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Receiving in-home respite when caring for a palliative family member at the end-of-life: family caregivers' experiences of the eShift model of care

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A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Health and Rehabilitation Sciences

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Abstract

Family caregivers are an important component of home-based palliative care as they provide the majority of unpaid assistance to their palliative family member, during their last days and weeks of life. The demands of caregiving often escalate at the end-of-life, which can result in substantial emotional and physical issues for the family caregiver. In 2010, in London Ontario, the South West Community Care Access Centre (now the South West Local Health Integration Network (SW LHIN)) developed a new model of palliative home care called “eShift” led by an interdisciplinary team of healthcare professionals, that focused care both on the patient and their family caregiver. The eShift model connects personal support workers, called eShift technicians, to a remote registered nurse (via technology) to offer palliative care in a client’s home and simultaneously provide family caregivers with respite. The purpose of this secondary data analysis was to explore the experiences of in-home respite among family caregivers who were caring for a palliative family member receiving eShift palliative home care, at the end-of-life. Overall, the fifteen family caregivers that participated in this study had a positive experience of in-home respite with eShift palliative home care, which enabled them to keep their family member at home until death. Specifically, family caregivers developed trust, had an opportunity for self-care and other activities and felt that the arrangement of services with eShift was comprehensive. This study has implications for public health policy as it offers insights into family caregivers’ experiences of in-home respite with the eShift model of palliative home care. In addition, it serves as a basis for future research on family caregivers’ experiences of in-home respite with eShift and other technology-enabled models of palliative home care.

Keywords: Family caregivers, palliative home care, in-home respite, end-of-life care, qualitative research

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Chapter 1: Introduction

Across Canada, the number of older adults is increasing (Sinha et al., 2016), which has contributed to an increase in the demand for home care services (Carriere, Keefe, Legare, Lin, & Rowe, 2007), including end-of-life palliative care and respite for family caregivers (Canadian Healthcare Association, 2009). Although end-of-life palliative care can be provided in a variety of settings such as hospitals, long-term care institutions, and one's home (Health Canada, 2007), the majority of Canadians prefer to die at home (Agar et al., 2008; Hansford & Meehan, 2007; Kitchen, Williams, Pong, & Wilson, 2011; Stajduhar, Allan, Cohen, & Heyland, 2008; Stajduhar & Davies, 2005; Wilson, Cohen, Deliens, Hewitt, & Houttekier, 2013). In addition, end-of-life care in the home can sustain or improve a patient's quality of life and reduce costs to the health care system (Canadian Hospice Palliative Care Association, 2018a; Ministry of Health and Long-Term Care [MOHLTC], 2015; Wholihan & Pace, 2012). Despite the preferences of Canadians and the benefits of receiving end-of-life care in one's home, over forty percent of Canadians continue to die in a hospital setting (Canadian Institute for Health Information, 2018).

Almost all individuals who are palliative or at the end-of-life have a family caregiver helping to care for them (Canadian Institute for Health Information, 2018). Family caregivers are an important component of home-based palliative care, as they provide over ninety percent of assistance to their palliative family member at the end-of-life (Cohen, 2010; Dunbrack, 2005) and family caregivers play an important role in supporting their family member's wish to die at home (Brazil, Bedard, & Willison, 2002; Health Quality Ontario [HQQ], 2016; Linderholm & Friedrichsen, 2010). Not surprisingly, the emotional and physical demands of family caregiving at the end-of-life are taxing and family caregivers are likely to experience increased anxiety, stress, and depression (Canadian Institute for Health Information, 2018; Funk et al., 2010; Hearson, Mclement, McMillan, & Harlos, 2011; Stajduhar et al., 2010; Williams et al., 2011).

Although in-home respite, which provides family caregivers with a short period of rest or relief from both the physical and emotional responsibilities from caregiving (Canadian Caregiver Coalition, 2014; Canadian Healthcare Association, 2012), is a publicly funded service for family caregivers in the province of Ontario (Canadian

Caregiver Coalition, 2014; Dunbrack, 2003), it is currently insufficient to support the needs of family caregivers (Fraser, 2016; [MOHLTC], 2015). This is due, in part, to the current shortage of health human resources such as nurses (Canadian Healthcare Association, 2012; Health Canada, 2015), which makes it difficult for family caregivers to find someone to care for their palliative family member in the home (Fraser, 2016). Recently, technology-enabled palliative home care models have been recognized as a promising solution (Care Partners, 2015; Holland et al., 2014; Ontario Telemedicine Network, 2016; Royackers, Regan, & Donelle, 2015). Without the development, implementation and evaluation of innovative care models to provide palliative home care for patients and in-home respite for family caregivers, the physical and emotional health of family caregivers remains at risk (Williams et al., 2011) and the costs of end-of-life care in other settings will continue to rise, placing a significant burden on the health care system (Canadian Hospice Palliative Care Association, 2018a).

Background and Significance

Changing Demographics

The Canadian population profile is changing due to an aging population (Canadian Healthcare Association, 2012; Canadian Hospice Palliative Care Association, 2010, Williams et al., 2011), which now constitutes the fastest growing segment in the country (Sinha et al., 2016). As such, for the first time ever, a greater proportion of Canadians are 65 years of age and older, in comparison to those 0-14 years (Statistics Canada, 2015). In Ontario, the number of seniors aged 65 years of age and older is expected to more than double from 2.2 million in 2015 to 4.5 million in 2041 (Ministry of Finance, 2016). The World Health Organization (2015) has optimistically stated “that with the right policies and services in place, population ageing should be viewed as a rich new opportunity for both individuals and societies” (p.3).

Home Care

The increase in the older adult population, in part, has contributed to the rise in demand for home care, with the majority of older adults preferring to receive care at home (Carriere et al., 2007; Morley, 2012; National Institute on Aging, 2018). Home care includes services provided in the home and community setting, such as curative interventions, end-of-life care, rehabilitation, and support for family caregivers such as

respite (Canadian Healthcare Association, 2009; Canadian Home Care Association, 2016; Home Care Ontario, 2014).

The Canada Health Act was created in 1984 and it mandated that each province and territory have health insurance plans that meet specific requirements for medically necessary health services, such as hospital and physician services, without any user fees or additional costs (Health Canada, 2015). Although the primary objective of the Canadian healthcare policy, as set out by the Health Act, is “to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access without financial or other barriers” (Government of Canada, 1984), home care was labelled an extended health service (Canadian Healthcare Association, 2009; [MOHLTC], 2015), meaning that it is independently organized and funded in each jurisdiction (Canadian Institute for Health Information, 2018; Health Canada, 2015; Health Council of Canada, 2012). Alarming, the 2009 *Special Senate Committee on Aging* reported that 90% of home care needs are not being met (Senate Committee, 2009), as many Canadians are not receiving the home care services that they require (Health Canada, 2008; Statistics Canada, 2014b).

In Ontario, the health care system strives to put patients first “with the right care, at the right time, in the right place” ([MOHLTC], 2015, p.1). In fact, the MOHLTC supports that the right place for many Ontarians is in their home, as appropriate care in this setting can sustain or improve a patient’s quality of life and simultaneously reduce costs to the health care system ([MOHLTC], 2015). However, in Ontario, gaps in home care coverage continue to persist and these gaps are particularly concerning for individuals 65 years of age or older who represent the majority of home care clients (Office of the Auditor General of Ontario, 2015).

Home Care and Palliative Care

Palliative care is a holistic approach to care with an overall goal of improving “the quality of living and dying for those facing life-threatening illnesses” (Health Canada, 2007). Specifically, palliative care strives to minimize unnecessary suffering by providing pain and symptom management for the patient as well as psychological, social, emotional and spiritual support for both the patient and their family caregiver (Health Canada, 2007; Williams et al., 2011). Palliative care aims to provide family caregivers

with support services including: advice from palliative health care providers, instructions on how to best care for their palliative family member, home support services to aid the caregiver with household chores, and caregiver respite (Canadian Hospice Palliative Care Association, 2018b). However, despite the attention Health Canada brings to the support family caregivers require, many family caregivers feel that the healthcare system has been unresponsive to their needs (Fraser, 2016; [MOHLTC], 2015). It is therefore imperative that caregivers are supported “with a broader basket of services that helps meet more than just the patient’s clinical needs” ([MOHLTC], 2015, p.9).

Individuals can receive publicly funded palliative care in their home, including visits from personal support workers, nurse practitioners, doctors, and counsellors ([HQO], 2016). However, the provision of palliative services varies (Robinson, Bottorff, McFee, Bissell, & Fyles, 2016) depending on factors such as the type of illness a person has and how severe it is ([HQO], 2016). For example, palliative care can be given at any stage of an individual’s disease, including: at the time of initial diagnosis and the provision of treatment(s) to prolong survival, when curative treatments are no longer effective, and at the end-of-life (Cancer Care Ontario, 2015; Hospice Palliative Care Ontario, 2018). In this study, the focus is on palliative care given at the end-of-life. The need for palliative care will soon amplify (Canadian Hospice Palliative Care Association, 2010; Canadian Institute for Health Information, 2018; Fraser, 2016). Specifically, it has been projected that by 2021 over 300,000 Canadians will die each year and 432,000 deaths are estimated in the year 2041 alone (Statistics Canada, 2010).

Family Caregivers and Palliative Home Care

A family caregiver is whomever a patient identifies as being family and can include family members and friends (Fraser, 2016). Family caregivers assist their family members with tasks such as transportation, housework and personal care (Canadian Institute for Health Information, 2018; [HQO], 2015; Statistics Canada, 2013). In 2015 alone, the cost of care provided by family caregivers in Canada was estimated to be \$30 billion dollars (Sinha et al., 2016).

In order to meet end-of-life care needs, nine out of ten individuals receiving home care services still require assistance from a family caregiver (Statistics Canada, 2014a) and almost all of palliative individuals have a family caregiver helping to care for them

(Canadian Institute for Health Information, 2018). Family caregivers may sometimes take on the role of caring for a palliative family member with little consideration for the implications it will have on their own lives (Robinson et al., 2016), as many believe it is their duty (Linderholm & Friedrichsen, 2010; Stajduhar, 2003). The demands of caregiving often escalate at the end-of-life which can result in substantial emotional issues, such as anxiety, stress, and depression (Canadian Institute for Health Information, 2018; Funk et al., 2010; Hearson et al., 2011; Schulz et al., 2003; Stajduhar et al., 2010; Williams et al., 2011). In addition, the physical demands involved in caregiving are taxing (Canadian Institute for Health Information, 2018; Funk et al., 2010; Hearson et al., 2011; Stajduhar et al., 2010; Williams et al., 2011) and sometimes pre-existing illnesses that the family caregiver has are made worse. Moreover, caring for someone at the end-of-life can result in sleep disturbances and feelings of fatigue among family caregivers (Funk et al., 2010; Hearson et al., 2011; Stajduhar et al., 2010; Williams et al., 2011). Another troubling consequence of providing end-of-life care is the increased financial burden on family caregivers (Canadian Institute for Health Information, 2018; Funk et al., 2010; Guerriere et al., 2010; Stajduhar, 2003; Stajduhar et al., 2010) including lost earnings (Canadian Institute for Health Information, 2018; Guerriere et al., 2010).

Researchers have also acknowledged the positive benefits of caregiving for someone at the end-of-life (Funk et al., 2010; Robinson, Pesut, & Bottorff, 2012; Stajduhar et al., 2008; Stajduhar et al., 2010; Williams et al., 2011). For example, caregiving can result in life-enriching experiences as it provides opportunities for “reciprocity, finding meaning in the situation, and for spending time with the patient” (Stajduhar et al., 2008, p. 29). However, recently released policy reports have acknowledged that family caregivers require greater supports. For example, the *Access to Palliative Care in Canada* report stated that nearly one-third of family caregivers of palliative home care clients experience distress, which includes feelings of anger and depression (Canadian Institute for Health Information, 2018). In addition, the *Canadian Caregiver Strategy* has advocated for the need to safeguard the health and wellbeing of family caregivers as well as the urgent need to “invest in research on family caregiving as a foundation for evidence –informed decision making” (Canadian Caregiver Coalition, 2014, p.1). Moreover, the Expert Group on Home and Community Care in Ontario,

authors of the *Bringing Care Home Report*, recommended having a greater emphasis on family caregiver support, including better access to respite care ([MOHLTC], 2015).

Respite

Respite provides family caregivers with a short period of rest or relief from both the physical and emotional responsibilities that result from caregiving (Canadian Caregiver Coalition, 2014; Canadian Healthcare Association, 2012). The emotional support is a critical aspect of respite in addition to the rest or relief from physical tasks (Canadian Association for Community Living, 2008; Nageswaran, 2009; Neff, 2009). Particularly at the end-of-life, caregivers achieve little relief from their concerns and worries about their family member (Whitmore, 2016). As such, to enhance the impact of respite family caregivers need to feel assured (Barrett et al., 2009; Canadian Association for Community Living, 2008) about their family member's care (Canadian Healthcare Association, 2012; Whitmore, 2016). Further, researchers such as Keefe and Manning (2005) have stressed that there is "no exactness to its measurement [respite] and it is unrealistic to expect total relief from stress and burden but rather only aspects of it" (p.7).

Respite can be delivered in-home by a health care provider, a sitting service, or another family member or friend depending on the needs of the patient and the caregiver (Canadian Healthcare Association, 2012). It can also be provided outside of the home at an organized program or in a healthcare environment (Canadian Healthcare Association, 2012). Moreover, respite can be offered as a network of services to support the caregiver or it can be provided only in times of crisis when it is absolutely necessary (Canadian Healthcare Association, 2012). Respite contributes to family caregivers' quality of life (Canadian Healthcare Association, 2012), and supports their health and well-being throughout their family caregiving experience (Sinha et al., 2016). For the purpose of this study, the focus will be on in-home respite for family caregivers caring for a family member at the end-of-life. In-home respite is a valuable source of support for caregivers (McCabe, Roberts, & Firth, 2008; Robinson et al., 2016) and some of the benefits include flexibility for the caregiver and a familiar setting that allows family routines to be maintained (Canadian Healthcare Association, 2012).

Across Canada, the financial support that family caregivers receive for respite varies from partially to fully publicly funded (Canadian Healthcare Association, 2012;

Sinha et al., 2016). In Ontario, a home care coordinator typically assesses a family caregiver's eligibility for in-home respite, based on factors such as the family caregiver's psychological capacity and financial means (Dunbrack, 2003). Typically, individuals who are eligible are assessed for respite for up to four hours a week, but in a palliative care situation they may require more (Dunbrack, 2003). In addition, those who are deemed eligible may still not receive the support they require, as there is currently insufficient public funding (Canadian Cancer Society, 2016; Dunbrack, 2003) and a limited number of home care workers available to provide in-home respite (Dunbrack, 2003; Smith, Graham, & Herbert, 2016).

Health Care Human Resources

In Canada, it is widely recognized that there is a general shortage of health human resources, including nurses (Canadian Healthcare Association, 2012; Health Canada, 2015), which has made it increasingly difficult for home care service delivery agencies to hire nurses to care for palliative patients in their home, especially overnight (Fraser, 2016). As such, the majority of paid individuals providing end-of-life care are personal support workers (PSWs; Canadian Healthcare Association, 2012; Zeytinoglu, Denton, Brookman, & Plenderleith, 2014). Although PSWs are trained to help palliative patients with their personal care, such as bathing and toileting (Personal Support Network of Ontario, 2018), they are generally not allowed to help patients with simple wound care and medication management (Ontario Health Human Resources Research Network, 2011; Zeytinoglu et al., 2014) because they are unregulated health care professionals (Zeytinoglu, et al., 2014). The limitations in the care that they can provide often results in caregivers feeling unable to leave their palliative family member with the PSW to have an opportunity for respite (Rallison & Raffin-Bouchal, 2013; Robinson et al., 2012; Smith et al., 2016).

In Ontario, task shifting has been recommended as a policy to mitigate the demands associated with home care services (Commission on the Reform of Ontario's Public Services, 2012; Denton, Brookman, Zeytinoglu, Plenderleith, & Barken, 2015; Health Professions Regulatory Advisory Council, 2006). Task shifting involves assigning tasks that are usually completed by a nurse to be done by a PSW (Ontario Health Human Resources Research Network, 2011), in order to improve health care coverage and make

more efficient use of health care providers such as PSWs (World Health Organization, 2008).

eHealth

eHealth is an all-encompassing term used to describe the use of information and communication technologies in the health care sector (Health Canada, 2010). eHealth has a variety of applications in health care delivery settings such as home care, primary care, and hospital care (Health Canada, 2010). Within home care, examples of eHealth include smart homes, which utilize safety technologies such as fall detection for people living with cognitive and functional disabilities (Chan, Esteve, Escriba, & Campo, 2008), as well as telemonitoring for individuals with heart failure, that allow clinicians to monitor patients remotely (Chaudhry et al., 2010). The promise of eHealth is that it can provide Canadians with better access to efficient quality care (eHealth Ontario, 2017; Health Canada, 2010; Information and Communications Technology Council, 2009).

A recent *Palliative and End-Of-Life Care Provincial Roundtable Report* advocates for more innovative service delivery models specific to end-of-life care (Fraser, 2016). Technology enabled care models have been recognized as a promising way to deliver home care, and specifically palliative home care (Care Partners, 2015; Holland et al., 2014; Ontario Telemedicine Network, 2016; Royackers et al., 2015)

The eShift Model of Palliative Home Care

In 2010, the South West Community Care Access Centre in London, Ontario (now called the South West Local Health Integration Network (SW LHIN)) initiated and implemented a new model of palliative home care called eShift ([HQO], 2011) in response to concerns about the shortage of nurses providing home care; particularly nurses with expertise in palliative care. This novel service delivery model was intended to “improve palliative clients’ quality of life during the final days of their life, reduce hospital emergency visits and decrease caregiver burden” ([HQO], 2011, p.1) The basic structure of the eShift palliative home care model involved a remotely-situated directing registered nurse (DRN) and a specially trained PSW, called an eShift technician, who cared for the patient, giving family caregivers an opportunity for in-home respite ([HQO], 2011; Regan & Donelle, 2015; Royackers et al., 2015). Each remote DRN worked with four or more eShift technicians, who each cared for a home care patient and their family

caregiver during their shift (Regan & Donelle, 2015; Royackers et al., 2015). Service provider organizations were able to offer day and night shifts to patients (Care Partners, 2015). eShift technicians had a smartphone with the eShift application, while the DRNs had a computer with the eShift application; real-time patient documentation was viewed using the eShift application dashboard. Patient care was directed, in part, by the DRN with the eShift technicians through the eShift portal (Regan & Donelle, 2015; Royackers et al., 2015). In addition, the eShift technicians were required to report regularly to the DRN on specific observations of the patient, and communication through the eShift system and by phone allowed eShift technicians to seek guidance related to the patient and their family caregiver when needed (Regan & Donelle, 2015). In this way, the eShift model was not a technological solution, but instead was a model that utilized technology to improve palliative home care (Regan & Donelle, 2015). Another key component and benefit of this model is that the technicians received additional training in palliative care ([HQO], 2011; Regan & Donelle, 2015). The DRN and eShift technicians in each service provider organization were trained to use the eShift technology, and eShift technicians were specifically trained on how to administer subcutaneous medications (Regan & Donelle, 2015; Royackers et al., 2015). Other members of the patient palliative care team included physicians, visiting nurses, nurse practitioners, home care coordinators, palliative care specialists, and a technology support person (Regan & Donelle, 2015; Royackers et al., 2015; Sensory Technologies, 2017). The current study investigated family caregivers' experiences of in-home respite with eShift, a new technology-enabled model of palliative home care, for individuals at the end-of-life.

This thesis is organized in three chapters. Chapter 1 provides relevant background material. Chapter two provides an overview of family caregivers' in-home respite experiences including a literature review, methods, findings, and discussion sections, along with implications and a conclusion. Finally, chapter three provides a summary discussion and implications from this study.

My Story

The desire to conduct this research evolved after my great aunt and great uncle passed away in a long-term care facility. When they first became ill, I witnessed the caregiving provided by my father and two aunts in order to keep them in their home,

which is where they wanted to receive care. When they both became palliative and needed end-of-life care, the demands of caregiving increased and it quickly became apparent that my great aunt and uncle needed care all day and night. Unfortunately, my father and two aunts were no longer able to meet all of their caregiving needs due to their competing roles and responsibilities outside of caregiving. As a result, my great aunt and great uncle were placed into a long-term care facility where they received end-of-life care. This experience inspired me to learn more about innovative palliative home care models that can be offered to individuals at the end-of-life. I was motivated and inspired to explore the experiences family caregivers had of the in-home respite provided with this technology-enabled model of palliative home care.

References

- Agar, M., Currow, D., Shelby-James, T., Plummer, J., Sanderson, C., & Abernethy, A. (2008). Preference for place of care and place of death in palliative care: Are these different questions? *Palliative Medicine*, 22(7), 787-95.
- Barrett, M., Wheatland, B., Haselby, P., Larson, A., Kristjanson, L., & Whyatt, D. (2009). Palliative respite services using nursing staff reduces hospitalization of patients and improves acceptance among carers. *International Journal of Palliative Nursing*, 15(8), 389-95.
- Brazil, K., Bedard, M., & Willison, K. (2002). Factors associated with home death for individuals who receive home support services: A retrospective cohort study. *BMC Palliative Care*, 1(1), 2.
- Canadian Association for Community Living. (2008). *Real respite for the whole family: A resource guide for organizing and delivering a family workshop on respite for individuals with an intellectual disability and their families*. Retrieved from <http://www.cacl.ca/sites/default/files/uploads/docs/Real%20Respite%20ENG%20complete.pdf>
- Canadian Cancer Society. (2016). *Right to care: Palliative care for all Canadians*. Retrieved from <https://www.cancer.ca/~media/cancer.ca/CW/get%20involved/take%20action/Palliative-care-report-2016-EN.pdf?la=en>
- Canadian Caregiver Coalition. (2014, February). *A Canadian caregiver strategy: Are we making progress?* Retrieved from http://www.carerscanada.ca/wp-content/uploads/2015/09/Pan-Canadian-Family-Caregiver-2013_WEB-PAGES-2.pdf
- Canadian Healthcare Association. (2009). *Home care in Canada: From the margins to the mainstream*. Ottawa, ON: Canada. Author. Retrieved from <http://www.homecareontario.ca/docs/default-source/publications->

mo/home_care_in_canada_from_the_margins_to_the_mainstream_web.pdf?sfvrsn=6

Canadian Healthcare Association. (2012). *Respite care in Canada*. Ottawa, ON: Canada. Author. Retrieved from http://www.healthcarecan.ca/wp-content/uploads/2012/11/Respite_Care_in_Canada_EN_web.pdf

Canadian Home Care Association. (2016). *About the CHCA*. Retrieved from <http://www.cdnhomecare.ca/content.php?doc=303>

Canadian Hospice Palliative Care Association. (2010, June). *Policy brief on hospice palliative care: Quality end-of-life care? It depends on where you live...and where you die*. Retrieved from http://www.chpca.net/media/7682/HPC_Policy_Brief_-_Systems_Approach_-_June_2010.pdf

Canadian Hospice Palliative Care Association. (2018a). *Cost-effectiveness of palliative care: A review of the literature*. Retrieved from <http://hpcintegration.ca/media/24434/TWF-Economics-report-Final.pdf>

Canadian Hospice Palliative Care Association. (2018b). *Family or informal caregivers*. Retrieved from <http://www.chpca.net/family-caregivers.aspx>

Canadian Institutes for Health Information. (2018). *Access to palliative care in Canada*. Retrieved from <https://www.cihi.ca/sites/default/files/document/access-palliative-care-2018-en-web.pdf>

Cancer Care Ontario. (2015, April). *Palliative care*. Retrieved from <https://www.cancercare.on.ca/pcs/palliative/>

Care Partners. (2015). *How our eShift palliative care program is helping deliver better care*. Retrieved from <http://carepartners.ca/how-our-eshift-palliative-care-program-is-helping-deliver-better-care/>

- Carriere, Y., Keefe, J., Legare, J., Lin, X., & Rowe, G. (2007). Population aging and immediate family composition: Implications for future home care services. *Genus*, 63(1/2), 1-31.
- Chan, M., Esteve, D., Escriba, C., & Campo, E. (2008). A review of smart homes – Present state and future challenges. *Computer Methods and Programs in Biomedicine*, 91, 55-81.
- Chaudhry, S.I., Mattera, J.A., Curtis, J.P., Spertus, J.A., Herrin, J., Lin, Z., ... Krumholz, H.M. (2010). Telemonitoring in patients with heart failure. *New England Journal of Medicine*, 363, 2301-2309.
- Cohen, R. (2010). *Brief on family caregivers of people at the end of life*. Retrieved from https://www.mcgill.ca/palliativecare/files/palliativecare/brief_on_family_caregivers_of_people_at_the_end_of_life.pdf
- Commission on the Reform of Ontario's Public Services (Drummond Report). (2012). *Public service for Ontarians: A path to sustainability and excellence*. Retrieved from <http://www.fin.gov.on.ca/en/reformcommission/chapters/report.pdf>
- Denton, M., Brookman, C., Zeytinoglu, I., Plenderleith, J., & Barken, R. (2015). Task shifting in the provision of home and social care in Ontario, Canada: Implications for quality of care. *Health & Social Care in the Community*, 23(5), 485-92.
- Dunbrack, J. (2003, February). *Respite for family caregivers – An environmental scan of publicly-funded programs in Canada*. Retrieved from <http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2003-respite-releve/index-eng.php>
- Dunbrack, J. (2005, March). *The information needs of informal caregivers involved in providing support to a critically ill loved one*. Retrieved from <http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2005-info-caregiver-aidant/index-eng.php>
- eHealth Ontario. (2017). *What's an electronic health record?* Retrieved from <http://www.ehealthontario.on.ca/en/ehrs-explained>

- Fraser, J. (2016, March). *Palliative and end-of-life care provincial roundtable report*. Retrieved from http://www.health.gov.on.ca/en/public/programs/palliative/pdf/palliative_report.pdf
- Funk, L., Stajduhar, K.I., Toye C., Aoun, S., Grande, G.E., & Todd, C.J. (2010). Part 2: home-based family caregiving at the end of life: A comprehensive review of published quantitative research (1998-2008). *Palliative Medicine*, 24, 573-593.
- Government of Canada. (1984). *Canada Health Act*. Retrieved from <http://laws-lois.justice.gc.ca/PDF/C-6.pdf>
- Guerriere, D.N., Zagorski, B., Fassbender, K., Masucci, L., Librach, L., & Coyte, P.C. (2010). Cost variations in ambulatory and home-based palliative care. *Palliative Medicine*, 24(5), 523-532.
- Hansford, P., & Meehan, H. (2007). Gold standard framework: Improving community care. *End of Life Care*, 3, 56-61.
- Health Canada. (2007, March). *Canadian strategy on palliative and end-of-life care*. Retrieved from <https://www.canada.ca/content/dam/canada/health-canada/migration/healthy-canadians/publications/health-system-systeme-sante/strategy-palliative-strategie-palliatifs/alt/strategy-palliative-strategie-palliatifs-eng.pdf>
- Health Canada. (2008, March). *Implementation guide to advance care planning in Canada: A case study of two health authorities*. Retrieved from <http://www.hc-sc.gc.ca/hcs-sss/pubs/palliat/2008-acp-guide-pps/index-eng.php>
- Health Canada. (2010, August). *eHealth*. Retrieved from <http://www.hc-sc.gc.ca/hcs-sss/ehealth-esante/index-eng.php>
- Health Canada. (2015, July). *Unleashing Innovation: Excellent healthcare for Canada*. Retrieved from <http://www.healthycanadians.gc.ca/publications/health-system-systeme-sante/report-healthcare-innovation-rapport-soins/alt/report-healthcare-innovation-rapport-soins-eng.pdf>

- Health Council of Canada. (2012, March). *Seniors in need, caregivers in distress: What are the home care priorities for seniors in Canada?* Retrieved from http://www.carp.ca/wp-content/uploads/2012/04/HCC_HomeCare_2d.pdf
- Health Professions Regulatory Advisory Council. (2006, April). *Regulation of health professions in Ontario: New directions*. Retrieved from http://www.hprac.org/en/reports/resources/New_Directions_April_2006_EN.pdf
- Health Quality Ontario. (2011). *eShift – Creating a virtual in home end of life care team*. Retrieved from <http://www.hqontario.ca/portals/0/Modals/pr/hc/en/pdf/success-story-south-west-en.pdf>
- Health Quality Ontario. (2015). *Measuring up: A yearly report on how Ontario's health system is performing*. Retrieved from <http://www.hqontario.ca/portals/0/Documents/pr/measuring-up-2015-en.pdf>
- Health Quality Ontario. (2016). *Palliative care report*. Retrieved from <http://www.hqontario.ca/Portals/0/documents/system-performance/palliative-care-report-en.pdf>
- Hearson, B., McClement, S., McMillan, D.E., & Harlos, M. (2011). Sleeping with one eye open: The sleep experience of family members providing palliative care at home. *Journal of Palliative Care*. 27(2), 69-78.
- Holland, D.E., Vanderboom, C.E., Ingram, C.J., Dose, A.M., Borkenhagen, L.S., Skadahl, P., ...Bowles, K.H. (2014). The feasibility of using technology to enhance the transition of palliative care for rural patients. *Computers, Informatics, Nursing*, 32(6), 257-66.
- Home Care Ontario. (2014). *Navigating the system*. Retrieved from <http://www.homecareontario.ca/home-care-services/about-home-care/navigating-the-system>
- Hospice Palliative Care Ontario. (2018). *About hospice palliative care*. Retrieved from <http://www.hpco.ca/who-we-are/about-hospice-palliative-care/>

- Information and Communications Technology Council. (2009). *eHealth in Canada: Current and Future Challenges*. Retrieved from https://www.ictc-ctic.ca/wp-content/uploads/2012/06/ICTC_eHealthSitAnalysis_EN_04-09.pdf
- Keefe, J., & Manning, M. (2005). *The cost effectiveness of respite – A literature review*. Health Canada, Home and Continuing Care Policy Unit, Health Care Policy Directorate.
- Kitchen, P., Williams, A., Pong, R.W., & Wilson, D. (2011). Socio-spatial patterns of home care use in Ontario, Canada: A case study. *Health & Place*, 17(1), 195-206.
- Linderholm, M., & Friedrichsen, M. (2010). A desire to be seen: Family caregivers' experiences of their caring role in palliative home care. *Cancer Nursing*, 33(1), 28-36.
- McCabe, M.P., Roberts, C., & Firth, L. (2008). Satisfaction with services among people with progressive neurological illnesses and their caregivers in Australia. *Nursing & Health Sciences*, 10, 29-215.
- Ministry of Finance. (2016). *Ontario population projections update, 2015-2041*. Retrieved from <http://www.fin.gov.on.ca/en/economy/demographics/projections/>
- Ministry of Health and Long-Term Care. (2015, March). *Bringing care home*. Retrieved from http://health.gov.on.ca/en/public/programs/ccac/docs/hcc_report.pdf
- Morley, J.E. (2012). Aging in place. *The Journal of Post-Acute and Long-Term Care Medicine*, 13(6), 489-492.
- Nageswaran, S. (2009). Respite care for children with special health care needs. *Archives of Pediatrics & Adolescent Medicine*, 163, 49-54.
- National Institute on Aging. (2018). *Aging in place: Growing old at home*. Retrieved from <https://www.nia.nih.gov/health/aging-place-growing-old-home>

- Neff, J.M. (2009). Respite care: An essentially unmet need for families with children with special health care needs. *Archives of Pediatrics & Adolescent Medicine*, 163, 89-90.
- Office of the Auditor General of Ontario. (2015). *Annual Report*. Retrieved from http://www.auditor.on.ca/en/content/annualreports/arreports/en15/2015AR_en_final.pdf
- Ontario Health Human Resources Research Network. (2011). *Task shifting in the provision of home and social care*. Retrieved from http://rorrhn-ohhrrn.ca/images/stories/docs/working%20paper%20series/wps_winter_2011_en.pdf
- Ontario Telemedicine Network. (2016). *Putting technology to work*. Retrieved from <https://otn.ca/putting-technology-work/>
- Personal Support Network of Ontario. (2018). *About PSWs*. Retrieved from <http://www.psno.ca/about-psws.html>
- Rallison, L.B., & Raffin-Bouchal, S. (2013). Living in the in-between: families caring for a child with a progressive neurodegenerative illness. *Qualitative Health Research*, 23(2), 194-206.
- Regan, S., & Donelle, L. (2015). Investigating the eShift model of palliative home care: Implications for planning, practice, and policy. Final report Year 1 findings. London, ON: Western University.
- Robinson, C.A., Bottorff, J.L., McFee, E., Bissell, L., & Fyles, G. (2016). Caring at home until death: enabled determination. *Support Care Cancer*, 25(4), 1229-1236.
- Robinson, C.A., Pesut, B., & Bottorff, J.L. (2012). Supporting rural family palliative caregivers. *Journal of Family Nursing*, 18(4), 467-490.

- Royackers, A., Regan, S., & Donelle, L. (2015). The eShift model of care: informal caregivers' experience of a new model of home-based palliative care. *Progress in Palliative Care*, 24(2), 84-92.
- Senate Committee. (2009, April). *Canada's aging population: Seizing an opportunity*. Retrieved from http://www.psno.ca/uploads/1/0/1/9/10197937/aging_final_report_jun0209.pdf
- Sensory Technologies. (2017). *eShift International Research Collaborative*. Retrieved from <https://www.eshiftcare.com/research>
- Schulz, R., Mendelsohn, A.B., Haley, W.E., Mahoney, D., Allen, R.S., Zhang, S.Z., ... Belle, S.H. (2003). End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *New England Journal of Medicine*, 249(20), 1936-1942.
- Sinha, S.K., Griffin, B., Ringer, T., Reppas-Rindlisbacher, C., Steward, E., Wong, I., Callan, S., Anderson, G. (2016). *An Evidence-Informed National Seniors Strategy for Canada – 2nd edition*. Toronto, ON: Alliance for a National Senior Strategy.
- Smith, C.H., Graham, C.A., & Herbert, A.R. (2016). Respite needs of families receiving palliative care. *Journal of Paediatrics and Child Health*, 53(2), 173-179.
- Stajduhar, K.I. (2003). Examining the perspectives of family members involved in the delivery of palliative care at home. *Journal of Palliative Care*, 19(1), 27-35.
- Stajduhar, K.I., Allan, D.E., Cohen, S.R., & Heyland, D.K. (2008). Preferences for location of death of seriously ill hospitalized patients: Perspectives from Canadian patients and their family caregivers. *Palliative Medicine*, 22, 85-88.
- Stajduhar, K.I., & Davies, B. (2005). Variations in the factors influencing family members' decision for palliative home care. *Palliative Medicine*, 19, 21-32.

- Stajduhar, K.I., Funk, L., Toye C., Grande, G.E., Aoun, S., & Todd, C.J. (2010). Part 1: home-based family caregiving at the end of life: A comprehensive review of published quantitative research (1998-2008). *Palliative Medicine*, 24, 573-593.
- Statistics Canada. (2010, June). *Population projections for Canada, provinces and territories 2009 to 2036*. Retrieved from <http://www.statcan.gc.ca/pub/91-520-x/91-520-x2010001-eng.pdf>
- Statistics Canada. (2013, September). *Portrait of caregivers, 2012*. Retrieved from <http://www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.htm>
- Statistics Canada. (2014a, June). *Receiving care at home. Spotlight on Canadians: Results from the general social survey*. Retrieved from <http://www.statcan.gc.ca/pub/89-652-x/89-652-x2014002-eng.pdf>
- Statistics Canada. (2014b, September). *Canadians with unmet home care needs*. Retrieved from <http://www.statcan.gc.ca/pub/75-006-x/2014001/article/14042-eng.pdf>
- Statistics Canada. (2015, September). *Canada's population estimates: Age and sex, July 1, 2015*. Retrieved from <http://www.statcan.gc.ca/daily-quotidien/150929/dq150929b-eng.pdf>
- Whitmore, K.E. (2016). The concept of respite care. *Nursing Forum*, 52(3), 180-187.
- Wholihan, D.J., & Pace, J.C. (2012). Community discussions: a vision for cutting the costs of end-of-life care. *Nursing Economics*, 30(3), 170-5.
- Williams, A.M., Eby, J.A., Crooks, V.A., Stajduhar, K., Giesbrecht, M., Vuksan, M.,...Allan, D. (2011). Canada's compassionate care benefit: Is it an adequate public health response to addressing the issue of caregiver burden in end-of-life care? *BMC Public Health*, 11, 1-15.

- Wilson, D.M., Cohen, J., Deliens, L., Hewitt, J.A., & Houttekier, D. (2013). The preferred place of the last days: Results of a representative population-based public survey. *Journal of Palliative Medicine*, 16, 502-508.
- World Health Organization. (2008). Task shifting: Global recommendations and guidelines. Geneva: World Health Organization.
- World Health Organization. (2015). *Summary: World report on aging and health*. Retrieved from http://apps.who.int/iris/bitstream/10665/186468/1/WHO_FWC_ALC_15.01_eng.pdf
- Zeytinoglu, I.U., Denton, M., Brookman, C., & Plenderleith, J. (2014). Task shifting policy in Ontario, Canada: Does it help personal support workers' intention to stay? *Health Policy*, 117, 179-186.

Chapter 2: Manuscript

Introduction

The Canadian population profile is changing due to an aging population (Sinha et al., 2016) and in Ontario alone, the number of older adults 65 years of age and older is expected to more than double from 2.2 million in 2015 to 4.5 million in 2041 (Ministry of Finance, 2016). The increase in the older adult population has, in part, contributed to an increase in the demand for home care services (Carriere, Keefe, Legare, Lin & Rowe, 2007) as older adults make up the largest segment of home care clients (Office of the Auditor General of Ontario, 2015). In addition, as the population ages, the need for palliative care is expected to increase substantially (Canadian Hospice Palliative Care Association, 2010; Fraser, 2016) as more individuals require end-of-life care (Statistics Canada, 2010). Although the majority of Canadians prefer to receive end-of-life care and die in their own home (Agar et al., 2008; Hansford & Meehan, 2007; Kitchen, Williams, Pong, & Wilson, 2011; Stajduhar, Allan, Cohen, & Heyland, 2008; Stajduhar & Davies, 2005; Wilson, Cohen, Deliens, Hewitt, & Houttekier, 2013), recent evidence indicates that over forty percent died in a hospital setting (Canadian Institute for Health Information, 2018).

Family caregivers provide up to ninety percent of assistance to their palliative family member at the end-of-life (Cohen, 2010; Dunbrack, 2005), and thus, are an integral factor in supporting a home death (Health Quality Ontario [HQO], 2016; Linderholm & Friedrichsen, 2010). The demands of caregiving often escalate at the end-of-life, increasing the likelihood of family caregivers experiencing physical and emotional problems (Funk et al., 2010; Hearson, McClement, McMillan, & Harlos, 2011; Stajduhar et al., 2010; Williams et al., 2011). In Ontario, in-home respite, which provides family caregivers with a short period of rest or relief from responsibilities of caregiving (Canadian Caregiver Coalition, 2014; Canadian Healthcare Association, 2012), is a publicly funded service (Canadian Caregiver Coalition, 2014; Dunbrack, 2003). However, the provision of in-home respite is currently insufficient (Fraser, 2016; Ministry of Health and Long-Term Care [MOHLTC], 2015) due to the current shortage of health human resources (Canadian Healthcare Association, 2012; Health Canada,

2015). As such, the hours of respite provided may not support the needs of most family caregivers (Dunbrack, 2003; Smith, Graham, & Herbert, 2016).

Recently, task shifting, which involves assigning tasks that are usually completed by a nurse to be done by a personal support worker (Ontario Health Human Resources Research Network, 2011), has been recognized as a policy to ameliorate the human resource challenges associated with home care services (Commission on the Reform of Ontario's Public Services, 2012; Denton, Brookman, Zeytinoglu, Plenderleith, & Barken, 2015; Health Professions Regulatory Advisory Council, 2006). Furthermore, greater attention has been given to the need for and promise of innovative, technology-enabled service delivery models specific to end-of-life care (Care Partners, 2015; Holland et al., 2014; Ontario Telemedicine Network, 2016; Royackers, Regan & Donelle, 2015). In Ontario, the implementation of a technology-enabled model of palliative home care for individuals at the end-of-life called eShift, provided patients in-home palliative care and supported family caregivers' respite. Researchers examined the experiences of family caregivers' in-home respite who had cared for family members receiving eShift palliative home care.

Literature Review

A literature review was conducted through electronic database searches of PubMed, CINAHL, and SCOPUS. The search included the following key terms: respite, respite care, respite services, caregiver, carer, palliative care, palliative home care, home care, terminal care, and end-of-life care. Hand searches were also conducted in related journals. Studies were included if they met the following inclusion criteria: 1) Published in English; 2) Published between 2005-2018 as 2005 was the year that the Ontario end-of-life strategy was developed, to improve access to palliative care in the home sector (Williams & Kelley, 2010; Williams, Kelley, Richards, & Whitfield, 2010) and this year also aligns closely with national policies in the Health Accords, which identified the need for more palliative home care services (Government of Canada, 2006); 3) Peer-reviewed; 4) Focused on palliative care for patients at the end-of-life; 5) Focused on palliative patients who were either adults or older adults as this is consistent with the population that received eShift; 6) Focused on in-home respite for the palliative patient's family caregiver; and 7) Research conducted in Canada, the United States, Australia, and the

United Kingdom as palliative care as a field has grown significantly in these locations. Eight relevant studies were identified and are summarized here.

Robinson, Bottorff, McFee, Bissell, and Fyles (2016), used a qualitative interpretive descriptive approach to understand what supports were effective in enabling family caregivers in British Columbia to care for their palliative family members at home until they died. Findings from 29 interviews indicated that family caregivers valued in-home respite so that they could leave the home for a short period of time or sleep (Robinson et al., 2016). Although family caregivers had a good experience of in-home respite provided by other family members, they did not have a good experience when paid providers were looking after their palliative family member as they felt they needed to supervise the paid providers and that the paid providers were limited in the tasks they could perform (Robinson et al., 2016). Furthermore, this study found that respite was most effective for the family caregiver if it was provided when they needed it and when they trusted that someone had the competence to provide care to their palliative family member (Robinson et al., 2016). The authors suggested that in-home respite for family caregivers could be strengthened if it is provided by paid healthcare providers who do not require supervision and who are not limited in the tasks they can perform (Robinson et al., 2016).

Robinson, Pesut, and Bottorff (2012), conducted a study to understand how to support the well-being of family caregivers who are caring for a palliative family member in a rural setting in British Columbia, Canada. This mixed method study included an assessment questionnaire, as well as a semi-structured interview with 23 family caregivers who had cared for a palliative family member at home until death (Robinson et al., 2012). The authors found that in-home respite, where a volunteer sat with the patient, was helpful for caregivers, but unfortunately constrained by the volunteer's inability to help with the patient's health care needs (Robinson et al., 2012). In addition, the authors determined that sometimes hospitalization of the palliative family member was one of the only times family caregivers had meaningful respite, as they were confident the patient was well cared for (Robinson et al., 2012). This study is important, as it demonstrates that although family caregivers may want in-home respite in rural settings, the caregiver needs to feel confident in the care being provided (Robinson et al., 2012).

Hansen, Cartwright, and Craig (2012), conducted a qualitative descriptive study of the experiences of 23 family caregivers providing care to a palliative family member at the end-of-life in a Pacific Northwest county in the United States, to identify the benefits and challenges of providing care in a rural setting (Hansen et al., 2012). The benefits of formal care by health care providers were that the family caregiver sometimes knew the provider on a personal level and the benefits of informal care included neighbours who provided in-home respite while the family caregiver took care of other household responsibilities (Hansen et al., 2012). In this rural setting, challenges with formal care included a limited availability of formal caregivers who were qualified (Hansen et al., 2012). Overall, the findings indicate the value of informal in-home respite and the difficulty of obtaining qualified formal caregivers (Hansen et al., 2012).

In a study by Hearson et al. (2011), the researchers conducted a mixed methods study to describe the sleep experiences of 13 family caregivers in Manitoba, Canada caring for a palliative family member with advanced cancer. A content analysis of the qualitative data identified the overarching theme, “sleeping with one eye open” (Hearson et al., 2011, p.72), which highlights the exhausting nature of always watching over a palliative family member and getting little and poor quality sleep (Hearson et al., 2011). Health care system-related factors that resulted in fragmented sleep included the quality of healthcare providers coming into the home to provide in-home respite (Hearson et al., 2011). According to the authors, effective in-home respite services must “reflect a level of quality that instills trust and acceptance in the patient and family” (Hearson et al., 2011, p.74). Family caregivers operationalize quality care as having consistent staff, and believing that the staff is capable and self-directed (Hearson et al., 2011). Family caregivers who received in-home respite at night felt that it promoted their ability to sleep and continue in their caregiving role (Hearson et al., 2011). This study was pivotal as it brought attention to the sleep disturbances that family caregivers face and provided suggestions for the development of high quality in-home respite services (Hearson et al., 2011).

A cross-sectional study was conducted in Sydney, Australia with 168 patient/family caregiver dyads with both high and low palliative care needs, to investigate family caregiver’s preferences for support services (Hall, Kenny, Hossain, Street, &

Knox, 2014). Although there were differences among family caregivers of palliative family members with high care needs and low care needs, the two groups both valued palliative care nursing visits and phone advice from a palliative care nurse (Hall et al., 2014). In terms of in-home respite, this study demonstrated that family caregivers for palliative family members with high care needs wanted in-home respite during the day and night (Hall et al., 2014).

Brazil et al. (2005) conducted a study in Ontario, Canada to examine service preferences among family caregivers caring for a palliative family member at the end-of-life. The researchers interviewed 373 family caregivers, over the phone, at two points in time, when first diagnosed as palliative and five months later, to determine the services they felt were most valuable and the services that were lacking (Brazil et al., 2005). Family caregivers reported that the five most valuable services included: in-home nursing care, family physicians, medical specialists, housekeeping, and religious support (Brazil et al., 2005). In addition, the five services they reported they would like more of included: housekeeping, caregiver respite, in-home nursing care, personal support workers, and self-help groups (Brazil et al., 2005). Findings from this study support that family caregivers believe that in-home respite is an important service that they want to receive when caring for a palliative family member at the end-of life (Brazil et al., 2005).

Brazil, Kaasalainen, Williams, and Rodriguez (2013) conducted a study in Northeastern Ontario that compared the experiences of 44 rural family caregivers and 55 urban family caregivers, who were providing end-of-life care to a palliative family member. The findings highlighted the similarities between the urban and rural family caregivers including the family caregivers' perceived burden of support (Brazil et al., 2013). However, the findings demonstrated that relative to family caregivers living in rural settings, the urban family caregivers reported greater use of respite services (Brazil et al., 2013). The author suggested that this difference in respite use, which includes in-home respite, may be explained by less respite being provided in rural areas as well as a lack of health providers who are able to provide in-home respite for family caregivers (Brazil et al., 2013).

Finally, a study by Royackers et al. (2015) utilized an interpretive descriptive methodology, to understand the experiences of eight family caregivers with the eShift

technology-enhanced model of palliative home care in Southwestern Ontario. The authors found that family caregivers were satisfied with the care delivered in their homes, felt supported by the eShift technician and the directing registered nurse (DRN) and were able to care for their family member until they died at home. The implementation of the eShift model of palliative home care made it possible for family caregivers to spend more time with other family members and friends, as well as have more time for themselves which is indicative of in-home respite (Royackers et al., 2015).

Gaps in the Literature

Although many researchers have investigated out-of-home respite services little attention has been given to the provision of in-home respite for family caregivers, particularly when caring for a palliative family member at the end-of-life. Moreover, only one article provided family caregivers in-home respite by a specially trained personal support worker, in a technology-enhanced model of care (Royackers et al., 2015). However, this study explored family caregivers' general experience with care provided with the eShift model of palliative home care and did not specifically examine family caregivers' experiences of in-home respite. In addition, none of the identified studies solely focused on family caregiver's experiences of in-home respite when caring for a palliative family member at the end-of-life. Instead, only by exploring topics including: family caregivers' experiences of providing palliative care (Brazil et al., 2013; Hansen et al., 2012; Royackers et al., 2015), family caregivers' experiences of sleep (Hearson et al., 2011), and the supports family caregivers felt were effective and/or preferred (Brazil et al., 2005; Hall et al., 2014; Robinson et al., 2012; Robinson et al., 2016), were researchers able to identify in-home respite as an outcome and/or a valuable support for family caregivers caring for a palliative family member at the end-of-life. This dearth of literature on the experiences family caregivers have of in-home respite, specifically in a technology-enhanced model of end-of-life palliative home care with specially trained personal support workers (called eShift technicians), is an important gap in the literature.

The eShift Model of Palliative Home Care: Study Context

In 2010, in Ontario, the South West Community Care Access Centre (CCAC; now the South West Local Health Integration Network (SW LHIN)) developed a technology-enabled model of palliative home care called "eShift" ([HQO], 2016), in response to

concerns about the shortage of nurses providing home care. Offered to individuals at the end-of-life, the eShift model connects eShift technicians to a directing registered nurse (DRN) situated remotely from the patient's home, to provide eight-hours of care to palliative patients and family caregivers (Regan & Donelle, 2015). In terms of technology, each eShift technician had a smartphone loaded with the eShift application and each DRN used a computer with the eShift application which enabled them to care for four or more home care patients and their family caregiver (Regan & Donelle, 2015; Royackers et al., 2015). The eShift application was specific to palliative care and developed by a team of palliative care experts and health care software engineers. While in the patient's home, the eShift technicians regularly reported their observations of specific patient indicators in 'real time' and had ongoing communication with the DRN either through the eShift portal or by phone communication (Regan & Donelle, 2015). The ongoing communication was pivotal as the eShift technicians were able to ask for guidance related to patient symptoms as well as patient medications as needed and family caregivers could also speak to the DRN when they had specific questions about their palliative family member's care and health status (Regan & Donelle, 2015). In this way, eShift technology, supported a model of care that enhanced access to palliative home care that was responsive to the needs of patients and their family caregivers (Regan & Donelle, 2015).

A critical component of eShift is that the technicians received additional training in palliative care, including medication administration (with oversight of the DRN and the visiting homecare nurse; Regan & Donelle, 2015). In addition to the DRN and technician, the circle of care also includes other members of the palliative care team, such as physicians, visiting nurses, home care coordinators, palliative care specialists, and a technology support person (Regan & Donelle, 2015; Royackers et al., 2015; Sensory Technologies, 2017).

Methods

A paradigm is defined as a "set of interrelated assumptions about the social world which provides a philosophical and conceptual framework for the organized study of that world" (Filstead, 1979, p.34). The naturalist paradigm, based on interpretivism, views knowledge as a co-created process between the researcher(s) and participants and sees the

world as consisting of multiple realities (Bowen, 2008; Guba & Lincoln, 1994). As such, researchers aiming to understand the lived experiences from those who live it on a daily basis should conduct research utilizing an interpretivist approach (Carpenter & Suto, 2008; Ponterotto, 2005), as it enables researchers to interpret and describe a specific human phenomenon such as the experiences family caregivers have of in-home respite (Bowen, 2008).

Qualitative description is a methodology, part of naturalistic inquiry, which uses low inference interpretation (Sandelowski, 2000), in order to understand a complex human experience (Maxwell, 1992; Sullivan-Bolyai, Bova, & Harper, 2005). The goal of qualitative description is to have participants describe an experience in their own words, so that the researcher(s) can then provide a rich description of the phenomena in language that is easy to understand (Magilvy & Thomas; 2009; Sandelowski, 2000; Sullivan-Bolyai et al., 2005). The results of a qualitative description study can answer questions about health care situations (Magilvy & Thomas; 2009; Sullivan-Bolyai et al., 2005) that are relevant to health care providers and policy makers (Sandelowski, 2000) and the results also provide a platform for further interventions and program improvements (Sullivan-Bolyai et al., 2005).

Primary Study

This study was part of the original eShift study (*Investigating the eShift model of palliative home care: Implications for planning, practice and policy*), which examined the implementation of the new eShift palliative home care model (Regan & Donelle, 2015). Specifically, this study focused on the qualitative responses relevant to in-home respite that were provided in the eShift Family/Friends Caregiver Survey and Interview (Appendix A), which included questions about family caregiver stress, family caregiver sleep, the positive aspects of family caregiving, and family caregivers' perceptions of eShift care (Regan & Donelle, 2015).

Setting and Sample Strategy

Recruitment of family caregivers in the eShift Family/Friends Caregiver Survey and Interview was supported by the SW LHIN. The SW LHIN home care coordinators were provided with an overview of the study and a script developed by the primary

researchers to inform potential participants about the study (Appendix B). Interested participants then contacted the primary researchers for further information.

To be included in the study, participants had to be a family caregiver over the age of 18 who cared for their palliative family member when they received eShift in Southwestern Ontario. Moreover, to be eligible, participants had to be able to read, write and speak in English; family caregivers were included in the study if their family member had passed away within the last year (Hassan, 2005). Finally, in qualitative research, sample size is not finite in numerical size (Lincoln & Guba, 1985; Morse, 2000; Sandelowski, 1995), but instead it is based on “factors such as depth and duration of the interview” (Al-Busaidi, 2008, p.11).

Ethics

Ethics for the primary study was obtained from Western University’s Research Ethics Board (REB; Appendix C). The original REB ethics approval included ethics approval for secondary data analysis. For more information on the letter of information and consent given to and signed by participants please see Appendix D.

Research Question

The research question guiding this secondary data analysis was: “What are the experiences of family caregivers receiving in-home respite as part of a new technology-enabled model of palliative home care, called eShift, for individuals at the end-of-life?”

Secondary Data

Secondary data analysis involves analyzing data that was gathered in a prior research study (Heaton, 2008; Szabo & Strang, 1997), by the researchers responsible for the original study or by a new secondary researcher (Szabo & Strang, 1997). Secondary data analysis has many known benefits such as generating new knowledge that maximizes the output of larger studies that are publicly or privately funded (Ruggiano & Perry, 2017; Thorne, 1998), is cost-effective (Miller, 1982; Reed, 1992; Ruggiano & Perry, 2017; Szabo & Strang, 1997), and is convenient for researchers (Miller, 1982; Reed, 1992; Szabo & Strang, 1997). Moreover, secondary data analysis decreases burden on participants (Estabrooks & Romyn, 1995; Heaton, 2004; Szabo & Strang, 1997) as well as community partners who work with researchers to identify, access, and recruit potential participants (Ruggiano & Perry, 2017).

To date, some researchers have stated that methodological problems can arise when researchers share qualitative data and secondary data analysis is conducted by a researcher who was not involved in data collection (Ruggiano & Perry, 2017; Szabo & Strang, 1997). This limitation can be overcome if the researcher is able to converse with the primary researchers about the original study, including the sampling, design, methods of data collection, and context (Perrino et al., 2013; Ruggiano & Perry, 2017). In addition, secondary data analysis prevents researchers from simultaneously collecting and analyzing their data (Szabo & Strang, 1997). However, this limitation can also be viewed as a benefit as “secondary analysts have the opportunity to view the data set with a detachment that may be difficult to achieve by the original researcher” (Szabo & Strang, 1997, p.67). In turn, this increases the credibility of the study, as the initial findings during analysis do not influence the subsequent interviews that are conducted with participants (Ruggiano & Perry, 2017).

Secondary Data Management and Analysis

The data available for analysis included the original audiotapes and verbatim transcripts from the interviews with 15 family caregivers. NVivo 10 © qualitative software (QSR International Pty Ltd) was used to organize the analysis of the transcribed interviews.

For this study, the researchers were aiming to describe a phenomenon, specifically the experiences family caregivers had of in-home respite with eShift palliative home care. Conventional content analysis was deemed the most appropriate type of content analysis for this study, as it is used to describe a phenomenon when there is no existing theory and/or little is known about it (Hsieh & Shannon, 2005; Lauri & Kyngas, 2005). Content analysis adheres to the naturalistic paradigm, as it aims to interpret meaning from the collected data (Hsieh & Shannon, 2005).

In conventional content analysis, researchers do not use preconceived codes (Elo & Kyngash, 2008; Hsieh & Shannon, 2005). Secondary data analysis began with the researcher repeatedly listening to all of the audiotapes and reading all of the transcripts (Burnard, 1991; Elo & Kyngash, 2008; Graneheim & Lundman, 2004; Polit & Beck, 2004), in order to “achieve immersion and obtain a sense of the whole” (Hsieh & Shannon, 2005, p.1279). The data was reviewed word for word to obtain codes based on

the exact words family caregivers used when describing in-home respite in the transcripts (Burnard, 1991; Elo & Kyngash, 2008; Hsieh & Shannon, 2005). Preliminary codes, which came directly from the text were generated; together with co-supervisors, the preliminary codes were reviewed to achieve consensus (Hsieh & Shannon, 2005).

With iterative analysis, the preliminary codes were refined to generate sub-themes based on their relationship to one another (Burnard, 1991; Hsieh & Shannon, 2005). Finally, themes that described the experiences family caregivers had of in-home respite, provided with eShift, were created to encompass the underlying meanings in each of the sub-themes (Elo & Kyngash, 2008; Graneheim & Lundman, 2004; Hsieh & Shannon, 2005).

Reflexivity

When conducting qualitative research, reflexivity is critical as researchers are encouraged to “engage in explicitly, self-aware analysis of their own role” (Krieger, 1991, p.89). In order to be reflexive, a journal was used to document the researcher’s thoughts throughout the analysis related to the topic of family caregivers and palliative care at the end-of-life (Finlay, 2002). Attention to personal values, biases, beliefs, and relevant lived experiences facilitated the secondary researcher’s reflection on how they may be influence the findings (Finlay, 2002; Guba, 1981; Guba & Lincoln, 1982; Tracy, 2010).

Establishing Trustworthiness

When completing a qualitative content analysis, researchers must focus on establishing trustworthiness (Bowen, 2008; Lincoln & Guba, 1985) as “every research study must be evaluated in relation to the procedures used to generate the findings” (Graneheim & Lundman, 2004, p. 109). Trustworthiness encompasses characteristics such as credibility, dependability and transferability in a qualitative research study (Graneheim & Lundman, 2004; Guba, 1981; Guba & Lincoln, 1982; Lincoln & Guba, 1985).

Credibility relates to how well the generated themes and subthemes encompass the data (Graneheim & Lundman, 2004; Guba, 1981; Guba & Lincoln, 1982). In order for findings to be credible, it is crucial that relevant data in the transcripts have not been systematically excluded and that irrelevant data have not been included (Graneheim &

Lundman, 2004). One of the largest threats to credibility in secondary data analysis is that some or all of the researchers may be interpreting data that they did not collect themselves (Heaton, 2008). Credibility was addressed, in part, by generating a description of each caregiver's overall experience, using the transcribed interviews, so that the researcher could look back at these notes when completing her data analysis. Moreover, the original primary investigators of the larger eShift study were included in this secondary data analysis (Ruggiano & Perry, 2017) so that the researcher was also able to ask them questions about the context of the original interviews. In addition, all of the researchers involved in this study individually coded the transcripts and came up with an initial coding scheme as well as subthemes. All emerging findings were then collectively discussed between the researcher and her co-supervisors (Bowen, 2008), which resulted in triangulation of the data meaning that all researchers were in agreement with the findings (Bowen, 2008; Graneheim & Lundman, 2004; Guba, 1981; Guba & Lincoln, 1982; Thorne, 1998).

Dependability is defined as “the degree to which data change over time and alterations are made in the researcher's decisions during the analysis process” (Graneheim & Lundman, 2004, p.110). In order to ensure the findings were dependable, a journaling process was used to act as an audit trail. This journaling strategy included detailed information on the rationale behind how the data was reviewed and coded, (Guba, 1981; Guba & Lincoln, 1982). Furthermore, the reflexive notes were used to reflect on how the researcher's personal subjectivities may have influenced the findings. Finally, any new insights were added to the journal to be discussed with co-supervisors during meetings (Graneheim & Lundman, 2004).

Transferability refers to the extent that findings can be transferred to other environments and populations (Polit & Hungler, 1999, p.717). Qualitative research focuses on generating culturally situated knowledge (Tracy, 2010), and the interpretive paradigm postulates that different people will have different experiences. As a result, the primary investigators used purposive sampling in order to get a wide range of information on the experiences of family caregivers with the eShift palliative home care model. A thick description of the context was provided in presenting the findings and relevant quotations (Guba, 1981; Guba & Lincoln, 1982), so that readers can confidently

decide for themselves if the findings can be transferred to other contexts (Guba & Lincoln, 1982).

Findings

The experiences of family caregivers receiving in-home respite as part of a new technology-enabled model of palliative home care for individuals at the end-of-life, called eShift, were captured in fifteen individual interviews with family caregivers. On average, interviews were 60-90 minutes in length. Thirteen of the family caregivers were female and two were male. Fourteen of the family caregivers discussed their experiences of in-home respite with eShift while they were caring for one palliative family member and one, an adult daughter, spoke about her experience while she was caring for both of her parents. In terms of the family caregivers' relationship to the palliative family member, seven were spouses, one was a partner, six were adult children and one was a friend. In addition, two family caregivers lived outside of the home and the remaining twelve lived in the same home as their palliative family member.

Three key themes, along with subthemes, emerged from the data analysis: **1) Developing trust** – family caregivers gained confidence in the quality of care provided by the eShift technician, family caregivers felt assured that they had good communication with the eShift care team and family caregivers built rapport with the eShift technician; **2) The opportunity for self-care and other activities** - family caregivers could focus on their own physical and emotional health, family caregivers could sleep through the night and family caregivers took time to engage in other activities; and **3) The comprehensive arrangement of services** - eShift palliative home care enabled family caregivers to keep their palliative family member at home until death and family caregivers felt it was difficult to secure eShift care (see Table 1 for a list of themes and sub-themes). The following sections describe the findings in more detail.

Table 1: Themes and Sub-Themes

| Themes | Sub-themes |
|------------------|--|
| Developing Trust | Family caregivers gained confidence in the quality of care provided by the eShift technician |

| | |
|--|---|
| | Family Caregivers felt assured that they had good communication with the eShift care team |
| | Family Caregivers built rapport with the eShift technician |
| The opportunity for self-care and other activities | Family caregivers could focus on their own physical and emotional health |
| | Family caregivers could sleep through the night |
| | Family caregivers took time to engage in other activities |
| The comprehensive arrangement of services | eShift care enabled the palliative family member to die at home |
| | Difficulty securing eShift care |

Theme 1: Developing Trust

Family caregivers shared that developing trust with the eShift care team was a critical component of their in-home respite. To begin, family caregivers who were confident in the quality of care being provided by the eShift technicians were able to trust the eShift technicians to look after their palliative family member throughout the night and therefore experience some relief from caregiving. In addition, in-home respite was facilitated when family caregivers trusted the verbal communications that they had with the eShift care team before, during and after the shift. Finally, as family caregivers built rapport with the eShift technicians, they were more trusting that the eShift technicians genuinely cared about their palliative family member, which resulted in a better experience of in-home respite.

Family caregivers gained confidence in the quality of care provided by the eShift technician

Family caregivers described having confidence in the quality of care being provided by the eShift technicians, which resulted in them trusting the eShift technicians

and being able to go to bed at night without worrying about their palliative family member. One family caregiver stated “I could go to bed knowing that he [palliative family member] was being looked after and that his needs would be met” (Family caregiver 14). Confidence in the care being provided was conveyed by a family caregiver who reported being less anxious about her father’s needs being met and stated, “I knew they [eShift technician] were there and I felt he was in better hands than with me” (Family caregiver 15). Family caregivers described feeling a sense of security as they trusted that the eShift technicians would take action in an emergency, allowing them to experience in-home respite. When discussing the benefits of eShift one family caregiver shared “Giving us the sense of security. That’s in the extra set of eyes” (Family caregiver 3).

Some family caregivers reported a lack of confidence in the quality of care being provided by one or more eShift technicians. This lack of confidence resulted in broken trust, which negatively impacted their experience of in-home respite. For example, one family caregiver described a night when she went to her husband’s room because she could not sleep and noticed that the eShift technician was sleeping. She shared how this incident resulted in her no longer having confidence in the care provided by this eShift technician and stated, “If that person came back two days later, I wouldn’t, I couldn’t sleep because I was worried. I said, oh, she must be, is she listening for him?” (Family caregiver 7). Another family caregiver recalled being extremely disturbed after finding a large bed sore on his wife and it caused him to become anxious and less trusting of the quality of care being provided. He stated repeatedly that he was haunted by the bed sore and that “...It shouldn’t have happened with all of the people that were there [with eShift]” (Family caregiver 11).

Family caregivers felt assured that they had good communication with the eShift care team

Family caregivers described feeling able to inform the eShift technician about their palliative family member’s condition when they arrived at the patient’s home for their evening shift and trusted that the eShift technician was up to date with their palliative family member’s needs and progress before they went to bed. This sentiment was captured by one caregiver who stated that she was “able to sleep knowing that when

the eShift technician came in I sat down with them and chatted with them about [palliative family member] for a while” (Family caregiver 10). Another family caregiver stated “I could go to bed and sleep knowing that if they needed me, they knew where I was” (Family caregiver 14). Finally, family caregivers described being able to sleep throughout the night because they trusted that the eShift technician would provide them with any important information and updates about their palliative family member’s progress in the morning. One family caregiver said that in the morning the eShift technician “Would sit and tell me how the night was, what he did, and if they had to phone the directing registered nurse to give him something” (Family caregiver 7).

Family caregivers also spoke about the importance of the communication that took place with the use of technology. In particular, family caregivers discussed the communications that they had either directly with the DRN or with the eShift technician who spoke to the DRN on behalf of the family caregiver. These communications with the DRN facilitated in-home respite as family caregivers trusted the medical advice provided by the DRN. One family caregiver shared an example of being worried about a medication that the eShift technician was going to administer to her palliative family member. The family caregiver indicated that she “talked to her [the DRN] and she explained what the medication was for” (Family caregiver 14).

However, not all communication experiences were positive. For example, one family caregiver shared that she felt that many of the questions she asked about her husband’s progress were unanswered. As a result, she continued to worry when eShift palliative home care was present and spent time using the internet to search for information during the night instead of going to sleep. She shared “they [the eShift technicians] need to talk progress” (Family caregiver 5).

One family caregiver who did not live with the palliative family member stated he did not know if and when the eShift technicians arrived as he did not trust that they would always be punctual. He explained that having an application that would notify him when the eShift technician showed up would be helpful because “I just need to know everything’s alright and that there’s somebody there” (Family caregiver 9).

Family caregivers built rapport with the eShift technician

Family caregivers reported developing positive relationships with the eShift technicians that allowed them to trust the eShift technicians and therefore experience relief from their caregiving tasks. Family caregivers first spoke about getting to know the eShift technicians on a personal level and spending time talking with them. One family caregiver looking after her mother shared:

We definitely tried to get to know [the eShift technicians]. We asked [the eShift technicians] personal questions and we spoke personally about our family and our mom. We wanted them to get to know a little bit more about the remarkable woman she was. (Family caregiver 3)

Family caregivers also described the eShift technicians as having many positive personal traits; which were critical to family caregivers, as it enabled them to trust that the eShift technicians would care for their family member's needs. One family caregiver exemplified this when she stated:

They were personable. I genuinely felt that they cared about my mom. They would talk to her and they were just all so sweet with her, which was nice. It wasn't just clinical. They were also personable with her and with me. (Family caregiver 4)

Trusting the eShift technicians facilitated family caregivers to relax and sleep through the night. One family caregiver explained that when a certain eShift technician with good qualities came over she "had excellent sleep. I had a really good sleep because I knew he was a good guy" (Family caregiver 7).

Furthermore, some family caregivers spoke about developing relationships with the eShift technicians. Only after taking time to build relationships, family caregivers trusted that the eShift technician would watch over their palliative family member which allowed them relief from caregiving. One family caregiver reported that she felt more comfortable after a week of eShift palliative home care because she "felt more assured getting to know the woman [eShift technician] coming in to look after her [palliative family member]" (Family caregiver 4). However, family caregivers shared that it was at times difficult to establish a rapport with the eShift technicians; one family caregiver explained "it's hard to establish a rapport but what I saw and what we did worked out fine for me" (Family caregiver 1).

Theme 2: The opportunity for self-care and other activities

Care provided with eShift palliative home care provided family caregivers with an opportunity to engage in self-care and other activities. As a result, family caregivers took time to focus on their own physical and emotional health, sleep throughout the night, as well as engage in leisure, work and volunteering activities.

Family caregivers could focus on their own physical and emotional health

The majority of family caregivers reported feeling physically drained as a consequence of the activities associated with caring for their palliative family member. This was captured by one family caregiver who reported that it became difficult for her to do “anything that required lifting him [palliative family member] or supporting his weight like getting up to go to the washroom or go to the shower and tub” (Family caregiver 8). These physically demanding tasks were even more challenging for family caregivers who were also managing their own health issues such as back and foot problems, cancers, and cardiac problems that resulted in limited capacity to provide the full spectrum of palliative care to their palliative family member.

With the introduction of eShift palliative home care, family caregivers described that the time away from their caregiving activities resulted in improvements to their physical health. One family caregiver explained “physically, things were getting better...physically, I was getting more relieved (Family caregiver 4). Finally, two family caregivers shared that the eShift palliative home care model did not help with all of the physical care tasks associated with caregiving. At times, certain eShift technicians were not able to lift the palliative family member depending on their size and the physical attributes of the palliative family member.

Family caregivers also reported feeling emotionally drained as a consequence of caring for a palliative family member and they described feeling overwhelmed and anxious about their caregiving tasks and of their ability to meet their palliative family member’s needs. With the introduction of the eShift model of palliative home care, many family caregivers shared that they felt emotionally supported by the eShift technician and reported that:

There were times I was very emotional and they [eShift technicians] handled me with kid gloves. Which was great because they were emotionally supportive.

(Family caregiver 4)

If in the middle of the night I had anxiety, I could get up and there was somebody here I could talk to. It really did help and took a lot of the stress off. (Family caregiver 12)

However, family caregivers explained that within a palliative context, even with eShift, “you never really shut off” (Family caregiver 12).

Family caregivers could sleep through the night

Family caregivers shared that they frequently felt exhausted and sleep-deprived from being vigilant to the needs of their palliative family member. Family caregivers reported that before eShift palliative home care:

I would sleep for maybe two hours at a time and wake up. And I would sleep during the night but that’s a broken sleep. (Family caregiver 1)

I was a hazard to myself going up and down the stairs several times a night being half asleep. (Family caregiver 4)

However, once eShift palliative home care was put in place, family caregivers explained that their sleep improved because they knew someone would be watching over their palliative family member throughout the night. One family caregiver stated that when an eShift technician was watching her mother she had better sleep because she “wasn’t as vigilant about watching her because I knew someone else was going to be” (Family caregiver 3).

Family caregivers also explained that they were also able to sleep better with eShift palliative home care because the visiting nurse had “a drug station set up in the kitchen and she [the nurse] pulled up all the medications and had them marked in bottles” (Family caregiver 1). As a result, once the eShift technician arrived at night “I could go to bed and not have to worry about drugs being given and given properly” (Family caregiver 1).

However, some family caregivers described difficulty with sleep during the nights with eShift palliative home care. Some family caregivers were not able to go to bed right away due to a lack of consistency with the eShift technicians. When new eShift

technicians came to the home, family caregivers described needing to spend time giving them a tour of their home and explaining the palliative family member's routine. One family caregiver shared "when he [a new eShift technician] came I had to go through everything with him again. So I didn't even go to bed until after midnight" (Family caregiver 1). As well, family caregivers described missing out on sleep or being unable to sleep when eShift technicians showed up late or not at all.

Family caregivers took time to engage in other activities

Family caregivers spoke about the impact of eShift on their ability to engage in activities including leisure, work, and volunteering. In terms of leisure activities, caregivers explained that when the palliative family member became ill they had to give up a lot of their everyday activities; it enabled caregivers to engage in leisure activities as demonstrated by one family caregiver who stated "well, they gave me in-home respite so I went bowling because I'm a bowler" (Family caregiver 5). However, this caregiver demonstrated that although the respite associated with eShift palliative family member care provided her with time-away from caregiving, she was ambivalent about taking time away stating that "I shouldn't have gone that day because my head was back here" (Family caregiver 5).

Many family caregivers discussed having other roles on top of caregiving, which included: raising animals, helping another family member do barn work each day, and taking care of children and a spouse. In terms of paid employment outside of the home before eShift palliative home care, the majority of family caregivers had already retired and two were unable to work due to a health issue. One family caregiver who was working before eShift palliative home care reported that she had to leave her position as soon as her mother got ill, in order to attend to her needs. This family caregiver only returned to work after her mother passed away. She explained "I had stopped working and I was home full time with her [palliative family] member]" (Family Caregiver 4). Another family caregiver who worked full-time explained that she had to work less hours when her husband was ill so that he did not have to remain at home alone all day. Although this family caregiver wanted to quit her job entirely, so that she could care for her husband throughout the day, she was unable to due to financial constraints. This was evident when she shared:

I didn't take work off until the two weeks before he [her husband] passed because he didn't want me to quit working because I was going to take the, some kind of leave that you could take but he said it wouldn't, we wouldn't make enough money to survive to do that. So he told me to keep working. So I did. (Family Caregiver 12)

The two remaining family caregivers who worked full time had their own business, which they described as being extremely stressful. Despite eliminating extraneous tasks and having more flexibility on when they could complete their work, they still reported having to continue working at the same capacity that they always had. Although one of the business owners who worked felt more rested in the morning before work due to the in-home respite provided with eShift palliative home care, the other business owner shared that eShift palliative home care did not help with her role at work because this service was only provided at night. This family caregiver explained that the stress of work was the same with eShift because "eShift was only here at night so I mean I wasn't working at night, right? So that's the hard part" (Family caregiver 14).

Another family caregiver looking after her husband shared that even with eShift "I had to stop [volunteering work]. I couldn't go [to volunteer at the school] because I couldn't leave him [during the day]. He was too confused" (Family caregiver 7).

Theme 3: The comprehensive arrangement of services

The comprehensive arrangement of services captures family caregivers who felt that eShift palliative home care enabled them to keep their palliative family members at home until death, in part, through the support provided for in-home respite.

eShift care enabled the palliative family member to die at home

Family caregivers reported that eShift palliative home care sustained them in their role as they had an opportunity for in-home respite. As a result, eShift enabled them to keep their family member at home until death. Family caregivers stated that:

I know for myself, physically, I couldn't have done it [continued in the caregiving role at home]. I would have collapsed at some point. I really physically couldn't have kept going if I didn't have them [the eShift technicians] (Family caregiver 4)
I don't think I would still be existing [without eShift care in the home]. (Family caregiver 8)

Without eShift palliative home care, some family caregiver shared that they would have had to put their palliative family member into the hospital or into a hospice program as they would not have been able to keep up with all of the tasks associated with caregiving. One family caregiver explained that without eShift “he [palliative family member] would have had to have gone into a hospital or hospice because I couldn’t do it” (Family Caregiver 8).

Many family caregivers highlighted that eShift would have been the preferred care for their palliative family member all day in addition to the night shift. One family caregiver looking after her husband highlighted the need for respite during the day when she said:

The only thing that would have helped me was to have them during the day too 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 weird things would happen. He’d be seeing things that weren’t there and I wasn’t used to that. (Family Caregiver 12)

Difficulty securing eShift care

Family caregivers stated that, at times, the home care provider agency was unable to consistently meet the demand for services at night due to inadequate staffing. One family caregiver described a few nights when an eShift technician did not come for the shift. She shared “A few times, I was notified that they were having trouble. They didn’t know if they could get anybody” (Family Caregiver 8). As a result, this family caregiver looked after her husband during the night which negatively impacted her own respite. Another family caregiver looking after her friend who lived outside of the home shared that it was extremely difficult when an eShift technician was not secured for a shift. She shared that after a few times of not having an eShift technician show up “It became very frustrating. That was more frustrating than anything. And, and I just found that the system felt very broken to me” (Family Caregiver 2). As a result, arranging care for her friend overnight became extremely difficult and time consuming. She explained:

...And they [the provider agency] were having trouble because they were overloaded as it was. So it became, actually, you know what really became hard for me was having to orchestrate everything and trying to find people to help me because I couldn’t be there all the time. (Family Caregiver 2)

Discussion

This study explored the experiences of fifteen family caregivers receiving in-home respite with eShift, which is a technology-enable model of palliative home care for individuals at the end-of-life. In the palliative end-of life context, family caregivers have reported that developing trust with the health care provider or individual watching their palliative family member is a critical element of their respite experience (Hansen et al., 2012; Hearson et al., 2011; Robinson et al., 2012; Robinson et al., 2016). In the eShift model of palliative home care, family caregivers developed trust with the eShift care team as a result of feeling confident in the quality of care being provided by the eShift technicians, the communication that took place with the eShift care team, and the relationships they developed with the eShift technicians, which allowed them to attain respite from their caregiving role.

Trust and quality of patient care established between the family caregiver and the eShift health care providers is consistent with other research that has highlighted that high quality care is an important component of developing trust (Hansen et al., 2012; Hearson et al., 2011; Robinson et al., 2012; Robinson et al., 2016). For example, in a study by Robinson et al. (2016), the authors found that in-home respite was most effective for family caregivers when they trusted that an individual was providing high quality care to their palliative family member. With the eShift model of palliative home care, family caregivers had confidence in the quality of care provided by the DRNs and the eShift technicians and trusted them to watch over the patient when they slept at night. This finding is important because unlike traditional models of in-home respite with one individual looking after a patient, family caregivers receiving in-home respite with the eShift model were cognizant that the eShift technicians had ongoing communications with the DRN throughout the shift and that the eShift technicians could ask the DRN for guidance when needed (Regan & Donelle, 2015).

The importance of trusting the communication with the eShift care team in order to achieve in-home respite, is consistent with other studies (Hall et al., 2014; Royackers et al., 2015). Royackers et al. (2015) found that the use of technology supported family caregivers to resolve problems and find answers to questions ‘in the moment’, as the eShift technician could communicate ‘in real time’ with the remote DRN, which is

indicative of supporting emotional in-home respite. Another study by Hall et al. (2014) determined that family caregivers valued the phone advice from a palliative care nurse, as it enabled them to ask questions about their palliative family caregiver when issues arose. Researchers have acknowledged the importance of communication between family caregivers and health care providers in the palliative home care context (Browne, Macdonald, May, Macleod, & Mair, 2014; Hassan et al., 2010; Jo, Brazil, Lohfeld, & Willson, 2007) in support of in-home respite, including keeping family caregivers up to date about the palliative family member's progress (Browne et al., 2014). In the present study, family caregivers living with the patient reported positive communication with eShift care providers including the eShift technician and DRN. In particular, the communications that family caregivers had with the DRN, which were supported by the eShift technology, would not have been possible in a traditional model of in-home respite where another family member, friend, volunteer, or a personal support worker is watching over the palliative family member in order to provide the family caregiver with an opportunity for in-home respite. Existing literature has shown that telehealth tools such as phone calls, text messages, and remote monitoring systems have the potential to enhance information sharing with family caregivers (Chi & Demiris, 2015; Chou et al., 2012; Dang et al., 2008; Mahoney, Tarlow, & Jones, 2003) and thus, need to be further explored in relation to providing in-home respite for family caregivers who are caring for a palliative family member.

With respect to building rapport with the eShift technicians, family caregivers felt that they had a better experience of in-home respite after they had developed a trusting relationship with the eShift technician over time. This finding is similar to researchers that found in-home respite to be most effective when staff was consistent as the caregiver was more likely to sleep throughout the night (Hearson et al. 2011; Royackers et al., 2015). Other studies, although not focused specifically on in-home respite, provide further support that consistency in health care providers builds trust (Abelson, Gold, Woodward, O'Connor, & Hutchison, 2004; Gantert, McWilliam, Ward-Griffin, & Allen, 2009; Woodward, Abelson, & Hutchison, 2001). The concept of "relational care" provides one explanation for the relationship between consistency in health care providers and family caregivers' development of trust in them. At its core, relational care

involves a professional, caring and mutually responsive partnership between a healthcare provider and health care receiver and/or family caregiver, that moves beyond prescriptive and outcome-oriented approaches (Doane & Varcoe, 2007; Zou, 2016). In this way, both the patient and the family caregiver's needs within complicated contexts can be understood over time (Doane & Varcoe, 2007; Jonsdottir, Litchfield, & Pharris, 2004; Zou, 2016).

The present study also found that the eShift model of palliative home care provided family caregivers an opportunity to focus on their own physical and emotional health, sleep, and engage in other activities. To begin, family caregivers were able to rest when the eShift technician was present, which is consistent with other studies that explored in-home respite in a palliative end-of-life context (Hearson et al., 2011; Robinson et al., 2016). Furthermore, this study brought significant attention to the emotional relief that family caregivers experienced when the eShift technicians were present. With eShift palliative home care, family caregivers felt emotionally supported by the eShift technicians and felt comfortable talking to them when they were stressed. Supportive in-home respite is critical as researchers have acknowledged that respite cannot simply be achieved from relief from physical tasks (Nageswaran, 2009; Neff, 2009), and caregivers can benefit from the emotional support provided by eShift health care providers.

Existing literature has also acknowledged that the physical health and emotional well-being of family caregivers is frequently overlooked and as a result, they are referred to as "hidden patients" (Kristjanson & Aoun, 2004). In fact, researchers have even suggested that the emotional needs of family caregivers far exceeds that of their palliative family member (Cain, MacLean, & Sellick, 2004; Grunfeld, Glossop, McDowell, & Danbrook, 1997). As such, the respite family caregivers experienced with eShift supports the importance of viewing the family caregiver and palliative family member as a unit of care in the palliative context (Cain et al., 2004; Clemmer, Ward-Griffin, & Forbes, 2008; Knapp & DelCampo, 1995; Linderhold & Friedrichsen, 2011).

Similar to other studies, family caregivers in the present study also discussed the importance of in-home respite in achieving necessary sleep; family caregivers with eShift palliative home care knew that the eShift technician would be watching their palliative

family member overnight (Hearson et al., 2011; Royackers et al., 2015). Specifically, patient medication administration by the eShift technician (with oversight by the DRN), which is unique to the eShift model of care, enabled family caregivers to sleep at night as they did not need to wake up to attend to this. This finding is similar to a study by Robinson et al. (2012) who found that in-home respite was negatively impacted when the individual looking after the patient was constrained in their ability to help with the palliative family member's health care needs.

Similar to family caregivers in other research studies, family caregivers in the present study had multiple roles outside of caregiving (Cain et al., 2004; Clemmer et al., 2008). As a result, even when eShift palliative home care was implemented, the majority of caregivers did not engage in a leisure activity and/or volunteer as the majority received eShift care at night and they did not want to leave their palliative family member at home during the day. Further, of the family caregivers who were working, the benefits of in-home respite with eShift palliative home care were mixed. One reported feeling rested in the morning as she was able to sleep whereas the other continued to be stressed even with eShift, as eShift palliative home care was not offered over a 24-hour period. These findings are important as they support the need for family caregivers to have extended in-home respite with patients at end-of-life (Aoun, Kristjanson, Hudson, Currow, & Rosenberg, 2005; Brazil et al., 2005), so that they have the ability to leave their home to run errands, go to work, volunteer and/or engage in leisure activities (Cain et al., 2004; Hall et al., 2014; Robinson et al., 2016). Further, one family caregiver spoke about not being able to leave her job completely due to financial constraints highlighting the need for financial support to care for family members in the home and community care setting (CARP, 2014; Flagler & Dong, 2010; Ontario Caregiver Coalition, 2018; Williams et al., 2011).

Finally, this study demonstrated that family caregivers felt that eShift palliative home care enabled them to keep their palliative family member at home until death. This finding is similar to the pilot study on eShift that was conducted by Royackers et al. (2015) which found that family caregivers felt that they may not have been able to fulfill their palliative family member's wish to die at home without eShift palliative home care. Moreover, the findings in the present study are also consistent with other studies that

have found that in-home respite supports the family caregiver in caring for their palliative family member at home (Aoun et al., 2005; Clark, Ferguson, & Nelson, 2000; Herber & Johnson, 2013).

Implications for Practice, Education, Research, and Policy

The findings from this study on family caregivers' experiences of in-home respite have important implications for practice, education, and research related to nursing and personal support worker practice and public health care policy.

Nursing and Personal Support Worker Practice

The findings from this study support the importance of communication between health care providers and family caregivers (Browne et al., 2014; Hassan et al., 2010; Jo et al., 2007) so that family caregivers are kept up to date on their palliative family member's progress (Browne et al., 2014). Further, the findings highlight the need for consistency among health care providers so that family caregivers can build trust with them (Abelson et al., 2004; Gantert et al., 2009; Woodward et al., 2001), which improves family caregiver's experience of in-home respite (Hearson et al., 2011).

Nursing and Personal Support Worker Education

As information technology continues to be used in the home care setting, it is critical that health care providers have more education and training opportunities related to information technology so that they are prepared and able to use it appropriately in practice (Desjardins, Cook, Jenkins, & Bakken, 2005; Fetter, 2009; Saba & Erdley, 2006). Furthermore, health care providers should also have more training on the importance of both the physical and emotional relief that contributes to in-home respite (Nageswaran, 2009; Neff, 2009; Whitmore, 2016) and to view the palliative family member and family caregiver as a "unit of care" (Cain et al., 2004; Clemmer et al., 2008; Knapp & DelCampo, 1995; Linderhold & Friedrichsen, 2011).

Future Research

Further research on in-home respite with the eShift model of palliative home care is needed to explore and describe the experience of in-home respite among family caregivers with varied demographic characteristics including: age, gender, and geographic location in order to provide additional information to inform education, practice and public health policy so that the eShift model of palliative home care is able

to meet the in-home respite needs of family caregivers who have varied demographic characteristics. Increased scholarly attention is also required to explore the impact on family caregiver respite if eShift palliative home care was extended beyond the eight hour shift of care to support family caregivers in their work, volunteer and leisure activities.

Public Health Policy

The respite family caregivers experienced with eShift aligns with the most recent *Canadian Caregiver Strategy*, which advocates for greater supports for caregivers to enhance both their physical health and well-being (Canadian Caregiver Coalition, 2014). Future health care policies related to in-home respite should consider the multiple roles that family caregivers have (Cain et al., 2004; Clemmer et al., 2008), and strive to provide opportunities for in-home respite during the day and night (Cain et al., 2004; Hall et al., 2014; Robinson et al., 2016).

Limitations

This study had a few limitations that need to be acknowledged. To begin, only family caregivers from Southwestern Ontario were eligible to participate, meaning that the findings are limited to this small area of the province. Further, to be eligible, family caregivers needed to be able to speak and understand English, which excluded family caregivers whose first language was not English.

Conclusion

The purpose of this secondary analysis was to describe the experiences of 15 family caregivers receiving in-home respite as part of a new technology-enabled model of palliative home care, called eShift, for individuals at the end-of-life. Overall, the fifteen family caregivers that participated in this study had a positive experience of in-home respite with eShift, which enabled them to keep their palliative family member at home until death. In fact, many family caregivers shared that eShift would have been the preferred care all day and night so that they could have more opportunities for in-home respite during the day. This study is an important contribution to the literature as it offers insights into family caregivers' experiences of in-home respite with the eShift model of care and serves as a basis for future research on family caregivers' experiences of in-home respite with eShift and other technology-enabled models of palliative home care.

References

- Abelson J., Gold, S.T., Woodward, C., O'Connor, D., & Hutchison, B. (2004). Managing under managed community care: The experiences of clients, providers and managers in Ontario's competitive home care sector. *Health Policy*, 68(3), 359-372.
- Agar, M., Currow, D., Shelby-James, T., Plummer, J., Sanderson, C., & Abernethy, A. (2008). Preference for place of care and place of death in palliative care: Are these different questions? *Palliative Medicine*, 22(7), 787-95.
- Al-Busaidi, Z.Q. (2008). Qualitative research and its uses in health care. *Sultan Qaboos University Medical Journal*, 8(1), 11-19.
- Aoun, S.M., Kristjanson, L.J., Hudson, P.L., Currow, D.C., & Rosenberg, J.P. (2005). The experience of supporting a dying relative: Reflections of caregivers. *Progress in Palliative Care*, 13(6), 319-325.
- Bowen, G.A. (2008). Naturalistic inquiry and the saturation concept: A research note. *Qualitative Research*, 8(1), 137-152.
- Brazil, K., Bedard, M., Krueger, P., Abernathy, T., Lohfeld, L., & Wilson, K. (2005). Service preferences among family caregivers of the terminally ill. *Journal of Palliative Medicine*, 8(1), 69-78.
- Brazil, K., Kaasalainen, S., Williams, A., & Rodriguez, C. (2013). Comparing the experiences of rural and urban family caregivers of the terminally ill. *Rural and Remote Health*, 13(1), 2250.
- Browne, S., Macdonald, S., May, C.R., Macleod, U., & Mair, F.S. (2014). Patient, carer and professional perspectives on barriers and facilitators to quality care in advanced heart failure. *PLOS One*, 9(3), 93288.
- Burnard, P. (1991). A method of analyzing interview transcripts in qualitative research. *Nurse Education Today*, 11, 461-466.

- Cain, R., MacLean, M., & Sellick, S. (2004). Giving support and getting help: Informal caregivers' experiences with palliative care services. *Palliative and Supportive Care*, 2, 256-272.
- Canadian Caregiver Coalition. (2014, February). *A Canadian caregiver strategy: Are we making progress?* Retrieved from http://www.carerscanada.ca/wp-content/uploads/2015/09/Pan-Canadian-Family-Caregiver-2013_WEB-PAGES-2.pdf
- Canadian Healthcare Association. (2012). *Respite care in Canada*. Ottawa, ON: Canada. Author. http://www.healthcarecan.ca/wp-content/uploads/2012/11/Respite_Care_in_Canada_EN_web.pdf
- Canadian Hospice Palliative Care Association. (2010, June). *Policy brief on hospice palliative care: Quality end-of-life care? It depends on where you live...and where you die*. Retrieved from http://www.chpca.net/media/7682/HPC_Policy_Brief_-_Systems_Approach_-_June_2010.pdf
- Canadian Institutes for Health Information. (2018). *Access to palliative care in Canada*. Retrieved from <https://www.cihi.ca/sites/default/files/document/access-palliative-care-2018-en-web.pdf>
- Care Partners. (2015). *How our eShift palliative care program is helping deliver better care*. Retrieved from <http://carepartners.ca/how-our-eshift-palliative-care-program-is-helping-deliver-better-care/>
- CARP. (2014). *CARP's new vision for caregiver support*. Retrieved from <http://www.carp.ca/wp-content/uploads/2014/02/Caregiver-Brief-Feb-2014.pdf>
- Carpenter, C., & Suto, M. (2008). Chapter 2: Why choose qualitative research in rehabilitation? In C. Carpenter & M. Suto, *Qualitative research for occupational and physical therapists: A practical guide* (pp.21-39). Oxford, Blackwell Publishing.

- Carriere, Y., Keefe, J., Legare, J., Lin, X., & Rowe, G. (2007). Population aging and immediate family composition: implications for future home care services. *Genus*, 63(1/2), 1-31.
- Chi, N-C., & Demiris, G. (2015). A systematic review of telehealth tools and interventions to support family caregivers. *Journal of Telemedicine and Telecare*, 21(1), 37-44.
- Chou, H.K., Yan, S.H., Lin, I.C., Tsai, M.T., Chen, C.C., & Woung, L.C. (2012). A pilot study of the telecare medical support system as an intervention in dementia care: the views and experiences of primary caregivers. *Journal of Nursing Research*, 20, 169-80.
- Clark, D., Ferguson, C., & Nelson, C. (2000). Macmillan carer schemes in England: results of a multicenter evaluation. *Palliative Medicine*, 14(2), 129-139.
- Clemmer, S.J., Ward-Griffin, C., & Forbes, D. (2008). Family members providing home-based palliative care to older adults: The enactment of multiple roles. *Canadian Journal on Aging*, 27, 267-283.
- Cohen, R. (2010). *Brief on family caregivers of people at the end of life*. Retrieved from https://www.mcgill.ca/palliativecare/files/palliativecare/brief_on_family_caregivers_of_people_at_the_end_of_life.pdf
- Commission on the Reform of Ontario's Public Services (Drummond Report). (2012). *Public service for Ontarians: A path to sustainability and excellence*. Retrieved from <http://www.fin.gov.on.ca/en/reformcommission/chapters/report.pdf>
- Dang, S., Remon, N., Harris, J., Malphurs., J., Sandals, L., Cabrera, A.L., & Nedd, N. (2008). Care coordination assisted by technology for multiethnic caregivers of persons with dementia: a pilot clinical demonstration project on caregiver burden and depression. *Journal of Telemedicine and Telecare*, 14(8), 443-7.

- Denton, M., Brookman, C., Zeytinoglu, I., Plenderleith, J., & Barken, R. (2015). Task shifting in the provision of home and social care in Ontario, Canada: Implications for quality of care. *Health & Social Care in the Community*, 23(5), 485-92.
- Desjardins, K.S., Cook, S.S., Jenkins, M., & Bakken, S. (2005). Effect of an informatics for evidence-based practice curriculum on nursing informatics competencies. *International Journal of Medical Informatics*, 74, 1012-1020.
- Doane, G.H., & Varcoe, C. (2007). Relational practice and nursing obligations. *Advances in Nursing Science*, 30(3), 192-205.
- Dunbrack, J. (2003, February). *Respite for family caregivers – an environmental scan of publicly-funded programs in Canada*. Retrieved from <http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2003-respite-releve/index-eng.php>
- Dunbrack, J. (2005, March). *The information needs of informal caregivers involved in providing support to a critically ill loved one*. Retrieved from <http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2005-info-caregiver-aidant/index-eng.php>
- Elo, S., & Kyngas, H. (2008). The qualitative content analysis process. *Advanced Nursing*, 62(1), 107-115.
- Estabrooks, C.A., & Romyn, D.M. (1995). Data sharing in nursing research: advantages and challenges. *Canadian Journal of Nursing Research*, 27(1), 77-88.
- Fetter, M.S. (2009). Baccalaureate nursing students' information technology competence – Agency perspective. *Journal of Professional Nursing*, 25(1), 42-49.
- Filstead, W.J. (1979). Qualitative methods: A needed perspective in evaluation research. In T.D. Cook & C.S. Reichardt (Eds.), *Qualitative and quantitative methods in evaluation research* (pp.33-48). Beverly Hills, CA: Sage.
- Finlay, L. (2002). Outing the researcher: The provenance, process, and practice of reflexivity. *Qualitative Health Research*, 12(4), 531-545.

- Flager, J., & Dong, W. (2010). The uncompassionate elements of the compassionate care benefits program: A critical analysis. *Global Health Promotion, 17*(1), 50-59.
- Fraser, J. (2016, March). *Palliative and end-of-life care provincial roundtable report*. Retrieved from http://www.health.gov.on.ca/en/public/programs/palliative/pdf/palliative_report.pdf
- Funk, L., Stajduhar, K.I., Toye C., Aoun, S., Grande, G.E., & Todd, C.J. (2010). Part 2: home-based family caregiving at the end of life: A comprehensive review of published quantitative research (1998-2008). *Palliative Medicine, 24*, 573-593.
- Gantert, T.W., McWilliam, C.L., Ward-Griffin, C., & Allen, N. (2009). Working it out together: Family caregivers' perceptions of relationship-building with in-home service providers. *Canadian Journal of Nursing Research, 41*(3), 44-63.
- Graneheim, U.H., & Lundman, B. (2003). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today, 24*, 105-112.
- Grunfeld, E., Glossop, R., McDowell, I., & Danbrook, C. (1997). Caring for elderly people at home: The consequences to caregivers. *Canadian Medical Association Journal, 157*(8), 1101-1105.
- Guba, E.G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Communication and Technology Journal, 29*(2), 75-91.
- Guba, E.G., & Lincoln, Y.S. (1982). Epistemological and methodological bases of naturalistic inquiry. *Educational Communication and Technology Journal, 30*(4), 233-252.
- Guba, E.G., & Lincoln, Y.S. (1994). Competing paradigms in qualitative research. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (pp.105-117). Thousand Oaks, CA: Sage.

- Hall, J., Kenny, P., Hossain, I., Street, D.J., & Knox, S.A. (2014). Providing informal care in terminal illness: An analysis of preferences for support using a discrete choice experiment. *Medical Decision Making*, 34(6), 731-745.
- Hansen, L., Cartwright, J., & Craig, C. (2012). End-of-life care for rural-dwelling older adults and their primary family caregivers. *Research in Gerontological Nursing*, 5(1), 6-15.
- Hansford, P., & Meehan, H. (2007). Gold standard framework: Improving community care. *End of Life Care*, 3, 56-61.
- Hassan, E. (2005). Recall bias can be a threat to retrospective and prospective research designs. *The Internet Journal of Epidemiology*, 3(2), 1-7.
- Hassan, F., Kernohan, W.G., McLaughlin, M., Waldron, M., McLaughlin, D., Chambers, H., & Cochrane, B. (2010). An exploration into the palliative and end-of-life experience of cares of people with Parkinson's disease. *Palliative Medicine*, 24(7), 731-6.
- Health Canada. (2015, July). *Unleashing Innovation: Excellent Healthcare for Canada*. Retrieved from <http://www.healthycanadians.gc.ca/publications/health-system-systeme-sante/report-healthcare-innovation-rapport-soins/alt/report-healthcare-innovation-rapport-soins-eng.pdf>
- Health Professions Regulatory Advisory Council. (2006, April). *Regulation of health professions in Ontario: New directions*. Retrieved from http://www.hprac.org/en/reports/resources/New_Directions_April_2006_EN.pdf
- Health Quality Ontario. (2016). *Palliative care report*. Retrieved from <http://www.hqontario.ca/Portals/0/documents/system-performance/palliative-care-report-en.pdf>
- Hearson, B., McClement, S., McMillan, D.E., & Harlos, M. (2011). Sleeping with one eye open: The sleep experience of family members providing palliative care at home. *Journal of Palliative Care*, 27(2), 69-78.

- Heaton, J. (2004). *Reworking Qualitative Data*. Thousand Oaks, CA: Sage.
- Heaton, J. (2008). Secondary analysis of qualitative data: An overview. *Historical Social Research, 33*, 333-45.
- Herber, O.R., & Johnson, B.M. (2013). The role of healthcare support workers in providing palliative and end-of-life care in the community: A systematic literature review. *Health & Social Care in the Community, 21*(3), 225-35.
- Holland, D.E., Vanderboom, C.E., Ingram, C.J., Dose, A.M., Borkenhagen, L.S., Skadahl, P., ...Bowles, K.H. (2014). The feasibility of using technology to enhance the transition of palliative care for rural patients. *Computers, Informatics, Nursing, 32*(6), 257-66.
- Hsieh, H.F., & Shannon, S.E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277-1288.
- Jo, S., Brazil, K., Lohfeld, L., & Willson, K. (2007). Caregiving at the end of life: Perspectives from spousal caregivers and care recipients. *Palliative & Supportive Care, 5*, 11-17.
- Jonsdottir, H., Litchfield, M., & Pharris, M.D. (2004). The relational core of nursing practice as partnership. *Journal of Advanced Nursing, 47*(3), 241-250.
- Kitchen, P., Williams, A., Pong, R.W., & Wilson, D. (2011). Socio-spatial patterns of home care use in Ontario, Canada: A case study. *Health & Place, 17*(1), 195-206.
- Knapp, E.R., & DelCampo, R.L. (1995). Developing family care plans: A systems perspective for helping hospice families. *American Journal of Hospice & Palliative Care, 12*, 39-47.
- Krieger, S. (1991). *Social science and the self: Personal essays on an art form*. New Brunswick, NJ: Rutgers University Press.

- Kristjanson, L., & Aoun, S. (2004). Palliative care for families: Remembering the hidden patients. *The Canadian Journal of Psychiatry*, 49(6), 359-65.
- Lauri, S., & Kyngas, H. (2005). *Developing Nursing Theories (Finnish: Hoitotieteen Teorian Kehittaminen)*. Werner Soderstrom, Dark Oy, Vantaa.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications.
- Linderholm, M., & Friedrichsen, M. (2010). A desire to be seen: Family caregivers' experiences of their caring role in palliative home care. *Cancer Nursing*, 33(1), 28-36.
- Magilvy, J.K., & Thomas, E. (2009). A first qualitative project: Qualitative descriptive design for novice researchers. *Journal for specialists in Pediatric Nursing*, 14(4), 298-300.
- Mahoney, D.F., Tarlow, B.J., & Jones, R.N. (2003). Effects of an automated telephone support system on caregiver burden and anxiety: Findings from the REACH for TLC intervention study. *The Gerontologist*, 43, 556-67.
- Maxwell, J.A. (1992) Understanding validity in qualitative research. *Harvard Educational Review*, 62, 273-300.
- Miller, J.D. (1982). Secondary analysis and science education research. *Journal of Research in Science Teaching*, 19(2), 712-725.
- Ministry of Finance. (2016). *Ontario population projections update, 2015-2041*. Retrieved from <http://www.fin.gov.on.ca/en/economy/demographics/projections/>
- Ministry of Health and Long-Term Care. (2015, March). *Bringing care home*. Retrieved from http://health.gov.on.ca/en/public/programs/ccac/docs/hcc_report.pdf
- Morse, J.M. (2000). Determining sample size. *Qualitative Health Research*, 10(1), 3-5.

- Nageswaran, S. (2009). Respite care for children with special health care needs. *Archives of Pediatrics & Adolescent Medicine*, 163, 49-54.
- Neff, J.M. (2009). Respite care: An essentially unmet need for families with children with special health care needs. *Archives of Pediatrics & Adolescent Medicine*, 163, 89-90.
- Office of the Auditor General of Ontario. (2015). *Annual report*. Retrieved from http://www.auditor.on.ca/en/content/annualreports/arreports/en15/2015AR_en_final.pdf
- Ontario Caregiver Coalition. (2018). *Caregiver allowance*. Retrieved from <http://www.ontariocaregivercoalition.ca/caregiver-allowance.html>
- Ontario Health Human Resources Research Network. (2015). *Task shifting in the provision of home and social care*. Retrieved from http://rorrhnsohhrn.ca/images/stories/docs/working%20paper%20series/wps_winter_2011_en.pdf
- Ontario Telemedicine Network. (2016). *Putting technology to work*. Retrieved from <https://otn.ca/putting-technology-work/>
- Perrino, T., Howe, G., Sperling, A., Beardslee, W., Sandler, I., Shern, D.,...Hendricks Brown, C. (2013). Advancing science through collaborative data sharing and synthesis. *Perspectives on Psychological Sciences*, 8, 433-444.
- Polit, D.E., & Beck, C.T. (2004). *Nursing Research. Principles and Methods*. Lippincott Williams & Wilkins, Philadelphia, PA.
- Ponterotto, J. (2005). Qualitative research in counseling psychology: A primer on research paradigms and philosophy of science. *Journal of Counselling Psychology*, 52(2), 126-136.
- Reed, J. (1992). Secondary data in nursing research. *Journal of Advanced Nursing*, 17(7), 877-883.

- Regan, S., & Donelle, L. (2015). Investigating the eShift model of palliative home care: Implications for planning, practice, and policy. Final report Year 1 findings. London, ON: Western University.
- Robinson, C.A., Bottorff, J.L., McFee, E., Bissell, L., & Fyles, G. (2016). Caring at home until death: Enabled determination. *Support Care Cancer*, 25(4), 1229-1236.
- Robinson, C.A., Pesut, B., & Bottorff, J.L. (2012). Supporting rural family palliative caregivers. *Journal of Family Nursing*, 18(4), 467-490.
- Royackers, A., Regan, S., & Donelle, L. (2015). The eShift model of care: informal caregivers' experience of a new model of home-based palliative care. *Progress in Palliative Care*, 24(2), 84-92.
- Ruggiano, N., & Perry, T.E. (2017). Conducting secondary analysis of qualitative data: Should we, can we, and how? *Qualitative Social Work*, 0(00), 1-17.
- Saba, V., & Erdley, W.S. (2006). Historical perspectives on nursing and the computer. In V. Saba, & K. McCormick (Eds.), *Essentials of nursing informatics*. New York: McGraw-Hill.
- Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing & Health*, 18, 179-183.
- Sandelowski, M. (2000). Focus on research methods: Whatever happened to qualitative description? *Research in Nursing & Health*, 23, 334-340.
- Sensory Technologies. (2017). *eShift International Research Collaborative*. Retrieved from <https://www.eshiftcare.com/research>
- Sinha, S.K., Griffin, B., Ringer, T., Reppas-Rindlisbacher, C., Steward, E., Wong, I., Callan, S., Anderson, G. (2016). An Evidence-Informed National Seniors Strategy for Canada – 2nd edition. Toronto, ON: Alliance for a National Senior Strategy.

- Smith, C.H., Graham, C.A., & Herbert, A.R. (2016). Respite needs of families receiving palliative care. *Journal of Paediatrics and Child Health*, 1-7.
- Stajduhar, K.I., Allan, D.E., Cohen, S.R., & Heyland, D.K. (2008). Preferences for location of death of seriously ill hospitalized patients: perspectives from Canadian patients and their family caregivers. *Palliative Medicine*, 22, 85-88.
- Stajduhar, K.I., & Davies, B. (2005) Variations in the factors influencing family members' decision for palliative home care. *Palliative Medicine*, 19, 21-32.
- Stajduhar, K.I., Funk, L., Toye C., Grande, G.E., Aoun, S., & Todd, C.J. (2010). Part 1: home-based family caregiving at the end of life: A comprehensive review of published quantitative research (1998-2008). *Palliative Medicine*, 24, 573-593.
- Statistics Canada. (2010, June). *Population projections for Canada, provinces and territories 2009 to 2036*. Retrieved from <http://www.statcan.gc.ca/pub/91-520-x/91-520-x2010001-eng.pdf>
- Sullivan-Boyai, S., Bova, C., & Harper, D. (2005). Developing and refining interventions in persons with health disparities: The use of qualitative description. *Nursing Outlook*, 53, 127-133.
- Szabo, V., & Strang, V.R. (1997). Secondary analysis of qualitative data. *Advances in Nursing Sciences*, 20, 66-74.
- Thorne, S. (1998). Ethical and representational issues in qualitative secondary analysis. *Qualitative Health Research*, 8(4), 547-555.
- Tracy, S.J. (2010). Qualitative quality: Eight 'big tent' criteria for excellent qualitative research. *Qualitative Inquiry*, 16(1), 837-851.
- Whitmore, K.E. (2016). The concept of respite care. *Nursing Forum*, 52(3), 180-187.
- Williams, A.M., Eby, J.A., Crooks, V.A., Stajduhar, K., Giesbrecht, M., Vuksan, M.,...Allan, D. (2011). Canada's compassionate care benefit: Is it an adequate

public health response to addressing the issue of caregiver burden in end-of-life care? *BMC Public Health*, 11, 1-15.

Williams, A.M., & Kelley, M.L. (2010). *A timeline of hospice palliative care policy and practice in Ontario, Canada*. Retrieved from http://www.virtualhospice.ca/Assets/HPC%20Evolution%20in%20Ontario_Report_April_2010_20120709110648.pdf

Williams, A.M., Kelley, M.L., Richards, J.L., & Whitfield, E.I. (2010). *A historical review of palliative care in Ontario*. Retrieved from http://www.palliative.mcmaster.ca/Projects/CAHSPR_Ontario.pdf

Wilson, D.M., Cohen, J., Deliens, L., Hewitt, J.A., & Houttekier, D. (2013). The preferred place of the last days: Results of a representative population-based public survey. *Journal of Palliative Medicine*, 16, 502-508.

Woodward, C., Abelson, J., & Hutchison, B. (2001, December). "My home is not my home anymore:" *Improving continuity of care in homecare*. Retrieved from http://www.chsrf.ca/Migrated/PDF/ResearchReports/OGC/woodward_final.pdf

Zou, P. (2016). Relational practice in nursing: A case analysis. *Nursing and Health Care*, 1(1), 9-13.

Chapter 3: Discussion and Implications for Practice, Research, Education and Policy

Overview of the Study

The purpose of this secondary data analysis was to understand the experiences family caregivers had of in-home respite while caring for a palliative family member receiving eShift palliative home care, at the end-of-life. The main question guiding the study was: “What are the experiences of family caregivers receiving in-home respite as part of a new technology-enabled model of palliative home care, called eShift, for individuals at the end-of-life?”. The secondary data was obtained from fifteen family caregivers from Southwestern, Ontario, who participated in *eShift Family/Friend Caregiver Survey and Interview*. The three themes that emerged from the data analysis were: *Developing trust; The opportunity for self-care and other activities; and The comprehensive arrangement of services*. Implications for nursing and personal support worker (PSW) practice, and education, future research, and public health care are discussed.

Nursing and PSW Practice

The findings from this study highlight the importance of providing high quality and relational care where trusting relationships developed between health care providers, patients, and family caregivers supports a positive experience of in-home respite (Hansen, Catwright, & Craig, 2012; Hearson, McClement, McMillan, & Harlos, 2011; Robinson, Bottorff, McFee, Bissell, & Fyles, 2016; Robinson, Pesut, & Bottorff, 2012). A study by Robison et al., (2016), demonstrated that when family caregivers do not trust health care providers’ ability to provide quality care, family caregivers could not get adequate rest and anxiety about their palliative family member was enhanced. Findings from the current study also reinforce the need for effective communication among health care providers and family caregivers (Browne, Macdonald, May, Macleod, & Mair, 2014; Hassan et al., 2010; Jo, Brazil, Lohfeld, & Willson, 2007) so that family caregivers feel they will be informed of their palliative family member’s progress (Browne et al., 2014) and subsequently have emotional relief. Moreover, the study supports the increased role that technology can play in the palliative home care context (Royackers, Regan, & Donelle, 2015), as this study has shown that enhanced in-home respite was facilitated via

the use of technology; the eShift technician and directing registered nurse (DRN) were able to address family caregivers questions (e.g., regarding medication administration) and concerns efficiently and in ‘real time’.

The findings also reinforce the importance of consistency with health care providers in the home setting as it facilitates the development of trust (Abelson, Gold, Woodward, O’Connor, & Hutchison, 2004; Gantert, McWilliam, Ward-Griffin, & Allen, 2009; Woodward, Abelson, & Hutchison, 2001), which improves family caregivers’ experience of in-home respite (Hearson et al., 2011). Finally, this study supports the importance of health care providers having the ability to provide drug administration throughout their shift, so that family caregivers can sleep without interruption.

Nursing and PSW Education

Researchers have suggested that information technology is quickly being infused into health care practice, however, its integration into health professional education has occurred at a much slower pace (Nagle & Clarke, 2004; Saba & Erdley, 2006). In the present study, the technology involved in the eShift model of palliative home care, supported the eShift technicians in regularly communicating about the progress of various palliative family members with the directing registered nurse (DRN), which was critical to in-home respite. For technology to be effective in supporting in-home respite, PSWs and nurses would benefit from enhanced education and training on information technology so that they are prepared and able to use it in practice (Desjardins, Cook, Jenkins, & Bakken, 2005; Fetter, 2009; Saba & Erdley, 2006). Of note, training in additional course content, distance learning and simulation have all been recommended to improve health care provider’s competency development in information technology (Fetter, 2009; Jensen, Kushniruk, & Nohr, 2015).

Furthermore, the present study highlights the importance of the emotional support that is a critical aspect of family caregivers in-home respite. Many family caregivers spoke of feeling emotionally supported by the eShift technicians and were comfortable talking to them at times of heightened distress. This finding reinforces the importance of relational care practice among health care professionals (Doane & Varcoe, 2007; Nageswaran, 2009; Neff, 2009; Whitmore, 2016). Further, it also demonstrates the importance of health care providers having a strong appreciation for the palliative family

member and family caregiver as a “unit of care” (Cain, MacLean, & Sellick, 2004; Clemmer, Ward-Griffin, & Forbes, 2008; Knapp & DelCampo, 1995; Linderhold & Friedrichsen, 2011), so that the health and emotional well-being of family caregivers remains an equal priority when health care providers are looking after a family caregiver’s palliative family member.

Future Research

To date, there has been a dearth of literature on in-home respite for family caregivers when caring for a palliative family member at the end-of-life and no articles have been found that specifically examined in-home respite in a technology-enhanced model of care. As such, this study was the first to examine the experiences of family caregivers receiving in-home respite with eShift palliative home care. However, further investigation is needed to better understand the ways women and men describe their experiences of in-home respite, the ways rural and urban family caregivers describe their experiences of in-home respite, the ways family caregivers with different cultural backgrounds describe their experiences of in-home respite, and the ways family caregivers living in and outside of the home describe their experiences of in-home respite. This research is pivotal as it will provide important information for health care providers and policy makers to be mindful of as well as improve the eShift model so that it is flexible and able to meet the in-home respite needs of family caregivers who have varied demographic characteristics (Sullivan-Bolyai et al., 2005). In addition, further research is warranted to determine if text messages, phone calls, and/or home monitoring improves the experience of in-home respite with eShift palliative home care, for family caregivers living outside of the home. Finally, more research is needed that looks at the extended periods (beyond an eight hour shift of care) of in-home respite with eShift palliative home care, to determine if it better supports caregivers to have relief to focus on work, volunteering and other leisure activities.

Public Health Policy

The results of this study have the potential to help policy makers make evidence-based decisions regarding in-home respite for family caregivers caring for a palliative family member at the end-of-life. The results of the present study illustrate that in-home respite with eShift palliative home care, supports family caregivers in keeping their

palliative family member at home until death, which is in alignment with Ontario's current policy direction that aims to put patients first "with the right care, at the right time, in the right place" (Ministry of Health and Long-Term Care [MOHLTC], 2015, p.1). Specifically, the MOHLTC believes that the right place for many Ontarians is in their home, as appropriate care in this setting can sustain or improve their quality of life, while reducing the financial burden to the health care system ([MOHLTC], 2015). The in-home respite that family caregivers' received with eShift palliative home care aligns with the government's policy direction as in enabled family caregivers to continue caring for their palliative family member at home until they died. In addition, policies that optimize the health of everyone in palliative end-of life context, including the palliative family members and family caregivers supports proactive rather than reactive health care practices (Clemmer et al., 2008). In-home respite that family caregivers received with eShift palliative home care is also aligned with the goals of the most recent *Canadian Caregiver Strategy*, which acknowledges that family caregivers require greater supports that enhance both their physical health and well-being (Canadian Caregiver Coalition, 2014). Of note, eShift palliative home care provided family caregivers with in-home respite so that they could sleep and it supported their well-being by providing them with emotional support so they were able to better manage the stress and worrying that often accompanies family caregiving at the end-of-life (Funk et al., 2010; Hearson et al., 2011; Stajduhar et al., 2010; Williams et al., 2011). Although family caregivers had a positive experience of the in-home respite provided with eShift, future policies need to be mindful of the multiple roles that family caregivers have (Cain et al., 2004; Clemmer et al., 2008), as family caregivers in the present study and other studies have brought attention to the need for increased opportunities for in-home respite (Aoun, Kristjanson, Hudson, Currow, & Rosenberg, 2005; Brazil et al., 2005) especially during the daytime (Cain et al., 2004; Hall, Kenny, Hossain, Street, & Knox, 2014; Robinson et al., 2016).

Conclusion

The purpose of study was to describe the experiences of family caregivers receiving in-home respite as part of a new technology-enabled model of palliative home care, called eShift, for individuals at the end-of-life. The findings have demonstrated that overall family caregivers had a positive experience of in-home respite with eShift, as they

developed trust with the eShift care team, had an opportunity for self-care and other activities, and felt that the arrangement of services was comprehensive, which enabled them to keep their palliative family member at home until death. Moreover, many family caregivers shared that extended access to eShift palliative home care would have been the preferred care model through the day and night as it would have provided them with more opportunities for in-home respite. Future research is needed to better understand the experiences of in-home respite with the eShift model of palliative home care by examining a variety of family caregivers' demographic factors including age, geographic location and gender.

References

- Abelson J., Gold, S.T., Woodward, C., O'Connor, D., & Hutchison, B. (2004). Managing under managed community care: The experiences of clients, providers and managers in Ontario's competitive home care sector. *Health Policy*, 68(3), 359-372.
- Aoun, S.M., Kristjanson, L.J., Hudson, P.L., Currow, D.C., & Rosenberg, J.P. (2005). The experience of supporting a dying relative: reflections of caregivers. *Progress in Palliative Care*, 13(6), 319-325.
- Brazil, K., Bedard, M., Krueger, P., Abernathy, T., Lohfeld, L., & Wilson, K. (2005). Service preferences among family caregivers of the terminally ill. *Journal of Palliative Medicine*, 8(1), 69-78.
- Browne, S., Macdonald, S., May, C.R., Macleod, U., & Mair, F.S. (2014). Patient, carer and professional perspectives on barriers and facilitators to quality care in advanced heart failure. *PLOS One*, 9(3), 93288.
- Cain, R., MacLean, M., & Sellick, S. (2004). Giving support and getting help: Informal caregivers' experiences with palliative care services. *Palliative and Supportive Care*, 2, 256-272.
- Canadian Caregiver Coalition. (2014, February). *A Canadian caregiver strategy: Are we making progress?* Retrieved from http://www.carerscanada.ca/wp-content/uploads/2015/09/Pan-Canadian-Family-Caregiver-2013_WEB-PAGES-2.pdf
- Clemmer, S.J., Ward-Griffin, C., & Forbes, D. (2008). Family members providing home-based palliative care to older adults: The enactment of multiple roles. *Canadian Journal on Aging*, 27, 267-283.
- Desjardins, K.S., Cook, S.S., Jenkins, M., Bakken, S. (2005). Effect of an informatics for evidence-based practice curriculum on nursing informatics competencies. *International Journal of Medical Informatics*, 74, 1012-1020.

- Doane, G.H., & Varcoe, C. (2007). Relational practice and nursing obligations. *Advances in Nursing Science*, 30(3), 192-205.
- Fetter, M.S. (2009). Baccalaureate nursing students' information technology competence – Agency perspective. *Journal of Professional Nursing*, 25(1), 42-49.
- Funk, L., Stajduhar, K.I., Toye C., Aoun, S., Grande, G.E., & Todd, C.J. (2010). Part 2: home-based family caregiving at the end of life: a comprehensive review of published quantitative research (1998-2008). *Palliative Medicine*, 24, 573-593.
- Gantert, T.W., McWilliam, C.L., Ward-Griffin, C., & Allen, N. (2009). Working it out together: Family caregivers' perceptions of relationship-building with in-home service providers. *Canadian Journal of Nursing Research*, 41(3), 44-63.
- Hall, J., Kenny, P., Hossain, I., Street, D.J., & Knox, S.A. (2014). Providing informal care in terminal illness: An analysis of preferences for support using a discrete choice experiment. *Medical Decision Making*, 34(6), 731-745.
- Hansen, L., Cartwright, J., & Craig, C. (2012). End-of-life care for rural-dwelling older adults and their primary family caregivers. *Research in Gerontological Nursing*, 5(1), 6-15.
- Hassan, F., Kernohan, W.G., McLaughlin, M., Waldron, M., McLaughlin, D., Chambers, H., & Cochrane, B. (2010). An exploration into the palliative and end-of-life experience of cares of people with Parkinson's disease. *Palliative Medicine*, 24(7), 731-6.
- Hearson, B., McClement, S., McMillan, D.E., & Harlos, M. (2011). Sleeping with one eye open: The sleep experience of family members providing palliative care at home. *Journal of Palliative Care*. 27(2), 69-78.
- Jensen, S., Kushniruk, A.W., & Nohr, C. (2015). Clinical simulation: A method for development and evaluation of clinical information systems. *Journal of Biomedical Informatics*, 54, 65-76.

- Jo, S., Brazil, K., Lohfeld, L., & Willson, K. (2007). Caregiving at the end of life: perspectives from spousal caregivers and care recipients. *Palliative & Supportive Care*, 5, 11-17.
- Knapp, E.R., & DelCampo, R.L. (1995). Developing family care plans: A systems perspective for helping hospice families. *American Journal of Hospice & Palliative Care*, 12, 39-47.
- Linderholm, M., & Friedrichsen, M. (2010). A desire to be seen: Family caregivers' experiences of their caring role in palliative home care. *Cancer Nursing*, 33(1), 28-36.
- Ministry of Health and Long-Term Care. (2015, March). *Bringing care home*. Retrieved from http://health.gov.on.ca/en/public/programs/ccac/docs/hcc_report.pdf
- Nageswaran, S. (2009). Respite care for children with special health care needs. *Archives of Pediatrics & Adolescent Medicine*, 163, 49-54.
- Neff, J.M. (2009). Respite care: An essentially unmet need for families with children with special health care needs. *Archives of Pediatrics & Adolescent Medicine*, 163, 89-90.
- Robinson, C.A., Bottorff, J.L., McFee, E., Bissell, L., & Fyles, G. (2016). Caring at home until death: enabled determination. *Support Care Cancer*, 25(4), 1229-1236.
- Robinson, C.A., Pesut, B., & Bottorff, J.L. (2012). Supporting rural family palliative caregivers. *Journal of Family Nursing*, 18(4), 467-490.
- Royackers, A., Regan, S., & Donelle, L. (2015). The eShift model of care: informal caregivers' experience of a new model of home-based palliative care. *Progress in Palliative Care*, 24(2), 84-92.
- Saba, V., & Erdley, W.S. (2006). Historical perspectives on nursing and the computer. In V. Saba, & K. McCormick (Eds.), *Essentials of nursing informatics*. New York: McGraw-Hill.

Stajduhar, K.I., Funk, L., Toyé C., Grande, G.E., Aoun, S., & Todd, C.J. (2010). Part 1: home-based family caregiving at the end of life: a comprehensive review of published quantitative research (1998-2008). *Palliative Medicine*, 24, 573-593.

Whitmore, K.E. (2016). The concept of respite care. *Nursing Forum*, 52(3), 180-187.

Williams, A.M., Eby, J.A., Crooks, V.A., Stajduhar, K., Giesbrecht, M., Vuksan, M., ... Allan, D. (2011). Canada's compassionate care benefit: Is it an adequate public health response to addressing the issue of caregiver burden in end-of-life care? *BMC Public Health*, 11, 1-15.

Woodward, C., Abelson, J., & Hutchison, B. (2001, December). "My home is not my home anymore:" *Improving continuity of care in homecare*. Retrieved from http://www.chsrf.ca/Migrated/PDF/ResearchReports/OGC/woodward_final.pdf

APPENDICES

Appendix A: The eShift Family/Friends Caregiver Survey and Interview

DRAFT INTERVIEW GUIDE – FAMILY CAREGIVER

Interviewer: Thank caregiver for their time. Provide overview of the study. Confirm consent form was signed and sent to the research coordinator. Reiterate that they do not need to answer a question if they are uncomfortable, they are welcome to ask you to restate the question or give an example if they don't understand.

Interviewer: *Do you have any questions before we get started?*

Interviewer: *I have to ask some basic questions about you and your [insert relationship] who was involved in eShift care. eShift care was provided in the last days or weeks of your [insert relationship]'s life. eShift included having a personal support worker coming into your home for extended periods of time such as overnight or all day to provide care to your [insert relationship]. The personal support worker was in contact through a smart phone to a nurse who was in constant contact with the personal support worker. Is that familiar to you?*

DEMOGRAPHICS

I am going to ask you some questions to help us understand more about you and your experience.

Interviewer note: 1. Sex Female ☐ Male ☐

2. Age _____ (years)

3. *Interviewer – ask this question only if the nature of the relationship was not known prior to the interview:* What was your relationship to the individual who received eShift? (e.g. spouse, partner, adult child)

4. When did your [insert relationship] pass away? _____ date

5. Describe your role as their caregiver? _____ (e.g. primary caregiver)

6. How long had you been caring for your [insert relationship] prior to receiving eShift care? _____ Months? Years? Since they became ill
7. How long did your [insert relationship] receive palliative care in the home before they passed away? # of _____ days _____ weeks _____ month(s)
8. How long did your [insert relationship] receive eShift care in the home before they passed away? # of _____ days _____ weeks _____ month(s)
9. How many hours per day of eShift care did your [insert relationship] receive? _____ # of hours
10. Was eShift care received mostly over night _____, during the day _____ or a mix of days and nights?
11. During your [insert relationship]'s palliative care experience, were you working outside the home? Please describe your working situation
_____ (e.g. full time? Hours at work?)
12. When caring for your [insert relationship] during their palliative experience, did you take a leave of absence or work less hours to be with them? Please describe _____

For the next questions I am going to ask that you reflect back on three points of time in your life. We are interested in understanding 1) your experiences in the days or weeks prior to eShift care when your [insert relationship] was palliative, 2) while receiving eShift care in those last days and weeks of your [insert relationship]'s life and 3) your present experience.

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| <i>SLEEP</i> (pre) | Prior to receiving eShift care but during your [insert relationship]'s palliative care experience, how would you rate your sleep quality? 1 = Very bad 2 = Fairly bad 3 = Fairly good 4 = Very good |
| <i>SLEEP</i> (during) | During the period when your [insert relationship] was <u>receiving eShift care</u> , how would you rate your sleep quality overall? 1 = Very bad 2 = Fairly bad 3 = Fairly good 4 = Very good |
| <i>SLEEP</i> (now) | How would you rate your sleep quality currently? 1 = Very bad 2 = Fairly bad 3 = Fairly good 4 = Very good |
| <i>SLEEP</i> *open ended* | During the period when your [insert relationship] was receiving eShift care, did having someone in your home help or hinder your sleep? (prompt – did having someone in the home at night help you sleep better?). Please explain. |

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| <i>Personal Medical/ Chronic Condition</i> | <p>While caring for your [insert relationship], were you also managing your own health issues? <i>Yes or No</i></p> <p>What were the main health concerns you were experiencing? (E.g. high blood pressure, diabetes, heart disease, etc) _____</p> |
| <i>Overall quality of health (pre)</i> | <p>We are interested in understanding your feeling of well-being. This may include emotional, social, and physical aspects of your life.</p> <p><u>Prior to receiving eShift care</u> but during your [insert relationship]'s palliative care experience, how would you have rated your overall health?</p> <p>1 = Poor 2 = Fair 3 = Good 4 = Very good 5 = Excellent</p> |

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|--|--|------------------|-----------------------|------------------|----------------|
| <i>Overall quality of health (during)</i> | <p><u>While receiving eShift care</u>, how would you have rated your overall health?</p> <p>1 = Poor 2 = Fair 3 = Good 4 = Very good 5 = Excellent</p> | | | | |
| <i>Overall quality of health (now)</i> | <p><u>Currently</u>, how would you rate your overall health?</p> <p>1 = Poor 2 = Fair 3 = Good 4 = Very good 5 = Excellent</p> | | | | |
| <p><i>STRESS/BURDEN (pre)</i></p> <p><i>Dumont, et al. 2008</i></p> <p><i>A new tool to assess family caregivers' burden during end-of-life care.</i></p> <p><i>Adapted*</i></p> | <p>I am going to ask about your experience both positive and difficult. The following questions are designed to help us understand the types of difficulties and challenges you faced as a caregiver.</p> <p><u>Prior to receiving eShift care but during your [insert relationship]'s palliative care experience</u>, how would you rate the following statements?</p> <table border="1" data-bbox="558 972 1588 1058"> <tr> <td>1 = Never</td> <td>2 = From time to time</td> <td>3 = Fairly often</td> <td>4 = Very often</td> </tr> </table> <ol style="list-style-type: none"> 1. Did you ever find that the tasks required in caring for your [insert relationship] demanding? 1 2 3 4 2. Did you feel unable to continue with your caregiving role at the time? 1 2 3 4 3. Did you feel overwhelmed by everything that was happening to you? 1 2 3 4 4. Did you feel prepared and able to provide the necessary care for your [insert relationship]? 1 2 3 4 5. Did you ever feel discouraged by all the tasks you had to accomplish? 1 2 3 4 6. Did you ever think that caregiving was too demanding of an experience for you? 1 2 3 4 7. Did you ever have the feeling that you had lost control over your life? 1 2 3 4 8. Did you feel emotionally drained? 1 2 3 4 | 1 = Never | 2 = From time to time | 3 = Fairly often | 4 = Very often |
| 1 = Never | 2 = From time to time | 3 = Fairly often | 4 = Very often | | |
| <p><i>STRESS/BURDEN (during)</i></p> <p><i>Dumont, et al. 2008</i></p> | <p><u>While receiving eShift care</u>, how would you rate the following statements?</p> <table border="1" data-bbox="558 1766 1588 1852"> <tr> <td>1 = Never</td> <td>2 = From time to time</td> <td>3 = Fairly often</td> <td>4 = Very often</td> </tr> </table> | 1 = Never | 2 = From time to time | 3 = Fairly often | 4 = Very often |
| 1 = Never | 2 = From time to time | 3 = Fairly often | 4 = Very often | | |

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| <p><i>A new tool to assess family caregivers' burden during end-of-life care.</i></p> <p><i>Adapted*</i></p> | <div><div><div>1.</div><div>Did you ever find that the tasks required in caring for your [insert relationship] demanding?</div><div>1234</div></div><div><div>2.</div><div>Did you feel unable to continue with your caregiving role at the time?</div><div>1234</div></div><div><div>3.</div><div>Did you feel overwhelmed by everything that was happening to you?</div><div>1234</div></div><div><div>4.</div><div>Did you feel prepared and able to provide the necessary care for your [insert relationship]?</div><div>1234</div></div><div><div>5.</div><div>Did you ever feel discouraged by all the tasks you had to accomplish?</div><div>1234</div></div><div><div>6.</div><div>Did you ever think that caregiving was too demanding of an experience for you?</div><div>1234</div></div><div><div>7.</div><div>Did you ever have the feeling that you had lost control over your life?</div><div>1234</div></div><div><div>8.</div><div>Did you feel emotionally drained?</div><div>1234</div></div></div> |
| <p><i>POSITIVE ASPECTS OF CAREGIVING</i></p> <p><i>Tarlow et al., 2004.</i></p> <p><i>Positive Aspects of Caregiving</i></p> | <div><div>Some caregivers say that, despite all the difficulties involved in giving care to a family member with memory or health problems, good things have come out of their caregiving experience too. I'm going to go over a few of the good things reported by some caregivers.</div><div>I would like you to tell me how much you agree or disagree with these statements.</div><div>Providing help to (insert relationship) has....</div><div>1- Disagree a lot, 2 – Disagree a little, 3 – neither agree or disagree, 4 – agree a little, 5 – agree a lot</div><div><div><div>1 = Disagree a lot</div><div>2 = Disagree a little</div><div>3 = Neither agree or disagree</div><div>4 = Agree a little</div><div>5 = Agree a lot</div></div></div><div><div><div>1.</div><div>Made me feel more useful</div><div>12345</div></div><div><div>2.</div><div>Made me feel good about myself</div><div>12345</div></div><div><div>3.</div><div>Made me feel needed</div><div>12345</div></div></div></div> |

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|--|---|---|---|---|---|---|
| | 4. Made me feel appreciated | 1 | 2 | 3 | 4 | 5 |
| | 5. Made me feel important | 1 | 2 | 3 | 4 | 5 |
| | 6. Made me feel strong and confident | 1 | 2 | 3 | 4 | 5 |
| | 7. Enabled me to appreciate life more | 1 | 2 | 3 | 4 | 5 |
| | 8. Enabled me to develop a more positive attitude toward life | 1 | 2 | 3 | 4 | 5 |
| | 9. Strengthened my relationships with others | 1 | 2 | 3 | 4 | 5 |

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| <div>PRESENTISM</div> <div>(pre)</div> <div>Stanford</div> <div>Presentism Scale</div> <div>(Merck, et al.,</div> <div>2001)</div> | <div>We are interested in understanding how caregiving for your [insert relationship] impacted your work. By work we mean paid employment or volunteer activities that you carried regularly. At the time that your [insert relationship] was receiving palliative care did you have paid employment or volunteer activities that you carried regularly? Yes_____ No _____</div> <div>(Interviewer: if the individual is retired or was not working prior to eShift care, skip these questions).</div> | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| | <div>Reflecting back to <u>just prior to receiving eShift care</u> for your [insert relationship], please describe <i>your</i> work experience at that time.</div> | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| | <table><tr><td>1 = Strongly Disagree</td><td>2 = Somewhat Disagree</td><td>3 = Uncertain</td><td>4 = Somewhat Agree</td><td>5 = Strongly Agree</td></tr></table> | 1 = Strongly Disagree | 2 = Somewhat Disagree | 3 = Uncertain | 4 = Somewhat Agree | 5 = Strongly Agree | | | | | | | | | | | | | | | | | | | | | | |
| | 1 = Strongly Disagree | 2 = Somewhat Disagree | 3 = Uncertain | 4 = Somewhat Agree | 5 = Strongly Agree | | | | | | | | | | | | | | | | | | | | | | | |
| <table><tr><td>1.</td><td>Because of my [insert relationship]’s needs, the stresses of my work were much harder to handle.</td><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td></tr><tr><td>2.</td><td>Despite having my [insert relationship]’s needs, I was able to finish hard tasks in my work.</td><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td></tr><tr><td>3.</td><td>My [insert relationship]’s needs distracted me from taking pleasure in my work.</td><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td></tr><tr><td>4.</td><td>I felt hopeless about finishing certain work tasks, due to my [insert relationship]’s needs.</td><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td></tr></table> | 1. | Because of my [insert relationship]’s needs, the stresses of my work were much harder to handle. | 1 | 2 | 3 | 4 | 5 | 2. | Despite having my [insert relationship]’s needs, I was able to finish hard tasks in my work. | 1 | 2 | 3 | 4 | 5 | 3. | My [insert relationship]’s needs distracted me from taking pleasure in my work. | 1 | 2 | 3 | 4 | 5 | 4. | I felt hopeless about finishing certain work tasks, due to my [insert relationship]’s needs. | 1 | 2 | 3 | 4 | 5 |
| 1. | Because of my [insert relationship]’s needs, the stresses of my work were much harder to handle. | 1 | 2 | 3 | 4 | 5 | | | | | | | | | | | | | | | | | | | | | | |
| 2. | Despite having my [insert relationship]’s needs, I was able to finish hard tasks in my work. | 1 | 2 | 3 | 4 | 5 | | | | | | | | | | | | | | | | | | | | | | |
| 3. | My [insert relationship]’s needs distracted me from taking pleasure in my work. | 1 | 2 | 3 | 4 | 5 | | | | | | | | | | | | | | | | | | | | | | |
| 4. | I felt hopeless about finishing certain work tasks, due to my [insert relationship]’s needs. | 1 | 2 | 3 | 4 | 5 | | | | | | | | | | | | | | | | | | | | | | |

| | <p>5. At work, I was able to focus on achieving my goals despite my [insert relationship]'s needs. 1 2 3 4 5</p> <p>6. Despite having my [insert relationship]'s needs, I felt energetic enough to complete all my work. 1 2 3 4 5</p> | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
|--|---|--------------------------|-----------------------------|-----------------------|--------------------------|-----------------------|---|--|--|--|-----------|---|--|--|--|-----------|--|--|--|--|-----------|---|--|--|--|-----------|---|--|--|--|-----------|--|--|--|--|-----------|
| <p><i>PRESENTISM</i> (during)</p> <p>Stanford Presentism Scale (Merck, et al., 2001)</p> | <p><u>While receiving eShift care</u> for your [insert relationship], please describe <i>your</i> work experience at that time:</p> <table border="1"> <thead> <tr> <th data-bbox="553 495 812 688">1 = Strongly Disagree</th> <th data-bbox="812 495 1029 688">2 = Somewhat Disagree</th> <th data-bbox="1029 495 1218 688">3 = Uncertain</th> <th data-bbox="1218 495 1406 688">4 = Somewhat Agree</th> <th data-bbox="1406 495 1624 688">5 = Strongly Agree</th> </tr> </thead> <tbody> <tr> <td data-bbox="553 688 812 772">1. Because of my [insert relationship]'s needs, the stresses of my work were much harder to handle.</td> <td data-bbox="812 688 1029 772"></td> <td data-bbox="1029 688 1218 772"></td> <td data-bbox="1218 688 1406 772"></td> <td data-bbox="1406 688 1624 772">1 2 3 4 5</td> </tr> <tr> <td data-bbox="553 772 812 856">2. Despite having my [insert relationship]'s needs, I was able to finish hard tasks in my work.</td> <td data-bbox="812 772 1029 856"></td> <td data-bbox="1029 772 1218 856"></td> <td data-bbox="1218 772 1406 856"></td> <td data-bbox="1406 772 1624 856">1 2 3 4 5</td> </tr> <tr> <td data-bbox="553 856 812 940">3. My [insert relationship]'s needs distracted me from taking pleasure in my work.</td> <td data-bbox="812 856 1029 940"></td> <td data-bbox="1029 856 1218 940"></td> <td data-bbox="1218 856 1406 940"></td> <td data-bbox="1406 856 1624 940">1 2 3 4 5</td> </tr> <tr> <td data-bbox="553 940 812 1024">4. I felt hopeless about finishing certain work tasks, due to my [insert relationship]'s needs.</td> <td data-bbox="812 940 1029 1024"></td> <td data-bbox="1029 940 1218 1024"></td> <td data-bbox="1218 940 1406 1024"></td> <td data-bbox="1406 940 1624 1024">1 2 3 4 5</td> </tr> <tr> <td data-bbox="553 1024 812 1108">5. At work, I was able to focus on achieving my goals despite my [insert relationship]'s needs.</td> <td data-bbox="812 1024 1029 1108"></td> <td data-bbox="1029 1024 1218 1108"></td> <td data-bbox="1218 1024 1406 1108"></td> <td data-bbox="1406 1024 1624 1108">1 2 3 4 5</td> </tr> <tr> <td data-bbox="553 1108 812 1161">6. Despite having my [insert relationship]'s needs, I felt energetic enough to complete all my work.</td> <td data-bbox="812 1108 1029 1161"></td> <td data-bbox="1029 1108 1218 1161"></td> <td data-bbox="1218 1108 1406 1161"></td> <td data-bbox="1406 1108 1624 1161">1 2 3 4 5</td> </tr> </tbody> </table> | 1 = Strongly Disagree | 2 = Somewhat Disagree | 3 = Uncertain | 4 = Somewhat Agree | 5 = Strongly Agree | 1. Because of my [insert relationship]'s needs, the stresses of my work were much harder to handle. | | | | 1 2 3 4 5 | 2. Despite having my [insert relationship]'s needs, I was able to finish hard tasks in my work. | | | | 1 2 3 4 5 | 3. My [insert relationship]'s needs distracted me from taking pleasure in my work. | | | | 1 2 3 4 5 | 4. I felt hopeless about finishing certain work tasks, due to my [insert relationship]'s needs. | | | | 1 2 3 4 5 | 5. At work, I was able to focus on achieving my goals despite my [insert relationship]'s needs. | | | | 1 2 3 4 5 | 6. Despite having my [insert relationship]'s needs, I felt energetic enough to complete all my work. | | | | 1 2 3 4 5 |
| 1 = Strongly Disagree | 2 = Somewhat Disagree | 3 = Uncertain | 4 = Somewhat Agree | 5 = Strongly Agree | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
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| <p><i>ECONOMIC</i></p> | <p>Reflecting back to when your [insert relationship] was receiving eShift care in the home:</p> <p>Did you have to call 911 for an emergency during eShift? Yes or No? _____</p> <p>If yes, please explain _____ Cannot Recall.</p> <p>Number of times: _____ Cannot Recall.</p> <p>Did your [insert relationship] have to travel by ambulance to the hospital while receiving eShift care? Yes or no? _____</p> <p>Number of times: _____ Cannot Recall.</p> <p>Was your [insert relationship] admitted to hospital while receiving eShift care? Yes or No? _____</p> <p>Number of Times: Cannot Recall. _____</p> | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |

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| | <p>Did you have an unanticipated end to eShift care to transfer your [insert relationship] to another care facility to die? Yes or no ____ . If yes, please describe (E.g. retirement home, nursing home, hospital, and hospice). Cannot Recall.</p> <p>Did your [insert relationship] see a family physician while receiving eShift care? (please circle: at the house or in office)? Yes or No? Number of times: ____ Cannot Recall.</p> <p>Did your [insert relationship] see a nurse practitioner while receiving care with eShift? Yes or No? Number of times: ____ Cannot Recall.</p> <p>Did your [insert relationship] receive any other health services at home? Yes or No. Please explain Cannot Recall</p> <p>Did your [insert relationship] receive health services that required them to leave their home for appointment? Yes or No. Please explain Cannot recall</p> <p>Were there any social services your [insert relationship] received while receiving eShift care? For example bereavement counsellor, meals on wheels, Yes or No, please explain Cannot recall</p> <p>Were there any additional out of pocket expenses by having your [insert relationship] at home to die? (E.g. paying for prescriptions, equipment, services) Please describe ____</p> <p>Did you have support from others (E.g. friends or family members) Financial? Personal? Social? E.g. Support network during this time.</p> <p>Can you speculate as to the potential costs of health care for [insert relationship] if you had not been able to received eShift care in the home?</p> <p>Can you speculate as to the potential impact on [insert relationship] being able to die at home if you had not been able to received eShift care in the home?</p> |
| <p><i>Overall quality of eShift care</i></p> | <p>In general, how would you describe the quality of the care your [insert relationship] received while being provided with eShift care?</p> <p>1 = Poor 2 = Fair 3 = Good 4 = Very good 5 = Excellent</p> |

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| <p><i>eShift Developed Questions</i></p> <p><i>(questions also appearing on healthcare provider survey – adopted for caregiver)</i></p> | <p>While receiving eShift care, please indicate how much you agree or disagree with the following statements.</p> <p>1 = Strongly Disagree 5 = Strongly Agree</p> <ol style="list-style-type: none"> 1. I established a positive relationship with the care technician/ personal support worker? 2. I established a positive relationship with the directing registered nurse? 3. I established a positive relationship with the visiting nurse? 4. I established a positive relationship with the care coordinators? 5. My [insert relationship] received care in a timely manner. 6. I received support in a timely manner. 7. My [insert relationship] received sufficient hours of care to meet their needs? 8. I would have benefited from access to the eShift online portal to access my [insert relationship]’s information <p>As a result of the eShift model of care:</p> <ol style="list-style-type: none"> 9. My [insert relationship]’s pain was well managed. 10. My [insert relationship] was able to die in their place of choice. 11. I felt confident in my knowledge and understanding about the dying process. 12. I was able to get the sleep I needed. 13. I was able to get the support I needed. 14. I was better able to manage emergency situations involving my [insert relationship]’s palliative care. 15. I felt part of the care team involved with my [insert relationship]’s care. |
|---|--|

We are interested in understanding your experiences with eShift and the care that was provided to you and your [insert relationship].

1. Can you tell me how you came to hear about eShift care? Who informed you about the program? What sort of information were you given? (e.g. information provided by care coordinator?)
2. eShift care is typically provided when patients want to die at home. What was your understanding as to why you and your [insert relationship] were getting eShift care? (E.g. who wanted eShift?)
3. Can you describe how you looked after your [insert relationship] at home while they were dying? How did this change as a result of receiving eShift care?

4. eShift care includes nurses visiting your home for short periods of time, nurses at distance, Care Technicians/Personal Support Workers and others. Please tell us about your experience interacting with these healthcare providers 1) Care Technicians/Personal Support Workers; 2) Directing Registered Nurses; 3) Visiting Nurses; 4) Others.
5. What was your initial reaction to having eShift in the home?
6. What were your initial expectations (if any) regarding the care your [insert relationship] would receive with eShift? Were those expectations met? Why or why not?
7. In your experience, what were some of the benefits of eShift care? What could be improved?
8. Is there anything else you would like to tell us about your experience with the eShift model of care?
9. Or any other aspects of the palliative care experience? What has this been like for them? Other family members? Work?

Appendix B: Recruitment Script

Draft Information and Telephone Script for Care Coordinator to Discuss Research Program with Family Caregiver

Project Title: Investigating the eShift model of palliative home care: Implications for planning, practice, and policy.

Principal Investigators:

Sandra Regan, PhD, RN, Associate Professor, School of Nursing, Western University

Lorie Donelle, PhD, RN, Associate Professor, School of Nursing, Western University

Care Coordinators,

This script can be used by SW CCAC Care Coordinators for telephone communication with potential participants for the eShift Study. We are looking for family caregivers of patients who received care through the eShift model in the SW CCAC. Patients will have died at **least three months ago and no more than one year ago**. A caregiver must be over 18 years of age and can be a spouse, partner, child, sibling, other family relation or friend who helped care for the patient as they passed away (preferably a caregiver who lived in the same home as patient). The caregiver must be able to speak, understand and read English.

If you have any questions about the study including recruitment and inclusion criteria, you can reach Sandra Regan.

Script for Care Coordinator Telephone Recruitment of Family Caregivers:

Hello _____,

This is [insert name] from the South West Community Care Access Centre. I am calling you to tell you about a study being conducted to evaluate the eShift model of palliative home care provided by our organization. Your [insert relationship] would have received eShift care approximately [insert time period when eShift care was provided] ago. The study is being conducted by researchers from Western University in London Ontario. The study will focus on family members and will explore your family's experiences receiving care with the eShift model. The researchers would like to interview you for 60-90 minutes, at a time and at a place that is convenient for you, such as your home or over the telephone. If you are interested in participating in this study, I can give you the phone number to call to get more information about the study. Would you prefer that I email you the phone number?

Thank-you for your time.

Appendix C: Research Ethics Board Approval



**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 Date noted above.

HSREB approval for this study remains valid until the HSREB Expiry Date noted above, conditional to timely submission and acceptance of HSREB Continuing Ethics Review. If an Updated Approval Notice is required prior to the HSREB Expiry Date, the Principal Investigator is responsible for completing and submitting 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), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice (ICH E6 R1), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical 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 they are 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

| | | | |
|---------------------------------------|---|---------------------------------------|-------------------------------------|
| <input type="checkbox"/> Erika Basile | <input checked="" type="checkbox"/> Grace Kelly | <input type="checkbox"/> Mina Mekhail | <input type="checkbox"/> Vikki Tran |
|---------------------------------------|---|---------------------------------------|-------------------------------------|

This is an official document. Please retain the original in your files.

Appendix D: Letter of Information and Consent Form



Regan & Donelle
UWO Ethics # 105350

Project Title: Investigating the eShift model of palliative home care: Implications for planning, practice, and policy.

Principal Investigators:

Sandra Regan, PhD, RN, Associate Professor, School of Nursing, Western University. Phone

Lorie Donelle, PhD, RN, Associate Professor, School of Nursing, Western University. Phone

Letter of Information

1. Invitation to Participate

You are being invited to participate in a research study designed to explore what it is like for family caregivers who have lived with and cared for a family member who received palliative care as part of the eShift model of palliative home care. This letter will provide you with the information you require to make an informed decision on participating in this research study. Please take the time to read this carefully and feel free to ask questions if anything is unclear or there are words or phrases you do not understand.

2. Purpose of the Letter

The purpose of this letter is to provide you with information required for you to make an informed decision regarding participation in this study.

3. Purpose of this Study

The purpose of this study is to understand the eShift model of palliative home care. We are interviewing 25-30 family caregivers about their experiences with the eShift model. These interviews will help us understand your experiences with the eShift model of palliative home care, the benefits of the model, and potential improvements in care that could be made.

4. Inclusion Criteria

To participate in this study, you must be over the age of 18 and able to read, write and speak English. You must have had a family who received palliative care through the eShift model in the South West Community Care Access Centre and who passed away a minimum of three months ago and up to one year ago. A caregiver can be a spouse, partner, child, sibling, other family relation or friend who helped care for the patient when they received palliative home care.

5. Exclusion Criteria

Individuals who are not caregivers of a family member who received palliative care as part of the eShift model are not eligible for this study.

6. Study Procedures

If you agree to participate, you will be asked to participate in an individual audio-taped interview. The interview includes questions about your experience as a caregiver as well as some of the benefits of eShift care including the impact of caregiving on your well-being. Audio-recording of the interview is required and if you do not wish the interview to be recorded, you should not participate in this study. It is anticipated that the interview will take about 60-90 minutes of your time. The interview(s) will take place at a location where you feel most comfortable such as your home or work place. The interview(s) can be done in person or over the telephone.



Regan & Donelle
UWO Ethics # 105350

7. Possible Risks and Harms

There are no known or anticipated risks associated with participating in this study. However, discussion of your recent experience may bring up feelings of bereavement. A list of bereavement services available in South West Ontario, that are free of charge, will be provided to you.

8. Possible Benefits

You may not directly benefit from participating in this study but information gathered may provide benefits to society as a whole which include information that may be beneficial to family caregivers and those receiving palliative care in the home setting. Information from the interviews will be shared with people who make decisions about home care service delivery and will be used to develop other studies of home care service delivery. The information you provide may assist those decision-makers to enhance home care services for others.

9. Compensation

You will be compensated with a \$20.00 gift card for your participation in this study.

10. Voluntary Participation

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time.

11. Confidentiality

For the publishing of this study, your name will be changed to a pseudonym and no identifying information will be linked to the data for the purpose of anonymity. During the audio-recorded interviews you are asked to refrain from disclosing information that will identify you or others. Should any identifying information be disclosed during the interview, it will not be included in the transcript. All data will be stored in a locked cabinet in Dr. Sandra Regan's research office at Western University, data will only be accessed by members of the research team, and computer files will be password protected and encrypted. Representatives of The University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research. Non-identifiable data will be kept for a minimum of 5 years after the study is completed for potential future secondary analysis and will then be shredded and destroyed to maintain confidentiality. If you choose to withdraw from this study, your data will be removed and destroyed from our database. You do not waive any legal rights by signing the consent form.

12. Contacts for Further Information

If you require any further information regarding this research project or your participation in the study you may contact Dr. Sandra Regan, at _____ or Dr. Lorie Donelle at _____

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Research Ethics at _____

13. Publication

If the results of the study are published, your name will not be used. If you would like to receive a copy of any potential study results, please contact Dr. Sandra Regan, at _____ or Dr. Lorie Donelle at _____

14. Consent

A Consent Form will be provided for you to sign prior to the interview. *This letter is yours to keep for future reference.*



Regan & Donelle
UWO Ethics # 105350

Consent Form

Project Title: Investigating the eShift model of palliative home care: Implications for planning, practice, and policy.

Study Investigator's Name:

Sandra Regan, PhD, RN, Associate Professor, School of Nursing, Western University.

Lorie Donelle, PhD, RN, Associate Professor, School of Nursing, Western University.

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

I consent to this interview being audio recorded ☐

Participant's Name (please print): _____

Participant's Signature: _____

Date: _____

Person obtaining informed consent (please print): _____

Signature: _____

Date: _____

Curriculum Vitae

| | |
|--|---|
| Name: | Ann Marie Corrado |
| Post-secondary Education and Degrees: | <p>The University of Western Ontario London, Ontario, Canada 2016-2018 MSc.</p> <p>The University of Western Ontario London, Ontario, Canada 2012-2016 HBS.</p> |
| Honours and Awards: | <p>AGE-WELL Visions for Change Policy Challenge (2018)</p> <p>Western Graduate Research Scholarship (2016-2018)</p> <p>AGE-WELL Summer Institute Recognition (2017)</p> <p>Best Oral Presentation at the HRS Research Conference (2017)</p> <p>The Brian Innes Health Sciences Award (2015)</p> <p>Central Ontario Leadership Seminar Eileen Krieger Scholarship (2012)</p> <p>The Western Scholarship of Excellence (2012)</p> |
| Related Work Experience: | <p>Research Assistant, School of Occupational Therapy The University of Western Ontario 2017-2018</p> <p>Research Assistant, Arthur Labatt Family School of Nursing The University of Western Ontario 2016-2017</p> <p>Teaching Assistant, School of Health Studies The University of Western Ontario 2016-2016</p> |

Accepted Manuscripts:

- 1) McGrath, C., & Corrado, A.M. (2018). The environmental factors that influence technology adoption for older adults with age-related vision loss. *British Journal of Occupational Therapy*.

- 2) Benjamin-Thomas, T., **Corrado, A.M.**, McGrath, C., Hand, C., & Laliberte Rudman, D. (2018). Working towards the promise of participatory action research: Learning from ageing research exemplars. *Journal of Qualitative Methods*.

Submitted Manuscripts (Under Review):

- 3) McGrath, C., & **Corrado, A.M.** (2017). Adaptations to support occupational engagement with age-related vision loss: A metasynthesis study. *Canadian Journal of Occupational Therapy*.