Exploring the role of a health system navigator to support chronically ill older adults through health care transitions

by

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AUTHOR'S DECLARATION

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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Abstract

Poorly executed transitions between health care settings can lead to poor outcomes and greater use of health care resources for older adults. Older adults with complex needs often receive care from many health care providers in multiple care settings, and face greater risk of experiencing fragmented care. System navigation roles have been suggested as an innovative strategy to address these challenges, yet there is a lack of consensus on the desired characteristics and effectiveness of the role. The goal of this research is to develop a framework for a system navigation role to enhance coordination of formal and community-based services to older persons with chronic disease through health care transitions. This research gathered information from multiple perspectives and a variety of data sources, including a systematic literature review, focus group interviews and in-depth interviews with a variety of health care consumers and providers. A critical analysis of collected data, using a frame derived from content analysis, sought to understand how older adults navigate the health care system, and subsequently to explore the potential of a "system navigator" role to facilitate successful transitions across care settings. Finally, following a grounded theory approach, a model was empirically derived to reflect what role system navigators may have on the experience of older adults navigating the health care system in Waterloo Wellington. This research study aimed to describe optimal care coordination practices across the continuum of care for complex, high-risk individuals, such as those with chronic disease or hip fracture. Ultimately, this study may lead to improved patient care coordination, safety and satisfaction during transitions and in accessing community services, which may assist patients to achieve a higher quality of life.

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CHAPTER 1: INTRODUCTION, BACKGROUND, RATIONALE AND RESEARCH OBJECTIVES

1.1 Introduction

Transitions between health care settings are difficult for patients in general (Institute of Medicine, 2001; Powell, 2006), but present even greater risks for older persons (Boling, 2009; Lin, Hung, Liao, Sheen & Jong, 2006; Naylor, 2004; Simpson, 2002). The trend towards functional specialization in medical care (Charlton & Andras, 2005) and the elderly patient's higher likelihood of having multiple morbidities (McMullan, McGlasson, Waddell, & Holmes, 2010), results in many touch points with the health system during an episode of care (Ma, Coleman, Fish, Lin, & Kramer, 2004). Consequently, there is increasing fragmentation in the care received by these elderly patients (Boyd et al., 2007; Clarfield, Bergman & Kane 2001; Golden, Tewary, Dang & Roos, 2010). With fragmentation comes threats associated with the incomplete transfer of information between health care providers (Kripalani et al., 2007; Golden, Tewary, Dang & Roos, 2010), and greater challenges in managing and coordinating care delivery to ensure optimal outcomes (Golden, Tewary, Dang & Roos, 2010; Grachek, 2000).

Improved efficiency through quality improvement tools such as critical pathways (Pearson, Kleefield, Soukop, Cook, & Lee, 2001) and a declining number of hospital beds (Devenny, 2007) are reducing lengths of hospital stay (Waterloo Wellington-Local Health Integration Network, 2009). Shorter hospital stays and the potential for home rehabilitation to improve outcomes for some patients (Kane et al., 2000) are two of many factors converging to place pressure on community care facilities and services which support elderly patients as they return to their residences. For the patient, transitions across the continuum of care can be a time of great vulnerability (Coleman, 2003; Forester, Murff, Peterson, Gandhi & Bates, 2003); yet they and their family or informal caregivers are often the only "common thread" as they access and coordinate care amongst a long list of providers (Coleman, 2003). When appropriate care or resources are not available in the community, older patients will often remain in higher level (and more resource intensive) care (Mayhew, 2009) exacerbating wait times for others needing the services.

Integration of healthcare providers across the continuum of care is viewed as a means to prevent unnecessary use of hospital resources (Golden Tewary, Dang & Roos, 2010), and improve access to care and user satisfaction (Grone & Garcia-Barbero, 2001). It has also been proposed as a solution to the fragmentation which results when multiple disciplines manage patients across a variety of geographic locations, particularly vulnerable populations such as the frail elderly (Kodner, 2009; Suter, Oelke, Adair & Armitage, 2009). However, there are substantial barriers to complete integration of health services, such as information sharing and funding models, and the results of integrated systems are mixed (Armitage, Suter, Oelke, & Adair, 2009; Kodner, 2009). Canadian models, such as System of Integrated Care for Older Persons (SIPA- French acronym) (Beland et al., 2006), PRISMA (Hebert et al., 2003) and

Comprehensive Home Option of Integrated Care (CHOICE) (CapitalCare, 2007) have shown positive outcomes for reductions in hospital and institutionalization costs, functional decline and caregiver burden, given the difficulty of addressing the complex issue of overall system integration, a variety of strategies implemented at an organizational level have been developed to help prevent hospital admissions or readmissions, accelerate discharges, and improve the quality of transitions between providers and healthcare settings. Many of these innovative programs have focused on the elderly. While there is evidence that the health of the elderly is improving (Lubitz, Cai, Kramarow, & Lentzner, 2003), the large majority of healthcare costs are incurred during the senior years (Alemayehu & Warner, 2004) making this an important target for transformative programs aimed at improving care and reducing overall costs to the system. One such innovation is the use of health care workers whose role is to facilitate safe and effective transitions across health care settings; roles commonly referred to as patient or system navigators.

System navigators were first established in the 1990s in association with the American Cancer Society (Dohan & Shrag, 2005; Freeman, 2006), and in June 2005 were entrenched into U.S. law as the "Patient Navigator, Outreach, and Chronic Disease Prevention Act" of 2003. Due to its origins in cancer care, the system navigator's role is intended to, "identify, anticipate, and help to alleviate barriers" in accessing cancer screening, timely diagnosis and treatment for patients from low socioeconomic communities (Freeman, 2006). The system navigator's focus on reducing barriers in cancer care delivery differentiates this role from other similar roles such as case managers and advocates, according to Dohan and Schrag's (2005) review of navigation services. Wells and colleagues' (2008) review of the effectiveness of the system navigator model in practice assumed a similar barrier-focused approach, and reported some impact on screening and adherence to treatment regimes in cancer care; although a lack of scientific rigour in study measurement precluded the assessment of other outcomes.

While there is evidence of success with some system navigation models of care, there has been insufficient research into the impact of system navigation roles on their target population. Further examination of system navigation models and outcomes is warranted given their growing adoption in a variety of healthcare settings.

1.2 Background

1.2.1 Seniors Navigating the Health Care System Across Care Transitions

The challenge of health system navigation for older adults is not a new issue, but it remains a major concern for older adults, their families, health care providers and health care decision makers (Boyd et al., 2009). The most significant instigator for these navigation challenges is the breakdown of support during care transitions, and the resulting problematic passage of some patients moving across care settings. Each care setting, from hospital to home care, shares responsibility for patients experiencing a care transition, yet with few accountability mechanisms, the locus of responsibility is often unclear, and gaps are inevitable.

Ontario has dedicated resources to improving the flow of patients through hospitals and emergency departments (Ontario Community Support Association, 2007) resulting in fast-paced, discharge-focused care. Shortened hospital stays, which accompany improved patient flow in hospitals, may be beneficial for frail seniors who decline in functioning 5% each day they spend in hospital (Rigg et al., 2006). However, in 2006, the Canadian Institute of Health Information found 19% of patients designated Alternative Levels of Care (ALC) - those no longer requiring acute services (OCSA, 2007) - had been discharged to their home without any supportive services (Jokovic et al., 2006). For this group of individuals, the majority of whom are frail older adults, the predominant long term goal is a return to their residence; but one in five individuals are not experiencing this successful transition from hospital to home (Jokovic et al., 2006).

Current health care services are often not meeting the needs of chronically ill individuals, across many levels of care (Chen, Brown, Archibald, Aliotta, Fox, 2000). For the purposes of this study, chronic illness is defined as diseases of long duration that generally progress slowly, such as heart disease, stroke, cancer and diabetes (WHO, 2011). Chronic disease is the leading cause of mortality in the world (WHO, 2011), and constitutes a great portion of health care service use. Older adults with three of more chronic health conditions reported using three times as many health care services, including emergency department visits, compared with older adults with no chronic disease (Canadian Institute for Health Information, 2011).

Not only is care often fragmented with little communication across settings and providers (Manian, 1999), care for individuals with chronic disease is commonly overly dependent on patient-initiated follow-up (Chen, Brown, Archibald, Aliotta, Fox, 2000). Proactively assisting older adults to

navigate the health system may help them access necessary care or services to better manage acute and chronic conditions.

Frailty is an increased state of vulnerability to adverse health outcomes as a result of the accumulation of age-associated deficits that reduce physiologic reserve across multiple systems (Rockwood et al., 1999; Espinoza & Walston, 2005; Rockwood et al. 2005; Bergman et al., 2007). Frailty is usually associated with chronic disease (Fried et al., 2001). Managing frailty among older adults is challenged by multiple medical and social issues as well as health systems that are unable to meet the needs of an increasingly frail population (Johri, Beland & Bergman, 2003). Frailty, as a chronic condition, requires an approach to care that includes prevention management of chronic conditions, and can be optimally managed within the Chronic Disease Prevention and Management Model (Heckman, 2011). This model address the role of the community, health system, patient and health care providers to prevent and manage the adverse outcomes related to chronic disease (Ministry of Health and Long Term Care, 2006), and the intensity of the intervention is tailored to their risk for adverse outcomes.

The Waterloo-Wellington Local Health Integration Network (WW-LHIN) is a regional health authority in southwest Ontario which coordinates a wide range of health care sectors, and is responsible for the development of "innovative, collaborative solutions leading to more timely access to high quality services for the residents of Waterloo Wellington" (WW-LHIN, 2011). Waterloo Wellington has a population of about 750 000, distributed across a mix of urban and rural land developments, from towns with populations of 6 000 to cities with populations close to 200 000 (WW-LHIN, 2009). As the overarching, health system governance structure in the Waterloo Wellington region, the LHIN is an important player in the development of a local system navigation strategy. According to their 2010 budgetary plans, the WW-LHIN funded initiatives to improve supportive care for individuals living at home; one of its largest investments was in community health services. This was a significant investment above the baseline funding amounts, at a 15 percent increase, double the amount of money allotted to the Community Care Access Centre and to Long-Term Care homes combined, and more than 4 times the dollar investment in hospital operations (WW-LHIN, 2009). This initiative includes not only formal home care services, but informal services such as transportation, meal preparation, exercise programs and education programs. The rationale for the large investment is to improve a variety of outcomes, identified by the seven priorities set by the WW-LHIN:

1. Improving Access to Emergency Department Care
2. Improving Access to Primary Care
3. Improving Access to and Coordination of Addictions and Mental Health Services

4. Improving Chronic Disease Management

5. Improving Outcomes for Stroke Patients through Integrated Programs

6. Decreasing ALC Days

7. Improving Patient Safety and Enhancing Quality of Care

(WW GSN Work Plan, 2010; WW-LHIN, 2009)

Despite these priority investments, emergency departments still respond to patients presenting with non-emergent needs, many of which have been directly attributed to a lack of patient knowledge of availability and accessibility of primary and community-based care (WW-LHIN, 2009). This may reflect a break down in linkage between patients and appropriate services and suggests the next challenge for the WW-LHIN is to coordinate these community- based health services which exist across the region to support the needs of the diverse aging population.

A recent community engagement feedback survey aimed to prioritize the health needs of individuals living in Waterloo Wellington, reported that the general public lacks knowledge about navigating the health care system. Also, the survey reported seniors' concerns about continuance of their care from one setting to another (WW-LHIN, 2009). A large investment in one health sector, such as community services in 2008-2009, should be coupled with a navigation strategy to ensure older adults are aware of the services and know how to access them.

As older adults continue to experience challenges while navigating the health system, it is clear that health care resources should continue to target programs which facilitate access to health services across the continuum of care. A combination of care coordination and advocacy, which could be provided by system navigators, may represent an appropriate solution to ensure coordinated care. Although the concept of a system navigator role is a relatively to chronically ill older adults, it is considered consistent with the best care coordination practices identified in a study by Chen and colleagues (2000). In this study, conducted by program evaluators and policy researchers, 29 case management and disease management programs were examined and three constructs were consistently identified across successful coordinated care programs: assessing the patient's needs and developing a care plan, implementing and delivering the care plan; and finally reassessing and adjusting the care plan to continue to meet the patient's needs.

While under the care of a provider or organization, that provider or organization assumes the responsibility for care coordination, however as the patient moves between providers or organizations the locus of responsibility is less clear. Health system indicators such as avoidable hospital admissions and emergency department use suggest the type and amount of navigation assistance for older adults during

care transitions, remains inadequate. The role and responsibilities of a system navigator requires further exploration. The following are salient questions to drive the enquiry: Does the navigator need to be a single role, or could it be shared across providers? What population would benefit most from navigation services? In what facility or organization would this role work best be based? What tools or structures are needed to support a system navigator role?

1.2.2 Hip Fractures, Discharge Planning and Support

System navigation interventions emanated from cancer care (Dohan & Schrag, 2005), but are starting to target frail, chronically ill older adults. Persons who experience a hip fracture are exemplars of this population, and may be at risk of similar poor health outcomes. Marengoni and colleagues (2009) report that only 0.2% of hip fractures occur in persons with no associated comorbidities. As part of this research study, interview data involving hip fracture patients, their caregivers and health care providers, will be used to understand the role a system navigator could play in their care. Hip fractures are the most common injury requiring hospitalization in older persons (Pickett et al., 1997). In 2005, Leslie and colleagues at the Osteoporosis Surveillance Expert Working Group (2009) reported age-adjusted rates of 80.9 hip fractures per 100, 000 people for females and 51.1 per 100, 000 for males, and age-specific incidence rates are predicted to double every 5 years for adults 65 years of age. As the population ages, and an increasing number of individuals are likely to survive to ages at which hip fractures are most common (Jaglal et al., 1996), cumulative incidence rates are a cause for serious concern. Hip fractures are a major cause of morbidity and mortality in the elderly population. The case-fatality rate in the twelve months following hip fracture can exceed 20% (Leslie et al., 2009). Hip fracture can also lead to serious morbidity and loss of independence, which can result in great economic costs (Randell et al., 2000). Furthermore, hip fracture is associated with deterioration of health-related quality of life (Zinden et al., 2010); women continue to suffer from that loss in quality of life irrespective of their recovery, for a year following hip fracture (Boonen et al., 2004).

There are numerous care transition trajectories as patients recover from hip fractures, and these involve receiving care from multiple health professionals (Mahomed et al., 2008) (Appendix A). As well, previous studies, such as the 'InfoRehab' Transitions project have shown hip fracture patients rely on the coordination services of two or more case managers as they transition through the health care system (Toscan et al., 2010). In addition, once patients with hip fractures are discharged from acute care, issues of safety and access to services have significant implications on overall patient recovery and health.

While approximately 70% of hip fracture patients who were living at home at the time of fracture return home following hospitalization (Beringer et al., 2006), more than half of seniors who return to a residence in the community report having at least one fall in the six months after surgery (Taylor et al., 2010). As well, the acute nature of hip fractures challenges the individual's ability to return to the lifestyle they enjoyed before the fracture. Nearly one third of hip fracture patients experience an acute illness that requires hospital readmission within six months of initial hospital discharge (Broockvar et al., 2004). In addition, 25-75% of hip fracture patients do not regain their pre-fracture functional level within one year after surgery (Koval et al., 1995, Young et al., 1996). The impact of a large proportion of hip fracture patients returning home, accompanied with functional limitations and co-morbid conditions (Young et al., 1996, Archibald, 2003), increases the need for, and challenges the accessibility of, long-term community support services.

Hip fracture patients may be at risk of fragmented care, which is exacerbated by fluctuating medical and functional conditions and has been cited as a barrier to achieving optimal outcomes (Broockvar et al., 2004). In addition, patients and their caregivers often report having insufficient information on how to manage their care post-transition, and describe being unable to determine the appropriate health care provider to contact when guidance on self-care is needed (Weaver et al., 1998). One approach to address these problems is to improve the linkage between acute and home-and community-based services through care management that provides information about how to access home- and community-based services (Wilber et al., 2003). This begins with a shift in focus from medical approaches to those of disease and injury prevention and management, characterized by linkages to a range of community based services and custodial care (Rigg, 2006). To address this shift, current studies on comprehensive discharge planning have shown promising results. Richards and Coast (2003) performed a systematic review of interventions to improve access to health and social care after discharge from hospital, and determined the most effective discharge plans combined a needs assessment, discharge planning and a method for facilitating the implementation of discharge plans. Similarly, Phillips and colleagues (2004) investigated comprehensive discharge planning, coupled with post-discharge support for older patients with congestive heart failure, which resulted in significantly reduced readmission rates and potential improvements in health outcomes such as survival and quality of life, without increasing costs. Despite differences in study populations (hip fracture and congestive heart failure patients), both involve management of patients with chronic illness and the use of discharge planning frameworks, suggesting the success of these interventions may not be unique to a single complex condition. In Ontario, the development of the discharge plan is the responsibility of the acute care multidisciplinary team, but the execution is the

responsibility of the case manager. Therefore, the case manager has an integral role in supporting hip fracture patients through care transitions which should be kept in mind in the exploration of system navigation models.

1.2.3 Potential System Navigation Models

In order to capture the wide range of terms and models that exist for system navigation, a broad approach to consulting the literature was required. The following sections are organized to first examine an international perspective which highlights many system navigator models, targeting different populations with varying role descriptions. Then, a Waterloo Wellington, Ontario focus narrows the discussion about system navigation roles to include: case managers, Waterloo Wellington programs and services that overlap with system navigation roles, and a new role introduced to Waterloo Wellington called the Intensive Geriatric Service Worker (IGSW).

1.2.3.1 International Models for Older Adults

System navigation roles are in their infancy not only in Canada, but internationally. While Canadian examples are valuable, international literature may contribute to the understanding of what role a system navigator could play in the health care system. A critical analysis of international literature identified programs and roles in many countries including the United States, United Kingdom, Netherlands and Australia. Many initiatives have had promising results by using system navigation programs to support older adults accessing health services (Boult et al., 2008; Naylor, 2004; Wilber, Allen, Shannon & Alongi, 2003), although there is great variety in their roles, description, and evaluation.

Specifically, there are three initiatives originating within the United States to mention: Care Advocacy for Rural Elders (CARE; Ritchie et al., 2002), a Care Advocate Program (Wilber, Allen, Shannon & Alongi, 2003), as well as the Patient Navigator Act. The goal of CARE is not to substitute for primary care, but based on identified problems, to educate participants and caregivers, to advocate for patients within the health care system, to connect them to services, and to monitor patient progress (Ritchie et al., 2002). Similarly, the purpose of the Care Advocate Program is to improve the linkage between acute and home or community based services. The program has shown reductions in hospitalizations, emergency room visits and nursing home days in high risk older persons (Wilber, Allen, Shannon & Alongi, 2003). Finally, the Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 identified unmet needs of cancer patients navigating the health care system, and introduced a new

Patient Navigator role. These health care providers are responsible for assisting with coordination of services, facilitating involvement in community organizations, anticipating, identifying and helping patients overcome barriers to timely access to health care, coordinating relevant health information and conducting outreach (Darnell, 2007).

In the United States there are four system navigation roles to highlight: Geriatric technician (Hornung, Brewer, Stein, Eleazer, Brown & Byrd, 1998), Guided care nurse (Boult et al., 2008), Advanced practice nurse for transitional care (Naylor, 2004) and Transition coach (Coleman, 2006). South Carolina has introduced a paraprofessional role, called a "geriatric technician" to work as a care coordinator between the physician, patient, family and service provider agencies (Hornung, Brewer, Stein, Eleazer, Brown & Byrd, 1998). This role has significantly improved the quality of health care received by a number of patients managed by the technician. Johns Hopkins University developed a Guided care nurse role, based in primary care, to work with families and patients to make more efficient use of health services (Boult et al., 2008). Preliminary findings indicate that Guided Care improves the quality of patients' care, reduces caregiver stress, improves physicians' satisfaction of care, and may reduce use of health care services (Boyd et al., 2009). Naylor (2004) took a similar approach, employing advance practice nurses to support heart failure patients with self management as they transition from hospital to home. Positive outcomes were achieved from this intervention, including lower rates of and longer times to rehospitalization, lower costs, and increased satisfaction with care and quality of life. Lastly, Coleman (2006) developed the Care Transitions intervention, where nurses coach patients and caregivers through care transitions. The intervention was effective in reducing hospital readmissions and hospital costs.

Countries outside North America have also been exploring and documenting system navigation roles. Although there were many navigation models to be considered, two models seemed to be most potentially relevant to the Canadian system. First, Coordination of Professional Care for the Elderly (COPA) in France, targets frail community-dwelling elders recruited through their Primary Care Providers to provide integrated, multidisciplinary care to meet the service needs of their patients (Vedel et al., 2009). A quasi-experimental study demonstrated a lower level of service utilization compared to national levels for their frail elderly patients, without compromise in quality of care. Second, the role of a community matron was established across the United Kingdom, as a professional responsible for coordinating the care of patients with long-term conditions and complex needs (Lillyman, Saxon, Treml, 2009). The aim of this role was to bridge the gap for patients and their caregivers between different care settings, and to prevent hospital readmissions by providing care and support in the home. Findings

suggest a need for further, more rigorous research of the tools and evaluation methods used to assess the outcomes of community matrons.

System navigator roles for high risk patients generally target populations whose medical complexity and circumstances result in a need for support in accessing appropriate care. Chronically ill older adults with multiple morbidities transition across multiple care settings and are at particularly high risk of receiving fragmented care. To date, there has not been a synthesis of the literature for system navigation for older persons with chronic illness. However, initial searching for the proposed study has indicated the need for a synthesis of the peer-reviewed literature and documentation of outcomes on relevant studies.

1.2.3.2 Ontario: Community Care Access Centre (Case Management)

The introduction of a new system navigator role may be warranted, given the current fragmented system. However, several role descriptions of system navigators are similar to case managers currently practicing in Ontario. Overall, case management holds a crucial role in the complex health care environment (Long, 2002) to coordinate health and social service for the elderly. It has been defined as, "an individual or small team responsible for navigating the patient through a complex process in the most efficient, effective and acceptable way" (Zwarenstein, 2005). Case management is a proficient way to organize services for the high-risk, high-cost sub-populations, which represent the largest generator of health care costs in developed countries (Casarin, 2002; Meier, 2004). The concept of case management is relevant to older persons with chronic illness or complex health problems, and is in line with the primary goal of patient-centred health care (Pruitt & Epping-Jordan, 2005). As the aging population expands, the demand for community-based care and the need for case management are expected to increase (Lee, 1998). Various studies have demonstrated the importance of case management as an innovative strategy to facilitate improvements in: patients' quality of life, hospital length of stay, hospital admissions, emergency room visits and costs, use of self-care and satisfaction of patient and professionals (Lee, 1998; Long, 2002; Oeseburg, Wynia, Middel, & Reijneveld, 2009).

Currently, in Ontario's health care system, the Community Care Access Centre (CCAC) employ case managers at three major care settings including hospitals, inpatient rehabilitation centres and home care. Following an accident or episode of acute illness, where an elderly person is hospitalized and requires supportive services upon discharge, patients may be assigned a number of case managers to expedite their transition home. Facilitating these patient transitions between care settings is one of the key functions of case management. However, care transitions rely on information sharing, and when this

communication breaks down, it has been shown to be a barrier to successful transfers. Coleman and Fox (2004) have linked problems with information sharing between health care sites during transitions with low quality care and poor patient satisfaction. In addition, the health care system has a common goal to discharge patients quickly. McWilliam and Sangster (1994) indicated that fast transitions can lead to poor discharge planning, care coordination and post-discharge interventions. Therefore, the role of the case manager to coordinate care is important, but continuity of care during transitions is difficult when the case manager is housed within a single care setting. There is a lack of research examining the efficiency of case manager 'handoffs' as chronically ill older adult transitions across health care settings. There may be opportunity for structural re-organization to allow case managers to follow their patients through the system, to enhance continuity of care.

According to the literature, the role of a case manager seems to overlap with the role of a system navigator. Successful case management models provide care coordination, advocacy, psychosocial support and education (Oeseburg et al., 2009). Most models highlight case manager responsibilities such as monitoring fluctuating patient need, eliminating fragmented care and arranging the provision of health services (Long, 2002). Typically, system navigator responsibilities include: home visits and phone support, care planning and coordination, patient advocacy and education and collaboration with health care providers (Hornung, Brewer, Stein, Eleazer, Brown & Byrd, 1998; Boult et al., 2008; Naylor, 2004; Coleman, 2006). It is evident there are common elements across case management and system navigation models. The goal of exploring the role of a system navigator is not to decide between a navigator and a case manager, but to understand how this role fits within the current structure of the system. Case management is well established in health care, and has shown positive outcomes, such as reducing readmissions and functional decline (Oeseburg et al., 2009), for many years. However, findings from the WW-LHIN community engagement survey show that older adults are still having difficulty navigating the system, which suggests the need for more navigation support, and perhaps tailored strategies to reach seniors with different needs (WW-LHIN, 2009).

Care coordination programs, such as case management, are most successful when they target those individuals who would benefit most from the service. Case management has shown the best outcomes with moderate-high risk, complex older adults, while different approaches may be more appropriate for older adults at both low and high risk for poor health outcomes (S. Gerber, personal communication, November 20, 2010).Therefore, the case management model may favour certain client profiles, such as acute rehabilitation for a hip replacement, as compared to a chronically ill older adult. Targeting those lower risk seniors who are no longer in need of formal health care services with less

intensive services may show positive outcomes, by taking a proactive approach to care. As well, targeting older persons at high risk of poor outcomes, with more intensive services may show positive outcomes. Examining those older adults not receiving or benefiting from case management, might provide greater insight into which groups might benefit from a system navigator intervention.

In the past 10 years, home care services in Canada have been increasingly targeted to post-acute patients with medical needs, leaving fewer supportive resources for persons with chronic disease (Forbes & Edge, 2009). In lockstep CCAC eligibility criteria are becoming increasingly narrow. In combination with an overall increase in demand for health services, tailored approaches such as system navigation models, need to be developed for all risk types of older adults to ensure appropriate access to services. The Home-At-Last Solution (OCSA, 2007) recognized that CCAC case managers are only involved in the discharge planning process for patients who meet the eligibility criteria. There are also "social admissions" or patients who are "failing to thrive" in the community who may benefit from a case management modeled service. Community support services, continuing on a long-term basis, are available to older persons to facilitate aging at home, yet many older adults are unaware these resources are available (Chen, Brown, Archibald, Aliotta, Fox, 2000). Therefore, the linkages between frail, older persons and appropriate community resources have the potential to be addressed and improved using some form of system navigation support. Ultimately, the challenge is to ensure appropriate services to all levels of care for older persons at risk of becoming increasingly frail.

Governance of and funding for navigation positions influences incumbents' scope of practice, authority, and the resources available to support clients. Gate-keeping expectations, for example, may limit their advocacy and facilitating capabilities to what is affordable or approved, rather than to what is necessary (Egan, Anderson & McTaggart, 2010). System navigators may be better positioned to advocate for a patient when they are not directly associated with a single sector of the health care system.

The CCAC in Waterloo Wellington offers navigation assistance to clients who are at lower risk for poor health outcomes and do not require the services of a case manager. This navigation is indirect and offered through the CCAC website which provides a comprehensive list of health care and community services, according to service area. As well, clients have the option of calling 310-CCAC for assistance with locating services in their area. Trained, un-regulated workers, called Informal Referral persons, direct callers to services they are actively seeking. These are considered self-management tools, and are available provincially. The website and telephone support may be one approach to assist with system navigation challenges, and a rigorous evaluation would demonstrate the value added. It supports

the notion that many interventions may be required with one common goal in order to reach all older adult profiles, and have positive outcomes across such a diverse population.

1.2.3.3 Waterloo-Wellington Programs

The region of Waterloo-Wellington has implemented several programs to assist older persons to navigate the health system in their community. Their intention is to reduce barriers to care for older persons, and in conjunction with other community services, proactively anticipate and manage prevention strategies. There are four initiatives receiving financial support from the WW-LHIN through the Aging at Home strategy: Home-At-Last, Make Yourself at Home Peer Support Program, Home First, Close to Home and the IGSW role.

The Home-At-Last program is a very short term service available to seniors to ease the discharge process to home, providing medications, meals and transportation during the first day at home from hospital (OCSA, 2007). The service employs Personal Support Workers (PSW) and targets individuals who lack caregiver support, transitioning from hospital to home.

The Make Yourself At Home Peer Support Program's goal is to assist elderly persons age at home (Guelph Wellington Seniors Association, 2010). This program involves home visits by caring and trained senior volunteers who connect their peer seniors to community support services. This support program was established in 2007, and receives Aging at Home funding from the Waterloo-Wellington LHIN for prevention and innovation strategies. It is run by the Guelph Wellington Seniors Association, a volunteer working group under the City of Guelph. The Make Yourself At Home Peer Support Program is an example of one approach to further establish care continuity with older persons requiring support beyond clinical case management.

Home First is a paradigm shift which has been rolled out provincially over the past two years (S. Gerber, personal communication, November 20, 2010). The steering committee is made of representatives from the CCAC, the local hospitals, and WW-LHIN. This initiative addresses the potentially negative consequences of older adults making life choices from a hospital bed. Health care providers are currently encouraging and supporting the postponement of important decision-making, such as selling assets, moving to some form of assisted living or planning for future health complications, until the elderly have returned to the security and familiar surroundings of their own residence. Therefore, health care providers are working to transition older adults home quickly, with information about their housing options and care plan.

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A program called Close to Home, based out of Mapleton Township, offers a variety of services and programs to seniors through the Seniors' Centre for Excellence. There are four offices connected to Family Health Teams across the township, and they offer navigation assistance, programming and health prevention and promotion tools. The aim of Close to Home is to link seniors with the services they need, because it was recognized that seniors and their caregivers are often not aware of what is available in their rural area. This program develops brochures, and also field calls and in-person inquiries to assist with system navigation (H. Edwards, personal communication, January 5, 2011).

The WW-LHIN has supported the implementation of Intensive Geriatric Service Workers (IGSW) beginning in emergency departments of local hospitals across the region. Their innovative role is to provide support to frail older adults with complex needs as they navigate the health system during care transitions (Paul, Higgs & McKinnon Wilson, 2010). Although a relatively new role, positive preliminary findings suggest this model warrants closer examination.

To summarize, there are many programs and services either directly targeting system navigation needs, or indirectly navigating older adults both within and outside Waterloo-Wellington. With so many programs and services across the LHIN and CCAC services, it is difficult to get a sense of when and how people access these services. Ultimately, it is important to understand where there is overlap and where there are gaps in services for older adults requiring system navigation.

1.2.4 Waterloo-Wellington Role: Intensive Geriatric Service Workers (IGSW)

The concept of a system navigator was introduced in 2006 to the Waterloo Wellington LHIN as part of a larger initiative to understand the needs of seniors in the area. In a consultation process with health care providers and consumers, system navigation was identified as a challenge, and the role of an Intensive Geriatric Service Worker (IGSW) was developed in collaboration of Waterloo Wellington Geriatric Services Network (WWGSN)[1] and Trellis Mental Health and Developmental Services (McAiney, 2010). This role was designed to address the priorities set out by Waterloo Wellington Local Health Integration Network to improve (Emergency Department) ED and ALC pressures at that time (McAiney, 2010). For

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[1] The Waterloo Wellington Geriatric Services Network (WWGSN) brings together representative from various organizations providing services to older adults, including: acute care, long-term care, primary care, community support services, senior's housing services, Specialized Geriatric Services, the Regional Geriatric Program, mental health services, the Community Care Access Centre, and Public Health. The mandate of this group is to provide leadership in the identification, development, implementation and evaluation of strategies to improve the system of care for older persons and caregivers across the Waterloo Wellington region (L. Hillier, personal communication May 12, 2011).

the purposes of the proposed research, the IGSW role will be explored as a model for system navigation. Due to the lack of literature on this role, the following information has been taken from the IGSW study protocol, developed by Dr. Carrie McAiney, the Principal Investigator, who is responsible for evaluating the impact of this role.

It is recognized that older persons with chronic disease are at particular risk of receiving fragmented care during care transitions, because they receive care from multiple providers across settings (Boling, 2009). The IGSW role "aims to provide intensive support and transition for frail seniors with complex health and social needs" (McAiney, 2010 p.1). Ultimately, it was felt the individuals who would most benefit from the program would be "frequent flyers" of the local emergency departments, and would already be flagged as a complex case by the Geriatric Emergency Management (GEM) Nurses. GEM Nurses are situated in emergency departments of hospitals to provide specialized frailty focused nursing services and geriatric assessment to older adults (RGPs of Ontario, 2011). Therefore, IGSWs have been strategically placed to work in collaboration with emergency departments linked with GEM Nurses, but can also be connected with seniors through Specialized Geriatric Services (SGS), and acute inpatient health professionals. Out of the first 351 referrals made since the program began, 208 (60 per cent) were from a GEM nurse. Eligibility criteria for IGSW services includes adults who are 65 years or older, are residents of Waterloo-Wellington and present as frail and medically complex, are at risk for hospital admission or readmission.

IGSWs aim to conduct a home visit 24-48 hours after a referral has been made by GEM nurses, SGS, CCAC case managers or other acute care health professionals. The interim evaluation found that on average, the IGSWs provide 3-12 hours of service per week to each patient, and that was a significant amount of flexibility in the activities each IGSW may perform. Overall, the role includes:

- Implementing care plans developed by health care professionals both in the ED and other care settings
- Encouraging and facilitating follow-up appointments at various health care settings
- Facilitating communication with health care providers
- Promoting self-directed care through education, "coaching", and navigation
- Developing and updating "health passports" to facilitate information sharing across health care providers
- Navigating the system of care and advocating for access to services

- Building system capacity and sustainability through education and mentorship of health care providers across the continuum of care

Currently, the criteria to receive assistance from an IGSW, include one or more of the following:
- Frequent user of the emergency department
- Recent hospital admission (last 90 days) and/or ED visit (last 30 days)
- Complexity of needs (number and/or type of support required)
- Socially isolated
- Resistant to assistance or support
- Ability to access services is limited due to financial reasons
- Language or cultural barrier
- MD or RN concern about ability to follow through with recommendations
- Caregiver burden, lack of caregiver support, or long distance caregiver

This navigation role has been in place since mid-October 2009, and is currently under an extensive 18-month evaluation.

SUMMARY OF LITERATURE

Overall, the literature establishes mixed support for the effectiveness of system navigation roles. However, there are important gaps in the literature which need to be explored. First, it would appear that system navigators would have the greatest impact on older adults needing to access multiple services across multiple care settings. Evidence is needed to support the intervention target groups. Risk stratification in chronic disease, such as the 'Kaiser triangle', distinguishes between people at highest risk of hospitalization or highly complex requiring case management, people who are at high-risk of requiring disease management, and people living with chronic conditions requiring supported self-care (NHS, 2006). This may be an important framework used to conceptualize service delivery, and will be considered when determining which segment of the older adult population an intervention would impact most. The 'Kaiser triangle' supports the notion that multiple strategies are needed to achieve positive outcomes across the chronically ill aging population (NHS, 2006). Second, the complexity of the patient group would likely need to be reflected in training and education of the system navigators, this qualification factor has been variable in existing models (for example, Boult at al., 2008 and Naylor, 2004). Third, descriptions of system navigator positions roles are highly variable depending on the sector

from which they originate. Intervention at the primary care level may be most effective by reaching the greatest number of older adults, since 98% of individuals in Waterloo Wellington have access to a family doctor (http://www.therecord.com/print/article/286392). As well, the structure of primary care in a health service organization such as a Family Health Team (FHT) or Community Health Centre (CHC) seems to be best suited to facilitate communication among providers at different settings. FHTs are a new way of delivering primary care in Ontario, and combine the expertise of many different health care providers to meet patients needs (Ontario MD Groups, 2011). CHCs are similar to FHTs, but take a broadened approach to health within a particular community, focused on not only primary care, but illness prevention and health promotion (Kitchener Downtown Community Health Centre, 2011). FHTs and CHCs are able to take a preventative, proactive approach to care, as they are best positioned to identify at risk patients who may benefit from system navigation assistance. Fourth, there is a lack of literature discussing what needs to be in place in the health system and community in order to successfully implement a new system navigation role. Technology, to aid in information sharing or social networking, may be critical to support a navigation role. The proposed research aims to gather data from several data sources to begin to address the gaps in the system navigation literature.

1.3 Rationale

The purpose of this study was to examine the perspectives of patients, caregivers and relevant health care providers to investigate what role a system navigator may play in the Waterloo-Wellington LHIN's plans to enhance transitional care of older adults. This research targeted a knowledge gap regarding the care of medically complex older adults (Habicht, Witham & McMurdo, 2008) and their caregivers, who are both often under-represented in research due to methodological challenges of care transitions research (Quinn et al., 2008). In addition, informal caregivers provide invaluable insight into the transitional experience of chronically ill older adults, as well as their needs for accessing community support services. In a study focused on discharge planning and informal support of hospitalized elderly, findings suggest that the primary informal caregivers influence the extent to which formal as well as other informal providers were involved in their loved one's care (Statistic Canada, 2005).

To date, system navigation work has taken a silo approach, and existing research is lacking on multiple perspectives to understand this common, complex issue. This study recognizes a broader approach of combining multiple perspectives to provide a more comprehensive understanding of system navigation needs and potential solutions in Waterloo Wellington. The methodology guiding this research brought together the voices of all players, from a variety of health care settings across the Waterloo-Wellington health care system. In sum, a combination of four data sources, with various data collection techniques, was a unique aspect of this study that has enhanced rigor and brought depth to the findings. This research may have important implications for future system navigation roles in Waterloo Wellington and other regions of Ontario.

1.4 Research Objectives

Overall, the main goal of this thesis was to examine what role a system navigator would play in the care of chronically ill older adults and to understand the challenges and considerations when implementing such a role.

Four primary research objectives guided the progress of this study:

1. ***To perform a systematic literature review to identify articles from peer-reviewed journals which employ a paid individual to assist chronically ill, elderly patients one-on-one as they navigate the transition across a healthcare setting, and to investigate the efficacy and efficiency of this role.***

2. *To identify challenges related to system navigation from multiple perspectives through focus group interviews, involving health care consumers and providers, in various care settings across Waterloo-Wellington.*

3. *To identify system navigation needs of hip fracture patients transitioning from acute care, to understand what a system navigator role would look like in Waterloo Wellington and its potential impacts on the care of hip fracture patients and their caregivers.*

4. *To understand the role of Intensive Geriatric Service Workers in the Waterloo-Wellington health system, the client groups they service, and the barriers and facilitators of their role working within the regional health system.*

Overall, this research will create a theory for a system navigator role in Waterloo Wellington, based on a combination of what is learned from these four objectives.

1.5 Methodological Approach

This research was guided by an interpretivist epidemiological stance (Daly, 2007) to best, "understand social and psychological phenomena from the perspectives of people involved" (Welman & Kruger, 1999, p. 189). In order to describe the reality of lived experiences for the patient, caregivers and relevant health care providers involved in care transitions, it was necessary to recognize that the phenomenon is co-constructed by the researcher and the participants through an interactive interview process (van Manen, 1997). Therefore, the researcher was considered inseparable from available knowledge surrounding chronically ill patients, hip fracture patients, their care transitions, and their access to health services (Hammersley, 2000). Furthermore, within an interpretivist stance, contextual factors of the research were recognized as important, and the underlying purpose was to capture unique, individual experiences. This study strived to understand continuity of care from the differing lenses of all relevant stakeholders, while searching for shared experiences (Daly, 2007).

A grounded theory approach was used to develop a framework to explain what role a system navigator may have in the care of chronically ill older adults. Grounded theory emphasizes the inductive creation of a theory, but also involves deductive testing of various ideas that existed prior to the research or emerged as part of the research (Glaser & Strauss, 1967). This is the most appropriate approach for this study, as it involves developing theoretical interpretations or explanations to illuminate processes of interest: care transitions for a defined population (Glaser & Strauss, 1967). In addition, an interpretivist

standpoint correlates well with grounded theory to allow for indeterminacy rather than causality seeking, and will guide the researcher to search for patterns and connections rather than a linear relationship in the data (Charmaz, 2006). Ultimately, an interpretivist approach allowed the researcher to develop a theory for a system navigation role for older adults with chronic disease, drawing on the researcher's thoughts, opinions and experiences based on conducting and analyzing the data.

Following an interpretivist approach to grounded theory methodology, a constant comparative method was utilized for each analysis procedure. The constant comparative method of analysis combines two approaches to analyzing the data: assessing and analyzing data to test a predetermined hypothesis, and searching for new concepts and their properties by constantly redesigning and reintegrating thoughts into the analysis process (Glaser, 1965). Overall, this process is characterized as a dynamic interplay between observations grounded in experience, and conceptualizations developed from those observations (Daly, 2007).

A variety of data collection methods were used to develop a potential framework for facilitating services to the elderly, including a systematic literature review, key informant interviews and focus group interviews, as well as interviews with patients, caregivers and various health care providers. A framework for the four data sources can be found in Appendix B. Strauss and Corbin (1990) describe the importance of researchers being theoretically sensitive to both the literature and the data surrounding the topic of interest. The systematic literature review provided an in-depth understanding of the current view on system navigation roles and accordingly informed the development of interview and focus group guides for qualitative data collection. In addition, this review was used to identify gaps in the existing literature related to current roles, the outcomes associated with those roles, and challenges with implementing system navigators. Interviews and focus groups were then conducted with various stakeholder groups in the Waterloo Wellington region, including services providers, patients and informal caregivers. These acted as an initial source of data for the researcher to become theoretically sensitive to current needs and structures of the region (Charmaz, 2006) and further refined their understanding of the principal issues. Lastly interviews were conducted with IGSWs who currently act as system navigators in the Waterloo-Wellington region. The IGSW role is currently the only model in our region for system navigation, and was used as a platform to develop a system navigator framework.

The analysis for all three qualitative data sets was approached in a similar manner (Graneheim & Lundman, 2004). Performing qualitative content analysis on the interview and focus group data identified different concepts related to system navigation for older adults with chronic disease or hip fracture. The Chronic Disease Prevention and Management (CDPM) framework was used as a model for delivering

care to chronically ill older adults, and helped to ground system navigation research in the context of Ontario's approach to preventing and managing chronic disease (Ministry of Health and Long Term Care, 2006). Ultimately, the final process to grounded theory developed a framework which illustrates how key concepts about system navigators fit together to understand what role it plays in the care of chronically ill older adults.

CHAPTER 2: SYSTEMATIC LITERATURE REVIEW

2.0   Data Source: Systematic Literature Review

To date, a number of system navigation models have been developed in a variety of health care settings, however there is a lack of consensus regarding the characteristics of this role. Few researchers have collected and synthesized data on system navigation models, and there have been no previous systematic reviews published. Patient navigation has been demonstrated as an integral part of cancer care (Freeman, 2006); however the potential of this role is starting to be explored for other older adults with chronic disease. Therefore, the purpose of the systematic review was to describe existing system navigator models relevant to chronic disease management for older adults and to investigate the potential impact of each model on patients, formal and informal caregivers and the broader health system. Since this review gathered international literature, the researcher comments on the feasibility and transferability of the system navigation models and outcomes to the Canadian health care system.

2.1 Methods

The lack of standardized terminology for this role impacted the search strategy for the systematic literature review, and consequently required the inclusion of a broad range of search terms. Articles were retrieved from three online bibliographic databases: the Cumulative Index to Nursing and Allied Health Literature (CINAHL), the Medical Literature Analysis and Retrieval System Online (Medline), and Cochrane Evidence Based Medicine reviews. Four search strings were used to gather a wide range of potentially relevant articles. Eight searches were conducted using various combinations of these search strings (Appendix C). References from relevant articles were hand searched to increase the article yield.

Two authors examined article titles only; articles which focused on mental health, children and the homeless were discarded (Appendix D) on the understanding that these populations have unique needs, and that the health care services and systems they access differ substantially from those used by older adults with chronic illnesses. Further, the role of the patient navigator in cancer care has been well documented by others, for example (Dohan & Schrag 2005), and these too were excluded.

The remaining full articles were obtained for review. Two authors separately reviewed each article using the following inclusion criteria: a) the article targeted older adults with chronic illness; b) involved patients making transitions across health care settings; c) described the roles and responsibilities of the patient or system navigator position; and d) involved a patient or system navigation intervention or pilot. Due to the prediction of few articles meeting the inclusion criteria, no restrictions were initially used based on the quality of the articles.

Two authors, the researcher and her colleague, eliminated irrelevant articles, following the outlined exclusion criteria, based on the content of its abstract. The remaining full articles were obtained for review. Two authors separately reviewed the articles guided by the inclusion criteria. Where there was disagreement between the two authors on eligibility, a third adjudicated. A data abstraction tool was used to collect information on research methods and analysis, role descriptions, qualifications, role goals and responsibilities, and outcomes information.

2.2 Results

The search generated a total of 6360 articles; 15 articles satisfied the inclusion/exclusion criteria and documented 10 discrete studies (Appendix D). The articles were published between 1999 and 2009 with most (n=13) published since 2000; of the 10 studies, 7 were conducted in the United States, two in Canada, and one in Australia. A summary table for the results of the systematic literature review can be found in Appendix E.

Description of Interventions

All but three of the articles targeted the transition from hospital to home; the three exceptions described different phases of the same program which uses a Guided Care nurse and electronic health record to meet the needs of multimorbid older adults under the care of a general practitioner in a primary care setting (Boyd et al. 2007, Boult et al. 2008, Boyd et al. 2009). Multiple chronic illnesses, which put participants at high risk for negative outcomes such as admission to hospital, were criteria for inclusion in five studies, while others focused on a particular condition such as heart disease (n=2), stroke (n=2) and hip fracture (n=1).

The 10 studies collected data using various methodologies; all of them conducted a randomized controlled trial to gather data. Parry et al. (2003), using the "Care Transitions" model, produced three separate articles which provide rich insight into the "Care Transitions" model: the first is a detailed description of the program, the second (Parry et al. 2006) reported outcomes of a randomised controlled trial (RCT), and finally a qualitative study (Coleman et al. 2006) used focus group and semi-structured interviews to investigate patients' perspectives on the intervention.

Ten different position titles were used in the 10 discrete studies documented in this review. The heterogeneity in titles belied the homogeneity in qualifications required for the positions. The majority of the studies (n=8) required qualifications as a registered nurse; some required expertise as an advanced

practice nurse (n=5). The one exception, which required a masters in social work, reflected the target population of stroke survivors and their caregivers, and the psycho-social focus of the study's goals (Clairborne 2006a & b).

The study interventions varied in terms of time of initiation and their duration. Some start immediately after admission to hospital, others post-discharge; they may last from pre-discharge up to 18 months after discharge. Of those models serving patients transitioning from hospital to home (n=9), discharge planning was included in all models except one of the Canadian studies (Gagnon et al. 1999). The different navigation models offered a variety of services including care planning, coordination of care, phone support, home visits, liaison with medical and community services, and patient and caregiver education. All navigation roles were supported by either physician mentorship, or a multi-disciplinary team. The two studies which focused on transitions between providers in the primary care setting targeted patient self-management and education, and both employed the use of electronic medical records; a key component of the Care Transitions Intervention (Parry et al. 2003) was the patients' use of a personal health record. Caregiver involvement was recognized as an important aspect of some interventions. All but one of the studies (n=9) recognized caregivers as important to the success of care transitions, and targeted these individuals in the navigation intervention for both education and support. The Care Transitions Intervention (Coleman 2006) focuses primarily on patient and caregiver enablement through education, coaching and advocacy.

Outcome Measurements

Beyond the stated goals, study outcome measures reflected key drivers for piloting navigation roles; generally these reflected concerns about optimizing resources allocated to high cost patients, and improving patients' experience of the health system. Some studies measured a broad range of outcomes which included patient reported quality of life, functional status and satisfaction as a result of the intervention, as well as institutional or system outcomes such as hospital admission or readmission, and length of stay. Gagnon et al. (1999) utilized standardized and validated instruments to collect self-reported data and direct chart review to measure quantitative hospitalization data. The outcomes revealed no significant difference between the intervention and control groups on self-reported quality of life and satisfaction data. The quantitative assessment of hospital use, however, indicated an increase in emergency department (ED) use in the group receiving navigation services. The authors speculate this outcome was influenced by any number of flaws in the design of the intervention including: difficulties in accessing intervention patients' primary care physician, necessitating assessment at the ED; unwieldy

paper documentation; administrative duties reducing nursing time; and the short duration of the trial (10 months).

All of the RCTs, except one which reported "lessons learned", measured quantitative indicators as outcomes of interest. Commonalities across studies were: unplanned hospital readmission rates; time to first readmission; hospital costs; and community service costs post-discharge, for those measuring hospital to home transitions. Claiborne's investigation, (2006a) of the impact of a navigation role on stroke patients post-discharge, focused on assessing the impact on outpatient physician reimbursements and emergency room (ER) reimbursements. ER costs in the control group were higher; however, the intervention group's outpatient physician reimbursements were higher than in the control group. Despite this discrepancy, the cost differential between ER and outpatient visits netted an average savings of $1000 per participant in the intervention group; it is unclear whether this figure factored in costs of program development, execution and administration. The qualitative assessment of the same study (Claiborne 2006a), conducted to "capture the patient's voice" showed no significant improvement in physical quality of life; however, the intervention did improve mental quality of life, depression symptoms, and disease self-management. Together these two papers suggest this intervention may be of value to patients, however, the impact on system cost is unclear.

The Guided Care Nurse model which enrolled older chronically ill adults in a community setting (Boult et al. 2008) used the Patient Assessment of Chronic Illness Care (PACIC) as a means of assessing patients' satisfaction with their care at baseline and then six months after the patients joined the program. In addition, the researchers conducted anonymous surveys with the primary care providers and system navigators a year after the start of the program. Those PCPs in the intervention group were more likely to record improvements in communication with patients and their informal caregivers, education for those caregivers, improvements to self-management, knowledge of patient medications and community referrals (Boult et al. 2008). Patients were more likely to rate the quality of their care as "high".

Naylor's (2004) study is a modified version of the transitional care model, originally implemented five years previously (Naylor, 1999). Initially, the target population for the transitional care intervention were hospitalized older adults. The target population in the subsequent study focused on patients with heart failure; the intervention started at hospital admission and extended for three months post-discharge, as compared to four weeks post-discharge in the previous study. In the former study, the intervention group had shorter time to readmission, and fewer numbers of readmissions and hospital days. Medicare reimbursements for the control group were double that of the intervention group at 24 weeks post-discharge. Similar results were noted with the heart failure study. In this case the authors noted that

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flexibility of the protocols and advanced practice nurse expertise to both treat and assess study participants (who suffered from heart failure and an average six active comorbid conditions), resulted in fewer readmissions for their heart disease and for co-existing conditions. The chronically ill elderly are over-represented in the hip fracture population and it was this group that was targeted by Kirchbaum's (2007) study using gerontological advanced practice nurses. Older individuals experience higher morbidity and mortality rates, and reduced function post hip-fracture. Therefore, the outcomes assessed in this study included the ability to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs), as well as perceptions of health and well-being. While the size of the sample reduced the statistical power of the results, the study showed that an average of two hours care coordination per month over a six month period resulted in statistically significant improvements in IADLs and home care activities. The emphasis on the post-acute care period for older patients (and their caregivers) when returning to the community was also evident in Lim et al.'s (2003) study. Statistically significant improvements were demonstrated in Assessment of Quality of Life scores at one month post discharge, and six month bed-day utilization for those in the intervention group, with reduced net costs over all.

Discussion

The system navigator role for the chronically ill older person is a relatively new one; all papers selected for this review were published after 1999 and the number of scientifically documented and researched articles on system navigator roles and their impact on outcomes for the chronically ill older population was scant.

In their review of the literature on patient navigation, Dohan and Schrag (2005) argue there is no shared understanding of the term. By their definition, the patient navigator role attends to non-medical determinants of care quality rather than medical determinants or clinical responsibilities. Including clinical responsibilities in navigation roles which support chronically ill older adults, reflects the needs of this high risk population, their oft-stated desire to return to their homes, and the need to assess and treat them there. The articles reviewed in this study suggest that balancing the medical and non-medical approaches to health system navigation may help to achieve positive outcomes for these patients, and the system.

This review included studies that target older persons with multiple morbidities, a population previously identified as having inherently higher risk in the outpatient setting (Ghandi & Lee 2010). Some studies targeted patients with conditions for which there is a very high risk of hospitalization, such

as those with heart failure (Campbell et al. 1998, Blaha et al. 2000, Naylor et al. 2004). Blaha's et al. (2000) navigation intervention with this population suggests that appropriate care for these roles, is not "one-size-fits-all". The individual patient's needs during a transition, and the concomitant support of the navigator will depend upon the burden of the disease, the time since discharge, and the duration of the intervention.

There are a number of considerations which impact the format, and potential success, of a system navigation program for transitioning older adults. Where the transition involves a move from hospital to home, the evidence suggests that the intervention should start prior to discharge, possibly as early as at or just after admission where possible. If the system navigator is serving high risk patients in the post-acute period following hospitalization, ensuring the system navigator has the necessary clinical skills to be able to accurately assess and recognize "red flags" in the course of contact with the patient, may be beneficial. This, of course, increases human resource and training costs; however, those studies which conducted economic evaluations suggest that the net financial benefits are positive.

The articles included in this literature review demonstrate mixed support for the effectiveness of system navigation roles. Two of the studies revealed little to no effect of the navigation position (Gagnon et al. 1999, Mayo et al. 2008); one resulted in higher use of emergency health services (Gagnon et al. 1999). While methodological design may account for some of the outcomes in these studies, it was noted that both were conducted in Canada, where there is a single payer, universal health care system, and a large proportion of hospital budgets come from global funding. Further, the study interventions as described were more passive than the other six models which focused on the chronic elderly transitioning from hospital. Both initiated care at either discharge or after, in contrast to most of the other models where system navigators intervened pre-discharge and often just after admission. Naylor's Transitional Care Model (2004), which followed patients from admission to three months post discharge, Lim et al.'s (2003) model, which started pre-discharge and followed patients for six months post-discharge, and Coleman's Care Transitions Intervention (2006), which started pre-discharge and continued for 28 days post-discharge, all recorded lower hospital utilization costs. All three models utilized a care plan or outlined clear treatment goals which were shared with patients.

Dohan & Schrag (2005) advocate that all staff should incorporate "navigation" concepts into their work, suggesting that "stepping outside strictly defined roles" ensures that there is organization-wide responsibility for patients' comfort and well-being. This notion will appeal to funders and policy-makers and therefore we suggest that research and health provider communities begin to test and document the impact of introducing system navigation constructs of care into daily workflows. A number of common

elements for system navigators' qualifications and responsibilities were noted amongst the reviewed studies and are listed in Table 1.

Table 1. List of Common Elements for System Navigator Qualifications & Responsibilities

Common Elements	Description
Qualifications	Post-secondary healthcare training (RN or MSW) Advanced gerontological training
Responsibilities	Skilled home visits and/or phone support/availability Medication management Care or treatment planning Service or care provider access and coordination Patient advocacy Patient and family education Assessment and management of health status Collaboration with health care providers

Patient advocate roles have traditionally been assumed by nurses. In the case of vulnerable populations with medically complex conditions, the nurse is uniquely positioned to understand and deliver both clinical services and support which might alleviate barriers to required services for either the patient or their informal caregivers. This may explain the domination of experienced nurse-trained personnel in the system navigation roles outlined in the literature. However, navigation roles are not exclusively nurse-delivered. One such program used to successfully coordinate service delivery to elderly residents in rural areas, introduced a paraprofessional "geriatric technician" who coordinated care and monitored treatment adherence (Hornung et al. 1997). Adoption of navigation roles in fee-for-service primary care settings will be driven by their efficacy in relieving administrative burden, improving patient care and enabling income generation within the practice (Hornung et al. 1997).

There is some evidence for the effectiveness of system navigation roles embedded in multi-disciplinary teams focused on removing barriers to effective care in the multimorbid frail elderly. Vedel et al. (2008) developed a primary care based model where preliminary results of using an integrated team of case managers, primary care providers and a community-based geriatrician, indicate lower emergency room use, fewer hospitalizations and fewer unnecessary referrals to long term care. The majority of navigation roles in this review were hospital-based, however those which were primary care based were also highly successful, with the added benefit of having enlisting hard-to-engage primary care providers early in program development (Vedel et al. 2008). There is growing evidence of the benefit to enrolling patients in primary care organizations which provide a patient-centred "medical home" to improve care across the health continuum (Rosenthal 2008). National health reform is moving many countries towards investments in more effective primary care mechanisms with a focus on health prevention and avoidance of higher cost care, and funding models which encourage multi-disciplinary teams of providers who are responsible for coordinating patients' care across the continuum (Davis et al 2005). The current political environment might therefore support further investigation of system navigation roles whose accountability for care resides with health care teams who have a long-term relationship with patients, and where the benefits of coordination would not only accrue to the patient and system through improved care quality, but also to providers responsible for the costs and outcomes of that care.

Varying degrees of freedom are available for the system navigation roles to advocate for services or resources. The degree of patient advocacy will often depend on how the navigation role is funded; private contractors will often experience less pressure to respond to externally imposed resource restraints (Rosenberg 1995, Feinberg 2004). This advocacy role, supported by Freeman (2006) in order to break down barriers to resources, was present to a greater or lesser degree in all the selected studies. Programs for marginalized and socio-economically challenged populations, particularly cancer patients, appear to place a heavier emphasis on the advocacy role. Governance of and funding for system navigation positions influence navigators' scope of practice, their authority, and the resources at their disposal to support clients. Gate-keeping expectations may limit their advocacy and facilitating capabilities to what is affordable or approved, rather than what is necessary (Egan et al. 2010).

Coleman (2003) suggests that transitional care has a number of foundational elements: a comprehensive care plan, healthcare providers trained in chronic care, and unimpeded information flow/transfer concerning a patient's clinical needs and personal preferences. At least two of the navigation studies incorporated the use of electronic medical records to assist health service providers with decision making (Parry et al. 2006, Boult et al. 2008). In one innovative program, a personal health record was

helping patients to track and engage with their own health data, and helped to direct conversations between patients and their care providers (Parry et al. 2003, Coleman 2006, Parry et al. 2006). There is abundant potential for adjunct technologies to facilitate information exchange and support clinical data gathering and monitoring (Luzinski et al. 2008, Golden et al. 2010), and to improve provider, patient and informal caregiver interactions. The need for up-to-date information to assist provider and patient decision-making is well documented in the literature (for example Charles et al. 1998). However, even without the assistance of sophisticated information systems, these system navigation roles appear to remove some asymmetry of information, which has prevented patients both engaging in their care and understanding options available to them.

The heterogeneity of interventions, patient populations, study designs and outcomes measurement makes comparative assessment of the 10 models of navigation intervention difficult. Naylor's (2004) description of one model's successive testing with different patient populations, and a variety of intervention periods, provides some evidence for an incremental and dynamic approach to developing appropriate navigation roles. Some case management models have demonstrated an "investment effect" (Toseland et al. 1997) where benefits of the intervention are not seen in the short term, but are evident in longer term follow-up. This phenomenon is inferred in the studies selected for this review, and supports the notion that system navigation interventions and their evaluation should occur over a sufficient period of time to accommodate investment costs and assimilation into the system.

The vast array of settings, providers and patients in health care produce a complex mix of solutions to integrating care across the continuum. As Vedel et al. (2008, pp 415) note, there is no "one size fits all" model. Claiborne (2006b) suggests that future research into these system navigation roles should focus on identifying what services patients want and for how long, and the most effective manner in which to deliver them. This helps avoid shotgun approaches to managing care delivery where patients who neither want nor need care, dilute the benefit to those who do.

2.3 Summary of Findings

This review has synthesized papers describing a number of system navigation models for which there is a mixed record of success in achieving individual program goals. The system navigator role is however in its infancy and has shown sufficient promise in diverting high risk older patients transitioning through the system from higher levels of care, to warrant further development and testing of the impact on quality and

cost of care, and on the experience of patients and their caregivers. Future investigation into the impact of system navigation roles might focus on those funded by a consortium of organizations which represent common transitional care pathways for vulnerable populations across the care continuum. Due to the complexity of providing care to multimorbid older adults, assessments of economic and clinical value should quantify benefits which accrue to the healthcare system as a whole rather than individual patients and a subset of their healthcare providers.

The findings from the systematic literature review were used to develop tailored interview guides for the subsequent data collection with patients, caregivers and various health care providers. As well, the common elements of system navigator qualifications and responsibilities helps to provide a foundation for a theory a system navigator role in Waterloo Wellington (Table 1).

CHAPTER 3: WW-LHIN FOCUS GROUPS

3.0   Data Source: WW-LHIN Focus Groups

3.1.   Introduction

Focus groups across Waterloo Wellington region involved key informants, including both health care providers and consumers, from various settings in the health care system. For the purposes of the present study, these key informants have been defined by Chambers and colleagues (1983) as individuals in the community who possess, "…considerable knowledge of and experience in the community, its people and their health and health care wants, needs, demands, use of services and supply of services" (p.16). The Lead Geriatrician for Waterloo Wellington, Dr. George Heckman, partnered with Trellis Mental Health and Addiction Services to identify specific individuals as key informants in the Waterloo-Wellington community who have considerable knowledge about health care for older adults. These individuals include physicians, nurses, community support services, home care, client groups (eg. Alzheimer's society), and allied health groups. The focus group findings will be used by the WW-LHIN to establish priorities for an Integrated Clinical Services Plan (ICSP) for frail seniors.

The identified objectives of this consultation process were to:

i)   Identify unmet needs and/or challenges faced by seniors in this region

ii)   Identify changes that are needed to existing health services for seniors

iii)   Describe the role of primary care in the support and provision of care to seniors

iv)   Identify key geriatric services that are needed to meet the health needs of seniors in this region and to identify priorities for an integrated clinical services plan for seniors

v)   Identify potential indicators with which to measure integration

vi)   Identify needs for education for care providers and administrators.

(L. Hillier, personal communication, May 12, 2011)

The objectives for this research overlapped with the objectives for the present study, and the researcher anticipated system navigation issues might be threaded within most of the discussion points for the focus groups. The overall goal of these focus groups in the context of this thesis was to achieve the second objective - to identify challenges related to system navigation from multiple perspectives across Waterloo-Wellington.

3.2.   Methods

Recruitment

Theoretical sampling was used to guide recruitment of these individuals, in maintaining a grounded theory approach (Daly, 2007). This sampling technique involves making decisions about who to talk to next, what questions to ask, and where to look for important information to gain a deeper understanding based on data in hand (Daly, 2007). Therefore, following this sampling technique, the study sample was only identified as a targeted group, consumers and health care providers across the region, and evolved as data collection ensued. The WW-GSN took responsibility for disseminating information about this initiative, and recruiting parties that were interested in participating. Then, Jane McKinnon-Wilson (JMW), Geriatric Services Systems Coordinator, Trellis Mental Health Developmental Services, and Dr. George Heckman, with the assistance of the Waterloo Wellington-Geriatric Services Network, organized focus groups as many clinical providers and consumer groups as possible. Groups ranged in size from 6 to 15 individuals. A table of the focus group organizations is included in Appendix G.

Data Collection

An interview guide was developed by Dr. George Heckman and JMW, with input from Dr. Carrie McAiney and Sandra Hamner (former CEO of Waterloo Wellington CCAC). The guide was informed by (1) a set of guiding principles developed by Dr. George Heckman with input from local geriatricians and WW-LHIN which served as a framework as the Integrated Clinical Services Plan (ICSP) and (2) a similar initiative to elicit health care priorities for seniors in the Hamilton Niagara Haldimand Brant LHIN. The guiding principles were used to facilitate the consultation process, and highlighted key concepts around the prevention and management of frailty. The interview guide was used to understand the current structure of health care for older adults, and to elicit concerns surrounding continuity of care across all systems of care. Additionally, key informants were asked about facilitators, barriers and recommendations for ongoing support for persons with chronic disease. The interview guide used for the focus groups is included in Appendix F. Interviews were conducted following focus group methods as defined by Krueger and Casey (2000), briefly, including six to 10 individuals in discussions that were powerful in evaluating and testing new ideas. In addition, the moderator made efforts to elicit feedback from each member of the focus groups, and guide discussions following the interview guide (Krueger & Casey, 2000).

The two sets of interview records, one from each recorder were transcribed and merged for accuracy. Finally, the field note transcripts were returned to each participating focus group, and were reviewed for accuracy of the researcher's documentation, by each group as a method of member checking

(Charmaz, 2006). The feedback from each group was added to the transcripts, and used to clarify or expand on initial thoughts raised. Data saturation was thought to be achieved after these 21 focus groups, by data collectors, Dr. George Heckman (GH), Jane McKinnon-Wilson (JMW), Susie Gregg (SG), and this notion was supported by initial data analyses. Each focus group seemed to confirm ideas identified by previous groups, and new ideas were raised less frequently (Charmaz, 2006).

Data Analysis

The researcher became involved in the project following the planning and execution stages of the research, therefore it is considered secondary data analysis. The author attended the final three focus groups, and participated in recording field notes for each group. The final three focus groups were tape recorded and transcribed verbatim. As the primary data analyst, it was important to attend some focus groups to understand the general process and dynamics of how the focus groups were conducted and documented.

All of the interview data were systematically analyzed by the researcher using NVivo8 software (QSR International Pty. Ltd., 2008). The analysis procedure involved coding the data for each participant, or group of participants, and comparing each new case with previous cases, guided by Charmaz (2006). Using line-by-line coding, common threads (codes) were generated; these codes were reorganized into categories. This was a process of building and clarifying categories and also identifying variation within and between those categories. Memo writing was used to actively record the process of conducting grounded theory, to preserve context, to describe how the researcher was thinking about a code, or to explain the development of a category (Strauss, 1987). Finally, theoretical coding involved theorizing about categories, by specifying connections and relationships between the categories, referred to as constant comparison (Glaser, 1965). The analysis procedure also involved comparing emergent patterns and themes with the existing literature (Glaser & Strauss, 1967; Charmaz, 2006). The analysis was a dynamic process involving the manual review of the transcribed interviews by research team members (GH, JMW, SG, BM) to verify the identified themes and overarching constructs represented in the data. The group of researchers discussed data collection and preliminary analyses over the course of the 21 focus groups. There is support in the literature of using combined manual and computer assisted methods to ensure reliability and validity of qualitative data analysis (Welsh, 2002).

3.3. Results

Table 2- Summary of Focus Group Findings within the CDPM Framework

Category	Subcategory	Codes from Data
Community	Resources and Policies	• Limited access and availability of transportation • Living in rural area restricts access to health services • Design more senior-friendly and affordable communities • Affordable pathways other than hospital to LTC • WW has many great services, accessing resources is often the complex task and requires multiple steps
Health System	Self-Management Support	• Improve early education for patients and families • Nurses don't have time to teach self-management • Need to tap into lower risk seniors before they become high risk
	Health Care Organizations	• Structure: need a single access point • Lack of integrated system restricts continuity of care/navigation • Transitional care most challenging to navigate, lack of communication between systems • Case managers: limited role due to system restrictions • Accessing specialized services only when needed to maintain resources for crisis situations • Better integration of geriatrics to improve follow-up, team approach
	Delivery System Design	• Provide timely follow-up in primary care

		• Need better linkages among providers, consistent information • IGSWs are key linkages in care delivery • Make system more seamless→ bundled services • Hospitals should be "fall-back" option, primary care first line • Programs need to be well connected to health services
	Decision Support	• Educate care providers/administrators on how to access services • People get "bounced around" when trying to take part in their care
	Clinical Information System	• Programs are not well connected to health services • Every provider needs access to patient health information • Consistent referral process • FHT could take on the role of coordinating care and providers • Need to monitor patients- timely follow up in primary care after change in health condition • Information exchange from hospital to community needs to improve to facilitate navigation
Patient-Team Interaction	Informed, Empowered Patient	• Complex patients: layers of problems, multiple complex conditions • Seniors need clear information about who to contact and how to access services, navigation assistance • Build capacity for seniors to access and navigate health/support services • Make system more user –friendly to help seniors navigate • System needs to be patient-centered, input from patients on needs • "Information paralysis", try to make education less overwhelming

	Prepared, Proactive Practice Team	• Need more awareness of roles for system efficiency and coordination
		• Who is responsible for the revolving door ED-CCAC-ED-CCAC
		• Caregivers need support, information, preparation to navigate system
		• Team of people to recognize and manage their risk

Sample Characteristics

Ultimately, the primary researchers arranged and conducted 21 focus groups. Focus group interviews were conducted between February 2 and July 6, 2010, in various locations across the Waterloo Wellington region, including Kitchener, Waterloo, Cambridge, St. Jacobs, Woolwich, Mount Forest and Fergus. In total, the focus groups brought together 186 representatives across health sectors and communities, including patients, caregivers, health care providers and administrators. Each interview was approximately 2 hours in length, and during each there were 2 recorders, (GH and JWM or SG). Three of the 21 interviews were recorded and transcribed, for the remaining detailed notes were documented by two independent note takers, generating approximately 130 pages of data, single spaced, and an additional 85 pages in transcriptions.

Coding Categories

Based on the qualitative content analysis procedure described previously, three major categories were identified: community, health system and patient-provider team. The researcher and team recognized these three categories were similar to the Chronic Disease Prevention and Management (CDPM) framework (MOHLTC, 2006). The purpose of this framework was to provide the Ministry with common areas of focus to guide efforts toward effective prevention and management of chronic diseases (MOHLTC, 2006). Condensed codes were organized then within each category and subcategory as determined by the CDPM framework (Table 2). Following the table, each category is described in detail; direct quotes from the participants were selected to reflect the participant's thoughts and feelings during interviews (Charmaz, 2006). However, where direct quotes were not possible with focus groups that were not recorded, the research tried to remain close to the data, and use the wording of the recorder to communicate the findings.

3.3.1. Community

In each focus group, participants felt that aspects of their community could improve the resources or policies which influence older adult's ability to navigate the health care system. The overarching message from participants was that Waterloo Wellington region has many great services, but accessing resources is often a complex task and requires multiple steps. At the conclusion of data collection, participants had identified numerous programs and services in their respective areas to help older adults become aware and access the help they need to age in place. For example, 'Close to Home' was introduced to the research team as a group of senior volunteers in Mapleton Township who took responsibility of gathering and synthesizing all programs and services in the township. A pamphlet was created to distribute to older adults in their communities who may benefit from various initiatives available to them. Also, this group of seniors is available for phone consultations if the pamphlet does not meet the needs of the older adult. Focus group members noted the system may need a central place, like the 'Close to Home' initiative, where older adults can come for navigation assistance, especially for those without family support.

On the other hand, there were several major deficits in communities related to system navigation for older adults. First, participants in all but two focus groups described their experiences with limited access and availability of transportation in their communities. This gap is two-fold; not only are older adults requiring help to navigate the system to find transportation services, but a lack of transportation services to link them with other important programs and services exacerbates system navigation challenges. Second, participants living or working in rural areas commented it was difficult to access health services. For example, one participant described her experience working with older adults needing to plan and transition to housing providing a higher level of care. She reflected,

"I just want to mention appropriate seniors housing. It's been an ongoing challenge in rural areas. There's some other communities that don't have really anything that's appropriate so a senior living for instance, who becomes more frail would really have to move out of their community pretty much to find some appropriate housing to find more seniors that might be in a community of other seniors and access to some you know common space socializing, that sort of thing."

Unfortunately, these comments about challenge in navigating the system were echoed across many different focus groups in rural areas of Waterloo Wellington region. In addition, participants recognized two changes in communities that would help older adults navigate the system. One, to design more senior-friendly and affordable communities to help seniors find and access the services and programs they need. For example, participants recognized the idea that "one stop shopping" may make it easier for older

adults to find the services they need. The other recommendation was to develop more affordable pathways for older adults to enter Long Term Care (LTC), other than through the hospital. Caregivers and health care providers reflected on their experiences working with older adults who had to wait until a health crisis to enter the LTC system, and agree that a more proactive approach could ease this transition. Overall, participants discussed important opportunities for more efficient pathways to access appropriate care in their own communities.

3.3.2. Health System

According to the CDPM framework, there are five components of the Health System which impact the care of chronically ill older adults. These components include: self management support, health care organizations, delivery system design, decision support and clinical information systems.

Self Management Support was recognized as an important aspect in preventing and managing chronic disease. Participants felt that improving early education for patients and families about the disease and the care options is a crucial, but often overlooked aspect of caring for persons with chronic disease. Caregivers at the Alzheimer Society focus groups expressed how overwhelmed they felt, and that,

"[early detection and education] would be a wonderful thing because not just so much for the person who might be the victim of all Alzheimer's it would be the preparedness for the caregiver because I think the assertiveness that we need you know like to just take on the task learning how to, I don't know, put in light bulbs. I mean there's a huge learning but if you, if mentally people can be prepared for the inevitable…then there can be positive, like if say they were diagnosed with mild cognitive disorder they could then take on life changing strategies."

The notion of giving patients and caregivers the tools to manage their disease correctly is not new, yet it remains unclear how to reach the people in need and how to deliver the appropriate tools. This seems to be a key element of system navigation, and in particular, self management; knowing who to contact, when to contact them and how to contact them. Focus groups reinforced that nurses do not have the time to teach self management in the hospital, and considering how stressful a hospital stay can be on the patient and family, this may not be the appropriate venue for all parties involved. Therefore, focus groups kept returning to the idea, "who is tapping into lower risk seniors before they become high risk?" Tools for self management are important for both low and high risk older adults, to keep them healthy for as long as possible. Self management support has significant implications for hospitalizations, care delivery and quality of care, and overlaps with concepts of system navigation.

The structure of Health Care Organizations was also introduced as a major component of chronic disease prevention and management. System navigation challenges were linked to how health care organizations work together to care for chronically ill older adults. The first issue, discussed in almost every focus group, was the need for a single access point into the system. Participants felt that the services and programs made available to a patient should not depend on where that person enters the system. The structure of the system needs to be set up to allow seniors to easily navigate services and programs that would best suit their needs. Another big issue raised by focus group participants was the lack of integration of the system which restricts continuity of care and the older adult's ability to navigate. One caregiver expressed the challenge of integration when she explained it as important to "know what the left hand and right hand are doing, but you need to be an octopus because that's what their system is, you don't know which way it's moving, where or when". Clearly, as health care providers are feeling overwhelmed by the lack of integration, older adults are having a very difficult time trying to navigate a system without communication between different parts. Another care provider noted that better integration of geriatric services could improve follow-up within different levels of care, using a team approach. By coordinating care in a more efficient way, another care provider noted that specialized services would only be solicited when needed, to maintain resources for crisis situations. However, participants recognized that without education and guidance, older adults and their families may not have the skills to navigate the individual systems of care. Discussions about integrated systems of care were coupled with conversations about the challenges of navigating during transitional care. During this time, the lack of communication between care settings is most prominent, and is thought to make it challenging for all parties involved to coordinate care transitions. Some focus groups felt case managers were ideally placed in the system to connect older adults with services, but there were several barriers to their role providing all the navigational support necessary for a person with chronic disease moving across care settings. These barriers were: large caseloads, lack of flexibility in the role, and too many hand offs between case managers in the system. In sum, the structure of the health care system heavily influences older adults', families' and health care provider's ability to navigate the system, and the focus groups confirmed key elements to assist with system navigation.

The delivery system design needs to accommodate the system navigation needs of older adults living with chronic disease. Participants felt that there are some changes in care delivery that could improve continuity of care, linkages among providers and information exchange. Navigating the system was discussed as a challenge following hospitalization or specialist appointments. Patients often receive

large amounts of new information when experiencing a change in their health condition. Therefore, timely follow-up in primary care was a common concern in focus groups involving patients, caregivers and care providers. This was partly related to poor information sharing among providers, but also patient's often don't know how or when to seek follow-up support in primary care. The delivery system design could improve on monitoring patients as they transition across the system to provide better navigation support. Improving linkages and ensuring consistent information is shared among providers should accompany interventions aimed at improving system navigation. Another suggestion from multiple focus groups was the development and implementation of health passports to link individual providers and to link patients to their providers. Next, focus groups discussed how older adults could navigate the system more efficiently, and use the appropriate services at the right time. Participants thought hospitals should be considered the "fall-back" option, and primary care should be the first place older adults seek care. This is not a new mindset, but requires system navigation assistance to persons with chronic disease who are typically using acute care as a substitute for primary care, as well as education about the appropriate use of acute care resources.

The focus groups were able to generate some recommendations to adapt the current delivery system design to the gaps in care delivery. The two most common ideas were to changes the pay structure of health care agencies, and further implementation of Intensive Geriatric Service Workers. First, in order to make the system more "seamless", members of the various focus groups supported a bundled service strategy; patients are referred to service provider agencies with a pot of money to provide treatment for their health conditions, rather than agencies getting paid per service provided. Second, focus groups were very positive about the implementation of IGSWs in their community, and felt adding more positions would be a valuable use of health care dollars. Key responsibilities of IGSWs were discussed related to delivery system design, such as linking providers and programs throughout care delivery, improving communication with the care team, and facilitating timely access to services. IGSWs were reported to work well with high risk seniors, and seniors who are resistive to services. Overall, focus group members were supportive of an integrated delivery system design, to effectively guide older adults with chronic disease through the system.

The next component of the CDPM framework is Decision Support. System navigation is an important element of decision support for both care providers and for patients and families as they make choices on where and how to seek health services. Focus groups recognized that both providers and

administrators would benefit from education on what services are available and how to access those services in different care settings. For example, a participant noted that family doctors need to know they can and should refer to support services in their communities. The ability of older adults to navigate the health care system relies on care providers' guidance, and communication among those providers. It was clear that system navigation is a shared responsibility across providers. Focus group participants felt that older adults get "bounced around" when trying to take part in their own care. Therefore, the problem is multifaceted; not only do patients struggle to find adequate support in navigating the system, but often they are not fully involved in the decision making process. In general, modifications to the way decisions are made about one's care may facilitate system navigation for older adults with chronic disease.

The last component of the health system in the CDPM framework describes the technology connecting patients to their health information. Clinical information systems are the foundation for a cohesive system, and there were several changes suggested at the focus groups to improve the function of these systems. Focus group participants felt the health system should use a consistent referral process, to ensure various care providers know how and where to direct referrals. For example, one participant commented on the various ways an older adult may become linked with community support services. Although multiple referral options may reach different groups of older adults, there is a lack of responsibility among the providers involved to always complete the referral. Therefore, making the system easy to navigate for the care providers, will also help older adults to navigate the system. Focus groups felt the system could improve on monitoring patients after a change in health status. Providing timely follow up in primary care following diagnostics, treatment, appointments and hospitalizations would remove some burden on older adults to independently navigate the system. Developing an immediate link with primary care may provide an opportunity to incorporate a navigation role FHT were discussed as having an ideal structure to coordinate care among their allied health professionals. Focus groups saw the various health care providers working under one roof as an opportunity to link early with patients to ensure they are connected with the services they need. However, focus groups felt the important piece of navigating an older adult is having one consistent person involved with the patient. One participant shared her knowledge of a FHT using a social worker as a system navigator within their team. Although limited information was known about this role, it was clear the social worker was designated as the navigator for that FHT, and would be a consistent resource for patients. Finally, information exchange between providers was a major topic of discussion, acting as a barrier to older adults navigating the system. Improving information exchange during care transitions is crucial to

facilitate navigation. One participant reflected on her experience working with a family whose relative was hospitalized:

> "I coached the family in getting a meeting with a team and the doctor to say exactly what they wanted. Well what turned out was nobody in that wing knew that this man was dying of cancer and was palliative and they're trying to rehabilitate his hip and there wasn't communication, nobody had a chart that showed what was going on with this man".

This was a communication issue between the acute care unit of a hospital and the rehabilitation unit of an inpatient rehabilitation centre, however, similar issues might be present within home and community health services. In each conversation about information exchange, focus groups agreed that every provider needs access to patient health information. Overall, clinical information systems should be moving in a few specific directions to facilitate system navigation, such as using a consistent, shared referral process, monitoring patients as they transition across care settings, and easing information exchange across care settings.

3.3.3. Patient and Team Interaction

The final category in the CDPM framework is Patient and Team Interaction, which clearly focus on the Informed, Empowered Patient and Prepared, Proactive Team. First, focus groups were quick to recognize that older adults with chronic disease are complex patients with multiple complex conditions and several layers of problems to address. Therefore, older adults need to be informed and empowered to navigate the system. Focus group participants felt that it is crucial for seniors to have clear information about who to contact and how to access services when health complications arise. By giving the patient the information they need to direct their care, we would be facilitating system navigation and self-management of chronic disease, which is appealing to the patient, family, and care provider experience, as well as system expenditures. Focus groups found it important not only to inform the patient, but also to make the system more user-friendly to help seniors navigate. For example, current telephone system mechanics make it challenging to get the services patient's need because they require seniors to follow multiple steps with an overwhelming number of options to choose from. Therefore, it is important to gather feedback from older adults using the tools to understand how to make them more user-friendly. Focus groups members appreciated being asked to share their first-hand experiences. They felt the system should mirror the consultation process, and become even more patient-centred by relying on input from patients and caregivers on their needs. One health care provider suggested, "talk directly to the seniors, find out what

they want, the resources that are available, and coordinate them so that more people know about them and use them effectively". This demonstrates the value of older adults' input on what makes a system user-friendly, to improve the way older adults navigate the health care system. Finally, several focus groups discussed the concept of "information paralysis", where seniors are overwhelmed with the amount of information they are given. Throughout the course of managing a chronic disease, older adults and their families are in stressful and often unfamiliar situations. Therefore, the educational information they are receiving needs to be clear and concise to reduce the overwhelming nature of hospitalizations, care transitions and system navigation. In sum, focus groups identified building capacity for seniors to access and navigate health and support services as a high priority for the future of health care.

Finally, the remaining component of the Patient and Team Interaction is a Prepared, Proactive Team. The care team is pivotal to the older adult's ability to prevent and manage chronic disease, and is particularly important to guide the patient through the system. Focus groups identified the need of a team of caregivers and care providers to recognize and manage the risks for older adults living with chronic disease. This includes a range of people, from educated caregivers aware of how to access appropriate services, to specialists changing medications or performing interventions. A key element to this team is to understand how all the pieces fit together to help the patient. Focus groups felt that current teams need more awareness of everyone's roles for system efficiency and care coordination. Since older adults with chronic disease need to access services from different care settings, this awareness should span across care levels and communities. Role clarity would also help care providers to problem solve for different patients, and help navigate the patients to use the right service at the right time. The revolving door between emergency departments and the CCAC, identified by focus group participants, may be avoided by guiding patients more effectively through the system. Focus groups acknowledged caregivers as one of the most important members of the care team, and that they have their own specific needs. Caregivers need support, and they need information and preparation to learn to navigate the system. One woman, caring for her husband with Alzheimer's Disease, shared her experience trying to coordinate his care at their home. She shared a list of 56 people who helped her care for her husband, and how she found it very difficult to remember where they needed to be, who would be visiting in a day and what everyone's role was. The capacity of caregivers to support the older adult largely influences the way they navigate the system.

In conclusion, these focus groups captured many voices of the care team, older persons and families, and help to gain an understanding of how teams can help navigate the older adult with chronic disease.

3.4. Summary of Findings

To summarize the findings of the focus groups conducted across the Waterloo Wellington region, one care provider's words come to mind: "[We] need a system where every door is the right door". Despite current strengths in services for older adults with chronic disease in Waterloo Wellington, the system of care for seniors has significant gaps. A Chronic Disease Prevention and Management framework addresses the major issues identified by focus group participants around the needs for improved access to care and improved structures to facilitate system navigation. The focus groups with consumers, caregiver and health care providers, yielded a general consensus that we need a more integrated system of care for seniors in this region. There is a need to change supports and structures to ensure adequate linkages between hospitals, primary care, (family practices, family health team, community health centres) and community support services. Without adequate linkages between care settings and providers, system navigation will continue to be a major challenge for older adults in our region. The concepts related to system navigation of older adults identified in the focus groups were used to help create a theory for a system navigator role in Waterloo Wellington. The focus group findings allowed the researcher to understand the high priority needs of older adults with chronic disease on our region, and ensure the framework was tailored to those needs.

The consultation process of health care consumers and providers for the WW-LHIN has been completed. The data were analyzed and currently an extensive report is near completion for the WW-LHIN to use to guide decision making of health care in our region. Priorities set by this report may be used by the WW-LHIN in determining future directions of research and financial support.

CHAPTER 4: HIP FRACTURE PATIENTS, CAREGIVERS AND HEALTHCARE PROVIDERS

4.0 Data Source: Hip Fracture Patients, Caregivers and Healthcare Providers

4.1 Introduction

InfoRehab Transitions is a CIHR-funded Emerging Team Grant, initiated to enhance musculoskeletal (MSK) rehabilitation through the better use of health information (InfoRehab, 2011). Overall the program of research is targeting the delivery of rehabilitation services, and appropriate access to care across the continuum with a focus on more effective use of health information. The main objectives of this team are:

> 1) With a focus on hip fracture patients, to understand the need for, use of, and exchange of health information across the continuum, with the use of ethnographic methods; and
>
> 2) To answer important questions relevant to rehabilitation of older persons with MSK disorders across the continuum of care, through advanced statistical analyses of large health information databases.

The qualitative arm of the study is centered on conducting interviews across the continuum of care for hip fracture patients, to involve all members of the patient's care network in informing a more integrated and effective model of MSK rehabilitation.

Linking with the InfoRehab team provided an opportunity to gain feedback on a system navigator role, based on real-time experience from multiple perspectives. The researchers spoke with participants as they were going through a health crisis, potentially gathering different ideas than if participants were later asked to reflect on their experiences. In addition, hip fracture patients were an appropriate group to study, as they are an exemplar study population of frail older adults, with multiple chronic conditions (Marengoni et al., 2009). Qualitative data were collected from patients who had had a hip fracture, as well as their formal and informal caregivers, to understand their experiences during care transitions. The overall goal of these interviews in the context of this thesis was to achieve the third objective - to identify system navigation needs of hip facture patients transitioning from acute care and understand the potential impact of system navigation on the care of patients and their caregivers.

For the purposes of this study, the interviews of interest explored the experiences of hip fracture patients and their informal and formal caregivers after they completed their final transition. The interviews obtained a preliminary assessment of the acceptability of existing models, or components of models in the Ontario health system, which were identified by the systematic literature review (Chambers et al., 1983). The interviews also provided an in-depth and patient centered view of transitions across the

continuum of care and complement the findings from the other data sources. These system navigation concepts will be incorporated into a theory for an ideal system navigation role.

4.2 Methods

Recruitment

Participants were recruited from Grand River Hospital, located in Kitchener, Ontario. This hospital is a multi-site facility providing acute, complex continuing and cancer care and is also affiliated with Freeport Health Centre, located in Kitchener, Ontario. These hip fracture patients and their informal caregivers will typically be living in urban Kitchener-Waterloo areas as well as in surrounding rural communities.

Research assistants were responsible for working together with charge nurses on the hospital's acute care floor, to identify potential participants and initiate recruitment. The research assistants reviewed the list of patients on the acute care unit weekly, and compared them to the inclusion criteria. The recruitment strategy followed a two phase consent process. First, the researcher organized for a health care provider, either the charge nurse or nurse assigned to that patient, to approach the participant and introduce the study and researcher. The nurse was given a script of how to describe the study, and invite potential participants to join the study. Then, if potential participants agreed (Phase 1 consent), the researcher held an information session with the patient and family to explain the study in detail. The patient was given an information pamphlet with the overall purpose of the study and more detailed information about their role. As well, participants and their families were given information letters and consent forms, to gather informed consent (Phase 2 consent).

The eligibility of criteria for participants was established to be:

1) Persons aged 65 years of age or older who had experienced a hip fracture

2) Were currently admitted to acute care (unit 6A or 6C) at Grand River Hospital

3) Had a discharge plan indicating that they would ultimately be discharged to home or long term care

4) Able to speak English

5) Were cognitively intact, as reported by the participant's health care providers in the acute care setting, OR have a substitute decision maker to give informed consent for patients with moderate or severe dementia.

In accordance with the grounded theory approach, theoretical sampling was used to seek out a variety of patients, to develop the emerging theory (Charmaz, 2006). Researchers were looking for

patients who differed by gender, age, culture, caregiver support, living situation and anticipated transition paths. Once participants were recruited for the study, and gave informed consent, their caregivers and health care providers were also recruited to participate in the study. Primary informal caregivers were selected by their level of involvement with the patient. Some participants had a single caregiver to provide most of the care; these caregivers were interviewed multiple times during each care transitions. Other participants had up to three informal caregivers involved in their care. In the case of multiple informal caregivers, interviews were conducted with each person for a different care transition, trying to capture their experience with the care transition they were most involved in. Since the 'InfoRehab' study is focused on transitional care, health care providers involved in the patient's care at each care setting, were invited for interviews. This allowed for the researchers to understand what happened as the patient moved from one setting to another, across the system. Pamphlets, information letters and consent forms were distributed to the caregivers and health care providers involved with the patient. This recruitment process was carried out each time a patient transitioned to another care setting. For example, Table 3 illustrates the interviews conducted for members of the care network of participant number one. As well, at each new care setting, researchers tried to recruit different types of health care providers to broaden the perspective of the study. The area shaded in grey is the group of interviews used for the purposes of this study. Finally, Table 4 shows all the individuals who were interviewed according to each patient participant. However, for this study, only the interviews with health care providers and caregivers involved in the patient's final transition were analyzed.

Table 3- Patient 1 Interviews, conducted at each care setting.

	Acute Care	Inpatient Rehabilitation	Retirement Home	Home
Patient 1	Patient Caregiver Nurse Case Manager	Patient Caregiver Occupational-Therapist	Patient Caregiver Physiotherapist	Patient Caregiver Physiotherapist Medical Doctor

Table 4- Interviews conducted for each Patient Participant

Patient	Informal Caregiver	Health Care Providers

Participant 1	Daughter	Nurse Physiotherapist Occupational therapist Medical Doctor Case Manager
Participant 2	Daughter-in-Law	Case Manager Occupational Therapist
Participant 3	Spouse	Physiotherapist Occupational therapist Case Manager
Participant 4	Daughter	Nurse Physiotherapist Occupational therapist Case Manager
Participant 5	Daughter	Nurse Physiotherapist Case Manager
Participant 6	Daughter	Case Manager Retirement Home Director

Data Collection

The 'InfoRehab' interview guides were developed prior to the identification of system navigation as a major concept of transitional care. Therefore, each interview guide, for patients, informal and formal caregivers, was modified to ask participants about their experience navigating the system during care transitions. The systematic literature review helped to inform the interview guide, by directing the researcher to ask questions about what is not yet known. First, the researcher wanted to understand any gaps in care delivery through their different transitions, with which a system navigator may or may not be positioned to assist. The literature review helped to determine what probes to use for this question, to cover each potential responsibility of the navigator. Then, participants were asked more directly if they felt hip fracture patients and their caregivers would benefit from having someone whose job is to help them transition smoothly across care settings, and to describe what that role might look like. Based on the

short period of time system navigators have been implemented and studied, the researcher felt it was important to gather information on what the participants thought the role should look like. Finally, each participant was asked to comment on the potential impact a system navigator role could have on the care of hip fracture patients. Although the literature review synthesized some outcomes for the system navigator models, the research thought it was important to understand all potential impacts that previous models did not account for in their outcome measurements. Finally, the interview guides (Appendix H) were flexible to ensure the study generated comprehensive findings and contributed to a widely applicable model (Charmaz, 2006).

Special considerations for interviewing older adults were informed by Domarad and Buschmann (1995). Since patients are unable to anticipate their needs before the care transition (LeClarc, Wells, Craig & Wilson, 2002), interviews were conducted when the patient had one to four days to reflect on their experience. As well, these researchers suggested breaking the interview into smaller sections to keep interviews short for the older adults recovering from surgery. In order to facilitate a comfortable conversation about a loved one, interviews with the patient's informal caregivers were conducted at a location of their choice. Interviews were audio recorded, transcribed verbatim and securely stored electronically.

Data Analysis

Interviews were considered secondary data, as a large portion of the data were collected by other researchers and the data were analyzed previously for a different purpose (Charmaz, 2006). The interview data were analyzed using an interpretivist stance. A qualitative content analysis approach (Graneheim & Lundman, 2004; Charmaz, 2006) was taken, as described in Chapter 3.

4.3 Results

Participant Characteristics

A total of six participants were recruited from Grand River Hospital. Participants differed based on characteristics such as gender, culture, age, living situations and support networks (Table 5). As well, six corresponding caregivers and nineteen health care providers were interviewed. For the purposes of this study, a total of 31 interviews were conducted across many care settings: retirement homes, long-term care, and residential homes. Data analysis and data collection occurred simultaneously, and it became evident when data saturation was reached because no significant new findings were further identified.

Table 5- Patient Characteristics

Patient	Gender	Marital Status	Transition
1	F	Widowed	Home → Acute Care → Inpatient Rehab → Retirement Home → Home Care
2	M	Widowed	Home → Acute Care → Inpatient Rehab → Home Care
3	M	Widowed	Home → Acute Care → Home Care
4	M	Married	Home → Acute Care → Home Care
5	F	Widowed	Home → Acute Care → Inpatient Rehab
6	F	Widowed	Long term Care → Acute Care → Long Term Care

Coding Categories

Based on the content analysis, three categories were identified. A summary table has been included to show the codes mentioned by study participants and how they were organized into larger categories (Table 6). Following the table, each category is described in detail; direct quotes from the participants were selected to reflect the participant's thoughts and feelings during interviews (Charmaz, 2006).

Table 6. Summary of Analysis of 'InfoRehab Transitions' Interview Data

CATEGORY	INTERVIEW CODES
Rationale for a system navigator role	- Can't assume family can coordinate/navigate - Need to be proactive with frail older adults - Need role that is the common thread with all of the information - HCP learn from experience, no information given about what's available - Only understand system once they have gone through it - Clients who lack motivation or have comorbidities need extra help to navigate - Important to start supporting person before they leave hospital - Overwhelmed with how many people are involved - HCP pressured to move people through system - No clear pathway to navigate - Overall it is difficult provide successful care transitions for elderly
A system navigator role should look like…	- Work with community case manager - Based in community - Open referral sources - In the hospital explain care path and guide expectations

	• Provide follow-up after hospitalization
	• Care advocate
	• Circulate through emergency department
Potential benefits of a system navigator	• Informed patients and families
	• Preparation and expectations
	• Lessen workload on hospital staff to ensure successful discharge
	• Manage care across transitions
	• Improve continuity of care
	• Help people make changes at home to reduce rehospitalization
	• Improve and facilitate communication between settings and providers

4.3.1 Rationale

The first category was named 'rationale for a system navigator role'; it describes the various reasons why participants felt a system navigator role would be helpful. During the interviews, each patient network highlighted several aspects to support a system navigation role based on their experience, as a patient, caregiver or health care provider. Although these individuals view the health system from different lenses, many of the major points were echoed across roles and settings. Overall, the participants expressed that it is difficult to provide successful care transitions for older adults experiencing a health crisis. In particular, many recognized that individuals with several co-morbidities, and individuals lacking motivation, are at an even higher risk of poor outcomes during care transitions. However, interviews with patients, caregivers and health care providers raised some important points to help older adults navigate these complex care transitions. First, many participants felt that the care team should not assume the family of the patients have the skills or capacity to coordinate care and navigate the system. In addition, although family caregivers are moving to care settings with the patient, there is still a need for a health professional to be the "common thread", whose job is to maintain all the information and have a clear picture of the process. For example, the researcher was told by all parties that patients and families are overwhelmed with how many people are involved in their care. Second, interviewees reiterated the importance of supporting the patient and family before they were discharged from hospital. Upon discharge, patients move from a care setting where they are dependent on their formal care providers, to a different setting where this dependence is shifted to either the informal caregiver or the patient, who is often feeling unprepared and overwhelmed. Finally, interviewees felt that there are areas to improve care transitions by taking a proactive approach. This had many meanings, from accessing services in the home before crisis or educating or assisting older adults in planning and preparing for transitioning between care settings.

Findings from the interviews with patients, caregivers and health care professionals echoed the findings of a system navigator role from the literature review.

The interviewees also suggested several challenges that patients, caregivers and health care providers are experiencing which support the implementation of system navigators. Health care providers, caregivers and even patients recognized the only way to learn how to navigate the system is to have previous experience in the system. For example, one caregiver working within the health care system commented, "I know the system because I have clients who deal with the system, right. I know how the system worked because of my work with them". This informal caregiver had worked as a health care provider most of her life; therefore she felt she was well positioned to understand care transitions. However, many caregivers, do not have the experience necessary to be prepared to understand and navigate care transitions following their loved one's hip fracture. As well, there is a lack of guidance for system navigation available to patients, families and care providers until a crisis situation. One care provider reflected, "we've had people fall through the cracks, where patients are thinking 'what do I do now, I'm home, I have all these new medications, I'm starting to have problems with them, who do I go to'." Interestingly, the care providers understand the overwhelming nature of care transitions, and are identifying gaps in care delivery which could be performed by a system navigator role. As mentioned previously, a proactive approach may be more appropriate to provide support during care transitions, rather than continually learning from experience. Finally, health care providers felt challenged by pressures to move people through the system. Another care provider stated, "you know overall the incredible pressure to get people moving through the system is difficult…working with clients you want to do what they want, you want to make them happy and see them progress and knowing the limits of the system is hard." Since health care funding cannot be expected to rapidly increase, the delivery system design may need to accommodate the fast paced care transitions with a system navigator. In conclusion, the interviews with patients, caregivers and health care providers built a strong rationale for how and why a system navigator may improve care to older adults after hip fracture.

4.3.2 Role

All parties involved had some feedback on what a system navigator role should look like (Table 6). Considering none of the individuals had experience with a navigator role, their suggestions were based on their experience during care transitions. Most commonly, participants thought the system navigator should be based in the community. One case manager said, "so the [system navigator] could communicate with the community case manager and say 'you know what, he's probably doing OK', or 'hey this is not

working you have to come here'. We wouldn't see that from hospital…so I think in the community would be a really good thing". The advantage of a system navigator in this situation would be their ability to assess the home situation once the person has transitioned home, and to give feedback to other health professionals on the care team. This case manager also pointed out how they could complement the role of the community case manager. Another code describing the role of a system navigator was having open referral sources. Geriatric care has many layers and involves many health professionals, and another health care provider felt that it would be important for this system navigator role to accept referrals from all sources. Next, participants identified the need for a health professional to prepare and explain the plan of care for these hip fracture patients. An informal caregiver offered,

" like even to just have someone there, to go through something like the care pathways with them…even if it was in the hospital…just to go through the care pathway and explain like this is what's going to happen, and this is what's going to happen next. I mean the case managers will go through the discharge plan with the client before they leave the hospital, it's just a matter of whether they understand everything that is said to them…maybe a follow-up call".

This statement touches on several important points to consider when developing a system navigator role. First, the system navigator needs to explain the care pathway and adequately prepare the patient and family for the upcoming care transitions. Second, she recognized that although case managers are responsible for navigating the patient through a discharge, there is a lack of follow-up to ensure the care plans are followed. Therefore the navigator would bridge the gap between care settings, where case managers are not able to provide all the support necessary. Finally, one patient had two important ideas for a system navigator role: to advocate for the patient and to support the patient immediately after the hip fracture. She could see the system navigator acting as a, "care advocate relating to planning the care". In addition, she thought, "they would also circulate through the emergency department". In sum, the overall key message the researcher identified was that the navigator should be working out of the community but also be very active in hospital settings to prepare patients for transitions and to explain care paths.

4.3.3 Benefits

Almost every participant interviewed could see potential benefits of a system navigator role. The researcher left the concept of a system navigator open for interpretation, and asked interviewees to describe what the role would look like for them. Then, interviewees were asked to comment on potential implications of a system navigator on any parties involved in care transitions. Responses were very similar, and touched on many of the issues previously raised by participants. Participants felt that a

system navigator role could keep patients and families informed during care transitions. For example, one health care provider reflected on their experience with the patient; rehabilitation length of stay is routinely one to two weeks, but the patient was under the assumption that she could stay for a month. The role of a system navigator was thought to inform the patient and family about what they can expect in each care setting. Patients, caregivers and health care providers expressed that a system navigator could help prepare patients and families for care transitions, and help synchronize their expectations with the new care setting. Participants noted a system navigator would facilitate communication between care settings and between providers. One care provider in acute care said, "we don't want something that I put together in hospital then to fall apart at home because of the information I didn't have or because it has been dismantled by the community case manager…it doesn't help the client, we need to be consistent in our approach". It was also thought that a system navigator would reduce the workload of hospital staff to ensure successful admission and discharge. Finally, some participants recognized the potential for system navigators to help people make changes influencing their health at home to reduce rehospitalizations. All parties came to the conclusion that a system navigator could manage care transitions to improve continuity of care.

4.4 Summary of Findings

Overall, the findings from this data set built a solid rationale to implement a system navigator role to assist hip fracture patients during care transitions. A powerful quote from a care provider illustrated why a system navigator might fit into our health care system: "It's not a system, as a system is made up of parts that interact and in the health care environment they don't interact. You know when you're in hospital there's not communication with the [health care providers] outside". Patients, caregivers and health care providers had valuable insight into how the system navigator could fill in some current gaps in care delivery. In addition, there is potential for this role to improve the experience of other older adults transitioning across the system; many comments could be generalized beyond a hip fracture patient's experience in various care settings. The findings from these interviews will be instrumental in creating a theory for system navigation for older adults, informed by patients, caregivers and health care providers with first-hand experience.

The 'InfoRehab Transitions' project is currently in the next phase of research. The study has established the needs of hip fracture patients, their caregivers and health care providers during transitional

care. Next, these findings are guiding the development and testing of different interventions to improve care transitions for older adults.

CHAPTER 5: INTENSIVE GERIATRIC SERVICE WORKERS

5.0   Data Source: Intensive Geriatric Service Workers

5.1 Introduction

The evaluation of the IGSW role in Waterloo-Wellington is a portion of an 18 month evaluation, led by Dr. Carrie McAiney. Overall, the goal of the evaluation is to understand the implementation and impact of the Waterloo Wellington Integrated Services for Seniors Project. The evaluation of the IGSW role has been divided into two sections: the development and implementation of the role, and the understanding of responsibilities and function of the role. The data reported in this chapter were collected within the second phase of the evaluation, and involved in-depth interviews with the IGSWs working in Waterloo-Wellington.

Currently, there are 9 IGSWs employed throughout Waterloo Wellington, including St. Joseph's Health Centre in Guelph, and Community Support Connections in Waterloo and Cambridge. They are non-regulated health professionals, and have a variety of responsibilities while caring for older adults who are transitioning across the health care system as described earlier in Chapter one. Since there is limited literature on the origins and rationale for this role, this research may help to document and communicate more information on the IGSW role. The flexibility of their responsibilities, the heterogeneity of the population they serve, and their unique positions across a diverse region such as Waterloo Wellington, made interviewing each IGSW essential in order to accurately capture and reflect their true experiences. These data were critical to understanding the landscape of system navigation in Waterloo Wellington region. The IGSW role was considered an exemplar of a system navigator; these interviews were used to compare and contrast what was learned as part of this project about system navigation roles and population needs on this region. Without exploring the IGSW role, there would be a limited understanding of the potential function and impact of the role. The overall goal of these interviews in the context of this thesis was to achieve the fourth objective – to understand the role of IGSWs in the Waterloo-Wellington health system, and assess the potential impact of this system navigation model on chronically ill older adults during transitional care.

5.2 Methods

Recruitment

All nine IGSWs working in the Waterloo Wellington region were recruited. Each IGSW was sent a recruitment letter for the larger evaluation study, by the lead evaluator (CM). The lead evaluator (CM) took appropriate measures to introduce the researcher to the IGSW lead Janice Paul (JP). CM also explained the interview process, and that each IGSW should expect the researcher to be contacting them for an interview. The IGSW lead then distributed this information to her team to ensure all parties involved were aware of the evaluation interviews. Formal consent was not used, as verbal consent was implied when participants scheduled and completed the interview. Ethics clearance for this evaluation project was received from McMaster University in January 2010.

Data Collection

Interviews were approximately 40-80 minutes in length, and were conducted in a location agreed on by both the researcher and participant. Interviewees were made aware of the researcher's intention to audio record and transcribe verbatim their discussion. A semi-structured interview guide was developed by the researcher which incorporated input from lead evaluators and other stakeholders of the WW-GSN (Appendix I). The interview guide was also informed by gaps in the literature and areas of interest from previous findings. In general, interviews with the IGSWs obtained in-depth information about their experiences, the activities they engage in with their clients, and how they feel they are working with the target population. Each interview was audio recorded, transcribed verbatim and securely stored electronically.

Data Analysis

A similar approach to qualitative content analysis (Graneheim & Lundman, 2004) was taken to these data, as described with previous data sets. However, categories for further analysis were the topics of the questions from the interview guide. Therefore, there were 8 main categories, such as descriptions of their role, or descriptions of the clients they worked with. Anonymous quotes have been used to illustrate and accurately reflect the expressions of the participants (Charmaz, 2006).

5.3 Results

Participant Characteristics

All of the nine IGSWs in Waterloo Wellington region were recruited to be interviewed. This sample included eight females, and one male. Eight of the IGSWs were hired at the beginning of the program, and one was later employed to fill a maternity leave. Therefore, all but one of the participants had been working as IGSWs for one and a half years. Each IGSW had previous experience with seniors, such as working with community support services, housing or mental health. In addition, there are a variety of cultures, ethnicities and languages practiced by the IGSWs, including Italian, German, French, Portuguese, Mennonite and Dutch. Finally, each IGSW is assigned to a specific region in Waterloo Wellington. The two IGSWs working out of Cambridge Community Support Connections, have divided the city of Cambridge and surrounding areas into two regions. Similarly, three IGSWs have determined boundaries for the City of Kitchener and Waterloo. Finally, three of the four IGSWs working out of St. Joseph's Health Centre share the City of Guelph, and one IGSW covers the rural areas north of Guelph (Table 7).

Table 7. IGSW Distribution across Waterloo Wellington Region

Region	Number of IGSWs
St. Joseph's Health Centre	4
City of Guelph	*3*
Rural area North of Guelph	*1*
Cambridge Community Support Connections	2
Waterloo Community Support Connections	3

Coding Categories

Based on the content analysis, three categories were identified: 1) IGSW role, 2) clients of IGSWs, and 3) barriers and facilitators of the IGSW role. Next, the data were separated across those categories by discussing current thoughts about their position, or predictions for the future related to working as an IGSW. A summary table has been included to show the codes mentioned by study participants (Table 8). Following the table, each category is described in detail; direct quotes from the participants were selected to reflect the participant's thoughts and feelings during interviews (Charmaz, 2006).

Table 8. Summary of Analysis of IGSW Interviews

	CURRENT THOUGHTS	PREDICTIONS FOR FUTURE
Role	- Advocates for seniors - Facilitating self-management - Various activities with clients, many beyond health - Facilitating care transitions - Description of time allotment - Flexibility in role to meet client's needs - Role is improving communication - Between providers - Quarterback: Provide "information bridge" between care providers and clients/families - Strategies to working with and for their clients - Problem solving as a team of IGSWs - Addressing financial barriers - Going over things several times - Helping them to slowly do things on own - Reduce anxiety at appointments	- Host agency makes it easy to connect with community support services, Guelph hospital - Could see a fit with CCAC, emergency department - Each area of the LHIN is different - Variety of host agencies
Clients	- Most successful with resistive people, clear goals - Most challenging groups of clients- addiction, cognitive issues - Referral sources (GEM vs. geriatric team) dictates medical vs. mental approach - Clients lack family support, are in crisis	- Concern of diluting service with high caseload - Could take a preventative approach - Expanding referral source to provide service to potential clients
Barriers and Facilitators	- System navigation - Complicated system to navigate - Overwhelmed once you're in need - IGSWs are helping seniors navigate - Connecting with services - Tour Guide - Helping families - Gaining the experience for the client - Introducing a new role to the system - Working with case managers has been positive, roles complement each other - Establishing role clarity was time consuming - Positive experience working with Doctors	

| | o Nurses | |
| | o Challenging to gain access to information | |

Current Thoughts

Role

Each IGSW gave a thorough description of their current role, and discussed many of the responsibilities they have in their client's care. Initially, participants were asked to divide up their work day or work week into the various activities, to understand their daily responsibilities. IGSWs typically allotted 30-50 percent of their time directly working with clients; this includes home visits and phone calls with clients. Then IGSWs said another 30-40 percent of their time is spent communicating with other services and connecting clients with the information and services they need. Finally, approximately 10-20 per cent of their time is reserved for documentation. Using this allotment of time as a foundation, participants were then asked specifics about each part of their role. IGSWs consistently highlighted five major functions of their role:

1) Advocating for seniors

2) Facilitating self management

3) Assisting clients with more than their health conditions

4) Having the flexibility to meet client's needs

5) Easing the transitions across care settings.

First, every IGSW said they act as advocates for their clients. One IGSW said, "we've advocated for clients, you know we've said this client needs this service or they need more money for these reasons, so we're there as their voice". As well, IGSWs felt they worked with clients to develop the tools and knowledge to properly manage their health conditions. For example, an IGSW shared,

> "so I will walk my clients through step by step what needs to be done and I'll repeat that as many times as it needs to be so that when I disengage myself I can feel confident that they can do these things for themselves now, whether it's grocery shopping, taking transportation, calling their family doctor, you know all these things are important for them to stay home independently and to stay out of the hospital as well, so that's part of the goal is to help people not always reach out to emergency department that they are able to cope with these things on their own".

Facilitating self-management is a key component in preventing and managing a chronic disease, as described in the CDPM framework in the previous chapter. Next, each participant mentioned activities they did with their clients that can be considered beyond health interventions. For example, they shared

the opinion that developing relationships with their clients was imperative to provide quality care. One IGSW reflected on her role as a, "very helpful and that non-threatening role that we play of going in and getting to build a relationship and build a rapport with them…getting them trusting us in what we are doing". IGSWs valued relationships with their clients and recognized their role is not limited to health services. Similarly, in each IGSW interview, they emphasized the flexibility in their role to meet each client's needs, both in how they work towards meeting goals with the client, and in how they manage their caseload. The flexibility of their role was evident when on IGSW said, "we can discharge when we feel they're ready and that, really great, we're not told you must discharge this person by this date… Like I said we're short term but often times we'll hold onto clients for a year maybe even a little bit more because we're just not confident about their condition…so there's that flexibility." IGSWs discussed their time with clients, and compared to other health care providers, they felt they were able to provide support most intensely for a longer period. Finally, care transitions are a time when older adults are vulnerable to poor outcomes, and IGSWs described their role as easing those transitions between care settings for their clients. One IGSW explained, "it's just kind of being that consistent person for them as well. I mean it can be overwhelming coming home from hospital and having these things thrown at you, I know myself even if I didn't have somebody that could by like let's sit down and really talk about all these things and really go through what's important to you, I don't know necessarily that a lot of things would get done". Typically IGSW involvement is triggered by an emergency department visit, initiated by a GEM nurse, however IGSWs are also instrumental if and when their clients are rehospitalized. One example an IGSW shared was, if a client goes to St. Mary's I will talk to the charge nurse and say what's going on with her and have they found anything with the tests…I'll talk with the family doctor or any other professional like CCAC…". Therefore, IGSWs are important for successful care transitions for both the patient and their health care providers. Overall, IGSWs shared a rich description of their role to illustrate how they are filling gaps in care delivery for older adults with complex health conditions.

IGSW Role is Improving Communication

In describing their role as an IGSW, participants also shared how their role was improving communication across the health system. Communication and information sharing is a major target of health system interventions, and IGSWs are forming important linkages across the system. IGSWs felt they were improving communication between providers. They provided a link between different health care providers across care settings who in other situations had not had the opportunity to share thoughts about a client's treatment or progression. As well, IGSWs described themselves as the quarterback in care delivery for their clients. An IGSW reflected, "I counted at one point, there was a case manager, there was

an OT, there was nursing…there was something like five different people and I was the only person who talked to all five parties". The IGSW provides an "information bridge" between care providers and clients and families. Improving communication between providers and clients impacts many aspects of the care for older adults. IGSWs explained that better communication has improved medication management, team meetings, care transitions and follow-up with care plans. IGSWs called themselves the eyes and ears of the system in the client's home, and are able to recognize red flags and prompt quick intervention. They helped to manage medication with their clients by quickly recognizing negative effects of medications in their clients. Furthermore, IGSWs have the knowledge and experience to consult with the proper health care provider, depending on the problem. For example, with complex cases, IGSWs have been known to facilitate team meets to problem-solve around a client. Finally, they are the common thread through care transitions, and provide continuous support following care transitions. IGSWs are crucial to following up with appointments and recommendations with other health care providers. One participant shared,

> "I think we are filling a lot of gaps. I hear a lot you know, 'I don't know how I would have actually got to these appointments if you weren't here'…there's a lot of scrambling around to get there but if I wasn't there and I wasn't kind of trying to make sure that they're following through with these recommendations, being that one constant person…a lot of them would slip through the cracks and end up back [in hospital]".

Participants described their role as improving communication between providers and clients, demonstrating their positive impact on many important aspects of care delivery.

Strategies to Working as an IGSW

IGSWs described strategies they have learned to help their clients during a time when they require extra help to navigate the system. First, IGSWs acknowledged their colleagues as valued resources for problem solving around a client. They recognized that sharing their experiences with other IGSWs helps everyone learn about what is available in the system. One participant commented, "we have a really good team set up here, you know I work closely with [the other Guelph IGSWs], just having that team you can come back and debrief or ask an opinion". IGSWs acknowledged their colleagues in several discussions as they mentored each other to navigate the system in areas of varying expertise. Second, IGSWs are learning strategies to help people financially gain access to services. They are removing financial barriers as they, "walk through the system to figure out where those funds are available it can be…time and knowledge [to find it]". In addition, IGSW have a "basket of funds" they can offer to clients in need of financial assistance, on a short or long term basis. IGSWs are also developing strategies to best approach older adults managing complex health conditions. For example, one IGSW shared how she goes

over things a couple times: "I will probably go out and see [my client again] in a week or so…that's one thing people just don't know how either because of dementia or because they just lack of knowledge how to get to their appointments or don't understand why they need to go to the doctor or why they need to check their blood sugars…". This IGSW had to visit her client multiple times to explain the importance of follow-up appointments and to ensure the recommendations of other health care providers were followed. Next, IGSWs are learning strategies to empower older adults to navigate and access services on their own. One way is to initially show them how to do a task, and then slowly pass over the responsibility to the client. An IGSW explained,

> "the best way is to kind of do it with them is so their first trip on the new transportation service we've set up…maybe meet them at their home, go with them in the transportation the first time and then kind of start letting go and cutting some strings and the next time ask them to book the appointment and maybe meet them there and then the next time just following through that they were able to book the transportation and get back and forth and if they need the finances to access a service".

This approach is important to teach their clients self-management skills, which may have long lasting effects on their health. Lastly, IGSWs found that follow up appointments cause their clients to feel worried and apprehensive. To encourage the clients to go to these appointments, IGSWs build a trusting relationship with their clients. One IGSW reflected on her experience: "the case managers I have been working with, actually book appointments together. Maybe an initial appointment or if it is an appointment that is going to make the client a little bit anxious then I can be there as well, knowing them a little better and giving the case manager a little background of what we had been seeing". Therefore, a trusting relationship benefits the client and IGSW, but can also be used to facilitate working relationships with other health care providers. Overall, IGSWs have learned many critical strategies to perform their role in a way that helps their clients to feel secure in their care and to improve health outcomes.

Clients

The IGSW service is currently offered to a complex group of older adults that meet a certain criteria as mentioned previously. IGSWs were asked to describe their clients in more detail, and reflect on the outcomes they achieved with different clients. When describing the common characteristics of their clients, IGSWs most often said their clients lack family support and are in some form of crisis. They felt that those two factors are two major barriers to helping an older adult navigate the system. IGSWs felt they were most successful with resistive older adults, because their role allows them to build a close relationship with the client and they can establish clear goals with the client. Although resistive older

adults are challenging to work with, IGSWs felt the most challenging group of client was those affected by addiction and cognitive issues. Finally, IGSWs commented on the referral sources, either the GEM nurse or specialized geriatric team, dictating which approach they will typically use. For example, GEM nurse referrals are triggered by an ED visit, therefore a medical approach is usually more appropriate with these clients. On the other hand, the specialized geriatric services will typically refer older adults with concerns about mental illness, therefore a cognitive approach is usually more appropriate. The difference between the two approaches was discussed as the mental illness approach requiring the IGSWs to consider how the mental illness will influence their strategies to help patients follow through with recommendations and appointments, such as consistency of approaches and care providers. A medical approach required more attention to the client's barriers due to restrictive comorbidities and precautions due to diseases and medications. In general, IGSWs are serving a challenging group of older adults, each experiencing some barrier to navigating the health care system.

Barriers and Facilitators

Interviews with the IGSWs revealed two main challenges they face while serving older adults, including barriers to navigating the system and considerations to introducing a new role to the health care system. In general, there was an overwhelming notion that the health care system is a very complicated system to navigate. One IGSW explained,

> "It's a very complicated system. There is a lot out there but people don't know that. They don't know that at all until they need it. I mean I can't tell you how many times I have heard, 'Oh, I didn't even know that existed'. And we hear that all the time. It is just…it is a hard system. Even the CCAC system is a very hard system to navigate because they are always changing their regulations."

This statement also shows that from a health care provider's perspective, the services that older adults need to age in place may exist, but they are just not getting connected with them. Another IGSW gave a powerful metaphor to depict system navigation for an older adult: "it's almost as if they're on this island by themselves and they just don't know where to start". Unfortunately, without better linkages across the system, older adults have not been able to connect with the services that may help them manage their health conditions. Furthermore, these problems are exacerbated for persons affected by dementia. An IGSW shared her experience connecting a dementia client with transportation services in their community: "there are great transportation services out there but you need to call in three days ahead and it is just too much for someone with dementia. So that is going to be a huge challenge coming down the

road". This IGSW illustrates how it is challenging to navigate the system, even when people are aware of the service. Also, she recognized that with increasing demands on the system due to a large aging population, it is important to quickly address these challenges. Another IGSW reflected, "there's a stigma related to any sort of reference to mental health or the fact that depression may be coming into play with their situation so I found that to be a huge barrier [to navigate the system]". IGSWs have directed attention to a health condition that even challenges them to navigate the system for their clients. It is crucial to address the barriers dementia clients face at each level of care in the system.

Next, IGSWs continued to express thoughts that represented the perspectives of previous clients. They speculated that their clients do not have the skills to navigate the system, and become overwhelmed once they need to develop those skills. One participant said, "if you're healthy and you're just going along there's nothing and then all of a sudden you have a stroke and you have something happen and you're inundated with all these services and you're just overwhelmed right or you do need some help but you don't have any idea what's out there until you really need it". It is evident that there is a lack of preparation for these crisis situations, but at this point, the IGSW continued on to explain that is where her job begins. Another IGSW focused on the challenges of navigating a care transition:

> "they don't know what services are available. When they go to hospital, the time they are in hospital is so short now that the workers don't have the time to even educate the clients on what is available out there. Even if they do, because they are in kind of a vulnerable state and they are not well, they probably wouldn't take it in to be able to go home and carry out those goals themselves…we see a lot of frail clients that do have some elements of dementia, memory loss or mental health issues; depression, anxiety so those are a lot of the barriers I see".

This demonstrates a shared responsibility among health care providers to assist clients navigate the system; the health care providers in the hospital are unable to prepare and educate clients, but information should be shared with the client throughout care transitions. As well, this IGSW points out several potential barriers from her experiences with clients, to support having a person whose job is to help navigate older adults with health conditions through the system. IGSWs introduced an important consideration when helping older adults navigate the system. Financial resources may act as a barrier for older adults to seek or access services. As one participant explained: "some of them think they have too little and some think they have too much and they don't even know. You know what is your income, your pensions are this, you try to help them understand…but unfortunately we are meeting too many people on the down slope". Not only from a health perspective but from a financial perspective, IGSWs felt that the services they provide may help people prepare for the crisis situations they experience later. Overall,

IGSWs were able to draw on their experiences with their clients to illustrate some of the challenges older adults and their care providers experience while navigating the health care system.

Lastly, IGSWs were asked to explain how they are helping their clients to navigate the system. There were four main concepts: connecting with services, guiding them through the system, helping families to learn to navigate the system and gaining experiences within the system to better serve clients. Firstly, and most prominent, IGSWs role is to connect clients with the services they need. A participant reflected,

> "I've worked in geriatrics for a long time so recognized there are big gaps in the system for sure and so this role certainly works to fill a lot of them, because you know what I encountered previously to working in this role was really that there are lots of services out there but other services don't know necessarily you know they were kind of silos that didn't really know that something else existed…but there really wasn't a position to link to all of those things so I mean navigationally…things are out there but people who need to access services don't know that they are and don't know how to. So my experiences have been good because for sure we fill that role for a specific group of people."

This reflection demonstrates the importance of the IGSW role, from the perspective of a health care provider who has worked in different roles across the system, and recognizes the gap the IGSW role is addressing. Secondly, the IGSWs are helping older adults to navigate the system by consistently guiding them on a care path that best suits their needs. One IGSW expressed, "I am sort of a tour guide along the way…literally walking them through the system". This was one of the most common statements made in the interviews, and although it sounds like a simple responsibility, it fills a major gap in system navigation needs for older adults. Third, the IGSW program is available to a variety of older adults, with varying support networks, but participants discussed how they try to also help families navigate the system. One IGSW related to the families she has worked with: "families don't know the system, I mean, why would they? So helping the families getting the services in place and to know what is out there too has been a huge help". Finally, IGSWs are helping older adults to navigate the system by expanding their knowledge of the system through training and experiences. One participant explained, "I find that once I've done it before I can kind of let them know what to expect, which is good. So the first time we do anything can be a little bit difficult". Since this system navigator role does not influence the structure of the health system, experience seems to be the most valuable tool for clients and health care providers alike to navigate the system. In sum, system navigation is the primary focus of the IGSW role, and many barriers and strategies were discussed to further understand how they are helping older adults navigate the health care system.

Next, IGSWs discussed the barriers and facilitators they experienced as being part of a new initiative in the health system. At first, IGSWs discussed their working relationships with other health care professionals. They reported having positive relationships with doctors and nurses. One IGSW reflected, "doctors for the most part, we have had very good experiences just because they see the need for [our role] and they see that we follow-up and get the people there and they are understanding". Next, participants discussed a mostly positively relationship with CCAC case managers. For example, one IGSW explained, "some case managers are hard to get along with but most of them are really good and treat us like equals…they will call and say can you check on this because we're worried about her and when you are going in can you check on...we work back and forth all the time". Overall, the case manager and IGSW roles complement each other to monitor the client, connect them with services and provide follow-up. Then, IGSWs discussed two major challenges they experienced as new members to the care team. The first challenge was that establishing role clarity among health care providers was time consuming. One participant commented,

> "I think since we started it's improved quite a bit as people are starting to understand the role and who we are and what it is that we're doing but I found in the beginning it was anytime you wanted to call to kind of make connections you had to go through the whole, what is your role and what do you do and prove that you are part of the circle of care and have any right to know.."

Although role clarity is improving as IGSWs spend more time in the community, it is important to consider this experience if more positions are added to the region, or if a new region adopted the IGSW model. The other challenge was accessing client information, and is related to role clarity. An IGSW explained the information sharing barrier:

> "it can be restrictive 'cause it's a new role and having other people not really understanding the role kind of getting a lot of information can sometimes be tough until they really get to understand what it is… it can be a little bit difficult to get information. I think that's been improving as people are starting to understand the role more and more."

Similarly, establishing and improving role clarity within the care team will facilitate information sharing. Overall, the IGSW has been adopted into the care team, and the challenges they faced during implementation are expected to diminish continually over time.

Predictions for the Future

Role

The next set of categories fits within the section of the IGSW predictions for the future. In this section, IGSWs reflected on their experience in their position thus far, and speculated on the directions

they could see the role evolving. First, conversations revolved around the host agency of the IGSWs, and if or how they could see their role fitting with other agencies. Each IGSW working within Community Support Connections, a community support service agency, felt they were easily connecting with the services offered at that agency. Since IGSWs use a large number of services from these agencies for their clients, they considered Community Support Connections a good fit. On the other hand, the IGSWs working within St. Joseph's Health Centre had a different link in the community, and felt more connected to the hospital in Guelph. Then, IGSWs were asked if more IGSWs were added to the program, where should the host agency be for the additional positions. About half thought that the IGSW program would benefit from having positions in a variety of health care settings across the system. Others saw major benefit in easily consulting with other IGSWs, and thought the positions should just be added to their current host agencies. As well, there were mixed suggestions for different host agencies. Some participants could see a fit with the CCAC, mostly because the, "role touches all parts of the system", and the CCAC is a large part of the health care system for older adults. However, the majority did not agree, and would not recommend it as a host agency. One participant explained her opinion, "I think it's good that we're not part of CCAC; that we're independent from them because this way we work with everybody but not for anybody". This opinion describes the role of the IGSW and how the host agency influences how they carry out their responsibilities. Some IGSWs suggested placing workers in the Emergency Departments of local hospitals to pick up their clients at the beginning of a crisis. This may improve the communication between providers and clients immediately after crisis occurs. One IGSW commented on working with a FHT previously, saying, "it's nice to be able to offer that sort of tag team approach if there's something medical going on they can deal with that and it frees us up to deal with the other things". Finally, an IGSW in Cambridge recognized that despite the influence of the host agency, each area of the WW-LHIN is different. While it is important where the IGSW is working, she expressed, "you kind of learn your own system and work within it". Therefore, experience and knowledge base of the IGSW is a factor to consider when placing IGSWs in the system.

Clients

Interview participants discussed the possibilities of serving different client groups and how that might look in the future. When asked about targeting another client group, each IGSW initially reacted with hesitation. They expressed a real concern that by increasing their caseloads, that would dilute the service delivered to each client. One IGSW said, "the balance is having the time to truly be involved on an intense level and there have been times where our caseload has been very high and it is hard to do that". With caseloads running between 20 and 30 clients at one time, IGSWs did not feel they had

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capacity to reach more older adults in the system. Then, the researcher asked if the program had more resources and staff, could the IGSW service to benefit other clients. Each participant agreed that expanding the referral source would allow IGSWs to provide service to a greater number of older adults who are also in need of system navigation support. One IGSW described the situation as, "There are a lot of seniors out there who need the help, I think that's a reality, I think there's a lot that get missed because they have to go through a GEM nurse or a geriatric team". Therefore, the current referral structure may need to be revisited to ensure all older adults are getting the service they need. Participants explored the idea of modifying the agencies or providers currently linked to the IGSW referral system. The two most common suggestions were community support services and CCAC. IGSWs reported that community support services are seeing the need to refer to the IGSW program, as they continue to, "[run] across people who don't fit the system". This statement shows how the IGSW role is useful and can be expanded to more older adults. In addition, the CCAC was suggested as an agency that might be able to refer proactively, because, "they see people [in need] on their caseload…not wait til they end up in hospital". In sum, IGSWs had ideas on how to reach more clients in need, and what the additional roles might look like. Finally, all but three IGSWs recommended their roles adopt a preventative approach in the future. An IGSW commented, "I can see that this role could work preventatively and proactively but it is not quite set up that way… some of those if we had gone in sooner…". Another IGSW shared, "Alzheimer's society, even CCAC can't refer, so they may have a client who is sort of on the verge, they really would need some support that way so that they don't get into crisis". Although the IGSW program is showing successes among their clients, improvements in how and when clients are referred should be addressed. Overall, the IGSW interviews generated some thoughtful ideas for future directions of the program.

5.4 Summary of Findings

The interviews with the IGSWs working in Waterloo Wellington generated important considerations for their current and future role. In general, the role has the potential to accomplish many great things for the system and for patients, and may fill gaps in the system identified in previous findings of this study. The researcher was able to explore and gather more information based on areas identified in the systematic literature review and previous data analyses. For example, the researcher initiated discussions on other client groups the IGSW role might benefit, the influence of host agencies and the challenges of implementing a system navigator role in this region – all of which were categories identified in the literature and previous data sources. Within this project, these data helped to inform the theory for a

system navigator role in the Waterloo Wellington region. This chapter was a major component of the theory as the IGSW role was is considered to be the most prominent model for system navigation of older adults with complex health conditions in the region. More broadly, these data may be highly influential on the future direction of the IGSW role. If the program were to expand, these data could inform which clients to target and what host agencies to explore. In addition, these data suggest there is a need to develop how IGSWs - and possibly other system navigators roles - are introduced to the system in order to address issues around role clarity.

CHAPTER 6: Discussion and Conclusions

6.0   Discussion and Conclusions

This study accumulated different datasets, each with a unique perspective on system navigation needs and roles for older adults affected by chronic disease. With each successive dataset, the researcher's knowledge base around system navigation for older adults developed further. New topics for data collection were discovered following each previous data analysis to allow the research to delve deeper into some important navigation concepts. More importantly, the research began to notice trends across data analyses, especially about the role of the system navigator. The findings from each data source were synthesized and brought together for a theory for the role of a system navigator in Waterloo Wellington region.

Describing the role of a health system navigator for older adults at risk of adverse outcomes from chronic disease

COMMON ROLE RESPONSIBILITIES (across all risk levels)

- Quarterback in care coordination
- Patient advocacy
- Involvement with/implementation of care plan

- Patient and family education
- Facilitate collaboration with health care providers
- Facilitate access to services
- Home and phone support as needed
- Transitional care support
- Developing and sharing strategies to working with client
- Activities beyond health

	LOW RISK OF ADVERSE OUTCOMES *Prevention, Proactive Approach*	MODERATE RISK OF ADVERSE OUTCOMES *Maintain Approach*	HIGH RISK OF ADVERSE OUTCOMES *Manage Approach*
Risk Specific Role Responsibilities	• Phone support or drop in centre • Capacity building in community	• No additional responsibilities for this risk category	• Assessment and management of health status • Intensive home visits • Timely follow-up after hospitalization • Prompt intervention when patient deteriorating • Medication management, consults when needed • Develop care plan
Training	• Volunteer/health worker with community knowledge and geriatric experience	• Health worker with community knowledge and geriatric experience	• Nurse, nurse practitioner
Host agency-	• Family Health Team/Community Health Centre, Community Support Services	• Family Health Team/Community Health Centre, Community Support	• ED/acute care
Referral source	• Health care providers in community	• Family Health Team/Community Health Centre, Community Support Services, Home care	• Specialized Geriatric Services, GEM nurses

Referral Criteria	• Anyone	*One of the following:* • Living alone • Frequent user of the emergency department • Complexity of needs (number and/or type of support required) • Socially isolated • Resistant to assistance or support • Ability to access services is limited due to financial reasons • Language or cultural barrier • MD or RN concern about ability to follow through with recommendations • Caregiver burden, lack of caregiver support or long distance caregiver	*Two or more of the following:* • Living alone • Frequent user of the emergency department • Recent hospital admission (last 90 days) and/or ED visit (30 days) • Complexity of needs (number and/or type of support required) • Socially isolated • Resistant to assistance or support • Ability to access services is limited due to financial reasons • Language or cultural barrier • MD or RN concern about ability to follow through with recommendations • Caregiver burden, lack of caregiver support or long distance caregiver

Describing the role of a health system navigator for older adults at risk of adverse outcomes from chronic disease is a theory that illustrates the potential role of system navigation in Waterloo Wellington region. It applies a tailored approach to older adults at different levels of risk for adverse outcomes and aims to prevent and manage chronic disease, frailty and geriatric conditions in order to achieve optimal outcomes for the patient and the health system. It is based on the notion that older adults may not all be at risk for the same outcomes during the same period of time in their lives. Age may not be the primary determinant of health care use (Cunliffe et.al, 2004; Canadian Institute for Health Information, 2011). The use of health care services is linked to comorbidities in older adults regardless of their age, once over 65 years (CIHI, 2011). Therefore, a system navigation theory should focus on managing chronic diseases and frailty similar to other interventions with older adults which stratify patients according to risk intensity for adverse outcomes, rather than age sub groups or disease types (Scott, 2008). As shown earlier, the role of a system navigator addresses the elements of the CDPM framework. Therefore, this system navigation theory divides the older adult population by the same risk categories that were established within the Chronic Disease Prevention and Management framework.

Prevention, Proactive Approach

Older adults at low risk for adverse events require low level of service, with the goal of preventing or living with a chronic disease. Most (75%) patients are expected to benefit from low-intensity chronic disease management, usually delivered by one or two providers, who usually include the primary care physician or nurse practitioner (Heckman, 2011). Therefore, within the theory for a system navigator role, this population receives the lowest level of system navigation assistance.

Maintain Approach

Older adults at moderate risk for adverse events require multidisciplinary team involvement to maintain optimal health status while living with one or more chronic illness(es) (Heckman, 2011). This population may require specialist support, either directly or indirectly through primary care, and constitute about 15 to 20 percent of patients (Heckman, 2011). This group of patients will receive a system navigation intervention at moderate intensity.

Manage Approach

Older adults at high risk for adverse events present the most complex cases for whom to provide care. Between 25 and 37 percent of older adults have four or more chronic diseases (Statistics Canada, 2009). For the purposes of this theory, persons with four or more chronic diseases are classified as high

risk for adverse outcomes. In addition, Koehler and colleagues (2009) targeted high risk elderly patients in a transitional care intervention, defining their high risk patients as having three or more chronic diseases and taking 5 or more medications. Since this study was also aiming to reduce hospital readmission and ED visit rates, this theory for the role of a system navigator adopts this classification of high risk elderly. Finally, since a large part of the role of a system navigator is supporting older adults during care transitions, the high risk individuals in this theory also will to have recently (within past 60 days) required emergency or acute care. This population should correspond to approximately 5-10% of the patients who require high-intensity Chronic Disease Management (Heckman, 2011).

Role Responsibilities

The first section of the theory highlights the role responsibilities of a system navigator. At the beginning, are responsibilities common to all system navigators, despite the risk type of their clients. The elements of this role are a synthesis of what was identified in the systematic literature review, and then further developed from the following focus groups and interviews. In some cases the data analysis added detail to a previously identified responsibility, or described a responsibility not yet discussed. For example, "care coordination" was previously identified as a responsibility of the system navigator from the literature review, but the "quarterback" description came from the interviews with the IGSWs. On the other hand, the performing tasks beyond health services to meet client needs was recognized as a crucial element of the system navigator role following interviews with the IGSWs.

Next, the theory addresses the inherent differences in a system navigator role, based on level of risk of their clients. For clients best suited for the 'Prevention, proactive approach', there are two unique responsibilities for a system navigator role. First, the navigators should be building capacity in the community for older adults to navigate the system. Depending on the community, this would mean working within the existing structures and providers to help older adults navigate the system. Second, the system navigator would maintain phone support or a drop-in center for older adults beginning to require a low level navigation support, similar to CCAC case management. This type of intervention recognizes that older adults require help with system navigation before they become heavily involved in the system; therefore it is the least intensive, most cost effective approach. For clients at moderate risk of frailty, the responsibilities of the navigator match the common responsibilities mentioned above.

Finally, the responsibilities for the system navigator role with older adults at high risk for frailty are intensive and require large amounts of resources. The role is focused on managing chronic diseases in older adults experiencing several additional barriers to care. For example, these system navigators initiate

intensive home visits, and are involved in developing a care plan. They are responsible for assessing and managing their client's health status and medications. In addition, they provide timely follow-up after hospitalization, connecting with people as early as in the emergency department. Since the system navigator would be involved in the person's care regardless of care setting, they would be best positioned to recognize deteriorating clients and prompt timely intervention. Therefore, a system navigator for highly complex clients navigates the multiple systems of care they will require, and is much more involved in their care as compared to a lower risk client. Although this theory adds another care provider for clients already receiving care from many health care providers, the intensity of this role in care delivery and system navigation may decrease the services required from other providers, facilitate effective information sharing, and direct clients to the appropriate level of care. This could have significant implications on health resource allocation, and overall costs to the system.

Training and Education Requirement

Education requirements are linked to the responsibilities of the system navigator role. Since the role of a system navigator for older adults in the low risk category is mostly focused on sharing and connecting clients with information, this position requires only geriatric training and experience in the field. Potentially, this role could be maintained by peer volunteers or paid health worker without professional training. Next, the moderate risk category position would require a slightly higher level of geriatric training and experience, and/or some level of geriatric education. Higher levels of training and education would be required to provide the support and education to the patient, family and other health care providers. Finally, the system navigator for high risk older adults would need to be a health professional, with graduate/professional level education. The role is a high level position, requiring the navigator to facilitate multiple health care services and to educate and recognize the red flags during the course of deteriorating health conditions. Overall, the training and education requires for a system navigator fluctuate based on their role responsibilities, and therefore the client groups they are working with.

Host Agency

The host agency has influence on the scope of the system navigator role, and is an important part of this theory. For older adults at each risk level of frailty, the system navigator should be working within

an agency from whom they would most commonly receive care. Older adults at low risk of frailty should be targeted within Community Support agencies, Family Health Teams, Community Health Centres and remaining independent family physicians. Community Support agencies have been found to connect well with the IGSW service, the exemplar system navigators for the Waterloo Wellington region. Then, there are two reasons FHTs and CHCs would best suit as host agencies for system navigators. First, the structure of these organizations facilitates communication across providers. Therefore, as stated in the IGSW interviews, a team with expertise to problem solve around clients might help to provide better care. Second, patients should be regularly visiting a provider connected to the organization, and could be quickly connected to a system navigator to help prevent chronic illness or maintain health status. In the focus groups and IGSW interviews, there were many conversations about the benefit of proactively targeting people at risk of poor health outcomes before a health crisis. Therefore, rather than waiting for patients to visit the hospital twice within 90 days to trigger service from an IGSW, this approach would rely on the health care providers upstream to recognize potential for deterioration in their clients, and refer to the system navigator within their organization. This approach would be appropriate to target older adults at low and moderate risk of frailty.

Next, persons at high risk for poor health outcomes are currently targeted by the IGSW service criteria. Since there is a gap in system navigation assistance for older adults before they reach a health crisis, there is a higher demand for interventions with those people already in the high risk category. However, as the three tiered approach to a system navigator role is implemented, less clients should be identified as high risk because they are successfully navigating the system with a less intensive approach. Currently, the IGSWs are servicing the high risk population, but might not be hosted in the ideal agency. The high risk clients are the individuals transitioning across supportive care settings, most commonly emergency departments and hospitals. There was strong support from patients, caregiver and health care providers to have a system navigator role connecting with patients while they are still in crisis, typically meaning in hospital or the emergency department. This notion was also supported in the literature, as system navigator interventions initiating as early as the emergency department were found to be more effective than similar interventions starting later along the care path.

Referral Source

The referral sources for each risk category are directly related to the host agency of the system navigator. For the low and moderate risk categories, health care providers in each organization should be

aware of the system navigator role, and recognize the clients that need their support. The high risk category is currently using the Specialized Geriatric Services and GEM nurses as the primary referral sources. Based on the IGSW interviews, this approach is effective in targeting high risk individuals.

Referral Criteria

The referral criteria need to be well defined as the population of risk types increases in complexity. Initially, at the low risk category, clients could be referred to the phone number or drop in centre based on the need for support. Since the intervention is not highly involved with each client, any older adult, or any family, friend or health care provider recognizing the need for additional support should be able to refer to this navigation service. Additional testing is necessary to assess capacity and impact of an intervention, because little is known about a broad navigational service. Next, moderate and high risk categories will use the same criteria, but have different requirements. Moderate risk individuals will need to meet only one criterion, while the high risk individuals will need to satisfy two or more criteria. It is important for these requirements to be well defined because the more intense system navigation intervention needs to be delivered to the appropriate individuals to show efficacy and provide sustainability.

This system navigation framework builds from the current IGSW model. The clients that IGSWs are working with fall in the moderate and high risk categories. After learning about the needs of different client groups, across the four data sets, the IGSW clients could be stratified further into the moderate and high risk categories as defined by the theory, to tailor approaches more effectively. Therefore, the IGSW model seems to fit best with the moderate risk approach, but would require a few changes to correspond with the theory presented. According to the theory, the current IGSWs would become less involved with emergency departments and acute care, and focus on navigating clients through primary and community based care. Then, a more intensive position might be implemented to manage the highest risk population. This role would require a high level of training, such as a nurse, or a nurse practitioner, to recognize red flags and facilitate proper education and treatment. The suggested criteria will be used to capture the individuals at highest risk for poor health outcomes. However, the position would challenge the health resources of the health care system, as nurses and nurse practitioners are in high demand. Overall, the theory requires more research and testing to clarify how to define and capture individuals within different risk categories. Since these characteristics reflect the roles of the system navigators, it would be important

to involve health care providers, caregivers and patients in a consensus gaining process, such as a Delphi survey.

Potential Outcome Measurements for the System Navigation Theory

The following are a list of outcomes that have been identified as possibly being impacted by the system navigator role, across client risk categories:

Table 9. Potential outcome measurements impacted by a system navigator role

Potential Outcomes of a System Navigator Role	
Health Care System Outcomes	• Reduced hospitalizations
	• Reduced hospital readmissions
	• Reduced ALC bed use
	• Reduced emergency room costs
	• Reduced acute care usage
	• Reduced time until next hospital admission
Health Care Provider Outcomes	• Role awareness/clarity in system
	• Improved communication across providers
Patient and Caregiver Outcomes	• Increased quality of care delivery ratings
	• Reduced caregiver burden
	• More appropriate service usage
	• Increased patient and caregiver satisfaction
	• Increased psychological well being
	• Increased adherence to self-care regimes
	• ADL and IADL improvements
	• Increased quality of life
	• Maintain independence longer
	• *"every door is the right door"*

Since this role has not been explored in-depth in the literature, the researcher was limited to generating a list of potential outcomes. The next steps for such an intervention would consider this list of outcomes to evaluate the impact of this role on the system, health care providers and patients and caregivers. An evaluation plan would need to be devised and implemented at the beginning of the role, with clear indicators for each measure. Some outcomes will be more recognizable, easier to measure, or demonstrate impact within a short time frame. Others will require the role to be embedded in the system for a longer

period of time to see effects, such as health care costs or maintained independence. A randomized controlled trial may be needed to demonstrate the overall effects of a system navigator role, to make further decisions on implementing the intervention, modifying the intervention or trying a different approach. Regardless, older adults are experiencing challenges navigating the system, and it is important to develop, test and implement potentially effective interventions.

6.1 Limitations

This study had several limitations, both in design and conceptualization. Each source of data is discussed with its own limitations, and then the researcher speculated on the limitations of the research as a whole study.

Systematic Literature Review

The intuitive logic of the navigator impact has resulted in such roles being in common use in health care quality improvement initiatives (Dohan & Schrag 2005); thus fewer skills or resources may have been allocated to rigorously document and evaluate their effectiveness than has gone to their implementation. Limiting this review process to articles written exclusively in English might also have reduced the output from the search process. The focus on transitions between care settings further reduced our sample, yet added a level of complexity which served to challenge the models' impact on outcome improvement for the target population.

In conducting this review of the literature, where no previous reviews had been done, strict boundaries needed to be set in order to stay focused and to report meaningful data. However, after conducting this review, the researcher noticed many directions the system navigation roles could explore, or for future reviews to investigate. Primarily, mental illness was excluded from the review if this was the outlined study population. Although mental illness often co-exists with other chronic diseases that were included in the review, another area for further research would be navigation interventions which targeted mental illness. Furthermore, system navigators have demonstrated effectiveness with many different vulnerable populations, including children, low socio-economic status individuals, older adults and certain disease types. It would be interesting to explore what other groups system navigator interventions have been implemented with, and to compare their implementation and outcomes.

WW-LHIN Focus Groups

The focus group data are considered secondary data, as the researcher was present for 3 of the 21 focus group interviews. Therefore, the researcher had to rely on notes recorded by the focus group facilitator and recorder; all conversation and nonverbal cues may not have been recorded in these transcripts. As well, the focus groups included a variety of individuals, not limited to or separated by their experience with disease type or care setting, or disciplinary background. This limits the ability for the researcher to comment or generalize findings because statements in the focus groups are only connected to the organization, without details on their role or background. However, such a diverse set of individuals provided insights and issues on many topics, across Waterloo-Wellington.

InfoRehab Transitions Project Interviews

Similarly, the 'InfoRehab' Transitions project interviews are considered secondary data. Despite this, the author had a good sense of the data, as she conducted approximately 20 of the 40 interviews in the data set, with patients, caregivers and health care providers in each care setting. Unlike the focus group data, these participants were recruited from one care setting Grand River Hospital, in Kitchener. As well, chronically ill older adults and hip fracture patients can have similar health conditions (Marengoni et al., 2009), but they may have different experiences in the health system, and may have differing care needs. One advantage to interviewing this sample of hip fracture patients was they had no prior experience with a health system navigator, such as the IGSWs. Therefore, the research was able to test the idea of a system navigator, without the influence of prior experiences with a navigator role.

Intensive Geriatric Service Worker Interviews

Finally, the IGSW role seems to fit well within the framework of a system navigator for older adults, but may not be representative of other system navigation interventions. However, the evaluation of the IGSWs is timely and systematically reviewing the literature at the same time helped to identify successes and shortcomings of the role as compared to others. Another limitation in collecting these data was social desirability bias. The IGSWs might have emphasized the positive impacts of their role for job security, and to make a positive impression with the researcher.

Overall, this study had several limitations to consider when interpreting the data. First, each data set was examined in a sequential order, and this might have influenced how these data were analyzed. However, it made most sense to learn first about system navigators with a literature review, then to understand what the needs were of older adults with complex health conditions by using data from

interviews and focus groups with patients, caregivers and health care providers. This led to comparing and contrasting what was learned previously to an exemplar model in the region to build a comprehensive model for a system navigator role. Second, the researcher believed in this study and had a vested interest in system navigation from her personal experiences. At the outset of the study, the researcher had expectations of some barriers to learning about system navigation and where the responsibility lies within the current system. Although she tried to maintain an open mind during data collection and analyses, her personal connection to the research could be considered a limitation as she solely analyzed these data, and might have been more receptive to favourable responses. The researcher stated at the outset of the study, she was taking an interpretivist standpoint to the study. Therefore, her own thoughts and feelings might have influenced collecting, analyzing or reporting the data. However, throughout the research process, the researcher solicited input from her committee and research colleagues to review the findings, many of whom participated in the data collection.

6.2 Conclusion and Next Steps

In sum, each objective of this study contributed to a knowledge base around system navigation roles and shaped the final framework for a system navigator role in the Waterloo Wellington region. Initially, the systematic literature review provided the researcher with an understanding of the current literature on system navigators, what that role has looked like in other interventions, and the efficacy and efficiency of this role. Next, challenges related to system navigation were identified from multiple perspectives, including health care consumers and providers, using focus group interviews. Then, system navigation needs were gathered from hip fracture patients, and their caregivers and health care providers, as they moved across care settings. As well, these interviews determined their perspective on what the role might look like, and potential impacts of such a role. Finally, interviews with the IGSWs across Waterloo Wellington region described one potential system navigator intervention. These interviews helped the researcher understand what was involved in the role, the clients this role was serving and how the role fit within the local health system. Overall, this research brought together the perspectives of a variety of individuals across the health system to create a theory for a system navigator role for older adults experiencing some level of risk of adverse outcomes related to their health status.

Implementing a system navigator role, such as the one presented in the theory, may not be the only approach to improve older adults ability to navigate the system. However, based on the findings

from this study, this role may fill some of the gaps in care delivery identified across the Waterloo Wellington region from the focus group interviews. Introducing a navigator to the system, is suggesting the current system is not organized in a way that individuals can connect with the right services when they need them. Therefore, one immediate approach is to have someone guide people through it. However, looking long-term, system navigator roles could influence the way the health care system is restructured. By continually approaching system navigation issues more upstream, eventually the system should be restructured to fit around the patients. Currently, patients have to fit into the system instead of the system being put together around the needs of a particular patient. By grounding care within each patient, there is potential for a shift in the funding and service models to follow and develop around each patient. The role of the system navigator stimulates this shift by standing in the middle to make the system bend for the patient instead of pulling the patient in different directions.

There were political and territorial issues that arose among different organizations and health care providers. Regardless of whether system navigation should be a single role or shared across providers, some organizations felt more responsible for navigation of patients than others. For example, system navigation is in the mandate at the CCAC for their case managers, but some interview guide questions and findings from this study, stimulated some defensive reactions from some care providers. However, there were mixed feelings about whether the home care sector needs to take responsibility for system navigation, as it's the entire system with which older adults will need support. The goal of exploring the role of a system navigator was not to decide between a navigator and a case manager, but to understand how this role fits within the current structure of the system.

Another important aspect of this study to consider is that the health system is fluid, and system navigation models need to reflect changes in the system. For example, Naylor's (2004) approach of modifying and further developing her intervention to support older adults with heart failure during care transitions improved subsequent outcomes in each study. Similarly, the flexibility of the IGSW role allows the workers to provide care that is necessary for each client. It is clear that a successful theory will be dynamic and reactive to the system and clients. Similarly, as health information technology evolves, this may influence the role for a system navigator. An area for further research might be to explore the concept of online resources aimed at helping older adults to navigate the system.

Finally, it is important to consider this research in the context of Ontario's health care system, and the region of Waterloo Wellington. The theory for a system navigation role takes into account the current landscape of the region, and builds from the existing structures, services and programs. A theory for

system navigators in another region of Ontario may need to be modified, and certainly other provinces would need to ground the role within their system. The function of the LHINs across Ontario largely influences care delivery, and therefore would most likely impact the function of system navigators should the structure of LHINs change in the future.

This study influenced three of the four pillars of strength identified by the Canadian Institutes for Health Research: clinical research; social, cultural, environmental, and population health; and health services/systems research. This research holds significant clinical implications for the care of chronically ill older adults, to improve the health and quality of life of individuals as they transition home from acute hospital care. Findings from this study could be extended to other groups of individuals at risk of hospitalization or who are frequently requiring expensive health services. Therefore, improvements to coordinating care and accessing health services may benefit a range of patient types. As well, system navigation models target self management, which is increasingly important in care for older adults living with chronic conditions.

This study recognizes the need for research within different subpopulations and explore the way the social environment impacts health. The combination of the perspectives of patients, caregivers and health care providers across many different health care settings, is a unique contribution to the literature. In addition, this research targets the need for further evaluation of quality of life and care satisfaction for patients and caregivers, recently identified by Oeseburg and colleagues (2009). Finally, this research elicits feedback on the efficiency of front line health care professionals who work as part of a multidisciplinary team.

This research incorporates perspectives of various users and health care providers across the WW-LHIN and has the potential to inform to decision making for health services in the region. This study links well with the Aging At Home strategy, which has seen more than $700 million in funding over the past three years through Ontario's LHINs. Ultimately, the Aging At Home strategy seeks to provide a wider range of home care and community support services available to seniors, to enable them to continue leading healthy and independent lives in their own homes. Twenty per cent of the funding has been reserved for innovative projects, which could be developed and informed using the results of this study (Ministry of Health and Long Term Care, 2010). As well, this research may suggest ways to link these health sectors which have been receiving individual funding, to enhance the accessibility of the health care system.

Moving forward, the WW-LHIN needs a system navigation strategy for the region. This study may be used to stimulate further interest in the potential for a system navigator role. However, it would be

helpful for decision makers to assess their resources and commit to a long term plan, aimed at restructuring the care delivery system in the region. This study has introduced one option to address the system navigation needs of different groups of seniors, but this intensive approach may be the first of several interventions to create better linkages of programs and services across the system. Overall, a system navigation strategy should be part of the movement for integrated care. An integrated system is a cohesive, coordinated model of delivering geriatric care (Leggat & Leatt, 1997). The key components of an integrated system align well with the theory for system navigation, and should include: timely access to services, service provision to fill gaps in care, a multidisciplinary team approach, linkages across the continuum of care, system navigation support for patients, caregivers and health care providers and information systems accessible across sectors and health care providers (L. Hillier, personal communication, May 12, 2011). There is evidence of integrated systems improving patient outcome measures (IGSW presentation, 2010). An integrated system, grounded by sustainable care delivery strategies, would build capacity in communities and local health care systems for older adults to navigate the system. Overall, this study may have implications for enhancing continuity of care and quality of life for chronically ill older adults.

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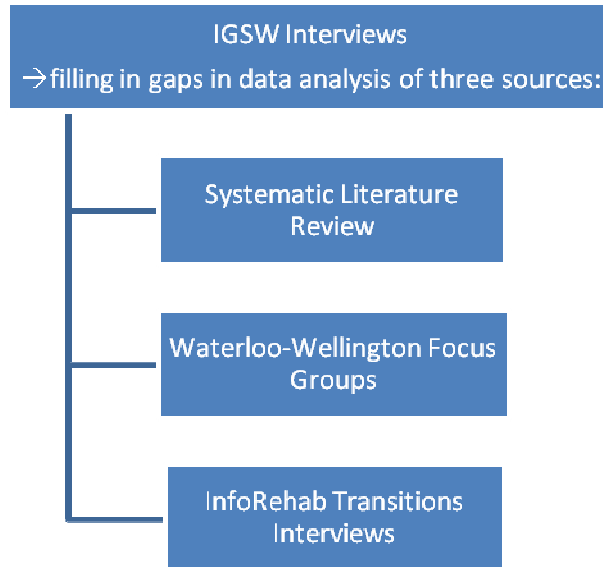
Appendices

Appendix A: Potential Hip Fracture Care Pathways

Retrieved from: http://gtarehabnetwork.ca/downloads/report-hipfracture-nov06.pdf
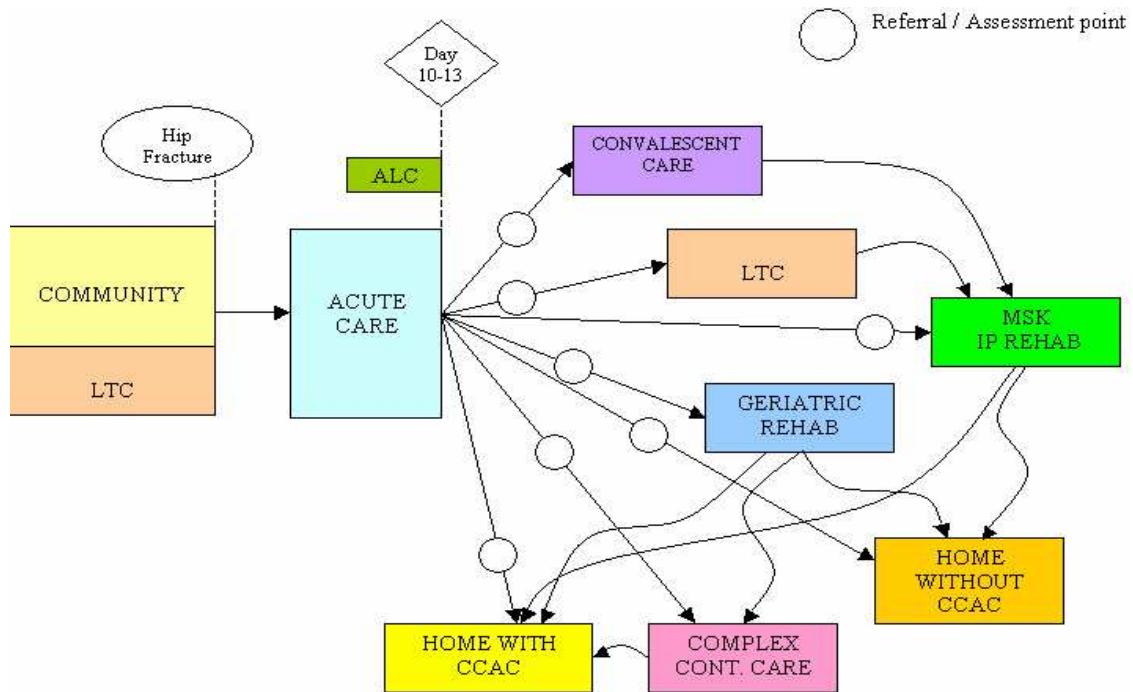
Appendix B: Framework for Four Data Sources

Appendix C: Search Strategy for Systematic Literature Review

Search 1:

"case management"[MeSH] OR "case management"[MeSH] OR "case manager"[TIAB] OR "care management"[TIAB] OR "care manager"[TIAB]

Search 2:

"patient discharge"[MeSH] OR "care transition" OR "patient transition" OR "patient transfer" OR "discharge planning" OR "discharge planning" OR "post-discharge support" OR "hospital discharge" OR "hand off" OR "hand-off" OR "transitional care" OR "follow"

Search 3:

Search 1 + Search 2

Search 4:

"coordinate care" OR "care coordinator" OR "guided care" OR "co-ordinate care" OR "care co-ordinator" OR "coordinating care" OR "co-ordinating care" OR "care coordination" OR "service coordination" OR "coordinate" OR "coordination" OR "care advocacy" OR "patient advocacy" OR "peer advocate"

[Search 4b:

"coordinate care"[TIAB] OR "care coordinator"[TIAB] OR "guided care"[TIAB] OR "co-ordinate care"[TIAB] OR "care co-ordinator"[TIAB] OR "coordinating care"[TIAB] OR "co-ordinating care"[TIAB] OR "care coordination"[TIAB] OR "service coordination"[TIAB]]*****

Search 5:

"patient navigator" OR "patient navigation" OR "system navigation" OR "system navigator" OR "health navigator" OR "health care navigator" OR "healthcare navigator" OR "care advocate" OR "patient advocate" OR "patient advocacy" OR "care facilitator" OR "nurse facilitator"

Search 6:

Search 1+ Search 4

Search 7:

Search 2 + Search 5

Search 8:

Search 4+ Search 5

Appendix D: Search flow for patient navigation models for chronically ill older adults

CINAHL
(N=1583)

PubMed
(N=3679)

Cochrane library
(N=3045)

Duplicates removed and titles scanned

Articles identified for abstract review
(N=6360)

Exclusion criteria:
- Other than English
- Papers focused on mental health
(N=1172), cancer care (N=339),
children (N=989), or homeless
populations (N=55)

Abstracts reviewed for relevancy to patient
navigation (N=3805)

Inclusion Criterion
- Described a patient navigation
intervention or pilot

Articles reviewed (N=231)

Inclusion criteria:
- Older adults with chronic illness
- Involved patients making transitions
either across health care settings or
across health care providers
- Described the roles and responsibilities
of the patient navigator position

Articles accepted (N=15)

Appendix E: Summary of Reviewed Articles

Study	Country	Target Population & Setting	Period of Care	Title	Qualifications	Goals	Duties	Outcome Evaluation
Naylor (1999)	USA	Older adults with at least 1 chronic illness (N=363). Hospital to home	Hospital admission through 4 weeks post discharge	Advanced Practice Nurse (APN Transitional Care)	Masters RNs with gerontological expertise	Improve patient outcomes Reduce service utilization Reduce costs	• Skilled nursing visits at home and in the hospital • Discharge planning • Phone calls to the patient, family, and health care team • Phone availability	RCT Reduced hospital readmission Reduced time to first readmission Reduced costs
Naylor (2004)	USA	Older patients hospitalized with heart failure (N=239).Hospital to home	Hospital admission through to 3 months post-discharge	Advanced Practice Nurse (APN Transitional Care)	Masters RNs with gerontological expertise	Optimize health status at discharge and transition home	• Daily visits during hospitalization, at least 8 home visits, weekly during first month, bimonthly thereafter • Create and manage discharge plan	RCT Lower rates and longer times to first rehospitalization Lower costs Increased

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Study	Country	Target Population & Setting	Period of Care	Title	Qualifications	Goals	Duties	Outcome Evaluation
Clairborne (2006a) & Clairborne (2006b)	USA	Older adults post discharged from stroke rehabilitation hospital (N=28). Hospital to home	1-2 weeks post discharge for three months	Care Coordinator	MSW	Improve stroke survivor care	• Screen, assess, refer & assist with quality of life and health status, psychosocial issues, service needs, advocate for entitlements, counsel for self-care, educate caregivers, monitor • Assess and manage health status on discharge • Collaborate with other health providers to coordinate care • Educate on condition and support patient and caregiver's goals	RCT No change in physical quality of life Improved mental quality of life Improved psychological satisfaction with care and quality of life

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Study	Country	Target Population & Setting	Period of Care	Title	Qualifications	Goals	Duties	Outcome Evaluation
							progress & refer • Home visit 1-2 weeks post discharge • Telephone calls & availability	well-being and cognitive functioning Improved adherence to self-care regimes
Lim et al. (2003)	Australia	Older adults discharged from hospital and requiring community services (N=598). Hospital to home	Pre-discharge to six months post hospital discharge	Post Acute Care (PAC) Coordinator	Allied health or nursing background	Coordinate community services post-hospital discharge	• Assess patients and help develop discharge plan • Phone follow up • Availability to patients • Liaison with, and coordination of service providers • Discharge patient from PAC program to community care	RCT No difference in unplanned readmissions, but bed-day use lower in PAC group – hospital utilization costs were lower as a result No significant

Study	Country	Target Population & Setting	Period of Care	Title	Qualifications	Goals	Duties	Outcome Evaluation
								difference in cost of community services post-discharge
Coleman (2006) Parry et al. (2006) Parry et al. (2003)	USA	Older adults with chronic illness hospitalized in an integrated delivery system (N=750). Hospital to home	Pre-discharge and 28 days post-discharge	Transition Coach (The Care Transitions Intervention)	RN – advanced practice expertise	Assist with medication self management Orient to personal health record Assist with timely follow up to primary or specialist care Understand how	● Meet with patient in hospital ● Home visits on discharge to manage and educate patient and caregivers about medications, coach on effective communication with health professionals, use of PHR ● 3 phone calls over 28 days	RCT Lower hospital readmission rates at 30, 90 and 180 days post discharge Lower hospital costs at 90 and 180 days post discharge

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Study	Country	Target Population & Setting	Period of Care	Title	Qualifications	Goals	Duties	Outcome Evaluation
						to recognize and respond to worsening condition	for support	
Blaha (2000)	USA	Older adults with health failure (N=58). Hospital to home	Pre-discharge from hospital to six months post-discharge	Case Manager (Partners in Care)	RN -Case Manager	Help patients and families attain and maintain optimal health status, access appropriate health resources, avert crises and inappropriate use of health services	• Discharge planning • Ongoing assessment and treatment • In person visits (first within two weeks of discharge) at home or clinic, and eight phone calls • Liaison with multidisciplinary team in clinic and home care	

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Study	Country	Target Population & Setting	Period of Care	Title	Qualifications	Goals	Duties	Outcome Evaluation
Krichbaum (2007)	USA	Older adults hospitalized for hip fracture repair (N=33). Hospital to home	Pre-discharge to 6 month post-acute care	Gerontologic Advanced Practice Nurse (Post Acute Care Coordinator)	RN – advanced practice expertise in gerontology	Contribute to improving the trajectory of recovering elders with hip fractures	• Discharge planning • Health assessment • Medications and treatments review • Review PT/OT • Teach patient and family • Evaluate progress • Once a week interaction in first month post discharge and twice a week until 6 months post surgery	RCT Significant improvement in ADLs and IADLs in intervention group at 12 months post discharge
Boult et al. (2008) Boyd et al. (2007	USA	Older 'high risk' adults with chronic conditions and complex needs.	18 months after start of the intervention	Guided Care Nurse	RN – with at least three years practice & experience	Higher perceived value of chronic care Enhance	• Comprehensive assessment at home • Creation and maintenance of an evidence-based care	RCT Intervention group were twice as likely to

Study	Country	Target Population & Setting	Period of Care	Title	Qualifications	Goals	Duties	Outcome Evaluation
Boyd et al. (2009)		(N=904) Community based			in geriatrics	primary care using disease management, self management, case management lifestyle modification, caregiver education and support and evaluation and management	plan and patient's self care plan • Monthly monitoring • Coaching for self management • Smoothing transitions in and out of hospitals • Coordinating all providers of care • Educate and support family caregivers • Access community resources	report higher quality of care (using PACIC). Primary care providers and nurses report improvements to care.
Gagnon et al. (1999)	Canada	Frail older people at risk for repeated	Post-discharge to 10 months from	Case Manager	RN – minimum 2 years	Reduce fragmentation of	• Monthly phone calls • Home visits every six	RCT No effect noted

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Study	Country	Target Population & Setting	Period of Care	Title	Qualifications	Goals	Duties	Outcome Evaluation
		hospital admissions and discharged from hospital emergency department in last 12 months (N=427) Hospital to home	joining the study		geriatric nursing	services Facilitate transitions	weeks minimum • Available by phone • Create care plan • Follow up with all visits to ED	except that intervention group were more likely to use emergency health services with no beneficial impact on health
Mayo et al. (2008)	Canada	Older stroke patients following hospitalization (N=190) Hospital to home	At discharge and 6 weeks post-discharge with 6 month follow up	Case manager	RN – with extensive experience in geriatric nursing	Reduced emergency visits Reduced non-elective hospitalizations	• Home visits and telephone contact • Surveillance • Information exchange • Medication management • Health system guidance • Active listening • Family support	RCT No significant effect on clinical outcomes nor health services utilization

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Study	Country	Target Population & Setting	Period of Care	Title	Qualifications	Goals	Duties	Outcome
							• Teaching • Risk identification	Evaluation

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Appendix F: WW LHIN: Consultation on Integrated Clinical Services Plan (ICSP) for frail seniors

Adapted by Ms. Jane McKinnon-Wilson, Geriatric Services, System Coordinator, Trellis Mental Health Developmental Services; and Dr. George Heckman, Geriatric Lead Physician, WW LHIN

To assist the Waterloo Wellington Local Health Integration Network (WW LHIN) develop and implement integrated clinical services plan for frail seniors, we are embarking on a priority-setting consultation process with interested stakeholders in order to identify and set relevant priorities.

We have developed a set of guiding principles that will serve as a framework as we develop an ICSP for frail seniors in the WW LHIN. Please refer to the accompanying document.

As part of our approach to developing this plan, we will be interviewing interested stakeholders over the course of the next several months. As a stakeholder, we ask that you review and reflect upon the questions below. Your responses, as well as those of other interviewees, will be analyzed to identify key geriatric service areas. Once these areas have been identified, we will proceed with a second phase of our consultation in which these services will be prioritized, again by the same interested stakeholders. As you consider these questions and reflect on needs and priorities related to IGS, please think about one or more clients/patients that you know of who have received (or are currently receiving) IGS, or are in need of IGS.

Interview Questions

1. Based on your experience what are the health needs of seniors and their caregivers in this area?

2. What are some unmet needs and/or challenges that seniors in our LHIN face?

3. What should be the role of primary care in the support and provision of care to seniors? Please consider the broader concept of primary care to include any of the following practice types or settings, including family practice, Family Health Teams, Community Health Centres, home care, hospitalists, emergency services, retirement homes, supportive living and long-term care.
   a. What is working well?
   b. What could be improved? How?

4. In thinking about the existing seniors health services, are there things that should be:
   a. started?
   b. stopped?
   c. done more often?
   d. considered?
   e. modified to better meet the needs of seniors? How?

5. Linkages among different health services are important if care for seniors is to be effective.
    a. Can you identify linkages that are working well?
    b. If not, where/how could these linkages be improved?

6. The overall goals of the Aging At Home strategy are to ensure that seniors' homes support them, that seniors have supportive social environments, that senior-centered care is easy to access, and that innovative solutions are found to keep seniors healthy. A number of key principles that underlie optimal care programs for seniors:
    -   Provision of person-centered care
    -   Commitment to enhancing quality of life and caregiver support
    -   Provision of services to promote older persons' health and independence
    -   Provision of evidence-based best-practice care
    -   Equal and timely access to services
    -   Early identification and intervention
    -   Flexibility in responsiveness to community and population needs
    -   Care and service coordination
    -   Respect for Diversity and Inclusiveness
    -   Ethical Principle of "Do No Harm"
    -   Accountability
    -   Aging in Place.
        a. How are the current seniors' services demonstrating these principles?
        b. How could an ICSP for frail seniors embody these principles better?

7. The aim of this exercise is to develop a plan to integrate and enhanced seniors' health services for the entire WW LHIN. We will need to know whether what we will be doing works or not.

    What types of outcomes should be measured to ascertain the effectiveness of this exercise?
    How should these outcomes be recorded and measured? By who?

8. Education of care providers and administrators, practicing now and in the years to come, is crucial for ensuring the ongoing success of an ICSP for frail seniors.

    Who should receive this education?
    How should it be delivered? In what settings?

9. What advice would you give to the WWLHIN regarding the priorities for an ICSP for frail seniors?

Appendix G: Focus Group Participants

IGSWs	Upper Grand FHT
WW Seniors Services	Lang's Farm CHC
GEM Nurses	Grand River Hospital Geriatric Service
Cambridge Memorial	Waterloo Region Public Health
Freeport Hospital Geriatric Services	Mount Forest Family Health Team
WW Dementia Network	Osteoporosis Society
St. Mary's General Geriatric service	LTC Physicians
WW CCAC Part 1	Woolwich CHC
WW CCAC Part 2	Guelph Alzheimer's Society
WW Adult Day Programs	KW Alzheimer's Society Caregivers

Appendix H: Questions inserted to Hip Fracture Interview Guides

<u>Hip Fracture Patients</u>

1. Can you identify any specific gaps in your care when leaving the hospital and getting started at [Freeport, home]? What could have made this process smoother?
   a. Medications
   b. Diet
   c. Follow-up medical appointments
   d. Physical activities I should and should not do
   e. How to manage my self-care
   f. How to manage other important activities (eg. Groceries, transportation)
   g. Caring for others (spouse, adult children who rely on my help)
   h. Financial concerns
   i. *** Who to talk to, how to ask my questions, what services I may be eligible for?
2. Do you feel that having someone whose job is to help you transition smoothly from [Freeport] to [home] would be helpful?
   a. [If yes,] What would this role look like? // How could this person help?
3. [If yes,] How could a health system navigator impact the care you received after your hip fracture?

<u>Informal Caregivers</u>

1. Can you identify any specific gaps in [patient's name]'s care when they were leaving the hospital and getting started at [Freeport, home]? What could have made this process smoother?
   a. Medications
   b. Diet
   c. Follow-up medical appointments
   d. Physical activities I should and should not do
   e. How to manage my self-care
   f. How to manage other important activities (eg. Groceries, transportation)
   g. Caring for others (spouse, adult children who rely on my help)
   h. Financial concerns
   i. *** Who to talk to, how to ask my questions, what services I may be eligible for?
2. Do you feel that having someone whose job is to help your [patient] transition smoothly from [Freeport] to [home] would be helpful?
   a. [If yes,] What would this role look like?// How could this person help?
3. [If yes,] How could a health system navigator impact the care [patient] received after their hip fracture?

<u>Health Care Providers</u>

1. Do you see the need for a person who can help hip fracture patients navigate the health care system? If yes, what would this role look like?
2. Are there any "types" or hip fracture patients who seem to be particularly in need of this kind of service?
3. [If yes to 1,] How could a health system navigator impact the care [patient] received after their hip fracture?

Appendix I: Interview Guide for IGSW Interviews

Evaluation of the Intensive Geriatric Support Worker (IGSW) Role

Activities

1. Please describe your experience as an Intensive Geriatric Service Worker in Waterloo-Wellington. Can you describe a typical day?

2. What common activities do you perform with your clients?

3. What unique experiences have you had with your clients?

4. What is/are your goal(s) as an IGSW working with an older person?
   **probe: around self-management?

5. In general, if you could divide up how you are spending your time in your role, how would you describe the different components of your job?

   a. How do you allot your time between these components?

6. What are the challenges experienced by seniors with system navigation?
   a. How are you helping seniors to navigate the health care system?
   b. What challenges to you have in helping seniors with this?

7. How are you helping seniors to stay in their homes?

8. Have your actual role responsibilities as an IGSW matched the responsibilities you expected before starting this job?

Impact

1. In your opinion, does your role make a difference in the lives of your clients? Families?
   a. If so, how?

2. What type of older person do you feel you are:
   a. Most successful with?
   b. Least successful with?
   **probe: relating to level of risk?

Performance

1. Please describe a time when you felt restricted in your role.

2. Please describe how your experiences before you began this position may influence the way you approach your clients?

3. Are there times in your job that you feel:

   a. uncomfortable?

   b. Unprepared?

   c. If yes to either of the above, what would help you feel more comfortable and/or prepared?

4. Introducing a new role into a care network could have barriers and/or facilitators, please describe your experience working with different health care professionals so we can better understand how IGSWs can work in the health system:

   a. Physicians

   b. Nurses

   c. CCAC

   d. Community support services (e.g., adult day programs, Meals on Wheels)

   **probe: Has this experience been different from your previous experiences working with these health care professionals?

5. How does the location in which you work out of impact your scope of practice? (eg. Community Support Connections vs. Hospital)

6. Currently, you're working closely with GEM nurses in the emergency department, are there other links in either the hospital or community where you feel your role could work with other client groups? What impact might you have on these other groups?

Additional Comments

1. Do you have any else you would like to add?