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The eShift Model of Care: Informal Caregivers' Experience of Caring for a Family Member who Received Palliative Care at Home

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THE eSHIFT MODEL OF CARE: INFORMAL CAREGIVERS' EXPERIENCE OF CARING FOR A FAMILY MEMBER WHO RECEIVED PALLIATIVE CARE AT HOME

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ABSTRACT

Amidst concerns about the capacity to meet the care needs of community dwelling clients, the South West Community Care Access Centre in London, Ontario piloted a new model of home care delivery to palliative care clients. The purpose of this interpretive description study was to describe the experiences of informal caregivers who have lived with and cared for a family member who received palliative care as part of the eShift model of home care. In this study, eight participants were purposively sampled and narrative data were collected through individual, audio-taped interviews using a semi-structured interview guide. The analysis and interpretation of the interviews revealed four main themes. The main themes include: *The Health Care Family; Making the Invisible Visible; There's No Place Like Home; and Burden of Love.* Overall, informal caregivers indicated they were very satisfied with care delivery, felt supported by health care providers, and were able to support their family member to die at home. Findings from this study contribute a greater understanding to what is known about informally caring for a family member who is receiving eShift palliative home care. This study offers implications regarding the use of technology and health human resources for nursing practice, education, research and future policy development in the home care sector.

Keywords: informal caregivers, home care, palliative care, health human resources, health information technology, eShift model of care

CO-AUTHORSHIP

Ashley Ralph completed the following work under the supervision of Dr. Sandra Regan and Dr. Lorie Donelle. Both members contributed to the work through their advisement on the conduct of the investigation, peer review of the interpretive analysis of the findings, and the content, cogency, and clarity of the writing.

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Chapter One - Introduction

Across Canada, provinces are facing health human resources challenges and it is predicted that without modification to the current situation, the demand for health services in the community will soon exceed the supply of human resources (Canadian Home Care Association, 2008a; Keefe, Knight, Martin-Matthews, & Legare, 2011; Underwood et al., 2009). In Canada, the number of older adults is increasing with many wishing to age at home (Canadian Home Care Association, 2008a; Canadian Hospice Palliative Care Association, 2008; Keefe et al., 2011). It is estimated that approximately 70 to 75 percent of care provided to support older adults to remain in their home is provided by a family member (Canadian Institute for Health Information [CIHI], 2010; Dunbrack, 2005; Health Council of Canada, 2012; Statistics Canada, 2002).

Home-based palliative care has become a significant trend in Canada and current end-of-life research suggests that Canadians prefer to die at home rather than in a hospital setting (CIHI, 2007). The impact of this trend is considerable given the predicted 33% increase in all cause mortality in Canada by the year 2020, resulting in 330,000 deaths per year (Statistics Canada, 2004). When clients choose to receive palliative care at home, family members may take on significant caregiver roles/duties that places them at risk for negative health outcomes (Hudson, Aranda, & Kristjanson, 2004; Linderholm & Friedrichson, 2010). Most informal caregivers require information and support from health providers to meet their own personal care needs and those of the family member they are caring for (Lefebvre, Levert, Pelchat, & Lepage, 2008). To effectively address these needs, health care providers’ roles are being re-envisioned using innovative initiatives, involving health information technology, to enhance home care service delivery and the quality of life for informal caregivers and clients at end-of-life (Canadian Home Care Association, 2008b; Russell, Rosenfeld, Ames, & Rosati, 2010). Without the development and implementation of new service delivery models in the home and community sectors of the health care system, there is a risk of a substantial escalation in the number of exhausted caregivers and unavoidable health care crises (Hudson et al., 2004; Linderholm & Friedrichsen, 2010; Ontario Home Care Association, 2010).

Background and Significance

Home Care

With the increased number of aging Ontarians, the closure of many acute care hospital beds, and aging clients' preference to receive care at home, transitioning care from hospital to home requires an increase in resource(s) to meet the unique care needs of Ontarians (Ministry of Health and Long-term Care [MOHLTC], 2012). Yet, while hospital and physician services are a universal entitlement under the Canada Health Act (CHA), home care services are considered an "extended health service" and therefore the standards and scope of entitlement of services falls under the mandate of individual provinces and territories (Canadian Home Care Association, 2008a; Duncan & Reutter, 2006). Significant reallocation of health care spending to the home and community health sector will allow more care to take place in the home and will support the promotion of Canadians' health, need for autonomy, control over decision-making, and independence (Krothe, 1997; Ontario Home Care Association, 2010).

Health Human Resources

The changing context and escalating demands in health care that impact the home and community care sector continue to emerge (Grissom, 2009; O'Brien-Pallas & Baumann, 2000; Victorian Order of Nurses (VON), 2005). A current and projected shortage of health human resources (HHRs), particularly registered nurses (RNs), increasingly creates challenges to deliver health care services (Canadian Home Care Association, 2003; Ellenbecker, Porell, Samia, Byleckie, & Milburn, 2008; VON, 2005). Increased dissatisfaction in the home care sector, caused by stress, burnout, increased work demands, and restructuring of the home care sector to control costs, has made it difficult to recruit and retain nurses (Ellenbecker et al., 2008; VON, 2005). Canada is facing a chronic shortage of trained health care workers and at the same time, the demand for health care services, in part related to the aging population, is rising (Ellenbecker et al., 2008; Keefe et al., 2011; World Health Organization (WHO), 2008). Service delivery models that innovatively and appropriately utilize HHRs, including regulated and unregulated health care providers, are suggested as one means of addressing this shortage (Canadian Health Services Research Foundation, 2006; WHO, 2008).

The terms unregulated care providers (UCPs) and unregulated health workers (UHWs) are used to describe health care providers (e.g., personal support workers (PSWs); home support workers (HSWs); health-care aides) who are not licensed or regulated by a professional, regulatory, or governmental body (Canadian Nurses Association, 2008; Pyper, 2004). In Canada, UCPs assist health professionals to provide care to clients in a number of different settings, including hospitals, long-term care facilities, rehabilitation clinics, and home or community care (Canadian Nurses

Association, 2008). Currently, UCPs are educated through formal education programs and through on-the-job training and experience (Canadian Nurses Association, 2008). UCPs form the largest class of workers in the community and home care sector (Keefe et al., 2011; Ontario Home Care Association, 2007).

UCPs have numerous position titles, work in a variety of settings, and provide clearly identified paid, non-professional services with limitations established by the Regulated Health Professions Act (RHPA) (Canadian Nurses Association, 2008; College of Nurses of Ontario, 2009). Services provided by UCPs include assistance with activities of daily living (e.g., personal hygiene, dressing, feeding); home management (e.g., shopping, meal preparation, housework); and social and recreational activities (e.g., friendly visiting). Services are usually performed under the direction of a registered nurse (RN), registered practical nurse (RPN), nurse practitioner (NP), client, family member, employer, or another regulated health professional (Canadian Nurses Association, 2008; College of Nurses of Ontario, 2009). In this study, personal support workers or PSWs, constitute the primary UCP role.

Palliative Care and Home Care

The demographics of the Canadian population are changing due to an aging population and longer life expectancy (Canadian Hospice Palliative Care Association, 2010; Williams et al., 2011). Specifically, in Ontario the proportion of individuals 65 years and older is expected to double in the next 13 years from approximately 1.5 million to 3.0 million (MOHLTC, 2010). An anticipated consequence of this change is an increased morbidity rate, an increased use of health care services, and subsequently end-of-life care needs (Canadian Hospice Palliative Care Association, 2010; Giesbrecht, Crooks, & Williams, 2010; Williams et al., 2011). With the predicted rise in morbidity and mortality rates over the next number of years, Canadians at end-of-life will require palliative care services. The World Health Organization (WHO) (2011) defines palliative care as:

> … an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual. (p.1)

The majority of deaths in Western countries, such as Canada, have an extended process of a few weeks to many months and many individuals die in hospital after an extended illness (Wilson et al., 2008; Wilson et al., 2009). Research evidence indicates that most Canadians at the end-of-life would prefer to die in their own home surrounded by family, yet approximately 70% of Canadian deaths occur in hospital (Canadian Hospice Palliative Care Association, 2006; CIHI, 2007; Stajduhar & Davies, 2005). The ability to accommodate clients' wish for an at-home death is dependent on the availability of resources in the community including health care providers, informal caregivers, and funding (Bee, Barnes, & Luker, 2008; Canadian Hospice Palliative Care Association, 2006; CIHI, 2007; Linderholm & Friedrichsen, 2010; Stajduhar & Davies, 2005; Wilson et al., 2009).

Only 16% to 30% of Canadians with a terminal illness have access to or receive community-based hospice and palliative care services (CIHI, 2007). Although hospice and palliative care are often used interchangeably, the terms refer to slightly different aspects of end-of-life care. Palliative care addresses individuals with life-threatening illnesses; however anyone, regardless of life expectancy, can receive this type of care (Bonebrake, Culver, Call, & Ward-Smith, 2010). Hospice care is for individuals who can no longer benefit from medical treatment and are in the last stages of a terminal illness with death anticipated within six months (Bonebrake et al., 2010). Palliative and hospice care involve complex, socio-cultural processes and therefore nurses and other health care providers need to be consciously aware to how their values, roles, and norms are socially constructed and conveyed when providing this type of care to clients (McWilliam, Ward-Griffin, Oudshoorn, & Krestick, 2008). Given the increased demand for end-of-life care, governments need to ensure that the dying individual and his/her family have access to hospice and palliative care services across health care sectors and settings to achieve optimal care (Canadian Hospice Palliative Care Association, 2010; Ward-Griffin, McWilliam, & Oudshoorn, 2012). In-home palliative care may offer a solution to address the increased demand for health care services and support clients' desires to die at home.

Informal Caregivers

Informal caregivers tend to be family members who provide unpaid care to individuals who are elderly, sick, or disabled (Canadian Hospice Palliative Care Association, 2004; Linderholm & Friedrichsen, 2010). For the purposes of this research, 'family' is understood as a broad and inclusive concept and is defined as "people with a strong and emotional, psychological and/or economic commitment to one another – regardless of the nature of their relationship. Family can include those connected by biology, adoption, marriage or friendship" (Family Mental Health Alliance, 2006, p. f).

Families are active agents of personal, social and cultural change and each individual’s definition of family will be different.

Informal caregiving has gained attention in the last two decades as the Canadian health care system has struggled to meet the demands of the aging population and the increase in prevalence of life-threatening illnesses, such as cancer (Stajduhar, 2003). With changing demographics and the closure of acute care hospital beds, there has been increased reliance on community-based care, and in turn, informal caregivers (Clemmer, Ward-Griffin, & Forbes, 2008; Stajduhar, 2003; Williams, Crooks, Giesbrecht, & Dykeman., 2010). According to the Canadian Caregiver Coalition (2008), “It’s not *if*, it’s *when* you will become a caregiver” (p.2).

Individuals at end-of-life have complex care needs and informal caregivers are asked to provide care to these palliative individuals when they themselves are dealing with their own sense of impending loss and grief (Canadian Hospice Palliative Care Association, 2004). Providing palliative services in the home has had a tremendous impact on Canada’s nearly two million informal caregivers, a group that provides practical and psychosocial care, supportive services, and care coordination worth up to $26 billion dollars annually, while sustaining $80 million dollars annually in out-of-pocket costs (Canadian Caregiver Coalition, 2008; Hollander, Liu, & Chappell, 2009; Williams et al., 2011). Without informal caregivers, it would be difficult for many palliative clients to remain at home.

Health Information Technology

E-health is an overarching term used to describe health care supported by health information technology (HIT) (Health Canada, 2010; Urowitz et al., 2008). E-health is the application of information and communication technologies in the health sector and encompasses a range of purposes from administrative functions to point of care health care delivery (Health Canada, 2010; Urowitz et al., 2008). In the home care setting, e-health can refer to a variety of technology enhanced aspects of care, including teleconsulting and remote vital signs monitoring systems that are used to monitor and treat clients with chronic disease (Health Canada, 2010). Examples of technology used in the home care setting include devices, such as laptops, tablets, and hand-held/smartphones, and software programs, such as associated documentation systems. Telehealth aims to bridge the gap between geographical distances and improve care delivery and health-related education (Demiris, Parker Oliver, Courtney, & Porock, 2005; Wade et al., 2010).

Most home care programs do not have dedicated funds for innovations in technology and have not been given priority in provincial and regional information technology plans (Canadian Home Care Association, 2008b). Because of the lack of a national health technology strategy for Canada, home care programs have taken fragmented approaches in developing technological initiatives through pilot projects (Canadian Home Care Association, 2008b). As the delivery of health services shift from acute care hospitals to the community, greater investment in technology solutions in the home care sector will be necessary. HIT has been shown to enhance quality of care, improve continuity of care and integrated care models, and achieve appropriate utilization of health care resources (Canadian Home Care Association, 2008b; Chaudhry et al., 2006; Russell et al., 2010).

The eShift Model of Care

Because of increased challenges in recruiting and retaining RNs and difficulty meeting demand for home care services, the South West Community Care Access Centre (South West CCAC) explored new models of delivering home care. The initial phase of the eShift model of care for medically-fragile children was introduced in 2008 and was then expanded in July 2010 for those clients at end-of-life. The eShift model of care is a home health care initiative that utilizes technology to provide care and support to clients and their families in a way that makes better use of HHRs (See Figure 1) (South West LHIN, 2010). The care model connects a personal support worker (PSW), who has received additional education in palliative care, working in the client's home with a remotely located nurse via a web-enabled iPhone (South West LHIN, 2010). The eShift model of care enables each delegating nurse to monitor and provide care for up to four home-based clients in diverse locations simultaneously from a remote location (South West LHIN, 2010).

The eShift model has transformed the traditional model of home care delivery of one nurse to one client, to one nurse ("the delegating nurse") working from home and connected via computer to up to four PSWs (with enhanced training) caring for one client each (e.g., one delegating nurse, four PSWs, and four clients). Other members of the eShift model include the primary care physician, visiting nurse, CCAC case manager, occupational therapist, physiotherapist, social worker, family member, and client. The HIT hardware (e.g., iPhone) and software (e.g., Community Care Manager (CCMe) system – electronic care data collection and real-time information system, eShift) allows nurses and PSWs to document client encounters and share information securely through a web portal. The technology also includes clinical decision support tools, a reference library, chat and phone capability, and a feature for ordering supplies (South West LHIN, 2010; South West LHIN, 2011).

The eShift model of care began as a pilot project in South Western Ontario; however increased funding from HealthForce Ontario and more recently, from the South West Local Health Integration Network (LHIN), has supported continued development and refinement of the eShift care model (South West LHIN, 2010). Initially, the eShift model of care was directed toward medically fragile paediatric clients who needed overnight home care services, but has since expanded to include those requiring palliative home care services (Healthcare Information Management & Communications, 2010). The goal of the eShift model is to appropriately utilize resource supply and demand, to electronically store client documentation in a centralized location, and to optimize HHRs using a new service delivery model that focuses on providing the right care, at the right time, and in the place of the client's choice (Healthcare Information Management & Communications, 2010; South West LHIN, 2011). It is anticipated that there will be a reduction in hospital readmissions; clients who are occupying a bed in a hospital who no longer require the intensity of resources/services in this setting could be discharged to the community; and most importantly, improved overall outcomes for palliative clients and their informal caregivers is anticipated (Healthcare Information Management & Communications, 2010; South West LHIN, 2011).

Given that eShift is a new service delivery model, there has been little opportunity to explore the experiences of informal caregivers who have had a palliative family member receive care from PSWs and remotely located nurses integrating technology in the care encounters. Most of the research conducted on HHRs and the integration of technology into the home health care sector has focused on the cost-effectiveness of innovative projects with limited inquiry about informal caregiver perspectives. As such, the purpose of this interpretive description study was to describe the experiences of informal caregivers who have lived with and cared for a family member who received palliative care as part of the eShift model of care. This included their experiences of having a PSW and remotely located delegating nurse provide care to their family member and the integration of technology into the care encounters. An interpretive description exploration of informal caregivers with the eShift model of care provided an in-depth, contextualized understanding of the experiences of informal caregivers, provided direction for nursing practice, education, research, and policy development and has advanced current understanding pertaining to home-based palliative care.

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Chapter Two - Manuscript

Background

Health care system restructuring in the 1990s, technological advancements, an aging population, and changes in public preference for health care delivery, have led to a shift in health care services from acute care institutions to the homes of Canadians (Peter et al., 2007; Wilson et al., 2009). In Ontario, the proportion of individuals 65 years and older is expected to double in the next 13 years from approximately 1.5 million to 3.0 million (Ministry of Health and Long-term Care (MOHLTC), 2010). Growing numbers of older adults wish to age at home and existing research evidence has reported that most Canadians (86 percent) (Canadian Hospice Palliative Care Association, 2008) who are at the end-of-life stage would prefer to die in their own home surrounded by family (Canadian Hospice Palliative Care Association, 2006; Canadian Institute for Health Information, 2007; Wiles, Leibing, Guberman, Reeve, & Allen, 2012; Wilson et al., 2009). Increased demand for home care services coupled with an existing shortage of health human resources (HHRs) in the home care sector may contribute to challenges in service delivery to clients receiving care in the home and has placed greater reliance on informal caregivers (Canadian Home Care Association, 2003; Clemmer, Ward-Griffin, & Forbes, 2008; Ellenbecker, Porell, Samia, Byleckie, & Milburn, 2008; VON, 2005).

Health-based technology has been suggested as one means of addressing the challenges in care delivery in the home (Demiris, Parker Oliver, & Wittenberg-Lyles, 2011; Russell, Rosenfeld, Ames, & Rosati, 2010; Vimarlund, Olve, Scandurra, & Koch, 2008). However, there is a gap in the literature on the implementation and effectiveness of innovative models of technology enhanced health care in the home care sector that make better use of resources, such as HHRs, to meet the increasing demand for service. The implementation of eShift, an innovative model of service delivery, presents an opportunity to examine the perspectives/experiences of informal caregivers within a technology enhanced home care delivery setting.

Literature Review

A comprehensive review of the literature from 2001 to 2011 was conducted using the following electronic databases: CINAHL, Proquest, MEDLINE, and Scopus. The search included nursing, information and technology, medical, and allied health literature. The key terms that were used in the literature search included: home care; technology; health information technology; nursing; palliative care; hospice; informal caregiver; and family caregiver. The search was limited to the English language and to peer-reviewed journals. Articles were also identified through a manual review of references in relevant articles. Based on a review of the literature, ten studies were identified that examined informal caregiver experiences of palliative home care and five studies examined technology use by informal caregivers in the home care setting.

Informal Caregiver Experiences in the Palliative Home Care Setting

To date, considerable research has focused on the experiences of informal caregivers who have cared for a palliative family member in the home. Researchers in one study presented the results of a systematic review which examined the practical information needs of informal caregivers providing home-based palliative care to individuals with advanced stages of cancer (Bee, Barnes & Luker, 2008). The researchers found there was a lack of practical guidance for informal caregivers, including inadequate information provision, inconsistent access to technical equipment and services, and lack of support from palliative health care providers (Bee et al., 2008).

Another study explored the influences of palliative care services on informal caregivers caring for a family member who is dying of cancer, HIV-related illnesses, or illnesses of later life (Cain, MacLean, & Sellick, 2004). Findings from this research indicate that health care providers focused the majority of their attention on the palliative client, leaving the informal caregiver with little support. Furthermore, informal caregivers were often not provided with resources, such as information regarding hospice/respite services in the community, information on the anticipated course of their family member's illness, or a group of consistent health care providers (Cain et al., 2004). The psychological needs of informal caregivers is also crucial for health care providers to consider as exhaustion is a leading reason why informal caregivers are unable to sustain their caregiving duties and rely on formal care services (Cain et al., 2004).

Harding and Higginson (2001) addressed obstacles in accessing and providing suitable interventions in home-based palliative care that meet the needs of informal caregivers. Findings have shown that informal caregivers are most often recognized as providers of care and less often identified as recipients of care (Harding & Higginson, 2001). Informal caregivers in this study reported high levels of anxiety and stress and the need for a caregivers' service, yet they were uncertain with respect to their own needs (e.g., practical, emotional, informational) (Harding & Higginson, 2001). These findings support the need for palliative home care interventions that recognize the important role played by informal caregivers, improve coping strategies, and ensure that interventions and services are widely accessible and appropriate for informal caregivers (Harding &

Higginson, 2001). Another qualitative research study examined the perspectives of informal caregivers and palliative care clients on the caregiving experience in home-based palliative care (Jo, Brazil, Lohfeld, & Willison, 2007). Informal caregivers expressed both physical and psychological burdens associated with the caregiving experience. Although palliative clients and informal caregivers were grateful for the home care services that were provided, they identified the need for additional services and expressed concern about the lack of communication among health care providers and poor coordination of services (Jo et al., 2007).

A qualitative secondary analysis study explored the enactment of multiple roles and experiences of informal caregivers providing home-based palliative care services to older adults with advanced stages of cancer (Clemmer, Ward-Griffin, & Forbes, 2008). Findings from this study found that family-centred care is often lacking in home-based palliative care (Clemmer et al., 2008). Informal caregivers are expected to provide the bulk of the care to family members in the home at end-of-life and therefore the notion of ‘family as client’ should be more consistently recognized by health care providers (Clemmer et al., 2008). Informal caregivers had to balance multiple roles (e.g., spouse, parent, child, employment, and gender role expectations), yet providing care for their family member took precedence and as a result they often neglected their own personal health needs (Clemmer et al., 2008). Hasson and colleagues (2010) explored palliative and end-of-life experiences of informal caregivers caring for a family member with Parkinson’s disease. Findings showed that the needs of informal caregivers had not been fully addressed (Hasson et al., 2010). Lack of communication between health care providers and informal care providers, lack of knowledge of palliative care and the disease trajectory, and lack of coordination and referral to end-of-life services posed a burden, physically and psychologically, on informal caregivers (Hasson et al., 2010).

A grounded theory study investigated the vulnerability of informal caregivers caring for a family member at end-of-life in the home (Proot et al., 2003). The study explored the experiences of informal caregivers, their needs when caring for a family member in the home, and the health care services that they received (Proot et al., 2003). The findings showed that informal caregivers required a continuous balance between the burden associated with caring for a family member at end-of-life in the home and their ability to cope in the informal caregiver role (Proot et al., 2003). Optimum balance was dependent on a number of factors that impinged on the informal caregiver’s vulnerability, such as care burden, support, impending death, fear, and isolation (Proot et al., 2003). The researchers recommended greater education and practical tools (e.g., development of an assessment tool) for nurses and general practitioners to increase their awareness of the vulnerable position of informal caregivers (Proot et al., 2003). A cross-sectional observational study investigated associations between the health-related quality of life of informal caregivers caring for a family member receiving palliative care at home, characteristics of the caregiver, and their caregiving situation (Kenny, Hall, Zapart, & Davis, 2010). The study concluded that health care providers (e.g., nurses) caring for palliative clients in the home need to be aware of potential health impairments of informal caregivers and need to ensure that adequate and appropriate support, treatment, and preventive health care services are made available to informal caregivers (Kenny et al, 2010).

To gain a deeper understanding of informal caregivers' experiences in the caregiving role and their needs for support, a qualitative study using a hermeneutic approach was conducted (Linderholm & Friedrichsen, 2010). Linderholm and Friedrichsen (2010) found that family members automatically assumed the role of primary caregiver without considering the long-term consequences. Moreover, informal caregivers felt isolated, powerless, and felt invisible at a time when they needed to be recognized and supported by health care providers (Linderholm & Friedrichsen, 2010). An ethnographic study examined the social context of informally caring for a palliative family member in the home setting (Stajduhar, 2003). Informal caregivers reported life-enriching experiences while caring for their family member in the home; however with the transition of palliative care services from hospital to home, some informal caregivers felt pressured to take on the caregiver role and caused them to feel exploited by the health care system (Stajduhar, 2003). Findings from all studies suggest the need to: include informal caregivers in the care team and to recognize the notion of 'family as client'; increase communication between informal and health care providers; improve care coordination; educate health care providers on the potential health impairments and vulnerable position of informal caregivers; provide information to informal caregivers on palliative care and disease trajectories; and indicate that there is a need for palliative care services and interventions in the home and community to support informal caregivers.

No studies were found that explored the experiences of informal caregivers that are involved in innovative service delivery models that utilize unregulated care providers (UCPs) and health information technology (HIT) in the palliative home care setting. Given that UCPs provide supportive care in the home, understanding this role and the relationship between UCPs and other members of the health care team, particularly informal caregivers, within the context home-based palliative care is important. Therefore, research is needed to explore the experiences of informal caregivers in a technology enhanced palliative home care setting and their relationships to all members of the health care team. In addition, no research was found that studied palliative care services and interventions in the home or community setting that had been developed to support informal caregivers caring for a palliative family member in the home.

Informal Caregivers and Technology Use in the Home Care Setting

In the literature review, little research was found on informal caregivers' use of technology in the home care setting. Much of the published research focuses on the use of information technologies that can bridge geographical distances, such as mobile devices and videoconferencing to assist informal caregivers in meeting their needs. For example, one study looked at the use of videophones for client and informal caregiver participation in hospice interprofessional team meetings (Parker Oliver, Demiris, & Wittenberg-Lyles, & Porock, 2010). In palliative care, the importance of the informal caregiver as proxy decision-maker and advocate for the client supports the notion of 'family as client' and the need to care for the family and not only the palliative care client (Parker Oliver et al., 2010). The inclusion of the informal caregiver in the 'unit of care' required additional coordination by the health care team, and technological devices, such as videophones, offered a potential solution to the challenges presented by geographical distances and improved communication among informal caregivers and other members of the health care team (Parker Oliver et al., 2010). Furthermore, having visual contact through videoconferencing, assisted the health care provider to better understand what the informal caregiver was saying by noting non-verbal cues (Parker Oliver et al., 2010).

A descriptive study looking at factors that influenced the receptiveness, use, and acceptance of telehealth videophones among 21 informal caregivers of stroke clients in the home setting found that for a number of caregivers, the use of telehealth services decreased their isolation and level of care burden (Buckley, Tran, & Prandoni, 2004). The videophones were used to assess the health care needs of the stroke survivor and family caregiver, as well as provide informational and emotional support to them (Buckley et al., 2004). Telehealth services in the home setting can be effective in assessing the health care needs of clients and informal caregivers, and also for emotional and informal support (Buckley et al., 2004). Receptiveness of informal caregivers toward telehealth videophones was dependent on: informal caregivers' concerns regarding privacy and confidentiality, convenience in terms of telehealth services availability, timing of when the technology was offered, perceived need for support by informal caregivers, and the level of informal caregiver burden (Buckley et al., 2004).

Hayes and colleagues (2011) report on the development of technologies, including a hand-held device, a sensing platform, and an activity recognition procedure for automatically recording infant movement for a premature infant discharged from hospital and cared for at home. Researchers concluded that parents from primarily low-income households were able to access technological interventions in the home that were similar to resources within the hospital setting (Hayes et al., 2011). Informal caregivers were active users of the home-based technology and especially appreciated the reminder function (e.g., prompts to attend to scheduled care tasks) and the communication function connecting them to other members of the health care team (Hayes et al., 2011). Moreover, informal caregivers can become members of the interprofessional health team by using the hand-held device to report accurate and timely data about the health and progress of their infant to other members of the care team (Hayes et al., 2011).

Similarly, researchers investigated informal caregivers' conceptions of, usage of, and information on products, technology, and Web-based services for home-based senior care (Edlund & Bjorklund, 2011). Informal caregivers reported contentment in their use of technological devices in the home setting, but there were notions suggesting hindrances to optimal use (Edlund & Bjorklund, 2011). Several informal caregivers expressed disinterest in learning how to use the Web-based services primarily due to their reported lack of technical knowledge and lack of instructional orientation (Edlund & Bjorklund, 2011). These findings reinforce the need for learning opportunities to acquire the necessary skills to utilize and benefit from Web-based services in the home (Edlund & Bjorklund, 2011).

With an increased number of individuals having access to the Internet, more clients and informal caregivers are able to benefit from the additional support and care of online interventions. The findings from an investigation of home Internet use for hospice home care recommend that Web-based technologies are a means to enhance, rather than replace traditional care (Washington, Demiris, Parker Oliver, & Day 2007). Health care providers who are providing hospice care need to understand the needs and expectations of clients and informal caregivers in order to design effective and efficient HIT interventions for the home setting (Washington et al., 2007).

Although studies have focused on informal caregivers' acceptance and use of Web-based interventions and health information technologies in the home care setting, they have not looked specifically at how the use of hand-held devices in the palliative home care setting by health care providers can affect the informal caregiving experience. There has been considerable research regarding clients' use of HIT in the home, however there is limited knowledge on informal caregivers' use of HIT in the home care setting. Furthermore, no studies were found that explored how the use of HIT can optimize HHRs into a new service delivery model that utilizes both UCPs and nurses. While HIT has not been used in the palliative home care sector to the same extent as other areas of the health care system, research suggests the potential of videoconferencing, Web-based applications, and mobile tools to support informal caregivers at home in their caregiving role. However, if HIT is to play a role in home-based palliative care, research is needed to explore appropriate ways of designing and implementing HIT systems in this particular health care setting, and the impact it has on the informal caregiving experience.

eShift Model of Care: Study Context

In response to concerns about the shortage of nurses to provide care to select populations of clients in the home care sector, the South West Community Care Access Centre (South West CCAC) developed the eShift[1] model of care (See Figure 1). The eShift model of care is a partnership among the South West CCAC, the South West LHIN, Sensory Technologies (a software engineering company), VON Canada, and Care Partners (nursing-based for profit organizations that provide health care services to clients in their homes). To date, the eShift model for home care has focused on two unique groups: complex paediatric care and more recently, a palliative care population

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[1] There is currently a patent pending on the e-Shift model of care.

(South West LHIN, 2010). The eShift health care team consists of nurses, PSWs, physicians, other allied health care providers as required, and a software engineer. Within this model of care, nurses, identified as ‘delegating nurses’ are ‘on shift’ in front of an Internet enabled computer, with access to telephone, fax, and smart phone devices and are located remotely from clients’ homes.

The traditional model of home care delivery has nursing and personal support/homemaking service ‘maximums’, set by the Ministry of Health and Long-Term Care. Under the current policy, home care clients are permitted 120 nursing or registered practical nursing (RPN) *visits* in a 30 day period, or 184 *hours* of RN service; or 227 *hours* of RPN service; or 206 *hours* of blended RN/RPN service. For personal support/homemaking services, home care clients are provided with 120 hours of support in the first 30 days of service and 90 hours in any subsequent 30 day period. The service maximums for nursing and personal support pertain to all home care clients, including those receiving palliative home care services.

A core component of the eShift model are the PSWs who have received additional education in palliative care. The PSWs and remotely located delegating nurse are connected by way of a hand-held device, an iPhone. The eShift mobile tool is a collaborative, client care centred, wireless smart-phone and web application information system for care documentation and real-time care coordination within the home care setting (Sensory Technologies, 2009). The software included in the HIT system consists of three components: (1) mobile, smart-phone applications (e.g., iPhone and eShift software); (2) web-based applications (e.g., applications to collaborate, schedule, and manage care delivery in real-time); and (3) client documentation and data storage

(Sensory Technologies, 2009). Essentially, eShift technology constitutes a mobile phone with customized software that enables the delegating nurse (remotely located) and PSW (in the client's home) to communicate, document and store client care information in one centralized location (Sensory Technologies, 2009).

The PSW observes and communicates his/her requested information, based on a client assessment, such as vital signs and client symptoms, to the delegating nurse with the hand-held device using the eShift system. The PSW is the delegating nurse's eyes, ears, and hands within the home setting and not a substitute of the nurse's knowledge, skills, and judgment. In providing care to the client at home, the delegating nurse monitors and reviews the information in real-time on the secure web portal and, when necessary, delegates specific care tasks back to the PSW. A visiting nurse continues to make routine visits to the client's home to perform nursing care tasks and can interact with the delegating nurse via telephone or in-person. If the delegating nurse assesses the need for higher-level care in the home, a higher-skilled assessment is authorized and delivered to the client by the visiting nurse (Healthcare Information Management & Communications, 2010). The eShift model is *not* a technological solution, but rather a new home care service delivery model that has transformed the traditional model of care delivery of one nurse to one client, to one nurse and multiple PSWs caring for several clients (e.g., one delegating nurse, four PSWs, and four clients).

The use of HIT in the home care setting has led to dramatic changes in health care delivery by expanding utilization of health providers and creating changes in how care is delivered (Canadian Healthcare Association, 2006). However, there is a gap in the literature on the experiences and involvement of informal caregivers who have had a palliative family member receive technology enhanced care from an UCP and remotely situated nurse partnership in the home care setting. The implementation of this innovative model of service delivery presents an opportunity to examine the perspectives and experiences of informal caregivers receiving ‘eShift’ care services.

Methodology

This study is guided by an interpretive description approach. Interpretive description was introduced in the late nineties by Thorne and colleagues (1997) and further refined by Thorne (2008) to develop knowledge that will advance nursing science and inform clinical practice (Hunt, 2009). Interpretive description incorporates methods from qualitative research methodologies, including phenomenology, grounded theory, and ethnography to answer complex, experiential, and contextually embedded questions relevant to nursing science. Interpretive description is intended to answer questions that illuminate knowledge through exploration of participant experiences and interpreted through the lens of nursing knowledge (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997). This approach reflects an evolution of qualitative methodology within the domain of the nursing profession.

The intended purpose of interpretive description is to answer questions that will generate clinical knowledge through exploration of participant experiences and at the same time use a methodological foundation rooted in nursing’s epistemological mandate (Thorne et al., 1997; Thorne, 2008). Nursing’s epistemological mandate recognizes that human health and illness experiences have shared realities, yet each individual client experience will be unique to their particular situation (Thorne et al., 1997). Thorne and colleagues (2004) recognize that the “blending” of qualitative approaches pushes the methodological rulebooks; however conforming to traditions that are focused on theoretical and empirical problems rather than practical problems, does not align with the complex, experiential questions that nurses face in their day-to-day work. The intention of interpretive description is not to construct a theory or to theorize, but rather to generate inquiries related to clinical problems of health and illness (Thorne, 2008).

Interpretive descriptions are capable of informing clinical understanding by capturing themes and patterns within subjective perceptions to develop practical knowledge (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004; Thorne et al., 1997). Clinical expertise is acknowledged as a useful beginning point for orienting research and guides the researcher to generate inquiries related to clinical problems.

Findings from an interpretive description study may be used to provide a foundation for assessment, planning, and interventional strategies that nurses can utilize in solving clinical issues in an educated and ethical manner (Thorne et al., 2004). Because interpretive description studies rely heavily on interpretation of collected data, study findings cannot be generalized into facts as the researcher's conclusions are based solely on their own interpretation of the collected data (Thorne et al., 2004). The utilization of study findings depends on the researcher's capacity to interpret them in a way that transforms the raw data into a structure that offers the nursing profession an extended or alternative understanding of the phenomenon of interest (Thorne et al., 2004).

Interpretive description is a methodology that extends beyond description of a particular phenomenon and attempts to answer the "so what" question that drives all applied disciplines (Thorne, 2008). Thus, interpretive description supported the current investigation to look beyond *what* experiences informal caregivers had while involved in the eShift model of care and to focus on *how* and *why* different components of the eShift model of care affected informal caregivers who were living with and caring for a palliative family member in the home. The goal of interpretive description in nursing is for researchers to understand the experiences of participants in great detail, abstract relevant themes from participants' experiences, and create practical knowledge that can be applied back to individual participants (Thorne et al., 1997).

Methods

Statement of the Purpose

The purpose of this interpretive description study was to describe the experiences of informal caregivers who have lived with and cared for a family member who received palliative care as part of the eShift model of care. This included their experiences of having a PSW and remotely located delegating nurse provide care to their family member and the integration of technology into the home care setting.

Research Question

The research question guiding this study is: "What are the experiences of informal caregivers living with and caring for a family member who received palliative care as part of the eShift model of care?"

Setting and Sampling Strategy

Purposive sampling was used to recruit participants that would provide insights and an in-depth understanding of the phenomenon under study (Thorne, 2008). Purposive sampling allowed for exploration of maximum variation in the phenomenon under study through participant selection (Lincoln & Guba, 1985; Sandelowski, 1995).

Interpretive description studies can be conducted on samples of almost any size; however the majority of studies within this approach are likely to involve 5 to 30 participants (Thorne, 2008).

The researcher worked collaboratively with case managers at the South West CCAC London office to recruit participants for this study. The South West CCAC case managers were briefed on the research purpose and on the inclusion/exclusion criteria for study participants. Using a script developed by the researcher (Appendix A), case managers contacted potential participants who met the inclusion criteria and invited them to volunteer for the study. The case managers then notified the researcher regarding interested participants. Those participants who were interested and agreed to be involved in the study received a phone call from the researcher to have any questions answered about the study and if they chose to participate, a time was set up for an interview. Before beginning the interview, the researcher reviewed the letter of information (Appendix B) with the participant and outlined the study in detail, answered any questions that participants had about the study, and had the participants sign the consent form. For inclusion in the study participants must have: been over the age of 18 years of age; been able to read, write and speak English; had a family member who received palliative care in the eShift model of care and who passed away a minimum of three months at the time of participation but no longer than three years ago; been the informal caregiver to the family member who received palliative care; lived with the family member who received palliative care while being a part of the eShift model of care; and were from London, Ontario and surrounding area. Geographical inclusion criteria were due to convenience, accessibility, and timelines of the researcher. In consultation with the South West CCAC, interview participants were considered eligible for inclusion in the study if their family member had passed away a minimum of three months at the time of participation but no longer than three years ago.

Protection of Human Rights

Ethics approval to conduct this investigation was obtained by Western University Research Ethics Board (REB) (Appendix C). A letter of agreement was provided by the South West CCAC with permission to recruit participants who had received 'eShift care'. A written letter of information was given to each participant outlining the study and consent was obtained from participants prior to their interview. Individuals were encouraged to ask questions and were reminded that their participation was voluntary and that they could withdraw from the study at any time with no penalty. Because of the nature of the research topic, interviews had the potential to trigger memories of emotionally intense experiences. In anticipation of this possibility, contact information for bereavement services in London, Ontario, that are free of charge, were provided to participants (Appendix D). All participant names were changed to pseudonyms and identifying information was eliminated from the data for the purpose of participant anonymity.

Data Collection

Data were collected through semi-structured, individual interviews with eight participants and field notes were written after each interview. A semi-structured interview guide (Appendix E) was developed to facilitate an in-depth exploration of the experiences of informal caregivers living with and caring for a family member who received palliative care as part of the eShift model of care. In an interview format, open-ended questions were used to gather data on informal caregivers' involvement with the eShift model of care. A research stipend of $25.00 was offered to participants for expenses incurred (travel, parking, child care, etc.) as a result of their study participation. Participants were advised of the possible need to meet for a second time for a maximum of one hour if a more in-depth understanding of their experiences was needed; however, follow-up interviews were not needed.

The interviews were conducted one-to-one in the participants' homes, at a place of convenience and comfort for both the participant and researcher, or by telephone. Interviews were digitally-recorded and transcribed verbatim, by either the researcher or a transcriptionist. The interviewer also took field notes immediately after the interview which included observational (e.g., objective description of actions, dialogue and context), theoretical (e.g., researcher's efforts to attach meaning to observations while in the field of study), methodological (e.g., reflections on the approaches and methods used) and personal notes (e.g., researcher's own personal feelings and perspectives while in the field of study) about the interview (Polit & Beck, 2008).

Data Analysis

Data analysis was based on inductive analysis (Thorne et al., 2004). NVivo 9 software was used to organize and analyze the rich detailed data. The first step of data analysis included listening to the audio recordings of the interviews and reading and re-reading through transcripts to gain a sense of the data as a whole. It is through this process that researchers immerse themselves in the data prior to beginning the coding process (Thorne, 2008). This allows the researcher to focus on processes, such as comprehending, synthesizing, theorizing, and re-contextualizing rather than solely sorting and coding (Morse, 1994; Thorne et al., 1997; Thorne, 2008).

The initial coding process involved creating codes based on the major topics covered in the semi-structured interview guide and on the literature review completed for this study. As data analysis progressed, additional concepts and codes were defined inductively. When reading through the transcripts, the researcher referred to the questions, “What am I learning about this?” (Thorne et al., 1997, p. 174), “Why is this here?” and “What does it mean?” (Thorne et al., 2004, p.13) periodically to support the inductive analysis and to prevent premature coding. In the final stages of data analysis, codes were then aggregated and broad themes were created.

For this research study, consistent with interpretive description (Thorne, 2008), constant comparative analysis was used to generate themes and patterns from the data and these were constantly compared with data elicited in earlier interviews so that commonalities and variations could be acquired (Polit & Beck, 2008). Eventually, the content of each individual interview was compared to all interviews.

According to interpretive description and as proposed by Lincoln and Guba (1985), data collection and data analysis should occur simultaneously (Thorne et al., 1997). By having periods of time between data collection and data analysis, the researcher was able to refine the research by making revisions to the semi-structured interview guide and reorient the inquiry according to new insights that emerged (Hunt, 2009).

For this study, the researcher’s co-supervisors performed second level coding and worked collaboratively with the researcher to aggregate the data and validate the findings. The data was analyzed independently by researchers; data was aggregated; and differences in analysis were discussed by researchers until consensus was achieved (Thorne, 2008).

Credibility

To ensure credibility, Thorne (2008) suggested four main evaluation and critique criteria: epistemological integrity; representative credibility; analytic logic; and interpretive authority. First, epistemological integrity was demonstrated by having the research question in this study be consistent with the stated epistemological foundation and have practical relevance to the profession of nursing. Second, representative credibility was achieved through in-depth, individual interviews with participants, the completion of field notes after each interview, and prolonged immersion in the data. Third, analytic logic was reached by having the researcher fully immersed in the data by transcribing interviews, reading and re-reading transcripts, and generating overarching themes of the phenomena under study. An inductive analysis was used to generate findings and an audit trail of the analysis process was completed. Lastly, interpretive authority was shown when the researcher took field notes after each interview which included observational, theoretical, methodological and personal notes from each interview and were then linked back to the phenomena under study. Moreover, discussion of findings and analysis of data was completed with the researcher's supervisors which assured that the researcher remained true to the participants' views and experiences.

Taking the larger disciplinary, social, and historical contexts into consideration, Thorne (2008) identified five additional evaluation criteria: moral defensibility;

disciplinary relevance; pragmatic obligation; contextual awareness; and probable truth. By adhering to the set of evaluative criteria in this study, the researcher was able to inevitably reflect on why certain questions were asked, how findings will further current knowledge and understanding of informal caregivers' experiences in home-based palliative care, and what nursing implications will result from the research process.

Findings

The experiences of informal caregivers who have lived with and cared for a family member who received palliative care as part of the eShift model of care were captured in eight individual interviews and through researcher field notes. Seven study participants were from urban communities and one participant was from a rural community. Four participants were male and four participants were female. Five of the participants were the spouse to the palliative family member, while the other three participants were the child to the palliative family member. Three participants were employed full-time while caring for their palliative family member; however, all employed participants found it difficult to maintain their employment while caring for their family member. Two other participants took a leave of absence from their job to care for their family member and the remaining three participants were retired.

Interviews for this study were conducted from February 2012 to June 2012. Six of the interviews took place in the participant's home, one interview took place in a community setting at the participant's request, and one interview was conducted by telephone. Interviews with participants lasted between 30 to 90 minutes. Participants were interviewed three to nine months after the death of their family member. Participants were involved with the eShift model of care ranging from three to four weeks before their family member passed away. All of the participants lived with and were the primary caregiver to their palliative family member, with a number of the participants having additional support from family and friends. The four themes and sub-themes that emerged from the analysis of data are: *1)* ***The Health Care Family*** - *consistency in health care providers, holistic support; 2)* ***Making the Invisible Visible*** - *technology: hand-held devices; 3)* ***There's No Place Like Home*** *– ability of family members to pass away in place of choice, personal space, client-centred care; and 4)* **Burden of Love** *– physical, psychological, and financial care challenges associated with informally caring for a palliative family member in the home.* The following sections describe the four themes in more detail.

The Health Care Family

All of the participants in this study described positive experiences with having a PSW in the home to provide end-of-life care to their family member. The relationships with the health care providers, predominantly PSWs, were described by the informal caregivers as "truly amazing" (Participant 5) and "supportive" (Participant 1). The PSWs spent the most time, often eight hours a day, with clients and informal caregivers and were therefore able to build close relationships. Several study participants described the PSWs as members of their family. This was described by participant 5 who stated:

> …The two PSWs we had on a regular basis they really were a part of the family so it was like you [informal caregiver] had someone there that could support you constantly. And you don't have that in a hospital….They [PSWs] became sisters to me. (Participant 5)

In addition to the care tasks associated with the client, PSWs also provided support to informal caregivers by spending time with them, discussing, and listening to their thoughts and experiences. Participants explained how members of the eShift care team considered them as ‘clients’ and made sure that they were coping and that their needs were being met. Participants revealed that this type of support resulted in them feeling less isolated in their caregiving roles. A number of participants felt that the PSWs engaged with their family as they would their own and that the PSWs were committed to their role in helping families care for their palliative family member during each stage of their end-of-life journey. This was expressed by another participant who explained:

> Well we had, mostly one girl [PSW] we had a lot, and she was like, another child. She just came in and she didn’t act like she was a staff person, she knew that she was going to be in the house for the day and she acted accordingly…she would sit and have a cup of tea and talk about her kids and…it was more informal and less, I don’t know, medical.......The PSW workers are part of the family when this is happening. They’re part of the process, they’re not just coming and going and they care…. (Participant 2)

The sub-themes within the theme ‘The Health Care Family’ include the importance of care consistency and the need for holistic care relations.

Consistency in health care providers. A number of participants appreciated having the same PSW providing care in their home and believed this consistency in care provision improved the quality of care that their family received. Most of the participants expressed a sense of comfort in knowing the person coming into their home each day and not having to retell their story to a new caregiver each day. One participant explained:

> …What I liked about it [eShift model of care] is that they [South West CCAC] tried to keep it consistent, same person, which is what I kept fighting for in the other programs....I praise the program for their continuity of care. (Participant 7)

Another participant expressed:

> …They don’t switch the people [PSWs] around too much….It’s nice to have the same people, I mean maybe not every day, but I mean if you have the same two people…it becomes a familiar face and it’s someone that you’re comfortable with, and you don’t feel like they’re invading your space. (Participant 2)

Holistic support. The importance of physical, psychosocial, and spiritual needs of the client and family when caring for a palliative family member in the home was discussed by many participants. Participants appreciated the holistic support that the PSWs provided and how the PSWs recognized the need for not only the physical support, but also psychosocial, and spiritual support of both the client and informal caregiver. Participants explained how the PSWs were invested in meeting their complex care needs and they were always there to support the family on any of the health care decisions that had to be made. For example, PSWs provided families with all of the possible options that were available to them and ensured the family that they were making the right decision on whatever decision they made. One participant explained:

> …It's just support in any way you can think of that helps, because your emotions are involved. You're [informal caregiver] stressed, you're upset, you're scared, and you're guilty that you're doing things wrong…….They're [PSWs] invested….They're part of the scenario while it's happening, whereas, you know, like the programs that are just generic helpers, that part is missing….You [informal caregiver] need that just as much as you need medical or the physical help, you need the moral, emotional, and stress support. (Participant 2)

Another participant revealed:

> …They [PSWs] were helpful and just for another person there that was not involved, that was not a family member and that's what families need at that time [end-of-life] is somebody that can actually stand back and say let's think about this for a minute because when you are the family, the emotions are there and you are quick to react…….Just having the support outside of the family, to know that we weren't alone. (Participant 4)

Making the Invisible Visible

A number of participants indicated that they had very little understanding of the HHRs and technology components of the eShift model of care. The following sections discuss the theme and sub-theme related to the technology components of the eShift model of care.

In the eShift model of care, many of the informal caregivers worked collaboratively with the PSWs as a team to provide the best possible care to the palliative member in the last days of his/her life. The informal caregiver was included in the care processes by the PSWs and in this way were visible members of the health care team. One participant stated:

> They [PSWs] were amazing, they truly were. They were kind, they were caring, they were compassionate. They knew when to back off, they knew when to step up. They taught us [informal caregiver] both a lot of things medically that we needed to do in order to keep mom's life going. I can't say enough about them, but they were truly amazing. (Participant 5)

Informal caregivers appreciated the support and knowledge of the PSWs and felt the PSWs in the eShift model of care were "fully capable" (Participant 8) to care for their palliative family members. However, participants had very little knowledge about which health care providers were involved in the eShift care team and what their roles were. One participant believed:

> There was just the PSWs, the 40 hour PSW….The visiting nurse came from the VON, I don't know if she was a part of the eShift, maybe she was and I'm not aware that she was a part of it. (Participant 7)

The PSWs were visible to the client and informal caregiver whereas the care provided by the delegating nurse through the PSW was invisible to the clients and their informal caregivers. Most participants did not realize that the PSW's work was directed by the remote delegating nurse and he/she was invisible in the care team. Therefore, many participants did not understand the practice limitations of the PSW role and were unaware that the nurse was 'providing' nursing care to their family member through communication with the PSW in the home. A number of participants had a difficult time distinguishing between the nurse and PSW and instead used the term “girls”. One participant demonstrated this by stating:

> …When I turn around and I say nurses I could be referring to the PSWs. (Participant 1)

Technology: Hand-held devices. In the eShift model of care, PSWs regularly communicated with the remote delegating nurse throughout their shift using a hand-held device. When asked how they felt about the use of technology as part of the caregiving experience, participants in this study were very accepting of PSWs using hand-held devices at point of care. A number of participants discussed their views as to how the use of technology in the home cut health care costs and improved communication among health care providers. Issues arising with their palliative family member were resolved quickly and efficiently because the PSW could be in touch with a nurse at all times. One participant described her thoughts on the use of the hand-held device in the eShift model of care:

> I thought it was great….My mother wasn’t technologically savvy or had a computer or anything,…but for the rest of the family, we all have BlackBerrys and iPhones and we just thought it was a really good way to augment the system and not cost the, the care costs would be lessened by having PSWs when really you didn’t need a nurse,…but the PSW needed the support of the nurse in case, you know they had questions or there was a change during the night…. (Participant 7)

The communication network between health care providers was perceived as efficient and effective as they could very quickly be in touch with a nurse for feedback or instruction if they needed to be. Nevertheless, most of the participants did not know how the technology component of the model of care worked. In fact, the majority of participants said that they did not care to know in any detail how the technology (hand-held smartphones – iPhones) worked and did not want to have more hands-on involvement. The few participants who were aware of the technology component of the eShift model of care understood that the PSW was connected to the remote delegating nurse via an iPhone and that the nurse could efficiently make changes to the care plan, including changes to the medication regimen, if needed. One participant explained:

> Well they [PSWs] mentioned what they were doing, but they didn't, I didn't know what they were inputting. I guess it was their observations. (Participant 8)

Another participant stated:

> …I noticed they had one [iPhone] but that's about all…. (Participant 3)

There's No Place Like Home

Participants described the home as being a comfortable, familiar, and preferred setting to provide end-of-life care for their loved one. In their own home participants felt a greater sense of control and unlike their experiences in the hospital setting, they did not have strangers walking in and out of their room. Similarly, extended family and friends did not have to worry about institutionally determined visiting schedules and could visit with their family member at all times. Having their family member cared for at home made it easier for family and friends to say their good-byes.

One participant explained it this way:

> …It was so much easier to be able to have people come into the house for her [palliative family member] to say her good-byes then for people to have to come in and out from a hospital setting….She was amongst her own things,…she could look out her window and see her yard, this was still her home so she still felt she had a great deal of dignity and that was very important to both of us. (Participant 5)

The sub-themes within the theme ‘There’s No Place Like Home’ include the ability of family members to pass away in place of choice, personal space, and client-centred care.

Ability of family members to pass away in place of choice. Participants were grateful to have the option of having their family member pass away at home. Clients’ desire to pass away at home was discussed by all participants. Informal caregivers discussed how they might not have been able to attend to their loved one’s wishes to remain in the home at end-of-life. They discussed potential scenarios if the eShift model of care was not in place including having to quit their job to care for their family member, go into financial debt to pay for additional home care services, or have to admit their family member to hospital. One participant revealed:

> …We found out the last results that the cancer was now deep in her brain and they said we [family] have a choice either going and booking [her] straight to palliative care or [she] could come home, and it didn’t take the thirty seconds to make the decision that [she] was coming home and so the doctors there, I assume the doctors referred us immediately to CCAC and CCAC was out here the very next day and they did a home assessment, decided on what was needed to have at that time and from thereon in they were very supportive. (Participant 1)

Furthermore, participants discussed how it would have been difficult to grieve with the added burden of guilt. Another participant explained:

> …I think I would’ve been left with some guilt about not being able to provide….I’m left with grief but no guilt about what I should’ve done, I could’ve done, and what ifs, I don’t have any of those and I think the eShift really helped with that. I didn’t have to kind of beat myself up for not being there 24 hours a day for her or be mad at my brothers for not stepping in when they could’ve….So, I think in that way it allows, it allows me anyways, I believe my brothers too,…the luxury of grieving…. (Participant 7)

Personal space. This sub-theme captures participants’ feelings of relief when the PSWs came to their home. The arrival of PSWs was often the only time that informal caregivers were allowed ‘time off’ from their caregiving duties/role and allowed informal caregivers to honour the clients’ wish to die at home. Participants provided extensive caregiving to their family member with little support from extended family, or additional services in the community, so when PSWs arrived for their shift the participants were exhausted, emotionally and physically. By the nature of existing policy regarding allowable caregiving hours, having PSWs rather than RNs in the home provided informal caregivers with additional hours for personal time, to get some sleep or spend time with other family and friends. One participant explained:

> It helped me a lot because I was able to do other things and go about my life knowing that somebody [PSW] was out here….I was being freed up….I could go out and do some shopping,…I couldn’t unless my [daughter] was here…to let me out. (Participant 8)

Another participant described:

> It [eShift model of care] just allowed me to…have time with my kids, before and after school, and to do the jobs that still needed to be done during business hours because my dad, my parents were past the point of driving at that point so I had always done the grocery shopping or taken them for groceries so that was still something we [family] had to do for them and of course…we had to make funeral arrangements, we had all those things to do that we were able to do, with the PSW there, allowing us to go out during the day time hours. (Participant 4)

Client-centred care. Most of the participants in this study appreciated how the eShift model of care was tailored to their specific needs. A number of participants described how they were given the option as to how many health care providers they would like in their care team and which shift would be most helpful to them. For example, participants selected whether they would have two or three health care providers (PSWs) and the shifts – days or nights – that health care providers worked.

One participant expressed:

> Well they [eShift staff] actually went beyond my expectations because I was able to coordinate scheduling for my mom. You know, who was going to be there when and what was really nice is they gave me the option of saying when the shifts were going to be, when we needed the PSW, and that we really could use the PSW for overnight care. (Participant 7)

Yet, another participant recommended improvements to the eShift model of care recognizing that each family's experience is different and that the model of care will need to be customized to meet each family's unique situation. The participant explained:

> …The eight to four shifts was the only thing offered……If they were to offer more shifts or shifts at different times that would be helpful. You know, customize it to the family…because no situation is the same. (Participant 4)

Burden of Love

Providing care to a family member was described as "exhausting" (Participant 2), and the "hardest thing I ever have had to deal with in my life" (Participant 1). The following sections describe the sub-themes that capture the physical, psychological, and financial care challenges that informal caregivers experienced. Due to the circumstances surrounding caring for a dying family member, not all of the care challenges could be completely eliminated, even with the provision of additional support. However, the eShift model did eliminate a number of the care challenges that families encountered in the last weeks of their family member's life.

Physical. Several participants explained the physical burden that they faced while informally caring for their palliative family member. The physical health of many of the participants was affected. For example, informal caregivers spoke of a lack of sleep, a lack of adequate nutrition, and some discussed back injuries from lifting family members prior to their enrollment in the eShift model. Caring for their family member was described as their number one priority and their own physical needs were often negated or neglected. However, once the eShift model of care was implemented and RNs (indirectly via technology) and PSWs (directly) were in the home for extended periods of time, informal caregivers were able to get some sleep, spend time with other family members and friends, or just appreciate time to themselves. One participant described her experiences before being enrolled in the eShift model of care:

> I felt like sometimes I was awfully, awfully tired, but it was more important to be with him, to eat with him…. (Participant 6)

Another participant explained:

> I had to go to work and do everything around the house, but I mean he [palliative family member] needed care through the night….He was not able to really get up and go to the washroom by himself, he needed help….If he needed to go to the washroom then I would have to get up at night and help him with that. And he couldn't get back in the bed without help,…and he was heavy…….Even if it was only an hour in the middle of the night, it still, it broke up your sleep and what have you. (Participant 2)

Psychological. Participants were not prepared for the emotional impact of caring for their dying family member. Health care providers in the eShift model of care explained the processes of approaching death to informal caregivers so that they "understood what mechanically or physically was happening" (Participant 1), but informal caregivers need "to have that extra understanding of the emotional stages they're going through" (Participant 7). However, by having PSWs in the home for extended periods of time in the eShift model of care, informal caregivers had someone to talk to, even in the middle of the night. Participants were grateful to have someone in the home that they felt comfortable being around and who could actively listen. Participants felt that others have to experience first-hand what it is like to care for a family member in the home at end-of-life to truly realize how emotionally draining it can be to the informal caregiver. One participant explained:

> I am sure she [palliative family member] never really realized the amount of emotional impact that would have on me….You got to go through it to really realize how emotionally draining it is…. (Participant 1)

Financial. A number of participants experienced a financial burden when caring for their palliative family member in the home. Participants found it difficult to remain employed because palliative clients need '24 hour care' in the home and for many informal caregivers there was a lack of family and community supports. Moreover, many participants had to take a leave of absence from work because there were limited resources and support in the community to assist them with their caregiving duties. Participants explained that without the eShift model of care and the increased number of health care provider hours it provided, it would have been difficult to manage the care on their own and it would have depleted them financially. One participant described:

> I can tell you right now without that pilot project [eShift model of care] I wouldn't know what I would have done, I have no idea. I certainly couldn't afford to go out and pay for personal nursing, the costs are astronomical. There would have been a different outcome as far as the house and everything because I think I would have probably have had to re- mortgage the house and all of that. It could have been financially devastating…….It may have destroyed us financially to make sure that she [palliative family member] stayed home. (Participant 1)

In summary, the participants in this study provided an in-depth understanding of the experiences of informal caregivers who have lived with and cared for a family member who is received palliative care in the home as part of the eShift model of care. All of the participants in this study were grateful for the additional services of the eShift model of care; they felt a part of the health care team rather than feeling they were the sole provider of care. Many participants felt they would not have been able to cope with an in-home death or respect their palliative family member's wish to pass away at home if the eShift model of care was not available to them.

Discussion

This study explored the experiences of eight individuals who provided end-of-life care to a family member at home. The four main points of discussion that have arisen and which are further examined relate to: the positive, interpersonal relationships between health care providers and informal caregivers; the unobtrusive nature of UCPs and technology in the eShift model; the home as a preferred setting to provide end-of-life care for a loved one; and the care challenges associated with caring for a palliative family member in the home.

Palliative care involves complex, dynamic interpersonal relationships between clients, informal caregivers, and health care providers (Ward-Griffin, McWilliam, & Oudshoorn, 2012b). In the eShift model of care, participants built close, personal relationships with the PSWs. Participants explained how the PSWs were invested in meeting their complex care needs and how the PSWs recognized the need for not only physical support, but also psychosocial, and spiritual support of both the client and informal caregiver. In the eShift model of care, informal caregivers described the PSWs as members of their family and that the PSWs took the time to sit down with them to discuss personal matters and get to know the informal caregiver and client as a "family".

Previous studies describe an inequitable distribution of care between health care providers and informal caregivers due to system-level constraints (Ward-Griffin, 2001; Ward-Griffin, 2012; Ward-Griffin & McKeever, 2000). The potentially "exploitive" labour process of downloading care to informal caregivers has been found to disadvantage family caregivers and place health care providers in a position of personal conflict with respect to values related to provision of care (Ward-Griffin & McKeever, 2000). However, the findings from this research study found that health care providers (RNs and PSWs) and informal caregivers shared the caregiving duties and worked as a team to provide the necessary care. Most often in palliative care the emotional and socio-cultural aspects of care get ignored because of competing interests (e.g., issues of workload, availability of resources, and organizational policies) that nurses and health care providers are obligated to attend to (Doane & Varcoe, 2007; Ward-Griffin et al., 2012b). Health professionals may view informal caregivers as both the problem and the solution to the care of the ill family member and potential power imbalances between informal caregivers and health professionals increases the complexity of care (Oudshoorn, Ward-Griffin, & McWilliam, 2007; Ward-Griffin & McKeever, 2000). Previous studies have found that health care providers perceive informal caregivers as mainly instrumental and clinical, ignoring the familial associations and how the informal caregiver is connected to the palliative family member (Guberman, Lavoie, Pepin, Lauzon, & Montejo, 2006). Nevertheless, consistent with what was shown in the current study, the support of informal caregivers goes beyond simply providing the necessary information and training to carry out tasks and instead involves the development of genuine relationships with the informal caregiver that values the relational aspects of care (Ward-Griffin, 2012).

Participants in the current study also indicated that the consistency in health care providers was an important element of the eShift model that contributed to positive relationships between health care providers and informal caregivers. This finding is supported by other studies that suggest consistency in health care providers positively affects the relationship between informal caregivers and health care providers by fostering relationship-building and trust (Abelson, Gold, Woodward, O'Connor, & Hutchison, 2004; Anderson & Parent, 2000; Gantert, McWilliam, Ward-Griffin, & Allen, 2009; Harju & Woodward, 2003; Kushner, Baranek, & Dewar, 2008; Woodward, Abelson, & Hutchison, 2001). However, contrary to current study findings, existing studies have shown that there is a lack of consistency of health care providers in the home care sector and informal caregivers felt overwhelmed and uncomfortable as a result of the large numbers and inconsistency in health care providers coming in and out of their lives (Abelson et al., 2004; Cain et al., 2004; Woodward et al., 2001).

The visibility of the PSW in the home in the eShift model of care contrasted with the 'invisibility' of the delegating nurse within this care model. A number of participants indicated that they had very little understanding of the HHRs components of the eShift model of care. Participants had a difficult time distinguishing between PSWs and nurses and the role of the remotely located delegating nurse often went unnoticed due to the lack of visibility. A number of informal caregivers did not recognize that the tasks completed by the PSW were being delegated by the remote delegating nurse. The knowledge work of nurses, such as critical thinking and evidence informed decision-making, are highlighted within this model of care. The delegating nurses' 'task' based activity, that tends to be the stereotypical view of nursing care, was minimal. Research has shown that there is a lack of understanding of what nurses do and as a result, nurses are portrayed as educated, essential health care professionals at the client's bedside and nearly invisible in other areas of the health care system (Ashton, 2012; Cabaniss, 2011). The role of the delegating nurse within the eShift model of home care highlights the knowledge, evidence informed decision-making skills, and caring that forms the foundation of nursing practice (Cabaniss, 2011; Howell, 2012).

Existing literature has shown that health care providers found it difficult to form relationships with informal caregivers due to lack of time and lack of consistency in health care provider assignment (Gantert et al., 2009). Furthermore, previous study findings revealed that health care providers viewed the role of informal caregiver as an invaluable partner in care (Gantert et al., 2009). Earlier studies explain how there is frequently not a true partnership between health care providers and informal caregivers and that informal caregivers receive little practical assistance to support them in their caregiving duties and many are left socially isolated without adequate resources (Cain et al., 2004; Keefe, 2011; Ward-Griffin & McKeever, 2000; Weinberg, Lusenhop, Gittell, & Kautz, 2007). Nevertheless, in the eShift model of care the informal caregiver felt as though they were a member of the interprofessional care team. Findings from the current study found how health care providers and informal caregivers shared the caregiving duties and worked together to care for the palliative family member. Ideally, family members need to be considered valuable members of the health care team and important contributors to shared decision-making among all care team members in primary care (Jansen, 2008). Informal caregivers are important sources of information and because communication between different sectors of the health care system can be disjointed, informing and educating informal caregivers is important so that they can serve as liaisons between different health care providers if necessary (Bradway & Hirschman, 2008). Whether appropriate or not, the home care sector relies heavily on informal caregivers and informal caregivers should be recognized as indispensable partners in the home care setting, not as resources to be exploited (Guberman, et al., 2006; Ward-Griffin, et al., 2012a; Ward-Griffin & McKeever, 2000; Ward-Griffin, et al., 2012b). In the current study, informal caregivers felt supported by and included in the care provided to their family member through the eShift model. However, further research on the eShift model of care is needed to fully explore questions related to informal caregivers' unpaid work and the idea of 'downloading' of care to family members from a burdened health care system.

The eShift model of care uses HIT to transform how health care providers communicate and practice in the home care setting and it has led to improved health care delivery for palliative clients and their families. Although participants had little knowledge about how the technology component of the eShift model of care worked, participants felt that the use of hand-held devices at point of care led to effective communication among health care providers, resulting in efficient care for their palliative family member. Participants explained how PSWs could very quickly and efficiently be in touch with a colleague for advice or instruction, if needed. The use of technology was unobtrusive to many of the informal caregivers in this study but was perceived as an enabler of care. Similarly, previous studies investigating nurses' use of technology at point of care, such as hand-held devices, reported enhanced collaboration and communication among health care providers within or between health care facilities (Doran & Mylopoulos, 2008; Goss & Carrico, 2002; Russell et al., 2010; Vimarlund et al., 2008). Moreover, the use of hand-held devices have allowed health care providers to access up-to-date, reliable health information for point-of-care decision-making (Doran &

Mylopoulos, 2008; Goss & Carrico, 2002; Russell et al., 2010; Vimarlund et al., 2008). Integrating and providing readily available access to social support networks, such as 24/7 access to the delegating nurse in the eShift model of care, is crucial for informal caregivers who are at risk of high levels of burden, particularly during the last days of their family member's life (Liu et al., 2011). Palliative clients and their informal caregivers spend the majority of their time in the home and therefore HIT, such as hand-held devices used in the eShift model of care, help to bridge geographical distance between care team members (delegating nurses and PSWs) and enhance communication and ultimately palliative care services (Demiris et al., 2011).

Contrary to findings from this study, research evidence suggests that the use of HIT creates significant cognitive, social, and cultural barriers and can interfere with health care delivery (Cashen, Dykes, & Gerber, 2004). For example, literacy, cultural differences, language, access to technology, and education level have been identified as issues in the utilization and integration of HIT in the care setting (Cashen et al., 2004). For example, health consumers are increasingly accessing health-related information and services on the Internet (Anderson, Rainey, & Eysenbach, 2003; Sanders et al., 2012). However, without appropriate direction from health care providers, low health literate clients/informal caregivers may access unsubstantiated health information on the Internet which may contradict previously established plans of care (Anderson et al., 2003). Again not the case with participants in the current study, the increased use of computer and/or remotely monitored devices, particularly in the home setting, may result in clients and informal caregivers having limited face-to-face contact with health care providers, which can strain the client-provider relationship (Anderson et al., 2003).

In fact, participants were pleased with the services that the eShift model of care offered and many participants felt they would not have been able to cope with an in-home death or respect their palliative family member's wishes to pass away at home if the eShift model of care was not available to them. Participants in this study were appreciative of the number of health care provider hours that they received in the eShift model of care. Informal caregivers were relieved, physically and emotionally, when the PSWs came to their home and they were able to get some sleep, spend time with other family members and friends, or just appreciate time to themselves. The importance of 'personal space' is supported by previous research that found that informal caregivers need to be relieved from their caregiving duties in order to restore their ability to continue caring for their palliative family member (Cangelosi, 2009; Dunbrack, 2005; Kondro, 2012; Mensie & Steffen, 2011).

The findings of this study suggested that the support received in the eShift model of care enabled informal caregivers to respect their family member's wish to pass away in their place of choice, their own home. Several authors have found that most individuals prefer to pass away at home with their loved ones present; however, for a home-based death to be realized, the availability of informal caregivers and their willingness to provide care is required (Bee et al., 2008; Canadian Hospice Palliative Care Association, 2006; Linderholm & Friedrichsen, 2010; Stajduhar & Davies, 2005; Wilson et al., 2009). In this study, informal caregivers perceived how the eShift model of care accounted for their specific needs and that they were involved in decisions regarding the number of health care providers they would like in their care team and the time of day providers would be most helpful in meeting their needs. Research indicates that symptoms for those individuals at end-of-life vary tremendously and in order to meet clients' diverse needs, a variety of interventions will need to be incorporated in to each specific client's care plan (Henke Yarbro, Hansen Frogge, & Goodman, 2005; Proot et al., 2004; Steinhauser et al., 2000). The importance of developing a flexible and adjustable care plan that will meet the changing needs of palliative clients and their families as the health of the client declines has been previously reported (Henke Yarbro et al., 2005; Proot et al., 2004; Steinhauser et al., 2000). Without the number of hours that the eShift model provided, informal caregivers revealed that they may not have been able to cope on their own with the minimal support that was "traditionally" available for home care and they may have had to admit their palliative family member to the hospital in the last days of their life.

Previous studies have found that true "family-centered" care appears to be frequently lacking and that the needs of informal caregivers providing home-based care have often been overlooked (Clemmer et al., 2008; Kovacs, Bellin, & Fauri, 2006). When palliative care is provided in the home, the client and informal caregiver need to be considered a "unit of care" by health care providers in order for home-based palliative care to remain sustainable (Brink, 2008; Cain et al., 2004). Informal caregivers are expected to provide the majority of the care to family members in the home at end-of-life and therefore the notion of 'family as client' should be recognized and applied to health care providers' every day practice in order to support and reduce the burden placed on family caregivers (Clemmer et al., 2008). The eShift model of home care incorporates a family-centred model which engages the client and family as partners in care and addresses not only their health needs, but their needs in their larger life context.

Although the eShift model of care was described as a “godsend” and supported informal caregivers on many levels to care for their palliative family member in the home, participants indicated that they were still faced with many care challenges. The study findings support previous research related to the burden associated with informally caring for a palliative family member at end-of-life (Demiris et al., 2005; Grbich, Parker, & Maddocks, 2001; Hudson, Aranda, & Kristjanson, 2004; Keefe, 2011; Linderholm & Friedrichsen, 2010; Proot et al., 2003; Schubart, Kinzle, & Farace, 2008; Stajduhar, 2003). Similar to findings from this study, previous literature has found that informal caregivers provide uncompensated care to their palliative family members for months on end which involves a significant amount of time and energy and requires the informal caregiver to perform care tasks that are physically, psychologically, and financially demanding (Canadian Hospice Palliative Care Association, 2004; Schubart et al., 2008; Stajduhar, 2003). Furthermore, like participants in the current study, other researchers have described how family members have a difficult time adjusting to their new role as informal caregiver and feel unprepared and overwhelmed with their caregiving duties and responsibilities (Bee et al., 2008; Hokenstad, Hart, Gould, Halper, & Levine, 2005; Hudson et al., 2004; Proot et al., 2003; Schubart et al., 2008; Stajduhar, 2003; Stajduhar & Davies, 2005).

Implications for Practice, Education, Research, and Policy

The findings from this research study have implications for nursing practice, research, education, and policy.

Practice. In home-based palliative care, informal caregivers are fundamental members of the health care team (Kovacs et al., 2006; Weinberg et al., 2007). Informal caregivers provide the bulk of the care and require appropriate and timely information and support from health care providers so that they can fulfill their role as caregiver (Brink, 2008; Docherty et al., 2008; Dunbrack, 2005). Findings from this study reinforce the need for consistency in health care providers for palliative clients and their informal caregiver(s) within the home care setting (Harju & Woodward, 2003; Kushner et al., 2008). Consistency in health care providers promotes supportive relationships between clients, informal caregivers, and the health care provider, improves continuity of care, and maximizes efficiency in the home care sector (Abelson et al., 2004; Harju & Woodward, 2003; Woodward et al., 2001). Similarly, interprofessional collaboration among health care providers is recognized as a means of enhancing client care and positive health outcomes, improving provider satisfaction, and the cost-effectiveness of care (Bainbridge, Nasmith, Orchard, & Wood, 2010; Fewster-Thuente & Velsor-Friedrich, 2008).

Education. In the eShift model of care the role of the delegating nurse is to monitor and provide care for up to four home-based clients in diverse locations simultaneously using Internet enabled computer technology. Health care settings are increasingly technology enabled and schools of nursing may need to adopt an educational approach that integrates the use of HIT along with the development and facilitation of critical thinking and evidence informed knowledge in students. For technological innovations to play a significant role in the health care system, all providers need ongoing education and training to properly utilize HIT (Fetter, 2009). Health care providers and informal caregivers work collaboratively in an interprofessional care team in the eShift model of care. Greater attention to interprofessional education (IPE) supports students and health care providers to develop competencies in the form of knowledge, skills, attitudes, and behaviours that enable greater collaborative practice among interprofessional care team members (Bainbridge et al., 2010; Orchard, 2010).

Research. This study has provided a more contextualized understanding of home-based palliative informal caregiving by evaluating a new service delivery model within the home care sector that integrates UCPs, regulated health care providers, families, clients, and technology into the care encounters. However, the current study is exploratory in nature and the findings suggest the need to better understand: the relationships between members of the care team, including those between the client, informal caregiver, and various health care providers; the effectiveness of UCPs as part of the interprofessional care team in home-based palliative care; the differences in the ways that women and men describe their experiences of informally caring for a palliative family member in the home; the difference in experiences of informal caregivers caring for a palliative family member in an urban versus a rural home setting; and how the visibility of the PSW in the home seems to change the informal caregiver's perception of the role of the remote delegating nurse in the eShift model of care.

Policy. The government of Ontario has outlined how Ontarians should have the right care, at the right time, in the right place (MOHLTC, 2012). The provincial government recognizes the need to move alternate level of care (ALC) clients, particularly seniors and those individuals with chronic illness, out of the hospital and in to the comfort of their own home (MOHLTC, 2012). Yet home-based informal caregivers are becoming "burnt out" and overwhelmed with their caregiving duties. These factors point to the need for the development of care practice policy that considers the informal caregiver experience, particularly those who are caring for a family member dying at home; new models of care that consider HHRs (regulated and non-regulated) and technology that support clients to die at home; and models that maximize the HHRs team.

Limitations

The findings in this study must be interpreted in the context of the following limitations. First, only informal caregivers from London, Ontario and surrounding area were eligible to participate in the study and therefore results were limited to the urban setting and a small area of the province. Second, study participation was limited to individuals who could speak and understand English, therefore excluding informal caregivers who are deaf or whose first language is not English.

Conclusion

The purpose of this study was to acquire an understanding of the experiences of informal caregivers who lived with and cared for a family member who received palliative care as part of the eShift model of care. This includes informal caregivers' experiences of having an UCP and remotely located delegating nurse provide care to their family member and the integration of HIT into the care encounters. The findings of this study have shown how the eShift model of care of the South West CCAC has addressed some key issues for informal caregivers, such as the importance of building close, interpersonal relationships with health care providers; consistency in health care providers; meeting informal caregivers' physical, psychological, and spiritual needs; the use of HIT in the home care setting; the importance of providing palliative family members with the option to pass away in their home; and the care challenges (e.g., physical, psychological, financial) associated with caring for a palliative family member in the home. Overall, the experiences of the informal caregivers regarding the eShift model of care were positive and many of the participants felt that an in-home death would not have been possible without the innovative care model. This study of a technology enhanced model of home care delivery provides initial insights into its use in home-based palliative care and provides a foundation for future research on the eShift model of care and other innovative service delivery models in the home care sector.

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Chapter Three - Discussion

Overview of the Study

The purpose of this interpretive description study was to describe the experiences of informal caregivers who have lived with and cared for a family member who received palliative care as part of the eShift model of care. This includes their experiences of having a PSW and remote delegating nurse provide care to their family member and the integration of technology into the care encounters. The main question that guided this study was, “What are the experiences of informal caregivers living with and caring for a family member who received palliative care as part of the eShift model of care?” The data for this study was obtained from eight informal caregivers that were involved in the eShift model of care from London, Ontario and surrounding area. The themes that emerged from the analysis of data are: *The Health Care Family; Making the Invisible Visible; There’s No Place Like Home; and Burden of Love.* The researcher has addressed implications for nursing practice, education, research, and policy development that have been derived from the current research study.

Implications for Nursing Practice

Findings from this study outline the importance of meeting the complex and dynamic needs of informal caregivers caring for a palliative family member within the home setting. Participants acknowledged the holistic support that health care providers in the eShift model of care provided and how PSWs, in particular, recognized the need for not only the physical support, but also psychosocial, and spiritual support of both the client and informal caregiver. When palliative care is provided in the home, the client and informal caregiver need to be considered a “unit of care” by health care providers in order for home-based palliative care to remain sustainable (Brink, 2008; Cain, MacLean, & Sellick, 2004). Informal caregivers provide the bulk of the care in the home; however if their needs are not being met, high levels of burden may result and both the client and informal caregiver will likely need to rely on external support provided by health care providers (Brink, 2008). The needs of informal caregivers have been categorized in the literature as physical, psychosocial, and informational (Cain et al., 2004; Docherty et al., 2008; Dunbrack, 2005; Kovacs, Bellin, & Fauri, 2006). Informal caregivers take on a key role in end-of-life care in the home and they require appropriate and timely information and support so that they can fulfill the role they have chosen or assumed (Docherty et al., 2008; Dunbrack, 2005). With the necessary support and sufficient resources, much of the physical and psychological distress of informal caregivers can be reduced (Cain et al., 2004; Kovacs et al., 2006; Weinberg, Lusenhop, Gittell, & Kautz, 2007).

Due to the social, economic, and technological changes that have taken place in the health care system, greater medical care has shifted from institutionally-based care to the home setting and greater responsibility is being placed on informal caregivers in the home (Cain et al., 2004; Dunbrack, 2005; Weinberg et al., 2007). In the home care sector, informal caregivers are being asked to take an active role as members of the health care team in managing care and carrying out medical interventions; however interactions between health care providers and informal caregivers often prove inadequate when it comes to properly training and supporting informal caregivers in their provider role (Docherty et al., 2008; Weinberg et al., 2007). Health care providers often do not identify informal caregivers as fundamental members of the health care team, causing informal caregivers to be ill-equipped to provide adequate, safe care to their family members (Kovacs et al., 2006; Weinberg et al., 2007). Ward-Griffin and McKeever (2000) explain how discrepancies in expectations between nurses and informal caregivers has resulted in a lack of fulfillment, a failure to exchange information, and missed opportunities to address informal caregiver and client needs. In the eShift model of care, health care providers built close, personal relationships with informal caregivers, were invested in working collaboratively with informal caregivers, and recognized the need for physical, psychosocial, and spiritual support of both the client and family. Consistent with what was shown in the current study, the support of informal caregivers goes beyond simply providing the necessary information and training to carry out tasks and instead involves the development of genuine relationships with the informal caregiver that values the relational aspects of care (Ward-Griffin, 2012). As Weinberg et al. (2007) explain, “Policymakers, health care administrators, and providers need to emphasize not only what services or kinds of information are delivered or how frequently but also the manner in which they are delivered” (p. 147).

Consistency of health care providers is a valued attribute perceived by clients and informal caregivers in the home care sector (Harju & Woodward, 2003; Kushner, Baranek, & Dewar, 2008). In this study, a number of informal caregivers were initially overwhelmed by the constant barrage of health care providers entering their home, their personal space. However, consistent and regularly scheduled health providers, an important aspect of the eShift model of care, improved the continuity of care and provided the context for relationship building and trust. With the introduction of managed competition in the home care sector in Ontario, the quality of care provided to clients and informal caregivers has been threatened by the lack of continuity among service providers (Abelson, Gold, Woodward, O'Connor, & Hutchison, 2004; Denton, Zeytinoglu, Davies, & Hunter, 2006; Harju & Woodward, 2003). Clients and their families may experience numerous providers and service agency changes during transition periods when agencies are competing for contracts (Denton et al., 2006; Kushner et al., 2008). These disruptions not only affect the client-provider relationship that takes time to establish, but also affects the supportive social relationships between clients, family members and the health care provider (Abelson et al., 2004; Anderson & Parent, 2000; Harju & Woodward, 2003).

The eShift model of care is premised on an interprofessional team of health care providers and the integration of UCPs, which is something that has not been discussed in the literature to a great extent. Interprofessional collaboration would be an important consideration for home care agencies as they plan their workforce. Interprofessional collaboration among health care providers in a variety of health care settings is recognized as a means of enhancing client care and positive health outcomes, improving provider satisfaction, and the cost-effectiveness of care (Bainbridge, Nasmith, Orchard, & Wood, 2010; Fewster-Thuente & Velsor-Friedrich, 2008). The eShift model of care provides preliminary evidence for a hybrid interprofessional care team that recognizes formal (e.g., nurses, unregulated care providers (UCPs)) and informal (family members) team members. Informally caring for a family member in the home is a role that family members consider to be both essential and expected of them (Gantert, McWilliam, Ward-Griffin, & Allen, 2009; Stajduhar, 2003). However, demographic and social changes have caused concerns around the ability of informal caregivers to provide the bulk of the care to family members in the home and there is a need for health care providers and informal caregivers to coordinate their efforts (Gantert et al., 2009). Lindeke and Siekert (2005) describe collaboration in the health care field as a multifaceted process that involves purposeful knowledge sharing and joint responsibility for client care. Due to material and human resource shortages, client safety issues, and the complex health care needs of clients in the home care sector, health care providers need to work collaboratively in interprofessional teams "to ensure consistent, continuous, and reliable care" (Bainbridge et al., 2010, p. 6). Interprofessional collaboration plays a key role in reducing errors, duplication of services, and the clarification of roles (Fewster-Thuente & Velsor-Friedrich, 2008). Specifically, palliative care relies greatly on a range of disciplines, knowledge, skill, and experience and due to the complexity of physical and psychosocial concerns of palliative clients and their families, collaboration among members of the entire health care team is essential to provide effective and efficient care (Blacker & Deveau, 2010; Crawford & Price, 2003). When collaboration takes place among the care team, including the client and family, goals of client care can be mutually agreed upon and each health provider is aware of and understands the process on how the goals will be attained to achieve optimal health of the client (Fewster-Thuente & Velsor-Friedrich, 2008).

Implications for Nursing Education

Within the eShift model of care the role of the delegating nurse is to direct care provided by PSWs in the home and to monitor and provide care for up to four home-based clients in diverse locations simultaneously from a remote location. Therefore, the delegating nurse does not provide hands-on care *per se*, but instead utilizes the critical thinking skills and evidence informed knowledge needed to care for home-based palliative clients. With increased complexity of care in the home care sector it is important for nurses to invest in developing critical thinking competencies and evidence informed knowledge in order to make calculated judgments in care (Berkow, Virkstis, Stewart, Aronson, & Donohue, 2011; Wangensteen, Johansson, Bjorkstrom, & Nordstrom, 2010). Moreover, as nurses begin to take on roles in technology enabled home care settings, nursing education may want to adopt an educational approach that integrates the development and facilitation of critical thinking and evidence informed knowledge in students.

Study findings suggest that the implementation of technology, such as hand-held devices, in the home care sector has enabled health care providers to communicate with each other more effectively and efficiently. Previous study findings have shown that hand-held devices assist health care providers, including UCPs, to collect and utilize up-to-date, evidence-based knowledge and information at point of care and in a secure manner (Doran, Bloomberg, & Mylopoulos., 2008; Garrett & Klein, 2008). In order for technological innovations to play a meaningful role in the health care system, all providers need ongoing education and training to effectively utilize health information technology (HIT) (Fetter, 2009). Currently, most health care organizations have their own policies regarding information technology (IT) practices and nursing students are receiving different training in HIT in their clinical practice settings, most of which is quite limited (Fetter, 2009). Fetter (2009) explains that if HIT is to become an assumed component of nursing practice then there needs to be consistency in systems and competencies within nursing schools and health care organizations. This study suggests that technology, combined with health human resources (HHRs), may play an important role in home care delivery within home care settings. Nursing education programs will want to consider the place of HIT as they examine nursing curriculum content.

Health care providers and informal caregivers work collaboratively in an interprofessional care team in the eShift model of care by sharing the decision-making and caregiving duties. In the eShift model of care, nurses and UCPs work closely with each other and are connected by way of a hand-held device, an iPhone. The use of HIT in the home care setting has expanded the utilization of health providers and has led to real-time care coordination among members of the care team. Through interprofessional education (IPE), students and health care providers can develop competencies in the form of knowledge, skills, attitudes, and behaviours that may enable them to practice collaboratively with members of their care team(s) (Bainbridge et al., 2010; Orchard, 2010). Most health professional education occurs in silos with little opportunity for faculty or students to learn and understand other discipline's roles or to collaborate with each other (Barnsteiner, Disch, Hall, Mayer, & Moore, 2007; Orchard, 2010). IPE that focuses on teamwork, collaboration, problem-solving, and decision-making beyond one specific discipline may result in an improved ability to navigate and better understand all aspects of the current health care system (Bainbridge et al., 2010; Barnsteiner et al., 2007; Orchard, 2010).

Implications for Nursing Research

The shifting of health care services from an institutional setting to the home has a significant impact on informal caregivers and it is evident how care provision in the home influences and shapes the experiences of informal caregivers who are caring for a palliative family member. Research conducted to date has provided an understanding of some of the individual experiences of informal caregivers caring for a palliative family member in the home (Canadian Hospice Palliative Care Association, 2004; Bee, Barnes, & Luker, 2008; Linderholm & Friedrichsen, 2010; Stajduhar, 2003; Stajduhar & Davies, 2005). This study has developed a more contextualized understanding by examining the experiences of informal caregivers involved in a new service delivery model within the home care sector that integrates personal support workers, remote delegating nurses, and technology into palliative care encounters. However, after completing this study, further avenues for investigation have been identified. Study findings suggest that there is a need to better understand: the relationships between members of the care team, including those between the client, informal caregiver, and various health care providers; the effectiveness of integrating UCPs as part of the interprofessional care team in home-based palliative care; the difference in the ways that women and men describe their experiences of informally caring for a palliative family member in the home; the difference in experiences of informal caregivers caring for a palliative family member in an urban versus a rural home setting; and how the visibility of the PSW in the home seems to change the informal caregiver's perception of the role of the remote delegating nurse in the eShift model of care. Nursing studies on the use of service delivery models that utilize personal support workers, remotely located registered nurses, and technology in care encounters are scarce, and therefore further research is needed to confirm this study's findings.

Implications for Policy Development

The findings from this study will provide some direction for policy makers to make informed decisions in the area of home-based palliative care. Findings from this study have shown that informal caregivers were satisfied with the services that the eShift model of care offered and for the additional hours of nursing care they received in the last three to four weeks of their family member’s life. The current policy document, Ontario’s Action Plan for Health Care, focuses on keeping seniors at home (Ministry of Health and Long-term Care [MOHLTC], 2012). The Ontario government has identified as a strategic priority improved access and availability of services that allow seniors to stay in their home by utilizing community support services, home care services, assistive devices, assisted living services/supportive housing, long-term care beds and end-of-life care (MOHLTC, 2012). The main focus of Ontario’s Aging at Home Strategy is innovation, finding new ways to provide supportive services to seniors and developing new preventive and wellness services (MOHLTC, 2010). The eShift model of care aligns with the current policy direction set by the government of Ontario which states that Ontarians should have the right care, at the right time, in the right place (MOHLTC, 2012). The provincial government recognizes the need to move alternate level of care (ALC) clients, particularly seniors and those individuals with chronic illness, out of the hospital and to their own home when possible (MOHLTC, 2012). However, with the shortage of HHRs, particularly registered nurses, and the growing demands in the home care sector, there has been an increased reliance on UCPs in all sectors of the Canadian health system (Canadian Nurses Association, 2009). The aim of the provincial government is to find ways to “fully maximize the potential of our range of health care professionals" (MOHLTC, 2012, p. 10). By expanding the scope of practice of a number of health care providers, they will be able to contribute their full potential to the well-being of clients (MOHLTC, 2012). Government policy decisions require robust evidence and the Ontario government has committed to evidence-informed decisions (MOHLTC, 2012). This study provides beginning evidence regarding a new model of care and its impact on informal caregivers and home care.

In the current study, participants described the physical, psychological, and financial burdens they encountered while informally caring for their palliative family member in the home. Participants experienced a lack of sleep, inadequate nutrition, lower back problems from lifting and transferring their palliative family member in and out of bed, and found the caregiving experience to be emotionally draining. Moreover, participants in this study found it difficult to remain employed and many participants took a leave of absence from work or their personal business suffered because of their caregiving duties. The impact of caring for a family member in the home has been well documented in the literature and recent research studies have documented that informal caregivers themselves report unmet needs and desire more information and support from health care providers (Hudson, Aranda, & Kristjanson, 2004; Stajduhar & Davies, 2005; Vogel, 2011). Informal caregivers are having to take on the bulk of the care of their family members and if governments continue to rely on families for their role in provision of care and support, then consideration must be given to the amount of stress informal caregiving has on these families - physically, mentally, and financially (Anderson & Parent, 2000; Canadian Hospice Palliative Care Association, 2004; Clemmer, Ward-Griffin, & Forbes, 2008; Stajduhar, 2003). As Anderson and Parent

(2000) explain, “Although short-term monetary gains may be achieved by limiting the dollars available to home care, the long-term consequences may be more costly” (p.21).

Conclusion

As the delivery of health care services continues to shift from institutional care settings to the home, new service delivery models which address the unique needs of those who require home-based services are needed. There is a need to better understand the complex and dynamic process of informally caring for a family member in the home at end-of-life. This interpretive description study describes the experiences of informal caregivers who have lived with and cared for a family member who received palliative care as part of the eShift model of care. The findings of this study have shown how the eShift model of care of the South West Community Care Access Centre (South West CCAC) has addressed some key issues for informal caregivers, such as the importance of building close, personal relationships with health care providers; consistency in health care providers; meeting informal caregivers’ physical, psychological, and spiritual needs; the use of HIT in the home care setting; the importance of allowing palliative family members to pass away in their home; and the physical, psychological, and financial challenges associated with caring for a palliative family member in the home. Overall, the experiences of informal caregivers regarding the eShift model of care were positive and many of the participants felt that an in-home death would not have been possible without the innovative care model. Future research is needed to better understand the experiences of those individuals who informally care for a palliative family member in the home and how the use of technology, and innovative models of care can be embedded in home-based palliative care. The current study is one of the first to examine this model of care and provides a foundation for future research on the eShift model of care.

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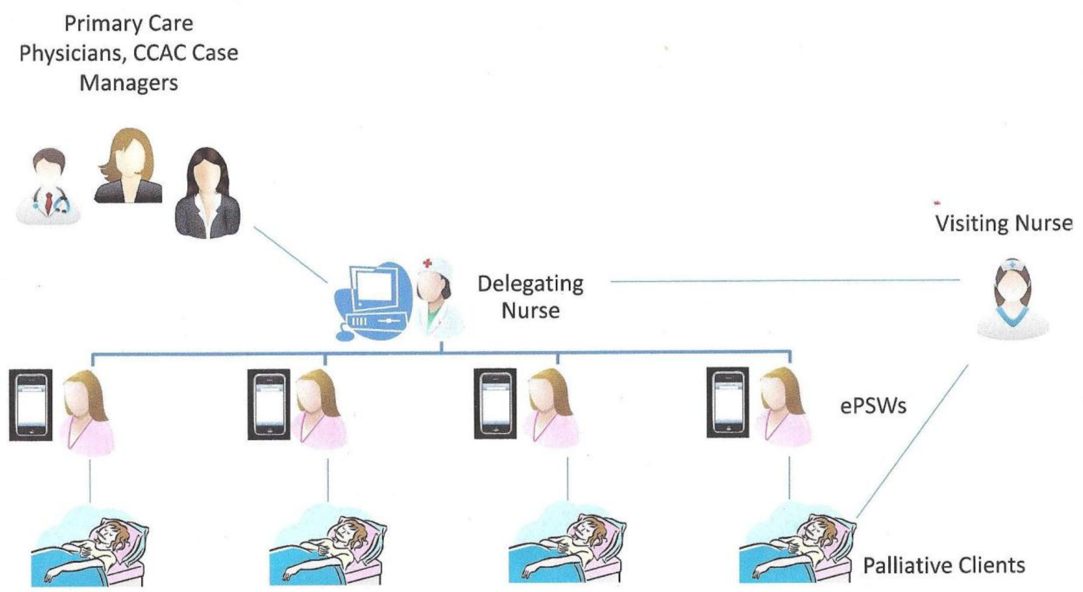
Figure 1

The eShift Model of Care



Appendix A

Script for Case Managers

Hello _________,

I would like to talk to you about a study being conducted to evaluate a component of the eShift model of care. The study is being conducted by a Master of Science in Nursing student, Ashley Ralph, in collaboration with Dr. Sandra Regan and Dr. Lorie Donelle, from Western University. The study will focus on caregivers and will explore their personal experiences and what it was like to have lived with and cared for a family member who received palliative care as part of the eShift model of care. Ms. Ralph would like to interview caregivers for a maximum of two hours and at a place that is convenient for you. After the first interview if Ms. Ralph requires a better understanding of your experience, she may ask to interview you for a second time for a maximum of one hour. If you are interested in participating in this study, I can send you a letter of information that outlines the study in more depth and you can contact me or one of the researchers if you would like to be a participant in the study.

Thank-you for your time.

Appendix B

Letter of Information and Consent to Participate in Research

Page 1 of 4 **Initial_______**

Study Title: The eShift Model of Care: Informal Caregivers' Experience of Caring for a Family Member who Received Palliative Care at Home

Graduate Student: Ashley Ralph, RN, BScN, MScN Graduate Student, School of Nursing, Western University

Study Investigators:

Sandra Regan, PhD, RN	Dr. Lorie Donelle, PhD, RN
Assistant Professor, School of Nursing	Assistant Professor, School of Nursing
Western University	Western University
London, Ontario	London, Ontario

Introduction

You are being invited to participate in a research study designed to explore what it is like for informal caregivers who have lived with and cared for a family member who received palliative care as part of the eShift model of care. This letter will provide you with the information you require to make an informed decision on participating in this research study. It is important for you to understand why the study is being conducted and what it will involve. 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.
You will be given a copy of this letter of information and consent form once it has been signed.

Purpose

The purpose of this research study is to describe the experiences of informal caregivers who have cared for a family member who received palliative care as part of the eShift model of care.

Number of Participants

There will be 6 to 12 participants involved in this study.

Who is Eligible to Participate?

To participate, you must be over the age of 18 and able to read, write and speak English. Participants must have had a family member who received palliative care in the eShift model of care that passed away a minimum of three months ago and up to three years post death, were the informal caregiver to the family member who received palliative care, and lived with the family member who received palliative care while being a part of the eShift model of care. Lastly, participants need to be from London, Ontario and surrounding area. A research stipend of $25.00 will be provided to you for expenses incurred (travel, parking, child care, etc.) as a result of study 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.

Data Collection Methods

Data for this study will be collected through individual, audio-taped interviews with you. Interviews will take place at your home, or at a place where you feel most comfortable. Interviews will last a maximum of two hours and will consist of 15 to 20 open-ended questions for you to answer. The researcher may ask you to meet a second time for a maximum of one hour if she requires a deeper understanding of your experience.

Information about Study Results

Once the study is complete, study findings will be: shared with the public in a journal; presented to employees at the South West Community Care Access Centre and interested stakeholders in the home care sector; a brief summary of the research report will be submitted to the London Free Press to inform the public on the advancements and available services in the home care setting; and lastly, an executive summary or briefing note will be developed to bring awareness to government and key decision-makers to inform them of the importance of investing money in home care services and in funding technology-based initiatives in the home care sector. If you would like a copy of the report, you can indicate that to the researcher at the time of the interview.

Anticipated Risks and Benefits for Participating in the Study

There are no known risks to your participation in this study. However, discussion of your recent experience may bring up feelings of bereavement. A list of bereavement services available in London, Ontario, that are free of charge, will be provided to you. If you agree to participate, you will contribute information that may be beneficial to future informal caregivers who are caring for a family member who is receiving palliative care in the home setting.

Page 3 of 4 Initial_______

Participation in Concurrent or Future Studies

If you are participating in another study at this time, please inform the researcher right away to determine if it is appropriate for you to participate in this study.

Privacy and 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. All data will be stored in a locked cabinet in Dr. Sandra Regan's office at Western University, will only be accessed by members of the research team, and computer files will be password protected. Non-identifiable data will be kept for 10 years after the study is complete for potential future secondary analysis and will then be shredded and destroyed to maintain confidentiality.

No Waiver of Rights

You do not waive any legal rights by signing the consent form.

Contact(s) for Study Questions or Issues

You can contact the study supervisors, Dr. Sandra Regan or Dr. Lorie Donelle if you have any questions regarding the study. They will attempt to answer any questions you may have prior to, during, or following the study. If you have any additional questions about your rights as a research participant or the conduct of the study you may contact the Office of Research Ethics.

Sincerely,

Ashley Ralph,
RN, BScN, MScN Graduate Student
Western University

Page 4 of 4 **Initial_______**

Study Title: The eShift Model of Care: Informal Caregivers' Experience of Caring for a Family Member who Received Palliative Care at Home

Participant Consent

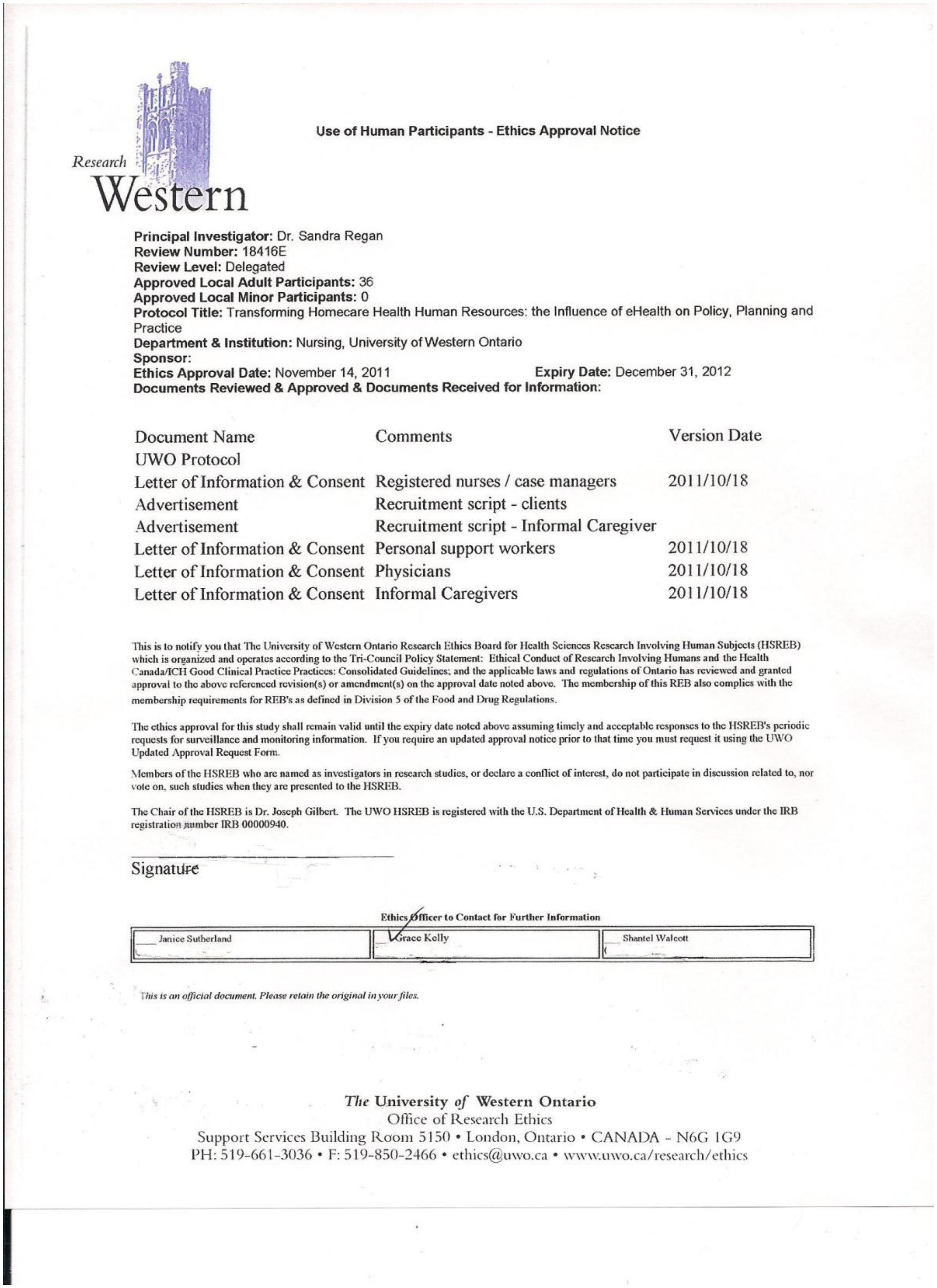
I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

Name of Participant: (Please print) ________________________________
Signature: ____
Date: _________________________________

Witness: (Please print) ____
Signature: ____
Date: _________________________________

Appendix C

Western University Ethics Approval



Research Western

Use of Human Participants - Ethics Approval Notice

Principal Investigator: Dr. Sandra Regan
Review Number: 18416E
Review Level: Delegated
Approved Local Adult Participants: 36
Approved Local Minor Participants: 0
Protocol Title: Transforming Homecare Health Human Resources: the Influence of eHealth on Policy, Planning and Practice
Department & Institution: Nursing, University of Western Ontario
Sponsor:
Ethics Approval Date: November 14, 2011 **Expiry Date:** December 31, 2012
Documents Reviewed & Approved & Documents Received for Information:

Document Name	Comments	Version Date
UWO Protocol		
Letter of Information & Consent	Registered nurses / case managers	2011/10/18
Advertisement	Recruitment script - clients	
Advertisement	Recruitment script - Informal Caregiver	
Letter of Information & Consent	Personal support workers	2011/10/18
Letter of Information & Consent	Physicians	2011/10/18
Letter of Information & Consent	Informal Caregivers	2011/10/18

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The UWO HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Signature

Ethics Officer to Contact for Further Information

___ Janice Sutherland	✓ Grace Kelly	___ Shantel Walcott

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

The University of Western Ontario
Office of Research Ethics
Support Services Building Room 5150 • London, Ontario • CANADA - N6G 1G9
PH: 519-661-3036 • F: 519-850-2466 • ethics@uwo.ca • www.uwo.ca/research/ethics

Appendix D

Bereavement Services

Describing your experiences of your family member who received palliative care as part of the eShift model of care may cause emotions to resurface. Please find bereavement services below that you can access in London, Ontario that are free of charge. Please remember that there is no timeline on bereavement.

Hospice of London

Bereavement support programs that are offered at Hospice of London include:

- Volunteer Visiting Program
- PATCH for Bereaved Children
- “Walking with Friends” Bereavement walking group
- Mindfulness for Healing
- Massage Therapy
- Reflexology
- Healing Touch and Bereavement Support
- Reiki
- Hair Care/Manicures
- BRIDGES (a support group for partner loss)

Appendix E

Semi-Structured Interview Guide

Today is _____________ at _____ and I will be interviewing participant ____________.

Caregiving Role: To start, I will be asking you questions about your caregiving experience with _________.

1. Can you please tell me about your relationship to ________ ?
2. How long were you a caregiver for your family member?
3. How long ago did your ________ pass away?
4. What was your role as a caregiver?

eShift Model of Care: The next few questions will focus on the eShift model of care and your experiences of participating in the program.

5. Can you please tell me how you came to know about the eShift model of care?
6. Can you tell me a bit about how the eShift model of care works?
7. For how long was _________ receiving care in the eShift model of care?
8. Before the eShift model of care, had you ever received any kind of services from the South West CCAC?
    - What kind of services have you received from the South West Community Care Access Centre (South West CCAC)?
9. What were your expectations of the eShift model of care?
    - Did the program achieve what you wanted it to?
10. How did the eShift model of care change the quality of care from previous care that was provided to your family member?
11. How did you feel about always having someone available/on-call, especially during the night, if you needed help?
12. How important was it to have your family member stay at home? What impact did the eShift model of care have on you to allow this to happen?
13. Did you receive day or night support and how did this support you as an informal caregiver?
14. How did the eShift model of care influence your relationship with your family member?

Personal Support Workers: The next set of questions will ask about the formal caregivers who came to your house and provided care to your family member.

15. You may have noticed that there were different care providers that came to your house while you were involved in the eShift model of care. Could you please tell me about the different care providers that came to your home and what their roles were in caring for your ________?
16. Focusing on the personal support worker, tell me about the kinds of things he/she did for you and your family member?
17. How did the care that the PSW provided differ from the care that the registered nurse provided?

18. How would you describe your role when formal caregivers, such as the PSWs, came to your house – did you see yourself as being ‘cared for’ or rather as a ‘care provider’?

Technology: The following questions will now ask about the technology component of the eShift model of care.

19. You may have noticed that the personal support worker used a device like a smart phone/cell phone. What did you think about this?
    a. Did the personal support worker ever explain to you how he/she used this?
    b. Do you think having this device assisted the personal support worker to provide care to you and your family member?

Final Thoughts: The last set of questions will ask about how you are coping with your loss and any final thoughts that you may have about the eShift model of care.

20. If given the chance to make the decision again, why would you, or why wouldn’t you be involved in the eShift model of care?
21. How have you been coping with your loss?
    a. Has any component of the eShift model of care changed the way you’ve felt during the bereavement process?
22. Are there any final thoughts or experiences that you would like to share with me about your involvement in the eShift model of care?

Appendix F

Curriculum Vitae

Name:	Ashley Ralph
Place of Birth:	London, Ontario, Canada
Year of Birth:	1987
Post-secondary Education and Degrees:	Western University London, Ontario, Canada 2006-2010 BScN with distinction
	Western University London, Ontario, Canada 2010-2012 MScN (c)
Related Work Experience:	Case Manager South West Community Care Access Centre 2012-Present
	Teaching Assistant Western University 2010-2011
	Graduate Research Assistant Western University 2012
Professional Associations:	Member, College of Nurses of Ontario 2010 – Present
	Member, Registered Nurses' Association of Ontario 2006 – Present
	Member, Sigma Theta Tau International, Iota Omicron Chapter 2011 – Present