relationship between the client and caregiver have a confounding effect on caregiver distress (Hagedoorn et al. 2008). Although these studies contribute to our knowledge of differences between male and female caregivers, there is a gap in our understanding of gendered expectations and exemptions that may lead to inequities.

Men and women have differed in the type and amount of care they have given. While evidence has indicated that female caregivers have twice the odds of providing support in toilet-related tasks than male caregivers (OR=1.98, p=.044), male caregivers are more than twice as likely to provide assistance with mobility-related tasks (Brazil et al., 2009). Additionally, care recipients who have a female caregiver have been less likely to receive support from family and friends in relation to personal care (OR=0.17, 95% CI= 0.05-0.53, p=0.002) (Brazil et al., 2009). Furthermore, gender has been found to have a significant effect on role incongruence for males (Allen, 1994; Ussher et al., 2013), as they have been less likely than their female counterparts to adapt to additional household responsibilities when providing care (Usher et al., 2013). It may be that women are

perceived to be naturally inclined to caregiving tasks and thereby adapt better to additional household and personal caregiving tasks. Also, because of these gendered assumptions, family members and friends may expect female spousal caregivers to take responsibility of caregiving tasks and therefore offer less assistance to them. Although research indicates significant sex/gender differences associated with providing care in the home, more knowledge is needed into how and why these differences occur, and how gendered expectations and exemptions may shape caregivers' health and health care experiences.

Additionally, studies have found that societal expectations function to construct gendered roles (Clemmer et al., 2008; Ussher & Sandoval, 2008). Based on traditional societal ideology that women are "natural caregivers," health care providers have influenced and expected women to adopt the caregiver role (Clemmer et al., 2008, p 272). Women have been positioned as expert caregivers, competent decision-makers, caring task-masters, and emotional supporters for the persons with cancer (Ussher & Sandoval, 2008). While the gendered nature of caregiving and the familial and cultural influences on hospice palliative care experiences have been illuminated, more attention needs to be paid to the resulting effects of these gendered expectations, and how broader institutional structures such as home care agencies, professional associations, and government shape gender relations in everyday hospice palliative home care.

3.2.3 Sex and gender and nurses. Nurses have been found to negotiate gender roles and manage relationships around cultural expectations of masculinity and femininity, potentially affecting the type and quality of care given. In response to male patients who view male nurses as homosexual predators (Evans, 2004), male nurses have

accentuated their heterogeneity by making reference to their wives (Fisher, 2009; Harding, 2007), and delivering care in a more authoritative, distant manner rather than a compassionate one (Evans, 2002; Evans & Frank, 2003; Fisher, 2009; O'Lynn & Krautscheid, 2011; Pullen & Simpson, 2009). Male nurses also have been characterized as heroes and protectors (Simpson, 2009) when frequently called upon for heavy lifting and care of aggressive patients (Pullen & Simpson, 2009; Whittock & Leonard, 2003). These findings suggest that gender relations have an impact on everyday practices and care delivery; however, what is not known is how this occurs during the vulnerable time period of hospice palliative home care.

For female nurses, exposure to sexual harassment, a result of negative gender relations, has been found to be widespread (Bronner, Pertez, & Ehrenfeld, 2003; McGuire, Dougherty, & Atkinson, 2006). Nurses often may not recall specific incidents, yet they have been able to narrate the prevalence of unwanted verbal sexual innuendoes, indicating the commonality and social conditioning of nurses' exposure to sexually harassing behaviours. Nurses subjected to sexually harassing behaviours have distanced themselves and have been reluctant to return to care, affecting female nurses' practices and the care given (McGuire et al., 2006).

However, there also has been evidence to suggest that female nurses spend significantly more time (mean=25.17 minutes) than male nurses (mean 15.02 minutes) developing therapeutic relationships (mean difference=10.14 minutes, $p<0.05$) (Torkelson & Seed, 2011). As research has indicated that male nurses are frequently asked to care for aggressive patients (Simpson, 2009; Pullen & Simpson, 2009; Whittock & Leonard, 2003), it may be that male nurses are caring for patients with whom the development of

relationships is more challenging, or that they are avoiding situations that may be interpreted as sexual. Clearly, more research is needed to provide context to gendered relations in the provision of nursing care, particularly during the vulnerable time of hospice palliative home care when clients and caregivers depend on health care services to meet informational, physical, and psychosocial needs (Funk et al., 2010).

In summary, while studies have related sex and gender differences from each the client, caregiver, and nurse perspectives, no studies have been found to date that investigate how gendered relations shape health care interactions between and among participants and the consequences to health and health care in hospice palliative home care. Furthermore, what is needed is an examination how gendered expectations and exemptions contained within cultural and institutional ideologies underpin policies and practices that influence everyday gendered relations. It is important to understand and challenge gender inequities during this time when clients and family members are entrenched in the process of imminent loss.

As a part of a larger study, this chapter examines gendered expectations and exemptions in the sociopolitical context of hospice palliative home care for clients and family caregivers with advanced cancer. The gendered processes of *Normalizing Gender Relations*, *Equalizing Gender Relations*, and *Regulating Gender Relations* (Chapter Four) and the socially constructed mechanisms of *Imbalance/Balance of Power* and *Preservation/Destruction of Gender Stereotypes* that (re)produce gender (in)equities in hospice palliative home care (Chapter Five) are reported elsewhere.

3.3 Methods

Informed by Dorothy Smith's critical feminist perspective (1987, 2005), I examined how gender relations shape client-family caregiver-nurse relationships within the sociopolitical context of hospice palliative home care. Hospice palliative home care involves institutions such as professional organizations, governmental agencies, and community agencies that potentially shape everyday gender relations. In this context, Smith's critical feminist perspective that provides a lens in which to analyze these types of structural influences on everyday activities was appropriate for this study. As the central purpose of Smith's critical feminist lens (1987) is focused on exposing the construction of oppressive relations, other social relations that may intersect with gender (e.g., ethnicity, age, class) to shape relationships and experiences were also considered.

In order to expose and understand the often hidden gendered attitudes, beliefs, and practices of gendered expectations and exemptions comprising gender relations within the culture of hospice palliative home care, a critical ethnography according to Thomas (1993, 2003) was employed. With its methods of interview, observation, and document review, this methodology was useful to uncover and challenge gender relations in this context.

3.3.1 Recruitment. Following ethics approval from the Research Ethics Board at Western University and the community nursing agency involved, senior clients (60 years of age and older) with cancer enrolled in a hospice palliative home care program were approached by case managers and asked if they were interested in the study. If clients and family caregivers showed interest, they were contacted by the researcher by telephone.

The primary nurse was contacted following approval from clients and caregivers. Six client-family caregiver-nurse triads agreed to enroll in the study.

3.3.2 Sample. Of the six clients recruited, three were males and three were females. All clients and caregivers were retired and ranged in age from 64 to 82 years (see Appendix E). Five caregivers were spouses and one caregiver was a neighbour identified by the client as a caregiver. Four female nurses were recruited, as two nurses cared for more than one client enrolled in the study. All nurses received additional palliative care training and were in the age range from 30 to 59 years. Two nurses had completed college diplomas and two had received university degrees. Additionally, two nurses worked part-time, while two worked full-time hours. All participants within the triads of client-family caregiver-nurse were Caucasian.

3.3.3 Data collection. Multiple data sources that included the in-depth interview, participant observation, and document review were used in order to understand gendered expectations and exemptions in the daily interactions of peoples' lives in hospice palliative home care. Data were collected from April 2012 to August 2013 and consisted of 127 hours in the field. To facilitate data management, all interviews, fieldnotes, and documents were entered into NVivo software.

3.3.3.1 Interview. A total of 22 individual semi-structured, in-depth interviews and three joint interviews with clients and caregivers were conducted in participants' homes. Lasting approximately 50 to 90 minutes, interviews were audio-taped and transcribed verbatim. Open-ended questions were asked to elicit rich responses. For example, participants were asked, "Does being a man or woman affect care, and if so, how?" For three triads, only one home visit and one interview with each member was

conducted because clients were too ill and strained to continue. Recruitment and attrition issues have been reported in palliative research and are to be expected (Jo, Brazil, Lohfeld, & Willison, 2007). For the remaining triads, following up with more than one interview allowed me to return to participants with findings in order to further reflect and refine the analysis (Guba & Lincoln, 1989; Lather, 1995).

3.3.3.2 Observation. Nine home visits by the agency nurse were observed to capture the dynamic patterns of relations and activities in the natural environment of everyday hospice palliative home care (Thomas, 1993, 2003). Observations of two home visits were made with three of the client-family caregiver-nurse triads and one home visit was completed for the remaining three triads, because of clients' impending deaths and related family stresses. Being present in the natural environment afforded context and therefore a better understanding of the interactions that occurred between and among clients, family caregivers, and nurses in everyday hospice palliative home care (Atkinson & Hammersley, 2007; Roper & Shapiro, 2000; Thomas, 1993). In particular, I observed the relationships within this setting and how gendered expectations and exemptions contained within social relations of gender affected experiences. I observed interactions related to care between and among clients, family caregivers, and nurses and took notice of verbal and non-verbal expressions that illuminated gender relations or taken-for-granted positions of dominance and the sources of power underlying those positions. Observations of interactions also were made during the time of interviews with participants and written in the form of fieldnotes for analysis.

3.3.3.3 Document review. As part of this ethnographic study, program and communication documents of participating nurses' employer agencies were retrieved

(Appendix I), since institutional documents align with the culture of the organization and shape taken-for-granted attitudes, beliefs, and practices that infiltrate to the everyday actualities of employees and users of the establishment (Perakyla, 2008; Smith, 1992). Twelve documents were collected and reviewed, including two program, five public communication and five professional association documents (see Appendix I). Findings from the document review illustrated the sociopolitical context within which clients, caregivers, and nurses experienced gendered expectations and exemptions within hospice palliative home care.

3.3.4 Data Analysis. Guided by Lofland, Snow, Anderson and Lofland (2006), I initially conducted thematic analysis by generating codes through multiple line-by-line readings. Codes were then categorized, compared, and contrasted, allowing the development and collapsing of themes. Themes were described, characterizing the category, when it occurred, and the people and processes involved. Data were continually compared with emerging concepts and themes and all other data sources including documents and memos. Diagramming was used to conceptualize relationships between and among the themes. More specifically, I asked how gender was embodied, practised, received, or transcended, and how gendered assumptions and roles played into interactions (Thomas 1993).

3.4 Findings

In Figure 2, Blue Subsection, I visually depict findings of a larger study examining gender relations in hospice palliative home care. In this section, I address the first research question: How do gender relations shape health and health care experiences within the sociopolitical context of hospice palliative home care? I describe one aspect of

gender relations in performing gender in hospice palliative home care, specifically gendered expectations and exemptions for women and men. As illustrated in Figure 2, Blue Subsection, embedded, gendered cultural attitudes, beliefs, and practices in hospice palliative home care dictate the norms and rules for the way in which men and women are expected to act, look, and feel. Historically, politically, and ideologically based, these taken-for-granted cultural attitudes, beliefs, and practices are central to shaping social institutions such as the family or the health care system, which organize and provide meaning to everyday activities (Smith, 1987, 2005). Gendered processes are described in Chapter Four. To meet, counter, or monitor gendered expectations and exemptions, men and women displayed power relations of *Asserting Power*, *Resisting Power*, and *Maintaining Power* while employing ideological processes of *Normalizing Gender Relations* and *Equalizing Gender Relations* and enacting gender relations in *Regulating Gender Relations*. Chapter Five highlights the socially constructed mechanisms that (re)produce gender (in)equities: *Preservation/Destruction of Gender Stereotypes* and *Imbalance/Balance of Power*. To promote understanding of the broader structural factors that shape gendered expectations and exemptions in hospice palliative home care, the sociopolitical context is first described.

Figure 2. Blue Subsection: Gendered Expectations and Exemptions
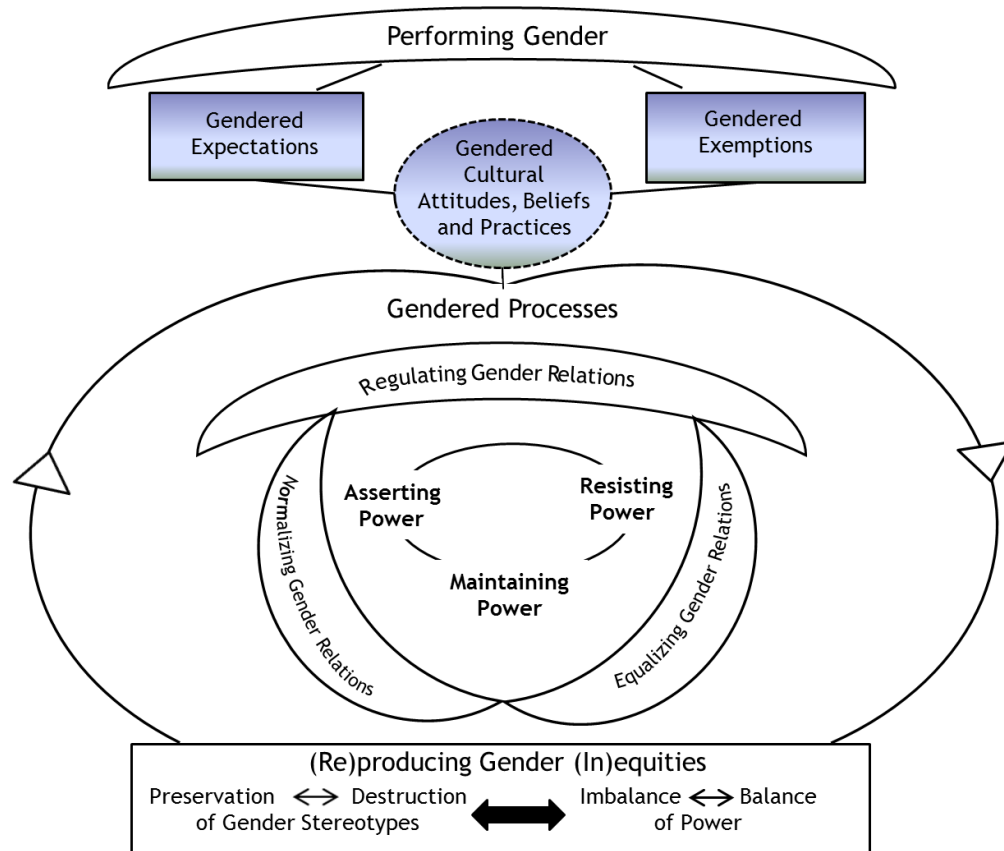
3.4.1 Gendered expectations and exemptions in the sociopolitical context of hospice palliative home care. As broader structures influence everyday gendered attitudes, beliefs, and practices (Smith, 1987, 2005), program and public communication documents from government and nursing agencies were examined. In promoting values of economic efficiency (England, 2010), a program document conveyed an orientation towards a cost-reductionist culture. Addressing the fragmented system, a cost-containment approach was advanced: "There is significant willingness to do HPC

[hospice palliative care] business differently, and the urgency to change is high due to health care system financial restraints and limited HPC human resources" (see Appendix I). Launching this new program policy, the word "value" in health care has been normatively used to imply that quality health care can be maintained despite a reduction in expenditures and resources to be used (Appendix I). In this context of system restraints, messages were conveyed to front-line workers to prudently manage hospice palliative home care resources, while simultaneously maintaining quality of care.

The emphasis of public communication and program documents has been that home is the preferred location for hospice palliative care. Care in the private spaces of home was idealized:

> …studies have confirmed that remaining at home is, by far, the best option for most people. Residing in your own home provides comfort, convenience, peace of mind, and above all, happiness (Appendix I).

In a program document promoting an integrated hospice palliative home care program, home is the preferred choice for the place of end-of-life, away from the disorder of the hospital. A nurse was quoted to describe her perception of the care received in the hospital:

> As a nurse on a medical floor, I have looked after many "Joes." I have seen struggles by the family with issues of DNR (do not resuscitate), helplessness, hopelessness, and anger. I go home after a shift feeling very frustrated and stressed, feeling that I have been too busy to provide care that is basic (e.g., no time to listen) (Appendix I).

In an economic strategy to shift hospice palliative care from acute care centres to home, these descriptions of hospital and home suggested a dichotomy of the public and private and care as belonging outside of social institutions where one is perceived to be a stranger. In this context, the moral and ethical responsibility of care has been linked to the

site of home and the situation of the family (Angus, 1994). Thus, cultural assumptions of home and family have been relied upon to support the normative ideal that care normally belongs in the private spaces of home (England, 2010). As a program document, these values have been conveyed in order to provide employees premises or "truths" on which to base their practices to provide cost-efficient care and shift the provision of care to home and care responsibilities and costs to family members. Public communication documents echo these values of home as the best place to receive care.

Public communication documents also have conveyed normalizing values of individual and familial responsibility to provide care work for ill relatives and thereby reduce reliance on government services and coffers. In online public communication documents, caregiving was portrayed as a cultural norm in Canada proclaiming, "We are a nation of caregivers – more than one in four Canadians coast to coast are everyday heroes providing unpaid care to family members or friends" (Appendix I). Using the word "we" suggested that being a member of this group of Canadians who provide care to family and friends is admirable and noble. Caregivers were represented positively as heroes and valued members of society. An implication has been made that family members, "others," who do not provide care work are unpatriotic, dishonourable, and decentred to the margins of Canadian society. Thus, family caregiving was established as a positive norm to support the interests of the home care agency (Van Dijk, 2006) and save resources through the transferring of care to family members.

Caregiving also was depicted as rewarding and "natural" in public communication documents: "Providing support is especially natural if you are helping someone who means a lot to you. Seeing yourself in the role of caregiver acknowledges the important

work you're doing" (Appendix I). Caregiving was normalized as a natural stage of development: "Most people will become a caregiver at some point in their lives…" (Appendix I). Taken-for-granted messages normalizing family expectations appeal to women's sense of identity as custodians of the home and family health (Armstrong et al., 2003; Heller, 1986; Angus, 1994; Ussher, 2013) and fault those who do not have the social supports to care for their family members. Thus, these messages constituted a clear expectation of family caregiving, particularly of women.

Although there was an expectation for family members, particularly women, to provide care in home, people using hospice palliative home care were referred to as 'individuals" in public communication documents. Caregivers were removed from their family context instead of contextualized to the care situation as wives, sons, or caregivers who have responsibilities, relationships, or health issues (Acker, 2012). This type of depersonalized, business-like approach decontextualizes and disregards the care work undertaken disproportionately by women (Armstrong & Armstrong, 2005; Decima Research Inc., 2002; Morris, 2001). Employing a gender-blind approach neglects to consider the conditions in which men and women provide care and actively support them during the vulnerable time of end-of-life.

 In summary, ideologies of familialism, individualism, and economic efficiency were evoked in these institutional discourses to support an underlying expectation that family members provide the bulk of care. Without actually referring to gender, government programs and home care agencies capitalized on traditional expectations of women to care for the home and the health of the family. Participants in this study also reinforced these expectations.

3.4.2 Gendered expectations of women. Participants believed and reinforced the gender stereotype that women are natural caregivers. A nurse described her nurturing role as a mother and a nurse:

> Women in general…have a nurturing role, a motherly role. I think…[patients] have a little bit extra trust involved, because they know that we are….nurturing and we are caring and will look after issues (Melanie, nurse).

Male clients also expressed the natural tendencies for women to be caregivers, as one client illustrated:

> The woman has a personal touch as a caregiver. From day one, she's a caregiver, and a guy is not. He is the care [recipient]….No matter what in life, you always expect -we don't take for granted- but it's a known that women are always more a helper than anyone else (Tom, client).

While the client stated that he did not take for granted that women are naturally the care providers, he still expected women to be caregivers. Expecting that women have natural tendencies to care exerts cultural pressure on women to show that they have caregiving qualities and suggests that caring is the best option for women, ultimately constraining women's choices to provide care or not. If a woman did not want or was unable to provide care, she would be evaluated harshly and made to feel inadequate as a woman. As a nurse stated:

> When I see a patient and the wife is sitting there and not saying anything, I almost look at that as a negative thing. I shouldn't, but I do, because I'm so used to the wife adding her information and giving more information, so that when you have a situation where they don't, it's like… you just kind of find it's strange…(Melanie, nurse).

In other words, women who did not meet social expectations to assume the "natural" caregiver role were marginalized or encouraged to assume the role.

Extending from the beliefs that women are natural caregivers, participants also believed that, as mothers and wives, women had more experience with caregiving and were more willing to provide care. One nurse stated:

> Women are better than men… as a caregiver because they're more willing. If they've had children, they are used to doing things like that. Even though it was on a little one, and now it's on a big one, it's a similar role (Veronica, nurse).

The transfer of care to female caregivers was justified by the belief that women would feel rewarded for meeting gendered expectations of providing care. Lori, the nurse stated:

> I said to Terri [female caregiver], "You need to let me know of any medications…. "That was one of her duties right from the very beginning. So that keeps them involved…and it gives them a feeling of meaningfulness because they are helping… (Lori).

These quotations illustrate how the gendered expectations of care work shaped nurses' expectations of women to provide care and reinforced practices to encourage and enlist women to the caregiver role.

Additionally, there was an implied understanding that women were responsible for the health of the family. Women were consulted by children and spouses about health matters and took over health matters instinctively, as one female caregiver described:

> When he had his blood clot and his leg was swelling…he said, "This is really starting to bother me." Well, I'm phoning to find out what our next step is and got him into the emergency (Laura, caregiver).

Notably, it was the female caregiver who reached out for medical help, rather than the male client. I observed that female clients, when possible, took over their own health needs because of self-expectations to be responsible, not only for the health of the family, but also their own health. Melanie, the nurse, conveyed her expectations of women to

assume responsibility for their own care as she stated, "A lot of the women, they look after themselves, even when they're sick."

Within their expected roles to provide care, women delivered more comprehensive and intricate care than men. Lori, the nurse, described the care work that a female caregiver provided:

> Terri [female caregiver] controls his medication… she has everything written out on med sheets….. She helps him with his insulin…She helps him with taking his blood sugars and getting everything organized, pretty much keeping him on schedule. Also with visitors, she's been telling everyone now when they want to come over to visit: she goes half an hour for each visit, that's because it's too much for him. She's there physically, but she's also supporting him emotionally as well… (Lori, nurse).

I observed that during home visits female clients and caregivers were anxious as they attempted to adhere to medication and treatment protocols that were beyond their skill and knowledge base. In hospice palliative home care in which it was expected that the terminally-ill client would deteriorate and require extensive care, nurses' practices to enlist and delegate work to women were supported by traditional beliefs of gendered expectations and exemptions.

Nurses reiterated agency discourses to "teach and reduce" (nurses, Helen, Melanie), meaning that nurses were expected to educate family members and transfer care to them to reduce costs. Nurses reiterated structural values of individualism and familialism when encouraging clients and family members to remain at home and be "as independent as possible" (nurses, Lori, Melanie, Veronique). Armed with knowledge of the disease process and the health care system, nurses used their power to delegate care work to women. As women were compelled to meet gendered expectations, nurses could

enlist women more easily to the caregiver role. Power strategies used to regulate gender relations in hospice palliative home care are elaborated elsewhere (see Chapter Four).

As there was an implicit understanding that family members, particularly women, provide extensive care to dying relatives, nurses and male clients expected women to provide care based on traditional beliefs that care is naturalized to be women's work. Furthermore, to facilitate the practice of enlisting women to provide care, nurses interpreted and used these ideological institutional discourses that women want and need to provide care to avoid censure and meet socially ascribed gendered expectations. Thus, while nurses were advantaged in being able to recruit women easily into the caregiver role, women were disadvantaged with few choices but to provide care, particularly given the social pressures to adhere to gendered expectations. Clearly, agency discourses of individualism, familialism, and cost containment permeated the culture of hospice palliative home care and shaped participants' gendered practices.

3.4.3 Gendered exemptions for women. As women experienced gendered expectations, there were fewer exemptions for them. Because of traditional beliefs that masculinity means that men are dominant, in control, and primarily positioned within the public sphere (Adams & Coltrane, 2004; Creighton & Ollife, 2010), women were exempted from concerns outside the home. The public sphere included concerns of capitalism and therefore finances and outside institutions such as the health care system. Male caregivers protected their ill wives from the chaos of the health care system. Exempting his spouse from this challenge, Gerry, a caregiver, dealt with the impenetrable system:

> Barb had a CAT scan done here in [city]; she went to [city hospital] and they
> corresponded. They were supposed to show you both CAT scans. They showed us

Barb's and there was a thing [on the scan]... it looks like it is all white. And I said to the doctor, 'What's that?' ….So there you go: if you don't ask, they don't tell you (Gerry, caregiver).

While female clients may have benefited by not having to deal with outside challenges of the public sphere, they were also disadvantaged because they had little control over finances and final decisions. Barb was barred by her husband to look at the will and other financial statements as she indicated "My husband…shredded the will and said that we didn't have a will" (Barb, client). As a caregiver, Laura lamented that she now had to take care of financial matters and other concerns outside of home:

> It's different than what it was.... now since Stan has been sick, my role now has changed and my awareness of him as a man and as a husband and as my supportive person in my life has become more alert, because I need him. Before [I would say] "We are going to go to [city] today because I want to go shopping." It was never, "Can we go to [city] today?" it was, "We are going." Well now it's all on the other side of the coin, so I realized how much I needed him for all kinds of things.… [Before] he would go outside and shovel the driveway or do the gardening without saying anything … Now I have to do them. And I liked it much better when I said, 'The windows need to be cleaned' and then he went out to clean them (Laura, caregiver).

Laura had to assume additional outside household responsibilities of maintaining the yard and reconciling financial statements, from which she had previously been exempted. As her husband took on these tasks outside the home prior to his illness, Laura had little knowledge of these concerns and was worried about this change in her and her husband's life. Relieved of outside pressures before their husbands' illnesses, women were typically passive actors and dependent on men for matters within the public sphere, or outside the home. While the gendered division of labor was useful during the marriage, women and men who took on new roles during end-of-life found this change stressful. As a

consequence, the gendered exemption for women to be free of circumstances outside the home simultaneously advantaged and disadvantaged female clients and caregivers.

  3.4.4 Gendered expectations of men. As women were normally exempted from matters out in the public sphere, there were expectations from female clients and nurses, and self-expectations for men to be strong, self-sufficient, and protectors of their homes from public institutions and affairs outside. As protectors, men ensured that women were receiving the proper care, often approaching health care providers to question their actions. Melanie, the nurse stated:

> Men definitely are the protectors and if they think something isn't right, they will get more involved, because they want to protect that spouse and they want everything… that can be done, to be done (Melanie, nurse).

Helen, the nurse, stated that she received several complaints from a male caregiver who interrogated her in relation to his wife's experiences in navigating the health care system:

> Jeff …says, 'How come she had to wait so long when you called the doctor? Why couldn't you make it happen faster?' …. He was blaming it on me. There's always a complaint at each visit (Helen, nurse).

Cultural expectations to be strong and self-sufficient also meant that men assumed responsibility to make significant household decisions, as one male caregiver related:

> It gets to the point where you get kind of down and if I show weakness around my wife, she gets weepy….Sometimes I don't agree with what [my wife] says and then I tell her, and she agrees with me…. Well, that's just me. It's just the way I was brought up. I'm a decision-maker…(Jeff, caregiver).

The responsibility of being protectors and decision-makers tended to preoccupy men and may have drawn them away from important and sensitive matters in hospice palliative home care, such as the discussion of existential issues (e.g., dealing with death) with wives and nurses. Overall, assuming the responsibility of protector was stress-producing for men, as they at times angrily lashed out at health care providers. However, under

expectations of appearing strong, men may have concealed their stress, perhaps causing even more mental strain.

Indeed, female clients and caregivers, and nurses, expected that male clients downplay their symptoms in an effort to appear strong. Women expected that men would push themselves beyond their capabilities and underrate their pain and symptoms, despite physical limitations because of illness. As one nurse stated:

> A lot of the men, even though they really can't do something, will push themselves and push themselves... "I can do it, I am a man, I am strong, I can still do this"…. I find a lot of times with the men, they under-medicate and underrate their pain…..A lot of times the wife will be the one wanting to answer it or the husband will say, "My pain's a two" and the wife will say, "Oh no, you told me this morning you could hardly stand it." So a lot of the information we get is from the wife, because a lot of men…don't want people to think they're sick. (Melanie, nurse).

Nurses and female caregivers may have been more liberal in giving pain treatment to men. Furthermore, cultural expectations to be strong were perpetuated as women expected that men would attempt to meet masculine norms. Rather than take a patient-centred approach to care, nurses instead tended to shape their practices around gendered expectations. Men ultimately were disadvantaged as reports of their own health may have been misinterpreted.

As men attempted to fulfil gendered expectations of independence and self-sufficiency, they were particularly distressed when their driver's licenses were revoked because of medical conditions or medication side-effects. As one wife described:

> Stan's independence has been taken away from him, which is very hard for him – the lack of driving. And me driving, and me taking over,…that has even been more demeaning for him. It's made it tougher for him (Laura).

One nurse advised Laura, a female caregiver, that male clients feel devastation when they are unable to drive. Stan frequently related his distress over his inability to drive and

admitted to driving in the neighbourhood without a license to maintain his driving skills.

Melanie, the nurse, recalled several instances in which men's dependence on others

caused distress:

> [Men] are so independent, and they don't like to ask people for help. And any of the patients who are men, and lose their [driver's] licence, they're very upset. They feel bad about how they have to depend on their wife or some other family member to drive them around, and that's a big concern (Melanie, nurse).

One client reported that he had stopped taking his pain medications in an attempt to

reclaim his license to drive. Thus, the expectation to be self-sufficient was illustrated by

participants' attention to male clients' needs to maintain their driver's license and remain

independent. Because of expectations for men to be strong and independent, male clients

became emotionally distressed. Nurses and caregivers reinforced these expectations by

acknowledging them. Ultimately, men were simultaneously advantaged and

disadvantaged because of these gendered expectations.

3.4.5 Gendered exemptions for men. Men were generally exempted from care

work. Nurses did not expect that men would provide physical care and give or monitor

any treatments:

> It's an added bonus when the husband is there. …But if they're not, then it's different. I don't think they don't care, I just think that's a typical man. He's out doing the gardening and looking after things, or going to the grocery store, and he'll do what his wife needs him to do, but he's not there to be the information giver….Another thing is with physical care- like dressing changes-I would expect… that if the man had a wound that the wife would do the dressing versus if the wife had the wound, the man do the dressing - not as likely. It does happen, but not as likely (Melanie, nurse).

Female clients also did not expect that their husbands would provide physical or intimate

care:

I'm just thankful I've got nurses and care people to help as things get worse…. I don't think Gerry [husband] would…wash me, or completely bathe me. I don't think he would do that. I don't think so (Barb, client).

Furthermore, men exempted themselves from care activities. Jeff, a male caregiver, did not partake in his wife's home visits with the nurse, though he set up the appointments. He stated: "I get everything started and then I go away, just get out of the way…. Then they [nurse and ill wife] talk and do their thing…." (Jeff, male caregiver). Jeff left the women to "do their thing," which clearly delineated the "other" and the taken-for-granted belief that care work is women's work. He refrained from being involved in home visits, and as his wife stated, he did not look at her incisions, drains, or dressings. As female clients and nurses did not expect men to provide physical care, men at times were not considered to be caregivers to their ill wives, even if they may have wanted to contribute to the care. From this perspective, men may have missed opportunities to care for their wives and develop intimate and meaningful moments during a time when their wives may have greater need for emotional connectedness.

While men were exempted from care work, they also at times were constrained by female caregivers from providing physical care, or cleaning and cooking. As women closely tied their identities to home and obligations to care for their family members and themselves, they excluded men from certain care tasks. Gerry attempted to help with the cooking and cleaning, but his wife, Barb, would intervene:

I try to help her all I can, but …I say, "Well, I'll do that." and I turn my back for one minute, and she is knee deep in it. I say, "What are you doing? I told you I would do it.'" What can you do? (Gerry, male caregiver).

I observed that Barb took pride in her home, closely linking the cleanliness and decor with her identity as a woman. Consistent with agency discourses in describing the home

as comforting, Barb ensured that the house was meticulously presented, even as she was experiencing discomfort and pain. As a consequence of cultural and familial norms that compel women to meet gendered expectations and avoid social censure, men were often excluded from care tasks traditionally held by women. In this way, men were disadvantaged, as they were not able to fully participate in caring for their wives. Furthermore, these actions may have inhibited men from learning how to assume household tasks, which they may need to undertake in future after they became widowed. It may be that participants' advanced ages influenced this exemption as they were in a generation in which there was a tendency to follow norms distinctly delineating the gendered division of household labor.

Finally, men were at times exempted from conversations related to care. While engaged in intense discussions with the female caregiver about medications and treatments, nurses often excluded male clients from these conversations. As a male client indicated:

> The nurse would come….She would have, not private talks with Laura, but talked a lot to her, rather than to me. She took my blood pressure, my temperature, and made sure that everything was okay. But a lot of discussion was between the nurse and Laura….And so it got to the point that they were developing a conversation and I - as a joke - would turn around and say, 'Hey, I'm the one that you came to see, not Laura' (Stan, male client).

I also observed during nursing home visits that men were often excluded from care conversations, as nurses addressed caregivers' knowledge gaps and biomedical issues. Nurses would often face solely toward the female client and would engage with the male caregiver only if asking a specific question about the care.

Additionally, I observed that nurses would often engage in social conversations with female clients and caregivers, whereas conversations with men were often limited. Helen described the social relationship she had with a female caregiver, Laura:

> [With Laura], we have a social [relationship] –but we keep it therapeutic too– but because she was in retail with clothes, she showed me how to tie a scarf, showed me where to go clothes shopping…. There's a social and a therapeutic level… and she knows I'm a mother…and a grandmother and [like me] she babysits a lot too (Helen, nurse).

There may have been a tendency for nurses to associate closely with women rather than men because of gendered roles and behaviours. Nurses' relationships with men may have been more distant, exempting men from conversations related to giving or receiving care and discussions around coping and emotions. As client-caregiver-nurse relationships influence experiences (Ward-Griffin, McWilliam, & Oudshoorn, 2012a, 2012b) and access to resources (Stajduhar, Funk, Roberts et al., 2010), participants' reification of gendered exemptions may have ultimately disadvantaged men.

In summary, gender exemptions simultaneously advantaged and disadvantaged men. While exempted from care work, men also may have missed opportunities to contribute to and be a part of the care for their wives. Because of traditional attitudes and beliefs of men to be strong and self-sufficient, men also were excluded from care conversations. Thus, gendered expectations and exemptions shaped experiences, resulting in both benefits and harms to men and women in hospice palliative home care.

3.5 Discussion

Gender relations in hospice palliative home care are shaped by gendered expectations and exemptions for men and women, as elucidated in this chapter. Study findings suggest that institutional discourses of individualism, familialism, and economic

efficiency shape gendered expectations and exemptions and therefore interactions in everyday hospice palliative home care. Gendered expectations and exemptions have simultaneously advantaged and disadvantaged both men and women, ultimately influencing how men and women act, feel, or behave and potentially creating gender inequities.

Similar to other studies (Anjos, Ward-Griffin, and Liepert, 2012; Clemmer et al., 2008; Usher & Sandoval, 2008), this study has revealed the influence of sociocultural gendered expectations and exemptions on health and health care experiences. As men experienced fewer expectations, they were able to limit their caregiver roles without social censure. Research in non-palliative contexts have indicated that while men's care work was made explicit, their caregiving role was considered less rigid in terms of the type of care given (e.g., less personal bodily care) (Anjos et all, 2012) and time and frequency of care (Marshall, 2006), suggesting that men have more control and choice in assuming and defining their caregiver role. In contrast, because of high expectations of women regarding the provision of care, women tended to assume the role gradually, at times unaware of making a decision or being given a choice to provide care (Stajduhar & Davies, 2005; Stoller & Miklowski, 2008) and with little regard for the social context of their situation by health care providers (Clemmer et al., 2008; Ussher et al., 2008). Additionally, because of gendered expectations for women to assume the responsibility of care of the home, female clients have found it difficult to relinquish their "tasks" and witness male caregivers in roles to which they were unaccustomed (McPherson, 2007). However, exemptions to provide personal care have excluded men from participating in care. Furthermore high expectations for men to be strong and independent may have

caused strain for men. In this context, men and women have been simultaneously advantaged and disadvantaged (Anjos et al., 2012). This indicates a need for consideration by family members and health care professionals of men's and women's capabilities and needs when determining if it is appropriate for end-of-life at home (Clemmer et al., 2008; Stajduhar & Davies, 2005). Health care providers should question their expectations for family members and women to provide care and consider the contextual factors that may limit their abilities. Nurses can facilitate discussion with regard to clients' and caregivers' wishes and concerns (Stajduhar & Davies, 2005) and take into account possible gendered expectations and exemptions that may influence their decisions for end-of-life at home. At a system level, there must be accountability measures that monitor the integration of gender and health in health care (Sen & Ostlin, 2008).

Additionally, this study has revealed that institutional discourses of individualism, familialism, and economic efficiency promote ideologies that rely upon cultural assumptions about gender (England, 2010). These neoliberal ideologies underpin institutional discourses to ultimately shape gendered expectations and exemptions and day-to-day gendered practices in hospice palliative home care. Studies have indicated that participants in palliative home care suffer the impact of limited resources (Clemmer et al., 2008; McWilliam et al., 2008; Oudshoorn et al., 2007; Stajduhar et al., 2008; Stajduhar, Funk & Roberts, 2010; Ward-Griffin et al., 2012a, 2012b). This study sheds light on the discourses of economic efficiency alongside normalizing discourses of individual and familial responsibility for in-home palliative care that produced and reinforced gendered expectations and exemptions and formed the basis of gendered practices in this context.

Constrained to work with limited resources, nurses in the present study tended to expect, and ultimately enlist, women rather than men to be caregivers for their ill relatives. This "conscription" of female caregivers, as described by Armstrong and colleagues (2003), was supported by traditional values of familialism in which there is an assumption in policy that the family will assume primary responsibility for care of its ill members (Leitner, 2013). Such implicit policies constrain participants' actions because few alternatives are offered to family members, particularly women, to opt out of caregiving. This policy strategy is a type of social coercion for those family members who find it difficult to opt in or out of providing care (Glen, 2010) because of gendered expectations and exemptions. Both men and women require opportunities to make decisions without social censure. Accordingly, policies must take into account specific needs of men and women to actively support them and enhance the conditions within which they provide care work. For example, if it is women who provide the majority of intricate and complex care, they should be offered an option to opt out of the caregiver role or additional agency support for training, reinforcement of learning, additional nursing hours, or respite. Men may need encouragement by nurses to assume the caregiver role. In other words, rather than a general strategy to treat all men and women the same, contextual factors such as gender need to be considered in the implementation of practices and policies (Calasanti & Bowen, 2006). Thus, policies should be made explicit and take into consideration the needs of both men and women.

Closely linked to familialism, individualism is based on the assumption that people can act for themselves and prevent and resolve health issues independently. Within this neoliberal ideology, there is an assumption that individuals are not limited by

social surroundings and can thrive without reliance on government or others (McGregor, 2001; England, 2010). Similar to findings from other studies (Guberman, Lavoie, Pepin, & Lauzon, 2006; Ward-Griffin et al., 2012b), health care providers in the present study reflected the ideal of the duty and obligation of family members to assume responsibility for care of ill relatives. Rather than viewing care in the home as a shared responsibility between paid and unpaid caregivers (Guberman et al., 2006) or considering family caregivers as clients also in need of care (Ward-Griffin, 2012b), these ideals of individualism and independence were embraced and adopted by nurses to meet system demands. Other studies have found that a cost-reductionist culture in home care has shaped nurses' interpretations of health promotion, as they use this concept alongside ideologies of individualism to promote independence and thus delegate care to family members (Ward-Griffin et al., 2012a; Stajduhar, Funk, Jakobsson, & Ohlen, 2009) and women in particular.

Although ideologies of individualism, familialism, and economic efficiency have supported and sustained socially constructed gendered expectations and exemptions, program documents have referred to people in hospice palliative home care as individuals instead of people with social relations and responsibilities. In essence, these agencies have been silent about gender. Similarly, participants in hospice palliative home care have discounted the issue of gender as they have reinforced gendered expectations and exemptions that often lead to inequities. This study has revealed nurses' non-reflexive approach to gender relations. Although reflection is a core component of nursing (College of Nurses of Ontario, 2014), nurses in this study rarely reflected on gender as they considered that gender did not have an influence on health and health care experiences.

Nursing standards and education must emphasize the need for nurses to engage in ongoing reflection not only regarding skills and knowledge, but also about their assumptions, beliefs, power, and political contexts in their daily gendered health care interactions (Boutilier & Mason, 2012).

Institutional discourses promoting ideals of individualism are based on allocating resources equally, rather than equitably. As all individuals are assumed to be treated equally under the premise of individualism, neoliberal proponents believe that there is no need to consider social conditions or consequences to policies (McGregor, 2001). As such, blame is placed on an individual unable to cope in hospice palliative home care, not on the inadequacy of financial or emotional resources needed to support care. Rather than promoting a behavioural approach to health, a social determinants of health perspective that takes into account the social constraints that influence individual agency should be adopted by policy makers and health care professionals. Included in this type of approach is a consideration of social relations such as gender and how they shape power relations, access to resources, rewards, and limitations. In other words, a social determinants of health perspective looks beyond biomedical issues to social conditions that influence health and health care (Raphael, 2012). In terms of professional discourses, nursing standards and nursing education programs have included health promotion in nursing mandates and curricula (Hills, Carroll, & Vollman, 2007); however, nursing remains largely focused on individuals in the acute care setting (Reimer Kirkham & Brown, 2006). Under the oppression of the organizational hierarchy of the health care system, nurses often feel powerless to make change (Hills et al., 2007). A focus on the social determinants of health will broaden nurses' goals and prospects.

Additionally, the profession of nursing needs to more attentive to gender relations. Awareness of gender relations requires that health care professionals acknowledge gender as a determinant of health and illness (Verdonk, Benchop, de Haes, & Lagro-Janssen, 2009). Gender must be understood as an institution pervasive in social establishments (e.g., family, law, economy or politics) that organize our lives in terms of expectations and processes (Acker, 1992; Lorber, 1994). This understanding requires health care professionals to examine relations of domination and oppression that shape our everyday world (Pauley, 2008; Smith, 1987). As ideologies are propagated by institutions to explain their structures and processes (Acker, 1992, Smith, 1987, 2005), it is important for nurses to be informed and critical of politics and policy. As such, in addition to a biomedical focus, nursing education and professional guidelines should emphasize political knowledge and advocacy (Reutter & Duncan, 2002) to enable nurses to question taken-for-granted premises that are advanced through the permeation of ideologies in standards, policies, and practices. Nurses can be empowered and more politically aware through education and associations such as the Registered Nurses Association of Ontario, which promotes a political advocacy role and provides a political voice for nurses. Also, nurses can participate on committees that set institutional policy. Intimately involved in everyday health care encounters that are shaped by policies from various institutions, nurses are well positioned within their mandate to identify and advocate for gender equity (Falk-Rafael, 2005).

Also, nursing associations need to pay more attention to gender relations. Although professional documents focus on therapeutic relationships and relational boundaries (Appendix I), there is insufficient knowledge and guidance offered to nurses

with regard to gender relations and their potential impact on health and health care. Thus, rather than reinforcing gender inequities, the profession of nursing needs to be proactive in advancing its mandate of social justice and maintaining the integrity of the profession (Falk-Rafael, 2005).

Finally, as gender relations are complex, interpersonal, and interactional, yet largely hidden, it is important to employ research designs that expose relational experiences in everyday settings and situations. A critical ethnography design (Thomas, 1993) permitted elicitation of subjective experiences, observation of relational processes, and review of structural ideologies. Additionally, a critical feminist lens (Smith, 1992; 2005) was vital to analyze the sociopolitical context of everyday gender relations. However, to provide a more comprehensive view, more research is needed to explore how gender relations interact with other social relations such as ethnicity and class. Intersectionality is a methodology that examines power dynamics such as gender, ethnicity, or class and how these social relations intersect to shape experiences. This methodology focuses on the experiences of the marginalized and sheds light on multiple inequities. Intersectionality is consistent with a health promotion approach in which health determinants (e.g. gender, education, income) that generate inequities are linked to health/illness and disease status (Graham, 2004; Hankivsky & Christoffersen, 2008; Ottawa Charter, 1986; Weber, 2005).

3.6 Conclusion

In critically examining gendered expectations and exemptions within the sociopolitical context of hospice palliative home care, this study has revealed the strong influence of neoliberal ideologies that emphasize individualism, familialism, and cost

containment policies. These ideologies rely upon and (re)produce traditional gendered expectations and exemptions, thus emphasizing the artificial divide between the public and private and male and female roles and norms in hospice palliative care. Rather than assume a gender-blind approach, policy makers and health care providers alike would benefit from greater awareness about gender, in order that they may address the needs of both men and women. From a moral, ethical, and human rights perspective, health care providers must be aware of gender relations and their effects on health and health care experiences. There is a need to address issues of equity from a social determinants of health perspective in which the aim is for all people to have fair opportunities for the social conditions that enhance health, particularly those disadvantaged by gender or other social relations such as class, or ethnicity (Raphael, 2012). Gender equity is particularly important during end-of-life when clients and family members are actively engaged in finding comfort and meaning in life and death. It is crucial to strive for gender equity in hospice palliative care not only for caregivers and care recipients, but also for health care professions such as nurses to advance as a profession and meet its mandates for advocacy and social justice.

3.7 References

Acker, J. (1992). From sex roles to gendered institutions. *Contemporary Sociology, 21* (5), 565-569. Retrieved from http://www.jstor.org/stable/2075528?origin=JSTOR-pdf

Adams, M., & Coltrane, S. (2005). Boys and men in families: The domestic production of gender, power and privilege. In M. Kimmel, J. Hearn, & R. Connell (Eds.) *Handbook of studies on men and masculinities* (pp.230-248). Thousand Oaks: Sage Publications.

Anjos, A., Ward-Griffin, C., Leipart, B. (2012). Understanding gendered expectations and exemptions experienced by male double-duty caregivers: A qualitative secondary analysis. *Canadian Journal of Nursing Research, 44* (3), 104-123. Retrieved from: http://www.ingentaconnect.com/content/mcgill/cjnr/2012/00000044/00000003/art00007

Allen, S. (1994). Gender differences in spousal caregiving and unmet need for care. *Journal of Gerontology, 49,* S187-S195.

Ando, M., Morita, T., O'Connor, S. (2007). Primary concerns of advanced cancer patients identified through the structured life review process: A qualitative study using a text mining technique. *Palliative & Supportive Care, 5*, 265-271. doi: 10.1017/S147895507000430

Angus, J. (1994). Women's paid/unpaid work and health: Exploring the social context of everyday life. *Canadian Journal of Nursing Research, 26* (4), 23-42.

Armstrong, P. & Armstrong, H. (2005). Public and private: Implications for care work. *The Sociological Review, 53* (s2), 167-187. doi: 10.1111/j.1467-954X.2005.00579.x

Armstrong, P., Boscoe, M., Clow, B., Grant, K., Pederson, A., Willson, K., Morrow, M. (2003). *Reading Romanow: The implications of the final report of the commission on the future of health care in Canada for women*. (Report by the National Coordinating Group on Health Care and Reform and Women) Retrieved from: *www.womenandhealthcarereform.ca/publications/reading-romanow.pdf*

Atkinson, P., & Hammersley, M. (2007).*Ethnography: Principles in practice* (3[rd]ed.).New York: Routledge.

Avemark, C., Ericsson, K., Ljunggren, G. (2003). Gender differences in experienced pain, mood, energy, appetite, and sleep by cancer patients in palliative care. *Vard Norden, 23* (1), 42-46.

Boutilier, M., & Mason, R. (2012). The reflexive practitioner in health promotion: From reflection to reflexivity. In A.Pederson, M, O'Neill, I. Rootman, & S. Dupere (Eds.). *Health Promotion in Canada: Critical Perspectives* ([3rd] Ed.) (pp 196-207). Toronto: Canadian Scholars' Press Inc.

Botoroff, J., Oliffe, J, Robinson, C., & Carey, J. (2011). Gender relations and health research: A review of current practices. *International Journal for Equity in Health, 10* (60). Retrieved from http://www.equityhealhtj.com/content/10/1/60

Braun, M., Mikulincer, M. Rydall, A., Walsh, A., Rodin, G. (2007). Hidden morbidity in cancer: spouse caregivers. *Journal of Clinical Oncology, 25* (30), 4829-4834.doi: 10.1200/JCO.2006.10.0909

Brazil, K., Thabane, L., Foster, G., & Bedard, M. (2009). Gender differences among Canadian spousal caregivers at the end of life. *Health and Social Care in the Community, 17* (2), 159-166. doi: 10.1111/j.1365-2524.2008.00813.x

Bronner, G., Pertez, C., & Ehrenfeld, M. (2003). Sexual harassment of nurses and nursing students. *Journal of Advanced Nursing, 42* (6), 637-644. Retrieved from: http://journals2.scholarsportal.info.proxy2.lib.uwo.ca:2048/journal.xqy?uri=/0309 2402

Brown, M. (2004). Between neoliberalism and cultural conservatism: spatial divisions and multiplications of hospice labor in the United States. *Gender, Place and Culture, 11* (1), 67-82. doi:10.1080/0966369042000188558

Burridge, H., Barnett, A., Clavarino, A. (2009) The impact of perceived stage of cancer on carers' anxiety and depression during the patients' final year of life. *Psycho-Oncology. 18*, 615-23.doi: 10.1002/pon.1435

Calasanti, T., Bowen, M. (2006). Spousal caregiving and crossing gender boundaries: Maintaining gendered identities. *Journal of Aging Studies, 20*, 253-263

Campbell, L., & Martin-Matthews, A. (2003). The gendered nature of men's filial care. *The Journals of Gerontology B, 58*, (6), S350-S358.

Canadian Cancer Society's Steering Committee on Cancer Statistics (2011). *Canadian Cancer Statistics 2011*. Toronto, ON: Canadian Cancer Society.

Canadian Hospice Palliative Care Association [CHPCA].(2002). *A model to guide hospice palliative care.* Retrieved from: www.chpca.net/uploads/.../model_to_guide.../Table-of-contents-etc.pdf

Carstairs, S. (2010). *Raising the bar: A roadmap for the future of palliative care in Canada*. Retrieved from

http://www.chpca.net/media/7859/Raising_the_Bar_June_2010.pdf

Chapman, K., & Peplar, C. (1998). Coping, hope and anticipatory grief in family members in palliative home care. *Cancer Nursing, 21,* 226-234

Cheung, W., Le., L., Gagliese, L., & Zimmerman, C. (2011). Age and gender differences in symptom intensity and symptom clusters among patients with metastatic cancer. *Supportive Care in Cancer, 19*, 417-423. doi: 10.1007/s00520-010-0865-2

Clark, S., Booth, Velikova, G., & Hewison, J. (2006). Social support: gender differences in cancer patients in the United Kingdom. *Cancer Nursing, 29* (1), 66-72. doi: http://dx.doi.org/10.1097/00002820-200601000-00012

Clemmer, S., Ward-Griffin, C., & Forbes, D. (2008). Family members providing home-based palliative care to older adults: The enactment of multiple roles. *Canadian Journal on Aging, 27 (3)*, 267-283.

College of Nurses of Ontario [CNO] (2014). The importance of being reflective. *The Standard*. Retrieved from http://www.cno.org/en/learn-about-standards-guidelines/magazines-newsletters/the-standard/the-standard-may-2014/the-importance-of-being-reflective/

Connell, R. (2012). Gender, health and theory: Conceptualizing the issue, in local and world perspective. *Social, Science, & Medicine, 74*, 1675-1683.

Costa-Requena, G., Cristofol, & Canete, J. (2012). Caregivers' morbidity in palliative care unit: predicting by gender, age, burden, and self-esteem. *Supportive Care in Cancer, 20* (1), 1465-1470. doi: 0.1007/s00520-011-1233-6

139

Creighton, G., & Oliffe, J. (2010). Theorising masculinities and men's health: A brief history with a view to practice. *Health Sociology Review, 19* (4), 409-318. doi: http://dx.doi.org.proxy1.lib.uwo.ca/10.5172/hesr.2010.19.4.409

Dale, J., Petrova, M., Munday, D., Koistinen-Harris, J., Lall, R., & Thomas, K. (2009). A national facilitation project to improve primary palliative care: impact of the Gold Standards Framework on process and self-rating of quality. *Quality & Safety in Health Care, 18* (3), 174-180.

Decima Research Inc. (2002). *National Profile of Family Caregivers in Canada.* Retrieved Oct 23, 2009, from http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/202/-caregi-interven/index-eng.php

DeMiglio, L., Dykeman, S., Williams, A., & Kelley, M. (2012). Evolution of palliative care in Ontario: The impact of geography, funding, and advocacy. *Journal of Rural and Community Development, 7* (4), 109-121.

Dumont, S., Turgeon, J., Allard, P., Gagnon. P., Charonneau, C., Vezina, L. (2006). Caring for a loved one with advanced cancer: Determinants of distress in family caregivers. *Palliative Medicine, 9* (4),912-921. doi: 10.1089/jpm.2006.9.912

England, K. (2010). Home, work and the shifting geographies of care. *Ethics, Place and Environment, 13* (2), 131-150. doi: 10.1080/13668791003778826

Evans, J. (2002). Cautious caregivers: gender stereotypes and the sexualization of men nurses' touch. *Journal of Advanced Nursing, 40* (4), 441-448. doi: 10.1046/j.1365-2648.2002.02392.x

Evans, J. (2004). Men nurses: a historical and feminist perspective. *Journal of Advanced Nursing, 47* (3), 321-328. doi: 10.1111/j.1365-2648.2004.03096.x

Evans, J., & Frank, B. (2003). Contradictions and tensions: Exploring relations of masculinities in the numerically female-dominated nursing profession. *The Journal of Men's Studies, 11* (3). Retrieved from: https://www-lib-uwo-ca.proxy1.lib.uwo.ca:2443/cgi-bin/ezpauthn.cgi/login?url=http://search.proquest.com.proxy1.lib.uwo.ca:2048/docview/222640838?accountid=15115

Falk-Rafael, A. (2005). Speaking truth to power: Nursing's legacy and moral imperative. *Advances in Nursing Science, 28* (3), 212-223.

Fife, B., Kennedy, V., & Robinson, L. (1994). Gender and adjustment to cancer: Clinical implications. *Journal of Psychosocial Oncology, 12* (1/2), 1-21.

Fisher, M. (2009). 'Being a chameleon: labor processes of male nurses performing bodywork. *Journal of Advanced Nursing, 65* (12), 2668-2677. doi: 10.1111/j136-2648.2009.05120.x

Funk, L., & Stajduhar, K. (2011). Analysis and proposed model of family caregivers' relationships with home health providers and perceptions of the quality of formal services. *Journal of Applied Gerontology, 32* (2). doi: 0.1177/0733464811408699

Funk, L., Stajduhar, K., Toye, C., Aoun, S., Grande, G. & Todd, C. (2010). Part 2: Home-based family caregiving at the end of life: a comprehensive review of published qualitative research (1998-2008). *Palliative Medicine, 24* (6), 594-607. doi: 1177/0269216310371411

Glazer, N. (1990). The home as workshop: Women as amateur nurses and medical care providers. *Gender & Society, 4* (4), 479-499. Retrieved from: http://www.jstor.org/stable/189750

Glen, E. (2010). *Forced to care: Coercion and caregiving in America*. Cambridge, Massachusetts: Harvard University Press.

Graham, M., & Palmer, A. (2002). Gender difference considerations for individuals with laryngectomies. *Contemporary Issues in Communication Science and Disorders, 29*, 59-67.

Graham, H. (2004). Social determinants and their unequal distribution: Clarifying policy understandings. *The Milbank Quarterly, 82*,1, 101-124.

Greimel, E., Padilla, G., & Grant, M. (1998). Gender differences in outcomes among patients with cancer. *Psycho-Oncology, 7*, 197-206.

Grov, E., Dahl, H., Moum, T., & Fossa, S. (2005). Anxiety, depression and quality of life in caregivers of patients with cancer in late palliative phase. *Annals of Oncology, 16*, 1185-1191. doi: 10.1093/annonc/mdi210

Grunfeld, E., Coyle, D., Whelan, T., Clinch J., Reyno, L., & Earl, C. (2004). Family caregiver burden: Results of a longitudinal study of breast cancer patients and their principle caregivers. *Canadian Medical Association, 170* (12), 1795-1801. doi: 10.1503/cmaj.1031205

Guba, E., & Lincoln, Y. (1989). *Fourth generation evaluation*. Newbury Park: Sage Publications.

Guberman, N., Lavoie, J., Pepin, J., Lauzon, S., & Montejo, M. (2006). Formal service practitioners' views of family caregivers' responsibilities and difficulties. *Canadian Journal on Aging, 25* (1), 25 (1), 43-53.

Hagedoorn, M., Buunk, B.P., Kuijer, R.G., Wobbes, T.., & Sanderman, R. (2000).

Couples dealing with cancer: Role and gender differences regarding depressive

symptoms and quality of life. *Psycho-Oncology, 9*, 232-242.

Hagedoorn, M., Sanderman, R., Bolks, H., & Tuinstra (2008). Distress in couples coping

with cancer. *Psychological Bulletin, 134* (1), 1-30. doi: 10.1037/0033-

2909.134.1.1

Hankivsky, O., & Christoffersen, A. (2008). Intersectionality and the determinants of

health: a Canadian perspective. *Critical Public Health, 18* (3), 271-283.

Harding, T. (2007). The construction of men who are nurses as gay. *Journal of Advanced*

Nursing, 60 (6), 636-644. doi: 10.1111/j.1365-2648.2007.04447.x

Hayes, R., Lee, W., Rayner, L., Price, A., Monroe, B., Hansford…Hotopf, M. (2011).

Gender differences in prevalence of depression among patients receiving palliatie

care: The role of dependency. *Palliative Medicine, 26* (5), 696-702. doi:

10.1177/0269216311416035

Heller, A. (1986*). Health and home: Women as health guardians in the home*. Ottawa:

Canadian Advisory Council on the Status of Women.

Hills, M., Carroll, S., & Vollman, A. (2007). Health promotion and health professionals

in Canada: Towards a shared vision of the health promotion landscape. In

A.Pederson, M, O'Neill, I. Rootman, & S. Dupere (Eds.). *Health Promotion in*

Canada: Critical Perspectives (2nd Ed.) (pp 330-46). Toronto: Canadian Scholars'

Press Inc.

Husain, A., Stewart, K., Arseneault, R., Moineddin, R., Cellarius, V., Librach, S., &

Dudgeon, D.(2007). Women experience higher levels of fatigue than men at the

end of life: A longitudinal home palliative care study. *Journal of Pain and Symptom Management, 33* (4), 389-397. doi: 10.1016/j.jpainsymman.2006.09.019

Im, I. (2006). White cancer patients' perception of gender and ethnic differences in pain experience. *Cancer Nursing, 29* (6), 441-450.

Im, I., Chee, W., Guevara, E., Hyun-Ju, L., Liu, Y., & Shin, H. (2008). Gender and ethnic differences in cancer patients' needs for help: An internet survey. *International Journal of Nursing Studies, 45*, 1192-1204.

Jack, B., & O'Brien, M. (2010). Dying at home: Community nurses' views on the impact of informal carers on cancer patients' place of death. *European Journal of Cancer Care*, 19 (5), 636-42. doi: 10.1111/j.1365-2354.2009.01103.x

Jacobs-Lawson, J., Schumacher, M., Hughes, T., & Arnold, S. (2010). Gender differences in psychosocial responses to lung cancer. *Gender Medicine, 7* (2), 137-147. doi: 10.1016/j.genm.2010.03.002.

Jo, S., Brazil, K., Lohfeld, L., & Willison, K. (2007). Caregiving at the end of life: Perspectives from spousal caregivers and care recipients. *Palliative and Supportive Care, 5,* 11-17.

Johnson, J., & Repta, R. (2012). Sex and gender: Beyond the binaries. In J. Oliffe, & L. Greaves (Eds.), *Designing and conducing gender, sex, and health research*, (pp 17-39). Thousand Oaks: SAGE Publications Inc.

Jones, J., Cohen, R., Zimmermann, C., Rodin, G. (2010). Quality of life and symptom burden in cancer patients admitted to an acute palliative care unit. *Journal of Palliative Care, 26* (2), 94-102. doi: 10.1111/j.1365-2648.2009.05051.x

Keller, M., & Henrich, G. (1999). Illness-related distress: Does it mean the same for men and women? Gender aspects in cancer patients' distress and adjustment. *Acta Oncologica, 38* (6), 747-755.

Kirkova, J., Rybicki, L., Walsh, D., & Aktas, A.(2012). Symptom prevalence in advanced cancer: age, gender, and performance status interactions. *American Journal of Hospice & Palliative Medicine, 29* (2), 139-145. doi: 10.1177/1049909111410965

Klemm, P., Hurst, M., Dearholt, S. & Trone, S. (1999). Cyber solace: Gender differences on internet cancer support groups. *Computers in Nursing, 17* (2), 65-72.

Lather, P. (1995). The validity of angels: interpretive and textual strategies in researching the lives of women with HIV/AIDS. *Qualitative Inquiry, 1* (1), 41-68.

Leitner, S. (2013). Varieties of familialism: The caring function of the family in comparative perspective. *European Studies, 5* (4), 1461-6996. doi: 10.1080/1461669032000127642

Lofland, J., Snow, D., Anderson, L., & Lofland, L. (2006). *Analyzing social settings: A guide to qualitative observation and analysis* (4th ed.). Toronto: Thomson, Wadsworth.

Lorber, J. (1994). "Night to his day": The social construction of gender. In J. Lorber (Ed.). *Paradoxes of gender* (pp 13-36). New York: Vail-Ballou Press.

McGregor, S. (2001). Neoliberalism and health care. *International Journal of Consumer Studies, 25 (*2), 82-89.

McGuire, T., Dougherty, D., & Atkinson, J. (2006). Paradoxing the dialectic: The impact of patients' sexual harassment in the discursive construction of nurses' caregiving

roles. *Management Communications Quarterly, 19* (3), 416-460. doi:
10.1177/0893318905280897

McIllmurray, M., Thomas, C., Francis, B., Morris, S., Soothill, K., & Alhamad, A.
(2001). The psychosocial needs of cancer patients: findings from an observational
study. *Journal of Cancer Care, 10*, 261-269.

Martin-Matthews, A. Sims-Gould, & Tong, C. (2013). Canada's complex and
fractionalized home care context: Perspectives of workers, elderly clients, family
carers and home care managers. *Canadian Review of Social Policy, 68/69*, 55-74

Milberg, A., & Strang, P. (2004). Exploring comprehensibility and manageability in
palliative home care: An interview study of dying cancer patients' informal carers.
Psycho-Oncology, 13, 605-618.

Morris, M. (2001). *Gender-sensitive home can community care and caregiving research:
A synthesis paper.* Retrieved from
www.womenandhealthcarereform.ca/publications/synthesis.pdf

Morse, S., & Fife, B. (1998). Coping with a partner's cancer: Adjustment at four stages of
the illness trajectory. *Oncology Nursing Forum, 25*, 751-760.

Mystakidou, K., Tsilika, E., Parpa, E., Hatzipli, I., Smyrnioti, M., Galanos, A., Vlahos,
L.(2008). Demographic and clinical predictors of spirituality in advanced cancer
patients: A randomized control study. *Journal of Clinical Nursing, 17* (13), 1779-
1785. doi: 10.1111/j.1365-2702.2008.02327.x

Mystakidou, K., Tsilka, E., Parpa, E., Katsouda, E., Sakkas, P., Galanos, A., Vlahos,
L.(2006). *Psycho-Oncology, 15*, 828-833. doi: 10.1002/pon.1029

Mystakidou, K., Parpa, E., Panagiotou, I., Tsilka, E., Galanos, A., & Gouliamos, A. (2013). Caregivers' anxiety and self-efficacy in palliative care. *European Journal of Cancer Care, 22*, 188-195. doi: 10.1111/ecc.1201

Nicholas, D. (2000). Men, masculinity, and cancer: Risk-factor behaviours, early detection, and psychosocial adaptation. *Journal of American College Health, 49,* 27-33.

O'Lynn, C., & Krautscheid, L. (2011). 'How should I touch you?': A qualitative study of attitudes on intimate touch in nursing care. *American Journal of Nursing, 11* (3), 24-31. doi: 10.1097/10.1097/01.NAJ.0000395237.83851.79

Ottawa Charter.(1986). *Ottawa Charter for Health Promotion.* First International Conference on Health Promotion.Ottawa, 21 November 1986 - WHO/HPR/HEP/95.1Retrieved from http://www.who.int/hpr/NPH/docs/ottawa_charter_hp.pdf

Oudshoorn, A., Ward-Griffin, C. & McWilliam, C. (2007). Client-nurse relationships in home-based palliative care: A critical analysis of power relations. *Journal of Clinical Nursing, 16*, 1435-1443. doi: 10.1111/j.1365-2702.2006.01720.

Pauly, B. (2008). Harm reduction through a social justice lens. *International Journal of Drug Policy, 19*, 4-10. doi: 10.1016/j/drugpo.2007.11.005

Payne, S., Smith, P., & Dean, S. (1999). Identifying concerns of informal carers in palliative care. *Palliative Medicine, 13*, 37-44.

Pullen, A., & Simpson, R. (2009). Managing difference in feminized work: Men, otherness and social practice. *Human Relations, 62* (4), 561-587. doi: 10.1177/0018726708101989

Raphael D. (2012). The importance of tackling health Inequalities. In D. Raphael (Ed.), *Tackling health inequalities: Lessons from international experiences* (pp 1-32). Canadian Scholars' Press: Canada

Reutter, L., & Duncan, S. (2002). Preparing nurses to promote health-enhancing public policies. *Policy, Politics & Nursing Practice, 3* (4), 294-305. doi: 10.1177/152715402237441

Rivera, H., & McMillian, S. (2010). Predictors of depression symptoms in hospice care. *Journal of Hospice & Palliative Nursing, 12* (6), 345-357. doi: 10.1097/NJH.0b013e3181f184f4

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

Salander, P., & Hamberg, K. (2005). Gender differences in patients' written narratives about being diagnosed with cancer. *Psycho-Oncology, 14*, 684-795. doi: 10.1002/pon.895.

Seale, C. (2006). Gender accommodation in online cancer support groups. *Health An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine, 10* (3), 345-360. doi: 10.1177/1363459306064495 1363-4593

Schultz, R., & Beach, S. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *American Medical Association, 282*, (23), 2215-2219.

Simpson, R. (2009). *Men in caring occupations: Doing gender differently*. NewYork: Palgrave MacMillan.

Smith, D. (1987). *The everyday world as problematic*. Massachusetts: Northeastern Press.

Smith, D. (1992). Sociology from Women's Experience: A reaffirmation. *Sociological Theory, 10* (1), 88-98. URL: http://www.jstor.org/stable/202020

Smith, D. (2005). Women's Standpoint: Embodied knowledge versus the Ruling Relations. *Institutional ethnography*: *A sociology for people* (pp. 7-26) Maryland: Alta Mira Press.

Spiroch, C., Walsh, D., Mazanec, P., Nelson, K. (2000). Ask the patient: A semi-structured interview study of quality of life in advanced cancer. *American Journal of Hospice & Palliative Care, 17* (4), 235-240. doi: 10.1177/104990910001700408

Stajduhar, K., & Davies, B. (2005). Variations and factors influencing family members' decisions for palliative home care. *Palliative Medicine, 19*, 21-32.

Stajduhar, K., Funk, L., Jakobsson, E., & Ohlen, J. (2008). A critical analysis of health promotion and 'empowerment' in the context of palliative family care-giving. *Nursing Inquiry, 17*, 221-230.

Stajduhar, K., Funk, L., Roberts, D., Cloutier-Fisher, D., McLeod, B., Wilkinson, C., & Purkis, M. (2010). Articulating the role of relationships in access to home care nursing at the end of life. *Qualitative Health Research, XX* (X), 1-15. doi: 10.1177/104973231037114

Stoller, E., Miklowski, C. (2008) Spouses caring for spouses: Untangling the influences of relationship and gender. In M. Szinovacz , A. Davey. (Eds.), *Caregiving contexts: Cultural, familial, and societal implications* (pp. 115–131). New York: Springer.

Thomas, J. (1993). *Doing critical ethnography*. Newbury Park, California: Sage
publications.

Torkelson, D., & Seed, M. (2011). Gender differences in the roles and functions of
inpatient psychiatric nurses. *Journal of Psychosocial Nursing, 49* (3), 41. doi:
10.3928/02793695-20110201-02

Ussher, J., & Sandoval, M. (2008). Gender differences in the construction and experience
of cancer care: The consequences of the gendered positioning of carers.
Psychology and Health, 23 (8), 945-963.

Ussher, J., Sandoval, M., Perz, J., Wong, W., & Butow, P. (2013). The gendered
construction and experience of difficulties and rewards in cancer care. *Qualitative
Health Research, 23* (7), 900-915. doi: DOI: 10.1177/1049732313484197

Van Dijk, T. (2006) Principles of critical discourse analysis. *Discourse & Society, 42*(2),
249-283. doi: 10.1177/0957926593004002006

Verdonk, P., Benshop, Y., de Haes, H., & Lagro-Janssen, T. (2009). From gender bias to
gender awareness in medical education. *Advances in Health Sciences Education,
14*, 135-152. doi: 10.1007/s10459-008-9100-z

Ward-Griffin, C., McWilliam, C., Oudshoorn, A. (2012a). Negotiating relational practice
patterns in palliative home care. *Journal of Palliative Care, 28* (2), 33-40. doi:
10.1177/1074840712462134

Ward-Griffin, C., McWilliam, C., Oudshoorn, A. (2012b). Relational experiences of
family caregivers providing home-based end-of-life care. *Journal of Family
Nursing, 18* (4), 91-516. doi: 10.1177/1074840712462134

Weber, L. (2005). Reconstructing the landscape of health disparities research: Promoting dialogue and collaboration between feminist intersectional and biomedical paradigms. In A. Schulz, & L. Mullings (Eds.), *Gender, race, class, and health: Intersectional approaches* (pp. 21-59). San Francisco: Jossey-Bass.

Wessels, H. DeGraeff, A., De Heus, M., Kruitwagen, C., Woltjer, G., Teunissen, S. &Voest, E. (2010). Gender-related needs and preferences in cancer care indicate the need for individualized approach to cancer patients. *The Oncologist, 15*, 648-655. doi: 10.1634/theoncologist.2009-0337

West, C., & Zimmerman, D. (1987). Doing gender. *Gender & Society, 1* (2), 125-151.

West, C., & Zimmerman, D. (2009). Accounting for doing gender. *Gender & Society, 23* (1), 112-122. doi: 10.1177/0891243208326529)

Whittock, M., & Leonard, L. (2003). Stepping outside the stereotype. A pilot study of the motivations and experiences of males in the nursing profession. *Journal of Nursing Management, 11*, 242-249. doi: 10.1046/j.1365-2834.2003.00379.x

Williams, A. (1996). The development of Ontario's home care program: A critical geographical analysis. *Social Science & Medicine, 42* (6), 937-948.

Williams A., (2002). Changing geographies of care: Employing the concept of therapeutic landscapes as a framework in examining home space. *Social Science & Medicine, 55* (1), 141-154. doi: 10.1016/S0277-9536(01)00209-X

Zimmerman, C., Burman, D., Follwell, M., Wakimoto, K., Seccareccia, D., Bryson, J….Rodin, G. (2009). Predictors of symptom severity and response in patients with metastatic cancer. *American Journal of Hospice and Palliative Medicine, 27* (3), 175-181. doi: 10.1177/1049909109347307

4. Chapter Four: Gendered Processes in Hospice Palliative Home Care

4.1 Background

Pervasive in all social encounters, gender is performed daily through activities and interactions (Lyons, 2009; McMullin, 2010). Gender relations are an embedded source of power, often creating differences in limitations and opportunities for well-being (Davison, Edwards, Webber, & Robinson, 2006; Lyons, 2009; McMullin, 2010). Based on the biological category of sex, gender is a social relation expressed and monitored according to culturally ascribed gendered attitudes, beliefs, and practices, shaping relationships and interactions, and influencing one's control, influence, or access to resources (Johnson & Repta, 2012). These social relations shape limitations and opportunities in health care experiences that vary the care received and the exposure to risks (Johnson & Repta, 2012).

In hospice palliative home care, there is evidence that men and women differ in the amount and type of care work they give and receive (Brazil, Thabane, Foster, & Bedard, 2009; Brown, 2004), negatively impacting on health (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Grov, Dahl, Moum, & Fossa, 2005; Grunfeld et al., 2004; Schultz & Beach, 1999) and health care delivery (Clark, Booth, Velikova, & Hewison, 2006; Salander & Hamberg, 2005). More specifically, research has indicated that women with cancer have reported more negative encounters with health care staff compared to men (Clark et al. 2006; Im, 2006; Peleg-Oren, Sherer & Soskolne, 2003; Salander & Hamberg, 2005), suggesting possible gender discrimination. Men have tended to rely solely on their wives for emotional support (Clark et al., 2006; Keller & Henrick, 1999; Salander &

Hamberg, 2005), while women have reported using wider social support networks (Greimel, Padilla, & Grant, 1998). In terms of providing care, women have been more likely to undertake toilet-related tasks (Brazil et al., 2009) and bodily care (Brown, 2004) compared to men. In contrast, men have provided instrumental care such as arranging pick-up of prescriptions and supplies (Brown, 2004). Additionally, female caregivers have reported more anxiety and depression (Brazil et al., 2009; Burridge, Barnett & Clavarino, 2009; Chapman & Peppler, 1998 ; Dumont et al., 2006; Hoogedoorn, Sanderman, Bolks, & Tuinstra, 2008; Mystakidou et al., 2012; Payne, Smith & Dean, 1999; Rivera & McMillan, 2010) than their male counterparts. However, male caregivers have reported more difficulties in adapting to added household tasks in the provision of cancer care (Ussher, Sandoval, Perz, Wong, & Butow, 2013). Although these sex and gender differences have been well documented in hospice palliative home care, there has been little investigation into how and why gendered processes occur in this context.

The term hospice palliative care has been used to unite the movements of hospice and palliative care (DeMiglio, Dykeman, Williams, & Kelley, 2012), both intended to promote an holistic philosophy of care for individuals and their family members facing life-limiting illness (Canadian Hospice Palliative Care Association [CHPCA], 2013). With goals to relieve suffering and improve quality of life, these movements strive for high standards (CHPCA, 2013) to actualize people's full health potential. These standards include the principles of justice, and more specifically, the fair treatment of individuals without discrimination of gender, class, ethnicity, religion, or age (CHPCA, 2013). Notions of high quality care are consistent with a growing national and international interest in equity in health (Doyle, 2000) and are especially relevant at end-of-life. During

this vulnerable time, clients with terminal illness and their family members face significant physical and emotional challenges (Clemmer, Ward-Griffin, & Forbes, 2008; Funk et al., 2010; McWilliam, Ward-Griffin, Oudshorrn & Krestick, 2008; Ward-Griffin, McWilliam, & Oudshoorn, 2012a,2012b) and may be unable or unwilling to confront issues of equity in order to focus on the challenges of end-of-life. In this context, it is important to promote gender equity in hospice palliative care through fair policies and practices.

Hospice palliative home care occurs within the unique setting of home in which relationships between and among clients, caregivers and health care providers is crucial to achieve efficient and high quality care (CHPCA, 2013; Stajduhar et al., 2010; Ward-Griffin, McWilliam, Oudshoorn, 2012a, 2012b). Home is a gendered space in which tradition dictates that men provide financially for the household and women care for the household (Angus, 1994; Armstrong & Armstrong, 2005; Glazer, 1990). The gendered culture of home makes hospice palliative home care an important setting in which to understand gendered processes, the how and why gender relations and potential gender inequities are (re)produced. Home also is a place in which inequitable practices (Clemmer et al., 2008; Stajduhar et al., 2010; Ussher & Sandoval, 2008) may be largely hidden (Armstrong & Armstrong, 2005). It is therefore vital to expose and challenge the conditions within which these gendered processes occur. Making visible the cultural and structural influences that shape gendered processes during end-of-life in the home will help to inform the development of strategies for policies and practices that optimize health and health care in this context. Given the social (Brazil, Howell, Bedard, Krueger, & Heidebrecht, 2005) and political (Romanow, 2002) trends towards death at home,

alongside the rising cancer incidence and mortality rates among the growing aging population (Canadian Cancer Society, 2011), it is both timely and imperative to address the processes that potentially lead to gender (in)equities in hospice palliative home care.

As a part of a critical ethnographic study examining gender relations within the sociopolitical context of hospice palliative home care for clients with cancer and their caregivers, the focus of this chapter was to answer the following research questions: (a) How and why do gendered processes operate to produce gender relations and potential gender inequities in hospice palliative home care? (b) What are the sociopolitical conditions within which gendered processes occur in this context? (c) What strategies related to policy and practice will enhance gender equity in this health care setting? As central figures to home care in assessing, facilitating, and providing services (CHPCA, 2002; Ontario Home Health Care Association, 2011), in Ontario, Canada, registered nurses are the health care providers selected within the triad of the client-family caregiver-provider in hospice palliative home care. Findings from this study also revealed that gender was influenced by sociopolitical discourses that reinforced gendered expectations and exemptions, shaping clients' family caregivers' and nurses' beliefs, attitudes and everyday practices (See Chapter Three). Gender (in)equities were (re)produced through the mechanisms of *Preservation/Destruction of Gender Stereotypes* and *Imbalance/Balance of Power* (See Chapter Five).

4.2 Literature Review

Much of the literature examining gender in hospice palliative home care identifies sex and gender differences. While researchers have sought an understanding of gender in relation to each the client, the family caregiver, and the nurse, there is limited

investigation of the dynamic interplay of gendered interactions between and among the participant triad of the client, family caregiver, and health care provider in this context. The selected literature review includes gender in relation to the client with cancer, the family caregiver, and the nurse and client-family-caregiver-nurse relationships. Studies examining all stages of cancer, including advanced cancer and palliative care, were included.

Research findings have been mixed with respect to sex/gender and clients with cancer in all stages of the disease, including palliative care. While research has shown that women rely on a wider social support network compared to men, who rely solely on their wives (Clark et al., 2006; Graham & Palmer, 2002; Greimel et al., 1998; Keller & Henrich, 1999; Salander & Hamberg, 2005), there have been contradictory reports of no gender differences in the emotional support that clients receive from health care providers and family members (Jacobs-Lawson, Schumacher, Hughes, & Arnold, 2010). Social support networks may have been viewed differently by participants in the various studies. For example, in terms of care provision and health care relationships, women have shown an interest in connecting with others (Ando, Morita, O'Connor, 2007; Wessels et al., 2010) and finding meaning (Mystakidou et al., 2006), whereas men perceive as important the receiving of information (Klemm, Hurst, Dearholt, & Trone, 1999; Seale, 2006).

Compared to men, women have expressed more disappointment in staff relationships and more negative experiences, suggesting possible gender discrimination of women (Im, 2006; Salander & Hamberg, 2005). For instance, women have reported that their pain had not been taken seriously by health care professionals, family and friends (Im, 2006). It may be that women are treated differently by health care providers and

family members because of traditional beliefs that women usually care for themselves and tolerate high levels of pain during the birthing process. Additionally, while research has suggested that women with cancer generally report lower quality of life scores (Jones, Cohen, Zimmerman & Rodin, 2010), and greater needs (McIllmurray et al., 2001) compared to their male counterparts, other studies have shown no gender differences in this context (Hagedoorn Buunk, Kuijer, Wobbes, & Sanderman, 2000; Hussain et al., 2007; Jacobs-Lawson, Schumacher, Hughes, & Arnold, 2010). Clearly, more analysis is needed that moves beyond sex and gender differences and provides the social context and conditions of gendered processes during this vulnerable time when clients and family members face serious, terminal illness.

In terms of family caregivers of individuals with cancer in end-of-life, studies investigating all stages of cancer care including end-of-life have highlighted the gendered nature of caregiving, indicating that women have been positioned as expert caregivers (Ussher & Sandoval, 2008). Women have been influenced to assume the caregiver role by health care providers and family members (Clemmer et al., 2008) based on traditional societal ideologies that women are natural nurturers (Angus, 1994; Armstrong & Armstrong, 2005; Clemmer et al., 2008; Glazer, 1990; Ward-Griffin et al., 2012b). Additionally, compared to their male counterparts, women have been more involved in providing toileting-related tasks (p=0.044) (Brazil et al., 2009) and intimate bodily care (Brown 2004), and have reported receiving less support in personal care tasks from other family members and friends (Brazil et al., 2009). However, men more than women have experienced difficulties in taking on additional responsibilities in the home when providing care for relatives with cancer (Allen, 1994; Ussher et al., 2013).

In terms of responses to caregiving, women have experienced more psychological distress (Brazil et al., 2009; Burridge et al., 2008; Chapman & Peppler, 1998; Dumont et al., 2006; Mystakidou et al., 2013; Payne et al., 1999; Rivera & McMillan, 2010) compared to their male counterparts. Women more than men have experienced higher levels of strain (Brazil et al., 2009; Payne et al., 1999) anxiety (Burridge et al., 2008; Dumont et al., 2006; Mystakidou et al., 2013), depression (Dumont et al., 2006), and negative emotions (Chapman & Peppler, 1998). Further research is needed to understand and challenge gendered processes that contribute to these differences in responses and experiences for male and female caregivers.

The literature investigating nurses and gender has suggested that nurses have negotiated gender roles and managed relationships around cultural expectations of masculinity and femininity, potentially affecting the type and quality of care given. In order not to be viewed as sexual predators, male nurses have been hesitant in their use of touch (Evans, 2002; Evans & Frank, 2003; Fisher, 2009; Harding, 2007; O'Lynn & Krautscheid, 2011) and have tended to deliver care in a distant manner (Milligan, 2001; Pullen & Simpson, 2009). Also, as strength and stoicism are associated with masculinity, male nurses have often been characterized as heroes (Simpson, 2009), frequently called upon for heavy lifting and caring of aggressive patients (Pullen & Simpson, 2009; Whittock & Leonard, 2003), while they also have been viewed to be calm, authoritative and thus well-suited to supervisory roles (Simpson, 2009). Female nurses reify male nurses' propensities to provide care in high tension areas such as emergency, while they reinforce assumptions of caring attributes as inherently female (Bolton, 2005; Simpson, 2009).

Female nurses subject to negative gender relations of unwanted verbal sexual innuendoes have distanced themselves and been reluctant to return to care, affecting nurses' practices and the care given (McGuire, Dougherty, & Atkinson, 2006). Still, female nurses have spent significantly more time (mean=25.17 minutes) than male nurses (mean 15.02 minutes) developing therapeutic relationships ($p<0.05$) (Torkelson & Seed, 2011). As research has indicated that male nurses are frequently asked to care for more aggressive patients (Pullen & Simpson, 2009; Simpson, 2009 Whittock & Leonard, 2003), it may be that male nurses are caring for patients with whom the development of relationships is more challenging, or that they are avoiding situations that may be interpreted as sexual. These studies were conducted in various hospital settings such as emergency, mental health, and medical units. Clearly, more research is needed to explicate gendered processes in the provision of nursing care, particularly in private home care settings, and during end-of-life.

Studies investigating relationships in hospice palliative home care have suggested that the development of satisfactory relationships between and among clients, family caregivers and nurses has been undermined by neoliberal policies of fiscal constraints and limited resources for home care (Clemmer et al., 2008; McWilliam et al., 2008; Mok & Chiu, 2004; Oudshoorn, Ward-Griffin, & McWilliam, 2007; Stajduhar, Nickel, Martin, & Funk, 2008; Ward-Griffin et al., 2008a). Clients in this context have been aware of nurses' limited time (Mok & Chiu, 2004), and have experienced powerlessness because of the lack of choice in the number of visits allowed (McWilliam et al.; Oudshoorn et al.). In terms of family caregivers, family members of ill clients have felt pressured to provide personal care (Clemmer et al., 2008; Linderholm & Friedrichsen, 2010; Stajduhar, Nickel,

Martin, & Funk, 2008) and have assumed the role of caregiver often feeling ill-prepared and uninformed (Linderholm & Friedrichsen; Stajduhar et al., 2008). In the context of limited resources, nurses have transferred care work to family members (Clemmer et al., 2008; Oudshoorn et al., 2007; Stajduhar, Funk, Roberts et al., 2010; Ward-Griffin et al., 2012a,b) and encouraged them to continue to provide care (Stolz, Linholdm, Uden & Willman, 2006). Some nurses have evaded personal relationships with clients and family caregivers to avoid becoming influenced in making decisions in the allocation of scarce resources (Stajduhar, Funk, Roberts et al., 2010). Clearly, relationships in hospice palliative home care influence the provision of care and the services offered; yet, there is little knowledge into how gendered processes shape client-family caregiver-nurse relationships and experiences that lead to inequities.

In summary, much of the literature on gender relations in hospice palliative home care has focused on sex and gender differences. There has been limited exploration of how and why gendered processes are enacted in health care interactions, particularly in this context of hospice palliative home care. An understanding of the gendered processes and the contextual factors that influence them is needed in order to challenge and redress practices and policies that lead to gendered care work and gendered (in)equities in hospice palliative home care.

4.3 Methods

I used a critical feminist lens guided by Dorothy Smith (1987, 2005) to foreground gender. Central to this perspective is that knowledge is relational as it is mediated through institutional texts and materialized in peoples' everyday lives. Starting with the actualities of everyday experiences, prevailing institutional discourses are exposed to reveal and

challenge the ways in which subordinate relations are formed (Smith, 1987, 2005). As a critical feminist lens is employed to redress hierarchical social relations and injustices (Kushner & Morrow, 2003; Pitre, Kushner, Raine, & Hegadoren, 2013), it is an appropriate lens to examine gendered processes which operate within the broader contexts of provincial government agencies, private nursing agencies, and professional nursing associations in everyday hospice palliative home care.

With this critical feminist lens, I employed critical ethnography as described by Thomas (1993, 2003) to bring a social cultural focus to this study. Culture is a dynamic relational process that validates the "what" and "why" of the world (Thomas, 1993), and shapes the "how" of everyday practices and social constructs such as gender. In critical ethnography, embedded assumptions and beliefs are uncovered to expose and challenge power-laden social processes and subsequent (in)equities.

4.3.1 Study setting.   In Ontario, the government agency, Community Care Access Centres (CCACs), assess eligibility of services and contract out to private nursing agencies which provide the actual services. In this context, the CCAC ultimately controls the number and nature of home visits (Williams, 2006). As health care providers who initially and periodically assess palliative home care clients for eligibility and needs (Ontario Association of CCACs, 2011), case managers were selected to identify potential senior clients (age 60 years and older) with cancer enrolled in the hospice palliative care program. Three case managers from two CCAC agencies were recruited to briefly explain the study to eligible clients and ask if they would be interested in participating in the study.

4.3.2 Recruitment. Case managers contacted me and provided names and contact information of clients who showed interest in the study. I telephoned clients and their corresponding family caregivers and primary nurses. As I have been investigating the culture of hospice palliative home care and as gender is relational, the unit of analysis was comprised of the home care triad which included the client, his or her family caregiver, and the primary nurse involved with that particular client and caregiver. Despite some recruitment issues because of clients' worsening conditions and family strain, I was successful in recruiting six client-family caregiver-nurse triads. Ethics approval was obtained from Western University and a regional CCAC Research Ethics Board.

4.3.3 Sample. Three male clients and three female clients were recruited. Five clients identified their spouses as the caregivers, and one client who was single identified a friend/neighbour and the friend's wife as caregivers. Clients and caregivers ranged in the age from 64 to 87 years and all were retired (See Appendix E). As two nurses cared for more than one client, four nurses were recruited, all female and ranging in age from 30 to 59. All four nurses completed additional palliative care education, while two received college diplomas and two completed university degrees. Two nurses were employed part-time and two nurses were employed full-time. All participants including clients, caregivers, and nurses, were Caucasian.

4.3.4 Data collection. Using ethnographic methods, I conducted in-depth interviews (n=25), observed agency home visits (n=9), and reviewed relevant institutional documents (n=12). During the time from April 2012 to August 2013, I spent 127 hours in the field. I managed data by entering transcripts, documents, fieldnotes, and memos into NVivo software.

4.3.4.1 Interview.   Initially, I conducted three joint interviews with clients and their caregivers. However, because clients and caregivers were constrained due to the other's presence, I asked if it was acceptable to conduct separate interviews. The subsequent 22 interviews were conducted individually, and elicited more free-flowing information-rich data. Interviewing in clients' and caregivers' homes where home care services were received, I asked open-ended questions that focused on if and how being a man or a woman affected their experiences. Because some clients' conditions worsened, I was able to conduct only one home visit and one interview with three clients and caregivers. While I was aware that in critical research there is a possibility of "false consciousness" in which non-dominant groups are accepting of dominant ideologies (Lather, 1995; Smith, 2005), I was able to return to the remaining three triads to clarify and refine analyses. I conducted interviews with nurses at a place and time convenient to them, which was at their homes and twice at a coffee shop.

4.3.4.2 Observation.   Of the nine home agency visits observed, I was able to make two home visits for three client-family caregiver-nurse triads, and only one home visit for three triads for whom clients' impending deaths prevented further contact. I attempted to make two home visits in order to capture patterns of interactions between and among the client, caregiver, and nurse within the triad. Observations made prior to and following interviews also afforded context and understanding of relations in the natural environment (Atkinson & Hammersley, 2007; Thomas, 1993). I observed verbal and non-verbal interactions and taken-for-granted positions of dominance, documenting them in the form of fieldnotes for analysis.

4.3.4.3 Document review. As documents shape the organizational culture and influence everyday actualities of people's lives (Perakyla, 2008; Prior, Hughes, & Peckhamm 2012; Smith, 1987, 2005), it was important to review program (n=2), professional (n=5) and public communication documents (n=5) (see Appendix I). I retrieved informational pamphlets from the private agencies to which nurses in the study were employed. By reviewing the documents, I was able to shed light on the socio-political context of hospice palliative home care.

4.3.5 Data analysis. I conducted analysis that was informed by Lofland, Snow, Anderson and Lofland (2006). Initially generating codes through iterative line-by-line readings, I subsequently categorized codes and further refined and collapsed them to develop broader themes. Continually comparing and contrasting emerging concepts and themes, I wrote memos to define and characterize the themes. Additionally, through the use of diagramming, I was able to conceptualize relationships among themes (Lofland et al., 2006). As gender is a social construct performed through daily interactions (Johnson, Greaves & Repta, 2009; West & Zimmerman, 1987, 2009), I examined how gender was projected, received, and practised (West & Zimmerman, 1987, 2009) in an effort to uncover gendered processes. Additionally, I questioned taken-for-granted gendered assumptions and roles and how these influenced processes. Documents were examined for their intended audience, inclusions, exclusions, depiction of power, and use of categories to describe people and events.

4.4 Findings

Three gendered processes of *Regulating Gender Relations, Normalizing Gender Relations*, and *Equalizing Gender Relations* (Figure 2. Green Subsection) were used in

response to meeting, countering, monitoring socially ascribed gendered expectations and exemptions (as described in Chapter Three). Embedded within these gendered processes were power relations of *Asserting Power*, *Resisting Power,* and *Maintaining Power*. The socially constructed mechanisms that underlie the (re)production of gender (in)equities is explicated in Chapter Five.

Figure 2. Green Subsection: Gendered Processes in Hospice Palliative Home Care
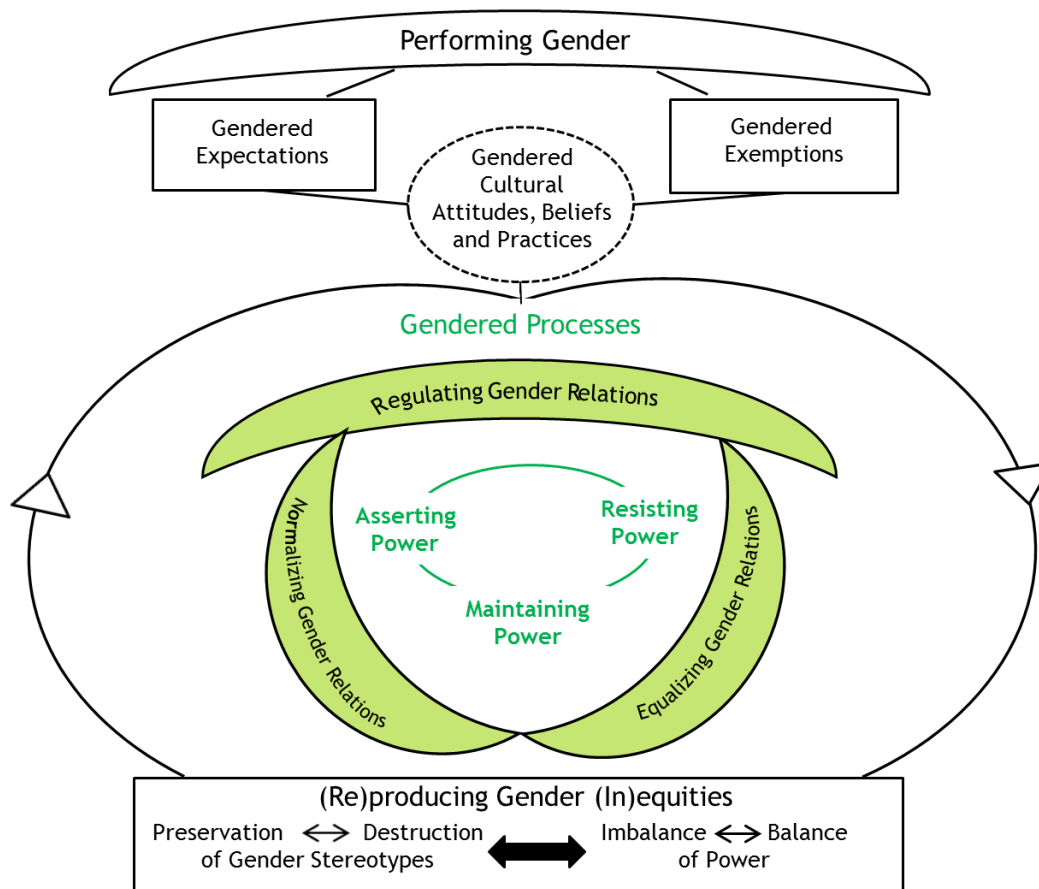
Regulating Gender Relations were specific gendered enactments used to assert, resist, or maintain power. *Normalizing Gender Relations* and *Equalizing Gender Relations* were contradictory ideological processes interpreted and used by participants to support the controlling acts of *Regulating Gender Relations*. For *Normalizing Gender Relations*, clients, family caregivers and nurses reified gendered attitudes and beliefs to support their gendered practices. In *Equalizing Gender Relations*, participants considered that treating men and women the same deflected gender as a contributing factor that

influenced health care interactions and experiences. Reinforcing gender differences while simultaneously being blind to gender served to conceal and maintain hierarchal relationships. In this context, gendered processes have (re)produced power relations of *Asserting Power, Maintaining Power* and *Resisting Power* in hospice palliative home care. Furthermore, institutional discourses have reflected and reinforced ideologies of gendered differences and an equalizing, gender-blind approach to hospice palliative home care. In this section, the (re)production of power relations are revealed through description of the gendered processes of *Regulating Gender Relations*, *Normalizing Gender Relations* and *Equalizing Gender Relations*.

      4.4.1 Regulating gender relations. *Regulating Gender Relations* was a way in which to control behaviours and actions of participants in hospice palliative home care. Mainly men and nurses regulated gender relations as they outlined roles and made unilateral decisions to serve self-interests to meet gendered expectations or system demands. *Regulating Gender Relations* was enacted through specific examples in which participants delegated roles and set boundaries.

      With intentions to enable death at home within a constrained system, nurses delegated care work to female caregivers, and anticipated a report from them. One nurse stated:

> That was one of the duties I gave [Terri, female caregiver] at the beginning when I got Rick's meds… And I [said], "You just need to let me know of any medications…..the changes or anything like that…" (Lori, nurse).

As nurses were *Asserting Power*, they were using their professional status to accord power and control over the female caregiver. Armed with biomedical knowledge, caregiving skills, and knowledge of the health care system, nurses were advantaged in

being able to influence the provision of care and how the female caregiver may be involved. Also, in an effort to meet system demands, nurses expected women to assess their ill relatives' conditions. Professional status then was an advantage that gave the nurse control over the home care situation. A more collaborative, relational family-centred approach to care would involve female and male caregivers in decision- making and include their preferences, capabilities, and decisions for involvement or non-involvement in the provision of care.

Nurses supported these regulating gendered actions by grounding this process in traditional gendered expectations that women are more inclined to care than men:

> Men on the whole have a hard time doing personal care for their parent or their wife but… there are always those exceptions that are fantastic. But on the whole… a 70/30 split maybe, women are better than men… as a caregiver, because they're more willing (Veronica, nurse).

Appealing to women's constraints to meet gendered expectations of taking responsibility for the health of the family and providing care (Angus, 1994; Armstrong & Armstrong, 2005; Glazer, 1990), nurses were able to delegate care with little resistance from women. In essence, nurses were *Asserting Power* and eliciting care work from female caregivers who complied with rather than resisted the delegated acts. This assertion of power was strategic in that it was used by nurses to meet client care needs and enable end-of-life at home within a resource-constrained system.

Nurses' enactments of regulating gender in hospice palliative home care were influenced by structural discourses of system constraints. Nurses transferred care work to women to meet system demands that required a limited number of visits. One nurse explained the demands of teaching care to family members in order to reduce the number of visits required:

> We try and teach [family members]…..Sometimes they're not willing to learn at all and… we just leave it in the case manager's hand, because we'll say, 'We've tried and tried and tried, and they're not willing to learn, and we're going to have to have more visits, we're going to need to give all the needles….'(Lori, nurse).

This nurse appealed to the government agency case manager for permission to provide the visits required. Additionally, the nurse implied that in receiving home care services, clients and family members would eventually learn and take over responsibility of care. One nurse interpreted the expectation of the agency for nurses to exert pressure on family members to be included in care:

> I always try to draw [the family member] in if they wish to [learn]. If they don't wish to, then I have to start looking at what can we do for this patient, because this patient needs back up. They need help through 24 hours - we're not there every day- and so then we have to try and force them to become included, and sometimes we will call the family member and say 'I'd like you to be there for that visit, I'm coming at this time.' And if they still won't, then we talk to the [case manager] (Veronica, nurse).

In hospice palliative home care in which extensive care is required at a time when numerous disease symptoms are manifested, nurses knew that a constant caregiver was needed to enable end-of-life at home. With little consideration of social contexts and working within a constrained system, nurses tended to delegate care to "willing" female caregivers who attempted to meet gendered expectations to care and thus avoid social censure.

A program document (Appendix I) echoed discourses of limited resources and familialism and revealed broader sociopolitical influences on nurses' daily gendered practices in hospice palliative home care. A program proposed to integrate services and improve continuity of care in hospice palliative home care has emphasized "value" in health care, or the highest quality care for the money spent (Appendix I). Employees have been encouraged to be creative and innovative in delivering care "efficiently." This

business model of cost-effectiveness has reverberated to front-line nurses to be prudent in the allocation of resources. In order to compensate for the limited services available, as illustrated by the preceding interview, nurses tended to transfer care to women, whom they perceived as experienced and willing. Under social constraints to meet gendered expectations to assume responsibility of health of their family members (Angus, 1994; Armstrong & Armstrong, 2005; Glazer, 1990), female caregivers had little choice.

The gendered process of *Regulating Gender Relations* within the family unit revealed that male caregivers were *Asserting Power* by assuming a primary decision-making role (Angus, 1994; Armstrong, & Armstrong, 2005). As head of the household, Jeff made the final decisions: Well, that's just me. It's just the way I was brought up. I'm a decision-maker. I can make her decision, no problem, if she can't (Jeff, caregiver). While Jeff made the decisions, he "permitted" his wife, Janet, to decide on future treatment. Janet resisted power over decisions related to her own body and stated, "Jeff doesn't want to lose me and I don't want to be gone, but only what I can take is what I'm going to do." Barb also resisted power when she covertly sought professional advice from a lawyer regarding the will:

> My husband was telling me that he shredded the will and that we didn't have a will….I wanted to see… what's in the will. "I don't remember" he said, and he always said he had shredded it and we didn't have a will. And so [the social worker] sat there one day and she said to him, "Gerry, if you have a will, let her see it. Let her have peace of mind"….. So, [later], I went to the lawyer… and I went to the bank without him knowing, and I feel okay with what I did (Barb, client).

Gerry actively was *Asserting Power* to maintain control while, in contrast, Barb and Janet were reservedly *Resisting Power* of their husbands' regulating behaviour patterns. To terminally-ill wives, it was important to secure financial and physical control within the

limited time they had to live. Female clients in this study had to cloak their assertion of control and quietly claim their right to make decisions. By enacting this passive resistance, women maintained their non-dominant feminine role, and thereby reinforced men's controlling power over some aspects of their lives. As such, men had greater power over decision-making while ill women were vulnerable to this assertion of power. Although gendered power resistance was a way in which to push back on a controlling or assertion of power, women in this study resisted power passively, rather than assertively.

All participants regulated gender relations by setting boundaries. These set boundaries were made known to others verbally and through actions in an attempt to control what men and women could or could not do. These actions of *Asserting Power* also served to pre-empt any resistance, resulting in the maintenance of gendered differences in hospice palliative home care. Setting boundaries was enacted unilaterally without collaboration or accommodation to others.

Men set clear boundaries and assertively resisted boundaries set upon them. While Jeff would greet the nurse at the beginning and end of the home visit, he would not attend the visit at a time in which care activities would take place. He described his relationship with the nurses:

> Well, I bring the lady [the nurse] in and take her over and get the chart out and bring some of the bandages and… then, they talk and do their thing….I don't listen to [the nurses] at all…. I'm listening to the pain management doctor and I'm asking him what's going on, because I think he knows a lot more than the nurses, so it doesn't register to me, I just talk to the doctor (Jeff, the male caregiver).

Comparing the female dominated profession of nurses to physicians, a historically male dominated position and role, Jeff discounted the nurses' professional status. In using gendered language and describing the nurse as a "lady," Jeff invoked traditional notions

of male chivalry (Messner, Duncan, & Jensen,1993) and denoted the subordinate and dependent role of women. Moreover, in stating that the women "do their thing," Jeff differentiated care work and situated this role delineation within the women's domain. In this masculine display of *Asserting Power*, gender was used as a resource to dominate the professional status of the nurse, according the male caregiver control over what he would do or not do. The nurse was shut out by the domineering attitudes and actions of the male caregiver.

Another male caregiver verbally demarcated clear boundaries, proclaiming he was not going to give his wife needles:

> When [Barb] first had her surgery and came home from the hospital…she was on a needle, and they had to inject it every morning. They wanted me to do it rather than have the nurse come here all the time. They would show me how to load the needle… I said, "No. I don't like needles myself and I know I would not be very good giving a needle to somebody else." So I just said, "No. I won't do it' and that's all there was too it. They never gave me a hard time [about it]." (Gerry, male caregiver).

Notably, nurses did not resist the boundaries that men had set. In contrast, nurses gradually convinced women to provide care, casting aside or resisting any boundaries set by them. Melanie, the nurse, described the gradual transfer of care:

> [A woman]… doesn't have a lot of confidence in herself….They've already convinced themselves, "Well I can't do that…" and they need a lot more nurturing…. to help convince them: "You can do this. Watch us do it and we'll give you the time to practice." and… I will take [a subcutaneous port] with me and leave it there for a few days. I'll get the woman to just practice twisting it in …so that they really feel comfortable and say, "I can do this." And then when they feel comfortable with that, then you move to the next step. Because women are nurturers, I don't think they have as many boundaries. They sort of have the attitude, "If it has to be done, I have to do it. I do the cooking, I do the cleaning, I do the shopping, I look after the kids. If I have to learn to give needles or bandage a wound up, then that's what I'll do" (Melanie, nurse).

Thus, while women's "set" boundaries were resisted by nurses, assertions of power by men were left unchallenged. As men presented a more powerful force, and gender dominated over class or professionalism, nurses may have been reluctant to resist men's assertions. By "accepting" ideals of the traditional male associated with control and power, nurses' gendered actions contributed to the reinforcement of this cultural belief.

Women also regulated gender relations for their spousal caregivers. Female clients prevented their husbands from viewing any bodily signs of their illness. Janet concealed her hair loss and wound from her husband. During a home visit, the agency nurse and I were permitted to observe Barb's ostomy care, while Barb would not permit her husband to look. Her nurse described the situation:

> The day we went and she wanted me to look at that ostomy… she made Gerry (husband) stay in the other room. I mean Gerry could have looked at it just as easily. I told her whether it was red or not, because that's all she wanted to know… He could have looked at it, but she wouldn't let him (Veronica, nurse).

Female clients were *Asserting Power* and setting boundaries on how their husbands could participate in their illness experiences, and at times excluded men from taking part in the intimate aspects of care. Compared to permeable boundaries between female caregivers and nurses, women had set this boundary rigidly against men, thereby shaping and reinforcing gendered processes, perhaps emphasizing the compelling strength of the social appeal to meet cultural gendered norms.

4.4.2 Normalizing gender relations. In the process of *Normalizing Gender Relations*, gendered attitudes, beliefs, and practices, founded on sex differences, were generalized and accentuated. Gendered behaviours of clients, caregivers, and nurses became normalized as the gendered process of *Regulating Gender Relations* was left unquestioned. As home and care work traditionally fall under the woman's domain, the

normalization of gender relations negatively influenced female clients' and caregivers'

health care experiences.

Participants supported the regulating of gender by constructing women as natural

and inevitable caregivers. As one nurse stated:

> I think women are born nurturers….We are used to being moms and wives and…you are a doctor and a nurse to your children and a teacher and...I think women just tend to be more compassionate and more caring....it is just part of our nature (Melanie, nurse).

According to Lori, the transfer of care occurred spontaneously suggesting that women

taking responsibility for care was a natural phenomenon inherent to women's experiences

in hospice palliative home care:

> Terri just kind of took on [the responsibility for monitoring and administering medications] …as things have progressed. She is kind of looking at them and …every time there's a new medication… she lets us know the dosage and… we kind of re-evaluate things (Lori, nurse).

The cultural belief of women's "natural" propensity to care was used to legitimize the

transfer of care from the nurse to the female caregiver. There was little reason to question

nurses' actions of *Asserting Power* because normalizing meant that it was unusual for

women to refuse to provide care to their family members.

Another form of normalizing was depicted when nurses and female clients

expressed that men were "naturally" disinclined to provide personal care, exempting men

from the physical dimension of care work. One nurse stated:

> [W]e kind of expect the [male caregiver] to be the one, "If we need this, you go buy it." And even supplies and medications, a lot of times, men get more involved in that because they know they can't do the physical part (Melanie, nurse).

Nurses and female clients normalized men's caring work to include only instrumental

care such as driving to medical appointments and retrieving medical supplies and

medications. Also, female clients and nurses tended to believe that husbands could not

provide the intimate care required at end-of-life. One nurse believed that a female client

would spend her final days in hospice, because her husband was incapable of providing

intensive, end-of-life care:

> I don't think Carol wants to die at home…she wants to die in hospice, but they want her to stay home as long as Bob can do it. But… she knows it's going to be hard on him and that… it's going to be a difficult thing (Veronica, nurse).

Normalizing men's exclusion from intimate care work reinforced the artificial division of

labor in the home and therefore the (re)production of power relations.

Regulating Gender Relations was also supported by normalizing discourses in

public communication documents such as nursing agency pamphlets. For instance,

caregiving has been depicted as natural and rewarding:

> You may not see yourself as a caregiver, but rather as someone simply supporting a person who needs you. Providing support is especially natural if you are helping someone who means a lot to you. Seeing yourself in the role of caregiver acknowledges the important work you're doing (Appendix I).

The assumption of caring for family members during end-of-life at home has been

depicted as natural. As women are predominately associated with the family and home

(Angus, 1994; Armstrong & Armstrong, 2005; Glazer, 1990), they are affected by these

normalizing depictions, particularly if they feel unable to provide care as they internalize

gendered expectations (Ussher et al., 2013). In this way, the regulation of women's care

work by participants was reinforced by institutional discourses of normalizing. In turn,

this process of *Normalizing Gender Relations* thus (re) produced the power relations of

Asserting Power and *Maintaining Power* over women.

4.4.3 Equalizing gender relations. While holding essentializing attitudes and

beliefs of what men and women should do, or not do, clients, caregivers, and nurses

ironically also believed that gender was not in play in hospice palliative home care. A consequence of deeply embedded attitudes, beliefs, and practices, this contradiction in approaches has highlighted the non-reflexive nature of gender relations (Martin, 2006). In the gendered process of *Equalizing Gender Relations*, participants claimed to treat men and women the same, suggesting an assumption of ethical and just treatment of home care participants during this vulnerable time. Yet, clients, caregivers, and nurses continued gendered practices and deflected the consequences of gendered enactments and processes. In this context, the contradictory ideologies of simultaneously *Normalizing Gender Relations* and *Equalizing Gender Relations*, assisted in concealing gendered practices and *Maintaining Power*.

In caring for clients and caregivers, nurses considered each individual's situation and condition; yet, in introducing and teaching care practices, nurses also claimed to use the same approach to enlist male or female caregivers. Lori claimed:

> I have the same approach to everyone. If they're willing to do it [provide care]…. I approach it the same sort of way; each, everyone the same (Lori, nurse).

The ideal of equality has been adopted by nurses, permitting them to assume that there were no issues related to gender equity. As such, nurses were non-reflexive about gender relations, the gendered aspect of care work, and effects on health and care, thus maintaining the status quo in hospice palliative home care. As Veronica stated:

> I would teach whichever [family member] is there. If it was the wife that was sick, I'd be teaching that husband; if it was the wife or the mother that was sick and there isn't a husband and it's the son who is the primary care giver, I teach that son…I don't differentiate in any way. They all are capable people… and if that's the main care provider, that's the one who gets taught…..I present the cases on their need, not on their gender (Veronica, nurse).

This statement implied that the "need" of the dying client was a priority over gender equity in hospice palliative home care. Yet, nurses also assessed caregivers' willingness and abilities to learn and provide care:

> [We] assess their [the client's and caregiver's] ability to learn. …. It all depends on, not necessarily education… but also personal education and what you've been through, too. So we kind of try to take a whole roundabout way.... (Lori, nurse).

Given that women have provided child or elder care more than men, it may be that nurses focused on women as probable caregivers. The contradiction of claiming to practice in an equalizing manner, while simultaneously individualizing approaches and enlisting women further conceals gendered enactments. Ironically, under the guise of claiming to practice in a professional and ethical manner, nurses inadvertently supported gendered practices as they employed a "gender-blind" approach.

Furthermore, clients and caregivers perceived that nurses as professionals should treat all clients and family members the same, without consideration of a person's social advantage or disadvantage. Instead, clients and caregivers expected that the nurse practice in a gender-blind manner:

> [The nurse] is very professional. It wouldn't matter if I was green, yellow or anything else. That is the way she [practises]. (Bob, caregiver).

Participants assumed that "professionals" provided equal and individualized care, which left unquestioned nurses' tendencies to transfer care work to women. Women often faced limited choices and men potentially were denied opportunities to provide care as a result a lack of reflection of gender in the uptake and use of the gendered process of *Equalizing Gender Relations.*

A gender-blind approach was also reflected in program and public communication documents. In a program document (Appendix I) being instituted during the time of the

study, the hospice palliative home care client was referred to as the "individual." Developed for decision-makers, agency employees, and other community sources to address a difficult-to-navigate system, this program did not identify the individual by gender or by role; that is, individuals were not considered caregivers, or men or women, or spouses, wives, husbands, daughters, or sons. The individual was considered a person without a gendered identity, personal or employment relations, and with few ties and obligations (Acker, 2012). There was no family context to this individual or consideration of gender even though it has been mostly women who provide care and take responsibility for the health of the family (Armstrong & Armstrong, 2005; Decima Research Inc., 2002; Glazer, 1990). Furthermore, it has been mostly women who have been underemployed and therefore are primarily considered available and most suitable to provide care. In other words, although female caregivers have assumed the majority of care, there has been little consideration given to them, rendering women's care work invisible. In this context of a gender-blind approach, the conditions, the health risks, or the complicated care tasks taken on predominately by women also have been hidden (Armstrong et al., 2003), thus setting additional hurdles for a group already disadvantaged. Furthermore, a gender-blind approach underpinning policies and shaping everyday practices only served to conceal and reinforce gendered processes.

4.5 Discussion

This critical ethnographic study has uncovered the gendered processes of *Regulating Gender Relations*, *Normalizing Gender Relations*, and *Equalizing Gender Relations.* A gender-based analysis examining the dynamic interactions within the triad of the client, family caregiver, and nurse has illuminated gender processes and how they are

integral to maintaining gendered attitudes, beliefs, and practices, shaping health care experiences, and therefore health, in hospice palliative home care. Furthermore, an understanding of how cultural and political influences shape gendered processes and strategies in this context has provided important insights. These findings illuminate several recommendations with respect to future research, education, policy, and practice.

In this study, ideological gendered attitudes, beliefs, and practices were often hidden by processes endorsing the notion of equality, leading to a deflection and lack awareness of the gendered processes in everyday hospice home care interactions. Similar to organizational gender studies (Acker, 2012), this lack of reflection leads to unexamined gender relations and a gender-blind approach in which it is believed that gender plays no influential part in day-to-day activities. In this context, gendered processes have been masked and made invisible (Acker, 2012), as they have become deeply embedded in everyday interactions, maintaining the gendered division of care work and blocking any form of condemnation or resistance (Martin, 2006). A non-reflexive approach to gender relations results in "doing" gender unconsciously and may explain why people like nurses who have good intentions may in fact cause harm (Martin, 2006).

Given this lack of reflection of gender relations, an acknowledgement of gender relations is needed in professional education of health professionals. Gender relations should be understood beyond categorical differences between men's and women's identities and roles to the dynamic interactions between and among men and women (Connell, 2012). This approach takes into account how men and women interrelate and influence opportunities and constraints in health and care (Schofield et al., 2000). The concept of gender relations also includes the interactions between sociopolitical structures

and how men and women are daily affected by them. Thus, gender relations must be viewed as an influencing factor that shapes health experiences and potentially (re)produces gender inequities (Connell, 2012).

Within this relational approach to gender relations, professionals need education and direction regarding engagement of ongoing reflexivity in order to check their assumptions and beliefs related to gender and equity. Reflection is viewed as an essential tool in nursing for continuing competency (College of Nurses, 2014). Through reflection upon significant situations, nurses identify their strengths and learning gaps (College of Nurses, 2014). However, alongside an inward focus, there also should be deliberate mindfulness of how self relates to, and affects others, emotionally, politically, personally, and professionally. Equally important, health professionals must have an awareness of how their own social locations create and sustain power to influence interactions and reproduce inequities (Boutilier & Mason, 2004).

As equity, ethics, and human rights are core values central to nursing (Canadian Nurses Association, 2008), then nursing education and practice of gender relations must be supported by professional documents. There is a need for nursing organizations to revisit gender relations. Nursing organizations actively critique gendered images of nurses in the media (Summers, 2014); however, there is little evidence of reflection upon nurses' own enactments of gender relations and how these may contribute to creating inequities in the delivery of health care. In this light, there also is a need to conduct research using a gender relational approach to better inform professional standards and practices. More research that examines how social relations such as gender affect

experiences and how health care providers can address these social factors to achieve equity in health and health care are needed.

Additionally, professional documents from nursing organizations (e.g., Standards of Practice: Ethics) tend to promote the concept of equality (Abrums & Leppa, 2001; Reimer Kirkham & Browne, 2006), a neoliberal ideology that originates from beliefs that individuals should be self-sufficient and therefore should be treated equally. Rather than viewing social conditions as forces that shape experiences, in a neoliberal concept of equality, the individual is seen as responsible for his or her own health and care without consideration of the context of social conditions that enable or limit individuals. In comparison, equity provides fair opportunities for health, which may mean the allotment of additional resources to those who are disadvantaged (Doyle, 2000; Chang, 2002). The endorsement of the same treatment for everyone, as seen in this study, may exclude those who are disadvantaged from achieving well-being. Thus, a critical examination of policy processes and recognition of the values that underpin them (Reutter & Duncan, 2002) needs to be included in the nursing professional documents and nursing curricula.

Nursing curricula that include knowledge of politics and political advocacy will better prepare nurses to question philosophies that counter nursing's social justice mandate (Falk-Rafael, 2005). A focus on policy advocacy entails a shift in thought from a focus on individual health issues to a social determinants of health perspective that highlights the social contexts that shape opportunities for health and health care (Reutter & Duncan, 2002). As social structures produce and reinforce values that organize everyday gendered practices, gendered social systems need to be considered in order to identify and challenge issues of gender equity (Connell, 2012; Ridgeway & Correll,

2004). Nurses are unable to exercise their responsibility for advocacy because they have not been exposed to the knowledge and tools to do so. Also, nurses and nursing students tend to focus on individual care and health care policy rather than public policy (Falk-Rafael, 2005; Reutter & Duncan, 2002). The relevance of policy processes and the roles of communities, professional organizations, and coalitions need to be included in nursing education (Reutter & Duncan, 2002). More specifically, nursing education should include practicum experiences that expose students to policy development in the different levels of government and citizen and professional groups (Reutter & Duncan, 2002). Policy advocacy should move beyond the domain of public health nurses and include nurses in all areas in order to take advantage of a collective voice (Falk-Rafael, 2005) and further drive change and advocacy towards social justice.

Nursing remains largely focused on care of the individual client (Reutter & Duncan, 2002) despite the promotion of a social justice agenda in nursing documents (e.g., "Social Justice, A Means to an End, an End in Itself") that advances the understanding and challenging of inequities. Nurses are well positioned for social advocacy, working within the context of relationships and ethical and philosophical frameworks that promote equity (Falk-Rafael, 2005). As health care professionals working in the front-lines, nurses witness the sociocultural and political effects of day-to-day health care encounters and can identify the health issues and needs of men and women (Falk-Rafael, 2005).

Similarly, program and public communication discourses couched within neoliberal ideologies of individualism and familialism have invoked gendered cultural norms through the idealization of caregiving as natural and rewarding. Other studies have

reported that family members often agree to take on the caregiver role under the perception that home is an ideal place for death in which a loved one peacefully dies (Stajduhar et al., 2003; Topf , Robinson, & Bottorff, 2013). Many caregivers have assumed the caregiver role with little knowledge of the complexities and challenges of caregiving during end-of-life (Linderholm & Friedchsen, 2010; Stajduhar et al., 2008; Topf et al., 2013). This study has enriched and expanded these findings in revealing how institutional discourses of familial ideologies have shaped "normative" caregiving notions within the home, which naturalize gendered care work, and neglect to consider the gendered processes involved in this type of care work. Instead of idealizing family caregiving, informational pamphlets should reflect the realities and challenges of care work to fully inform and support caregivers, who are predominately women. In order to address support needs, and mobilize the resources and services available, men's and women's contribution to care work at home must be recognized and integrated in all levels in the development of end-of-life home care policies. Furthermore, more research is required that include men's and women's voices and determine their needs.

Findings from this study also have revealed the use and abuse of the power associated with gender relations. While gender relations in hospice palliative home care were shaped by conflicting powers of assertion and resistance, female clients and caregivers did little to oppose assertions of power by men and nurses. The imbalance of power may be more prevalent in this context because of the vulnerable positions of clients and caregivers. However, reflective of findings from other studies (Clemmer et al., 2008; Glazer, 1990; Ward-Griffin et al., 2012b), socio-cultural beliefs that naturalize women to be family caregivers have placed heavy constraints on women to enact gendered norms.

In this study, nurses faced little resistance when delegating care work to women because of high expectations for women to provide care. Similarly, Oudshoorn et al., (2007) found that clients responded passively to the domineering power of nurses in home care. In this study, there was evidence of a "passive" resistance; for instance, a female client opposed her husband's wishes by arranging her will and finances without his knowledge. While a passive resistance at the individual level may be considered necessary to generate a collective response, this also may be viewed as accommodating those in dominant positions (Hollander & Einwohner, 2004). Power and resistance have been shown to be complex, social, and interactional constructions that involve people expressing, resisting, and observing power (Hollander & Einwohner, 2004). As end-of-life is a vulnerable time period, more research is needed that includes an exploration of power relations. Furthermore, research is needed that permits elicitation of subjective data as well as observations of interactions to enable investigation of the dynamic and complex qualities of power and resistance. In particular, a better understanding is needed of women's resistance to social constraints to enact gendered expectations and assume care work.

Finally, study findings have provided insight into how gender relations interact with other social relations to affect experiences. In relationships between nurses and women, professional status was dominant over gender relations, making it easier for nurses to delegate care to women. In contrast, the professional status of the nurse was overpowered by men's gender status, advantaging men to dominate and control situations. To date there has been no research found that has examined the influences of intersecting social relations of clients, caregivers, and providers in this context. The methodology of intersectionality is consistent with a social determinants of health

approach of examining social determinants such as gender, ethnicity, or class that shape health and health care experiences (Graham, 2004; Hankivisky & Christoffersen, 2008). This methodology is important to provide a comprehensive analysis of the ways in which dominant and subordinate relationships are (re)produced, thus presenting relevant strategies for redressing intersecting multiple inequities (Dhamoon & Hankivsky, 2011).

4.6 Conclusion

The examination of gendered processes in hospice palliative home care has revealed that contradictory ideologies were used and interpreted by participants to regulate gender relations. Embedded within gendered processes were power relations that reinforced the reproduction of gendered enactments. Furthermore, day-to-day gendered interactions were influenced by institutional discourses promoting ideologies of individualism and familialism. Gendered processes afford differential opportunities, rewards, and risks and must be exposed and understood to promote gender equity. This study has provided insights and recommendations to strive towards gender equity and therefore quality hospice palliative home care.

4.7 References

Abrums, M. & Leppa, C. (2001). Beyond cultural competence: Teaching about race,
gender, class and sexual orientation. *Journal of Nursing Education, 40* (6), 270-
275.

Acker, J. (2012). Gendered organizations and intersectionality: problems and
possibilities. *Equity, Diversity and Inclusion*. 31 (3), 214-224. doi:
10.1108/02610151211209072

Ando, M., Morita, T., O'Connor, S. (2007). Primary concerns of advanced cancer patients
identified through the structured life review process: A qualitative study using a
text mining technique. *Palliative & Supportive Care, 5*, 265-271. doi:
10.1017/S147895507000430

Angus, J. (1994). Women's paid/unpaid work and health: Exploring the social context of
everyday life. *Canadian Journal of Nursing Research, 26* (4), 23-42.

Armstrong, P. & Armstrong, H. (2005). Public and private: Implications for care work.
The Sociological Review, 53 (s2), 167-187. doi: 10.1111/j.1467-
954X.2005.00579.x

Armstrong, P., Boscoe, M., Clow, B., Grant, K., Pederson, A., Willson, K., Morrow, M.
(2003). *Reading Romanow: The implications of the final report of the commission
on the future of health care in Canada for women*. (Report by the National
Coordinating Group on Health Care and Reform and Women) Retrieved from:
www.womenandhealthcarereform.ca/publications/reading-romanow.pdf

Atkinson, P., & Hammersley, M. (2007).*Ethnography: Principles in practice*
(3rd ed.).New York: Routledge.

Bolton, S. (2005). Women's work, dirty work: The gynaecology nurse as 'other.' *Gender, Work and Organization, 12* (2), 169-186. doi: 10.1111/j.1468-0432.2005.00268.x

Boutilier, M., & Mason, R. (2012). The reflexive practitioner in health promotion: From reflection to reflexivity. In I. Rootman, S. Dupere, A. Pederson, & M. O'Neill (Eds.) *Health promotion in Canada: Critical perspective on practice* (pp. 196-207). Toronto: Canadian Scholars' Press Inc.

Braun, M., Mikulincer, M. Rydall, A., Walsh, A., Rodin, G. (2007). Hidden morbidity in cancer: spouse caregivers. *Journal of Clinical Oncology, 25* (30), 4829-4834.doi: 10.1200/JCO.2006.10.0909

Brazil, K., Howell, D., Bedard, M., Krueger, P., & Heidebrecht, C. (2005).Preferences for place of care and place of death among informal caregivers of the terminally ill. *Palliative Medicine, 19*, 492-499

Brazil, K., Thabane, L., Foster, G., & Bedard, M. (2009). Gender differences among Canadian spousal caregivers at the end of life. *Health and Social Care in the Community, 17* (2), 159-166. doi: 10.1111/j.1365-2524.2008.00813.x

Brown, M. (2004). Between neoliberalism and cultural conservatism: spatial divisions and multiplications of hospice labor in the United States. *Gender, Place and Culture, 11* (1), 67-82. doi:10.1080/0966369042000188558

Burridge, H., Barnett, A., Clavarino, A. (2009) The impact of perceived stage of cancer on carers' anxiety and depression during the patients' final year of life. *Psycho-Oncology. 18*, 615-23.doi: 10.1002/pon.1435

Canadian Cancer Society's Steering Committee on Cancer Statistics (2011). *Canadian Cancer Statistics 2011*. Toronto, ON: Canadian Cancer Society.

Canadian Hospice Palliative Care Association [CHPCA] (2013). *A model to guide hospice palliative care.* Retrieved from http://www.chpca.net/media/319547/norms-of-practice-eng-web.pdf

Chang, W. (2002). The meaning and goals of equity in health. *Journal of Epidemiology and Community Health, 56*, 488-491.

Chapman, K., & Peplar, C. (1998). Coping, hope and anticipatory grief in family members in palliative home care. *Cancer Nursing, 21*, 226-234.

Clark, S., Booth, Velikova, G., & Hewison, J. (2006). Social support: gender differences in cancer patients in the United Kingdom. *Cancer Nursing, 29* (1), 66-72. Retrieved from: http://ovidsp.tx.ovid.com.proxy1.lib.uwo.ca/sp3.10.0b/ovidweb.cgi?&S=BNHCFPIOHMDDLKCANCNKJDDCLEHIAA00&Link+Set=S.sh.37.38.42.48%7c12%7csl_10

Clemmer, S., Ward-Griffin, C., & Forbes, D. (2008). Family members providing home-based palliative care to older adults: The enactment of multiple roles. *Canadian Journal on Aging, 27 (3)*, 267-283.

College of Nurses of Ontario (2014). The importance of being reflective. *The Standard*. Retrieved from http://www.cno.org/en/learn-about-standards-guidelines/magazines-newsletters/the-standard/the-standard-may-2014/the-importance-of-being-reflective/

Connell, R. (2012). Gender, health and theory: Conceptualizing the issue, in local and
world perspective. *Social, Science, & Medicine, 74*, 1675-1683.

Davison, C., & Edwards, N., Webber, J., & Robinson, S.(2006). Development of a social
justice gauge and it use to review the Canadian Nurses Association's Code of
Ethics for registered nurses. *Advances in Nursing Science, 29* (4), E13-E26.
Retrieved from:
http://ovidsp.tx.ovid.com.proxy1.lib.uwo.ca/sp3.10.0b/ovidweb.cgi?&S=BNHCF
PIOHMDDLKCANCNKJDDCLEHIAA00&Link+Set=S.sh.22.23.26.29%7c10%
7csl_10

Dhamoon RK, Hankivsky O. (2011) Why the theory and practice of intersectionality
matter to health research and policy. In: O. Hankivsky, (Ed.) *Health inequities in
Canada: Intersectional frameworks and practices.* (pp15-50). Vancouver: UBC
Press.

Decima Research Inc. (2002). *National profile of family caregivers in Canada.* Retrieved
from http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/202/-caregi-
interven/index-eng.php

DeMiglio, L., Dykeman, S., Williams, A., & Kelley, M. (2012). Evolution of palliative
care in Ontario: The impact of geography, funding, and advocacy. *Journal of
Rural and Community Development, 7* (4), 109-121.

Doyle, L. (2000). Gender equity in health: debates and dilemmas. *Social Science &
Medicine, 51*, 931-939.

Dumont, S., Turgeon, J., Allard, P., Gagnon. P., Charonneau, C., Vezina, L. (2006). Caring for a loved one with advanced cancer: Determinants of distress in family caregivers. *Palliative Medicine, 9* (4),912-921. doi: 10.1089/jpm.2006.9.912

Im, E. (2006). White cancer patients' perception of gender and ethnic differences in pain experience. *Cancer Nursing, 29* (6), 441-450.

Evans, J. (2002). Cautious caregivers: gender stereotypes and the sexualization of men nurses' touch. *Journal of Advanced Nursing, 40* (4), 441-448. doi: 10.1046/j.1365-2648.2002.02392.x

Evans, J., & Frank, B. (2003). Contradictions and tensions: Exploring relations of masculinities in the numerically female-dominated nursing profession. *The Journal of Men's Studies, 11* (3). Retrieved from: https://www-lib-uwo-ca.proxy1.lib.uwo.ca:2443/cgi-bin/ezpauthn.cgi/login?url=http://search.proquest.com.proxy1.lib.uwo.ca:2048/docview/222640838?accountid=15115

Falk-Rafael, A. (2005). Speaking truth to power: Nursing's legacy and moral imperative. *Advances in Nursing Science, 28* (3), 212-223.

Fisher, M. (2009). 'Being a chameleon: labor processes of male nurses performing bodywork. *Journal of Advanced Nursing, 65* (12), 2668-2677. doi: 10.1111/j136-2648.2009.05120.x

Funk, L., Stajduhar, K., Toye, C., Aoun, S., Grande, G. & Todd, C. (2010). Part 2: Home-based family caregiving at the end of life: a comprehensive review of published qualitative research (1998-2008). *Palliative Medicine, 24* (6), 594-607. doi:10.1177/0269216310371411

Glazer, N. (1990). The home as workshop: Women as amateur nurses and medical care providers. *Gender & Society, 4* (4), 479-499. Retrieved from: http://www.jstor.org/stable/189750

Graham, M., & Palmer, A. (2002). Gender difference considerations for individuals with laryngectomies. *Contemporary Issues in Communication Science and Disorders, 29*, 59-67.

Graham, H. (2004). Social determinants and their unequal distribution: Clarifying policy understandings. *The Milbank Quarterly, 82*,1, 101-124.

Greimel, E., Padilla, G., & Grant, M. (1998). Gender differences in outcomes among patients with cancer. *Psycho-Oncology, 7*, 197-206.

Grov, E., Dahl, H., Moum, T., & Fossa, S. (2005). Anxiety, depression and quality of life in caregivers of patients with cancer in late palliative phase. *Annals of Oncology, 16*, 1185-1191. doi: 10.1093/annonc/mdi210

Grunfeld, E., Coyle, D., Whelan, T., Clinch J., Reyno, L., & Earl, C. (2004). Family caregiver burden: Results of a longitudinal study of breast cancer patients and their principle caregivers. *Canadian Medical Association, 170* (12), 1795-1801. doi: 10.1503/cmaj.1031205

Hagedoorn, M., Buunk, B.P., Kuijer, R.G., Wobbes, T.., & Sanderman, R. (2000). Couples dealing with cancer: Role and gender differences regarding depressive symptoms and quality of life. *Psycho-Oncology, 9*, 232-242.

Hagedoorn, M., Sanderman, R., Bolks, H., & Tuinstra (2008). Distress in couples coping with cancer. *Psychological Bulletin, 134* (1), 1-30. doi: 10.1037/0033-2909.134.1.1

Hankivsky, O., & Christoffersen, A. (2008). Intersectionality and the determinants of health: a Canadian perspective. *Critical Public Health, 18* (3), 271-283.

Harding, T. (2007). The construction of men who are nurses as gay. *Journal of Advanced Nursing, 60* (6), 636-644. doi: 10.1111/j.1365-2648.2007.04447.x

Hollander J., & Einwohner, R. (2004). Conceptualizing resistance. *Sociological forum, 19* (4), 533-551.

Husain, A., Stewart, K., Arseneault, R., Moineddin, R., Cellarius, V., Librach, S., & Dudgeon, D. (2007). Women experience higher levels of fatigue than men at the end of life: A longitudinal home palliative care study. *Journal of Pain and Symptom Management, 33* (4), 389-397. doi: 10.1016/j.jpainsymman.2006.09.019

Jacobs-Lawson, J., Schumacher, M., Hughes, T., & Arnold, S. (2010). Gender differences in psychosocial responses to lung cancer. *Gender Medicine, 7* (2), 137-147. doi: 10.1016/j.genm.2010.03.002.

Johnson, J., & Repta, R. (2012). Sex and gender: Beyond the binaries. In J. Oliffe, & L. Greaves (Eds.), *Designing and conducting gender, sex, and health research* (pp 17-39). Thousand Oaks: SAGE Publications Inc.

Johnson, J., Greaves, L., & Repta, R. (2007). *Better science with sex and gender: A primer for health research.* Women's Health Research Network.

Jones, J., Cohen, R., Zimmermann, C., Rodin, G. (2010). Quality of life and symptom burden in cancer patients admitted to an acute palliative care unit. *Journal of Palliative Care, 26* (2), 94-102. doi

Keller, M., & Henrich, G. (1999). Illness-related distress: Does it mean the same for men and women? Gender aspects in cancer patients' distress and adjustment. *Acta Oncologica, 38* (6), 747-755.

Klemm, P., Hurst, M., Dearholt, S. & Trone, S. (1999). Cyber solace: Gender differences on internet cancer support groups. *Computers in Nursing, 17* (2), 65-72.

Kushner, K., & Morrow, R. (2003). Grounded theory, feminist theory, critical theory: Toward theoretical triangulation. *Advances in Nursing Science, 26* (1), 30-43. Retrieved from: http://ovidsp.tx.ovid.com.proxy1.lib.uwo.ca/sp 3.10.0b/ovidweb.cgi?&S=NHEFFPBMLBDDLKGKNCNKJCDCCGFIAA00&Link+Set=S.sh.22.23.26.29%7c10%7csl_10

Lather, P. (1995). The validity of angels: interpretive and textual strategies in researching the lives of women with HIV/AIDS. *Qualitative Inquiry, 1* (1), 41-68.

Linderholm, M., & Friedrichsen M. (2010). A desire to be seen: Family caregivers' experiences of their caring role in palliative home care. *Cancer Nursing, 33* (1), 28-37.

Lyons, A. (2009). Masculinities, femininities, behaviour and health. *Social and Personality Psychology Compass*, ¾, 394-412. doi: 10.1111/j.1751-9004.2009.00192x

Lofland, J., Snow, D., Anderson, L., & Lofland, L. (2006). *Analyzing social settings: A guide to qualitative observation and analysis* (4th ed.). Toronto: Thomson, Wadsworth.

McGuire, T., Dougherty, D., & Atkinson, J. (2006). Paradoxing the dialectic: The impact of patients' sexual harassment in the discursive construction of nurses' caregiving

roles. *Management Communications Quarterly, 19* (3), 416-460. doi: 10.1177/0893318905280897

McIllmurray, M., Thomas, C., Francis, B., Morris, S., Soothill, K., & Alhamad, A. (2001). The psychosocial needs of cancer patients: findings from an observational study. *Journal of Cancer Care, 10*, 261-269.

McMullin, J. (2010). *Understanding social inequality: Intersections of class, age, gender, ethnicity and race in Canada* (2nd ed.). Toronto: Oxford University Press.

McWilliam, C., Ward-Griffin, C., Oudshoorn, A. & Krestick, E. (2008).Living while dying/dying while living: Older clients' socio-cultural experience of home-based palliative care. *Journal of Hospice and Palliative Nursing, 10*(6), 338-349.

Martin, P.Y. (2006). Practising gender at work: further thoughts on reflexivity. *Gender, Work and Organization, 13* (3), 254-276. doi: 10.1111/j.1468-0432.2006.00307.x

Messner, M., Duncan, M.C., Jensen, K. (1993). Separating the men from the girls: the gendered language of televised sports. *Gender & Society, 7* (1), 121-137.

Milligan, F. (2001). The concept of care in male nurse work: an ontological hermeneutic study in acute hospitals. *Journal of Advanced Nursing, 35* (1), 7-16. doi: 10.1046/j.1365-2648.2001.01818.x

Mok., E., & Chiu, P. (2004). Nurse-patient relationships in palliative care. *Journal of Advanced Nursing, 48* (5), 475-483.

Mystakidou, K., Parpa, E., Panagiotou, I., Tsilika, E., Galanos, A., & Gouliamos, A. (2012). Caregivers' anxiety and self-efficacy in palliative care. *European Journal of Cancer Care, 22*, 188-195. doi: 10.1111/ecc.12012

Mystakidou, K., Tsilka, E., Parpa, E., Katsouda, E., Sakkas, P., Galanos, A., Vlahos, L.(2006). Demographic and clinical predictors of preparatory grief in a sample of advanced cancer patients. *Psycho-Oncology, 15*, 828-833. doi: 10.1002/pon.1029

Mystakidou, K., Parpa, E., Panagiotou, I., Tsilka, E., Galanos, A., & Gouliamos, A. (2013). Caregivers' anxiety and self-efficacy in palliative care. *European Journal of Cancer Care, 22*, 188-195. doi: 10.1111/ecc.1201

Oudshoorn, A., Ward-Griffin, C. & McWilliam, C. (2007). Client-nurse relationships in home-based palliative care: A critical analysis of power relations. *Journal of Clinical Nursing, 16*, 1435-1443. doi: 10.1111/j.1365-2702.2006.01720.

Ontario Home Care Association (2011). *Home care nursing in Ontario*. Retrieved from http://www.homecareontario.ca/docs/default-source/HHR/hc-nsg-in-ontario---mar-2011---final-rev.pdf?sfvrsn=8

O'Lynn, C., & Krautscheid, L. (2011). 'How should I touch you?': A qualitative study of attitudes on intimate touch in nursing care. *American Journal of Nursing, 11* (3), 24-31. doi: 10.1097/10.1097/01.NAJ.0000395237.83851.79

Payne, S., Smith, P., & Dean, S. (1999). Identifying concerns of informal carers in palliative care. *Palliative Medicine, 13*, 37-44.

Peleg-Oren, N., Sherer, M., & Soskolne, V. (2003). Effect of gender and the social and psychological adjustment of cancer patients. *Social Work in Health Care, 37* (3), 17-33. doi: 10.1300/J01v37n03_02

Perakyla, A. (2008). Analyzing talk and text. In N.K. Denzin and Y.S. Lincoln (Eds.), *Collecting and interpreting qualitative materials* (pp. 869-885) (3rd ed.). Thousand Oaks, CA: Sage

Pitre, N., Kushner, K., Raine, K., Hegadoren, K. (2013). Critical feminist narrative inquiry: Advancing knowledge through double-hermeneutic narrative analysis. *Advances in Nursing Science, 36* (2), 118-132. doi: 10.1097/ANS.0b013e3182902064

Prior, L., Hughes, D., Peckham, S. (2012). The discursive turn in policy analysis and the validation of policy stories. *Journal of Social Policy, 41* (2), 272-289. doi:10.1017/S0047279411000821

Pullen, A., & Simpson, R. (2009). Managing difference in feminized work: Men, otherness and social practice. *Human Relations, 62* (4), 561-587. doi: 10.1177/0018726708101989

Reutter, L., & Duncan, S. (2002). Preparing nurses to promote health-enhancing public policies. *Policy, Politics & Nursing Practice, 3* (4), 294-305. doi: 10.1177/152715402237441

Ridgeway, C., & Correll, S. (2004). Unpacking the gender system: A theoretical perspective on gender beliefs and social relations. *Gender & Society, 18* (4), 51-531. doi: 10.1177/0891243204265269

Rivera, H., & McMillian, S. (2010). Predictors of depression symptoms in hospice care. *Journal of Hospice & Palliative Nursing, 12* (6), 345-357. doi: 10.1097/NJH.0b013e3181f184f4

Salander, P., & Hamberg, K. (2005). Gender differences in patients' written narratives about being diagnosed with cancer. *Psycho-Oncology, 14*, 684-795. doi: 10.1002/pon.895.

Schofield, T., Connell, R., Walker, L., Wood, J., & Butland, D. (2000). Understanding men's health and illness: A gender relations approach to policy, research and practice. *Journal of American College, 48* (6), 247-256.

Schultz, R., & Beach, S. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *American Medical Association, 282*, (23), 2215-2219.

Seale, C. (2006). Gender accommodation in online cancer support groups. *Health An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine, 10* (3), 345-360. doi: 10.1177/1363459306064495 1363-4593

Simpson, R. (2009). *Men in caring occupations: Doing gender differently*. NewYork: Palgrave MacMillan.

Smith, D. (1987). The everyday world as problematic. Massachusetts: Northeastern Press.

Smith, D. (1992). Sociology from Women's Experience: A reaffirmation. Sociological Theory, 10 (1), 88-98. URL: http://www.jstor.org/stable/202020

Smith, D. (2005). Women's Standpoint: Embodied knowledge versus the Ruling Relations. *Institutional ethnography: A sociology for people* (pp. 7-26) Maryland: Alta Mira Press.

Stajduhar, K. (2003). Examining the perspectives of family members involved in the delivery of palliative care at home. *Journal of Palliative Care, 19* (1), 27-35.

Stajduhar, K., Funk, L., Roberts, D., Cloutier-Fisher, D., McLeod, B., Wilkinson, C., & Purkis, M. (2010). Articulating the role of relationships in access to home care nursing at the end of life. *Qualitative Health Research, XX* (X), 1-15. doi: 10.1177/104973231037114

Stajduhar, K., Nickel, D., Martin, W., & Funk, L. (2008). Situated/being situated: Client and co-worker roles of family caregivers in hospice palliative care. *Social Science & Medicine, 67*, 1789-1797. doi: 10.1016/j.socscimed.208.09.012

Summers, S. (2014). Changing how the world thinks about nursing. *Canadian Nurse*. Retrieved from http://www.truthaboutnursing.org/press/coverage/c/2014-01_canadian_nurse.pdf

Thomas, J. (1993). *Doing critical ethnography*. Newbury Park, California: Sage publications.

Thomas, J. (2003). Critical ethnography, meanings, and symbolic violence. In R.B. Clair (Ed.), *Expressions of Ethnography: Novel approaches to qualitative research* (pp 45-65). Albany: State University of New York.

Topf, L., Robinson, C., & Bottorff, J. (2013). When a desired home death does not occur: the consequences of broken promises. *Journal of Palliative Medicine, 16* (8), 875-880. doi: 0.1089/jpm.2012.0541

Torkelson, D., & Seed, M. (2011). Gender differences in the roles and functions of inpatient psychiatric nurses. *Journal of Psychosocial Nursing, 49* (3), 41. doi: 10.3928/02793695-20110201-02

Ussher, J., & Sandoval, M. (2008). Gender differences in the construction and experience of cancer care: The consequences of the gendered positioning of carers. *Psychology and Health, 23* (8), 945-963.

Ussher, J., Sandoval, M., Perez, J., Wong, W., & Butow, P. (2013). The gendered construction and experience of difficulties and rewards in cancer care. *Qualitative Health Research, 23* (7), 900-915. doi: DOI: 10.1177/1049732313484197

Ward-Griffin, C., McWilliam, C., Oudshoorn, A. (2012a). Negotiating relational practice patterns in palliative home care. *Journal of Palliative Care, 28* (2), 33-40. doi: 10.1177/1074840712462134

Ward-Griffin, C., McWilliam, C., Oudshoorn, A. (2012b). Relational experiences of family caregivers providing home-based end-of-life care. *Journal of Family Nursing, 18* (4), 91-516. doi: 10.1177/1074840712462134

West, C., & Zimmerman, D. (1987). Doing gender. *Gender & Society, 1* (2), 125-151.

West, C., & Zimmerman, D. (2009). Accounting for doing gender. *Gender & Society, 23* (1), 112-122. doi: 10.1177/0891243208326529)

Williams A., (2002). Changing geographies of care: Employing the concept of therapeutic landscapes as a framework in examining home space. *Social Science & Medicine, 55* (1), 141-154. doi: 10.1016/S0277-9536(01)00209-X

Williams, A. (2006) Restructing home care in the 1990s: Geographical differentiation in Ontario, Canada. *Health & Place, 12*, 222-238. doi: 10.1016/j.healthplace.2004.09.002

Wessels, H. DeGraeff, A., De Heus, M., Kruitwagen, C., Woltjer, G., Teunissen, S. &Voest, E. (2010). Gender-related needs and preferences in cancer care indicate the need for individualized approach to cancer patients. *The Oncologist, 15*, 648-655. doi: 10.1634/theoncologist.2009-0337

West, C., & Zimmerman, D. (1987). Doing gender. *Gender & Society, 1* (2), 125-151.

Whittock, M., & Leonard, L. (2003). Stepping outside the stereotype. A pilot study of the motivations and experiences of males in the nursing profession. *Journal of Nursing Management, 11*, 242-249. doi: 10.1046/j.1365-2834.2003.00379.x

5. Chapter Five: (Re)producing Gender (In)equities in Hospice Palliative Home Care

5.1 Introduction

Hospice palliative home care has become increasingly essential as the aging population has doubled to 5 million in the past 30 years, and is predicted to triple to 15 million by 2060 (Canadian Hospice Palliative Care Association [CHPCA], 2012). In addition to demographic trends, other social factors have arisen to heighten the demands of hospice palliative home care. For instance, Canadians have indicated a preference to die at home to avoid hospitals that have been perceived to be unsafe (Gravel et al., 2007; World Health Organization [WHO], 2011a) and offer little care and support that is sensitive to the needs during end-of-life (Stajduhar, Allen, Cohen, & Heyland, 2008; Stajduhar & Davies, 2005). Furthermore, because home care has been perceived to be cost-effective, policy makers have shifted care of the sick and dying from hospital to home (Armstrong & Armstrong, 2005).

Hospice palliative home care has been reported to be complex and encompassing both for family caregivers who often draw upon physical, emotional, and mental resources (Clemmer, Ward-Griffin & Forbes, 2008; McWilliam, Ward-Griffin, Oudshoorn, & Krestick, 2008; Funk et al., 2010; Ward-Griffin, Oudshoorn & Krestick, 2008; Ward-Griffin, McWilliam & Oudshoorn, 2012a, 2012b), and for clients, who have struggled to find meaning in their end-of-life experiences (McWilliam et al., 2008). Alongside providing emotional support and making critical care decisions, family caregivers have been asked to provide increasingly more advanced and technical treatments (Haley, 2003; Funk et al., 2010). While caregivers have experienced positive benefits and rewards in caring for terminally-ill family members (Funk et al., 2010; Jo,

Brazil, Lohfield, & Willison, 2007; Ussher, Sandoval, Perz, Wong, & Butow, 2013), many have experienced negative health outcomes (Stajduhar, Funk, Toye et al., 2010) and an increased risk of early death (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Funk et al., 2010; Schlutz & Beach, 1999). Often in fragile conditions and dependent on others to meet needs, both clients and caregivers frequently face challenges during this vulnerable time of end-of-life. However, because of clients' debilitating states, the emotional context of the caregiving relationship, and caregivers' strong moral feelings to care (Exley & Allen, 2007; Stajduhar & Davies, 2005), few clients and caregivers will see or challenge inequitable situations. In this context, it is vital to ensure that policies and practices in hospice palliative home care promote gender equity. As health is a critical condition of human functioning and capabilities (Sen, 2002) and a "resource for everyday life" (Ottawa Charter, 1986, para. 3), it is crucial to achieve equity in health and health care in order that all individuals, regardless of gender, class, or age, have opportunities to actualize their full potential.

Despite the recognition of end-of-life as a vulnerable time period (Funk et al., 2010; Ward-Griffin et al., 2012 a, 2012b), there has been little research to date that has investigated equity in hospice palliative home care. While there has been palliative research investigating the unequal distribution of material resources according to income (Burge, Lawson, & Dawson, 2003; Burge, Lawson, Johnston and Grunfield, 2008; Lewis, DiGiacomo, Currow, & Davidson, 2001; Tang & McCorkle, 2001; Walsh, Todd, Caress, & Chew-Graham, 2009), few studies have adopted a health promotion perspective that views the inequitable distribution of social resources as sources of inequities in health and health care (Raphael, 2012). For example, social locations such as gender have an impact

on the distribution of power and resources and therefore enhance or limit opportunities for optimal health and health care experiences (Raphael, 2012; Sen & Ostlin, 2008).

Gender relations also can have an impact on how health care providers express and respond to the health needs of men and women (Sen & Ostlin, 2008). In examining the role of relationships in access to hospice palliative home care, Stajduhar, Funk, Roberts, and colleagues (2010) found that nurses negotiated relationships, at times creating emotional distance with clients and caregivers to ensure that relationships did not lead to biased decisions and thus the inappropriate allocation of resources. While this study has highlighted the significance of social power relationships in shaping experiences and possible inequities, little is known of how gender and other social relations influence access to resources, decision-making power, or authority in the context of end-of-life.

Examining gender equity in hospice palliative home care is essential because home is an institution in which gendered practices have been learned and the unequal gendered division of labor has been exemplified (Armstrong & Armstrong, 2005; England, 2010; Glazer, 1990). Home has been conceptualized as a place of refuge, comfort, and intimacy; yet, home also has been a place of oppression, violence and tyranny (England, 2010; Glazer, 1990). The private spaces of home in which care takes place are largely hidden, potentially concealing inequities. Additionally, the experience of home has been influenced politically as policies have been developed to transfer care work from hospital to home (Armstrong & Armstrong, 2005). As men and women have the right to flourish, particularly in their homes where they are living, working, and dying, it is imperative to strive for gender equity in hospice palliative home care. The ultimate

aim of this critical feminist analysis of gender relations was to expose and explicate (in)equities experienced by men and women during the vulnerable time of end-of-life in hospice palliative home care. Alongside the growing aging population and the rising incidence and mortality rates of cancer among the elderly (Canadian Cancer Society, 2011), now is the time to promote equity in this context.

5.2 Theoretical Background

Inequities in health and health care have been defined as differences that are unnecessary and unjust (Whitehead & Dahlgren, 2006). These unfair differences are brought to question in the interest of social justice, the concern for equal distribution of resources of a society (Rawls, 1971). However, this distributive form of justice stems from an economical perspective in which individuals are afforded resources according to merit (Pauly, 2008; Pauly, MacKinnon, & Varcoe, 2009; Reimer Kirkham & Browne, 2006). For this study, I employed a "social determinants of health" perspective of equity in which social determinants such as gender are considered central to accessing resources and therefore positive health outcomes (Raphael, 2012). Access to resources involves the availability of services, as well as the ways in which services are delivered, such that health care providers convey respect and include people, rather than discriminate and exclude them (Pauly et al., 2009). From this critical health promotion perspective, optimizing the health of people necessarily involves equitable access to the social conditions that enhance health (Raphael, 2012). Such an approach requires examination of the allocation of material as well as non-material resources, which include political, social, and symbolic means that afford control, time for relaxation, or recognition of work

(Armstrong, 2009). These resources are often conferred through power relations such as gender, one of the most influential social determinants of health (Sen & Ostlin, 2008).

Gender is a social determinant of health that affects health and health care through cultural and social structures that construct gendered identities and roles. Culture constitutes the shared attitudes and beliefs of a group that validate the "what" and "why" of social norms and practices (Thomas, 1993). Social structures are organized relationships (Connell, 2009) comprised of institutions such as corporations, government bureaucracies, professional associations, or mass media that organize our everyday world (Smith, 1987, 2005). These broader social structures confer power and status and dictate responsibilities of home and work (Lorber, 1994). Such hierarchal relations constrain men's and women's attitudes and behaviours and thus obstacles to well-being (Doyle, 2000; Marmot, Friel, Bell, Houweling, & Taylor, 2008; Spitzer, 2005). In this context, an equity analysis must include examination of cultural and structural influences that may lead to the (re)production of gender (in)equities. Such an analysis is crucial to inform and guide policy development and promote strategies for gender equity. Furthermore, unless these issues are redressed, inequities may be worsened, creating intensified social injustices, particularly for those in potentially vulnerable situations, such as the clients and caregivers in hospice palliative home care.

The purpose of this critical analysis was to expose and explicate the socially constructed mechanisms that (re)produce gender (in)equities in hospice palliative home care for clients with cancer and their family caregivers. This analysis was part of a larger study examining gender relations in hospice palliative home care. Gendered expectations

and exemptions and the gendered processes in hospice palliative home care have been reported elsewhere (See Chapters Three and Four).

5.3 Literature Review

To date, no studies were found specifically examining gender inequities in hospice palliative home care for clients with cancer and their caregivers. While a few studies have examined client-family caregiver-nurse interactions, most have analyzed sex and gender differences in relation to either the client, family caregiver, or the nurse. This selected literature review has been categorized accordingly. Studies that have investigated all stages of the cancer illness trajectory and involve palliative and end-of-life have been included.

5.3.1 Gender equity and clients in hospice palliative home care. Most studies examining gender equity investigated gender differences related to access to material resources (Burge et al., 2003; Burge et al., 2008; Lewis et al., 2001; Tang & McCorkle, 2001; Walsh et al., 2009). To date, studies have not specifically examined equity in terms of social resources available for men and women with cancer in hospice palliative home care. However, studies have identified the potential for inequitable care of women and men. For example, women have reported more negative health care interactions (Clark, Booth, Velikova, & Hewison, 2006; Im, 2006). Women have reported that, because they were associated with childbirth and a high pain tolerance, health care providers did not take their pain seriously and failed to manage their pain adequately (Im, 2006). Another study has found that women were dissatisfied that emotional support was not consistently offered (Clark et al., 2006). Also, women, more than men, have reported using a wider social network that includes family members, friends and professions (Clark et al.;

Greimel, Padilla, & Grant, 1998; Keller & Henrich, 1999), suggesting that they may be offered less help because traditional beliefs that women should care for themselves and others. With regard to men, traditional notions that men are strong and independent may prevent them from discussing emotions and may exclude them from receiving emotional support that they may need (Clark et al., 2006.) These studies have pointed to possible gender inequities in relation to social and supportive resources; however, in order to identify the mechanisms that (re)produce gender (in)equities, more research that provides rich descriptions of gender (in)equities that transpire through everyday social interactions in hospice palliative home care is needed.

5.3.2 Gender equity and the family caregiver in hospice palliative home care. There has been evidence to indicate that men and women differ in the amount and type of care they give in home-based palliative care. In a qualitative study of 40 in-depth interviews with paid and unpaid caregivers, Brown (2004) found that women in home hospice carried out the hands-on physical tasks that involved bodily care, while men completed "distant" tasks such as the picking up of prescriptions and other supplies outside the home. Brazil, Thabane, Foster, & Bedard (2009) surveyed spousal caregivers (n=283) and reported that women had nearly twice the odds of providing toilet-related tasks as men (OR=1.98, p=0.044) and female caregivers involved in giving personal care had lower odds of receiving informal supports from family and friends (OR=0.17, p=0.002). However, male caregivers have reported role incongruence in terms of providing care for family members with cancer (Allen, 1994; Ussher et al., 2013). It may be that traditional gendered divisions of labor in the home influence the work that is expected of male and female caregivers. While these study findings suggest that gender

inequities may exist in hospice palliative home care, there is a gap in knowledge of the social and political contextual influences that contribute to potentially unfair situations related to gender.

One study explored health care providers' perspectives (n=50) of how the intersections of difference influenced experiences in palliative care (Giesbrecht, Crooks, Williams & Hankivsky, 2012). Health care providers expressed that men require more support in order to fulfill the caregiver role. Authors from this study suggested that this gendered bias may have affected the amount and type of supports allocated for men. While knowledge of health care providers' perspectives is valuable, interviews and observations of client-family caregiver-provider triad interactions are important to acquire a more in-depth analysis of the relationships and the social structures that shape gender (in)equities.

Other qualitative studies exploring experiences in hospice palliative home care have revealed how societal expectations have functioned to construct gendered roles (Clemmer et al., 2008; Ussher & Sandoval, 2008). In an interpretive ethnographic study, Clemmer and colleagues (2008) concluded that social ideologies of women's traditional roles led to family members' and health care providers' high expectations of women to assume responsibility for care. In a critical realist study (Ussher & Sandoval, 2008) involving 50 informal caregivers of clients in early and advanced stages of cancer, women were positioned as expert caregivers because of traditional beliefs that women were natural caregivers. While these studies have illuminated social gendered beliefs and attitudes that contribute to gender differences in expectations to provide care, little is known about how broader social factors such as institutional policies and discourses

influence gender differences in access to resources, quality of services, or decision-making power that may result in inequities in well-being. As political ideologies and structures shape how social resources are distributed, it is vital to include an analysis of political and institutional influences on gender (in)equities and strategize appropriate action for change.

5.3.3 Gender equity and nurses in hospice palliative home care.

There is an absence of studies in hospice palliative home care that examine nurses and gender relations. Studies have been retrieved from a variety of medical areas such as psychiatry and obstetrics. Findings have suggested that male nurses have practiced in an authoritative and distant manner (Fisher, 2009; Pullen & Simpson 2009) in response to cultural assumptions that male nurses are sexual predators (Evans, 2004; Evans & Frank, 2003; Fisher, 2009; O'Lynn & Krautscheid, 2011). These evasive behaviours may potentially deny male nurses the opportunity of developing a type of relational practice. Additionally, because of these discriminatory attitudes, men and women in hospice palliative home care may be denied the compassionate care needed during vulnerable times. With regard to female nurses, negative gender relations of sexual harassment have led nurses to distance themselves from men (McGuire, Dougherty, & Atkinson, 2006). It may be that female nurses' relationships with men are kept at a distance in order to prevent sexually harassing behaviours, potentially denying male client and caregivers' access to care. These studies have examined gender relations from the perspective of nurses. Examination of the dynamics of gender relations between and among clients, family caregivers, and nurses will not only elicit rich descriptions, but since gender is a

co-construction among people and structures, this analysis also will provide a broader contextual understanding of how gender (in)equities occur.

In summary, an examination of the social dynamics of gender relations between and among clients, family caregivers, and nurses in hospice palliative home care is important to provide context and rich knowledge to promote greater understanding of the social conditions that shape gender (in)equities. This is consistent with a social determinants of health approach that includes an analysis of the cultural and structural factors that (re)produce (in)equities in health and health care and is important to inform policies and practices for change. As clients and caregivers face overwhelming physical, emotional and spiritual challenges during end-of-life (Clemmer et al., 2008; Funk et al., 2010; McWilliam, et al. 2008; Ward-Griffin et al., 2012a, 2012b), it is imperative to strive towards gender equity during this vulnerable period in hospice palliative home care.

5.4 Methods

As it is important to examine the structural influences (e.g., institutional policies and practices) that (re)produce gender (in)equities in everyday hospice palliative home care, Dorothy Smith's (1987; 2005) critical feminist perspective was used. Smith's emphasis on the impact of structural influences on the everyday lives of individuals permitted a framework through which to critically examine how governments and nursing agencies could influence gender relations and therefore the allocation of resources during end-of-life in the home. As Smith's (1987, 2005) critical feminist perspective is concerned with the construction of dominant and subordinate relations, I also considered

how other social determinants such as age and class affect health and health care experiences.

A critical ethnographic methodology informed by Thomas (1993, 2003) was employed to uncover gendered attitudes, beliefs, and practices in the culture of hospice palliative home care. Ethnographic methods of in-depth interviews alongside observations of non-verbal expressions and gestures were appropriate to capture the dynamics of gender relations (Atkinson & Hammersley, 2007). Review of program, public communication, and professional documents provided a broader social context of the institutional influences on everyday gender relations (Smith, 1987).

5.4.1 Recruitment and sample. Case managers who assess and manage home care clients in government home care agencies approached potential senior clients with cancer and family caregivers and asked if they would be interested in participating in the study. If interested, the client, the corresponding family caregiver, and primary nurse of the home care triad were contacted. Clients were over the age of 60 years and enrolled in the palliative care program, thus receiving care focused on quality of life rather than cure. Three female and three male clients were recruited, ranging in age from 64 to 82 years (See Appendix E). Caregivers were spouses of the clients with the exception of one man who was divorced, identifying neighbours as his caregivers. Since two nurses cared for more than one client, a total of four female nurses were recruited. Ranging in the age from 30 to 59 years, two nurses earned college diplomas and two completed university degrees, while all four nurses received additional palliative care training. Two nurses were employed part-time and two nurses worked full-time hours. All participants were

Caucasian. Ethics approval was obtained from Western University and the regional government agency Research Ethics Review Board.

5.4.2 Data collection. Spending 127 hours in the field, from April 2012 to August 2013, I conducted in-depth interviews (n=25), observations of agency nurse home visits (n=9) and review of documents (n=12). To manage the data, which includes the numbering, coding, filing, and retrieving of data, I entered all interview transcripts, fieldnotes, and documents into NVivo software.

In an attempt to capture the dynamics of gender relations, I initially conducted three joint interviews with clients and caregivers. However, the remaining 22 interviews were conducted individually to permit participants to speak freely, without feeling constrained by the presence of another person (Atkinson & Hammersley, 2007; Taylor & deVocht, 2011). Interviews lasting approximately 50 to 90 minutes were audiotaped and transcribed verbatim. To elicit information-rich data, I asked open-ended questions such as "Do you think being a man/woman affected your experience, and if so, how?" As may be expected in end-of-life research (Jo, Brazil, Lohfeld, & Willison, 2007), three clients became too ill and strained to continue, resulting in only one interview for three triads, each consisting of the client, family caregiver and nurse. I was able to return to the remaining three triads to conduct more than one interview, permitting participants to reflect on gender relations. I was therefore able to refine analysis through comparison of responses and co-construct understandings (Guba & Lincoln, 1989; Lather, 1995).

In the natural environment of everyday hospice palliative home care, I observed nine home visits by the agency nurse. This allowed me to contextualize the interactions between and among men and women and capture relational patterns and power

differentials for a better understanding of gender relations (Atkinson & Hammersley, 2007). Similar to the interviews, only one home visit was made with three triads and three home visits for two triads. As soon as it was possible, I wrote observations in the form of fieldnotes for analysis.

As is consistent with an ethnographic study, I also conducted a review on program, professional, and public communication documents (Appendix I). Public communication documents were retrieved from agencies in which nurses were employed. This analysis was important as institutional documents reflect the culture of the organization, shape everyday attitudes, beliefs, and practices (Perakyla, 2008; Smith, 1992), and echo the political background and context within which they are written.

5.4.3 Data analysis. I used Lofland, Snow, Anderson and Lofland (2006) to guide my analysis. Through an iterative process, I read transcripts line-by-line to generate initial codes. To develop and collapse themes, I categorized, compared, and contrasted codes. Using all data sources to compare and contrast emerging themes, I also attempted to characterize them, noting when, how, and who were involved. I conceptualized relationships between and among themes through the use of diagramming (Lofland et al., 2006). Throughout analysis, I used a critical lens to note gendered assumptions, roles, and power, and how gender was depicted and received. I identified any contradictions or power imbalances, and asked 'who is best served?' or 'who is disadvantaged?' by this situation. I also questioned taken-for-granted gendered actions or behaviours. I scrutinized my own perspectives and gendered biases and assumptions by writing in a journal throughout the study. Program, public communication, and nursing professional documents were examined for the purpose, presuppositions, timing, content

(inclusions/exclusions), and the intended audience. Consistent with a critical perspective, I was attentive for dominant discourses that may be used to downplay, understate, or/and reinforce power. I also noted the significance of how people were categorized.

5.5 Findings

A gender-based analysis has illuminated gendered expectations and exemptions, gendered processes and the mechanisms that (re)produce gender (in)equities (Figure 2. Yellow Subsection). In this section, I focus on the two integral socially constructed mechanisms of gender (in)equities in hospice palliative home care: *Preservation/Destruction of Gender Stereotypes* and an *Imbalance/Balance of Power*. As stereotypes are widely shared cultural beliefs and ideas about persons or things, gender stereotypes constitute the norms and rules of how men and women should look, feel, and behave (Ridgeway & Correll, 2004). Regarding the second mechanism, power is a force that influences one's control and creates differences in opportunities and limitations for well-being (Davison, Edwards, Webber, & Robinson, 2006; Lyons, 2009; McMullin, 2010). The mechanisms related to gender stereotyping and power were not mutually exclusive, and instead were dynamic, often occurring simultaneously, influencing and reinforcing one another. The dialectic movement within each mechanism of *Preservation/Destruction of Gender Stereotypes* and *Imbalance/Balance of Power* also was dynamic, the movement within each category influenced by broader social contexts. While there were glimpses of gender equity in this study, gender inequities were predominant. Gender stereotypes and power imbalances obstructed well-being, as conditions were created in which there were limited choices, exclusion, and undue strain

for both men and women in this context. The following subsections illuminate these two mechanisms.

Figure 2. Yellow Subsection: (Re)producing Gender (In)equities in Hospice Palliative Home care
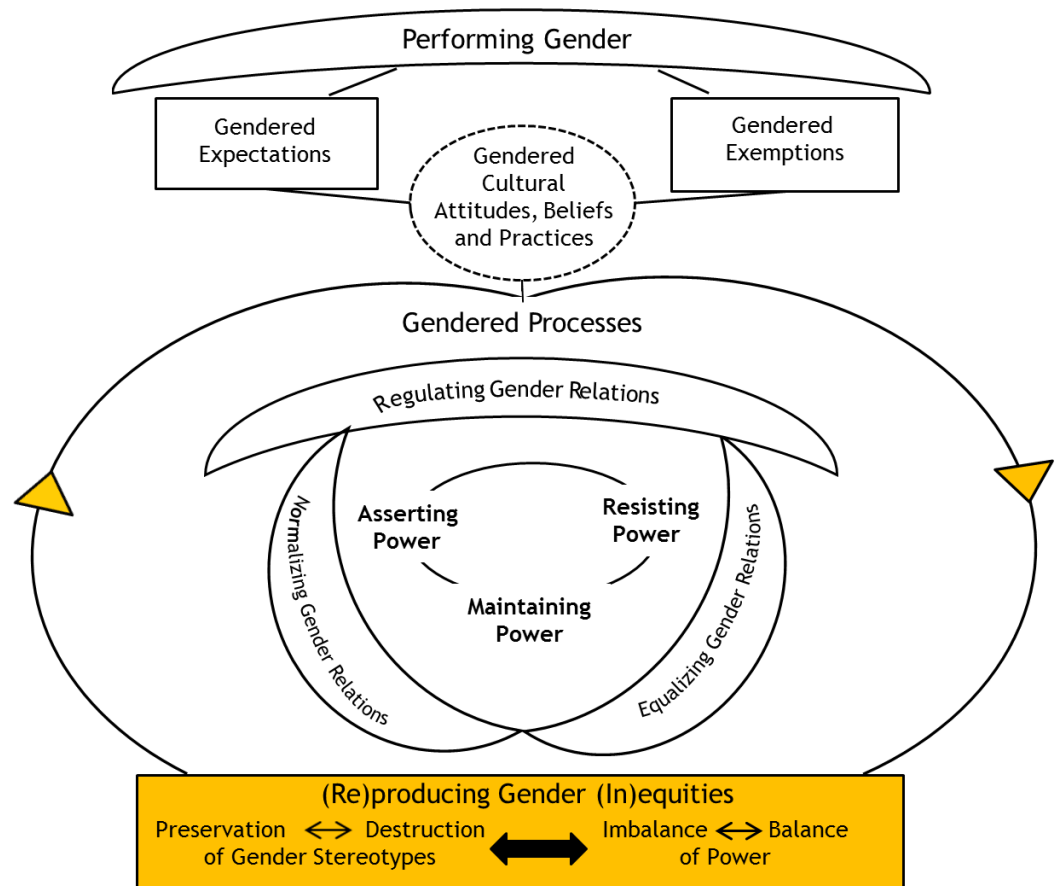
5.5.1 Preservation/destruction of gender stereotypes. (Re)production of gender inequities in hospice palliative home care were shaped by the gender stereotyping of men's and women's expected roles and behaviours. Nurses expressed their attitudes and beliefs of women's roles as caregivers. A nurse stated, "The woman palliative patient is more concerned with protecting the husband because women are generally the nurturers.

So, women are going to be worried about their husbands" (Veronica, nurse). With stereotypical beliefs that women possess innate caring qualities, nurses had a tendency to expect that women, rather than men, would assume responsibility of care for ill relatives. In contrast, participants largely dismissed men's lack of natural caregiving qualities. One participant stated:

> I think men don't have the compassion, or they don't have the patience or the know-how on how to be a caregiver. And I'm not too sure men would even be able to understand what one is going through (Stan, client).

Viewing men as naturally disinclined to care meant opportunities for participants to exempt men from care activities. Men's exclusion from care activities constituted a gender inequity that disadvantaged both men and women, as female clients and male caregivers missed chances for finding intimacy and meaning during the stage of end-of-life.

As men were perceived to be disinclined to caregiving, they also were characterized as providers working outside the home. A male client stated:

> I probably was never the caregiver that [my wife] has been. I traveled a lot, and not that I would travel if she was ill, badly ill, but if she had the flu or something like that, then I tried to look after her, but what I did was very limited. I don't know how to cook …. I probably wouldn't be able to offer her the same care as she would offer me. (Stan, male client).

Separating the private home that was associated with caring from the public world, this male client reinforced stereotypical gendered attitudes, beliefs, and practices.

The gender stereotyping of male and female ascribed attitudes, beliefs, and practices by men and nurses further reinforced gender inequities as female clients and caregivers were constrained to act within socially ascribed feminine roles. Although feeling ill, female clients contributed to this construction of gender inequities, as they

found it difficult to step out of stereotypical roles as wives. As one female client

described:

> It's troublesome [being a hospice palliative home care client]. You know, I've
> always been a giver, and now I have to rely on my husband to help me and it's
> hard on me to… do that…..[He'll] get my beverages, do my dishes, do my
> wash… just generally all good things that I can't do anymore (Janet, client).

Internalizing the gender stereotyping of women as caregivers and keepers of the home

(Ussher et al., 2013), Janet expressed distress that she was unable to carry out her

feminine, domestic "duties." Although another female client, Barb, was experiencing

discomfort and pain, she also was reluctant to give up her gendered tasks of cleaning and

cooking, often taking over the food preparation when her husband had started. In showing

distinction and bias of "feminine" duties and roles, female clients and caregivers

reinforced gender stereotypes, at times causing undue strain. This gender inequity was

spawned because of women's needs to conform to stereotypical gendered attitudes,

beliefs, and practices.

Stereotypical ascribed roles viewing women in a subordinate role to men also

contributed to the construction of gender inequities. One client stated:

> The woman's got a personal touch as a caregiver. From day one, she's a caregiver
> and a guy is not. He's the care recipient…. It's like no matter what in life, you
> always expect – we don't expect – we don't take for granted- but it's known that
> women are always more a helper than anyone else (Tom, client).

Tom denoted a hierarchal relationship in his statement that "women are always more a

helper," drawing on traditional beliefs that men assume a dominant role in the family

while women are the "helper." These gendered attitudes sanctioned hierarchal

relationships between men and women and may have limited freedom of choice, thus

reproducing inequities. By conflating sexist attitudes with benevolent intentions, these

ambiguous actions mask and further entrench cultural assumptions. The hidden qualities of these gendered beliefs are particularly unfair as they would be difficult for women to resist these subtle, yet insidious, gendered stereotypes about care work.

Participants contributed to the social construction of gender inequities by denying that gender relations came into play, attributing gendered attitudes, beliefs, and practices to individual personalities. As one nurse stated, "Sometimes it's more of a personality thing too. It's not so much gender…" (Veronica, nurse). One caregiver ascribed gendered attitudes to the older generation, implying that gender interactions were becoming a non-issue:

> Some guys are extremely caregiving and thoughtful - more our children's generation than our generation because of what has occurred through life experiences. I witness it with my own children… how the guys are so much more thoughtful than my generation of guys were. They share duties. They do things differently (Laura, caregiver).

Although nurses denied that they considered gender in their interactions or care decisions, they tended to hold different expectations for men and women. Veronica, a nurse, stated, "I present the cases on their need, not their gender or their financial status or anything like that….I treat everyone the same, male or female." However, the nurse also expected men to be less involved in the care for their dying wives at home, as she said of a male caregiver, "I don't think Bob will know what to do unless…family are able to step in and be there. I don't think [his wife] would be a candidate for staying at home until end-of-life. I think she would go to hospice because I don't think he could handle it." Compared to blatant gender stereotyping, these subtle forms of gender discrimination may be considered more socially acceptable. Also, rather than practicing principles of equity, the nurse endorsed principles of equality that potentially marginalize the already

disadvantaged. Furthermore, in stating that care was given based on needs rather than gender, the nurse implied that, for her, gender or gender equity was low in priority in hospice palliative home care.

The contradictory behaviour of gender stereotyping alongside the "denying" of gender also was reflected in structural discourses. Home care agency discourses promulgating ideologies of individualism and familialism placed high expectations on women to care. The discourses of individualism suggested that individuals are to blame if they are unable to take on the caregiver role. In one public communication document (Appendix I) the difficulty of caregiving has been acknowledged and advice has been given to "take care of yourself," "build coping skills," "set limits," "ask for help," "arm yourself," and "stay connected." Suggestions were made to maintain one's spirit: "make a cup of tea," "do some stretching," "practice deep breathing," and "turn on some music." Without referring to outside social conditions that may affect experiences, these instructions implied that there are choices and that motivation is derived through individual attributes, instead of social supports or economic resources to assist a relative in end-of-life at home. As women are culturally ascribed the role of keepers of the home and of the health of the family (Armstrong & Armstrong, 2005), these messages may have exerted social pressures on women to enact gendered norms, even when they are without resources to support them in the provision of care. For example, as women are expected to provide care, they may not receive support such as reprieve from care responsibilities from other family members; yet, women may feel constrained to conform to gendered expectations. Thus, without referring to gender, neoliberal ideologies of

individualism and familialism have cultivated and (re)produced gender "norms" and gender inequities.

In adhering to stereotypical gendered roles and behaviours, men and women in hospice palliative home care reified (or made real) and sustained traditional gendered attitudes, beliefs, and practices. However, participants largely denied the existence of gender stereotyping while simultaneously sanctioning essentializing characterizations of femininity and masculinity. These contradictory patterns of gender relations were reinforced by broader social contexts supporting neoliberal ideals of individualism and familialism.

While there was evidence of gender stereotyping in hospice palliative home care, there were also glimpses of gender equity. As an example, one male caregiver ensured that he was present during agency nurse home visits, ready to offer information, learn about treatments or medications, and ask questions. However, while the nurse's attention was solely on the female client, she also was holding assumptions that the male caregiver would not be able to provide care to his wife during end-of-life at home. In another example of gender equity, nurses and female caregivers reacted sensitively to men's reactions to losing their driver's licenses and independence. As one male client stated:

> [The nurse may discuss with my wife] "You can expect this" and "Don't be surprised if this happens." ….So they might discuss… what kind of feeling I might have because I can't drive….The nurse is telling Laura [my wife] that most men who get their license taken away… have a big issue with that -Because I can't jump in the car and go and do what I want to do- It's taking your freedom away… and so preparing Laura as to how I might react to that (Stan, client).

This is an example of men's responses to losing their ability drive and therefore their independence, and how women respond sensitively to these gendered effects. However, specific attention to gendered stereotyping can also be considered a reinforcement and

perpetuation of gendered inequities, bringing into question the conceptualization of "gender-sensitive" care. Still, these examples that modify or address gender stereotypes shed light on opportunities to move toward gender equity in hospice palliative home care.

5.5.2 Imbalance/balance of power. An (im)balance of power transpired among nurses and male and female caregivers. Nurses tended to exert power when they delegated care work to female caregivers. One nurse stated:

> [O]ne of the duties I gave [Terri, female caregivers] … she was the one giving [the medications]. I [said] you just need to let me know of any… changes or anything like that because we really need to keep on top of it (Lori, nurse).

In comparison, nurses appeared not to contest men's decisions to stay outside the domain of care work. Unlike female caregivers, one male caregiver made himself unavailable during the times of agency home care visits by the nurse, hampering any opportunities for the nurse to converse with him about providing treatment and personal care. Rather than delegating work, the nurse took a more subtle, indirect approach to involve the man in the care of his ill wife:

> [The male caregiver] is not there the whole time. He'll go on the computer and maybe talk to me at the beginning and talk to me at the end…. I'll say, "I'm glad you're around and I'll give a rundown of what's going on" (Helen, nurse).

This example also illustrates how male caregivers may use gender as a resource to resist female nurses' attempts to include them into the circle of care. In comparison, women tended to have fewer choices in assuming a caregiver role, as nurses used their power to delegate work.

An imbalance of power also (re)produced inequities between husbands and wives and was revealed in men's decision-making power. As the "head of the household," the male caregiver asserted his power: "The nurses wanted to put a hospital bed in our

room…..I said you're not bringing a hospital bed here. If she needs a hospital bed she should go to the hospital" (Gerry, male caregiver). Gerry's decision was final, suppressing any opinion his wife held and constituting a clear inequity in decision-making about care.

Nurses also experienced an imbalance of power when case managers from the government agency made final decisions about the amount and type of care needed. One nurse indicated that at times she had to "fight" with the agency for the power to make decisions:

> If I have any concerns… then I ask the case manager [of the government agency] for more visits and hope I get them….We're not in control of how many visits we get, the agency is. At times we're not providing enough visits…. and we have to fight for the ones who need it (Veronica, nurse).

Nurses at times possessed power over clients and caregivers because of their education and knowledge base, not only delegating work, but also structuring home visits, and influencing care decisions about access to material resources. However, nurses also lacked decision-making power about the plan of care, such as the services made available to clients and the frequency of nurse visits. While being placed in a position of responsibility to monitor clients and caregivers in the home, nurses were also situated as subordinate, their knowledge power at times in competition with physicians' "superior" knowledge and expertise. Barb's physician challenged the palliative nurse's decisions in managing pain. Barb clearly gave precedence to the physician's directions:

> I talked to my doctor yesterday and he wants to be the main [health care provider]...like he is the one that is going to look after my medication. That's it. I think that he made the nurse understand that (Barb, client).

Jeff, a male caregiver, dismissed nurses' opinions and discussions and preferred to have discussions with the doctors:

> [I] don't listen to the nurses at all. I'm listening to the pain management doctor and I'm asking him what's going on because I think he knows a lot more than the nurses, so it doesn't register to me, I just talk to the doctor (Jeff, client).

Nurses could also impart power. A female client described how a nurse would make her feel significant and her visits personalized:

> Veronica has had more time with me…whereas the girl I used to have, she would just come in and give me a fragmin needle and be on her way. They're on a busy, busy schedule… [but] with Veronica, she takes her time. And I say, "I'm holding you up." She says, "No, no, no. Don't worry about it. Your time is your time when you're getting looked at."

The nurse provided time, compassion, and comfort for the female client. Although the female client assumed responsibility for her own care because of traditional notions of femininity, this example highlights the dynamic nature of power and the opportunities to balance power between nurses and clients. Affording power to clients or caregivers moves towards gender equity as power establishes conditions in which people can gain a sense of control and, in this case, progress through the developmental stage of end-of-life. However, this example can also be viewed as the nurses' focus on the needs and rights of the client in end-of-life over the needs of the family (Ward-Griffin et al., 2012b). Neoliberal ideologies of individualism, the rights of the individual over the welfare of the collective, reinforce and (re)produce these cultural attitudes.

In summary, hierarchies worked to sustain taken-for-granted power relations and shape participants' health care experiences. Men clearly displayed decision-making power over women. Because of traditional beliefs that men are the head of the household, female clients and caregivers experienced a lack of decision-making power and faced limited choices. Yet, there were also glimpses of a flattening of power hierarchies and therefore opportunities for equitable care. Overall, these power (im)balances were shaped

by gender stereotypes, in turn (re)producing gendered discriminatory patterns and behaviours and thus limited choices, undue strain, and social exclusion.

5.6 Discussion

Using a critical feminist lens, this study has exposed two socially constructed integral mechanisms of gender (in)equities for men and women in hospice palliative home care: *Preservation/Destruction of Gender Stereotypes* and *Balance/Imbalance of Power*. Findings reflect data from six triads comprised each of a client with cancer, a caregiver, and nurse and afford significant insights in relation to the social conditions that contribute to (in)equities. Study findings suggest that subtle discriminatory practices through gender stereotyping and power imbalances served to (re)produce gender inequities. Influenced by neoliberal ideologies of individualism, familialism, and egalitarianism, health care providers at times contributed to the reinforcement of gender inequities. Finally, the consequences of gender stereotyping and power imbalances were undue strain, constrained choices, and social exclusion and led to limited opportunities for men and women to optimize health care experiences and well-being, and make meaning during the stage of end-of-life.

This study has revealed that participants in hospice palliative home care hold implicit understandings of stereotypical gendered attitudes, beliefs, and practices, while simultaneously denying any gender stereotyping. While blatant forms of gender stereotyping (e.g., viewing women negatively as subordinates, or sanctioning gendered behaviours) may be seen as socially unacceptable (Swim & Heyers, 2009), subtle and contradictory forms are accepted as everyday attitudes and behaviours and not easily recognized (Martin, 2006). These subtle forms of gender stereotyping can be harmful

because they may be viewed as normal and accepted without question (Martin, 2006). This masking of gender inequities that limits options for women and men and renders it difficult to resist and change inequitable practices, must be exposed. In this light, there is a need for greater recognition and awareness of gender relations as influential in determining health, illness, and health care experiences in health care providers' everyday practices (Celik, Largo-Janssen, Widdershoven, & Abma, 2011). In employing a gender lens, health care providers would recognize gender as present in the everyday organizing of social life and question assumptions and ideologies that underpin gendered attitudes and practices (Howard & Hollander, 2000). Furthermore, there would be an acknowledgement of gender as a power relation that potentially oppresses and marginalizes and thus (re)produces gender inequities. With this awareness of gender, nurses can break down gender stereotypes and ensure that their practices are inclusive of both men and women. Nurses also can openly address women's and men's propensities to conform to gender stereotypes and take into consideration the contextual factors that may facilitate or hinder involvement or non-involvement in the provision of end-of-life care.

The contradicting, ambiguous attitudes of denying gender stereotypes while simultaneously evoking them may be attributed to time and system constraints and a lack of reflection upon gender inequities (Risberg, Johanssonb, & Hamberg, 2011). The impact of system constraints (e.g., workloads, scheduling) on everyday nurses' practices has been well documented (Clemmer et al., 2008; Oudshoorn, Ward-Griffin, & McWilliam, 2007; Ward-Griffin et al., 2012a, 2012b). Similar to the present study, nurses have expressed a sense of powerlessness over the scarce availability of services in home care, leading them to evade challenging situations and enact a "disabling" type of practice

(Ward-Griffin et al., 2012a, p 39) in which nursing tasks are prioritized. While nurses must be supported by agencies and nursing organizations and afforded more time and resources in relation to their everyday practices, they also must be aware of their ethical obligations to promote equity. Nurses need to practice a more relational, enabling type of practice (Ward-Griffin et al., 2012a) that would involve an awareness and respect of clients' and caregivers' social locations, a value for both clients and caregivers (e.g., in decision-making), and consideration of the contextual factors within which clients are supported or hindered in optimizing well-being (Hartrick, Doane, & Varcoe, 2005). Attention to relationships and relationship work between and among clients, family caregivers, and nurses has been recommended as a core competency for home care nurses (Stajduhar, Funk & Roberts et al., 2010). In addition to developing greater awareness and promoting a relational practice, nurses can discuss their concerns with colleagues and join committees or form groups to face administrators of agencies and address equity issues in order to make changes (Pauly, MacKinnon, & Varcoe, 2009). Nurses also can join interest groups in professional organizations such as the Registered Nurses Association of Ontario to help them to voice inequities and take community and political action (Pauly et al., 2009).

In order for nurses to be able to advocate for additional resources and promote gender equity, they must recognize gender relations as significant to health and health care experiences. Similar to other research findings (Brown, 2004), participants from the present study denied the significance of gender relations as they considered gender relations to be unimportant, particularly relative to the individual needs of the client experiencing end-of-life. While care of the individual client is essential in the provision of

hospice palliative home care, there often is a singular focus on the individual client (Stajduhar & Davies, 2005; Ward-Griffin et al., 2012b) at the expense of the rights of the caregiver (Brown, 2004). Ward-Griffin and colleagues (2012b) found that nurses focused on caregivers primarily to mobilize care for the client. Consistent with the philosophy of palliative care, family members must be viewed as part of the unit of care (WHO, 2011b). As such, health care providers must address family caregivers deliberately as clients in the provision of care, rather than persons to be recruited for care (Guberman, Lavoie, Pepin, Lauzon, &Montejo, 2006; Ward-Griffin et al., 2012b). However, nurses also must recognize that caregivers focusing on the individual at end-of-life and clinging to gender stereotypes (e.g., women must be natural caregivers or men are unable to provide personal care), may not see themselves as clients in need of care (Funk et al., 2010; Higgins & Harding, 2001; Ward-Griffin et al., 2012b) and instead may see caregiving as an obligation and duty, or see their roles outside the domain of the home. In prioritizing clients' needs over their own (Stajduhar & Davies, 2005; Ward-Griffin et al., 2012b), caregivers may be reluctant to accept care. A reflective and relational practice is thus important for health care providers to develop trusting and respectful relationships and engage in meaningful conversations about constraints and choices in involvement of care.

The denial of the significance of gender relations has been observed in educational contexts in which student teachers learn about gender stereotyping and discrimination in the classroom (Titus, 2000). Similar to participants in this study, student teachers attributed negative gendered attitudes, beliefs, and practices to individual personalities or to an older generation believed to have fixed notions about gender roles and behaviours (Titus, 2000). Also, concealing gendered attitudes, beliefs, and practices under the

ideology of equal treatment of all individuals, participants easily justified and resolved

issues of gender equity (Celik et al., 2011) and dissociated themselves from "others" who

engage in gender stereotyping (Titan, 2000). In this form of "distancing" (Titan, 2000),

people can feel satisfied that they have addressed issues of gender equity. For nurses in

this study, this distancing led to a sense of complacency and inaction, permitting nurses to

deny gender inequities, while dealing with more immediate biomedical issues in hospice

palliative home care.

In this study, nurses also considered that gender inequities were low in priority in

relation to the biomedical issues in hospice palliative home care. Similarly, Risberg et al.

(2011) found that medical educators and students perceived gender relations to be self-

evident, unscientific, and low in priority of subjects to be learned, particularly in

comparison to biology-based topics. In defining and legitimizing the profession, nursing

has adopted the biomedical model of care (Falk-Rafael, 2005) and focused on clinical

aspects of care. Emphasis of care on biomedical tasks has been considered a barrier to

developing meaningful relationships amongst providers and family caregivers

(Andershed, 2006), reinforcing the need for a relational approach to nursing. With this

focus on the biomedical, Falk-Rafael (2005) contends that there has been limited attention

paid in nursing to the broader social structures that affect health.

If we are to expect nurses to advocate for gender equity and optimize well-being

in hospice palliative home care, gender must be acknowledged and understood as

relational not only in terms of individual relationships between and among men and

women, but also as relational between groups of people and institutions that influence

ideologies, processes, or the distribution of resources and power that organize our

everyday gendered lives (Acker, 1992; Smith, 1987). In this context, nurses must have knowledge of political and ideological discourses that reinforce gender stereotypes and gender inequities. Pauly and colleagues (2009) have suggested that the charting systems within health care focus on physician-related concerns and therefore limit nurses' assessments and contributions in addressing contextual factors that affect health and health care experiences. Nurses may challenge these types of charting policies to ensure the inclusion of social conditions that affect health and health care in the care of the client and family, alongside the biomedical focus. Instead of solely focusing on downstream approaches, nurses should pay attention to social justice issues and employ the complex upstream solutions that challenge the status quo and address the root causes of inequities (Falk-Rafael, 2005).

Nursing education, then, must prepare nurses for policy and advocacy work (Reutter & Duncan, 2002). In addition to the acquisition of clinical skills and knowledge, graduate nursing schools need to emphasize the importance of political knowledge in making social change towards equity and social justice (Baum, 2009; Reutter & Duncan, 2002). Critical knowledge of political ideologies that underpin policies will help to prevent nurses from unwittingly embracing philosophies that counter equity. Nurses in this study adopted ideologies that relied on gender stereotypes, inadvertently reinforcing gendered attitudes, beliefs, and practices and gender inequities. Disseminated through institutional discourses, ideologies organize social relations and regulate our attitudes and behaviours in everyday interactions (Smith, 1987, 2005). Nurses need to learn to problematize these unquestioned "truths" that serve the interests of those in power to the detriment of the less dominant.

Nursing curricula that include courses in political science, economics, or social work and/or policy would broaden nurses' perspectives in identifying and addressing social inequities (Reutter & Duncan, 2002). Knowledge of how professional organizations and community groups work to influence policies will assist nurses to recognize the importance of supporting causes outside of their everyday clinical practices. Being exposed to collaborative partnerships, coalitions, and "grass-roots" alliances (e.g. women's groups) as well as political networks will encourage nurses to actively engage in the political process and learn how to identify and challenge inequities (Reutter & Duncan, 2002; Baum, 2007). Organizations such as the Registered Nurses' Association of Ontario (RNAO) can provide tools to facilitate public policy advocacy. For example, the RNAO holds assemblies to provide opportunities to meet with local ministers, voices issues in government forums, and tables and chooses nursing policies to prioritize. Additionally, nursing curricula that include the social determinants of health will broaden nurses' perspectives to look beyond the biomedical to social conditions and factors that create stereotypes and power imbalances and affect health and health care experiences. Specific courses on gender relations would be beneficial to advance the concept of gender as relational at individual and structural levels. Moreover, nursing instructors can role model relational practices and feminist principles of being attentive to and respectful of students' social locations and recognizing the different values and knowledge students and clients bring with them.

Additionally, nursing organizations need to revisit the underlying assumptions that frame ethics and social justice principles in fundamental nursing documents. Social justice discourses in nursing literature and ethical theories have been found to endorse

ideals of individualism and egalitarianism (Reimer Kirkham & Browne, 2006), which promote the ideology that individuals who have equal access to resources are responsible for their own health needs, without regard to their social situations. Nursing scholars have noted the contradictions between social justice and individualism and fairness and equal access to resources in nursing discourses, rendering it difficult for nursing to meet its responsibility to advance social justice (Reimer Kirkham & Browne, 2006). Analyses of nursing documents regarding social justice and ethics (e.g. "Social Justice: A Means to an End, an End in Itself") have revealed the use of weak language in discourses of social justice (Davison et al.). Davison and colleagues have noted that, while these nursing documents encourage nurses to address issues of equity, they do not emphasize the importance of social justice by stating that nurses "must," instead of "should," meet their responsibilities to promote equity, as stated in standards related to the administration of medications. Furthermore, little direction is given in relation to promoting social justice and making change at institutional and societal levels (Davison et al., 2006). Professional documents (e.g., "Standards or Practice, Ethics") that set standards of care echo the primacy of clinical care of the individual and the one-to-one client-nurse relationship (Bekemeier & Butterfield, 2005; Reimer Kirkham & Brown, 2006; Reutter & Kushner, 2010), thus legitimizing nurses' concerns for the client over other family members and sacrificing psychosocial issues such as gender equity for biomedical ones. Furthermore, nursing theories such as the "Health Belief Model" promote a behavioural approach that places the onus of health and healthy behaviours on individuals, rather than structural policies and practices (Browne, 2001). These fundamental documents to which nurses look for guidance reflect ideologies that contradict principles of social justice and

obfuscate nurses' understandings of their responsibilities to promote equity. In this light, nursing leaders must revisit key nursing documents and view them with a critical lens.

In regard to the second mechanism of imbalance/ balance of power, nurses in this study held the capacity to impart or abuse power. Similarly, Hall and McWilliam (2006) found that while nurses at times felt disempowered by system policies and procedures, an imbalance of power involving the domineering "expert" role of the nurse and the "dependent" patient permeated the culture of home care. A relational practice has been promoted in which there is critical reflection of the ways in which power comes into play in health care encounters (Hartrick et al., 2007; Hall & McWilliam, 2006). Consistent with a social determinants of health approach, within a relational practice, nurses exercise awareness of contextual factors that influence relationships, including the broader social structures that impact on day-to-day activities. There also must be critical reflection of how nurses express and respond to social relations such as gender, ethnicity, or class (Hartrick et al., 2007).

Additionally, social relations affect the power to make decisions, which is critical during end-of-life, a time in which terminally ill clients may choose how they want to live the remainder of their days. Research has indicated that most clients at end-of-life want to participate in decision-making (Belanger, Rodriguez, Groleau, 2011). While health care professionals' approaches to framing and presenting knowledge have been shown to have an impact on clients' decision-making (Drought & Koenig, 2002), much of the research to date has explored medical decision-making between the physician and the client who is ill (Belanger et al., 2011). The findings from this study afford an understanding of the

power (im)balances that may unfold during this time, impeding participatory decision-making.

While significant decisions are frequently made in palliative care with regard to treatment, symptom management, or advance directives, for example (Belanger et al., 2011), daily mundane care decisions also are made and may include limiting the number of visitors or daily routines that can affect the comfort and dignity of the client (Botoroff et al., 1998). Studies that have examined decision-making to adopt or maintain the caregiver role in palliative care have described choices based on love, spontaneity, or even indifference (Stajduhar & Davies, 2005; Stajduhar, Funk, Roberts et al., 2010); however, few have examined gender as an influencing factor in this context. More qualitative research that explores social relationships and the gendered effects on the decision-making experiences for clients, caregivers, and health care providers in hospice palliative home care is needed. Because few people will admit to sexist attitudes and behaviours (Acker, 2012), it is important to conduct qualitative research that exposes contradictions, as well as permits observations of interactions among men and women and how they shape practices and experiences that lead to inequities.

5.7 Conclusion

This study has exposed how contradictory gendered attitudes, beliefs, and practices of reinforcing gender stereotypes while simultaneously denying gender relations serve to conceal gender inequities. The focus of care on the individual experiencing end-of-life in hospice palliative home care has permitted participants to discount gender as an important factor that (re)produces inequities. Furthermore, while promoting a social justice mandate, nursing discourses also have endorsed ideals of individualism and

egalitarianism, which are reflected in nurses' attitudes, beliefs and practices, and countering goals towards equity. This study also has addressed power imbalances as they unfold in this context. Finally, this study offers glimpses of hope towards gender equity in hospice palliative hoe care. Because end-of-life at home has often been reported to be challenging, conflicting, and filled with negative emotions (Funk et al., 2010; Ward-Griffin et al., 2012a, 2012b), this is a time when issues of gender equity are likely set aside to meet other needs. Recommendations have been made for nursing policy, practice, research, and education.

5.8 References

Acker, J. (2012). Gendered organizations and intersectionality: problems and

possibilities. *Equity, Diversity and Inclusion*. 31 (3), 214-224. doi:

10.1108/02610151211209072

Allen, S. (1994). Gender differences in spousal caregiving and unmet need for care.

Journal of Gerontology, 49, S187-S195.

Andershed, B. (2006) Relative in end-of-life care, Part 1: A systematic review of the

literature the five last years, January 1994-February 2004. *Journal of Clinical

Nursing, 15*, 1158-1169. doi: 10.1111/j1365-2702.2006.01473.x

Armstrong, P., & Armstrong, H. (2002). *Thinking it through: women, work and caring in

the new millennium.* Halifax, NS: Maritime Centre of Excellence for Women's

Health. Retrieved from: http://www.cewh-cesf.ca/PDF/acewh/thinking.pdf

Armstrong, P. (2009). Public policy, gender, & health. In D. Raphael (Ed.), *Social

determinants of health: A Canadian perspective* (pp. 350-361).

Armstrong, P. & Armstrong, H. (2005). Public and private: Implications for care work.

The Sociological Review, 53 (s2), 167-187. doi: 10.1111/j.1467-

954X.2005.00579.x

Atkinson, P., & Hammersley, M. (2007).*Ethnography: Principles in practice*

(3rded.).New York: Routledge

Baum, F. (2007). Cracking the nut of health equity: top down and bottom up pressure for

action on the social determinants of health. *Promotion & Education, 14* (2), 90-98.

doi: 10.1177/10253823070140022002

Bekemeier, B., &Butterfeld, P. (2005). Unreconciled inconsistencies: A critical review of the concept of social justice in 3 national nursing documents. *Advances in Nursing Science, 28* (2), 152-62. doi: 10.1177/0894318411429034

Belanger, E., Rodriguez, C., & Groleau, D. (2011). Shared decision-making in palliative care: A systematic mixed studies review using narrative synthesis. *Palliative Medicine, 25* (3), 242-261. doi: 10.1177/0269216310389348

Botoroff, J., Steele, R., Davies, B., Garossino, C., Poterfield, P, Shaw, M. (1998). Striving for balance: palliative care patients' experiences of making everyday choices. *Journal of Palliative Care, 14,* 7-17.

Braun, M., Mikulincer, M. Rydall, A., Walsh, A., Rodin, G. (2007). Hidden morbidity in cancer: spouse caregivers. *Journal of Clinical Oncology, 25* (30), 4829-4834.doi: 10.1200/JCO.2006.10.0909

Brazil, K., Thabane, L., Foster, G., & Bedard, M. (2009). Gender differences among Canadian spousal caregivers at the end of life. *Health and Social Care in the Community, 17* (2), 159-166. doi: 10.1111/j.1365-2524.2008.00813.x

Brown, M. (2004). Between neoliberalism and cultural conservatism: spatial divisions and multiplications of hospice labor in the United States. *Gender, Place and Culture, 11* (1), 67-82. doi:10.1080/0966369042000188558

Browne, A. (2001). The influence of liberal political ideology on nursing science. *Nursing Inquiry, 8,* 118-129.

Burge, F., Lawson, B., & Johnstong, G. (2003). Trends in the place of death of cancer patients 1992-1997. *Canadian Medical Association Journal, 168* (3), 265-270. Retrieved from: http://www.cmaj.ca/content/168/3/265.abstract

Burge, F., Lawson, B., Johnston, G., & Grunfield. (2008). A population-based study of

age inequalities in access to palliative care among cancer patients. *Medical Care,*

26 (12), 1203-1211. doi: 10.1097/MLR.0b013e31817d931d

Canadian Cancer Society's Steering Committee on Cancer Statistics (2011). *Canadian*

Cancer

Statistics 2011. Toronto, ON: Canadian Cancer Society.

Canadian Hospice Palliative Care Association [CHPCA] (2012). *Fact Sheet: Hospice*

palliative care in Canada. Retrieved from:

www.chpca.net/media/.../fact_sheet_hpc_in_canada_may_2012_final.pd

Celik, H., Largo-Janssen, T., Widdershoven, G., & Abma, T. (2011). Bringing gender

sensitivity into healthcare practice: A systematic review. *Patient Education and*

Counseling, 84, 143-149. doi: 10.1016/j.pec.2010.07.016

Clark, S., Booth, Velikova, G., & Hewison, J. (2006). Social support: gender differences

in cancer patients in the United Kingdom. Cancer *Nursing, 29* (1), 66-72.

Retrieved from:

http://ovidsp.tx.ovid.com.proxy1.lib.uwo.ca/sp3.10.0b/ovidweb.cgi?&S=BNHCF

PIOHMDDLKCANCNKJDDCLEHIAA00&Link+Set=S.sh.37.38.42.48%7c12%

7csl_10

Clemmer, S., Ward-Griffin, C., & Forbes, D. (2008). Family members providing home-

based palliative care to older adults: The enactment of multiple roles. *Canadian*

Journal on Aging, 27 (3), 267-283.

Connell, R. (2009). *Gender*. Cambridge: Polity Press.

Davison, C., & Edwards, N., Webber, J., & Robinson, S.(2006). Development of a social justice gauge and it use to review the Canadian Nurses Association's Code of Ethics for registered nurses. *Advances in Nursing Science, 29* (4), E13-E26. Retrieved from: http://ovidsp.tx.ovid.com.proxy1.lib.uwo.ca/sp3.10.0b/ovidweb.cgi?&S=BNHCF PIOHMDDLKCANCNKJDDCLEHIAA00&Link+Set=S.sh.22.23.26.29%7c10% 7csl_10

Doyle, L. (2000). Gender equity in health: debates and dilemmas. *Social Science & Medicine, 51*, 931-939.

Drought, T., & Koenig, B. (2002). "Choice" in end-of-life decision-making: Researching fact or fiction? *The Gerontologist, 42* (Special issue 111), 114-128. doi: 10.1093/geront/42.suppl_3.114

England, K. (2010). Home, work and the shifting geographies of care. *Ethics, Place and Environment, 13* (2), 131-150. doi: 10.1080/13668791003778826

Evans, J. (2004). Men nurses: a historical and feminist perspective. *Journal of Advanced Nursing, 47* (3), 321-328. doi: 10.1111/j.1365-2648.2004.03096.x

Exley, C. & Allen, D. (2007) A critical examination of home care: End of life care as an illustrative case. *Social Science and Medicine* 65 (11) 2317-2327.

Falk-Rafael, A. (2005). Speaking truth to power: Nursing's legacy and moral imperative. *Advances in Nursing Science, 28* (3), 212-223.

Fisher, M. (2009). 'Being a chameleon: labor processes of male nurses performing bodywork. *Journal of Advanced Nursing, 65* (12), 2668-2677. doi: 10.1111/j136-2648.2009.05120.x

Funk, L., Stajduhar, K., Toye, C., Aoun, S., Grande, G. & Todd, C. (2010). Part 2: Home-based family caregiving at the end of life: a comprehensive review of published qualitative research (1998-2008). *Palliative Medicine, 24* (6), 594-607. doi: 10.1177/0269216310371411

Giesbrecht, M., Crooks, V.A., Williams, A., Hankivsky, O. (2012). Critically examining diversity in end-of-life caregiving: Implications for equitable caregiver support and Canada's compassionate care benefit. *International Journal for Equity in Health*, 11:65. Retrieved from: http://www.equityhealthj.com/content/11/1/65

Glazer, N. (1990). The home as workshop: Women as amateur nurses and medical care providers. *Gender & Society, 4* (4), 479-499. Retrieved from: http://www.jstor.org/stable/189750

Gravel., D., Taylor, G., Ofner, M., Johnston, Loeb, M., Roth, V.,…Matlow, F. (2007). Point prevalence survey for healthcare-associated infections within Canadian adult acute-care hospitals. *Journal of Hospital Infection, 66*, 243e-248e. doi:10.1016/j.jhin.2007.04.008

Greimel, E., Padilla, G., & Grant, M. (1998). Gender differences in outcomes among patients with cancer. *Psycho-Oncology, 7*, 197-206.

Guba, E., & Lincoln, Y. (1989). *Fourth generation evaluation*. Newbury Park: Sage Publications.

Guberman, N., Lavoie, J. Pepin, J., Lauzon, S., Montejo, M. (2006). Formal service practitioners' views of family caregivers' responsibilities and difficulties.

Canadian Journal on Aging, 25 (1), 43-53. doi:

http://dx.doi.org/10.1353/cja.2006.0024

Harding, R., & Higginson, I. (2001). Working with ambivalence: Informal caregivers of

patients at the end of life. *Support Cancer Care, 9*, 642-645.

Haley, (2003). Family caregivers of elderly patients with cancer: Understanding and

minimizing the burden of care. *Supportive Oncology, 1* (2), 25-29. Retrieved

from: jso.imng.com/jso/journal/articles/0104s225.pdf

Hall, J., & McWilliam, C. (2006). About the culture of in-home nursing. *Home Health*

Care Services Quarterly, 25 (3/4), 75-90. doi: 10.1300/j027v25n3_05

Hartrick, Doane, G., & Varcoe, C. (2005). *Family nursing as relational inquiry:*

Developing health promoting practice. Philadelphia: Lippincott Williams &

Wilkins.

Howard, J. & Hollander J. (2000*). Gendered situations, gendered selves: A gender lens*

on social psychology. Oxford: Ultamira Press.

Im, E. (2006). White cancer patients' perception of gender and ethnic differences in pain

experience. *Cancer Nursing, 29* (6), 441-450.

Jo, S., Brazil, K., Lohfeld, L., & Willison, K. (2007). Caregiving at the end of life:

Perspectives from spousal caregivers and care recipients. *Palliative and*

Supportive Care, 5, 11-17.

Keller, M., & Henrich, G. (1999). Illness-related distress: Does it mean the same for men

and women? Gender aspects in cancer patients' distress and adjustment. *Acta*

Oncologica, 38 (6), 747-755.

Lather, P. (1995). The validity of angels: interpretive and textual strategies in researching the lives of women with HIV/AIDS. *Qualitative Inquiry, 1* (1), 41-68.

Lewis, J., DiGiacomo, M., Currow, D., & Davidson, P. (2011). Dying in the margins: Understanding palliative care and socioeconomic deprivation in the developed world. *Journal of Pain & Symptom Management.* Advance online publication. doi: 10.1016/j.jpainsymman.2010.10.265.

Lofland, J., Snow, D., Anderson, L., & Lofland, L. (2006). *Analyzing social settings: A guide to qualitative observation and analysis* (4th ed.). Toronto: Thomson, Wadsworth.

Lorber, J. (1994). "Night to his day": The social construction of gender. In J. Lorber (Ed.). *Paradoxes of gender* (pp 13-36). New York: Vail-Ballou Press.

Lyons, A. (2009). Masculinities, femininities, behaviour and health. *Social and Personality Psychology Compass*, ¾, 394-412. doi: 10.1111/j.1751-9004.2009.00192x

McGuire, T., Dougherty, D., & Atkinson, J. (2006). Paradoxing the dialectic: The impact of patients' sexual harassment in the discursive construction of nurses' caregiving roles. *Management Communications Quarterly, 19* (3), 416-460. doi: 10.1177/0893318905280897

McMullin, J. (2010). *Understanding social inequality: Intersections of class, age, gender, ethnicity and race in Canada* (2nd ed.). Toronto: Oxford University Press.

McWilliam, C., Ward-Griffin, C., Oudshoorn, A. & Krestick, E. (2008).Living while dying/dying while living: Older clients' socio-cultural experience of home-based palliative care. *Journal of Hospice and Palliative Nursing, 10*(6), 338-349.

Marmot, M., Friel, S., Bell, R., Houweling, T., & Taylor, S. (2008). Closing the gap in a generation: Health equity through action on the social determinants of health. *The Lancet, 372*, 1661-69. doi: doi:10.1016/S0140-6736(08)61690-6

O'Lynn, C., & Krautscheid, L. (2011). 'How should I touch you?': A qualitative study of attitudes on intimate touch in nursing care. *American Journal of Nursing, 11* (3), 24-31. doi: 10.1097/10.1097/01.NAJ.0000395237.83851.79

Ottawa Charter.(1986). Ottawa Charter for Health Promotion. *First International Conference on Health Promotion.Ottawa*, 21 November 1986 - WHO/HPR/HEP/95.1Retrieved from http://www.who.int/hpr/NPH/docs/ottawa_charter_hp.pdf

Oudshoorn, A., Ward-Griffin, C. & McWilliam, C. (2007). Client-nurse relationships in home-based palliative care: A critical analysis of power relations. *Journal of Clinical Nursing, 16*, 1435-1443. doi: 10.1111/j.1365-2702.2006.01720.

Pauly, B. (2008). Harm reduction through a social justice lens. *International Journal of Drug Policy, 19,* 4-10. doi.1016/j.drugpo.2007.005

Pauly, B., McKinnon, K., & Varcoe, C. (2009). Revisiting "Who gets care?": Health equity as an arena for nursing action. *Advances in Nursing Science, 32* (2), 118-127.

Perakyla, A. (2008). Analyzing talk and text. In N.K. Denzin and Y.S. Lincoln (Eds.), *Collecting and interpreting qualitative materials* (pp. 869-885) (3rd ed.). Thousand Oaks, CA: Sage

Raphael, D. (2012). The importance of tackling health inequalities. In D. Rapheal (Ed.), *Tackling health inequalities: Lessons from international experiences* (pp 1-33). Toronto: Canadian Scholar's Press.

Rawls, J. (1971) *A theory of justice*. Oxford University Press: Oxford.

Reimer Kirkham, S., Browne, A. (2006). Toward a critical theoretical interpretation of social justice discourses in nursing. *Advances in Nursing Science, 29* (4), 324-339. Retrieved from http://journals.lww.com/advancesinnursingscience/Abstract/2006/10000/Toward_a_Critical_Theoretical_Interpretation_of.6.aspx

Reutter, L., & Duncan, S. (2002). Preparing nurses to promote health-enhancing public policies. *Policy, Politics & Nursing Practice, 3* (4), 294-305. doi: 10.1177/152715402237441

Reutter, L., & Kushner, K. (2010). Health equity through action on the social determinants of health: Taking up the challenge in nursing. *Nursing Inquiry, 17* (3), 269-280. doi: 10.1111/j.1440-1800.2010.00500.x

Ridgeway, C., & Correll, S. (2004). Unpacking the gender system: A theoretical perspective on gender beliefs and social relations. *Gender & Society, 18* (4), 510-513. doi: 1177/0891243204265269

Risberg,, G., Johanssonb, E., Hamberg, K. (2011). 'Important…but of low status': male education leaders' views on gender in medicine. *Medical Education, 45*, 613-645. doi: 10.1111/j.1365-2923.2010.03920.x

Schultz, R., & Beach, S. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *American Medical Association, 282*, (23), 2215-2219.

Sen, A. (2002). Why health equity? *Health Economics, 11*: 659-666. doi: 10.1002/hec.762

Sen, G., & Ostlin, P. (2008). Gender inequity in health: why it exists and how we can change it. *Global Public Health, 3* (S1), 1-12.

Simpson, R. (2009*). Men in caring occupations: Doing gender differently*. NewYork: Palgrave MacMillan.

Spitzer, D. (2005). Engendering Disparities. *Canadian Journal of Public Health, 96* (2), S78-S96. doi

Smith, D. (1987). *The everyday world as problematic*. Massachusetts: Northeastern Press.

Smith, D. (1992). Sociology from Women's Experience: A reaffirmation. *Sociological Theory, 10* (1), 88-98. URL: http://www.jstor.org/stable/202020

Smith, D. (2005). Women's Standpoint: Embodied knowledge versus the Ruling Relations. In *Institutional ethnography: A sociology for people* (pp. 7-26) Maryland: Alta Mira Press.

Stajduhar, K., Allan, D., Cohen, & Heyland, D. (2008). Preferences for location of death of seriously ill hospital patients: Perspectives from Canadian patients and their family caregivers. *Palliative Medicine, 22*, 85-88.

Stajduhar, K., & Davies, B. (2005). Variations and factors influencing family members' decisions for palliative home care. *Palliative Medicine, 19*, 21-32.

Stajduhar, K., Funk, L., Roberts, D., Cloutier-Fisher, D., McLeod, B., Wilkinson, C., & Purkis, M. (2010). Articulating the role of relationships in access to home care nursing at the end of life. *Qualitative Health Research, XX* (X), 1-15. doi: 10.1177/104973231037114

Stajduhar, K., Funk, L., Toye, C., Grande, G., Aoun, S., & Todd, C. (2010). Home-based family caregiving at the end-of-life: a comprehensive review of published quantitative research (1998-2008). *Palliative Medicine, 24* (6), 573-593. doi: 10.1177/0269216310371412

Swim, J. & Heyers, L. (2009). Sexism. In T. Nelson (Ed.), *Handbook of prejudice, stereotyping, and discrimination* (pp. 4-07-424). New York: Taylor & Francis Group

Tang, S., & McCorkle, R. (2001). Determinants of place of death for terminal cancer patients. *Cancer Investigation, 19* (2), 165-180.

Taylor, B., & de Vocht, H. (2011). Interviewing separately or as couples? Considerations of authenticity of method. *Qualitative Health Research, XX* (X), 1-12. doi: 10.1177/1049732311415288

Thomas, J. (1993). *Doing critical ethnography*. Newbury Park, California: Sage publications.

Thomas, J. (2003). Critical ethnography, meanings, and symbolic violence. In R.B. Clair (Ed.), *Expressions of Ethnography: Novel approaches to qualitative research* (pp 45-65). Albany: State University of New York.

Titus, J. (2000). Engaging student resistance to feminism: 'how is this stuff going to make us better teachers?' *Gender and Education, 12 (1*), 21-37. doi: 10.1080/09540250020382

Ussher, J., & Sandoval, M. (2008). Gender differences in the construction and experience of cancer care: The consequences of the gendered positioning of carers. *Psychology and Health, 23* (8), 945-963.

Ussher, J., Sandoval, M., Perez, J., Wong, W., & Butow, P. (2013). The gendered construction and experience of difficulties and rewards in cancer care. *Qualitative Health Research, 23* (7), 900-915. doi: DOI: 10.1177/1049732313484197

Verdonk, P., Benshop, Y., de Haes, H., & Lagro-Janssen, T. (2009). From gender bias to gender awareness in medical education. *Advances in Health Sciences Education, 14*, 135-152. doi: 10.1007/s10459-008-9100-z

Walsh, C., Todd, C., Caress, A., & Chew-Graham, C. (2009). Patterns of access to community palliative care services: A literature review. *Journal of Pain & Symptom Management, 37* (5), 884-910.doi: 10.1016/j.jpainsymman.2008.05.004

Ward-Griffin, C., McWilliam, C., Oudshoorn, A. (2012a). Negotiating relational practice patterns in palliative home care. *Journal of Palliative Care, 28* (2), 33-40. doi: 10.1177/1074840712462134

Ward-Griffin, C., McWilliam, C., Oudshoorn, A. (2012b). Relational experiences of family caregivers providing home-based end-of-life care. *Journal of Family Nursing, 18* (4), 91-516. doi: 10.1177/1074840712462134

Whitehead, M., & Dahlgren, G., (2006). *Levelling up (part 1): A discussion paper on concepts and principles for tackling social inequities in health*. WHO Collaborating Centre for Policy Research on Social Determinants of Health. Retrieved from:

http://www.google.ca/url?sa=t&rct=j&q=&esrc=s&frm=1&source=web&cd=2&ved=0CDgQFjAB&url=http%3A%2F%2Fwww.who.int%2Fsocial_determinants%2Fresources%2Fleveling_up_part1.pdf&ei=auakUrG8EqWyygGdk4GoBQ&usg=AFQjCNE6nRR_6s1kVu5mErF9K-aLBMjsDw&bvm=bv.57752919,d.aWc

World Health Organization [WHO]. (2011a). *Report on the burden of endemic health care-associated infection worldwide*. Retrieved from

whqlibdoc.who.int/publications/2011/9789241501507_eng.pdf

World Health Organization [WHO]. (2011b). *WHO definition of palliative care*.

Retrieved from http://www.who.int/cancer/palliative/definition/en/

6. Chapter Six: Discussion

Guided by a critical feminist lens (Smith, 1987, 2005), the purpose of this study was to examine gender relations in hospice palliative home care. Specifically, I sought to uncover sociopolitical influences on gender relations between and among clients, caregivers, and nurses in this context. I addressed the following research questions: 1) How do gender relations shape health care experiences within the socio-political context of hospice palliative home care for clients with cancer and their caregivers?; 2) How do gendered processes operate to create gender relations and potential gender inequities in this context?; and 3) What are the socially constructed mechanisms and consequences that (re)produce gender (in)equities in hospice palliative home care?

In this critical ethnographic study (Thomas, 1993, 2003), I used methods of interview, observation, and document review to uncover taken-for-granted attitudes, beliefs, and practices that create power relations. Interviews were conducted with each member of the six client-family caregiver-nurse triads involved in the culture of hospice palliative home care. Open-ended interviews were important to elicit information-rich data about relationships and experiences in hospice palliative home care. Observations of agency home visits afforded context in the natural environment of home care. I observed how social interactions were influenced by gender relations by being attentive to power and the use of power in everyday interactions (Atkinson & Hammersley 2007; Thomas, 2003). Finally, institutional discourses were analyzed from program, public communication, and professional documents to expose ideologies that shape gendered practices in hospice palliative home care (Atkinson & Hammersley, 2007; Smith, 2005).

In the field from April 2012 to August 2013, my overall goals were to expose how gender relations shape relationships and health care experiences in the sociopolitical context of hospice palliative home care and how policies and practices can promote gender equity in this context.

6.1 Summary of Study Findings

This study illuminated three interrelated components within hospice palliative home care: gendered expectations and exemptions, gendered processes, and the (re)production of gender (in)equities (Figure 2). Each component contributed to the reinforcement of gender relations and is explicated in detail in Chapters Three, Four, and Five respectively.

Figure 2. Gender Relations in Hospice Palliative Home Care
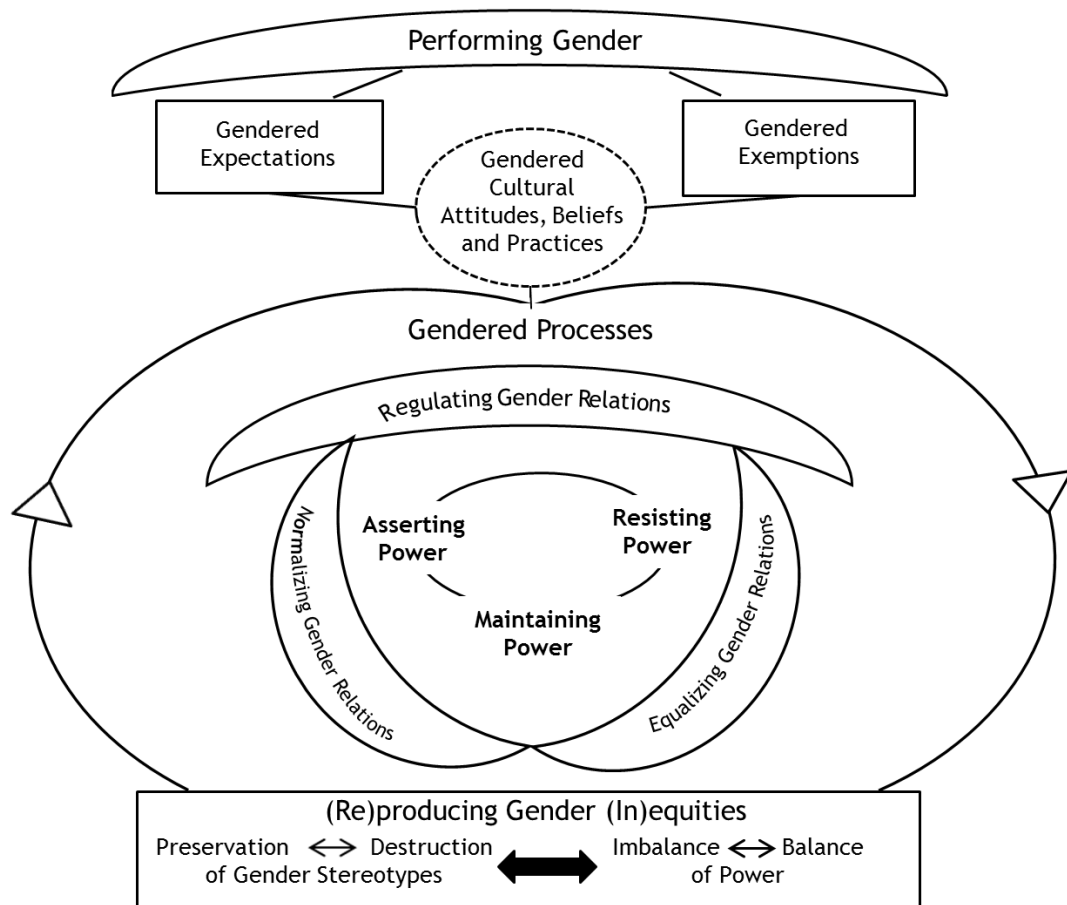
Chapter Three, "Gendered Expectations and Exemptions in Hospice Palliative

Home Care," identifies sociopolitical factors that reinforce embedded cultural attitudes,

beliefs, and practices of gendered expectations and exemptions for men and women in

hospice palliative home care. Study findings suggest that men and women are both

advantaged and disadvantaged by gendered expectations and exemptions. This chapter

also illuminates the sociopolitical factors that shape gendered expectations and

exemptions and everyday health care experiences in hospice palliative home care.

Chapter Four, "Gendered Processes in Hospice Palliative Home Care," reveals that participants use ideological processes of *Normalizing Gender Relations* and *Equalizing Gender Relations* to enact the *Regulating of Gender Relations*. Embedded within these processes are power relations of *Asserting Power*, *Resisting Power*, and *Maintaining Power*. In the *Regulating of Gender Relations*, men and women assert power to control gendered attitudes, beliefs, and practices. During *Normalizing Gender Relations*, participants naturalize taken-for-granted gendered attitudes and beliefs to maintain their gendered practices. Gender is disregarded as participants assume equality of treatment of men and women. The simultaneous embracing of ideological processes of *Normalizing Gender Relations* and *Equalizing Gender Relations* conceals the controlling of gendered attitudes, beliefs, and practices, thus reinforcing and maintaining gender relations and potential gender inequities.

Chapter Five, "(Re)producing Gender (In)equities in Hospice Palliative Home Care," exposes the socially constructed mechanisms of *Preservation/Destruction of Gender Stereotypes* and *Imbalance/Balance of Power.* The gender stereotyping of men's and women's attitudes, beliefs, and practices and the correlated imbalance of power (re)produce gender (in)equities. Glimpses of the destruction of gender stereotypes and balances of power in relationships show potential strategies to achieve gender equity in this context.

6.2 Major Insights

Threaded through the findings were two major insights: the structural impact on everyday interactions and the disregard for gender relations in hospice palliative home

care. In the following section, I discuss these insights and the key implications related to them.

6.2.1 The structural impact on everyday gendered interactions in hospice palliative home care.

This study highlights how institutional discourses influence gendered practices in hospice palliative home care, thus shaping day-to-day interactions at both personal and systemic levels. Gender is prevalent in the processes, practices, and ideologies (Acker, 1992; Martin, 2004) that constitute the culture of hospice palliative home care. Ideologies are the philosophies and principles which inform how we understand and interpret social relations and our position in them (Brodie, 2002; Hall, 2000).

Ideological discourses reinforcing traditional gendered attitudes, beliefs and practices are constructed as unquestioned truths. Everyday citizens are unaware of adopting these "truths" that are created by taken-for-granted statements (e.g., girls are nurturing and caring) (Hall, 2000). Ideologies thus come into play without conscious thought, and yet, they inform us of our position in society and how to behave and practice within those positions. According to Smith (1987), ideologies are the ideas and values of social institutions that organize our everyday lives. Thus, ideologies control social relations and regulate our attitudes, beliefs, and practices in day-to-day gendered interactions and situations. Notably, ideologies are formed from similar concepts that have different meanings (Hall, 2000). For example, as feminists promote the ideal of individual choice and freedom, neoliberal proponents adopt the ideology of "individualism" with very different connotations that advance the idea of the self-reliant individual who chooses his or her own path to success or failure. Within this neoliberal

ideology, individual experiences are influenced by personal qualities, rather than social conditions, which is divergent from feminist principles that include the impact of power relations in everyday activities (Smith, 1987; Sprague, 2005). Consequently, the concept of individuality is used with a different meaning that obscures understandings (Hall, 2000). Thus, as attitudes and values are embedded within ideologies, taken-for-granted truths about gender are concealed and difficult to recognize and resist (Martin, 2004).

This study revealed that neoliberal ideologies and discourses are reflected in participants' gendered attitudes, beliefs, and practices. Neoliberal ideologies favour the privatization of government public services to the private sector or market. Within a neoliberal philosophy, government funding of services is considered insufficient and an interference to the free market. Cost-effective businesses in the free market are perceived to lead to an economy that better allocates resources, satisfies customers, and stimulates growth (England, 2010; McGregor, 2001). Because the free market determines quality, cost, and access, a government that supports neoliberalism relies on market forces to resolve all issues, including those related to equity (England, 2010). Furthermore, the viewpoint of the ideal neoliberal "individual" as self-reliant, genderless, decontextualized, and unaffected by social problems, permits a neoliberal-based government to pay less attention to certain social issues in home care, such as gender equity (England, 2010).

In the Ontario context, neoliberal ideologies have led to home care restructuring from a public service model to a managed competition model in which government agencies contract out to a competitive market of nursing agencies that provide the actual care services (England, 2010). Alongside other cost-saving policies (e.g., rationing of services, narrowing eligibility criteria for home care), the move to a competitive market

has resulted in increased workloads and added stress for health care workers (England, 2010; Martin Mathews, Sims-Gould, & Tong, 2012). A "downloading" of responsibility of care from paid to unpaid caregivers has occurred and care has shifted from the state, not only to private markets, but also to family members and mainly women who have been left to fill in the service gaps (Armstrong & Armstrong, 2005; England, 2010).

In opposition to a social liberal philosophy in which concern for welfare of the collective is primary, the neoliberal value of individualism promotes the image of the individual who can tend to her/his family's needs independent of government assistance. Implied in this message is that an inability to care for one's family lies solely with the individual and family rather than the social conditions that enable or hinder one's ability to meet health and health care needs. The underlying assumption of individualism is egalitarianism, the belief that all individuals have equal opportunities for health and health care and those unable to resolve health issues are deficient (Browne, 2001).

In this study, nurses adopted ideologies of individualism, familialism, and egalitarianism to meet system demands. For example, believing that women are willing and experienced in providing care, nurses tended to enlist women to assume responsibility of care, while typically exempting men from care work. In this way, nurses inadvertently acted as agents to assist and support this neoliberal sociopolitical shift. As Brown (2004) states, these "neoliberal ideologies rarely work on their own" (p. 69). The propagation of ideologies is dependent upon individuals who embrace the embedded values and use them to support certain behaviours and actions. Appearing as "truths," these ideologies were accepted uncritically in this study. However, in order to meet ethical and social justice mandates, nurses need knowledge and awareness of insidious

ideologies that permeate health care. Without such knowledge, nurses inadvertently reinforce the values that underpin these ideologies (Browne, 2001) that potentially lead to gender inequities.

Professional nursing organizations also espouse neoliberal ideologies. Professional nursing documents (e.g., College of Nurses of Ontario standards of practice) focus on individual care, the individual client-nurse relationship, and the rhetoric of equal treatment for all (Reimer Kirkham & Browne, 2006). Although social justice is promoted in national nursing standards (e.g., Canadian Nurses' Association, 2010), the concept is largely framed around access to resources for individuals (Reimer Kirkham & Browne, 2006). Nurses are advised to act on an individual basis, make fair decisions, and not discriminate (Reimer Kirkham & Browne, 2006). Also, nursing continues to focus on theories geared toward individual motivation and lifestyle changes (e.g., Health Belief Model) (Browne, 2001). Embedded within ideologies of individualism and egalitarianism, these documents may have led the nurses in the present study to perceive that professional standards and policies support their gendered beliefs. As leaders of the profession, nursing associations need to revisit nursing standards of practices to ensure that documents reflect social justice values committed to addressing the social, political, and environmental factors that contribute to inequities (Reimer Kirkham & Browne, 2006).

6.2.2 A disregard for gender equity. Study participants in the context of hospice palliative home care tended to disregard thoughts of gender relations and gender equity. Although palliative care philosophy has promoted the family caregiver as a unit of care alongside the individual with terminal illness (Stajduhar et al., 2010; World Health

Organization, 2014), there is evidence to indicate that, in practice, the focus of care is on the individual client (Clemmer, Ward-Griffin, Forbes, 2008; Ward-Griffin, McWilliam & Oudshoorn, 2012b). The rights of the individual in attaining the goal of a "good" death are forefront in hospice palliative home care (Brown, 2004). However, as Brown (2004) states, attainment of these goals comes to fruition at the expense of the rights of the family caregiver in the home, where claims of justice, typically associated with the public world outside the home, are considered inappropriate. In this study, gender relations were regarded as unimportant because of a focus on the care of the individual at end-of-life and the tasks involved in that care. Few questioned this disregard for gender equity as it was obscured and concealed through ideological gendered processes and a denial of the importance of gender relations.

Chapter Four revealed that participants interpret and use ideological processes of *Normalizing Gender Relations* and *Equalizing Gender Relations* to support the more practical "doing" of gender (West & Zimmerman, 1987), the everyday gendered practices that constitute *Regulating Gender Relations*. Participants tended to adopt the concept of treating men and women alike while they obscured their tendencies to simultaneously normalize gendered attitudes, beliefs, and practices. Nurses embraced the ideal of normalizing women's nurturing role to enlist women as caregivers and meet system demands, while at the same time, they disregarded any accountability to gender equity by claiming equality of care. The valuing of equality over equity, a premise of individualism, legitimizes participants' actions to be non-reflexive about gender and thus avoids the issue of gender equity. Gender inequities are easily avoided since the focus is on more

"immediate" biophysical tasks, particularly within a cost-containment environment in which time and resources are limited.

Another contradictory gendered relational pattern was revealed in Chapter Five, "(Re)producing Gender (In)equities in Hospice Palliative Home Care"*,* in which discriminatory patterns of sexual stereotyping were in direct opposition to the denial of gendered attitudes, beliefs, and practices. Denying meant that gender relations did not significantly come into play and participants were subsequently blind to gender relations and their impact on health care experiences. In other words, gender equity was not a priority in hospice palliative care. Similar to the contradictory gendered ideological processes in Chapter Four, participants adopted embedded neoliberal values to support and disregard their enactments of gender. In disregarding gender relations, participants prioritized the needs of the clients and sacrificed the rights of the caregiver to opt in or out of caregiving, for example. Because of the sensitive nature of palliative care, those who challenge the rights and freedoms of caregivers during end-of-life may be viewed negatively, likely deterring anyone from challenging gender inequities in hospice palliative home care. In other words, the culture of hospice palliative home care is such that anyone placing issues such as gender equity above the client's concerns of end-of-life are condemned and hampered. While clients' concerns are significant during this time, addressing gender inequities is also a priority because these unfair differences in treatment and services potentially undermine the well-being of those who are disadvantaged. Therefore, it is important to ask: When is a good time to address gender equity in hospice palliative home care?

As the biomedical model of care predominates in health care (Celik Lagro-Jannsen, Widdershoven & Abma, 2011; Risberg, Johansson & Hamberg, 2011; Titus, 2000), social relations such as gender are considered to be unimportant in the overall hierarchy of health care knowledge (Celik et al., 2011; Titus, 2000). In the profession of nursing, a medical-based science model is emphasized in order to lay claim to nurses' critical role in health care (Armstrong & Armstrong, 2005). Additionally, some consider the topic of gender relations to be unscientific; others have viewed feminist thought as an exaggeration of differences and male-bashing (Titus, 2000). Similar to participants in the present study, health care providers (Risberg et al., 2011) disregard gender relations because of the low status they appoint to the issue of gender (in)equities in health care interactions.

The focus on the individual client and a disregard for gender relations can also be attributed to the heavy workloads and limited time for care that health care providers confront (Ward-Griffin, McWilliam, & Oudshoorn, 2012a). Restructuring of the health care system so that more care is provided in the home leads to a complex and demanding type of work (Armstrong & Armstrong, 2005). As a part of this restructuring, the casualization of home care labor, restriction of care hours, and increased workloads (Martin- Matthews et al., 2013) contributes to the strain nurses experience in working in an environment with increasing work demands and time constraints (Martin-Matthews, et al., 2013; Ward-Griffin et al., 2012a). In such a cost-reductionist environment, reflection and discussion of gender (in)equities tend to be neglected to focus on the medical aspects of client care. Furthermore, similar to this study, nurses tend to turn their attention to

caregivers largely with the intention of transferring care work (Ward-Griffin et al., 2012b).

As health care providers disregard gender equity, they also deflect the upholding of morals and human rights principles in their actual day-to-day practice. In other words, there is a gap between ideals of quality care and actual practice (Falk-Rafael, 2005). However, nurses may feel powerless to act because of heavy workloads and limited time and energy. Also, they may be hesitant to raise issues about gender equity that may jeopardize their positions at their government agencies (Reutter & Kushner, 2010). Nurses may be more empowered to act collectively by joining nursing organizations with political connections and information and tools for advocacy (e.g. Registered Nurses' Association [RNAO]). If reluctant to stand out and voice concerns, nurses may remain anonymous within a collective (Falk-Rafael, 2005). A "top down" and "bottom up" approach (Baum, 2007) may be taken by joining grass-roots organizations such as end-of-life interest groups, or women's groups (Falk-Rafael, 2005; Reutter & Duncan, 2002) alongside policy advocacy at government levels. Furthermore, mechanisms should be put in place to ensure accountability for gender equity (Sen & Ostlin, 2008). For example, in light of gendered expectations and exemptions, case managers may periodically assess if women and men are afforded opportunities to make choices without social censure.

To move the focus of care beyond an individual and biomedical model of care, nursing education must emphasize a social determinants of health perspective that examines how social factors such as gender, class, or ethnicity create or limit opportunities for health and care (Raphael, 2012). Within this perspective, there is a view that policies shape the social, political, and emotional conditions in order for people to

make choices, have control, and be recognized (Armstrong, 2009). The point of intervention, then, is found at the policy level, rather than the individual level. However, even though nursing and medical curricula often incorporate a health promotion perspective, policy advocacy is taught as "lip service" without offering experiential examples of actual collaborative efforts, or contact with policy makers and grassroots groups (Baum, Begin, Houweling, & Taylor, 2009; Reutter & Duncan, 2002). Reutter and Duncan (2002) promote policy advocacy as a practice of nursing and have specific policy courses for nursing students, which include, among other topics, approaches to policy advocacy, the framing of problems, policy networks, and coalition advocacy. Practicum experience in this course includes working with coalitions, stakeholders, and agencies to gain knowledge and participate in addressing policy issues. Furthermore, nurse educators can play a crucial by role modelling the breaking down of gender stereotypes and practicing a relational (Doane & Varcoe, 2005), feminist approach that attends to power relations with students and clients. Equally important, graduate students need to be encouraged to build skills and knowledge for policy advocacy in addition to clinical skills (Baum, et al., 2009).

Additionally, university programs need to develop courses for health care providers on gender relations and how they impact on health care interactions and health care. An interprofessional model of education that includes students from various programs such as political science, aging, or gender studies exemplifies how to promote interdisciplinary collaboration. Moreover, intersectionality as an approach for analyzing how gender intersects with other relations would provide a more comprehensive understanding multiple inequities. Examination of multiple inequities is essential to

capture a comprehensive understanding of marginalized and vulnerable persons (Crenshaw,1991; Weber, 2005). Consistent with a social determinants of health approach (Raphael & Curry-Stevens, 2004), intersectionality is a methodological approach that provides a lens through which to view intersecting inequities stemming from social determinants such as gender, ethnicity, or class (Weber, 2005), which are linked to health/illness and disease (Graham, 2004; Hankivsky & Christoffersen, 2008; Ottawa Charter, 1986; Weber, 2005). Using a multi-level approach, intersectionality includes analysis of how agency and structure interplay to (re)produce processes of domination and subordination (Dhamoon & Hankivsky, 2012). In this light, the focus of research is on the vulnerable and marginalized and how policies and practices can address issues of equity for people confronting multiple inequities.

More specifically related to palliative care, educators must emphasize the importance of treating the family as a unit of care with due regard for their enactments of gender. A relational approach to care that focuses on family, sociopolitical contexts, and differing experiences enhances knowledge and skills of how to approach families (Doane & Varcoe, 2004). In this way, nurses will be better able to recognize and understand family caregivers' meanings and experiences (Doane & Varcoe, 2004) and respond to their needs. Consistent with a relational approach, nurses should "be with" at-home clients and family members rather than "doing to/doing for," (Hall & McWilliam, 2006, .p 85), thus balancing power relations and dismantling the "expert" medical position assumed by some (Hall & McWilliam, 2006; Ward-Griffin, Oudshoorn, & Krestick, 2008).

As gender is relational, research should include the triad, the client, caregiver, and health care provider involved in hospice palliative home care. Most palliative care research is derived from individual perspectives (Stajduhar et al., 2010). However, research has shown that caregiving is often shared by networks of people rather than individual caregivers (Fast, Keating, Otfinowski & Derksen, 2004). As such, studies should be conducted that include the network of care and the complex social relations that affect experiences. A critical ethnographic design permits a view of the culture of palliative care and employs various methods to capture dynamic relations and social influences on everyday interactions.

6.3 Study Strengths and Limitations

A major strength of this study is the methodological approach used. As gender relations (re)produce power relations and gender (in)equities (Connell, 2012), a methodology is needed to capture the dynamics of gender between and among participants and between and among sociopolitical forces and people involved in everyday hospice palliative home care. A critical ethnographic method provides the methods of interview, observation, and review of documents to capture gender relations between and among individuals and individuals and social structures. This approach provides a perspective through which to view cultural and historical influences on power relations. As social interactions shape the opportunities and constraints of health and health care (Connell, 2012; Schofield, Connell, Walker, Wood, & Butland, 2000), a critical feminist lens is valuable to examine structural influences on everyday life for clients, family caregivers, and nurses in this context. Furthermore, with a focus on the

social construction of marginalized or disadvantaged groups, this lens is essential to expose dominant ideologies and practices (Smith, 2005).

Because gender relations are often hidden, it is important to expose contradictions between statements and actions or principles and practices. Simultaneous use of interview, observation, and document review methods is important to reveal these contradictions. As contradictions can initially appear confusing, this triangulation of methods aids in the creation of knowledge and strengthens the findings. For example, contradictions had become evident when nurses stated their principled beliefs of gender equality, yet adopted ideological views reinforcing gender stereotypes to support gendered attitudes, beliefs and practices. Methods of interview, observation, and document review together helped to highlight and construct knowledge.

Similarly, a critical perspective is important to expose power relations often concealed by the propagation of values that underpin ideologies. The purpose of critical studies is to question and challenge these taken-for-granted ideas that are accepted as "truths," and examine how dominant ideologies shape cultural attitudes, beliefs, and practices to advantage some while disadvantaging others (Smith, 2005; Thomas, 2003). For this study, I questioned assumptions and everyday attitudes, beliefs and practices. I also was attentive to contradictions and examined social relations in the context of power.

One limitation of this study is the lack of representation of diverse groups. All participants were Caucasian and middle class. Additionally, all nurses were women. With the exception of one triad with neighbours as caregivers, all family caregivers were spouses, affording insight into gender relations for spousal caregivers. However, inclusion of different groups such as sons or grand-daughters may have revealed

additional findings. As social relations such as gender intersect with other relations such as ethnicity, age, and class, multiple social relations create different experiences and potentially different solutions. Thus, a diversity of social groups may have shed light on the intersections of gender with other social relations. As men and women differ in ethnicity or class within their groups, it is important to examine multiple inequities and acquire a fuller understanding of these marginalized experiences (Weber, 2005).

Additionally, I encountered recruitment and attrition issues as clients' conditions deteriorated, which may have contributed to the homogenous group represented in this study, as case managers who recruited may have felt uncomfortable with certain groups or compelled to safeguard them. In the future, I would employ specific strategies to recruit diverse groups in hospice palliative home care. I would spend more time with case managers who recruit so that they are more familiar with me and comfortable to refer potential participants to the study. Furthermore, as I spend time in the field with the case managers, I could recommend potential participants. Also, I could develop strategies to target disadvantaged groups. Such a strategy may involve joining interest groups such as support groups for clients and family members experiencing end-of-life.

Finally, the sample of six clients, six family caregivers, and four nurses may be considered small to non-qualitative researchers; however this sample generated detailed data that were sufficient to develop themes and concepts and reveal a comprehensive understanding of gender relations in hospice palliative home care (Brod, Tesler, & Christensen, 2009; Sandelowski, 1995). Furthermore, the sample size permitted in-depth analysis of data as opposed to a superficial view that may result from too large a sample size in this type of research (Sandelowski, 1995).

Nevertheless, the implications for this study move beyond hospice palliative care, as the practice, policy, and education of gender relations and/or policy advocacy can include health care encounters and situations involving various disease processes (e.g. Alzheimer's disease or congestive heart failure) and in diverse health care settings such as long term or acute care settings. Moreover, as gender relations involve and influence all health care team members and their interactions, this study has implications that extend to other health care professionals in addition to nurses.

6.4 The Research Process: Reflections and Methodological Issues

While I was aware of potential recruitment issues in conducting palliative care research, I was not prepared for the barriers that I confronted in relation to conducting research on gender relations. The word "gender," or the thought of men and women as a major organizing principle in social situations, evoked deeply rooted emotions that raised moral and social justice questions for participants and myself. I later realized that the issue of gender during the time of end-of-life was an influencing factor not only affecting the research process (e.g., interviews), but also was a unique aspect and important finding in hospice palliative home care. Conducting a gender-based study using a critical feminist perspective also raised methodological challenges for a novice researcher. In this section, I reflect on conducting gender research during end-of-life and consequently the challenges I faced concerning power, legitimation, and praxis (Denzin & Lincoln, 2005) in conducting critical feminist research.

6.4.1 Conducting gender research during vulnerable times. Recognizing the importance of reflexivity in conducting critical research, I promptly and dutifully reflected on my personal attitudes, beliefs, and practices early in the research process. I

reflected on my openness to gender relations, my unequivocal acceptance of male nurses and caregivers, and the right of women to refuse the caregiver role. I was influenced by the literature and became aware of my own reinforcement of traditional gendered assumptions. For instance, I thought about how I conceptualized "caring" as nurturing and closely associated this with women. I reflected on how I made generalizations and treated male nurses differently by elevating them to highly technical and efficient nurses. After reflecting and writing about gender, I conducted my first interviews for the study, naively thinking that I was an open and ethical nurse, student, and researcher, and that in admitting to some of my stereotypical beliefs about men and women, I had purged myself and was knowledgeable about gender and gender equity.

In actuality, I found that, because of my background, upbringing, and acceptance of taken-for-granted gendered values and behaviours, my thoughts about gender attitudes, beliefs, and practices were deeply entrenched. In essence, I "did" or performed gender, as I expressed gender and reacted to the behaviours of men and women (West & Zimmerman, 1987). As Patricia Martin (2006) states, "Even if people could leave gender at the door, gender would still be present because it was already there" (p. 255). This attests to the inescapable embedded quality of gender relations that are difficult to expose, even upon deep reflection. During initial interviews, I inadvertently reinforced gender as I commented on a female client's meticulously clean home, relating her womanhood to the appearance of the home. Because of my lack of understanding of gender relations, my reflections were superficial as I divulged my ideals about gender equity, of the ethical and righteous person that *I wanted to be*, not my actual rooted attitudes, beliefs, and practices about gender. Facing my gendered biases and assumptions was disconcerting because I

had to admit that I was not the person or nurse that I had envisioned. Indeed, I had to turn the research "gaze" on myself and expose my instinctive responses to participants' gender, class, or age and the assumptions that shaped them.

Similarly, clients, caregivers and nurses in hospice palliative home care struggled with questions about gender, and possibly offered "socially acceptable" answers, reflecting the just people whom they strove to be. Acker (2012) speaks to this point when she states that no one wants to be seen as sexist or unfair, making research about gender difficult to conduct. During a second interview, one nurse repeated "I don't know" to most questions, indicating her frustration and perhaps showing conscious awareness of possible inequitable gendered responses and behaviours. Clients and caregivers also fervently denied holding and practising gendered assumptions and biases, abruptly closing the conversation about gender. Similarly, Lewis (2007) found that study participants considered gender to be irrelevant. Also, it may be that participants felt uncomfortable because they were aware of gender inequities and yet, adhered to, and reinforced them (Lewis, 2007). Consequently, I changed my approach of asking and attempting to link each answer to gender to intently listening to participants' stories, observing gendered attitudes, beliefs, and practices, and searching for contradictions (Lather, 2004; Lewis, 2007; Martin, 2006).

Participants in hospice palliative home also struggled with gender equity issues because they were focused on the client and his or her end-of-life experience. In this sense, conducting gender research during the vulnerable time of end-of-life was at times received negatively and a challenge, as gender was denied and questions were rebuffed. Clients, caregivers, and nurses reacted to the topic of gender relations as though it was

"taboo" to stray from the priority and focus of the individual at end-of-life. While the clients' rights and experiences should be a primary focus, gender equity also is crucial. Neglecting to consider gender relations in hospice palliative home care reinforces the status quo in which women predominately provide care without adequate resources and men are excluded as they are inadvertently directed away from care. In other words, gender inequities remain, potentially causing strain, particularly during end-of-life when clients and caregivers may already face emotional, physical, and financial challenges (Funk et al., 2010; Ward-Griffin et al., 2012a, 2012b).

6.4.2 (Re)presenting participants. As gendered attitudes, beliefs and practices were often guarded or disregarded, I was concerned whether I could (re)present participants' experiences without (re)producing dominant patterns of power (England, 1994), which I sought to expose and dismantle under a critical feminist lens. Identified as the "crisis of representation," this issue challenges notions of power, legitimation, and praxis in the process of conducting qualitative research (Denzin & Lincoln, 2005). Although these challenges often blur in terms of the topic of the issues and solutions to them (Denzin & Lincoln, 2005), they are discussed separately in this section.

6.4.2.1 Issues of power. Power is fluid between researchers and study participants. Researchers exert power in the research questions asked and the study designs used, while participants may hold power during the stages of recruitment and data collection in deciding whether or not to participate in answering questions. Ultimately, researchers have power in interpreting and writing the findings (Sprague & Kobrynowicz, 2005). Strategies to counter the researcher's power are to engage in dialogic interviews, return to participants with interpretations, and focus on co-creating knowledge (England,

1994; Sprague & Kobrynowicz, 2005; Hesse-Biber, Leavy, & Yaiser, 2004). There also must be some specific strategies used to detect and interrogate one's assumptions (Hesse-Biber et al., 2004).

One strategy I employed was to be attentive to my instinctive reactions and responses to participants' social locations. In reflecting on these responses, I was able to draw out deeply rooted assumptions and biases I held. For example, recalling my father's experience of losing his ability to drive during his illness, I deeply empathized with men's reactions to losing their independence when their driver's licenses were revoked. I questioned if this reaction was rooted in traditional beliefs that men should be self-sufficient. I asked, was I reinforcing gendered expectations for men? Or is this true for both men and women? Reflection was continuous and many times uncomfortable (Sprague & Kobrynowicz, 2004) as I exposed myself as a person who at times may have reinforced gendered attitudes and behaviours. I engaged in reflection throughout the research process: in the formulation of the research questions, during data collection, interpretation and writing, in a sense, unlearning my gendered attitudes, behaviours and practices (Lather, 2004). While my deeply entrenched gendered attitudes cannot be eliminated, I remain reflexive and continually question my gendered expressions and responses.

Another strategy I used to diminish the power relationship between the researcher and the researched while avoiding a detached relationship (Hesse-Biber & Lakenby, 2005) was to attempt to connect with study participants. I participated in activities by retrieving equipment needed or at times by sharing my knowledge and experiences. I also shared my personal experiences with clients and caregivers, thus engaging in a reciprocal

relationship (Olesen, 2005). More importantly, as I gained more experience in interviewing, I attempted not to interrupt and guide the discussions, even when the topic was irrelevant. This afforded participants a chance to tell the stories that were significant and challenging to them. In this way, I could show my respect and empathy and connect with participants and avoid objectifying them. Legitimacy was thus derived from relationships and reflexivity rather than a power position of objectivity (Lather, 2004).

   6.4.2.2 Issues of legitimation. With an emphasis on epistemology and power relations in feminist critical research (Hesse-Biber, Leavy, & Yaiser, 2005), it is vital to ask: Whose stories are being told? How can I respect participants' perspectives and ensure that they are (re)presented (Kincheloe & McLaren, 2005; Lather, 2004)? Lather (2004) contends that the more relevant questions to ask are: What is the focus of my analysis? How has this knowledge been co-created? Am I representing a generalized experience, or the sociopolitical forces that shape everyday practices? In other words, I had to continually search for and question contradictions, grand narratives, dichotomies, or conventional theories. I tried not to take data at face value and easily accept closure (Lather, 1993). New to critical research, I found the implementation of these strategies challenging. However, my advisory committee members ensured that I was open to alternative views, inclusive, and yet interrogating. For example, I was questioned about men's views and how men could be disadvantaged, forcing me to examine all perspectives equitably.

   I was able to return to participants with preliminary findings. This process afforded me opportunities to further interrogate my findings and positionality. To ensure interpretations were grounded in participants' experiences, I kept an audit trail, recording

areas of confusion and decision points as well as my assumptions and biases (Guba & Lincoln, 1989). I recorded in my journal the times when I had to question if my interpretations were influenced by my own assumptions. Several decision points were made in collapsing themes. Furthermore, I was able to triangulate the different methods and strengthen findings.

I was conscious of the possibility of "false consciousness," in which dominant discourses shape understandings and organize positions in society, of which everyday people may be unaware (Lather, 1986). One female caregiver, Laura, to whom I had returned with preliminary interpretations, responded negatively to the findings and appeared to reflect neoliberal ideologies. Laura normalized nurses' behaviours in recruiting family caregivers, as well as peoples' propensities to be independent, representative of neoliberal ideologies that people should be self-sufficient and provide care for their ill relatives. Ironically, she stated that as nurses make family members "feel at home," caregivers are more willing to assume care work. In the same interview, Laura expressed the heavy social and self-expectations she felt to provide care. During the home visits, I noticed Laura's level of anxiety in assuming the role of spousal caregiver. Yet, Laura described the home care experience as one that was dependent upon personal qualities rather than social relations and social conditions. I questioned if this response was "false consciousness," related to anxiety, or, as Laura also stated, a generational phenomenon in which older people hold stricter rules of men's and women's expected attitudes, beliefs, and practices.

As I was conducting emancipatory research, my response to Laura's contradictions should have been to uncover the inconsistencies and "structures of

oppression" (Gorelik, 1991, p. 466). However, in rejecting her claims, would I be imposing my views on her, and in effect, undermining a basic feminist tenet to disrupt power relations and respect subjective knowledge (Gorelik, 1991; Smith, 1987)? How is this in keeping with the co-creation of knowledge? Lather (1986) notes that a central aspect of critical inquiry is to assist less dominant people by exposing ideologies that control understandings. If the focus of critical feminist research is to reveal discourses that distort everyday understandings (Lather, 1986), then false consciousness is inherent in this type of research. As Lather (1986) suggested, I engaged in dialogic interviews in which the researcher discloses information about her/himself, conducted sequential interviews to allow deeper probing, and negotiated interpretations. I appreciated that this type of inquiry involves deep respect for human capacity, while at the same time, skepticism of simple understandings (Lather, 1986).

Others question the concept of false consciousness because it implies that there is one truth to be revealed, of which only the researcher is aware, while the participant is not (Gorelik, 1991). Acker, Barry and Esseveld (1983) contend that this concept neglects to appreciate the agency of determined individuals who comprehend their own lives. False consciousness is thus considered to be unsatisfactory as it is related to interpretation. If a relational approach that centres on the value of respect for individuals is to be used, then people's sense of agency also must be recognized along with the structural impact on everyday lives. In this context, feminist approaches tend to place too little emphasis on agency. Yet, there is a risk of reinforcing hegemonic discourses if we are to place too much emphasis on individual agency and interpretations (Sprague, 2005).

I agree with Lather's (1986) suggestions for engaging in reciprocal reflexivity, critique, and co-creation of interpretations, while exposing dominant discourses and social relations. While reflexivity may not change the power relationships inherent in the researcher/researched relationship, ongoing reflexivity helps us to remain cognizant of hierarchies and potential unfair situations (England, 1994). Feminists agree that these issues of false consciousness, power, and validity need to be further investigated and theorized (Acker et al., 1983; Gorelik, 1991; Lather, 1986). In Laura's case, I interpreted her response as a contradiction in gender relations, while I still respected her sense of agency and situation. I will continue to reflect on these concepts as I continue to conduct critical research.

6.4.2.3 Issues of praxis. A central aspect of a feminist approach is to conduct research for, rather than about, women (Hesse-Biber & Leckney, 2004). While today feminist studies have been changed to studies concerned with gender as an organizing principle in social situations, conducting research "for" rather than "about" means taking transformative action to make changes to promote gender equity for men and women. Social change towards equity is best done from a "bottom up, top down" approach in which grass roots movements apply pressures for policy makers to work towards transformative action (Baum, 2007).

Advocacy towards social change then may occur at different levels, including the individual, organisational, and political levels. While there was evidence of conscious awareness by participants in this study, clients' and caregivers' intense focus on end-of-life was a barrier to involvement at the grass roots level. However, I may be able to follow-up with caregiver participants in due time. Given that structural influences shape

gendered attitudes, beliefs, and practices, advocacy at the policy level would be essential and in keeping with a social determinants of health approach that addresses the root causes of inequities (Reutter & Kushner, 2010).

Advocating at the policy level for gender equity first requires alliance building at all levels (Evans, 2005). I have been searching for citizen groups with common interests to reach goals of equity for older adults. For example, I have been exploring groups such as the Canadian Association of Retired Persons (CARP), End-of-Life Networks, the Canadian Caregiver Coalition, or the Canadian Home Care Association. I will determine the groups that best match shared goals of equity for men and women. Additionally, I plan to continue in leadership roles of my regional Registered Nurses' Association of Ontario (RNAO) group and the RNAO palliative care interest group association. The RNAO focuses on political advocacy and facilitates the lobbying of regional, provincial, and federal politicians. Furthermore, RNAO takes on social issues and facilitates actions towards them. More recently, RNAO endorsed the policy of affording refugees health care (RNAO, 2014). The palliative care interest group has associations with the Hospice Palliative Care Association and de Souza Institute, and while this group is in its nascent stages, it is well connected. I will unite my roles as researcher, educator, and activist to continue to educate, advocate, and research gender inequities, particularly during end-of-life.

6.5 Conclusion

As gender equity is crucial to achieving quality hospice palliative home care, the focus of this research was to examine gender relations in this context. Employing a critical feminist lens, the purpose of this critical ethnographic study was to examine

gender relations in the sociopolitical context of hospice palliative home care, reveal gendered processes, and expose the socially constructed mechanisms that (re)produce gender (in)equities. Findings from this study illuminated the sociopolitical impact on day-to-day gendered expectations and exemptions, gendered processes, and the consequent gender inequities in hospice palliative home care. If we are to achieve quality and equitable hospice palliative home care, institutions and health care providers must acknowledge and be aware of gender relations as dynamic social interactions that affect health and health care. This study was important to shed light on how professional associations and educational institutes can support health care providers toward equitable practices. More specifically, study findings reflect the need for the nursing profession to take a lead and revisit gender relations and redress gender inequities. As an ethical and human rights issue, there is a moral imperative for nursing to pay attention to gender relations and equity in health care encounters. This is vital to maintain the integrity of the profession.

6.6 References

Acker, J., (1992). Gendered Institutions: From sex roles to gendered institutions. *Contemporary Sociology, 21* (5), 565-569.

Acker, J., Berry, K., & Esseveld, J. (1983). Objectivity and truth: Problems in doing feminist research. *Women's Studies International Forum, 6,* 423-435.

Acker, J. (2012). Gendered organizations and intersectionality: problems and possibilities. *Equity, Diversity and Inclusion*. 31 (3), 214-224. doi: 10.1108/02610151211209072

Armstrong, P., & Armstrong, H. (2002). *Thinking it through: women, work and caring in the new millennium.* Halifax, NS: Maritime Centre of Excellence for Women's Health. Retrieved from: http://www.cewh-cesf.ca/PDF/acewh/thinking.pdf

Armstrong, P. & Armstrong, H. (2005). Public and private: Implications for care work. *The Sociological Review, 53* (s2), 167-187. doi: 10.1111/j.1467-954X.2005.00579.x

Armstrong, P. (2009). Public policy, gender, & health. In D. Raphael (Ed.), *Social determinants of health: A Canadian perspective* (pp. 350-361).

Atkinson, P., & Hammersley, M. (2007). *Ethnography: Principles in practice* (3rded.).New York: Routledge.

Baum, F. (2007). Cracking the nut of health equity: top down and bottom up pressure for action on the social determinants of health. *Promotion & Education, 14* (2), 90-98. doi: 10.1177/10253823070140022002

Baum, F., Begin, M., Houweling, T., Taylor, S. (2009). Changes not for the fainthearted: reorienting health care systems toward health equity through action on social determinants of health. *American Journal on Public Health, 99* (11), 1967-1974.

Brod, M., Tesler, L., & Christensen, T. (2009). Qualitative research and content validity: developing best practices based on science and experience. *Qualitative of Life Research, 18*: 1262-1278. doi: 10.1007/s11136-009-9540-9

Brodie, J. (2002). The great undoing: State formation, gender politics, and social policy in Canada. In C. Kingfisher (Ed.) *Western welfare in decline: Globalization and women's poverty.* Philadelphia: University of Philadelphia Press.

Brown, M. (2004). Between neoliberalism and cultural conservatism: spatial divisions and multiplications of hospice labor in the United States. *Gender, Place and Culture, 11* (1), 67-82. doi:10.1080/0966369042000188558

Browne, A. (2001). The influence of liberal political ideology on nursing science. *Nursing Inquiry, 8,* 118-129.

Celik, H., Largo-Janssen, T., Widdershoven, G., & Abma, T. (2011). Bringing gender sensitivity into healthcare practice: A systematic review. *Patient Education and Counseling, 84*, 143-149. doi: 10.1016/j.pec.2010.07.016

Clemmer, S., Ward-Griffin, C., & Forbes, D. (2008). Family members providing home-based palliative care to older adults: The enactment of multiple roles. *Canadian Journal on Aging, 27* (3), 267-283.

Connell, R. (2012). Gender, health and theory: Conceptualizing the issue, in local and world perspective. *Social, Science, & Medicine, 74*, 1675-1683.

Crenshaw, K. (1991). Mapping the margins: Intersectionality, identity politics, and violence against women of color. *Stanford Law Review, 43*, 1241-1299.

Denzin, N., & Lincoln, Y. (2005). The discipline and practice of qualitative research. In N. Denzin & Y. Lincoln (Eds.) *The sage handbook of qualitative research* (3rd ed.) (pp 1-33).

Dhamoon, R., Hankivisky, O. (2011). Why the theory and practice of intersectionality matter to health research and policy. In O. Hankivsky, S. deLeeuw, J. Lee, B. Vissandjee, N. Khanlou (Eds*.), Health inequities in Canada: Intersectional frameworks and practices* (pp. 16-50). Vancouver: UBC Press.

Doane, G., & Varcoe, C. (2005). *Family nursing as relational inquiry: Developing health promoting practice.* Philadelphia: Lippincott Williams & Wilkins.

England, K. (2010). Home, work and the shifting geographies of care. *Ethics, Place and Environment, 13* (2), 131-150. doi: 10.1080/13668791003778826

England, K. (1994). Getting personal: reflexivity, positionality and feminist research. *Professional Geographer, 46* (1), 80-89.

Evans, K. (2005). A guide to feminist advocacy. *Gender and Development, 13* (3), 10-19. Retrieved from: http://www.jstor.org/stable/20053159

Falk-Rafael, A. (2005). Speaking truth to power: Nursing's legacy and moral imperative. *Advances in Nursing Science, 28* (3), 212-223.

Fast, J., Keating, N., Otfinowski, P., & Derksen, L. (2004). Characteristics of family/friend care networks of frail seniors. *Canadian Journal on Aging, 23* (1), 5-19.

Funk, L. & Stajduhar, K. (2010). Home-based family caregiving at the end of life: a comprehensive review of published qualitative research (1998-2008*). Palliative Medicine, 24 (6)*, 594-607. doi: 10.1177/0269216310371411

Gorelick, S. (1991). Contradictions of feminist methodology. *Gender & Society, 5*, 459-479. doi: 10.1177/089124391005004002

Graham, H. (2004). Social determinants and their unequal distribution: Clarifying policy understandings. *The Milbank Quarterly, 82*,1, 101-124.

Guba, E., & Lincoln, Y. (1989). *Fourth generation evaluation*. Newbury Park: Sage Publications.

Hall, J., & McWilliam, C. (2006). About the culture of in-home nursing. *Home Health Care Services Quarterly, 25* (3/4), 75-90. doi: 10.1300/j027v25n3_05

Hall, S. (2000). *Racist ideologies and the media in Media Studies: A reader*. New York: New York University Press.

Hankivsky, O., & Christoffersen, A. (2008). Intersectionality and the determinants of health: a Canadian perspective. *Critical Public Health, 18* (3), 271-283.

Hesse-Biber, S., Leavy, P., & Yaiser. Feminist approaches to research as a process: reconceptualising epistemology, methodology, and method. In S. Hesse-Biber & L. Yaiser (Eds.). *Feminist perspectives in social research* (pp 3-26) New York: Oxford University Press.

Hesse-Biber, S., & Leckney, D. (2004). How feminists practice social research. In S. Hesse-Biber & L. Yaiser (Eds.). *Feminist perspectives in social research* (pp 209-226) New York: Oxford University Press.

Kincheloe, J., & McLaren, P. (2005). Rethinking critical theory and qualitative research. In N. Denzin& Y. Lincoln (Eds.), *Handbook of qualitative research* (pp. 303-342) (3rded.). Thousand Oaks: Sage Publications.

Lather, P. (1986). Research as praxis. *Harvard Educational Review, 56* (3), 257-277.

Lather, P. (1993). Fertile obsession: validity after poststructuralism. *The Sociological Quarterly, 34* (4), 673-693.

Lather, P. (2004). Critical inquiry in qualitative research: Feminist and poststructural perspectives science 'after truth'. In K. deMarrais & S. Lapan (Eds.) *Foundations for research: Methods of inquiry in education and the social sciences* (pp 203-215)*.*Mahwah: Lawrence Erlbaum Associates, Inc.

Lewis, L. (2007). Epistemic authority and the gender lens. *The Sociological Review, 55* (2), 273-292. doi: 10.1111/j.1467-954X.2007.00705.x

McGregor, S. (2001). Neoliberalism and health care*. International Journal of Consumer Studies, 25 (*2), 82-89.

McWilliam, C., Ward-Griffin, C. Oudshoorn, A., Krestick, E. (2008). Living while dying/dying while living: Older clients' sociocultural experience of home-based palliative care. *Journal of Hospice and Palliative Care, 10* (6), 338-349. doi: 10.1097/01.NJH.0000319190.93906.7d

Martin, P. (2004). Gender as social institution. *Social Forces, 82* (4), 1249-1273.

Martin, P. (2006). Practising gender at work: further thoughts on reflexivity. *Gender, Work and Organization, 13* (3), 254-276. doi: 10.1111/j.1468-0432.2006.00307.x

Martin-Matthews, A., Sims-Gould, J., Tong, C. (2012). Canada's complex and fractionalized home care context: Perspectives of workers, elderly clients, family carers, and home care managers. *Canadian Review of Social Policy, 68-69*, 55-74.

Olesen, V. (2005). Early millennial feminist qualitative research: challenges and contours. In N. Denzin & Y. Lincoln (Eds.) *The sage handbook of qualitative research* (3rd ed.) (pp 235-278).

Ottawa Charter.(1986). *Ottawa Charter for Health Promotion.* First International Conference on Health Promotion.Ottawa, 21 November 1986 - WHO/HPR/HEP/95.1Retrieved from http://www.who.int/hpr/NPH/docs/ottawa_charter_hp.pdf

Raphael, D. (2012). The importance of tackling health inequalities. In D. Rapheal (Ed.), *Tackling health inequalities: Lessons from international experiences* (pp 1-33). Toronto: Canadian Scholar's Press.

Raphael, D., & Curry-Stevens, A. (2004). Addressing and surmounting the political and social barriers to health. In D. Raphael (Ed.). *Social determinants of health: Canadian perspectives*.Toronto: Canadian Scholars' Press.

Registered Nurses' Association of Ontario. *Urgent action required: Reject dangerous cuts to refugee health care.* Retrieved from: http://rnao.ca/news/urgent-action-required-reject-dangerous-cuts-refugee-health-care

Reimer Kirkham, S., Browne, A. (2006). Toward a critical theoretical interpretation of social justice discourses in nursing. *Advances in Nursing Science, 29* (4), 324-339. Retrieved from:

http://journals.lww.com/advancesinnursingscience/Abstract/2006/10000/Toward_
a_Critical_Theoretical_Interpretation_of.6.aspx

Reutter, L., & Duncan, S. (2002). Preparing nurses to promote health-enhancing public policies. *Policy, Politics & Nursing Practice, 3* (4), 294-305.

Reutter, L., & Kushner, K. (2010). Health equity through action on the social determinants of health: Taking up the challenge in nursing. *Nursing Inquiry, 17* (3), 269-280. doi: 10.1111/j.1440-1800.2010.00500.x

Ridgeway, C. (2009). Framed before we know it: How gender shapes social relations. *Gender & Society, 23* (2), 145-160. doi: 1177/0891242083330313

Risberg,, G., Johanssonb, E., Hamberg, K. (2011). 'Important…but of low status': male education leaders' views on gender in medicine. *Medical Education, 45*, 613-645. doi: 10.1111/j.1365-2923.2010.03920.x

Sandelowski, M. (1995). Focus on qualitative methods: Sample size in qualitative research. *Research in Nursing and Health, 18,* 179-183.

Schofield, T., Connell, R., Walker, L., Wood, J., & Butland, D. (2000). Understanding men's health and illness: A gender relations approach to policy, research and practice. *Journal of American College, 48* (6), 247-256.

Sen, G., & Ostlin, P. (2008). Gender inequity in health: why it exists and how we can change it. *Global Public Health, 3* (S1), 1-12.

Smith, D. (1987). The everyday world as problematic. Massachusetts: Northeastern Press.

Smith, D. (2005). Women's Standpoint: Embodied knowledge versus the Ruling Relations. In *Institutional ethnography: A sociology for people* (pp. 7-26) Maryland: Alta Mira Press.

Sprague, J. (2005). *Feminist methodologies for critical researchers: Bridging differences*. New York: Altamira.

Sprague, J. & Kobrynowicz D. (2005). A feminist epistemology. In S. Hesse-Biber & L. Yaiser (Eds.). *Feminist perspectives in social research* (pp 78-100) New York: Oxford University Press.

Stajduhar, K., Funk, L., Toye, C., Grande, G., Aoun, S., & Todd, C. (2010). Part 1: Home-based family caregiving at the end of life: A comprehensive review of published quantitative research. *Palliative Medicine, 24* (6), 573-93. doi: 10.1177026921631034471412

Thomas, J. (1993). *Doing critical ethnography*. Newbury Park, California: Sage publications.

Thomas, J. (2003). Critical ethnography, meanings, and symbolic violence. In R.B. Clair (Ed.), *Expressions of Ethnography: Novel approaches to qualitative research* (pp 45-65). Albany: State University of New York.

Titus, J. (2000). Engaging student resistance to feminism: 'how is this stuff going to make us better teachers?' *Gender and Education, 12 (1)*, 21-37. doi: 10.1080/09540250020382

Ward-Griffin, C., McWilliam, C., Oudshoorn, A. (2012a). Negotiating relational practice patterns in palliative home care. *Journal of Palliative Care, 28* (2), 33-40. doi: 10.1177/1074840712462134

Ward-Griffin, C., McWilliam, C., Oudshoorn, A. (2012b). Relational experiences of family caregivers providing home-based end-of-life care. *Journal of Family Nursing, 18* (4), 91-516. doi: 10.1177/1074840712462134

Weber, L. (2005). Reconstructing the landscape of health disparities research: Promoting

dialogue and collaboration between feminist intersectional and biomedical

paradigms. In A. Schulz, & L. Mullings (Eds.), *Gender, race, class, and health:

Intersectional approaches* (pp. 21-59). San Francisco: Jossey-Bass.

West, C., & Zimmerman, D. (1987). Doing gender. *Gender & Society, 1* (2), 125-151.

World Health Organization (2014). *WHO definition of palliative care*. Retrieved from:

http://www.who.int/cancer/palliative/definition/en/

Appendices

Appendix A: Research Ethics Board Approvals

Use of Human Participants - Ethics Approval Notice

Research
Western

Principal Investigator: Dr. Catherine Ward-Griffin
File Number:102141
Review Level:Delegated
Approved Local Adult Participants:30
Approved Local Minor Participants:0
Protocol Title:Gender and Class Relations in Hospice Palliative Home Care for Clients with Cancer and their Family Caregivers: A Critical Analysis - 18697E
Department & Institution:Health Sciences\Nursing,Western University
Sponsor:deSouza Institute

Ethics Approval Date:April 05, 2012 Expiry Date:December 31, 2013
Documents Reviewed & Approved & Documents Received for Information:

Document Name	Comments	Version Date
Revised Western University Protocol	Administrative changes to the letter of information and the notice of recruitment script have been requested by the research partner.	
Other	Notice of Recruitment for Clients and Caregivers.	2012/04/05
Revised Letter of Information & Consent	Clients	2012/04/05
Revised Letter of Information & Consent	Family Caregivers	2012/04/05
Revised Letter of Information & Consent	Primary Nurses Assigned Care to Clients and Family Caregivers	2012/04/05

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement:Å Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the University of Western Ontario Updated Approval Request Form.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The HSREB is registered with the U.S. Department of Health & Human Services

Ethics Officer to Contact for Further Information

This is an official document. Please retain the original in your files.

The University *of* Western Ontario
Office of Research Ethics

Western Research

Research Ethics

Use of Human Participants - Ethics Approval Notice

Principal Investigator: Dr. Catherine Ward-Griffin
File Number: 102141
Review Level: Delegated
Approved Local Adult Participants: 30
Approved Local Minor Participants: 0
Protocol Title: Gender and Class Relations in Hospice Palliative Home Care for Clients with Cancer and their Family Caregivers: A Critical Analysis - 18697E
Department & Institution: Health Sciences\Nursing,Western University
Sponsor: deSouza Institute

Ethics Approval Date: February 07, 2013 **Expiry Date:** December 31, 2014
Documents Reviewed & Approved & Documents Received for Information:

Document Name	Comments	Version Date
Revised Study End Date	The study end date has been extended to December 31, 2014 to allow for continuation of the study.	

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the University of Western Ontario Updated Approval Request Form.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Signature

Ethics Officer to Contact for Further Information

This is an official document. Please retain the original in your files.
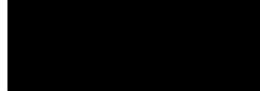
Western University, Research,

HOMEWOOD

improving life

May 17, 2012

Nisha Sutherland, PhD (Candidate),
Primary Investigator,

██████████████

"Gender and Class Relations in Hospice Palliative Home Care for
Clients with Cancer and their Family Caregivers: A Critical Analysis."

This is to confirm that approval has been granted for the above-mentioned study on behalf of WWCCAC.
Should your study continue for more than one year, you are required to request a renewal at least 2
weeks before the expiry date, May 16, 2013.

Please know that further approval is required from Homewood Research Ethics Board (REB) prior to
making any significant changes to the protocol, consent process or advertisement of the study.

Homewood REB needs to be promptly informed of adverse events and/or reactions that may arise from
this study as per standard practice.

All researchers are required to enter into a Privacy Agreement with the appropriate custodian of clients'
personal health information prior to the commencement of the study. All researchers and their staff are
responsible for possessing knowledge of, and ensuring compliance with, privacy legislation
requirements, e.g. Personal Health Information Protection Act, 2004.

Upon completion of the study, Homewood REB would appreciate confirmation of the completion of the
study and a brief summary of the results.

Homewood REB is constituted and functions in accordance with the ICH GCP and the Tri-Council Policy
Statement (Ethical Conduct for Research Involving Humans) guidelines 2.

With best wishes,

██████████████

██████████████, Homewood Health Centre Research Ethics Board

██████████████████████████

████████████████████████████████████

HOMEWOOD

improving life

April 16, 2013

Nisha Sutherland, PhD (Candidate),
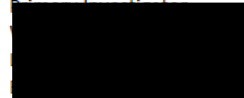
**"Gender and Class Relations in Hospice Palliative Home Care for
Clients with Cancer and their Family Caregivers: A Critical Analysis."**

This is to confirm that re-approval has been granted, as per your request dated April 13, 2013, for the above-mentioned study on behalf of WWCCAC until December 31, 2013. You are required to request a renewal at least 2 weeks before this expiry date should you wish to extend this study.

Please know that further approval is required from Homewood Research Ethics Board (REB) prior to making any significant changes to the protocol, consent process or advertisement of the study.

Homewood REB needs to be promptly informed of adverse events and/or reactions that may arise from this study as per standard practice.

All researchers are required to enter into a Privacy Agreement with the appropriate custodian of clients' personal health information prior to the commencement of the study. All researchers and their staff are responsible for possessing knowledge of, and ensuring compliance with, privacy legislation requirements, e.g. Personal Health Information Protection Act, 2004.

Upon completion of the study, Homewood REB would appreciate confirmation of the completion of the study and a brief summary of the results.

Homewood REB is constituted and functions in accordance with the ICH GCP and the Tri-Council Policy Statement (Ethical Conduct for Research Involving Humans) guidelines 2.

With best wishes,

, Homewood Health Centre Research Ethics Board

HOMEWOOD CORPORATION • HOMEWOOD HEALTH CENTRE • HOMEWOOD EMPLOYEE HEALTH • OAKWOOD RETIREMENT COMMUNITIES

www.homewood.org

Appendix B: Notice of Recruitment for Clients and Caregivers

You are being invited to participate in a research study that I am conducting for my PhD dissertation at the University of Western Ontario. The title of the study is, "Gender and Class Relations in Hospice Palliative Home Care for Clients with Cancer and their Family Caregivers: A Critical Analysis."

The purpose of this study is to look at how the interconnecting influences of income, education and being a man or a woman affect relationships and experiences in palliative home care. Information from this study will help to identify health promoting strategies for fair, high-quality hospice palliative home care for clients and families with cancer.

If you take part in the study, you will be asked the following:

- To participate in two to three interviews with me in your home lasting approximately 50 to 75 minutes. I will be recording the interviews.
- To allow me to come on two visits with your home care nurse so that I can learn more about how you work with the nurse.
- To complete a form asking your age, income level, and educational level.

There are no known risks involved in participating in this study. Talking about these issues may result in some unexpected emotional reactions. I will have a list of resources that you can call if needed. You may stop the study at any time, even after the study has started. Any information that you will provide will not be identified to you, as your name will not be on any documents. You may not benefit directly from this study; however, your participation may help others in similar situations.

If you have any questions about this study, please feel free to contact me, Nisha Sutherland, PhD Student, by telephone at ▓▓▓▓▓▓▓ or by e-mail at ▓▓▓▓▓▓ or my supervisor, Dr. Catherine Ward-Griffin, Professor, Arthur Labatt School of Nursing, at ▓▓▓▓▓▓▓▓▓▓▓▓▓▓▓▓▓

Appendix C-1: Letter of Information for Clients

Western

Gender and Class Relations in Hospice Palliative Home Care for Clients with Cancer and their Family Caregivers: A Critical Analysis

As a client with cancer receiving hospice palliative home care with a focus on quality of life, you are being invited to participate in a research study that I am conducting for my PhD dissertation at the University of Western Ontario. The purpose of this study is to look at how the interconnecting influences of income, education and being a man or a woman affect relationships and experiences in hospice palliative home care. The study will involve approximately 5 clients, 5 family caregivers and 5 nurses. Information from this study will help to identify health promoting strategies for fair, high-quality hospice palliative home care for clients with cancer and their family caregivers.

If you take part in the study, I will be asking you to participate in two interviews in your home lasting approximately 50 to 75 minutes. You will have a choice of being interviewed alone or with your relative. I will be audiotaping the interviews and will be typing them at a later time. I will also be observing two home care visits from the nurse and may be taking notes after. Your primary nurse will also be interviewed at a later date and time. Before the interviews and home care visits, I will ask you to complete a form that asks for information about your age, educational level, and other details that will help me describe the people participating in the study.

There are no known risks involved in participating in this study, however you may feel emotional upset. I will have a list of resources for you to call if needed. You may stop the study at any time, even after the study has started. Information that you provide will be kept confidential. Your names will be removed from all documents and reports, and will be replaced with coded numbers. All information will remain in a secure location for 7 years and will only be available to me and my PhD advisory committee. The results of this study will be written for publication and presented at appropriate academic conferences; however, the results will be presented with other participants and you will never be personally identified. You may not benefit directly from this study; however, your participation may help others in similar situations.

You will be given a copy of this letter of information and consent form once it is signed. A summary of the findings will be provided to you if you wish. Please provide contact information if you would like to receive a copy of the study findings.

If you have any questions about this study, please feel free to contact me, Nisha Sutherland, PhD Student, by telephone at▬▬▬▬▬ or by e-mail at ▬▬▬▬@▬▬▬▬or my supervisor, Dr. Catherine Ward-Griffin, Professor, Arthur Labatt Family School of Nursing at ▬▬▬▬▬▬▬▬ or by e-mail at ▬▬▬▬▬▬If you have any questions about the conduct of this study or your rights as a research participant, please contact the Director, Office of Research Ethics, The University of Western Ontario, ▬▬▬▬▬▬

Western

<u>Appendix C-2: Letter of Information for Family Caregivers</u>

Gender and Class Relations in Hospice Palliative Home Care for Clients with Cancer and their Family Caregivers: A Critical Analysis

As a family member caring for a relative with cancer and receiving hospice palliative home care with a focus on quality of life, you are being invited to participate in a research study that I am conducting for my PhD dissertation at the University of Western Ontario. The purpose of this study is to look at how the interconnecting influences of income, education and being a man or a woman affect relationships and experiences in palliative home care. The study will involve approximately 5 clients, 5 family caregivers and 5 nurses. Information from this study will help to identify health promoting strategies for fair, high-quality hospice palliative home care, particularly for clients with cancer and their caregivers.

If you take part in the study I will be asking you to participate in two to three interviews in your home lasting approximately 50 to 75 minutes. You will have a choice of being interviewed alone or with your relative. I will be audiotaping the interviews and typing them at a later time. I will also be observing two home visits by your nurse and writing notes after. Your primary nurse will also be interviewed at a later date and time. Before the interviews and home care visits, I will ask you to complete a form that provides information about your age, educational level, and other details that will help me describe the people participating in the study.

There are no known risks involved in participating in this study, however you may feel emotional upset. I will have a list of resources for you to call if needed. You may stop the study at any time, even after the study has started. Information that you provide will be kept confidential. Your names will be removed from all documents and reports and will be replaced with coded numbers. All information will remain in a secure location for 7 years and will only be available to me and my PhD supervisory committee. The results of this study will be written for publication and presented at appropriate academic conferences; however, the results will be presented with other participants and you will never be personally identified. You may not benefit directly from this study; however, your participation may help others in similar situations.

You will be given a copy of this letter of information and consent form once it is signed. A summary of the findings will be provided to you if you wish. Please provide contact information if you would like to receive a copy of the study findings.

If you have any questions about this study, please feel free to contact me, Nisha Sutherland, PhD Student, by telephone at ▮▮▮▮▮ or by e-mail at ▮▮▮▮▮▮, or my supervisor, Dr. Catherine Ward-Griffin, Professor, Arthur Labatt Family School of Nursing at ▮▮▮▮▮▮ or by e-mail at ▮▮▮▮▮ If you have any questions about the conduct of this study or your rights as a research participant, please contact the Director, Office of Research Ethics, The University of Western Ontario, ▮▮▮▮▮

Appendix C-3: Letter of Information for Primary Nurses Assigned Care to Clients and Family Caregivers

Gender and Class Relations in Hospice Palliative Home Care for Clients with Cancer and their Family Caregivers: A Critical Analysis

As a primary nurse assigned to clients with cancer and family members receiving hospice palliative home care with a focus on quality of life, you are being invited to participate in a research study that I am conducting for my PhD dissertation at University of Western Ontario. The purpose of this study is to look at how the interconnecting influences of income, education and being a man or a woman affect relationships and experiences in hospice palliative home care. The study will involve approximately 5 clients, 5 family caregivers and 5 nurses. Information from this study will help to identify health promoting strategies for fair, optimal hospice palliative home care for clients and families with cancer.

If you take part in the study, you will be asked to participate in two to three interviews at a place and time that is convenient to you. The interviews will last approximately 50 to 75 minutes. Interviews will be audiotaped and transcribed. I will also be observing two home care visits that you make, and taking notes after. Before the interviews and home care visits, you will also be asked to complete a demographic questionnaire that asks information about your age, educational level, and other details that will help me describe the people participating in the study.

There are no known risks involved in participating in this study. You may stop the study at any time, even after the study has started. Information that you provide will be kept confidential. Your name will be removed from all documents and reports and will be replaced with coded numbers. All information will remain in a secure location for 7 years and will only be available to me and my PhD supervisory committee. The results of this study will be written for publication and presented at appropriate academic conferences; however, the results will be presented with other participants and you will never be personally identified. You may not benefit directly from this study; however, your participation may help others in similar situations.

You will be given a copy of this letter of information and consent form once it is signed. A summary of the findings will be provided to you if you wish. Please provide contact information if you would like to receive a copy of study findings.

If you have any questions about this study, please feel free to contact me, Nisha Sutherland, PhD Student, by telephone at ▮▮▮▮▮▮▮▮▮ by e-mail at ▮▮▮▮▮▮▮▮▮ or my supervisor, Dr. Catherine Ward-Griffin, Professor, Arthur Labatt Family School of Nursing at ▮▮▮▮▮▮▮▮▮ or by e-mail at ▮▮▮▮▮▮▮▮▮ If you have any questions about the conduct of this study or your rights as a research participant, please contact the Director, Office of Research Ethics, The University of Western Ontario ▮▮▮▮▮▮▮▮▮

Appendix D

Consent Form

Consent Form

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate in the research project, "Gender and Class Relations in Hospice Palliative Home Care for Clients with Cancer and their Family Caregivers: A Critical Analysis" conducted by Nisha Sutherland, doctoral student, from the University of Western Ontario. I have been provided with the opportunity to discuss this research, and all my questions have been answered to my satisfaction.

Participant (Print name)

_____

Signature of Participant   Date

_____   _____

Individual Obtaining Consent (Print name)

_____

Signature   of Individual Obtaining Consent

_____

Appendix E

Demographic Table

	Age	Cancer (Date Diagnosed)	Education	Occupation	Employment Status	Annual Income
1. Client- Caregiver-Nurse Triad						
Barb	71	Ovarian (May 2009)	Grade 9	Factory worker	Retired	$10-19,000
Gerry	82		Grade 8	Inspector	Retired	Chose not to answer
Veronica	49		College Diploma *CAPCE	General Category Nurse	Part-time	$60-80,000
2. Client- Caregiver-Nurse Triad						
Carol	70	Colon (Oct 2008)	High School Diploma	Store Clerk	Retired 2007	$10 to 19,000
Bob	82		Grade 8	Paratrooper; salesman; factory worker; bus driver	Retired 1995	$10 to 19,000
Veronica (as noted above)						
3. Client-Caregiver-Nurse Triad						
Rick	72	Pancreas (Sept 2011)	High School Diploma	Head Custodian	Retired	$30 to 39,000
Terri	65		High School Diploma	Store Clerk	Disability	$10 to 19,000
Lori	30		University Degree Palliative care training by agency	General Category Nurse	Full Time	$60-80,000
4. Client- Caregiver- Nurse Triad						
Tom	75	Lung (May 2012)	High School Diploma	Security guard; Auxiliary policeman	Retired	Canada Pension
Dan	68		Grade 8	Retired taxi driver	Retired	$10-19,000

	Age	Cancer (Date Diagnosed)	Education	Occupation	Employment Status	Annual Income
Dora	67		College diploma	Food service worker	Retired	Chose not to answer
Melanie	50		College Diploma Palliative Care Courses	General Category Nurse	Part-time	$30 – 39,000
5. Client- Caregiver-Nurse Triad						
Stan	69	Brain (May 2009)	High School Diploma	Quality Engineer	Retired	Chose not to answer
Laura	69		College Diploma	"Domestic engineer"	Retired	Chose not to answer
Helen	63		University Degree *CAPSE	General Category Nurse	Full-time	Greater than $80,000
6. Client-Caregiver-Nurse Triad						
Janet	1948 (64)	Ovarian (Oct 2011)	High School Diploma	Store Clerk	Retired due to illness/sick leave	$10 to 19,000
Jeff	1948 (64)		College Diploma	Millwright	Retired 4 weeks prior to study	$40 to 49,000
Helen (as noted above)						

* CAPSE: Comprehensive Advanced Palliative Care Education

Appendix F-1: Client Demographic Questionnaire

1. **What year were you born?** _____

2. **When were you first diagnosed with cancer?** _____

3. **What type of cancer do you have?**

   □ brain □   □ colorectal   □ lung   □ prostate

   □ bladder   □ renal   □   □ stomach   □ liver

   □ other (please specify)_____

4. **What is your highest level of education?**

   □ Below High School   □ □ High School Diploma □ □ College

   Diploma

   □ Baccalaureate Degree   □ Masters/ PhD Degree   □

   Other_____

5. **What is your occupation?** _____

6. **What is your employment status?**

   □ Retired   □ Sick leave   □ Other (Casual,

   contract)

   □ Unemployed   □ Disability

7. **What was your 2010 personal income level before taxes?**

   □ $0 to $9,999   □ $30,000 to $39,999   □ $60,000 to

   $79,999

   □ $10,000 to $19,999   □ $40,000 to $49,999   □ greater than

   $80,000

   □ $20,000 to $29,999   □ $50,000 to 59,999

Appendix F-2: Family Caregiver Demographic Questionnaire

1. **What year were you born?** _____

2. **What is your highest level of education?**

    □ Below High School   □ □ High School Diploma □ □ College

    Diploma

    □ Baccalaureate Degree   □ Post-Graduate Degree   □

    Other_____

3. **What is your occupation?** _____

4. **What is your employment status?**

    □ Retired   □ Part-time   □ Other (Casual, contract)

    □ Unemployed   □ Full-time

5. **What was your 2010 personal income level before taxes?**

    □ $0 to $9,999   □ $30,000 to $39,999   □ $60,000 to

    $79,999

    □ $10,000 to $19,999   □ $40,000 to $49,999   □ greater than

    $80,000

    □ $20,000 to $29,999   □ $50,000 to 59,999

Appendix F-3: Nurse Demographic Questionnaire

1. **What year were you born?** _____

2. **What is your nursing classification?**

   □ General □ Extended Class

3. **What is your highest level of education?**

   □ Below High School □ □ High School Diploma □ □ College Diploma

   □ Baccalaureate Degree □ Masters/PhD Degree □

   Other_____

4. **What is your employment status?**

   □ Full-time (>than 30 hours/week) □ Part-time (<30 hours/week)

   □ Other (casual or contract)

5. **What was your 2010 household income level before taxes?**

   □ $0 to $9,999 □ $30,000 to $39,999 □ $60,000 to $79,999

   □ $10,000 to $19,999 □ $40,000 to $49,999 □ greater than $80,000

   □ $20,000 to $29,999 □ $50,000 to 59,999

6. **What specialist training have you had in hospice palliative care?**_____

Appendix G-1: Client Interview Guide

1. Tell me what it is like to receive hospice palliative home care.

2. What is it like to be a mother/wife (father, husband) in hospice palliative home care?

3. Does being a man/woman affect the care that you receive in hospice palliative home care?

   Probes: How does being a man/woman affect the care you receive in hospice palliative home care? How does being a man/ woman affect your relationships with your family member or friend/ and the nurse(s)? OR Can you give me an example of when being a man/ woman did not matter with respect to the care you received?

4. What is it like to be a (occupation e.g. accountant) and receive hospice palliative home care?

   Probes: How does being a (occupation) affect the care that you receive? How does being a (occupation) affect your relationship with your family member or friend/ and the nurse(s)? OR Can you give me an example of how this occupation has not affected this experience?

5. Does your level of education affect the care that you receive in hospice palliative home care?

   Probes: How does your education affect the care that you receive in hospice palliative home care? How does your level of education affect your relationship with your family member or friend/ and the nurse(s)? OR Can you give me an

example of when your education did not affect your hospice palliative care experience?

6. Does your level of income/ financial status affect the care that you receive in hospice palliative home care?

Probes? How does your level of income/financial status affect the care that you receive in hospice palliative home care? How does your level of income/financial status affect your relationships in hospice palliative home care? Can you give me an example of how your level of income/financial status did not affect your experiences in this context?

7. Do your different class statuses (education, occupation, level of income) affect your hospice palliative care experiences?

Probes: How do your class statuses affect your experiences? How do your class statuses affect your relationships? OR Can you give me an example of when your class statuses did not affect your hospice palliative care experiences?

8. How does being a man/woman in your different class statuses affect your hospice palliative care experiences?

Probes: What are some daily challenges you face in relation to your gender and class? OR Can you give me an example of when your gender and class did not affect your experience?

9. What kinds of personal and professional supports do you have to help you to stay at home?

Probes: How does your gender and class affect the kind of support you are receiving?

10. In the context of receiving hospice palliative home care, how would you describe your relationship with your family caregiver/friend?

Probes: How does your family caregiver/friend involve you in your own care? How does gender and class affect this relationship? What would you like changed about this care, if anything? What would you like to see changed in this relationship? Describe, explain, elaborate, give an example.

11. How would you describe your relationship with your primary nurse?

Probes: How does gender and class affect this relationship? Does your gender and class help and/or hinder the relationship? How have the class and gender of the nurse affected this relationship? Give examples. What would you like to see changed in this relationship?

12. How are care decisions made in relation to your nurse?

Probes: How does the nurse involve you in your own care? Does your class and gender influence how much you are involved/not involved? What concerns can/can't you discuss with your nurse(s)? Give an example. What would you like to see changed in relation to care decisions?

13. How has participating in this study changed your views? Behaviours?

14. Is there anything you would like to talk about before we end the interview?

Appendix G-2: Family Caregiver Interview Guide

1. Tell me what it is like to receive hospice palliative home care.

2. Tell me how your gender (being a man or a woman) and class (education, income, occupation) affect the care that you receive in hospice palliative home care?

3. What kinds of personal and professional supports do you have to help your care recipient (husband, wife, son, daughter, friend, niece, nephew, uncle, aunt) stay at home?

   Probes: Tell me how you were able to get this help/these services.

   How does your gender and class affect the kind of support you are receiving?

4. In the context of receiving hospice palliative home care, how would you describe your relationship with your care recipient?

   Probes: How does your gender or class affect your role in hospice palliative home care? How does the gender and class of your care recipient affect your role in hospice palliative home care? What would you like changed about this care, if anything? Describe, explain, elaborate.

5. How would you describe your relationship with the primary nurse?

   Probes: How does your gender and class affect this relationship? How does your gender and class help or hinder the relationship? How have the class and sex of the nurse affected this relationship?

6. How are care decisions made in relation to the nurse?

<u>Probes</u>: How does the nurse involve you in your own care? How does your class and gender influence how much you are involved/not involved? What concerns can/can't you discuss with your nurse(s)?

7. What would you like to see changed in the relationship (s) with your care recipient/nurse (s)?

8. How has participating in this study changed your views? Behaviours?

9. Is there anything you would like to talk about before we end the interview?

Appendix G-3: Nurse Interview Guide

1. Tell me about providing hospice palliative home care.

2. How would you describe your relationship with the client?

   Probes: How does your gender (being a man/woman) and your class (education, income, and occupation) influence this relationship? What would you like changed in terms of care, if anything? Can you give me an example when the gender or class of a client influenced this relationship? Describe, explain, elaborate.

3. How would you describe your relationship with the caregiver?

   Probes: How does your gender (being a man/woman) and your class (education, income, and occupation) influence this relationship? What would you like changed in this care, if anything? Can you give me an example when the gender or class of a client influenced this relationship? Describe, explain, elaborate.

4. How have care decisions been made?

   Probes: Can you provide an example of when a care decision has been made? Describe. How has the client's gender and class influenced care decisions? Can you give me an example of when a client's gender or class has influenced care decisions? How has the caregiver's gender and class influenced care decisions? Can you give me an example when the caregiver's gender or class influenced care decisions? Describe, explain, elaborate.

5. Tell me about the services the client and caregiver receives.

   Probes: Tell me how these services came into place. What helps or hinders in accessing these services? How has the gender and class of the client influenced

the services he or she receives? Can you give me an example of when the gender and class of a client affected services? Describe, explain, elaborate. How has the gender or class of the caregiver influenced the services received? Can you give me an example of when the gender and class of a caregiver affected services? Describe, explain or elaborate. How much are you in control of the care provided to this client/ caregiver?

6. What would you like to see changed in terms of the care offered?

7. What would you like to see changed in the relationship with the client/caregiver?

8. What would you like to see changed in terms of policies/practices?

9. How has participating in this study changed your views? Behaviours?

10. Is there anything else you would like to tell me before we close?

Appendix H: Fieldnote Guide

Date/Time:

Client- family caregiver-nurse case code:

1. Describe the physical environment and the use of space.
2. Describe the people involved (dress, behaviours, roles, interactions and movements).
3. In chronological order, describe the goals and interactions in the process of activities.
4. Describe the dialogue (verbal and non-verbal expressions).
5. Describe observations in terms of social relations of class and gender.
6. Reflect on impressions and feelings.
7. Describe initial analysis/interpretation.
8. Describe any contradictions, indecisions or complications.
9. Question routine processes/hidden assumptions/power normality.
10. Reflect on my personal stance that may influence impressions and feelings.
11. Reflect on how my gender and class may influence my interpretations.
12. Reflect on how my gender and class may affect others.

This fieldnote guide was adapted from:

Lather, P. (1995). The validity of angels: interpretive and textual strategies in researching

the lives of women with HIV/AIDS. *Qualitative Inquiry, 1* (1), 41-68.

Lofland, J., Snow, D., Anderson, L., &Lofland, L. (2006). *Analyzing social settings: A*

guide to qualitative observation and analysis (4[th]ed.). Toronto: Thomson,

Wadsworth.

Mulhall, A. (2003). In the field: notes on observation in qualitative research. *Journal of*

Advanced Nursing, 41 (3), 306-313.

Wolfinger, N. (2002). On writing fieldnotes: collection strategies and background

expectations. *Qualitative Research, 2* (1), 85-95.

Appendix I

Documents

Document	Title	Year
Program Documents	1. Integrated Hospice Palliative Care Program	2010
	2. Integrated Client Care Project Palliative Care Program Launch	2011
Public Communication Documents	1. A Guide to Living Well	2013
	2. Understanding Hospice Palliative Care	2013
	3. Palliative Care: Caring for Family Caregivers	2013
	4. Living Each Day to the Fullest	2013
	5. Palliative Care	2013
Professional Documents	1. College of Nurses of Ontario: Standards of Practice, Ethics	2009
	2. College of Nurses of Ontario: Professional Standards	2000
	3. College of Nurses of Ontario: Therapeutic Nurse-Client Relationships	2006
	4. Registered Nurses Association of Ontario: Establishing Therapeutic Relationships	2002
	5. Canadian Nurses' Association: Social Justice, A Means to an End, an End in Itself	2010

<div align="center">

Curriculum Vitae

</div>

NAME: Nisha Sutherland

EDUCATION

Bachelor of Science in Nursing, 2004
McMaster University

Masters of Science in Nursing, 2008
McMaster University

Ph.D., 2009- in progress
Western University

HONOURS AND AWARDS

1. Canadian Institutes of Health Research (CIHR)/ Institute of Cancer Research Travel Award, $1000 (2014).

2. Nursing Research Interest Group (NRIG) Scholarship, $1500 (2014).

3. Registered Nurses' Federation of Ontario (RNFOO) Dr. Joan Lesmond Memorial Award, $2,500 (2014).

4. Ontario Graduate Scholarship, $15,000 (2014).

5. CIHR Institute of Gender and Health Fall Institute, Invited Attendee (2012).

6. CIHR Institute of Aging, Summer Program in Aging, Invited Attendee (2012).

7. The Canadian Association of Gerontology (CAG) Travel Grant Award, $537 (2012).

8. de Souza Fellowship, $20,000 (2010-2011).

RELATED WORK EXPERIENCE

Research Coordinator, Community Dementia Care, Knowledge Translation: It Takes a Community
July 2013 – July 2-14

Research Co-coordinator, Community Dementia Care: Knowledge Translation
Research Grant
January 2013-April 2013

Research Assistant, Building Partnerships in Community-based Dementia Care
January 2011- December 2012

Research Assistant, Double Duty Caregivers
January 2010-May 2011

PUBLICATIONS

A. PAPERS IN REFEREED JOURNALS

1. Ward-Griffin, C., Brown, J., St.Amant, O., **Sutherland, N**., Keefe, J., & Kerr, M. (2014). Nurses negotiating professional-familial care boundaries: Striving for balance. *Journal of Family Nursing* (25% Data collection and analysis).

2. St. Amant, O., Ward-Griffin, C., Brown, J., **Sutherland, N**., Martin-Matthews, A., Keefe, J. & Kerr, M. (2014) Professionalizing familial care: Examining nurses' unpaid family care work. *Advances in Nursing Science* (25% Data Collection and written analysis).

3. **Sutherland, N**. (2009). The meaning of being in transition to end-of-life care for female partners of spouses with cancer. *Palliative & Supportive Care, 7, 423-433.*

B. ABSTRACTS/ PRESENTATIONS AT PROFESSIONAL MEETINGS (REFEREED)

a. International

1. **Sutherland, N.** Ward-Griffin, C., McWilliam, C. & Stajduhar, K. (September 2014). Gendered expectations and exemptions. *20th International Conference on Palliative Care*

2. **Sutherland, N**., Ward-Griffn, C., McWilliam, C., & Stajduhar, K. (June, 2013). Gender relations in hospice palliative home care: A critical analysis. *In Sickness and In Health (ISIH) 5th International Conference*

3. Ward-Griffin, C., St-Amant, O**., Sutherland, N**., Brown, J. (June, 2013). Striving for balance: gendered inequities in double duty caregiving. *In Sickness and In Health, ISIH 5th International Conference.*

4. **Sutherland, N**., Ward-Griffin, C., McWilliam, C., & Stajduhar, K. (October, 2012). Gender and class relations in hospice palliative home care for clients with cancer and

their family caregivers: A critical analysis. *Advancing Excellence in Gender, Sex and Health Research* (poster presentation).

5. Ward-Griffin, C., Brown, J., St-Amant, O., **Sutherland, N**., Martin-Matthews, A., Keefe, J., Kerr, M. (October, 2012). Striving for Balance: Health, equity and double duty caregiving. *International Conference Advancing Excellence in Gender, Sex and Health Research.*

6. Ward-Griffin, C., Brown, J., St-Amant, O., **Sutherland, N**., Martin-Matthews, A., Keefe, J., Kerr, M. (June, 2011). Professionalizing Familial Care: Nurses Caring for Elderly Relatives*. 10th International Family Nursing Conference*.

b. National

1. **Sutherland, N**. Ward-Griffin, C., McWilliam, C. & Stajduhar, K. (June 2014) Gendered processes in hospice palliative home care. *9th National Community Health Nurses Conference.*

2. **Sutherland, N.,** Ward-Griffin, C., McWilliam, C. & Stajduhar, K. (2014). Ideological processes supporting gendered enactments in hospice palliative home care. *National Institute for the Care of the Elderly* (Poster presentation)

3. **Sutherland, N**., Ward-Griffin, C**.,** McWilliam, C., & Stajduhar, K. (2012). Gender & class relations in hospice palliative home care for seniors with cancer. *The Canadian Association on Gerontology's 41st Annual Scientific and Educational Meeting* (Poster presentation).

4. Ward-Griffin, C**.,** McWilliam, C., Kloseck, M., Orange, J.B., Wong, C., & DeForge, R., St.Amant, O., **Sutherland, N**. (October 19, 2012). Navigating Community Dementia Care: Relationships Matter. *The Canadian Association on Gerontology's 41st Annual Scientific and Educational Meeting*.

5. Ward-Griffin, C., McWilliam, C., Orange, JB., Klosek, KM., Wong, C., DeForge, R., St. Amant, O., & **Sutherland, N.** (October, 2012). Navigating the home and community dementia care system: Relationships matter. *Paper presented at the Canadian Home Care Association Summit, October 2012.*

6. Ward-Griffin, C., Brown, J., Martin-Matthews, A., Keefe, J., Kerr, M., St-Amant, O., **Sutherland, N**. (2011). Examining the Health Experiences of Double Duty Caregivers: Striving for Balance. *40th Annual Scientific and Educational Meeting of the CAG*.

7. Ward-Griffin, C., McWilliam, C., Orange, J.B., Klosek, M., Wong, C., & DeForge, R., St. Amant, O., & **Sutherland, N**. (2011). Building partnerships in community-based dementia care: A critical constructivist grounded theory. Paper presented at *the International Institute of Qualitative Methods – Qualitative Health Research Conference*.

8. Ward-Griffin, C**.**, Brown, J.B., Martin-Matthews, A., Keefe, J., Kerr, M., St-Amant, O., **Sutherland, N**. (October 2011). Examining the health experiences of double duty caregivers: Striving for balance. *Canadian Association on Gerontology 40th Annual Scientific & Education Meeting*.

c. Provincial/Regional

1. **Sutherland N**., Ward-Griffin, C., McWilliam, C., & Stajduhar, K. (2014). 'Hidden' gendered processes in hospice palliative home care. *Aging, Rehabilitation, and Geriatric Care ARGC/Faculty of Health Sciences Symposium, Western University.*

2. **Sutherland, N**., Ward-Griffn, C., McWilliam, C., & Stajduhar, K. (2013). Negotiating gender relations in hospice palliative home care: A critical analysis of nurses' assumptions and practices. 26th *Annual Research Conference, Sigma Theta Tau International, Iota Omicron Chapter*.

3. **Sutherland, N**., Ward-Griffin, C., McWilliam, C., & Stajduhar, K. (2012*). Using an intersectional lens to examine gender and class relations in hospice palliative home care*. 25th Annual Research Conference, Sigma Theta Tau International, Iota Omicron Chapter.

3. **Sutherland, N.**, Ward-Griffin, C., McWilliam, C., & Stajduhar, K. (2012). Gender and class relations in hospice palliative home care for clients with cancer and their family caregivers: A critical analysis*. Aging, Rehabilitation, and Geriatric Care Research Centre, Lawson Health Research Institute*(Poster presentation).

4. St-Amant, O.,**Sutherland, N**., Ward-Griffin, C., Brown, J., & Kerr, M. (2011, May). Policy and practice implications for double duty caregivers: A critical-structural health promotion approach. *The 2nd Annual Research Conference 'Nursing Research: The Path to Excellence' of the Iota Omicron Chapter Sigma, Theta, Tau Honor Society*.

5. **Sutherland, N**., Deforge, R., Tsang, T., & Ward-Griffin, C. (2011). Relational networks for older adults with early Alzheimer Disease. *Annual Interdisciplinary Research Event, Centre for Population, Health and Aging, University of Western Ontario* (Poster presentation).

6. **Sutherland, N**. (2010). The meaning of being in transition to end-of-life care for female partners of spouses with cancer. 2010 Annual Hospice Palliative Care Conference

7. **Sutherland, N**. (2010). Women's experiences during their spouses' transition to end-of-life care. 3rd Biennial Nursing Conference, University of Windsor.