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Examining eShift through the Caregiver Policy Lens: A Content Analysis

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Abstract

Purpose: This research study intended to understand how a new model of palliative home care in Ontario, Canada called eShift aligned with the needs of caregivers who cared for a family member at the end-of-life.

Methods: A qualitative secondary analysis using a deductive content analysis of 14 caregiver interviews, three decision-maker interviews, and six home care agency documents collected in a three-year study and were analyzed using the Caregiver Policy Lens framework.

Findings: The eShift model of care met caregivers' needs through timely access to respite, education, collaborating with the health care team, and physical and psychological support. Caregivers were supported in their caregiving role, however, they indicated continuity of care could be improved.

Conclusion: This study suggests that the eShift model of palliative home care provides many of the supports needed by caregivers while they care for family members in the home at the end-of-life.

Keywords: caregivers, caregiver needs, home care, palliative care, The eShift model of care, The Caregiver Policy Lens

Co-Authorship

Ashlee Worrall completed the following work under the supervision of Dr. Sandra Regan and Dr. Lorie Donelle. Both members contributed to the work through their advisement on the conduct of the secondary analysis, peer review of the qualitative description analysis of the findings, the content, rigor, and clarity of the writing.

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Chapter 1: Introduction

In Canada and other developed countries throughout the world, there are significant concerns regarding the provision of end-of-life palliative care to adequately address the needs of those dying and their family/friend caregivers (Williams et al. 2011). End-of-life palliative care is an approach to care with a focus on quality of life for the dying person and their family, through an interdisciplinary approach to alleviate discomfort and provide dignity at the end-of-life (World Health Organization, 2015). It is estimated that 70% of Canadians do not have access to end-of-life palliative care services, in part because Canada lacks a national program to ensure these services are provided (Canadian Hospice Palliative Care Association, 2013; Williams et al. 2011).

Since the 1990s, restructuring of Canada's health care system has occurred, with the focus on deinstitutionalizing many public services from hospitals and providing them in communities, and to a large extent by families (Keefe, 2011; Tourangeau, Patterson, Sarri, Thomson, & Cranley, 2017). Restructuring of Canada's health care system has assisted with meeting the wishes of many individuals to die at home. However, there is inadequate funding in provincial government budgets to fully meet the need for in-home palliative care (Flagler & Weixhen, 2010). Currently, home care in Ontario only receives 4% to 5% of the overall provincial health spending, despite a 60% increase in service utilization since 1995, along with an inability to meet the rise in the demand for home care nurses (Cote & Fox, 2007; Flagler & Weixhen, 2010; Tourrangeau et al., 2017). The lack of funding to meet the health care needs of individuals at their end-of-life and the lack the of health human resources in the community have left many family caregivers to provide end-of-life care to their family members, and this has become a concern for health care planners and policy makers (Flagler & Weixhen, 2010; Keefe, Martin-Mathews, & Legare, 2011).

In order to increase access to home care services at the end-of-life, the roles of health care workers are changing with the use of technology, allowing for increased quality of life, support, and information for patients and family caregivers (Canadian Nurses Association, 2013).

Technology has become an integral component in home care, supporting health care workers in providing more effective and efficient care. The use of technology can better enable patient education, patient monitoring by the health care team, point-of-care documentation, and improve health care provider communication (Canadian Nurses Association, 2013; Parker et al., 2014). A new model of palliative home care implemented in Southwestern Ontario, eShift, is an example of the use of technology. The eShift model of care combines communication and documentation technology with innovative utilization of health care human resources to assist in meeting the needs of patients and their families in the home (Regan & Donelle, 2015; Royackers, Regan, & Donelle, 2016). However, research is needed to understand how this new model of care aligns with the needs of the caregivers.

Background and Significance

Family and Friend Caregiver

Within the palliative context, family/friend caregivers (referred to going forward as caregivers) are family, friends, and neighbours who provide unpaid care and support for a person who is dying (Canadian Hospice Care Association, 2004; Keefe, 2011). Caregivers work to provide mental, emotional, and physical support to the person in need through a broad range of services and supports, such as assistance with activities of daily living, including cooking, shopping, and home maintenance; personal care activities, such as bathing, dressing, toileting, and medication administration; care management, including arranging formal and informal services; and social and emotional support, which includes loss, grief, and bereavement care (Canadian Hospice Care Association, 2004; Keefe, 2011).

In 2012, according to Statistics Canada, 8.1 million Canadians were caregivers, of which 28% of caregivers provided care to someone at their end-of-life, with 41% of that providing end-of-life care for their parent (Sinha, 2015). Caregivers provide an array of services for their family members including transportation, housework maintenance, coordinating appointments, assisting with finances, helping with medical treatments, and providing personal care (Sinha, 2015). At the end-of-life, it is estimated that caregivers spend an average of 54-69 hours per week caring

for their dying family member at home (Canadian Hospice Palliative Care Association, 2013; Rowland, Hanratty, Pilling, van den Berg, & Grande, 2017).

The demographics of caregivers indicate that 77% are female, with the majority (70%) being 45 years of age or older. Female caregivers are most often homemakers or retired, however, this demographic is changing, as many women are now working and also caring for their own children (Stajduhar, 2013; Williams et al. 2011). In addition, many caregivers come from diverse income and social positions, although in general, their household income is below the Canadian average income (Canadian Hospice Palliative Care Association, 2013; Williams et al. 2011).

Many caregivers endure significant economic and non-economic costs and consequences related to caregiving. Economic costs include out-of-pocket expenses for health and non-health services, equipment supplies, medications, and loss of income and benefits from current or future employment (Keefe, 2011). Keefe (2011) reported that 40% of family caregivers spent $100-$300 a month on caregiving, and another 25% spent more than $300 per month on caregiving. These additional costs, coupled with the fact that most caregivers' household incomes are below the Canadian average income, contribute significantly to the financial strain placed on caregivers (Keefe, 2011). Furthermore, in Ontario patients and caregivers living in low socioeconomic neighbourhoods are less likely to receive home care end-of-life services, compared to those in affluent neighbourhoods (Health Quality Ontario, 2016a). The non-economic costs caregivers endure include a reduction in social activities and leisure time due to providing care, making it difficult to maintain social networks, and resulting in lost friendships (Keefe, 2011).

End-of-life palliative care has its own unique challenges for caregivers, as it requires the caregiver to provide care and emotional support to a family member during a time when they are also dealing with their own loss and grief. Caregivers often experience health issues when providing care, such as stress, anxiety, depression, sleep deprivation, fatigue, physical pain, and chronic health conditions (Williams et al. 2011). Williams et al. (2011) reported that being a caregiver puts a person at increased risk of morbidity and mortality. Despite the abovementioned health concerns and stresses of caregiving, many caregivers report they had a positive experience

providing end-of-life palliative care to their family member and felt appreciated in providing care (Canadian Hospice Palliative Care Association, 2013).

End-of-Life Palliative Care and Home Care

The demographics of Canada's population are rapidly changing, as Canadians aged 65 years and older are currently the fastest-growing age group. By 2036, older Canadians are estimated to make up a quarter of Canada's total population, which is double the population of older adults reported in 2009 (Canadian Hospice Palliative Care Association, 2014). The aging population also mirrors the projections for an increased death rate in Canada (Dykeman & Williams, 2013). It has been asserted by researchers and advocacy groups that Canadians at the end-of-life have the right to die with dignity, however, access to end-of-life palliative care, including home, community, and hospital, is inequitable and has become a privilege rather than a universal entitlement (Williams et al., 2011).

End-of-life palliative care is an approach to care with a focus on quality of life for the dying person and their family, through an interdisciplinary approach to alleviate discomfort and provide dignity at the end-of-life (World Health Organization, 2015). For the purpose of this study, end-of-life palliative care will be defined as care for individuals who have a diagnosis of six months or less to live. Dying with dignity for many Canadians means dying in their place of choice, which for 75% of Canadians is at home. However, almost 70% of deaths within Canada occur in hospitals (Canadian Hospice Palliative Association, 2013; Health Quality Ontario, 2016b). With the wishes of most Canadians to die at home and the increase in the number of older adults, much of the onus has been placed on caregivers to provide care for their dying family member (Dykeman & Williams, 2013). Funding for end-of-life palliative care varies by province, and currently only a small number of provinces have designated hospice palliative care as a core service under their provincial health plans, meaning home-based palliative care services in the remaining provinces are included in the provincial home care budgets. Having palliative care services under home care budgets makes the funding extremely vulnerable to budget reductions (Canadian Hospice Palliative Care Association, 2014).

In 2004, the federal, provincial, and territorial First Ministers committed to a 10-year plan to strengthen health care, identifying the need for home based hospice palliative care services as a key policy direction, which included paying for some end-of-life home care services by 2006. To support the First Ministers commitment to address the needs of home-based palliative care patients, the Canadian Hospice Palliative Care Association and Canadian Home Care Association created four Pan-Canadian Gold Standard categories for policy on funding for home care services by the provincial and territorial government including: case management, nursing, palliative-specific pharmaceuticals, and personal care at the end-of-life (Canadian Hospice Palliative Care Association, 2006). The Gold Standards were created with the assistance of many experts in palliative and home care and provide a benchmark for all provinces and territories on the ideal level of care and support that should be provided to individuals receiving end-of-life palliative care in the home (Canadian Hospice Palliative Care Association, 2006). There have been some achievements made towards these "gold standards" by all provinces, such as offering some form of palliative drug coverage for home care patients (Canadian Hospice Palliative Care Association, 2014). However, there are gaps in palliative care policies, as outlined by the Pan-Canadian Gold Standards, throughout the provinces and territories.

In Ontario, some progress has been made towards achieving the "gold standards", such as palliative drug coverage for home care patients, and access to 24 hours, seven days a week case management. However, there are still some fundamental issues that need to be addressed in Ontario for the "gold standards" to be met. In Ontario, 70% of those in need of end-of-life palliative care services, such as multi-disciplinary teams trained to alleviate suffering and improve quality of life, do not receive them. Furthermore, the amount and kind of home care services each patient receives varies greatly, as typically a Local Health Integration Network (formerly the responsibility of Community Care Access Centres) representative assesses the needs of the individual and family (Carstairs, 2010; Government of Ontario, 2014; McMaster University, 2016). Ontario is lacking health human resources trained in palliative care, and continues to have limited access to palliative services in rural areas, making the provision of adequate palliative home care services inaccessible to some of those in need (Canadian Hospice Palliative Care Association, 2014). As a result of the lack of accessible home-based palliative

care, many patients are utilizing acute care services at the end-of-life (DeCaria et al, 2017). An Ontario study found that between the years 2002-2005, 84% of patients with cancer accessed the emergency department within the last six months of life and 40% accessed the emergency department during the last two weeks of life (Barbera, Taylor, & Dudgeon, 2010). The most common reasons for visiting the emergency department included complications from cancer or infections and symptoms such as dyspnea malaise, fatigue, and abdominal pain. The researchers further observed pain and failure to cope as common reasons for the patients visiting the emergency department. The authors reported that 77.2% of patients in the study died within 2 weeks of being admitted to acute care, 4.8% were pronounced dead on arrival to hospital, and 5.2% died in the emergency room. The authors suggested that if appropriate supports were in place, some of the patients could have remained at home to die instead of being admitted into acute care settings (Barbera et al., 2010). A study by Sutradhar and colleagues found Ontario patients receiving palliative care services in the home had a decreased rate of emergency room visits compared to patients who were palliative and only received standard homecare nursing visits (Sutradhar, Barbera, & Seow, 2017). Therefore, assisting people at the end-of-life, and their caregivers, with palliative care in the home could reduce emergency room visits and acute care admissions.

Policy for Caregivers at the End-of-Life

While challenges faced by caregivers are well documented in the literature, few end-of-life palliative care policies in Ontario or Canada consider the specific needs of the caregiver. Currently, the only policy in place for caregivers is a federal policy, "Compassionate Care Benefits", which provides financial support through employment insurance benefits for those who meet the eligibility criteria (Government of Canada, 2016). Compassionate Care Benefits criteria specifies caregivers must work at least 600 hours in a year, with a 40% decrease in regular earnings related to providing care, a medical certificate that the individual is at risk of death within 52 weeks, and signed consent from the care recipient or their power of attorney (Government of Canada, 2016). Compassionate Care Benefits is not an end-of-life program, rather an employment insurance program. Consequently, a significant number of people do not

qualify for benefits, leaving many Ontario caregivers with little support and resources (Osborne et al., 2005).

Although not specific to caregivers at the end-of-life, in 2015, the Ontario Ministry of Health and Long-Term Care launched an initiative "Patients First: A Roadmap to Strengthen Home and Community Care", which plans to improve home and community care through quality, consistency, and integration of services (Health Quality Ontario, 2016a; Ministry of Health and Long-Term Care, 2015). Within the Roadmap, caregivers are specifically addressed along with measures to help them, including education, supports for better resources, framework for consistent home care assessment, funding for the patient or caregiver to hire their own provider, and a one-stop online resource for caregivers (Health Quality Ontario, 2016a; Ministry of Health and Long-Term Care, 2015).

The Caregiver Policy Lens

In order to address challenges faced by caregivers, a Canadian framework titled, "The Caregiver Policy Lens" has been developed, which is intended to analyze policies, programs, and services from the caregivers' perspective (MacCourt & Krawczyk, 2012). The Caregiver Policy Lens was the framework used to guide this study. The Caregiver Policy Lens was created through consultation with caregivers and a review of the literature. The Caregiver Policy Lens provides a common framework for policy development, which is thought to be effective in identifying unintended consequences of programs or policies on caregivers. The Caregiver Policy Lens is also used to educate and raise awareness of caregiver's challenges, needs, and perspectives (MacCourt & Krawczyk, 2012).

There are eleven categories of the Caregiver Policy Lens including process factors, which relate to collaboration and inclusion of caregivers in the development of evidence-informed policy and program. The policy or program is assessed on its ability to be accessible and sustainable for caregivers and systems, while allowing the caregivers choice. The Caregiver Policy Lens also evaluates the fairness of the policy or program, ensuring diverse and marginalized individuals are included or have access, and that the program or policy respects the caregiver (MacCourt &

Krawczyk, 2012). A more in-depth description of the eleven categories of the Caregiver Policy Lens can be found in Appendix A.

The eShift Model of Care

The eShift model of care is a new home-based palliative care model developed in Ontario in response to nursing shortages and the growing demand of people wishing to die at home. The eShift model of care was developed in collaboration with the South West Community Care Access Centre (now the South West Local Health Integration Network), a software/technology provider, and home care services providers (Regan & Donelle, 2015; Royackers et al., 2016). The eShift model of palliative home care utilizes an inter-professional health care team and documentation/communication technology to support families and provide care to individuals who wish to die at home (Regan & Donelle, 2015; Royackers et al., 2016). The role of eShift health care providers will be reviewed in this section.

Directing Registered Nurse. The eShift model of care operates with a registered nurse situated remotely, called the Directing Registered Nurse (DRN), who is responsible for four or more technicians who are caring for palliative care patients in the home. Connected through wireless technology, the DRN receives and analyzes reports with the patient data transmitted from the technicians. Under regulatory directive and through the use of technology, the nurse delegates the tasks to be performed to the technician, such as medication administration or turning and repositioning the patient (Regan & Donelle, 2015; Royackers et al., 2016).

Technicians. The technicians are personal support workers or home care aids with extended training in palliative care. They provide care for one patient in their home for eight consecutive hours per day. The DRN and the technician are remotely connected to each other using wireless technology. The technician is equipped with a smartphone to access the online eShift palliative care system. The eShift palliative care system guides the technician to report patient status, care documentation, and real-time care coordination with the DRN. The technician receives education on how to use the technology system to report their observations of a patient's signs and symptoms to the DRN through the secured online application. The technician receives directives

from the DRN and carries out the identified treatment plan, such as turning and repositioning or medication administration (Regan & Donelle, 2015; Royackers et al., 2016).

Visiting Nurse. A visiting nurse goes to see the palliative patient routinely to perform nursing care tasks. The visiting nurse is responsible for drawing up and labeling medications that the technician can administer, if directed by the DRN. The visiting nurse also interacts with the DRN, and if it is deemed necessary, the visiting nurse will provide higher-level care or higher-skilled assessment in the home (Regan & Donelle, 2015; Royackers et al., 2016).

Additional eShift care providers. There are many team partners involved in the care of the patient through eShift, including Care Coordinators, who assist in developing the plan of care, physicians and nurse practitioner who assess and treat the patient, allied health care professionals, such as physiotherapy or social workers, are consulted as needed, and technological support personnel to ensure technology is available at all times.

Researchers at the University of Western Ontario conducted a three-year study and developed a framework to describe and explain the eShift model of care, understand the benefits and outcomes of the eShift model, and to explore the financial impact of the eShift model (Donelle & Regan, 2017a/b). Care providers reported the eShift model of care decreased health care costs, as patients were able to remain at home with trained care providers, who were able to provide education about the dying process and support caregivers. The eShift model of care assisted in reducing ambulance calls, emergency rooms visits, and hospitalization (Regan & Donelle, 2015). Areas for improvement identified by caregivers included improved communication among health care providers, continuity of care to decrease the number of health care providers entering the house, and increased hours of care at home through eShift (Donelle & Regan, 2017a).

Since eShift is a new model of care, it is important to understand how it aligns with the needs of caregivers who cared for a family member or friend who received eShift in the home. This study was conducted using content analysis of secondary data using the Caregiver Policy Lens framework (MacCourt & Krawczyk, 2012). This study included interviews with 15 caregivers, three decision makers who were integral in developing and implementing eShift, and six agency

documents which provided insight to the development, evaluation, and information provided to families regarding eShift. Analysis of these interviews and documents has provided direction for nursing research, home care practices, and policy development and has advanced current understanding pertaining to eShift.

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Chapter 2: Manuscript

Background

Currently, 70% of individuals in Canada who die at home are not receiving end-of-life services they need due to restructuring of Canada's health care system in the 1990s, a lack of home care funding, an aging population, and a lack of health human resources, along with an increase in the number of people wishing to die at home (Canadian Hospice Palliative Care Association, 2013; Fowler & Hammer, 2013; Williams et al. 2011). The abovementioned factors mean family members or friends are providing the care to the dying person (Williams et al. 2011). Being a caregiver for a family member/friend at the end-of-life has many challenges, such as providing physical care and emotional support to the dying individual while dealing with their loss and grief, putting the caregiver at an increased risk of morbidity and mortality (Bialon & Coke, 2012; Giesbrecht, Crooks, Williams, & Hankivsky, 2012; Williams et al. 2011).

The federal and provincial government has recognized the importance of end-of-life care in the patient's home, to which they provide different avenues of influence and funding for those who meet the criteria. However, there still remains a gap in policy for caregivers at the federal and provincial levels. Currently, the federal government manages and funds some homecare services under its jurisdiction, this includes Veterans Affairs Canada and Indian and Northern Affairs Canada. The federal government also offers financial assistance through the Caregiver tax credits and employment insurance for the Compassionate Care Benefits with job protection (Canadian Healthcare Association, 2009; Chenier, 2000; Government of Canada 2016). Provincial governments have implemented and are working on policies and programs to meet the palliative care needs of patients who wish to die at home and their caregivers, such as funding for nursing and personal care, medical supplies, tests, transportation, and home hospice services (Government of Ontario, 2014; Ministry of Health and Long-Term Care, 2015). With the recognition by health care planners and policy makers that increased support is needed for individuals to die in their place of choice, work has been done to develop new models of care utilizing technology, impacting the roles of health care providers (Flagler & Weixhen, 2010;

Keefe, Martin-Mathews, & Legare, 2011; Royackers, Regan, & Donelle, 2016). One newly developed model of care in Ontario is eShift, which is a home-based palliative care model that utilizes an inter-professional health care team and documentation/communication technology to support families and provide care to individuals who wish to die at home (Regan & Donelle, 2015; Royackers, et al., 2016). The eShift model of care operates with an off-site directing registered nurse (DRN) who is responsible for four or more technicians who are personal support workers (PSW) with extended training in palliative care. The technician provides care for one patient in their home for eight consecutive hours per day. The DRN and technician are connected through the online eShift application, in which the technician reports the patient's status to the DRN, who in turn reviews the data and directs care to the technician via technology (i.e., smartphone and computer devices). The technician then carries out the identified treatment plan from the DRN, such as turning and repositioning or medication administration (Royackers et al., 2016). Since eShift is a new model of care, it is important to understand how it aligns with the needs of caregivers who cared for a family member or friend who received eShift in the home. This study was conducted using content analysis of secondary data using The Caregiver Policy Lens framework to analyze 14 caregiver interviews for 15 patients, one participant had two family members receive eShift, while two family members participated in an interview about the same patient; three decision maker interviews, who were integral leaders in the development and establishment of eShift; and six agency documents related to eShift from home care agencies and the community care access center (MacCourt & Krawczyk, 2012).

Literature Review

The purpose of this literature review is to provide a summary and critical evaluation of the policies and the current state of knowledge related to family/friend caregivers providing end-of-life care in the home. A review of literature was conducted using the following methods:

1. A keyword search was conducted in PubMed, Scopus, and CINAHL. The keywords included: caregivers, caregiver burden, caregiver support, family coping, patient-family relations, family, home health care, home care, palliative care, terminal care, policy, health policy studies, health policy, policy studies, and The Caregiver Policy Lens.

2. The search was limited to the English language, articles from Canada, United Kingdom, Australia, and the United States, from 2007 to present. Articles related to paediatric palliative care were excluded. Where possible, primary sources of literature were used and Canadian studies were selected where applicable.

3. A manual search of the literature was conducted using references in obtained articles to identify additional papers.

In total 28 articles that met the inclusion criteria were included in this literature review, seven of which were related to policy, and one related to the eShift model of care.

Caregiver Providing End-of-Life Care in the Home

Please refer to Appendix B for a detailed description of each study identified.

Caregiver Experience

Thirteen studies reported on the experiences of caregivers who have cared for a terminal family member in the home. The studies are discussed in four themes.

Uncoordinated and unorganized services. Common among four of the studies was the finding that home palliative care and clinical services were uncoordinated and unorganized. Researchers found caregivers spent significant periods of time navigating the health care system due to a lack of coordination of care and the number of health care providers involved in their family member/ friend's care. The time caregivers spent navigating the healthcare system took them away from caring for their palliative family member (Brazil, Bainbridge, Ploeg, Krueger, Taniguchi, & Marshall, 2012; Hasson et al., 2010; Mohammed et al., 2017; Robinson, Bottorff, McFee, Bissell, & Fyles, 2017).

Accessibility to home palliative care services. Four studies explored accessibility of palliative care in the home at the end-of-life (Funk, Stajduhar, & Cloutier-Fisher, 2011; Jo, Brazil, Lohfeld, & Willison, 2007; Robinson et al., 2017; Sekelja, Butow and Tattersall, 2010). Findings from the above-mentioned studies indicated that patients and their family caregivers would have

benefitted from palliative care providers' (palliative trained nurses, doctors, and allied health professionals) input to the plan of care earlier in the patient's disease trajectory. Family members reported palliative care support should start when patients' symptoms become too difficult to control or when the patient needs help in the home, as many did not receive palliative care measures until two weeks before the patient's death (Sekelja et al., 2010). Furthermore, caregivers indicated that as the needs of the patient increased, they needed more home care services than what they had received to assist with the physical tasks (Jo et al., 2007). Researchers also found family caregivers did not request or access home care palliative services because they did not want to be seen as abusing the health care system, they felt unprepared to receive the help, or they did not know what services to request (Funk et al., 2011; Robinson et al., 2017).

Respite. Respite provides the caregivers a break from their caregiving duties, such as physical care and medication administration for the person in need. Respite was cited as an important factor in allowing caregivers to continue in their caregiving role (Ewing & Grande, 2012). The authors of four studies found that caregivers preferred respite provided in the house of the family member, especially at night, allowing for uninterrupted sleep, with the health care provider caring for the patient (Ewing & Grande, 2012; Jack, O'Brien, Scrutton, Baldry, & Groves, 2014; Kenny, Hall, Zapart, & Davis, 2010; Robinson et al., 2017).

Guidance and education from health care providers. The authors of four studies found caregivers valued guidance and education from health care providers on how to provide care and to learn what services were available to them. However, caregivers did not always receive guidance they perceived as helpful related to lack of communication, conflicting information, and health care provider time constraints (Harding et al., 2012; Hasson et al., 2010; Ewing & Grande, 2012; Mohammed et al., 2017; Stajduhar, Funk, & Outcalt, 2013). Caregivers wanted information about management of their family member/friend's symptoms, medications, knowledge about equipment available to them, information about the illness, and support in providing personal care before a crisis or problem occurred (Ewing & Grande, 2012; Stajduhar et al., 2013). Two studies focused on the positive aspects of caregiving found that the caregivers'

comfort in caring for their family member was increased from obtaining information from health care workers on how to provide care for the patient. Caregivers who were well informed and able to seek advice and help before they were overburdened were able to cope best with their caregiving responsibilities (Giebrecht, Wolse, Crooks, & Strajduhar, 2015; Stajduhar, Martin, Barwich, & Flyes, 2008).

Caregiver Burden and Distress

Researchers of nine studies focused on caregiver burden and distress when providing end-of-life care in the home and found declining health of the family member and being unprepared to be a caregiver as the greatest contributors to caregivers' perceived burden and distress.

Declining health of the family member. The most frequently cited cause of caregiver burden and distress was the declining health status of the dying family member, which was reported in five studies (Bialon & Coke, 2012; Guerriere et al., 2016; Hirdes, Freeman, Smith, & Stolee, 2012; Kenny et al., 2010; Waldrop & Meeker, 2011). Authors investigating the effects of caregiver burden found caregivers physical and mental health declined as caregiver demands increased; especially when caregivers did not have appropriate supports in place to allow for respite. The lack of respite for their caregivers resulted in some patients being admitted to a facility for palliative care (Bialon & Coke, 2012; Kenny et al., 2010; Waldrop & Meeker, 2011).

An additional source of burden for caregivers, cited in three articles, was the feeling of being unprepared for a caregiver role. This was usually due to a lack of education in providing care or from being unsuccessful in accessing and receiving support from health care providers (Bialon & Coke, 2012; Metha, Chan, & Cohen, 2014; Topf, Robinson, & Bottorff, 2013). In one study, unpreparedness of the caregivers led caregivers to be unable to fulfill their promise of keeping their family member at home to die (Topf et al., 2013).

End-of-Life Care in the Home and Caregiver Policies

In this section, studies on policies focused on caregivers providing end-of-life care in the home are reviewed. Seven articles related to caregiver policy were found, five of which focused on the

Canadian Compassionate Care Benefits (CCB) (Crooks et al., 2012; Dykeman & Williams, 2013; Giesbrecht, Crooks, and Williams, 2010; Williams, Crooks, Giesbrecht, & Dykeman, 2010; Williams et al., 2011). The Canadian CCB is a federal policy that provides income assistance and job protected leave from work for those who qualify (Government of Canada, 2016). In order for the CCB to meet its full potential within the current criteria, the following improvements are needed: 1) increased awareness of the program; 2) making information on the program more accessible; 3) helping caregivers determine when to take their leave (Dykeman & Williams, 2013). Improvements that could be made to the current policy included increased financial compensation, streamlining the application process, and changing the eligibility requirements so more caregivers qualify (Crooks et al., 2012; Giesbrecht et al., 2010; Williams et al., 2010; Williams et al., 2011).

Two articles addressing end-of-life palliative care for caregivers indicated there are challenges in creating and implementing policy for caregivers (Exley & Allen, 2007; O'Connor, Groom, Watson, & Harris, 2016). Exley and Allen (2007) examined the "unacknowledged contradictions and strains" (p.2318) that are found within home care policies and the challenges they create for family caregivers. The authors found the lack of policy for caregivers has created social expectations and obligations for caregivers that they cannot meet (Exley and Allen, 2007). O'Connor and colleagues (2016) discussed the challenges they encountered, such as structural issues related to differing professional values, roles, and communication styles, in trying to create a policy that would assist staff in identifying family caregivers and patients at risk of suicide while receiving home-based end-of-life palliative care (O'Connor et al., 2016).

The eShift Model of Palliative Home Care

One article has been published about the eShift model of palliative home care. The authors of this study, using interpretive description methodology, conducted eight interviews with caregivers who cared for a family member who received eShift. Findings from this study indicated that caregivers were satisfied with the care their family member received and had positive experiences with the health care providers in the home with the use of technology-enhanced palliative care. Caregivers were better able to support their family member to achieve

their desired home death through the support they received from the health care providers (Royackers et al., 2016). Caregivers reported the presence of the technician in the house allowed them to have time to themselves, time to sleep, and time with other family members and friends, and the opportunity to have another person in the house to talk to (Royackers et al., 2016).

Summary of the Literature Review

In summary, the findings from the studies in this literature review suggest two major gaps in the research: 1) a lack of research on the needs of caregivers when caring for a palliative family member and 2) policy to support caregivers providing end-of-life care for a person in the home. Unsurprisingly, the research that focused on caregiver experience suggested that lack of information about palliative services, lack of coordination of services, lack of education about providing care, and lack of support in providing care were causes of caregiver burden and stress. Policy research on caregivers providing end-of-life palliative care in the home has been limited to the Canadian Employment Insurance Compassionate Care Benefit program. However, many of the researchers recognized the important contributions of caregivers and provided implications and recommendations for policy development.

Statement of the Problem

A new model of palliative home care in southwestern Ontario, eShift, is innovative in its use of technology and health human resources to assist people to die at home (Regan & Donelle, 2015; Royackers et al., 2016). The eShift model has simultaneously addressed the needs of the dying patient in their home, and assisted with the needs of caregivers, by allowing them to have periods of respite at home. Little research has been conducted to examine the how eShift meets the needs of caregivers. Analyzing this from a policy perspective is an important extension of the current research on eShift and may provide insights on how future health care services can incorporate the needs of caregivers.

Methodology

The purpose of this study was to understand how the eShift model of palliative home care aligned with caregivers' needs through a content analysis of secondary data using The Caregiver Policy Lens framework (MacCourt & Krawczyk, 2012).

Study Design

This study was guided by qualitative description methodology (Sandelowski, 2000; Magilvy & Thomas, 2009). The goal of qualitative description is to offer readers a comprehensive and accurate summary of a phenomenon or event in which the meaning that the participants ascribed to the phenomenon or event is accurate (Sandelowski, 2000; Magilvy & Thomas, 2009). Qualitative description is grounded in the language and meaning of a phenomenon of the participants as much as possible, through use of their own words and descriptions (Sandelowski, 2000). A qualitative description study design is well suited for phenomena emerging from practice or policy, making it ideal to understand the caregivers' experience of eShift as it relates to policy (Sandelowski, 2000). Since eShift is a relatively new model of care, with little published on the caregiver aspects, particularly as it relates to policy, the use of qualitative description is justifiable for this study. This description will be based on the caregivers' experience as it relates to policy, allowing the researcher to stay close to the data, both for the analytical process and presentation of the data (Neergaard, Olesen, Sand Andersen, & Sondergaard, 2009).

Theoretical Framework

The Caregiver Policy Lens developed by MacCourt & Krawczyk (2012) is a Canadian framework intended to support development and analysis of policies, programs, and services from the caregivers' perspective. As well, the Caregiver Policy Lens facilitates understanding of the direct and indirect effects of policies on caregivers. The Caregiver Policy Lens was created based on the assertion that most public policies are created without taking into account the impact they have on the caregivers, which in turn can have negative consequences on caregivers

(MacCourt & Krawczyk, 2012). The framework can be used to develop new programs or policies, and to critique and evaluate proposed or existing programs and policies. The framework also ensures when programs and policies are developed that a consistent approach is used to ensure the needs of the caregiver are considered (MacCourt & Krawczyk, 2012). There are eleven categories of the Caregiver Policy Lens, listed in Table 1.

Table 1: The Caregiver Policy Lens Categories

Category	Description
Caregiver inclusion and voice	Recognizing and valuing caregivers in development and care of care recipients
Collaboration	Open and innovative forms of communication with the caregiver, limiting story retelling
Evidence informed	Informed by evidence through experiential knowledge and scholarly literature
Respect and dignity	Acknowledging and supporting the caregiver and their relationship with the care recipient
Diversity and marginalization	Ensuring diverse caregivers and care recipients do not experience inequities
Choice, self-determination, and independence	Providing information and evaluation of caregiver's willingness in providing care
Accessibility	Services available to caregivers with appropriate adaptations to accommodate
Caregiver assessment	Caregiver needs assessed and addressed
Sustaining caregivers	Provide caregivers with respite, knowledge, skills and education to support their role
Sustaining systems	Flexibility within programs, health care providers educated to support caregivers
Fairness and equity	Ensuring the program does not cause a disadvantage to others while benefiting some

Adapted from MacCourt & Krawczyk, 2012.

A more in depth description of the eleven categories of the Caregiver Policy Lens can be found in Appendix A. The Caregiver Policy Lens has never been used to inform research. In this study, the 11 components were used to conduct the analysis and to organize the presentation of the findings.

Methods

The methods for this research study included a secondary analysis using a deductive content analysis of caregiver interviews, decision-maker interviews, and agency documents collected in a three-year study of the eShift model (Donelle & Regan, 2017a/b). Ethical approval for the primary study (Investigating the eShift model of palliative home care: Implications for planning, practice and policy) was obtained from Western University Health Science Research Ethics Board (# 105350). See Appendix C for the Ethics Certificate.

Statement of the Purpose

The purpose of this study was to explore a new model of palliative home care, called eShift, through the Caregiver Policy Lens. This was accomplished by completing a qualitative description study and secondary analysis of the experiences of caregivers who lived and cared for their family member while receiving the eShift model of palliative care during the final weeks of life. Decision-maker interviews and agency documents were also analyzed to gain insight to the policy and creation of eShift.

Research Question

The research question guiding this study is: "How does the eShift model of palliative home care align with caregiver needs?"

Setting and Sampling Strategy

Sample sizes typical for qualitative description studies range from three to twenty participants depending on the quality of the interviews (Magilvy &Thomas, 2009). However, other authors, such as Sandelowski, do not make reference to what is deemed an adequate sample size for qualitative description, rather that it be a matter of the judgment and experience of the researcher through evaluation of the quality of the information collected within the context of the study being conducted (Sandelowski, 1995; Sandelowski, 2010).

Participants for the family/friend caregiver interviews (n=14) were recruited through the South West Local Health Integration Network (LHIN), formerly the responsibility of Community Care Access Centres (CCAC) Care Coordinators and consisted of family/friends who had a family member/friend who received eShift care in South West Ontario. Caregivers were recruited between 3-12 months after their family member/friend died. Interviews were conducted with caregivers on the phone or in-person, and on average interviews lasted between 1-1.5 hours (Donelle & Regan, 2017a). Interviews were digitally recorded and transcribed verbatim.

The family/friend caregiver interviews consisted of 14 interviews for 15 patients, one participant had two family members receive eShift, while two family members participated in an interview about the same patient. Participants were from both urban and rural settings within southwestern Ontario, the majority were female (86%), over half of the caregivers were spouses (53%), six were adult children (40%), and one was a friend of the care recipient, with the average age of caregivers being 61 years old and ranging from 40 to 80 years of age (Donelle & Regan, 2017a). The length of time patients received eShift varied among participants, seven received eShift for two to three months, five for two to three weeks, and three received eShift from one to five days. All interviews were conducted within one year of the care recipient's death to control for recall bias (Donelle & Regan, 2017a). Additionally, three decision-maker interviews and six agency documents were analyzed to provide insight on how the eShift model was created, how the policies and procedures were created, and to gain an in-depth understanding of how eShift aligns with the needs of the caregivers. The decision maker interviews consisted of two homecare agency leadership personnel, who were instrumental in developing the eShift model in their

communities, and a senior leader for the regional homecare provider responsible for assessment of services, including palliative home care, and contracting with homecare agencies. The six documents analyzed were from different home care agencies and the community care access center and consisted of: 1) an eShift program evaluation, 2) a policy of complex care shift nursing, 3) eShift project charter, 4) a fact sheet of complex shift nursing programs in the home, 5) agency information about eShift, and 6) a welcome package to eShift for families.

Data Collection

This study was a secondary analysis of previously gathered interviews of caregivers, decision-makers, and agency documents, which is a credible way of generating knowledge that contributes to nursing, as it expands our understanding of a phenomenon (Szabo & Strang, 1997). There are potential disadvantages of using secondary data, such as lack of control in creating the data sets. However, one important advantage to completing a secondary analysis is sensitivity to the caregivers, as they do not face respondent burden caused by multiple interviews (Szabo & Strang, 1997). Sensitivity to caregivers of loved ones at the end-of-life is important, as research has established that these particular caregivers are already experiencing stress and burnout (Szabo & Strang, 1997). Using a secondary analysis of eShift interviews with caregivers, key decision makers, and agency documents allowed for continued research of the eShift model of care without the recruitment of additional caregivers or re-interviewing caregivers (Szabo & Strang, 1997). Qualitative research designs are relatively flexible, allowing for variable degrees of breadth and depth coverage of the interview topics, allowing the researcher to meet the aims of this secondary study (Heaton, 2008).

Data Analysis

Data analysis was based on a deductive content analysis of secondary data using the Caregiver Policy Lens framework (Elo & Kyngas, 2008; Hsieh & Shannon, 2005; MacCourt & Krawczyk, 2012). Data from the original study was made available on the secured university online portal, where it was organized and analyzed using NVivo 11, a qualitative data analysis software (NVivo qualitative data analysis Software, 2015).

Content analysis is described as "a systematic and objective means of describing and quantifying phenomena. It is also known as a method of analyzing documents" (Elo & Kyngas, 2008, pp.108). Content analysis allows the researcher to make replicable and valid inferences from data to provide knowledge, new insights, representation of facts and a guide to action (Elo & Kyngas, 2008). An advantage of using content analysis is that it is not rigidly linked to text or technique, allowing the researcher creativity in analyzing data (Gomes Campos & Turato, 2009).

For this particular study, a deductive approach to content analysis was used. The researcher analyzed existing data in a new context using the categories of the Caregiver Policy Lens framework (Elo & Kyngas, 2008; Hsieh & Shannon, 2005). A deductive content analysis approach provides direction in the initial coding and the relationship between codes by moving from a general approach to a more specific one (Elo & Kyngas, 2008; Hsieh & Shannon, 2005). There are three phases of a deductive content analysis: preparation, organization, and reporting, which will be described below (Elo & Kyngas, 2008).

Preparation

The preparation phase consists of selecting the unit of analysis, which for this study included 14 caregiver interviews, three decision-maker interviews, and six agency documents. The aim of the preparation phase is to become completely familiarized and sensitized to the data by being immersed in it (Elo & Kyngas, 2008). To achieve this, the researcher read each transcript and document in its entirety, without any attempt to code.

Organization

Organization of deductive content analysis involves testing categories, concepts, models or hypotheses (Elo & Kyngas, 2008). The organization phase was completed by creating a structured categorization matrix with codes according to category, which was based on the categories and principles of the Caregiver Policy Lens (MacCourt & Krawczyk, 2012). Each category from the Caregiver Policy Lens was a major code or first order code and included sub-codes. The sub-codes were the main codes used to code phrases and sentences in the interview

transcripts and documents. The Caregiver Policy Lens is a structured model, therefore only aspects that fit the matrix of analysis were chosen from the data (Elo & Kyngas, 2008). Refer to Appendix D for a list of the categories and sub-codes.

A second reading of all interviews and documents was completed and coded line-by-line using the pre-established categories and sub-codes. The 11 categories were not revised, as the writer sought to understand how eShift aligned with caregivers needs through the Caregiver Policy Lens.

Reporting

Reporting involves the description of the content within the categories, describing the phenomenon. Findings should be presented in sufficient detail, so that it is meaningful and understandable to the reader (Elo & Kyngas, 2008). A detailed description of research findings can be found under the heading "Findings" within this chapter.

Approaches for Creating Trustworthiness

"The aim of trustworthiness in a qualitative inquiry is to support the argument that the inquiry's findings are worth paying attention to" (Elo et al., 2014, pp.2). The same three phases (i.e. preparation, organization, and reporting) presented for data analysis of a deductive content analysis were used for trustworthiness.

Preparation

The preparation phase involved a secondary analysis of the 14 caregiver interviews, three decision-maker interviews, and six agency documents. A deductive content analysis approach was conducted using a categorization matrix, based on the categories and principles of the Caregiver Policy Lens. A draft of the matrix is included in Appendix D.

Organization

The coding categories for this study were the 11 categories outlined in the Caregiver Policy Lens, which were created by health care and social services providers who completed many interviews with caregivers. Face validity increases trustworthiness, therefore the primary investigators were asked to evaluate the findings from the analysis to ensure they matched reality (Elo et al., 2014; MacCourt & Krawczyk, 2012). Double-coding was completed by the thesis supervisors to ensure that code definitions were clear and did not overlap (Elo et al., 2014). In addition, memos were created in a separate Microsoft Word document as coding took place to further develop reflection on patterns of data and categorical relationships (Hardwood & Garry, 2003; Polit & Beck, 2016). Finally, reflexivity was completed by developing a reflexive journal and through conversations with the thesis supervisor, which assisted in creating a greater understanding of developed assumptions and positions during this phase (Cohen & Crabtree, 2006).

Reporting

The reporting phase allows readers to make sense of the findings in ways that are useful and meaningful (Elo et al., 2014). Reporting of results is linked to transferability, conformability, and credibility.

Transferability. Transferability refers to the extent the findings from the research can be transferred to other groups or settings. Transferability is determined by the reader, consequently, sufficient description on the research process has been provided, along with an in-depth overview of both the eShift program and its relation to caregivers from a policy perspective (Elo et al., 2014).

Conformability. Conformability was achieved in the reporting phase through the use of representative quotations from coded interviews and documents to show the connection between data and results (Elo et al., 2014).

Credibility. Credibility has been demonstrated in the reporting phase by ensuring sufficient descriptive data, such as participant quotes within the reports, to ensure readers have confidence in the rigor of the study (Elo et al., 2014). Links have been made describing how the Caregiver Policy Lens can be used to inform policy and test new models of care, such as eShift.

Protection of Human Rights

The original researchers obtained informed consent from the study participants, which included the provision for secondary analysis of the data. This author is bound by the same confidentiality and privacy standards of the primary researchers (Szabo & Strang, 1997). All data, including copies of the transcripts and NVivo files, were password protected and only accessed by this researcher and her supervisors. All identifying information of participants was eliminated to protect anonymity.

Findings

The findings are presented based on ten of the 11 categories of the Caregiver Policy Lens (MacCourt & Krawczyk, 2012). The "respect and dignity" category was not specifically discussed, but it was addressed within the other categories. Each category includes sub-categories and supporting quotes. Analysis of caregiver interviews (CGI), decision maker interviews (DMI) and documents (DOC) provided insight into the eShift model of palliative homecare.

Caregiver Inclusion and Voice

Caregiver inclusion involves recognizing and valuing caregivers' perspectives. Caregiver inclusion and knowledge on the development of policy, programs, and care plans helps to ensure that they are comprehensive (MacCourt & Krawczyk, 2012). In the interviews and documents, caregiver inclusion and voice was described as 1) recognizing and valuing the caregivers as individuals and 2) collaboration and consultation about care plans and significant changes in service provision.

Recognizing and valuing the caregivers as individuals. The eShift model was created to provide care to individuals wishing to die at home and support their caregivers. The eShift model of care provides the "caregiver some relief" (DMI 2) through extended hours of in-home care provided by technicians (PSWs), who receive additional training on palliative care including medication administration under the direction of the Directing Registered Nurse (DRN). The eShift model works with the caregivers to allow the "caregiver to manage with the client at home" (DMI 2). The decision makers also acknowledge that through eShift the "caregiver becomes a (care) recipient" (DMI 1), as the program provided skilled health care teams who manage patient care, therefore allowing the caregivers to sleep at night. Through an evaluation of the eShift model, the homecare agency reported that 92.3% of caregivers who received care through the eShift model did not suffer burnout (DOC 1).

Collaboration and consultation about care plans and significant changes in service provision. Most of the caregivers interviewed indicated that they were part of the care team looking after their family member or friend. Being part of the team was explained by one caregiver, who stated she would communicate with the technician when they arrived, allowing for a better night sleep:

> "So we'd had about a 10-minute little interview and I'd say well, he had a pretty good day, or he was irritated today, or whatever, just kind of fill her [technician] in. But generally, by 10 after 10:00, I was going to bed, knowing they were here and his needs would be covered (CGI 3).

A decision maker further described how the care plan for a patient receiving eShift is an interactive online form that continually evolves based on input from all members of the patient's care team, including family members:

> "…we created an intake form which actually was transformed into a [kardex] or an information sheet for palliative care specifically. We also found that …we needed to have a… really active every day changing, evolving care plan… It's updated based on the family's report. It's updated based on the visiting nurse's report. And it's updated based on how the night progresses (DMI 1).

Collaboration

Collaboration refers to open and innovative forms of communication between organizations and with caregivers, in which the caregiver's stories do not have to be retold (MacCourt & Krawczyk, 2012). The eShift model supports collaboration through technology, with the DRN and technician connected by an information system accessed using electronic devices. As well, there is collaboration with the different agencies and health care providers in a patient's care. Participants spoke about collaboration as 1) adequate collaboration and communication between agencies and health care providers, 2) mechanisms in place for the caregivers and health care providers to exchange information, and 3) roles and responsibilities of each agency and health care providers providing services made clear.

Adequate collaboration and communication between agencies and health care providers. The implementation of the eShift model has "opened up more communication and more sharing" (DMI 1) between health care agencies and health care providers to ensure seamless care for the patient and their family. One decision maker stated that cross-agency collaboration occurs in training staff for eShift.

Another decision-maker indicated that the eShift model was the first program in the community in which communication occurred in real time using new digital technology, which has assisted in decreased patient admissions to hospitals. As stated by the decision maker:

"The communication necessary to get a visiting nurse there, whether it be in the middle of the night or immediately at the beginning of the next day, whereas under regular shift nursing care or [technician] care for palliative, it would have been a report to somebody and… the direction … would have been to send them to hospital or call the ambulance" (DMI 2).

One caregiver looking after her husband stated the care was "organized so well" (CGI 1) between the visiting nurse drawing up and labeling all the medications and the technician being directed by the DRN to give the medications.

A caregiver whose husband died while eShift staff were present in the house described how the communication between the DRN and technician made for a positive experience, "So you know

that whole connection with phones and eShift…it's great…And it worked out fine… he [the technician] had obviously immediately been in touch…with his nurse" (CGI 1).

Two caregivers reported incidents in which collaboration for medication administration between agencies was not possible due to the agency policy making it the family's responsibility to administer the medications. As described by one caregiver:

> "Well, it was very bad because I had to be woken up every two hours to give him drugs. And that was in part because eShift is one company…[and the] nurse that was here was another company. And the two companies were fighting or don't agree on whatever…. So the one company draws up the drugs but the other company won't give them because the other company's drawing up the drugs. So they're giving them to a layman who knows nothing about drugs and saying, "Here. You inject your father" (CGI 14).

One decision maker acknowledged the current structure of home care service delivery in general and the barrier with having different agencies involved in a patient's home care and the impact on palliative home care:

> "So I mean, it (LHIN's software tool) pretty much assigns clients on a random basis based on things like market share or volumes and therefore tries to keep a balance with the multiple agencies but it's not built around the client…[LHIN] in working with us, all the partners, …it's not realistic to have six different agencies involved in client care especially when they have different approaches and philosophies and different beliefs around clinical practice" (DMI 2)

Mechanisms in place for the caregivers and health care providers to exchange information.

The majority of caregivers indicated they were updated and informed about their dying family member's condition and spoke with the oncoming technician to inform them of the patient's day. As stated by one caregiver:

> "And when I went to bed, I felt confident that… I'd made them familiar with what was going on during the day…we had a lot of positive communication before and after their shift" (CGI 4).

Clarity of roles and responsibilities of each agency and worker providing services.

Typically, caregivers were provided with information about home care, and eShift in particular, by the homecare coordinators during the intake interview. However, caregivers had different levels of recall and understanding about the role of service provider agencies (e.g. Victoria Order

of Nurses) and the different health care providers in their home. Information about eShift and the roles of health care members was provided to patients and family members in agency 'welcome packages', which states "eShift involves specially trained PSWs receiving support from an off-site Registered Nurse through a Smartphone application. The PSW carries out activities on behalf of the nurse while providing care for our palliative…clients" (DOC 6).

Although information about eShift and health care providers' roles and responsibilities were provided to caregivers, some caregivers still indicated they were unsure of the roles and responsibilities of the DRN with the technician. Four caregivers reported they had direct contact with the DRN or that the technician communicated to them their interactions with the DRN overnight. However, other caregivers were unsure to what extent the DRN was involved in the patient's care. One caregiver spoke to her lack of understanding on how often the DRN and technician interacted: "I often wondered how much they interacted. But maybe they don't have to, you know, unless there's a problem" (CGI 5). One decision maker indicated it is now the agency's practice to have the technician make families aware of whom the DRN is for the night and to make families' aware they are welcome to speak to the nurse at any time.

Evidence Informed

In order to achieve optimal results, programs or policies should be informed by the best available evidence, including experiential knowledge and scholarly literature. Optimal results require monitoring and evaluation of the program or policy (MacCourt & Krawczyk, 2012).

The extent to which caregivers were involved in the design of eShift is unknown, as it was not discussed within the caregivers or decision maker interviews. However, both the decision maker interviews and agency documents provide insights regarding how evidence was utilized and how evidence informed the development and implementation of the eShift model. Caregivers did have a role in ongoing refinements to the eShift model. The evidence informed category was addressed as 1) based on current evidence and 2) mechanisms in place to obtain input and feedback from caregivers.

Based on current evidence. The development of the eShift model was discussed in two documents and in the decision maker interviews. One document by Red Cross Care Partners (now Care Partners) stated, "Some fundamental drivers for this program [eShift] were based on assumptions and research" (DOC 4). One decision maker's decision to offer eShift at night was informed by her own beliefs and her experience as an administrator. She stated, "in my heart of hearts I thought the hardest time is at night more so than during the day" (DMI 1).

Mechanisms in place to obtain input and feedback from caregivers. Caregivers provided feedback on the eShift model through different research opportunities, which led to positive changes in eShift. One decision maker described the findings of from an early study conducted by university researchers Dr. Donelle and Dr. Regan:

> "Really from your first research study, which was a pivotal point for us, was learning that the one thing families struggled with was having to get up and give medications all night long. And we kind of thought of that but nobody really didn't say it to us and yet they expressed that so freely in your research. That was, for us, a moment where we had a big meeting and we said, "We are failing still in meeting the needs of each family member and these patients" (DMI 1).

As a result of the research findings, the agency decided to educate the PSWs in giving medications under the direction of the DRN, to allow the family to sleep at night.

The decision makers acknowledged administrative data collection for eShift is in early stages, and that work was required to improve collection of data and maintenance of a database. In addition, the decision makers reported having difficulty with the number of agencies involved in a patient's care, as they are all collecting and measuring data in different ways, and it is not being shared with one another. As stated by one decision maker who reported not receiving data from another company:

> "We can't run data ourselves so we have no capability. They do say that they will share data. We don't get very much data yet. They keep promising us and sort of huge amounts of data to be able to make decisions on" (DMI 1).

Diversity and Marginalization

Caregivers are a diverse group who can be marginalized for various reasons, including gender, location, income, and the family member's illness (MacCourt & Krawczyk, 2012). Diversity and marginalization were briefly discussed within the interviews through: 1) promotion of well-being, or avoidance of negative effects, for caregivers and care recipients who may be marginalized and 2) eligibility criteria, application processes, and other processes presented clearly, and in a variety of mediums.

Promotion of well-being, or avoidance of negative effects, for caregivers and care recipients who may be marginalized. The eShift model of palliative home care was offered to patients and caregivers regardless of gender or geographic location and for some, even when caregivers were not available in the home.

Living with the care recipient. eShift care is provided regardless of whether the caregivers resided inside or outside of the home of the care recipient. Many of the caregivers reported their quality of sleep improved with the presence of eShift. One caregiver whose husband lived at home with her while receiving eShift stated: "The benefits of eShift, it takes some of the responsibility from you" (CGI 5).

Women, men, and rural caregivers. eShift care is provided based on need not gender or location. Both male and female caregivers participated in the interviews, with the majority being female. Caregiver participants reported living in rural or urban dwellings while receiving eShift. As stated by one caregiver who lived in a rural area while caring for her parent:

> "I was concerned being out for about 20 minutes outside of [place], where we're in a rural area. I didn't know how it would work, but it never seemed to be difficult for anyone… to support us" (CGI 4).

Employed. While of the majority of caregivers were retired, some of caregivers indicated they continued to work or volunteer while their family member received eShift care. One adult child caregiver stated: "I was able to continue working more than I would have otherwise been able to do had I been on full time care" (CGI 6). However, other caregivers reported changing their

work hours or stopping their work or volunteer work when their family member became palliative. One decision maker explained eShift is now becoming more flexible to meet "family needs" (DMI 2).

Caring for someone with compromised cognition. Two caregivers reported their family member's cognitive status declined, making it increasingly difficult to care for them. However, with the addition of eShift, they were able to manage keeping their family member at home. One caregiver explained she was able to keep her spouse at home when his illness made him "violent and unhappy" (CGI 8), because someone was in their home to provide care for him.

Eligibility criteria, application processes, and other processes presented clearly, and in a variety of mediums. Decision maker interviews and agency documents provided some information about eligibility criteria for eShift care, however, there was a lack of consistency as to when a patient and family qualified for eShift care. The patient's Palliative Performance Score (PPS), a measure of a person's physical status at the end-of-life (Anderson et al., 1996), was one of the main criteria for initiating the eShift model. However, different agencies had different thresholds for the PPS. Some agencies initiated eShift when the PPS was 30% or less, while other agencies used 40% or less. No explanation was provided as to why different thresholds were used. While the PPS was an important criterion for initiating eShift care, interviews with decision makers indicated that caregiver experiences were also considered in decisions.

Choice, Self-Determination, and Independence

Caregivers have the right to choose their level of involvement in their family member's care, therefore, health care providers need to provide information and continually explore the caregiver's willingness and level of involvement in providing care (MacCourt & Krawczyk, 2012). Choice, self-determination, and independence were categorized through 1) clear information provided to caregivers to make informed choices, 2) caregivers informed about and offered services available to the care recipient proactively and prior to crisis, 3) caregivers' willingness to provide care, the boundaries of their care, and the care recipient's needs reviewed

on a regular basis, and at critical transition points during the care, and 4) plan in place if the caregiver chooses to end part or all of their caregiving role.

Clear information provided to caregivers to make informed choices. The majority of the caregivers reported being accepting of eShift when it was offered to them. However, one of the decision makers acknowledged that timing and information for caregivers to start eShift needs to improve, as some families are not accepting help until a crisis occurs. The decision maker's comment was further corroborated by a caregiver who indicated she was not provided with enough information to make an informed choice about starting eShift:

> "More information to let the caregiver know what's happening…to accept that we do need the help … Because really, in our mind, we don't think we do" (CGI 11).

Caregivers informed about and offered services available to the care recipient proactively and prior to crisis. The majority of family members and caregivers accepted eShift when it was offered to them. However, two caregivers indicated their family member was offered eShift at an earlier time than they were willing to accept it, resulting in them only receiving eShift for a limited period of time. As stated by one caregiver, "I'm not sure because I knew about the program and everything so …I just think I had to hit bottom before I knew I needed help" (CGI 9).

Caregivers' willingness to provide care, the boundaries of their care, and the care recipient's needs to be reviewed on a regular basis, and at critical transition points during the care. Three caregivers reported being able to discharge their family member from hospital to home at the end-of-life with the presence of eShift. One caregiver described being able to bring her mother home and have her with the family for the final days of her life due to the presence of eShift:

> "We knew we wanted her at home…I didn't want her in a hospital and, she was happy to be at home. We're a big family. I'm one of seven kids…So I couldn't imagine her being away from family at that time just in case it (death) happened through the night and we weren't there" (CGI 4).

One family reported they were told eShift services were going to be taken away despite the caregivers wanting them to continue because the patient's status did not decline as rapidly as projected. As expressed by the family caregivers when told services were going to be taken away:

> CGI 8B "we were both going if you take that [eShift]away, "we're screwed."… Like he has to go into hospice right away…Because we can't". CGI 8A "And there was no way to get him in right away"… CGI 8B "No. Because there was a wait list"… CGI 8A "I was hoping he wouldn't. I'm hoping…he could die at home because that's what he wanted" (CGI 8A/B).

Plan in place if the caregiver chooses to end part or all of their caregiving role. Two caregivers each reported having a plan in place to transfer their family member into hospital or hospice care when they felt unable to continue with their roles as caregiver. However, eShift was able to support families to keep their dying family member at home as long as possible before transferring to hospital or hospice. As reported by one caregiver whose husband was transferred to hospital to die:

> "[name], [name] and I had discussed this and he said he did not want to pass away at home. And when I, there was the one night the eShift was here and he had lost control of his bladder and I knew that was the start. And that's when things went into motion and the next day he went to the hospital and three days later he was gone" (CGI 12).

One caregiver reported her mother wanting to limit her caregiving role for her husband and have him transferred to hospice, however, she unable to due to the hospice wait list:

> " [the homecare agency], were trying for the final four days of life to get him into a hospice because my mom just didn't feel she could take care of him during the day and that's where she thought he should be. And they kept saying he's first on the list… anyways, my father passed (at home)" (CGI 14).

Accessibility

Accessibility is about ensuring programs and policies are accessible and responsive to caregiver needs (MacCourt & Krawczyk, 2012). The eShift model of care addresses accessibility through the timely provision of palliative care in the home and by reducing financial barriers to palliative care. However, a lack of human and financial resources to adequately staff eShift and lack

awareness about eShift may pose barriers in accessing it. Accessibility is described as 1) sufficient resources attached to eShift to ensure services are available in a timely manner, 2) practical barriers addressed, and 3) information about the program easily available.

Sufficient resources attached to eShift to ensure services are available in a timely manner. All caregivers interviewed indicated that their dying family member received eShift care in a timely manner. Although one caregiver wanted eShift care "longer and more often" (CGI 11), her dying family member was not agreeable to it. One caregiver explained how quickly her partner was able to receive eShift services:

> "I was getting pretty tired. And [name's] son… phoned [name] and he said, "[The patient] needs more help."…And we had a meeting that day. There was ten of us here. And the girls left at 2:30 and by 4:00 o'clock, eShift was coming in that night" (CGI 13).

One decision maker acknowledged that funding for eShift limits their patient caseload despite an increase demand for palliative homecare services. As discussed by the decision maker:

> "it's been difficult because the caseload grew really, really fast to the point that we were managing 35 clients on any given day and then because of funding limitations and those regulatory limits, it collapsed and now we've stabilized at around 20 [clients] on a typical day" (DMI 2).

Practical barriers addressed. Once patients and caregivers had access to eShift, many of the practical barriers, such as cost and transportation, were addressed. The eShift model combined with other provincial policies (e.g. Ontario Drug Benefit) covered most of the costs of care with little to no out-of-pocket expenses for patients and families. One caregiver expressed how she felt about the financial savings using eShift:

> "Oh my god, it was phenomenal! I mean the bed and the nursing care, and everything else, I mean it was, I would say that ten days at home easily fifty thousand dollars. It's just it's [eShift] a tremendous, tremendous, all of the medications, the needles, everything! It is really truly a tremendous program" (CGI 3).

Out-of-pocket expenses by caregivers included ambulances, a portion of prescription medications, and some specialty items that families chose not to obtain for the home through the LHIN or that were not covered by the LHIN

Information about the program easily available. Caregivers reported learning about eShift through internet searches, friends, or through the LHIN staff. However, some caregivers and decision makers indicated that there was a lack of awareness about eShift by external groups. One caregiver explained:

> "Maybe the physicians of [place] need to know these things or [LHIN] or the paramedics or whoever has to get stuck in the physicians' office. So when people become elderly or …their kids are taking care of them or they get to a certain age of 65 and you're going to get that senior's check … have this information so you know about this program" (CGI 14).

This lack of awareness about the eShift model of palliative homecare was further reiterated by a decision maker who stated that in some areas, patients and caregivers are only receiving eShift for a short time because "awareness of the program [eShift model] because really it is still very young" (DMI 1); therefore, families and health care decision-makers are needing time be aware and accepting of care through the eShift model.

Caregiver Assessment

Caregiver assessment means ensuring caregivers have their own needs assessed (MacCourt & Krawczyk, 2012). The caregiver assessment in the eShift model is characterized through 1) caregivers explicitly asked about their own needs and how they might be best addressed and 2) caregivers asked to identify changes needed to the support and services they need/use.

Caregivers explicitly asked about their own needs and how they might be best addressed. Decision makers discussed the process by which they assess and track caregivers' needs and experiences including caregiver stress. As stated by a decision maker:

> "The caregiver stress…We do track it. That's one of the metrics throughout that individual person's journey that we keep a very close eye to keep track of where the family is. That's why not only from the feedback from the [technician] but my local managers and educators in my office in [place] who have touch points" (DMI 2).

Caregivers asked to identify changes needed to the support and services they need/use. Caregivers spoke about how their changing needs were identified. For example, through

conversations with physicians, health care team members, or eShift providers, some caregivers reported requesting and receiving increased eShift care hours or more flexible scheduling of hours thus assisting them to continue in their caregiver roles. As stated by one caregiver who was working and caring for her mother:

> "I asked for someone to come from 7 at night until 7 in the morning so that they could start to get her ready for bed if I was still helping my husband… I have other things I need to do and owning your own business is tough" (CGI 14).

The eShift health care providers also assessed the needs of caregivers and advocated for additional hours to be added to the patient's care to prevent caregiver burnout. One caregiver, who looked after her husband and had been reluctant to accept care, spoke to how care was gradually increased for her husband:

> "I know that they had started … coming … maybe one every other night and then I think they started to come more often…so whether, through their care they knew that [name] needed that or I needed it, I'm not sure" (CGI 12).

Sustaining Caregivers

Sustaining caregivers is about providing caregivers with access to support systems available to them, ensuring there are appropriate staff and education provided, with a focus on access to "the right programs at the right time" (MacCourt & Krawczyk, 2012, p.29). The eShift model plays an important role in sustaining caregivers by 1) personal relationship building, 2) providing emotional/psychological support, 3) providing practical support, 4) providing respite, 5) aiding in healthy aging, 6) individualized information about the medical, cognitive, and functional needs of the care recipient being cared for.

Personal relationship building. Caregivers reported being able to build positive relationships with different health care members of the eShift program, including the technicians, DRNs, visiting nurses, and care coordinators. One caregiver described her experience with the eShift model of care and the health care team members caring for her mother:

> "It was great. Even just phone calls when they didn't need to come in for a visit… I felt incredibly supported through it all… I honestly didn't know if I could have her at home

till the end. And I'm so glad we were able to, for her as well as for us. And I couldn't have done it without the support" (CGI 4).

Ten caregivers reported not having a relationship with the DRN because they were not in direct contact with them. However, the caregivers that did connect with the DRNs reported having positive encounters with them.

Emotional/ psychological support. The majority of caregivers described feeling very supported by the eShift team. Two caregivers reported finding it helpful having someone in the house with them at night when they were feeling emotional or had anxiety, as they were able to talk with the technicians. As stated by one caregiver, "Well, you kind of knew if in the middle of the night you had anxiety. So you could get up and there was somebody here you could talk to" (CGI 13).

Practical support. The health care providers were most often described by the practical supports, such as supplies and equipment provided through eShift. The inclusion of eShift for a dying family member allowed caregivers to continue being caregivers for their family member in the home. As explained by one caregiver:

> "I know for myself, physically, I couldn't …have kept going if I didn't have them [eShift] in. And I was able to sleep…because those few nights leading up to them…being put in place… I was a hazard to myself going up and down the stairs several times a night being half asleep" (CGI 4).

Caregivers discussed the importance of practical supports in assisting them in their caregiver role and in reducing the burden of trying to leave the house for appointments. Practical supports brought into the home included health care professionals beyond the core eShift team, such as nurse practitioners, physicians, social workers and therapists, as well as medical supplies, such as beds, walkers, and railings.

Respite. Respite was an outcome of eShift, as the presence of health care providers alleviated some of the caregiver's responsibility and provided them with a sense of security. As stated by one caregiver, "it would be just the security of having them here and less worry for the caregiver" (CGI 11). Additionally, caregivers reported having eShift at night helped them cope.

As stated by one caregiver, "I mean I can give meds during the day. That's not a problem. But again, getting up every 4 hours at night would make me crazy" (CGI 6). Caregivers reported their quality of sleep improved with the presence of eShift, as they were more secure having a health care provider present. One caregiver stated, "It was security knowing he was going to be looked after. And I could go to bed and sleep knowing that, you know, if they needed me, they knew where I was" (CGI 13).

The Caregiver Policy Lens states that respite should be offered regularly and when the caregiver needs it (MacCourt & Krawczyk, 2012). A few caregivers specified they could have benefited from eShift care during the day. One caregiver, whose spouse developed cognitive issues, explained:

> "So that's the only thing that would have helped us, to have them during the day because I didn't have anybody during the day and that's when I'd have to feed him and give him his pills. And sometimes he would have, weird things would happen. He'd be seeing things that weren't there and I wasn't used to that" (CGI 11).

However, policies developed by the provincial government may impede the hours of care provided in the home. For example, one decision maker highlighted the governments' legislative maximum of 206 hours of in-home nursing care per patient in a 30 day period, and eShift care hours are included in these hours.

Individualized information about the medical, cognitive, and functional needs of the care recipient being care for. Caregivers had mixed responses about whether or not they were informed of the death and dying process of their family member. One caregiver spoke about her experience of feeling informed as follows:

> "So you know, I had lots of access to a lot of information and helping me to understand things as they were going along so" (CGI 4).

While another caregiver commented on how the information about the death and dying process was lacking, especially in the hospital, to understand her husband was palliative:

> "And as I said about communicating the death process with you and, and your caregiver, that was lacking because I'm saying if [name] heard them say and he, as I said, he had

impeccable hearing. And I was never told. That's wrong. That's definitely wrong" (CGI 5).

Sustaining Systems

Sustaining systems involves flexibility within programs and policies and ensuring health care providers have the appropriate education and training to support caregivers (MacCourt & Krawczyk, 2012). eShift addresses sustaining systems through 1) service flexibility and 2) service providers.

Service flexibility. Service flexibility includes 1) services offered proactively before needs reach crisis proportion and 2) sufficient capacity and flexibility to respond to crisis in a timely manner without escalating needs.

Services offered proactively before needs reach crises proportion. Overwhelmingly, eShift was offered and provided to caregivers before a patient or caregiver was in a crisis. As stated by one caregiver who was not living with the care recipient:

> "Well, if they [eShift] weren't there, that would have been devastating and she couldn't have remained at home. Like there would be no way because I couldn't have stayed there all night and I don't know, there's nobody that would have...so, really, the eShift was a blessing and if they weren't there, she would have had to go into a hospital situation, hospice situation because it just wouldn't have worked" (CGI 2).

The presence of eShift in the home resulted in the majority of caregivers reporting that their family member was able to die in their place of choice, whether it be in the home or having arrangements with eShift staff to be transferred to hospital when death was imminent. One decision maker commented that they track patient care using the eShift dashboard that consists of an overview of patient data, to ensure practical barriers and flags that could prevent patients and families from being successful with a home death are addressed.

Sufficient capacity and flexibility to respond to crisis in a timely manner without escalating needs. The eShift program has the capacity and flexibility to respond to crisis in a timely manner without escalating needs, such as preventing transfers to the emergency department. Some caregivers reported being better able to handle emergency situations related to the palliative care

of their family member because of eShift, such as cognitive changes. The majority of caregivers reported that they did not have to call an ambulance while eShift was present, and the few caregivers that reported calling an ambulance did so when eShift was not present in the home. As stated by one caregiver: "Twice, she had to go by ambulance, not on the eShift but through the day" (CGI 2).

The ability of the eShift providers to respond to crisis in a timely manner was further explained by a decision maker and within one of the documents. Reduced emergency visits and hospital admissions have occurred with the inclusion of eShift in a patient's care. As stated by the decision maker:

> "So we have an extremely high success rate in terms of managing client care without the need for intervention, going to hospital, those kinds of things. It does happen. There's times when you just, there's no other choice" (DMI 2).

Service providers. Service provider assessment factors includes 1) service providers' knowledge, skills and supervision, 2) services providers kept to a minimum, and 3) service providers educated and sensitive to the needs of caregivers

Service providers' knowledge, skills and supervision. Most caregivers reported their family member received high quality care and that their family member's pain was well managed. Many caregivers spoke about health care providers having the time, skill, and support to develop a caring and trusting relationship with the caregiver and patient. One caregiver stated:

> "I think it went exactly how it should go. I think his physical and his mental well-being was cared for very well. And, I don't think some sleep-deprived, crazed caregiver would have come nearly as close to providing that. So... in my mind, it's a perfect model" (CGI 6).

However, some caregivers mentioned instances with health care providers where the provider lacked experience to deal with the situation at hand, such as a death, or the health care provider was not educated to perform certain tasks, such as medication administration. The inability of the technician to perform medication administration under direction of the DRN resulted in family

members being woken up to administer the medications. One caregiver explained her experience with eShift as follows:

> "So the first few nights I actually had somebody who was trained to do, to push the meds but because we were sent home with them from the hospital, they were in a different syringe than what he said he was allowed to use. So he didn't do it. And then for the following, I think, five nights, or four nights, we had somebody who wasn't allowed but she just was not trained" (CGI 3).

Services providers kept to a minimum. Decision makers report they have small teams and continuity of health care providers going into the home. However, caregivers varied on their reports of consistency, or lack of consistency, with health care providers going into the home. A few caregivers had positive experiences related to having consistent caregivers. As stated by one caregiver:

> "My dad, we were fortunate to have the same one three or four times a couple of times. So that was kind of cool that you could, you know…You would establish more relationship with the people that are here longer, I guess" (CGI 14).

Other caregivers reported the difficulty with having different caregivers all the time. One caregiver explained:

> "Number of people in, this could be streamlined so much more…I kept track of, from, and I don't know whether it was in the last time or the time I started. I stopped at 27 names…Of people that I had talked to" (CGI 5).

Service providers educated and sensitive to the needs of caregivers. In the decision maker interviews and documents, the eShift staff was often praised for their commitment to helping patients and caregivers, including obtaining additional education. As stated by one decision maker:

> "family members, I think, often express to us that they were concerned that they weren't doing everything for their loved one's comfort. And so then they panic and think, "Oh my goodness! Maybe there's something that should be happening and we don't know. So we better call 911." So by the directing … RN being able to provide that reassurance and normalizing that that breathing pattern is normal; that gurgling is normal …suggesting they give medications to manage those symptoms, helps people" (DMI 1).

Caregivers also spoke to the technicians being sensitive to their needs. One caregiver, who was caring for her mother, stated, "there were times I was very emotional and, you know, they kind of handled me with kid gloves" (CGI 4).

Fairness and Equity

Fairness and equity strives to ensure that a program or policy does not benefit some groups while causing disadvantages to others (MacCourt & Krawczyk, 2012). The eShift model was created to address a community need to allow people to die in their own home and to assist in preventing caregiver burnout through the collaborative use of human health resources and technology.

Individual needs balanced with those of the larger group. One decision maker stated that prior to the initiation of eShift, their company was not receiving requests from the LHIIN for palliative care shifts as they did not have nurses to cover the shifts in the community. The decision maker explained, "We did realize that people do die in hospital a lot and that that's sort of the only option they have" (DMI 1), as they were unable to support individuals to stay in their home. Decision makers and agency documents stated that eShift has assisted with discharging palliative patients into the community, decreased emergency room visits, decreased hospital admissions, allowed patients to die in their place of choice, and prevented caregiver burnout (DOC 1). Decision makers and documents reported the inclusion of the eShift program has provided health care agencies with the ability to expand outside their established boundaries to meet the needs of patients and their families. Health care agencies have even collaborated with one another to provide eShift care to patients and families.

However, as indicated throughout the decision maker interviews, there were times when the need for eShift was greater than provider's ability to cover the shifts, and when this occurs the LHIN has stated, "priority will be given to families who require night shifts in order to sleep or who are caring for a family member who is nearing end of life" (DOC 5).

Discussion

This study analyzed 14 caregiver interviews, three decision maker interviews, and six agency documents to understand how the eShift model of palliative home care aligns with caregiver needs through the Caregiver Policy Lens. Ten of the 11 categories within the Caregiver Policy Lens were explored, with the category "respect and dignity" being addressed throughout the categories. The main categories of focus within the interviews and agency documents were with accessibility, collaboration, sustaining caregivers, and sustaining systems, which reduced caregiver burnout and will be the focus of discussion in this section. Areas for improvement that were identified included explaining the role of the DRN with the technician to the caregiver, minimizing the number of health care providers and agencies involved, and providing earlier awareness of the program to allow caregivers time to accept the program. Areas that were not clearly addressed in the interviews and agency documents were "evidenced informed" and "diversity and marginalization".

Accessibility

Findings from this study indicated that all caregivers reported that they and their family member had access to eShift care in a timely manner. Caregivers commented on how quickly eShift started once it was offered to them, in some cases allowing caregivers to bring family members home from hospital to die. The literature indicates that caregivers who were either unsuccessful in accessing or receiving adequate support or the services were brought on too late in the family member's health care journey (Sekelja et al., 2010; Topf et al., 2013). Furthermore, Keefe and colleagues (2011), report that caregivers endure significant economic costs related to caregiving (Keefe et al, 2011). Contrary to the Keefe and colleagues (2011), this study found eShift combined with other provincial policies (e.g. Ontario Drug Benefit) covered most of the costs of caregiving.

Collaboration

eShift, is a new model of palliative home care that involves interagency and inter-professional collaboration, organization, and communication between and among health care agencies, health care providers, and the patients' families. Collaboration between agencies and health care providers can enhance the experience for patients, caregivers, and health care professionals, through sharing past experiences, fostering common goals in palliative care, and mutual emotional support (Shaw, Kearney, Glenns, McKay, 2016). Through interagency and inter-professional collaboration, the majority of caregivers had positive experiences with eShift in the home, however, caregivers suggested continuity of health care providers coming into the home could be improved. Additionally, when interagency policies were not aligned with one another regarding medication administration, it caused the caregivers to have to be woken up in the night to administer medications, affecting their sleep and time away from their caregiving role. This finding is consistent with the literature in which caregivers reported their experiences being affected by health care services coordination, communication, and consistency of health care providers in the home (Brazil et al., 2012; Hasson et al., 2010; Jo et al., 2007). At the time of the primary study, when findings regarding issues with medication administration and caregiver sleep disruption were brought to the attention of decision makers, policies were changed to address this issue.

Sustaining Caregivers

A major benefit cited by caregivers in this study was having health care workers in the home, alleviating some of the responsibility of being a caregiver, resulting in improved sleep. Findings in literature report that caregivers overall health decreases when the caregiving demands increase, due to loss of sleep, fatigue, and stress (Bialon & Coke, 2012; Kenny et al., 2010; Totman, Pistrang, Smith, Hennessey, & Martin, 2015). The eShift model of care may address the overall health of the caregiver by adding the assistance of health care providers as the family member's caregiving demands increase. Other literature has found that caregivers value the presence of health care providers in the home as it supports them in living a "normal" life, especially when the health care providers are present during the night (Ewing & Grande, 2012;

Jack et al., 2014). Findings from this study further support these findings, as many of the participants reported that the presence of a health care provider at night increased their ability to cope in caregiving for their family member during the day. Since the majority of care at the end-of-life is provided by family caregivers (Canadian Hospice Palliative Care Association, 2013), eShift may sustain the caregiver's physical and mental health by decreasing the burden of caregiving and providing respite.

Sustaining Systems

Authors of previous studies described that many caregivers experience distress when they are not receiving appropriate supports from the government and health care providers to help avoid the family member from experiencing a crisis, such as emergency room visits or hospitalization (Guerriere et al., 2016; Waldrop & Meeker, 2011). Findings from this study found that with the presence of eShift team in the home and the connection of the technician to the DRN through real-time communication, caregivers reported being better able to handle emergency situations and support their family member to die in their place of choice, be it home, hospice, or hospital. Caregivers and health care providers ability to manage a crisis was evident as only two family members were admitted to hospital in this study, both admissions occurred when eShift was not present in the house. In the province of Ontario approximately 40% of oncological palliative patients access the emergency department within the last two weeks of life (Barbera, Taylor, Dudgeon, 2010). Studies further reported that caregiver burden increased when the functional status of the dying family member declined (Guerriere et al., 2016; Hirdes et al., 2012; Waldrop & Meeker, 2011). Waldrop and Meeker (2011) reported the family members functional status decline equated to the family member being admitted to a palliative care facility to die. However, with the presence of eShift in the home, only one caregiver reported an unanticipated transfer to hospital for their family member to die.

Use of the Caregiver Policy Lens

The Caregiver Policy Lens is a useful starting framework in the development, implementation, and evaluation of new and existing models of care and policies to examine the effects on

caregivers. Examining the effects of policy and programs for caregivers providing care at the end-of-life is extremely important as research has shown these caregivers have significantly higher rates of self-assessed poor health and experience more financial and social burdens than short-term (less than two years) and long-term (two years or longer) caregivers (Williams, Wang, & Kitchen, 2014). The Caregiver Policy Lens is not specific to end-of-life care, however, findings from this study suggest that it thoroughly addresses the needs of end-of-life caregivers, with consideration to respite, continuity of health care providers, diversity of caregivers, and accessibility. Overall, The Caregiver Policy Lens is a good starting point in recognizing the important role and needs caregivers have with the health care team.

Study Strengths and Limitations

As with all studies, certain limitations exist. This study was a secondary analysis of data, therefore the researcher had no control in generating the data set, which limited the ability to fully apply categories in The Caregiver Policy Lens in the analysis (Szabo & Strang, 1997). However, the variety of data sources analyzed in this study, including caregiver interviews, decision-maker interviews, and documents, provided rich data to answer the research question posed.

Conclusion

The purpose of this study was to understand how eShift aligns with the needs of caregivers using The Caregiver Policy Lens. The findings of this study have shown how the eShift model of care addressed some the challenges researchers have identified caregivers encounter in their caregiving role, such as timely access to palliative home care, respite, coordination of care, and support in handling emergency situations in the home. Overall, caregivers had positive experiences with the presence of eShift health care workers in the home, most notably with accessibility, sustaining caregivers, and sustaining systems. Collaboration between agencies, health care workers, and families was an essential component of the caregivers having a positive experience in providing care for a dying family member at home. Inclusion of caregiver

experiences and perspectives in early development and on-going implementation of the eShift model of care, in part contributed to the positive experience of caregivers.

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Chapter 3: Conclusion and Implications

Overview of the Study

The purpose of this study was to understand how the eShift model of care aligned with the needs of caregivers who cared for a family member who received eShift, a new model of palliative home care. The research question that guided this study was: "How does the eShift model of palliative home care align with caregiver needs?" The data for this study included secondary analysis of 14 caregiver interviews for 15 patients, one participant had two family members receive eShift, while two caregivers participated in an interview about the same patient; three decision maker interviews, who were integral leaders in the development and establishment of eShift; and six agency documents related to eShift from home care agencies and the community care access center. The interviews and documents were analyzed using the Caregiver Policy Lens framework, intended for the development and analysis of policy, programs, and services from the caregivers' perspective, to ensure the needs of caregivers are considered (MacCourt & Krawczyk, 2012). Ten of the 11 Caregiver Policy Lens framework categories were used to analyze the data, with "Respect and Dignity" being addressed throughout. The findings from this study indicated that the eShift model of care met several of the identified needs of caregivers, such as providing support in the caregiver role; supporting caregiver well-being; and confidence in the caregiver role; and their ability to handle an emergency situation. Caregivers' needs were met through timely access to respite, education, being an active member in the health care team, and physical and psychological support. Caregivers referenced the eShift model of care as providing them with "security" in their caregiver role. Security was defined by caregivers as health care provider's physical presence in the home which allowed them time away from their caregiving role, providing them with expert knowledge to answer their questions about the death and dying process, and providing them support when anxious or grieving. Additionally, this study found when continuity of care was lacking, it negatively impacted caregiver's needs, as it affected their respite and well-being. In this chapter, the researcher has addressed implications for policy development, nursing research, and nursing practice.

Implications and Recommendations for Policy Development

The findings from this study will help policy makers make informed decisions regarding caregivers providing end-of-life care in the home. In this section, the researcher will discuss implications for policy at the service delivery level, specifically for the Local Health Integration Networks (LHINs) and home care agencies, and provincial government policy level.

Health Service Delivery Policy: Local Health Integration Networks and Home Care Agencies

Caregivers indicated that the eShift health care providers supported them to keep their family member at home, as it provided the caregivers respite and security in their caregiving role, while allowing them time for the grieving process. Researchers have found when caregivers do not have appropriate supports in place, such as support from health care providers trained in end-of-life palliative care, it necessitates admission to a facility for palliative care for some patients (Bialon & Coke, 2012; Kenny, Hall, Zapart, & Davis, 2010; Waldrop & Meeker, 2011). Therefore, with the benefits of supporting caregivers so the family member can stay at home to die, it is suggested the Local Health Integration Networks (LHINs) consider the expansion of the eShift model of palliative home care to all LHINs in the province.

Consistency of health care providers was often mentioned by caregivers in this study. Caregivers who had consistent health care providers in the home indicated that they were confident in the care their family member received. Other caregivers indicated the number of health care providers going into the home needed to be minimized because it contributed to disrupted sleep and lack of confidence in care. Interviews with decision makers identified that patients are assigned to agencies based on market shares that attempt to balance the patient caseloads between multiple home care agencies rather than the needs of the patient, therefore impacting continuity among health care providers. This finding aligns with research that consistency of health care providers in the home is highly valued by caregivers (Brazil et al., 2012; Hasson et al., 2010; Mohammed et al., 2017; Robinson, Bottorff, McFee, Bissell, & Fyles, 2017). In order to improve the continuity of health care providers, it is suggested the LHINs and home care

agencies focus efforts on scheduling health care providers to minimize the number of providers interacting with families and ensure more consistent care for patients and families.

Provincial Government Policy

Findings from this study have shown that caregivers reported the eShift model of care was accessible and receptive to their needs and their family member/ friend's needs. Ontario currently has two policy documents, "Patients First: Action Plan for Health Care" (Ministry of Health and Long-Term Care, 2015a) and "Patients First: A Roadmap to Strengthen Home and Community Care", (Ministry of Health and Long-Term Care, 2015b) which provide strategic priorities to improve access and availability of services for patients and caregivers, utilizing technology (Ministry of Health and Long-Term Care, 2015a; Ministry of Health and Long-Term Care, 2015b).

The eShift model of care, through the use of technology, improves access to health care services and the coordination of care for patients by expanding the scope of care health care providers can provide. By expanding the scope of health care providers, one registered nurse now has the ability to direct care for four or more patients in the community, allowing more patients and caregivers to receive nursing care (Royackers, Regan, & Donelle, 2016). In this study, caregivers reported that they had access to the eShift model of care in a timely manner. Caregivers further reported most health care services were brought into the house, allowing them to keep their family member at home. Additional findings from this study indicated caregivers were better able to handle emergency situations and support their family member to die in their place of choice with the presence of the eShift team in the home and the connection of the technician to the directing registered nurse through real-time communication. The abovementioned findings align with the "Patients First: Action Plan for Health Care" policy set out by the government with it aims to improve the health care experience for patients (Ministry of Health and Long-Term Care, 2015a). Improving patient experience will help caregivers to be successful in their role, reduce the time spent on navigating the system, and reduce caregiver distress (Mohammed et al., 2017; Ministry of Health and Long-Term Care, 2015a; Waldrop & Meeker, 2011). As found by various researchers, when caregivers do not have access or sufficient support from

health care providers, the dying family member was likely to be admitted into hospital to alleviate caregiver burden (Bialon & Coke, 2012; Kenny et al, 2010; Mohammed et al., 2017; Waldrop & Meeker, 2011). However, with the presence of eShift in the home, only one caregiver reported an unanticipated transfer to hospital for their family member to die. Therefore, coordination of home end-of-life palliative care, which provides timely access and sufficient support to caregivers, will assist in preventable hospital admissions related to caregiver burden and assist in meeting the wishes of patients to die with dignity, in their place of choice (Mohammed et al., 2017).

Findings from this study indicated that most patients and caregivers had choice in determining where the patient would die. Some families were able to bring or keep their family member home to die with the inclusion of eShift, while other families were able to keep their family member home to palliate with eShift, then have a planned transfer to a facility to die. This is an important finding, as researchers have found when caregivers are unable to meet the needs of their family member at the end-of-life to die in their place of choice, caregivers experience complicated bereavement (Topf, Robinson, & Bottorff, 2013). The eShift model of care aligns with the current policy direction of the Government of Ontario policy document, "Patients First: A Roadmap to Strengthen Home and Community Care", in which one strategic priority is to provide patients and families with greater choice for palliative and end-of-life care (Ministry of Health and Long-Term Care, 2015b). This study provides beginning evidence regarding the eShift model of care and the health care workers ability to collaborate with patients and families in creating and fulling an interactive care plan that includes choice in place of death allowing patients to die with dignity and the caregiver to fulfil the wishes of their dying family member.

In order to achieve greater choice for palliative and end-of-life care, the government's aim is to expand access and equity for patients and family when accessing end-of-life care in the home and community. Findings from this study have shown caregivers found the eShift model of care to be accessible and available in a timely manner, even to rural families. Additionally, through eShift and other provincial policies (e.g. Ontario Drug Benefits) there were little out-of-pocket expenses for patients and families. This study provides beginning evidence that eShift

demonstrates sensitivity to diverse and marginalized populations. Therefore, provincial governments should consider how models of care such as eShift can be expanded to enhance palliative home care across Ontario. This may require enhanced funding to LHINs to support expansion and examining current provincial polices that might enable or impede caregivers receiving needed hours of care and other services.

Implications for Nursing Research

Family caregiving at the end-of-life has become an international research priority (Percival, Lesseter, Purdy, & Wye, 2013). In Canada, it is estimated that family members and friends provide 80-90% of end-of-life care to a dying family member (Percival et al., 2013; Stajduhar et al., 2010). To date, much of the literature around caregivers has provided an understanding of caregiver's experience and caregiver's burden when caring for a family member in the home. A review of the literature suggest that there is a notable gap in 1) understanding the needs of caregivers for a palliative family member and 2) policy for caregivers at the patient's end-of-life. This study has developed a greater understanding of how a new model of care, eShift, aligns with the needs of caregivers by providing caregivers needed respite at night, the ability to better handle emergency situations, and communication about the care being provided to their family member. However, after completing this study, further avenues for research have been identified. Findings from this study suggest there is a need to better understand: how to assist caregivers in receiving more assistance when the patient is not willing to receive health care in the home; supporting and communicating with caregivers who do not live with the care recipient; multi-agency collaboration with continuity of care; and educating and collaborating with caregivers as part of the health care team. Nursing research on the needs of caregivers should incorporate a policy perspective to better inform decision-making about policies and programs.

Finally, the Caregiver Policy Lens is a newly developed Canadian framework, and to date it has never been used to inform research. Nursing research on how it applies to short-term, long-term and end-of-life caregivers is needed to understand its applicability across sectors (MacCourt & Krawczyk, 2012).

Implications for Nursing Practice

Caregivers are said to be the backbone of end-of-life care, especially in the home, as they provide the majority of the care for the dying family member (Canadian Hospice Palliative Care Association, 2013; Martin, Olano-Lizarrage, & Saracibar-Razquin, 2016). Findings from this study outlined the importance of the inter-professional team partnering with caregivers and being aware of their needs in order to ensure caregivers are successful in caring for a palliative family member or friend in the home. Participants in this study acknowledged the eShift model of care addressed the overall health of the caregiver through physical, psychosocial support, and respite they received by having health care providers in the home. These findings are important as palliative care not only involves providing for the needs of the patient, but the family as well (Linderholm & Friedrichsen, 2010). The importance of partnering with the caregiver and family is also recognized by the World Health Organization, as they stress families should be offered support during the caring process (Linderholm & Friedrichsen, 2010; World Health Organization, 2018).

The eShift model of care involves collaboration with patients and family members and multi-disciplinary teams through the use of interactive online document systems that continually evolve based on input from all members of the patient's health care team, including the family. Through this collaboration, members of the eShift model of care team assess and track how the family caregiver is coping and their willingness to provide care. Tracking how the caregiver is coping and their willingness to provide care can ensure a plan is in place for the patient if the caregiver chooses to end or limit their caregiver role. Additionally, tracking how the caregiver is coping could ensure caregivers receive adequate support from health care providers; as researchers have found inadequate support from health care providers can necessity patients being admitted into hospitals or hospices to die (Topf, Robinson, & Bottorff, 2013; Waldrop & Meeker, 2011).

In this study, caregivers had diverse views on whether they were informed of the death and dying process of their family member. However, family members did report being better able to handle perceived emergency situations because health care providers trained in palliative care were able

to explain what was occurring with the family member. Research has shown that caregivers have a better chance of adapting to their role as caregiver at the end-of-life if they have the proper resources and feel capable to provide care (Holm et al., 2015; Holm, Henriksson et al., 2015). The resources needed by caregivers to feel capable at caregiving include preparedness, adequate information, feeling competent in providing care, and focusing on the positive aspects of caregiving. The information most often sought by caregivers includes information on the caregiving role, pain and symptom management, providing personal care, use of equipment, and the dying process (Ewing & Grande, 2012; Harding et al., 2012; Holm et al., 2015; Holm, Henriksson, et al., 2015). Home care agencies need to ensure employees have a strong understanding of the death and dying process with the ability to communicate it with families. Health care providers need to ensure they have consistent and open communication with patients and families regarding the death and dying process.

Implications and Recommendations for Nursing Education

Nursing schools need to incorporate informatics competencies into the educational programs, to ensure nurses have the knowledge, skills, and attitudes to facilitate communication within interdisciplinary teams, including patients and families through the use of informatics tools (Skiba, Connors, Jeffreis, 2008). Nursing schools must ensure nursing graduates are able to manage information technology and complicated clinical judgments to be able to practice effectively within technology informed models of care, such as eShift (Button, Harrington, & Belan, 2014; Nagle & Clarke, 2004)

Finally, since more deaths are likely to occur in the home in the future, home care nurses will play an even more important role in supporting caregivers to meet their family member's end-of-life needs (Dykeman & Williams, 2013). Therefore, it is important nursing education programs ensure that graduates are able to provide patients and their caregivers with information about the death and dying experience.

Conclusion

Through the restructuring of Canada's health care system and the wishes of individuals to die at home, end-of-life care is shifting from being provided in the hospital to the community. Caregivers are said to be the backbone of end-of-life care, however, there is a lack of understanding of the needs of caregivers for a palliative family member, and a lack of policy to support caregivers at the end-of-life. This study sought to understand how the eShift model of palliative home care aligns with the needs of caregivers who cared for a family member at the end-of-life. The findings from this study have shown that the eShift model of care addresses many of the identified needs to of caregivers including timely access to care, respite, involvement in patient's plan of care, little to no out-of-pocket expenses, coordination of care, and ability to handle perceived emergency situations. Overall, caregivers reported having a positive experience with the eShift model of care. Policy makers, researchers and health care providers need to consider the unique needs of caregivers in end-of-life palliative home care services when developing, implementing and evaluation policies and programs.

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Appendices

Appendix A - The Caregiver Policy Lens

Table 2 The Caregiver Policy Lens

Process Factors	Key Focus for Services Providers	Considerations
Caregiver Inclusion and Voice	Inclusion Equality Engagement	Caregiver inclusion in development Consultation of caregivers with program changes
Collaboration	Communication Partnership Linkages with caregivers Breaking down silos	Clear communication regarding roles and responsibilities of service providers Mechanisms to allow for caregiver and worker updates/exchange information Knowledgeable staff to refer caregivers
Evidence Informed	Peer reviewed literature Experiential knowledge Monitoring Evaluation Collecting Analyzing	Ability for caregiver to provide input and feedback Ability for diverse caregivers to provide input and feedback
Assessing Policies and Programs		

Respect and dignity	Acknowledge Respect Value Active partnership Positive language	Recognition of the important relationship between caregiver and care recipient Recognition of other roles and responsibilities caregivers have Protocols between agencies to benefit the caregiver
Diversity and marginalization	Awareness of caregiver: Ethnicity Cultural diversity Faith Income Mental health Sexual orientation	Relevant information present clearly and simply Information availability in a variety of mediums Interpreters available
Care, self-determination, and independence	Choice Partnership Strong communication	Clear information provided to makes informed choices Information and services provided before crisis arises Caregivers boundaries and willingness to provide care reviewed regularly Plans in place if the caregiver limits or ends their role Alternative options provided to caregiver

Accessibility	Accessible Responsive Knowledge of systems and pathways Providing culturally sensitive information	Interpretation services provided Practical barriers addressed
Caregiver assessment	Promoting resiliency Supporting resiliency Proactive Non-judgmental Knowledge of programs and services	Caregiver needs are explicitly asked Caregivers asked to identify changes needed to the support and services being used
Sustaining caregivers	Helping caregivers through: Information Education Skills Respite Supports	Education provided Training required provided Emotional/psychological support provided
Sustaining systems	Human resource support Education Competent Knowledgeable System capacity	Flexibility in policies Providing services providers with proper training, education, time, and support Proactive in provided supports before crisis is reached

| Fairness and Equity | Fair to caregivers today and in the future | Eligibility criteria disclosed with rationale |
| | understanding the effects of the program on businesses, economy, or people in society | Individual needs balanced with larger groups |

Adapted from MacCourt & Krawczyk, 2012.

Appendix B - Characteristics and Details of Included Studies for Caregivers

Table 3 Characteristics of Included Studies for Caregivers

First author (year)	Study design	Study population	Participants	Location	Objective	Outcomes measured/ Findings
Jo et al. 2007	qualitative research	Palliative care patients and their spousal caregiver	Number: 10 (dyads) Female: 3 (FCG) Male: 7 (FCG) Age range: 60-88	South-Central Ontario, Canada	examine the perspectives of both the spousal caregiver and care recipient on the end-of-life caregiving experience in home-based palliative care	5 themes: positive/negative aspects of the caregiving experience, spousal relationship, formal supports, and informal supports
Stajduhar et al. 2008	interpretive descriptive	Active FCGs with patients who had a diagnosis of 6 months or less to live	Number: 29 Female: 26 Male: 3 Age range: 40-85	Western, Canada	describe factors influencing family caregivers' ability to cope with providing such care	5 factors influencing FCGs ability to cope: approach to life; patient's illness experience; patient's recognition of FCG; quality of relationship between patient and FCG; and FCGs sense of security

Hasson et al. 2010	exploratory descriptive design	Former FCGs of people with Parkinson's disease	Number: 15 Female: 4 Male:11 Age range: 55-65	Northern Ireland, United Kingdom	understand the experiences of FGCs who cared for someone with Parkinson's disease	4 themes were present: FGCs role and burden, palliative care, bereavement, and access to health and social care services
Kenny at el. 2010	cross-sectional observational study of the HRQOL	FCG of patients receiving home palliative care	Number: 178 Female:127 Male: 51 Mean: 61.7	Sydney, Australia	investigate associations between health and a range of caregiving context variables, that are potential stressors or resources, among current FGCs	FCGs have better physical health and worse mental health than the general population. FCGs whose health deteriorated in the last year was associated with patient's care needs.
Sekelja et al. 2010	Qualitative research	Bereaved FCGs of patients with metastatic cancer	Number: 30 Female:16 Male: 14 Age range: 53-87	Sydney, Australia	investigate how bereaved FCGs experienced palliative care during the patient's illness and after the patient died and to explore FCGs subsequent preference for palliative care contact	5 major themes: meaning of palliative care, timing of palliative care, valued aspects of palliative care, end-of-life issues, preparation for death and the role of palliative care in preparing for and after the patient's death

| Funk et al.

2011 | qualitative research | Bereaved FCGs who provided care to a dying family member at home | Number: 26

Female:2

Male: 4

Age range: 32-87 | Western Canada | identify and explore motivations behind the "nonuse" of home health services | Reasons FCGs did not ask for help included: personal reasons, coping needs, and a lack of knowledge |
|---|---|---|---|---|---|---|
| Waldrop et al.

2011 | cross-sectional exploratory descriptive design, using qualitative methods | FCGs of people who relocated from home to a freestanding hospice | Number: 37

Female:30

Male: 7

Age range: 26-83 | Buffalo, New York, USA | Explore FGCs perceptions of the crises that preceded and were resolved by relocation during end-of-life care | Caregiver's experience 3 stages: the inter-relationship between illness trajectory and reciprocal suffering, crisis, and resolution (settled and unsettled) |
| Bialon et al.

2012 | Phenomenology | Bereaved FCG of terminally ill family member | Number: 9

Female:7

Male: 2

Age range: <50-64 | Middle Georgia, USA | Explore short and long term effects of caregiver burden on FCG's physical and emotional health | FCGs experienced a decline in health, role conflict, lack of physical and educational support, importance of faith |

| Brazil et al.

2012 | Client-Centred Care Questionnaire | Families of a deceased family member who had been designated as palliative and had received formal home care services by a Community Care Access Centre | Number: 111

Female:77

Male: 30

Mean age: 61 | South central Ontario, Canada | evaluate the patient-centeredness of community palliative care from the perspective

of family members who were responsible for the care of a terminally ill family member | Positive: program accessibility, responsive care, contact numbers of service providers.

Negative: arrangement and organization of care, changing of caregivers and times, and saying something as possible when it wasn't |
|---|---|---|---|---|---|---|
| Ewing et al.

2012 | Qualitative design | FCGs six to nine months post bereavement | Number: 75

Female:45

Male: 30

Age range: 35-82 | United Kingdom | Explore FCG's perspectives of key aspects of support needed during provision of end-of-life care at home and to develop a carer support needs assessment tool suitable for use in everyday practice | FCGs fell into 2 categories of needs: support to enable them to provide care and personal support for themselves |

Harding et al. 2012	cross-sectional qualitative study	FCGs who currently provided a combination of any physical and emotional unpaid care to their relative or friend at home	Number: 20 Female:11 Male: 9 Age range:25-79	London, England	generate evidence to inform a subsequent appropriate intervention based on caregivers' experiences	Needs: prepared for their caring role, to be visible to professionals, to receive clear and specific information, and emotional support. Challenges: uncertainty, distress at witnessing disease progression, financial, personal time, own health and sleep
Hirdes et al. 2012	Secondary analyses on interRAI PC	Client and caregivers, reviews of charts, consultations with other health professionals, and direct observations of the client	Number: 3929 Female:2019 Male: 1910 Age range: 18-85+	Ontario, Canada	examines client characteristics, and caregiver and health service variables as predictors of caregiver distress among community-based palliative care clients	Caregiver distress was evident among about 22% of palliative home care clients. Highest predictors of burden were hours of care, professional care, clinical instability, depressive symptoms, cognitive impairment,

Stajduhar et al. 2013	Qualitative secondary analysis	Interviews from 4 data sets with current and bereaved FCGs	Number: 156 Female: unknown Male: unknown Age range: 18+	Western Canada	explore how family members describe the learning involved in providing palliative care, with a focus on how they learn	4 themes of how FCGs learn: trial and error, active information seeking, application of previous knowledge or skills, and guided by others
Topf et al. 2013	Qualitative interpretive description	Bereaved FGC whose family member died in hospital after home care was no longer sustainable for the caregiver	Number: 18 Female:13 Male: 5 Age range: 23-91	Western Canada	Gain a better understanding of the experience of FCGs when circumstances prevented home death for a family member with cancer	Lack of preparedness, difficulty accessing professional support and information, inadequate help led to home death not being possible
Jack et al. 2014	Qualitative study	Bereaved FCGs who had experienced HAH services	Number: 20 Female:11 Male: 4 Age range: 20-89	United Kingdom	explore bereaved FCG's perceptions and experiences of a hospice at home service.	Positive experience with 3 themes: valued presence, in good hands, supporting normal life

Metha et al. 2014	secondary analysis guided by interpretive description	FCGs who were identified by patients with advanced cancer at the EOL as the person most involved in the management of their pain	Number: 24 Female:16 Male: 8 Age range: 25-90	Quebec, Canada	highlight the sources of distress experienced by family caregivers managing pain at home	FCGs experience distress at different phases of the pain management process leading them to feel: Overwhelmingly responsible; unsupported; unprepared; and distress watching family member in pain
Giesbrecht et al. 2015	secondary analysis using intersectionality lens and qualitative case study approach	FCGs of palliative patients	Number: 16 Looked at 2 case studies out of the 16 interviews	British Columbia, Canada	identify socio-environmental factors that facilitate family caregivers' capacity for resilience	Resilience influenced by: access to social networks, education/knowledge/awareness, employment status, housing status, geographic location, and life-course stage.
Totman et al. 2015	qualitative study	Recently bereaved FCGs of patients with cancer who were cared for at home	Number: 15 Female: 11 Male: 4	London, England	Explore the emotional challenges experienced by FCGs and how FCGs perceive health care professionals as helping or hindering them in dealing with these challenges	Yalom's four 'existential conditions': responsibility, isolation, death, and meaningfulness

Guerriere et al. 2016	Longitudinal, prospective cohort design	Current FCGs	Number: 327 Female: 223 Male: 104 Age range: <60-80+	Southern Ontario, Canada	identify the socio-demographic, clinical, health services utilization and economic factors, measured at various points along the palliative care trajectory, that account for caregiver burden	caregiver burden increased over time, Higher caregiver burden occurred: women had near the EOL, higher FCG education, lower patient education, higher family care-giving burden time costs, higher PSW costs, higher ED visits
Royackers et al. 2016	Pilot study, using interpretive description	Bereaved FCGs	Number: 8	Ontario, Canada	Examine the experienced of FCGs whose palliative family member received the eShift model of care	4 themes: The health care family-consistent health care workers, there's no place like home-the preferred setting, making the invisible visible- not understanding the role of health care providers, burden of love- caregiving is exhausting

Mohammed et al. 2017	Qualitative study	Bereaved FCGs of patients with cancer who completed a 4-month-cluster-randomized controlled trail	Number: 61 Female: 44 Make: 33 Mean: 60	Toronto, Ontario, Canada	Describe bereaved caregivers' experience of interacting with home care services while providing care at home	FCGs had to take charge, often with inadequate formal support. Subcategories-navigating the system, engaging with professional caregivers, preparing for death, managing after death
Robinson et al. 2017	Qualitiative interpretive descriptive study	Bereaved family caregivers, less than 6 months	Number: 29 Female: 19 Male: 10 Age range: 1922-1981	British Columbia, Canada	Describe the experiences of bereaved FCGs whose family member with advanced cancer were successful in achieving a home death	4 themes identified: the context of providing care, the FCGs determination, enabled determination, and previous experience with providing care

FCG: Family Care Giver

Table 4 Details of Included Studies for Caregiver Policy

First author (year)	Study design	Study population	Participants	Location	Objective	Outcomes measured/ Findings
Exley 2007	Reconceptualiz ation of data from 3 qualitative studies	Terminally ill patients and FCGs were interviewed in 3 separate studies and re-examined	Number: 93 patients: 46 FCGs: 37	United Kingdom	examine the unacknowledged contradictions and strains contained within 'home care' policies and the challenges these create for FCGs	policy trends to move care to the home have created social expectations and obligations for FCGs which modern society is unprepared
Giesbrecht et al, 2010	Patton's utilisation-focused evaluative approach	Front –line palliative care providers	Number: 50	Canada	Explore front-line palliative care providers knowledge/ experience of CCB and gather suggestions for improvement	Although CCB is important it can be hard to access front-line providers need more information on the program and the program needs to be easier to access
Williams et al. 2010	utilization-focused evaluation	FCGs Front-line palliative providers Human Resource professionals and employers	Number: 134 FCGs: 57 Front-line: 50 HR: 27	Canada	Informing program and policy development	An important step to recognizing FCGs however not reaching its potential

Willian et al. 2011	Analysis FCG interviews through the population health promotion model	FCGs providing EOL care	Number: 57 CCB recipient: 22 Non-applicant: 30 Denied CCB: 5	Canada	Examine FCG as a public health issue, based on the FCG perspectives	CCB is the beginning of developing a public health policy, as it recognizes FCGs, but needs to be revisited to build a healthy public policy that alleviated burden experienced by many FCGs
Crooks et al. 2012	Qualitative	FCGs providing EOL care	Number: 57 CCB recipient: 22 Non-applicant: 30 Denied CCB: 5	Canada	Understand how FCGs view CCB, any challenges and improvements noted from FCGs, and to make policy-relevant recommendations for CCB improvement.	there are gaps between respondents' ideal expectations and their experienced realities.
Dykeman 2013	Exploratory intervention	Social workers	Number: 8 Female: N/A Male: N/A	Toronto, Canada	Review knowledge tools previous designed with social workers after 6 months of use with them	Awareness about CCB need to happen early in the disease progression and information about CCB is needed in more locations

O'Connor et al. 2016	Description of the process of developing a suicide guideline in palliative care	Description of a working party trying to create policy for terminal patients and FCGs at risk of sucide	N/A	Melbourne, Australia	Description of the working party experiencing in creating policy that would cover the needs of teams in dealing with patient and FCGs at risk of suicide	Organizational guidelines for staff who encounter issues of suicide among either clients or FCGs receiving homebased palliative care was developed

FCG: Family Care Giver; CCB: Compassionate Care Benefits

Appendix C - Western University Health Science Research Ethics Board – Ethics Certificate for Primary Study

Western Research

Research Ethics

Western University Health Science Research Ethics Board
HSREB Delegated Initial Approval Notice

Principal Investigator: Dr. Sandra Regan
Department & Institution: Health Sciences\Nursing,Western University

HSREB File Number: 105350
Study Title: Investigating the eShift model of palliative home care: Implications for planning, practice, and policy.
Sponsor:

HSREB Initial Approval Date: August 29, 2014
HSREB Expiry Date: August 31, 2017

Documents Approved and/or Received for Information:

Document Name	Comments	Version Date
Other	List of bereavement services	2014/05/06
Instruments	Interview Guide - Physicians	2014/05/13
Instruments	Interview Guide Decision-maker	2014/05/13
Instruments	Interview Guide Registered Nurse/Case manager/care coordinators	2014/05/13
Instruments	Interview Guide Personal Support Workers	2014/05/13
Instruments	Interview Guide Allied Health Workers	2014/05/13
Instruments	Interview Guide Informal Caregivers/Family Members	2014/05/13
Instruments	Interview Guide Clients	2014/05/13
Recruitment Items	Email script to recruit participants for the study.	2014/05/13
Other	Participant Agreement for Funding	
Revised Western University Protocol	Revised Protocol 105350 August 2014	2014/08/19
Revised Letter of Information & Consent	Revised LOI Client August 2014	2014/08/19
Revised Letter of Information & Consent	Revised LOI Healthcare Providers August 2014	2014/08/19
Revised Letter of Information & Consent	Revised LOI Decision-makers August 2014	2014/08/19
Revised Letter of Information & Consent	Revised LOI Informal caregivers August 2014	2014/08/19

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above named study, as of the HSREB Initial Approval Datenoted above.

HSREB approval for this study remains valid until the HSREB Expiry Date noted above, conditional to timely submission and acceptance of HSREB ContinuingEthics Review. If an Updated Approval Notice is required prior to the HSREB Expiry Date, the Principal Investigator is responsible for completing andsubmitting an HSREB Updated Approval Form in a timely fashion.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), theInternational Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical PracticePractices (ICH E6 R1), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health CanadaMedical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when theyare presented to the REB.

The HSREB is Registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Ethics Officer, on behalf of Dr. Joseph Gilbert, HSREB Chair

Ethics Officer to Contact for Further Information

Erika Basile	Grace Kelly	Mina Mekhail	Vikki Tran
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This is an official document. Please retain the original in your files.

Western University, Research, Support Services Bldg., Rm. 5150
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Appendix D – The Caregiver Policy Lens Category and Principle Matrix

Accessibility

Information about the program easily available

Practical Barriers addressed such as cost and transportation

Sufficient resources attached to the program to ensure services are available in a timely manner

Caregiver Assessment

Caregivers asked about their own needs that might need to be addressed

Caregivers asked to identify changes needed to support and services used

Caregiver Inclusion and Voice

Caregiver inclusion on significant changes in service provision

Caregivers included in developing care plans for the care recipient

Choice, Self-Determination and Independence

Are other options to provide care explored with care recipient and caregiver such as additional community services?

Caregiver informed about and offered services available to the care recipient proactively and prior to crisis

Caregiver provided clear information to make informed choices about care required and potential changes

Caregivers' willingness to provide care, boundaries of their care, and care recipient's needs reviewed on a regular basis or at critical points

Plan in place if the caregiver chooses to limit or end caregiving role

Collaboration

Adequate communication between agencies so caregiver does not have to repeat information

Mechanisms in place for caregiver and workers to exchange information or update

Roles and responsibilities of each agency and worker made clear to the caregiver

Diversity and Marginalization

Eligibility criteria, application processes and other information presented clearly and simply

Relevant information available in a variety of mediums to reach caregivers who are isolated or living in rural and remote areas

Staff available to interpret policies and programs

Evidence Informed

Diverse caregiver engagement to provide input and feedback

Obtain input and feedback from caregivers

Fairness and Equity

Consider individual needs of caregiver and collective needs

Does the program create economic or social disadvantage for any population inside or outside the health sector

Individual needs balanced with those of the larger group

Program ensure the caregiver does not accumulate disadvantages

Miscellaneous

Quotes

Respect and Dignity

Program reflect recognition of the importance of the relationship between they care recipient and caregiver

Program take into account caregivers have other roles and responsibilities outside their caregiver roles

Protocols in place between agencies and workers so caregivers do not have to repeat information over and over

Sustaining Caregivers

Access to support groups

Emotional and psychological support such as time to themselves

Healthy aging

Information about community resources and support to navigate the system

Information about the medical cognitive and functional needs of the care recipient being cared for

Personal counseling for issues related to caregiving when needed such as grief

Personal relationship building such as support trust and encouragement

Practical support such as connection to resources and information about the caregiving journey

Respite offered regularly and in the form preferred and when caregiver needs it

Sustaining Systems

Menu of options of provide for the information support and education needs of caregivers

Service providers educated about and sensitive to the needs of caregivers and how to support them

Service providers have time skills and support to develop caring trusting relationships does it take into account the caregiver preferred schedule

Service providers kept to a min encouraging trust and relationship building and continuity of care

Services affordable

Services offered proactively and provided before needs reach crisis proportion

Services providers knowledgeable and skilled to provide sensitive and competent care to care recipients and or caregivers

Sufficient capacity and flexibility to respond to a crisis in a timely manner without escalating needs

Sufficient flexibility in policies for preventative action

Transportation attached to the care recipient's program

*All sub-codes had a sub-codes titled "Positive" and "Needs Improvement"

Adapted from MacCourt & Krawczyk, 2012.

Curriculum Vitae

Name:	Ashlee Worrall
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Year of Birth:	1985
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